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Fighting against the "evil"

Religious and cultural construction of the first psychotic experience of youth living in São Paulo, Brazil

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A thesis submitted to the Faculty of Graduate Studies and Research in partial fullfilment of the requirements of the degree of Ph.D in Anthropology



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In memory of my father Anatol Redko, my brother Alexandre
Redko, and my "adopted brother" Marco Luiz de Castro.

In honour of all the young patients and their families who had the openness and kindness of sharing with me some of their good and bad moments.

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ABSTRACT

The outbreak of the first psychotic episode disarrays the person's everyday experience and of significant others. This work takes the notion of experience as the key mediating variable to understand how the cultural and social frame affects the experience of psychosis. Culture contributes to the articulation of the experience of psychosis through its influence on individual, family, and community reactions. I focused on the first psychotic experience of low-income youth living in São Paulo. Brazil because one can see more clearly the role played by the cultural and social dimensions, since the process of experiencing psychosis is not yet totally settled.

I emphasized the basic strategies created by psychotic patients and their families to reorganize their experience of themselves and of the world, and the dynamics and underpinning of
these strategies in relation to cultural signifiers. I particularly explored how psychotic patients and
their families appropriate, borrow and transform cultural signifiers, and more specifically
religious signifiers, in their attempt to cope with psychosis. Religious signifiers are pervasive and
diverse in Brazilian culture; furthermore different people may or may not resort to or be affected
by religious idioms and signifiers in a similar way. A wide range of variation in the use of
religious idioms and signifiers can be expected among patients, at different moments of their life
history, and when the experiences of patients and significant others are compared. Religion can
have a positive impact over the experience of psychosis, a negative, or even a neutral impact
depending on the person and circumstances

My work also demonstrates that psychotic patients are subjected to a double-process of marginality due to their poor living conditions and to urban violence; and to the fact that their marginality is further accentuated by the psychotic episode. People's reactions also vary and change in relation to the kinds of behaviours manifested by psychotic patients, in addition to the social role of each family member and the family dynamics at play. More generally, people's reactions work in a kind of "feed-back loop," since family reactions modify the subjective world and reactions of patients, while patients' reactions modify family attitudes and behaviours.

RÉSUMÉ

L'émergence d'un premier épisode psychotique désorganise l'expérience quotidienne du sujet atteint et de ses proches. Cette thèse utilise la notion d'expérience comme variable intermediaire clef afin de comprendre comment le cadre culturel et social influence l'expérience de la psychose. La culture contribue à l'articulation de cette expérience par son action sur les réactions de l'individu, de la famille et de la communauté. Je me suis intéressée au premier épisode chez des jeunes à faible revenu vivant à São Paulo, au Brésil, parce qu'on peut mieux y voir le rôle joué par les dimensions culturelles et sociales alors que le processus psychotique n'est pas encore complètement installé.

J'ai mis l'accent sur les stratégies de base créées par les patients psychotiques et leur famille pour réorganiser leur expérience d'eux-mêmes et du monde, et sur la dynamique et les points d'appui de ces stratégies en relation avec les signifiants culturels. Plus particulièrement, j'ai exploré de quelle façon les patients et leurs familles s'approprient, empruntent et transforment ces signifiants culturels, spécialement les signifiants religieux, dans leur effort pour vivre avec la psychose. Les signifiants religieux sont omniprésent et variés dans la culture brésilienne; de plus, differentes personnes peuvoir y avoir recoure ou non, ou être affectées par les idiomes et signifiants religieux de diverses façons. On peut s'attendre à des variations importantes dans la maniere donc les patients recourent à des idioms et des signifiants religieux et dans la façon ils le font à différents moments de leur vie. Il en va de même lorsque l'on compare leur expériences et celle de leurs proches. La religion peut avoir un impact positif ou négatif sur l'expérience de la psychose ou même avoir un impact neutre selon les personnes et les circonstances.

J'ai aussi voulu montrer que les patients psychotiques sont sujets à un double processus de marginalisation, à cause de leur pauvreté et de la violence urbaine et en raison de la marginalisation que vient accentuer l'épisode psychotique. Les réactions des gens varient également et changent selon les comportements manifestés par les patients psychotiques, selon le rôle social de chaque membre de la famille et selon la dynamique familiale. Plus généralement, les réactions des gens forment une sorte d'une "boucle de rétroaction", puisque les réactions de la famille modifient le monde subjectif et les réactions des patients, alors que les réactions des patients modifient les attitudes et comportements des familles.

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Chapter 1 - Introduction

The fact of the psychoses is a puzzle to us. They are the unsolved problem of human life as such. The fact that they exist is the concern of everyone. That they are there and that the world and human life is such as to make them possible and inevitable not only gives us pause but makes us shudder. [Karl Jaspers, General Psychopathology, 1964 (1923)]

It was my birthday. I had invited some friends over to celebrate the occasion much in the way most undergraduate students do: a lot of partying, drinking, loud music and dancing. It didn't happen quite in this way. My brother was so excited that year with the fact that he began studying in medical school that he had invited some of his school mates to come to my party as well. We soon discovered that he had invited more than one hundred medical students but all these people would not even fit inside our apartment. During that whole evening my sister, some close friends and myself had to take turns at the front door of the building to apologize to every new guest that my birthday party had been cancelled. My brother was very restless upstairs trying to convince my aunt who is a medical doctor that he had articulated a "secret plan" in order to "save all the sick, poor and dispriveleged people of the world" because he was already a "great doctor." Nobody slept one minute that night and we took my brother to see a psychiatrist soon afterwards. After fifteen days of anti-psychotic medication my brother "calmed down" and happily returned to his school activities. We had also experienced in a very confusing, painful, and intimate way what a first psychotic episode was all about.

Almost fifteen years later I returned to São Paulo to begin fieldwork with youth who were suffering a first psychotic episode. My brother was still struggling to accept the fact that psychosis (bipolar disorder) now comprised his everyday experience for many years. He didn't talk much since he was very withdrawn in himself, yet suddenly he decided to open up his mouth in order to break-up with his girlfriend. Less than a week

later just after the family supper, while I was washing the dishes, my mother was working with the computer, and my stepfather was taking a shower, my brother went to the balcony to take some fresh air. He jumped from the apartment building. He died immediately. We all miss my brother very much until today. He was also the family member who questioned most deeply about what is considered "normal" in everyday life through the ups and downs of repetitive psychotic episodes. We have learned, and suffered, and laughed, and changed ourselves; we have experienced a lot with him in all these years. Yet the intricate experience that he himself had with psychosis still remains a puzzle to each and every one of us.

After my brother's first psychotic episode I started to read with enthusiasm all the social sciences literature that dealt with the problem of mental illness. Basaglia, Laing, Goffman, and Foucault soon became common authors to me. During those years the "human rights" of psychiatric patients was constantly being acknowledged by the media while several psychiatric hospitals were being shut down or "humanized" due to the inhospitable conditions that was offered to their chronic patients. This was the initial movement towards a community-based approach for psychiatric patients in Brazil. Juqueri soon became the major example of this whole "humanization" movement since it was the oldest, the biggest and most problematic psychiatric hospital of São Paulo. By coincidence the boyfriend of one of my school-mates worked as a psychologist in Juqueri. It is not so difficult to guess the next step. I started to visit weekly one of the female wards of Juqueri's psychiatric hospital together with two other school-mates and this became my first fieldwork experience while I was still in undergraduate school.

For more than two years I visited the female patients of Juqueri. They were chronic psychiatric patients abandoned by their families in the hospital and with no possibility of return to community life. They have shared with me some of their sorrow, solitude, hope, and suffering. They have also revealed to me how the category of "mentally ill" patient was socially and culturally constructed inside the institution. They did not consider themselves as "crazy," and they would always indicate in which ways any "other" patient could be considered more "crazy" than themselves. They were

construct a more positive image of themselves. They had no way out of this situation. Some of them even attempted to run away from the psychiatric hospital. Some days later they would come back of their own will because they found no conditions to survive in the community by themselves. They had no money, no job, no family nor any other social support. After so many years of psychiatric hospitalization they held a very vague memory about how was their life experience before or what has brought them there in the first place (Redko, 1991).

Meanwhile my brother had other psychotic episodes. He also had to be hospitalized for a short period. The whole family shuddered. I preferred to pause and leave aside any investigation related with mental illness to some other time in the future. Many years have passed before I found the interest and the courage to touch this matter again from a scientific perspective. Since I had already been trained in anthropology and clinical epidemiology I had the chance to collaborate with a group of psychiatrists who belonged to the International Clinical Epidemiology Network (INCLEN) which has one unit at the UNIFESP- Escola Paulista de Medicina, in São Paulo. During that period a small group of researchers oriented by Dr. Jair Mari started to do a series of investigations related with the epidemiology of schizophrenia, although some of them were also investigating issues related with the experience of schizophrenic patients and their families. I was extremely touched after reading some qualitative interviews conducted with family members of schizophrenic patients. I also became very excited with the possibility of integrating my doctoral research proposal within this collective research perspective. This would also allow me to recast some of the questions about psychosis that still remained very present to my personal experience.

It is well known that most often the first psychotic episode strikes during the critical developmental phase of early adulthood or late adolescence (Goldstein, 1995; Häfner et al., 1994). I find particularly important to target the youth during the outbreak of their first psychotic episode because what they are experiencing during this period disrupts their everyday lives and that of their significant others in ways that were not

imagined before by any of them. Psychosis drastically changes their experience of themselves and of the world during a crucial time in their lifecycle. However, these youth are not yet marginalized by society like those people in Juqueri who have already developed a long and unavoidable "career" as psychiatric patients. I thought that it would be relevant to identify and describe what is most helpful for them during this initial period of intense crisis. As an anthropologist I was particularly interested by the role played by cultural signifiers in the lives of these young people, their families, and their close social network during the emergence of a first psychotic episode. During this period we can expect to see more clearly the role played by cultural and social dimensions because the process of experiencing psychosis is not yet totally settled.

Very few societies have been investigated in depth to address the role played by social and cultural factors in schizophrenia. The relevance of investigating these collective factors is reinforced by numerous epidemiologic studies indicating that course and outcome of schizophrenia vary across societies (Murphy, 1982; Jablenski et al.,1992). The most sound evidence is given by the WHO Determinants of Outcome of Severe Mental Disorders (DOSMD) Study which identified first-episode schizophrenia in ten different countries and confirmed a more favorable course and outcome of schizophrenia in Third World Countries. More recently, the *World Mental Health* report (Desjarlais, Eisenberg, Good and Kleinman, 1995:43) prepared by the Harvard Medical School hypothesized that the following factors could explain the better course and outcome of schizophrenia in some societies:

1- Conceptions of the cause and course of schizophrenia held by a certain social group (including mental health professionals) strongly influence their response to people who are sick and both directly and indirectly influence the course of psychosis. For example, where schizophrenia is considered an essential part of the self that cannot be expected to change, the course is more likely to be chronic. In contrast, other conceptions facilitate recovery (e.g., the sick person is possessed by spirits that can be exorcised).

- 2- The influence of family support on the course of illness.
- 3- The work environment and level of involvement in the wage economy.
- 4- Characteristics of treatment settings, as well as specific treatments can influence outcomes both positively and negatively. For instance, psychosocial interventions can unintentionally produce dependency, instead of rehabilitating mentally ill patients.

The World Mental Health Report acknowledges that despite many similarities, mental health problems worldwide take shape in particular cultural patterns. Furthermore, cross-cultural comparisons should be complemented by the examination of intra-countries variations which could also enlighten the role played by social and cultural factors (Cooper & Sartorius, 1977). In order to meet the challenges of social and cultural diversity, the development of ethnographic studies and interdisciplinary research approaches are highly recommended principles of the actual research agenda. In addition, ethnographic studies should precede epidemiological and intervention studies to provide descriptive maps of local problems, perspectives, social realities and resources. The actual research agenda aims at examining the role played by social and cultural factors during the onset, course and outcome of psychosis.

In that context, the "new-cross-cultural psychiatry" opens interesting avenues of exploration. It reformulates significantly the very notion of mental illness by emphasizing that this is also an **experience** imbued with **meaning** and that the personal and collective meaning of symptoms further contribute to the evolution of psychiatric disorders (e.g. Corin, 1990; Kleinman & Good, 1985; Littlewood, 1993). One could say that "new cross-cultural psychiatry" invites both to consider psychosis "from the inside" in examining how psychosis affects a person's self experience and position towards the world, and to resituate it within a larger cultural context. One of the objectives is to identify which elements of the social and cultural matrix have the most chances of directly influencing the articulation of the experience in a particular culture, and to examine the mediations through which they have an impact on the experience.

In my own work I adopt Corin's suggestion (1998, 1994) that **experience** is the key mediating variable in order to understand the pathways through which the social and cultural frame affect the course of psychosis. This approach considers both **culture** and **experience** as complex, heterogeneous realities and is broad enough to investigate the cultural grounding of conceptions, behaviours, feelings, and reactions, while remaining focused enough in order to relate this cultural "web" to the personal experience of real individuals. The availability of a cultural matrix that can be used for articulating the experience of psychosis does not implicate that individuals relate to this cultural matrix in a similar way. One has to identify the heterogeneous ways people may appropriate the cultural idioms which are available to them. Corin hypothesizes that culture contributes to the articulation of psychotic experience through its influence on individual, family and community reactions (e.g. Scheper-Hughes, 1987).

In my work I have focused on the subjective experience of young people with early psychosis and the ways it is shaped by culture and local interactions. My insider knowledge of Brazilian culture suggested that religion would act as a major mediator of this process in a way reminiscent of Obeyesekere's (1990, 1985) notion of "work of culture" where cultural signifiers resonate with psychic processes. Generally speaking it has been documented in Brazil that people tend to resort to one or several religious settings when faced with a variety of difficulties including health and mental health problems in the context of complex help-seeking pathways (Queiroz, 1991; Laplantine, 1990; Montero, 1985; Loyola, 1984). This also appears to apply to psychotic phenomena.

Initial qualitative interviews collected from family members of schizophrenic patients at UNIFESP in São Paulo suggested to Villares (1996) that the problema espiritual (spiritual problem) was among the major cultural signifiers used to explain the nature of schizophrenia, in addition to the problema de cabeça (head problem) and the problema de nervoso (nervous problem). These labels also indicate the avenues resorted to by these families for coping with the problem. This idea that popular concepts of mental illness reflect culturally constituted reactions and coping strategies is in consonance with the anthropological literature (e.g. Waxler, 1979; Jenkins, 1988a,

1988b). Still this tells very little about how certain cultural signifiers such as "spiritual problem" influence the experience of psychosis and its evolution, and how they are integrated in the everyday lives of patients and family members. It also says very little about the ways people use, appropriate and transform cultural signifiers in their attempt to cope with psychosis. One also has to take into account that religious signifiers are pervasive and diverse in the Brazilian environment.

In this work I intend to investigate the basic strategies created by psychotic patients and their families in order to reorganize their experience of themselves and of the world, and of the dynamics and underpinning of these strategies in relation to cultural signifiers. I am particularly interested by the different interactions between psychotic and religious experience. I will explore how young people who are suffering a first psychotic episode resort to religion and how religious signifiers appear to be involved in the framing of the psychotic experience and in family and community reactions.

My basic hypothesis is that resorting to cultural signifiers, and more specifically to religious signifiers, contributes to articulating personal and interpersonal reactions to psychotic symptoms and, therefore, to framing the further evolution of the disorder. The experience and manifestations of psychosis can be permeated with religion, particularly when people resort to religious idioms of distress (eg. problema espiritual, spirit possession). One can wonder how far and in which ways religious idioms are transformed when the psychotic episode develops. One can consider that each individual will not resort to and be affected by religious idioms or religious signifiers in a similar way. A wide range of variation in the use of religious idioms and signifiers can be expected among patients, at different moments of one's life history, and when the experiences of patients and significant others are compared. In addition, religion can have a positive impact over the experience of psychosis, or a negative or even neutral impact depending on the person and circumstances.

Chapter 2 introduces a few theoretical benchmarks that open avenues for examining the relationship between culture and psychosis. It pays particular attention to

the notion of experience and to the ways it is affected in psychosis. I will first examine how psychosis is problematized in a cross-cultural perspective. Afterwards the major anthropological approaches to psychosis will be explored regarding the ways people with psychosis relate to their personal, interpersonal and social world. I will then turn to anthropological approaches to the notion of experience. This discussion will be complemented by illustrating how some authors from European psychiatric phenomenology like Minkowski, Binswanger and Blankenburg understand psychosis as a basic transformation of the co-ordinates of the experience of being-in-the-world and being-beyond-the-world. The chapter ends with an exposition of anthropological approaches to the notion of experience that give more emphasis to religious idioms and rituals. The notion of "work of culture" provides an interesting perspective from which to examine "culture" as a basic process of transformation of the experience.

Chapter 3 aims at describing the social context of this study. I begin by introducing the living conditions of the urban poor who live in São Paulo and with a brief description of the particular living conditions of the low social class families with a psychotic member who participated in this study. I will then adopt a broader perspective and describe the way different urban spaces of São Paulo are already marked by poverty, violence, and fear. I argue that this general atmosphere constitutes a background under which the psychotic person's experience has to be resituated. One can say that they are subjected to a double process of marginality: they share with their families a status of marginality due to their poor living conditions, a condition of marginality further accentuated by the unfolding of psychosis.

Usually my first contact with the young patients occurred in the psychiatric emergency room. Chapter 4 describes these people's trajectories in psychiatric care and more specifically, the situation encountered in the emergency room. It examines the decision taken at that time regarding the further orientation of the patient within the psychiatric system, and illustrates the central importance given to anti-psychotic medication from the perspective of the various actors. Interviews and ethnographic fieldwork clearly reveals that mental health professionals are only aware of a small facet

of patient's everyday experience. They also indicate that most young people and their families make a strong effort to keep psychiatric help in a position of "marginal" significance in relation to the rest of their everyday lives.

I have suggested earlier that psychotic experience develops in a social and interpersonal context that influences its articulation and further evolution. Chapter 5 explores the family and community reactions towards young persons with psychosis. I begin by describing the kinds of behaviours and manifestations that were mentioned the most regularly by patients and family members in relation to their impact on family life and the basic type of reaction they evoke. I also illustrate how these reactions vary and change in relation to the social role of each family member and the family dynamics at play. More generally, people's reactions work in a kind of "feed-back loop," since family reactions modify the subjective world and reactions of patients, while patients' reactions modify family attitudes and behaviours. Family reactions are also situated in relation to the fear of loucura (craziness) and stigmatization manifested by patients and family members in the broader context of community life. I also came to the conclusion that notions like "tolerance" and "support" do not capture the complex dynamic of family life when one member becomes psychotic. They provide a distorted and reified vision of ambiguous, heterogeneous and sometimes paradoxical realities.

Chapter 6, 7, and 8 focus on the major contribution I intend to bring with this work by discussing the various interactions between religious experience and psychotic experience. The sixth chapter is mainly descriptive and provides the background context by mapping out the profusion of religions that may be adopted by the urban poor of São Paulo. It also reveals how people easily resort to different religions in order to cope with the problem of illness. The seventh chapter presents a detailed description about the different ways patients and family members resort to religious sources of help. It begins by comparing the personal and family significance of religion before and after the outbreak of psychosis. I also try to demonstrate some convergences and divergences between the patient and family's perspective towards the most recurrent religious forms of help that they sought. The eighth chapter discusses the significance of religion on the

patients' attempts to reorganize their experience of themselves and of the world during the psychotic episode; it illustrates a range of ways of manipulating and/or transforming religious idioms and signifiers. This is also contrasted with the perspective of family members in relation to the meanings they attribute to religious signifiers and etiologies; especially when they take into consideration the experience of patients. In sum, what is being explored are the most recurrent ways that religious idioms and signifiers shape and transform the experience of psychosis.

I decided to include the methodological discussion here to introduce the reader to the different phases of the fieldwork and to some of the complexities involved in conducting research among people who are suffering from a first psychotic episode. I will complement this presentation with a self-reflection on my relationship with these young people and their families.

Methods

The first phase of fieldwork consisted in the recruitment and participant observation of patients inside the psychiatric setting. The second phase unfolded by interviewing these patients and their families in addition to following them in their everyday lives. The context of the psychiatric care system will be described briefly before proceeding with the methodological discussion.

Context of Psychiatric Care

Psychiatric care in Brazil has been mostly hospital-based until the early 1980s, when initiatives and changes in the mental health policy towards a community-based approach began to happen. As a consequence of the community mental health movement, a 36% reduction in the number of psychiatric beds occurred from 1984 and 1996, and this affected more the public sector (37%) than the private sector (15%). Although the number of psychiatric hospitalizations decreased in the same period, community-based resources

for psychiatric treatment did not increase at the same rate. Nowadays the frequent shortage of beds influences psychiatrists in the way they choose which patients should be hospitalized (Menezes, Rodrigues and Mann, 1997; Menezes & Mann, 1993; Botega, 1997).

In São Paulo, the psychiatric care system is relatively well organized when compared to some other areas of the country. People can have access to one of the following psychiatric services of the public sector: in-patient facilities, emergency services, psychiatric outpatient clinics and mental health teams in primary care centres. Most people with psychiatric problems tend to resort to services delivered by the public sector because private health care is extremely expensive for the majority of the population, and most private health care plans do not cover psychiatric care, particularly in-patient care. The different forms of psychiatric services provided by the public sector are free of charge and linked into a network, even though independently run by the federal or state government, and by the municipality (Menezes, Rodrigues, and Mann, 1997).

Statistics indicate that in 1994 in almost 60% of the families who live in the city of São Paulo (there seem to be no social class differences here), at least one family member resorted to health care (public or private) in the past 30 days (SEADE, 1994). In addition, 3,7% of all the hospital beds (public and private) in São Paulo were occupied by people with psychiatric problems, with an average stay of 46,3 days for psychiatric beds covered by the government in 1996 (Ministério da Saúde, 1996). Schizophrenia was the most common psychiatric diagnosis (34,6%) associated with psychiatric hospitalization in the State of São Paulo in 1995 (Botega, 1997). Health care services in the city of São Paulo carried out an average of 55.500 monthly psychiatric consultations during the same period (SEADE & IBGE, 1997).

In São Paulo, pathways to care for the individual who presents a psychotic disorder vary. The most common way to resort to the psychiatric care system is through the emergency room where patients know they are seen by a psychiatrist on the same day.

After receiving treatment there for a short period, they may be referred to one of the outpatient clinics, admitted to a psychiatric hospital, or sent back home with a prescription. The indication for psychiatric hospitalization has diminished, for instance, in the psychiatric emergency of São Paulo Hospital approximately 6.3% of the patients (independent of psychiatric diagnosis) received indication of psychiatric hospitalization in 1989, while 40% of the patients who resorted to this emergency room were hospitalized in 1976. The psychiatric emergency frequently functions as the core interface between the individual and the other hospital and community mental health services. (Menezes & Mann, 1993; Menon, 1994).

Research Site

The São Paulo Hospital is considered to be a very important place of reference linked with a medical school run by the federal government (UNIFESP- Escola Paulista de Medicina). It is therefore associated with expectations of good quality health care. In situations of emergency people often prefer to resort to this well-known university hospital rather than to the local primary health care centre. The São Paulo Hospital serves primarily the population of the South Region that corresponds to its catchment area. The region is known to be inhabited by the poorest strata of São Paulo's population. However, the psychiatric emergency of the São Paulo Hospital accepts patients from all over the city. No data are available about the socio-economic level of the clientele who are treated in the São Paulo Hospital.

My decision to choose the psychiatric emergency of the São Paulo Hospital as my entry point for the research responds to several reasons. First, my position as a social scientist fellow of the INCLEN Research and Training Unit at UNIFESP-Escola Paulista de Medicina facilitated the negotiations with the Department of Psychiatry of the São Paulo Hospital. Second, given the great flux of patients that this psychiatric emergency room receives everyday, I was more likely to find quickly a greater number of cases of people going through a first psychotic episode than in any local primary health care centre. Third it would have been unfeasible to detect in a short period of time a

reasonable number of people who were suffering a first psychotic episode from a place outside of the psychiatric services (e.g. neighbourhood, religious group). This would also have been difficult to defend on ethical grounds because of the risk of stigmatization entailed in this process and because my basic training being anthropology, I do not have the appropriate clinical skills to make a psychiatric diagnosis. I am aware that my recruitment strategy caused me to miss cases that have never made any contact with the psychiatric emergency, and that it has in some way biased my sample. But my intention is not to provide representative data. It is rather to explore in depth the role of cultural and religious signifiers in the personal and interpersonal articulation of psychotic experience in a well-bounded sample of people.

The psychiatric emergency room of São Paulo Hospital provides in average 376 consultations every month. Normally patients do not receive more than three consultations at the psychiatric emergency of São Paulo Hospital. Afterwards the emergency room psychiatrist may transfer the patient to one of the internal psychiatric services of this hospital, provided that there is vacancy available in the service that is most adequate to deal with the patient's problem. Besides the psychiatric emergency room, the São Paulo Hospital offers a series of psychiatric services linked to the Department of Psychiatry: Schizophrenia Programme, Affective Disorders Programme, Drug Addiction Programme, Obsessive-Compulsive Disorders Programme, Day-Hospital Programme¹ (for outpatients), Pedagogic Ambulatory, Crisis Ambulatory (for acute cases), Child Psychiatry Programme, and one Psychiatric Ward. The São Paulo Hospital only has a female psychiatric ward with eighteen beds (with an average stay of three weeks). Most of the times patients are transferred to another psychiatric service outside of the São Paulo Hospital. For instance, primary care centres, day-hospitals, or psychiatric hospitals. When a male patient needs a psychiatric hospitalization, or if there is no vacant bed for a female patient, the emergency room psychiatrist contacts by telephone the city's

¹ This Programme only started to be offered in a restricted way during my fieldwork. It is expected that it will function like a Day-Hospital in the future. Day-Hospital is a community psychiatric Programme run by the municipality of São Paulo where patients stay the whole day doing activities inside the hospital; they go back home to sleep every night.

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pool of psychiatric hospitals to discover which institutions have some vacancy available that day.

In my study, most contacts with first episode psychotic patients were done in the emergency room, a few other cases were directly approached through the Schizophrenia Programme of São Paulo Hospital for two main reasons: First, some cases go directly to the Schizophrenia Programme without going through the psychiatric emergency; second, this accelerated the rhythm of selection of the study sample.

The speed of sample selection was very important because I wanted to reserve enough time to follow some patients in a prospective way. I should also mention that this study stimulated the Schizophrenia Programme to create therapeutic procedures more appropriate to first episode psychosis (e.g. family education sessions, psychotherapy groups), and to launch new epidemiological investigations. The Schizophrenia Programme also opened its doors to provide treatment to all the patients who were collaborating with my study, even though this did not always translate in practice. In some cases the emergency room psychiatrist preferred to direct the patient to another place different from the Schizophrenia Programme, while in others patients abandoned the psychiatric treatment.

Sampling

The twenty-one patients (11 females, 10 males) with a first episode of schizophrenia who participated in this study were first contacted at the psychiatric emergency, or in some circumstances at the Schizophrenia Programme of the São Paulo Hospital.² The selection of patients followed the general principle of homogeneity. The homogeneity of the sample was guaranteed by three inclusion criteria:

² According to the emergency room records a total of 284 patients with a diagnosis of schizophrenia resorted to the emergency room during the period of October 1997 until March 1998. It is not possible to determine with precision through the emergency room records what proportion of the patients diagnosed with schizophrenia were suffering a first psychotic episode. Based on my participant observation in the emergency room during this period I estimate that approximately 35 patients received a diagnosis of first episode non-affective psychosis. I am very thankful to Dr. Osvladir Custódio and Dr. Miguel Jorge who

- 1) First episode psychosis.
- 2) Diagnosis of schizophrenia.
- 3) Age of patients between 17 and 29.

I have chosen to work with a homogeneous sample of patients for two main reasons. The first one is related to the nature of qualitative data analysis. Since the samples are always small, the possibility of saturation of the data is more likely when the sample obeys certain criteria of homogeneity. The second relates the issue of diagnoses according to European phenomenological psychiatrists: the mode of being-in-the-world of patients with schizophrenia is characterized by a basic alteration of the experience that differs from other psychiatric disorders. One could therefore hypothesize that the interactions between the experience of schizophrenia, religion and other cultural signifiers may also be different. Patients with other psychiatric disorders may experience religion in a different way.

I have already mentioned that my interest in first episode psychosis is related to the fact that the influence of social and cultural factors is not yet settled during the emergence of the problem. As I wanted to keep the study sample as homogeneous as possible in relation to the standard psychiatric classification, the first episode psychotic patients who participated in this study had to receive an initial diagnosis of "schizophrenia" (F20) or of "acute and transient psychotic disorders" (F23) according to the ICD-10 criteria (see the definitions in Appendix A).³ F20 and F23 are the major sub-

allowed me to have free access to all the emergency room records, even though they were not yet computerized.

³ Brazilian psychiatrists use both the ICD-10 and DSM-IV classifications to establish a psychiatric diagnosis. On one hand, the federal government requires the utilization of ICD-10 for payment of fees in the public health care services. On the other hand, DSM-IV is often used for research purposes. One issue for which the DSM-IV differs radically from the ICD-10 classification is that continuous signs of the disturbance should persist for at least 6 months to justify a diagnosis of schizophrenia. This 6-month period must include at least one month of symptoms (or less if successfully treated). The ICD-10 only establishes that schizophrenic symptoms should have been clearly present for most of the time during a period of at least one month before this kind of diagnosis is made.

categories in the category of "schizophrenia, schizotypal and delusional disorders" (F20-F29). Some first episode psychotic patients were not selected because they were first classified by the emergency room psychiatrists under the "mood [affective] disorders" (F30-39) category, the most common diagnosis being that of "bipolar affective disorder."

The diagnosis of first episode schizophrenia had to be confirmed by two different psychiatrists before inviting the patient to participate. I was also careful to check the psychiatric diagnosis in a more standardized way. Patients who participated in this study were interviewed by a psychiatric resident who was trained in applying the SCID/DSM-IV (First, Spitzer, Gibbon and Williams, 1997). We usually waited a period of six months before inviting each patient to respond to this standardized psychiatric diagnostic interview. A total of sixteen patients answered the SCID/DSM-IV. We concluded that in some cases a longer duration of illness was needed before establishing the definitive psychiatric diagnosis. Furthermore, the SCID/DSM-IV was in process of validation for the Brazilian environment and some small adaptations were still necessary. The comparison between the initial ICD-10 diagnosis provided by psychiatrists and the DSM-IV diagnosis provided by the SCID/DSM-IV interview some months later is illustrated in This process of diagnosis validation in two phases (ICD-10 and Appendix B. SCID/DSM-IV) allows the comparison of research data and conclusions with what has been published in the psychiatric literature. It also gives the research credibility for the clinician and facilitates discussion with them about the relevance of this kind of anthropological research to their clinical practice. Finally, it facilitates publications aimed at both clinical and social science audiences.

⁴ In many circumstances it is very difficult to predict the clinical evolution of first episode psychosis. The increasing duration of illness seems to be the most important factor that contributes to differentiate schizophrenia from other psychotic disorders (McGorry, 1994) For this reason it is very likely that some patients with initial schizophrenia were misdiagnosed under some other category, particularly in the mood disorders. In the same way, some patients who will later develop mood disorders were initially classified under the category "schizophrenia," and more particularly the category of "acute and transient psychotic disorders."

Age is another criterion that ensured a basic homogeneity of the sample. It responds to the idea that young people share life experiences common to their age, regardless of the fact that they are going through a first psychotic episode. Epidemiological studies also indicate that it is very infrequent for cases of schizophrenia to begin before adolescence or in people older than 50. Furthermore, the incidence of schizophrenia seems to be more pronounced for both men and women who are between 20 to 29 years old (Goldstein 1995; Häfner et al. 1994).

Data Collection

During the first six months of fieldwork I spent most days of the week in the emergency room making ethnographic observations and waiting for new cases of a first psychotic episode to appear. I also asked the emergency room psychiatrist in charge whether a new case appeared during the time that I was away from the emergency room. I also checked the emergency room records to be more assured. During my first contact with the patient I tried to set up a time to meet him or her another day. Generally it was during this second encounter that I explained the purposes of my study in a very simple manner before inviting the patient to participate.

During the following weeks, when the young person felt in better conditions to participate in an interview, I tried to arrange another meeting to elicit the first elements of the patient's life narrative, using the *Turning Point Interview* (TPI). The TPI is a qualitative semi-structured questionnaire for the retrospective evaluation of the development of signs and difficulties, interpretations and reactions in early schizophrenia. It is presently being developed and validated against Häfner's et al. (1992) IRAOS (Interview for the Retrospective Assessment of Schizophrenia) at the Douglas Hospital Psychosocial Research Unit in Montreal under the coordination of Dr. Ellen Corin and Dr. Alain Lesage. The TPI aims at documenting the significant stages in the evolution of problems from their onset: it describes the perceived evolution of signs and symptoms,

⁵ From the total of twenty-one patients who participated in this study, two patients refused to respond the SCID/DSM-IV, while three patients were lost at the follow-up because they had either abandoned the psychiatric treatment or moved out of town.

personal and family interpretations and reactions, interpersonal relationships and the help-seeking process. I have translated the TPI to Portuguese before using it as the preliminary grid of interview for this study.

After interviewing the patient I applied on another occasion a parallel version of the TPI to a significant other, frequently the mother, in order to have access to her own perception of the story. Afterwards I asked whether they would be willing to collaborate even further by receiving me in their homes periodically. Twelve patients and their respective families accepted to welcome me in their homes several times (Claudia, Milton, Leonardo, Eduardo, Jonas, Carmen, Dora, José, Luana, Maurício, Sarah, and Gisela). Hélio was living in a temporary place and soon disappeared. I preferred to interrupt the prospective follow-up of Daniel because psychiatrists started to raise doubts concerning the diagnosis of psychotic disorder. The remaining patients (or their families) preferred to restrict their participation to the hospital setting (Alice, Solange, Edilson, Kátia, Maria, Raquel, and Mateus). Concerning the TPI interviews, they seem to have a similar quality level, irrespective of the place where the interview was conducted (hospital or patient's home). In fact, most families who initially rejected the home visits but still maintained some contact with me through the Schizophrenia Programme became more receptive to the home visits with the passage of time. I preferred not to follow them afterwards, because I was already following the other twelve families for a longer period of months. All twenty-one families were followed retrospectively (TPI and life narratives) while the sub-group of twelve families were followed longitudinally as well (participant observation).

The first elements of the perceived life history collected through the TPI were complemented, enriched and modified during the longitudinal phase through complementary interviews and informal conversations as far as possible. I have also followed these twelve patients through their daily life trying to reconstruct their life strategies, their interactions with their family, social network and neighbours. I paid special attention to their direct or indirect contact with religious settings in order to understand their significance to them. In addition, this longitudinal phase propitiated me

with the chance to interview other significant people who belonged to the social network of the patient. Besides the patient and the mother, in many cases I was also able to conduct tape-recorded interviews with brothers and sisters, the father, neighbours, boyfriends, girlfriends, cousins, and psychiatrists. I also had the opportunity to tape-record six clinical meetings of the Schizophrenia Programme at the São Paulo Hospital. In these clinical meetings psychiatrists and other health professionals discussed difficulties and future procedures for specific patients who were invited to come to this meeting to tell their story to the whole group of clinicians. I have recorded only the clinical meetings of those patients who were participating in this study.

After a couple of months of fieldwork I already had the chance to make the first contact with some patients and their families. Gradually I spent less time in the emergency room and more time meeting these people in their places of life. In the sixth month I completed the TPI with the twenty-one patients who agreed to participate in this study and at least one of their relatives. I stopped going to the emergency room. The last six months of fieldwork were completely dedicated to follow more closely the everyday lives of the twelve patients who had accepted to participate in the longitudinal phase of my research. The SCID-DSM-IV interview was also applied during this period.

Ethical considerations

I followed the basic rules established by the Ethics Committee of the São Paulo Hospital in order to be allowed to conduct the initial phases of my fieldwork in this setting. For this reason before conducting the TPI interviews I asked every patient to sign a consent form confirming that they had agreed to participate in this study. The consent form was signed only after I read and explained clearly to the patient the information letter that describes the basic purposes of the study and what he or she was expected to do in order to collaborate. This information letter also guaranteed the same quality of medical treatment in case the person preferred to interrupt his or her participation during the follow-up phase, or if they were not interested in participating at all. I have noticed that most patients paid very little attention to the contents of this letter, even though they

usually appreciated receiving this kind of information. A copy of the information letter and of the consent form is included in Appendix C. Only after interviewing the patient did I ask his or her permission to interview one of the family members with the TPI.

I always explained to every patient beforehand that the SCID/DSM-IV diagnostic interview was also associated with this study. After the patient gave me the verbal consent that he or she would accept to be interviewed by the psychiatrist, I scheduled a meeting between them. Since in this case the patient was only going to the hospital in response to my request I thought it would be ethical to give them five dollars to cover their travel expenses plus a small lunch. Although patients allowed photos to be taken, any photos in which they appear will not be presented in this work to protect their identities. In addition, all the patients' names introduced in the text are fictitious.

The consent form, the letter of information and the small gratuity for the SCID/DSM-IV interview are commonplace ethical procedures in clinical settings. These ethical procedures however tell very little about the constant ethical challenges that emerged during fieldwork while I tried to establish a more meaningful relationship with these young people and their significant others.

Doing Fieldwork with Psychotic Youth

Several young people explained that they accepted my invitation to participate in this study because they felt that sharing their life experiences with me could be useful to help other people who confront similar problems. Their family members usually evoked similar reasons in relation to their own participation. Although this reflects their good intentions towards research participation it still reveals very little about how our interpersonal relations have evolved with the progression of fieldwork. When I returned to Montreal I mailed back a postcard to the twelve young people with whom I had a closer contact during fieldwork. Since I was not expecting any response I was very touched to receive three different letters some months later. Luana, Milton, and Dora

wrote back to tell about the recent events in their lives and how they were hoping to meet me again soon. I was already aware that this fieldwork with psychotic people greatly affected my personal experience in unexpected ways. These letters also suggest that I may have touched their lives in ways that I have not yet imagined.

During my initial contacts with these young people being around them was often more important than trying to do any talking. Thus, I had to exercise my patience and control the eagerness of a researcher who needed to "add new cases" to her study. During the few weeks that Gisela was interned in the psychiatric ward of the São Paulo Hospital I spent some time trying to talk with her almost everyday. The most common response she gave was "I want to go home, take me out of here. I get sick in this sad bed." Her medical files describe that Gisela constantly isolated herself from the other ward patients and that she remained very quiet in bed most of the time. She started to talk a little more and agreed to receive me in her house only a couple of months later while she was still being treated at the outpatient clinic.

Luana's story

My first contact with Luana is unforgettable. While the emergency psychiatrist was having a hard time to obtain Luana's medical history the whole emergency room suddenly turned upside down because another patient became very agitated; this other patient started to shake and to toss objects and to scream: "God. Devil, God, Devil...." She also tried to break the furniture and tear up all the medical files on top of the desk. The patient's violent behavior terrified Luana instantaneously. The psychiatrist left the room to call the nurse and the security guard in order for them to administer anti-psychotic injection to the agitated patient. The patient became even more overexcited when she noticed that Luana was very frightened with her behavior.

Luana suddenly tried to kneel down in front of this patient as a sign of penitence. I started to hold Luana's hands with a protective intention. When Luana gained some confidence to raise from her "kneeling down" position she hugged me very tightly until the whole atmosphere calmed down several minutes later. I had conquered Luana's attention much more with all this hugging than with any presuming good intentions of a researcher. With progression of fieldwork I observed that she always liked to kiss and hug me every time we met. Even in those days that Luana was feeling too impatient to talk with me, she never forgot to give me a quick hug before leaving the room. Often I ended up spending much more time talking with the mother and sisters, than with Luana.

More important than "being-there" was the concomitant "being-together" presence I always tried to establish with the psychotic youth and their families. This obliges me to reflect about the ways I played out my role of anthropologist in parallel to what these families perceived and expected from my "being-together" presence. I always tried to express empathy towards the suffering of these patients and their families. But "empathy" is a very vague term and according to Binswanger (1994a:226) "wherever feeling and feelings are introduced, we have to grope as in a fog." He clarifies the notion of empathy by examining the feeling or feelings in regard to their phenomenal mode of being and their phenomenological content. In this way empathy may be interpreted in terms of chaleur intime (warmth), as a vocal or sound phenomenon, or as phenomena of touch, sharing, participation, and identification. These different modes of expression refer to certain phenomenal, intentional and pre-intentional modes of "being-together" and "co-being" and they need to be analyzed before the total phenomenon of empathy becomes comprehensive and more clarifying. However, the limits of empathic possibilities are purely subjective and vary according to the emphatic ability and imagination of the investigator.

It is very clear to me that what we have mostly shared together was my limited participation in the daily lives of patients and their families, and I was not necessarily

understanding all the meanings they were attributing to their suffering and modes of being-in-the-world. Regarding particularly the patients, "being-together" with in terms of touch, *chaleur intime*, and sound (even when that only meant long periods of silence) was often very significant. Despite all my efforts to react with compassion and mildness towards them, sometimes I was disturbed and reacted with some impatience and discomfort, like any other person. These different reactions enabled me not only to observe the patients: almost at each instant I had the possibility of comparing their psychic life and mode-of-being-in the world with mine:

It was like two melodies being played simultaneously; although these two melodies are as unharmonious as possible, nevertheless, a certain balance becomes established between the notes of the one and the other and permits us to penetrate a bit more deeply into our patient's psyche. (Minkowski, 1994:129)

Sometimes I found myself in a difficult position because I tried to establish a relationship with several members of the family, and most particularly with those individuals whom I had interviewed in a more formal way. It was not always easy but I tried my best by being extremely careful not to reveal to any other member of the family what was told to me during any interview in order to guarantee the confidentiality of all the interviews. I would be very naïve to expect that they had told me every detail about their lives, especially concerning those morally charged topics like drug addiction, sexual behavior, family intrigues, or black magic. Even so, they have shared a lot with me. A more prolonged contact usually made them feel more comfortable to reveal details about their lives that were simply disguised or not mentioned in our first encounters. For instance, Jonas took several months before he revealed to me his drug consumption habits. He probably had not done so before because in many of our conversations his mother was always around. She still had no knowledge about his drug consumption habits, yet he frequently locked himself in his bedroom to smoke pot since he dreaded the idea of going out in the streets during his illness.

The first time I interviewed Jonas he emphasized to me all the dread he was experiencing towards people whom he met in the street and in the hospital. He was

puzzled because he was not able to identify the source of this fear. Since it was one of our first encounters I had the insight to ask Jonas whether he felt this unexplainable fear while talking with me:

<u>Jonas</u>: I don't really know. It is a generalized fear I don't even know how to classify it for you...

<u>Cristina</u>: But did you feel any of this fear while talking with me today? <u>Jonas</u>: No I didn't have any problem. [...] From the moment that people know that I am having a problem I find much easier to talk with them. Now if they don't know it gets very complicated...

Jonas's position reminds me of Minkowski's phenomenological analysis of a schizophrenic patient with whom he had the opportunity to spend day and night together during a period of two months as his personal physician. In many circumstances the patient only perceived Minkowski as one of the many "persecutors" that constantly dreaded him. Minkowski however recognizes that the patient's relationship with him cannot be exclusively understood as that of a relationship between victim and persecutor:

Through all this, he [patient] nevertheless attempted to safeguard a certain communion of thought with others. Although I was seen as a murderer and an executioner, he did not run from me; on the contrary, my presence helped him to a certain extent because I knew the same things that he knew and he could, thus, speak freely with me. If I were gone for a while, he needed to tell me all the new discoveries that he had made during my absence. [Minkowski, 1994:137]

Another important discovery that Minkowski made while "being-together" with this schizophrenic patient is the fact that psychotic symptoms fluctuate; in some occasions patients manifest them intensely, while in others they seem to act like their "normal" selves. I also noticed that these contradictory modes of being-in-the-world and their implications at an interpersonal level for people who suffer from psychosis:

The alternating of symptoms and its various forms establishes thusly a sort of current which runs between normal life and the pathological psyche. It is like the ebb and flow of the sea; now it is calm and the prevalent attitude is one of contact –one cannot keep from feeling an upsurge of hope; now it is a high sea, everything tearing loose, and once again all is submerged. [Minkowski, 1994:130]

Carmen's story

Carmen's life world is very much restricted to her relationship with her mother, to watching T.V. at home, and going to school. But it has been like that since she was a small child. The only time in her life that she slept outside of her home was when she was interned in the psychiatric hospital. She is a black girl adopted by a white mother who is presently widowed and retired. Her only other close contacts are an old couple of neighbors that she calls grandma and grandpa, and the sporadic visits of her brother. Given this scenario Carmen received my visits as a very special event. She soon became very attached to me, as well as her mother. But this involvement sometimes put me in a difficult situation, since both Carmen and her mother expected that I would take sides whenever they had some common intrigue.

I had been visiting Carmen for several months already when she left the following message on my pager: "come urgent." This message worried me but I was only able to come to Carmen's house the next day. Carmen was walking up the street and when she saw me she came into my direction and greeted me with a smile. After this we approached her mother who was sitting at the front of her house chatting with two other women neighbours (one of them is Carmen's "grandma"). Yet the mother was so angry that she warned me as soon as we greeted her: "You should never give any attention to Carmen anymore because she lies too much, she is a lazy bum and she doesn't like to work." One of the neighbours took advantage of the mother's indignation and exploded with Carmen: "You are nothing more than a thief, you took \$5 dollars from my kitchen yesterday and I am going to call the police... Don't you have any

⁶ I decided to rent a pager so the young people could be able to leave me a message in case they needed to talk with me. It introduced a kind of reciprocity in our relationship since they received me in their homes several times.

consideration for your mother that has taken you away from the garbage can [to adopt] and you are just a black girl. Everyone here in the street is gossiping that you can only be a lesbian because you always walk around wearing this cap [that makes her look like a boy] and you keep rubbing your thighs."

The mother started to cry, yet she continued to scorn her daughter: "When you were a baby I took you out from the garbage can, you never respect anybody, you never respect me, not even your grandmother you respect. You only treat me like a cleaning lady because you never give any help with the house chores. You are just a lazy bum because you have no willingness to work... At least if you were sick but you are not sick, it has been several months that I took out your medication and you are feeling well, you simply don't want to work." The neighbour complemented: "You don't even have any consideration for the fact that your mother is a sick woman! It is your mother who needs a psychiatrist to tolerate you."

They were all enraged because Carmen only wanted money to buy silly, little things, so she was constantly taking money from people's wallets. She also sold her cousin's walkman without his permission and for a very ridiculous price. Since the accusations and blackmail were only accumulating in a "crescendo," the whole atmosphere was so tense and combative that it became impossible for any one present to bring forth any conciliation. Carmen felt extremely worthless and hurt with so many painful and repetitive comments that she preferred to leave the scene.

I followed Carmen and asked her why she had paged me the previous day: "I think that all those things that I felt before [during the psychotic episode] I am feeling them all over again." I asked what exactly she was feeling she was only able to say: "I am getting scared... I am not sleeping... I have fear, I have fear." Since the mother was so upset with

the overall behaviour of her daughter she didn't pay any attention to the subtle signs of increasing fear and difficulties to sleep that Carmen was experiencing. Yet I could also understand the mother's annoyance because I had a hard time that day to explain to Carmen that I was not going to buy the expensive birthday present that she so much wanted.

My greatest shock, nervousness and preoccupation that day was the fact that Carmen's mother stopped to give any medication to her daughter, although they were still going periodically to the São Paulo Hospital because the psychiatrist was still prescribing medication. The only explanation the mother gave me was that her daughter was feeling much better without any medication because she stopped to suffer from the side effects. I felt a sudden urge to tell the mother after the confusion that it would be better for her to discuss all these issues with Carmen's psychiatrist. The mother simply replied that the psychiatrist never had time to talk with them. She also asked me to convince the psychiatrist to set up a longer period of time in their next consultation. Although this would certainly mean even more interference on my part without much thinking I accepted to phone the psychiatrist because I was extremely concerned with Carmen's well being after this episode.

When they went to talk to the psychiatrist in the following week they told him about this episode. Even though he was very disappointed that they were not following his recommendations he didn't think that Carmen was becoming sick again. During the next few weeks because Carmen abandoned school, the mother decided to put her to work in a small store up the street. It didn't last long because Carmen created confusion with the store's owner in the same way that she had created conflicts inside the school. At this point the mother started to notice that her daughter "was talking to herself" and "laughing alone for no reason" which she considered strange behaviours. But the fact that Carmen was

not studying or working was still bothering her the most. During this period even though she did not conceive herself as a religious person she tried to engage her daughter in a Pentecostal religious group that took care of the moral recovery of problematic youth. The pastor only went to their home a couple of times because Carmen became progressively more aggressive and even threatened to kill her mother so that she ended up being interned in a psychiatric hospital for the second time. It was her birthday.

The few times during fieldwork that I suddenly found myself enmeshed in some family conflict I really was not sure what was the best position to take. Some would say that I might have failed in my efforts of not taking sides. At least I tried to be honest with them and with myself. Others would say that I might have failed in my efforts of not disclosing any information to third parties. For instance, when I phoned the psychiatrist to express my concern over Carmen's situation. It is impossible for me to imagine how anyone could enter again and again in the houses and the lives of these people without "being-together" with them and emotionally involved. Yes, I tried my best to withhold my shock and irritation when I heard all the accusations that Carmen received. Carmen's mother was also very ashamed of the fact that I had witnessed their intrigue. I will never forget Carmen's mother expression of relief and contentment when I returned to visit them two weeks later. She was very afraid that I would never come back again. That evening Carmen was very impregnated with anti-psychotic medication, yet her face was glowing in happiness because I had come to her birthday party.

Another circumstance that was a constant challenge in ethical terms was when I had to visit those young people who decided to abandon the psychiatric treatment. Sometimes I felt a certain uneasiness deep inside my heart. It was like having a flea under the ear asking me whether they would experience psychotic symptoms again one day. I believe that I have always respected their option of interrupting the psychiatric treatment. But sometimes they were not very sure themselves if they should have done so. More frequently it was the mother who would ask me if I agreed with their position. I preferred

to be honest with my beliefs. I would say that I thought that it would be better if there were a consensus between the patient and psychiatrist before making a decision. But my opinion was never heard. The fact that these young people were rejecting the medication and psychiatrists was very difficult to change. Why continue to take medication if they were feeling so much better without?

Leonardo's story

My pager beeps again: "phone urgent." Why would Leonardo's cousin send me this kind of message? She was very desperate. The whole family was shattered because they had to hospitalize Leonardo in the psychiatric hospital for the first time. It all happened after Leonardo destroyed his father's car with an ax. He became very violent and aggressive with the whole family. He also tried to kill himself. Yet he stayed in the hospital less than three days. He jumped the fence and ran away from the hospital that morning. I panicked. I also remembered the first time that my brother had to be hospitalized. This made me to accept to go and talk to Leonardo's family that evening. Maybe I could be of some support.

It had been more than nine months since I met Leonardo for the first time in the emergency room. As soon as he was transferred to the Schizophrenia Programme he interrupted the psychiatric treatment and church attendance at the same time. When I arrived at Leonardo's home that evening several neighbors and family members were talking outside. Church people had also come during the day to pray. They were somewhat relieved. They were not expecting that Leonardo would come back home after running away from the hospital. They expected him to be revolted but he was only very tired. He walked for more than seven hours before coming back home. He was frothing and impregnated He had bruises all over his body. The family was very confused without knowing what to do.

The mother wanted to keep her son at home. The father wanted to hospitalize him. They asked me to talk with Leonardo because they thought that he would listen to me.

Leonardo: But Cristina does God exist?

Cristina: Yes, I believe so.

Leonardo: No. I don't think that God exists.

Cristina: May be it is because you are suffering a lot.

Leonardo: Yes, I am suffering a lot.

He was seeing the "masked men" (hallucinations). The same "men" who were persecuting him during his first psychotic episode because he had robbed a car. He believed that he needed to stay at home to protect his family from the "masked men." Nobody told him that but he imagined the "masked men" had invaded his house, messed up with every thing and raped all the members of his family. He never destroyed his father's car, he was only fighting against the "masked men." The hospital was not a place for him. He didn't need to take any medication. His place was at home to protect the whole family. The hospital was worse than a prison. He always managed to escape from the police not to get in prison. Why would he have to be imprisoned inside the hospital? But he was not worried anymore. It was a "top secret" how he did this but he gained a lot of money. His family was not going to have any money difficulties anymore. He was a rich man now. He just had to remember the password of his bank account. He forgot the password: that was his only problem. Now he would be able to fulfill everyone's dreams. Even my own dreams.

I only listened. It was useless to tell Leonardo that it would be good to take the medication. I even tried, but I didn't insist. He asked me to sleep in their house that night. It was so late, there were not many buses running in the street anymore and the subway was already closed. I accepted. His whole family seemed to be more alleviated to have my

company that night. Leonardo's parents wanted to take him back to the psychiatric hospital without telling him where they were going. I interfered once more. I believed that if they did that they were running the risk of not having their son trusting them later on. They agreed with me. Then Leonardo's mother decided to go to the São Paulo Hospital to obtain more medication for her son. I explained to her that in the emergency room they only give medication if they see the patient. She was able to convince her son to go to the emergency room just to receive more medication because he liked and trusted the psychiatrist who worked there. We arrived there very early in the morning. This time Leonardo was hospitalized in a place that had very high fences.

Some people might say that I should not have gone to Leonardo's home that night. This would not be part of my role as an anthropologist. I only needed to tape-record the interviews and that would be more than enough. But I wanted to understand more. I also wanted to be present to what would not come out in the taped interviews. The episode of Leonardo's hospitalization is probably the occasion that I have interfered the most in the lives of these families. I know today that it would be an illusion to believe that I could have maintained an "objective" and "neutral" position of researcher all the time. I am not even sure if that is possible in the kind of research I have proposed here. In some way or the other I have always interfered (or influenced) the lives of these people. Even if it was only by being with them. There were times that I didn't really know what was the most "ethical" position to take. Whenever that happened I tried to use my good sense. But I also tried to act with my heart.

These people have never really understood the meaning of the word anthropologist. It was only a very funny and exotic name. They usually perceived me as "the person who works in the hospital." Ironically, this condition of "being from the hospital" was particularly significant to those families whose patient had abandoned the psychiatric treatment. It seemed that my presence brought to them some sense of reassurance that the psychosis did not come back. I was also seen by some families as

some kind of "psychologist" because I always liked to listen to the young people who were in trouble. During the episode of Leonardo's hospitalization his mother explained to me that "sometimes to talk is better than to take any medication," that is why she always appreciated my visits so I could talk with her son. I also remember the sense of importance that was given to me when some of these young people presented me to outsiders: "she is my psychologist," they would proudly say. In some cases I also became a close friend of the family as well.

I was not raised in a religious background. I was baptized Catholic and that was about it. My own knowledge of the bible is very scarce. Sometimes the people whom I worked with were very surprised by my radiant curiosity towards their religious life since I didn't exactly have a religious life of my own. They imagined that I had received a call to follow a religious path now. They were not totally wrong in their perceptions since I have also been searching for the meanings of religion in my personal life. Some of them were very enthusiastic to introduce me into their religious life, specially the mothers. Yet their personal religious life was not as consistent as I had first imagined. It also gained new and important significance after the outbreak of psychosis as psychosis transforms and is transformed by religious experience.

I hope with this work to have overcome prevalent conceptions which conceive psychosis merely as a deviation and defect in "normal" behaviour, or in other words, as a vivid expression of abnormality. I was helped by some of the insights of European phenomenological psychiatrists who understand the modes of being-in-the-world and being-beyond-the-world of a psychotic patient as "deviations" in the structure of that particular person's existence, or the "disruption" of his or her *condition humaine*.

Chapter 2 - Psychosis, Culture, and Experience

The anthropologist creates the illusion of finality and continuity and coherent meaning, when in fact even the simplest illness episode has more complex resonances than can be accounted for by the analytic models that are available to us. The abstraction of a definitive cultural form out of the inchoate transitoriness and recalcitrant uncertainties of the everyday experience of illness does violence to the personally idiosyncratic and the situationally particular, to the "blooming buzzing" confusion of the stream of living. [Kleinman, Writing at the Margin, 1995: 100-101]

Psychosis in Cross-Cultural Perspective

The debate around psychosis between psychiatry and anthropology is old. Since 1904, when Kraeplin made his trip to Java, with the intention of detecting some cases of "dementia praecox," other psychiatrists have progressively identified patients with classic schizophrenic symptoms all over the world (Leff, 1981). In parallel, transcultural psychiatrists also identified a certain number of issues in cross-cultural research: on the one hand, regarding similarities and differences in the manifestation of psychosis, and on the other, in incidence and prevalence rates across cultures and societies. Anthropologists entered the debate in suggesting a close relationship between schizophrenia and the social and cultural context. For instance, Fortes and Mayer (1966) suggest that while the traditional life of the Tallensi in northern Ghana was insulated from the outside world, it was free from the stresses that precipitate psychosis. They argue that the emergence of psychosis among the Tallensi is associated with social-cultural disintegration and rapid social change when they became more engaged with the modern urbanized South which also represented a breakdown in family structures and a cleavage in values. Devereux (1980), the founder of French ethnopsychiatry, defined schizophrenia as a type of psychosis characteristic of a complex civilized society, that is, as a Western "ethnic"

psychosis that would express the nature and difficulty of modern man trying to adapt to a disoriented environment.

Although it is well known today that psychotic disturbances are found in all human groups, the universality of the psychiatric category schizophrenia, and its diagnostic criteria, remain controversial, especially when compared in a cross-cultural perspective (Murphy, 1982; Kleinman, 1988). Western psychiatrists observed that the majority of psychotic patients they had the chance to treat in non-Western settings (e.g. Africa and Asia), frequently presented a disease process characterized by acute onset, fulminant but short clinical course, and more often than not, complete remission (Lin & Kleinman, 1988). These clinical experiences suggest that the course and outcome of schizophrenia in these "developing" countries might have a better prognosis, with less chronicity, than what is commonly observed in the industrialized Western settings (Murphy, 1968, 1982). Murphy and Raman (1971) published the first careful study, based on a comparison between a 12-year follow-up of treated schizophrenics living in Mauritius, and an analogous sample of schizophrenic patients treated in England. They confirmed the fact that Mauritian schizophrenics presented a much better evolution (fewer relapses, more patients functioning normally and symptom-free) than the control group of similar patients followed-up in England. Additionally, this better prognosis could not be accounted for in terms of difference in incidence rates, better treatment, shorter hospitalizations, or easier environmental conditions. Consequently, this discrepancy in the proportion of social recovery may be related to the nature of schizophrenia in both cultures, or to the influence of these cultures on schizophrenia.

Much of cross-cultural research in psychiatry assumes that schizophrenia occurs in all societies and can be detected with standardized diagnostic techniques. For testing this theory, in the late 1960s, the WHO launched the International Pilot Study of Schizophrenia (IPPS) to explore whether schizophrenia exists in different parts of the world. Methodologically, the IPSS aimed at developing standardized instruments and procedures for psychiatric assessment that would be reliable across cultural settings; it

also explored similarities and dissimilarities of symptomatology, and whether the course and outcome differed from country to country (Sartorius, Jablenski, Shapiro, 1978, 1977).

The IPPS was followed by the WHO investigation of the Determinants of Outcome of Severe Mental Disorders (DOSMD) (Sartorius et al., 1986; Jablensky et al., 1992). The DOSMD was carried out in 10 countries and addressed some of the methodological shortcomings raised by the IPSS. Fundamentally, the study tried to identify (within each catchment area): all individuals presenting a schizophrenic symptomatology and whom were making first time contact with any type of "helpingagency" in the community, rather than just using a hospital-based sample (like the IPSS). It also aimed to explore the role of a few psychosocial factors in explaining differential outcomes of schizophrenia across societies. The DOSMD's two-year follow-up only confirmed the initial IPSS conclusions of:

- (1) Patients from Third Word countries have a better outcome.
- (2) Schizophrenia is ubiquitous, appears with similar incidence in different cultures.
- (3) Clinical features are more remarkable for their similarities, rather than differences (Jablensky et al., 1992).

The WHO epidemiological studies confirm the universality of schizophrenia and its differential outcome between countries, showing a better prognosis in Third Word countries. One could say that these studies have raised more questions than they have responded to (Jablenski, Sartorius, Cooper, Anker, Bertelsen, 1994; Jablenski et al., 1992). Kleinman (1988) criticized the finding that schizophrenia manifests more similarities in symptomatology cross-culturally than not. He noticed that the authors of the DOSMD emphasized similarities in their findings, while at the same time disregarding or minimizing differences. Similarity was partially accounted for by selection criteria, such as demanding that patients to be included in the study display a certain number of symptoms associated with the Western definition of schizophrenia. This led to select a sample of patients who were homogeneous as to their symptoms.

Consequently, patients who presented a certain degree of heterogeneity, and therefore the greatest cultural differences in symptomatology, were simply excluded from the study. Even if "core" symptoms can be found worldwide, this is not enough evidence to prove an uniform pattern of incidence or phenomenology (Murphy, 1982; Murphy, Wittkower, Fried, Ellenberger, 1963). Psychiatrists have a strong bias towards discovering cross-cultural similarities and universals in mental illness, while they simultaneously deemphasize the cultural differences: this is what Kleinman (1988) calls the "category fallacy" in cross-cultural psychiatry research.

Three sub-studies included in the second World Health Organization's crosscultural investigation of schizophrenia (DOSMD) tried to explore in more detail potential cultural influences:

- (1) A first study including nine countries which confirmed that stressful life events precede within a three week period the acute onset of schizophrenia (Day et al., 1987).
- (2) A study comparing the symptomatic and behavioural expression of schizophrenia in India and Nigeria (Katz et al., 1988).
- (3) A study focusing on the relatives' expressed emotion in Aarhus and Chandigarh, India (Leff et al., 1990, 1987).

The WHO sub-study (Katz et al., 1988) which compares cross-culturally the expression and behaviours associated with schizophrenia found that Indian schizophrenics were described by family members as manifesting a more affective and "self-centred" orientation; while Nigerian schizophrenics presented a highly "suspicious," bizarre, and anxious quality in their basic behavioural pattern. These findings were interpreted against the background of the main characteristics of interpersonal relationships and of the notion of person in the two cultural settings. Other authors have argued that the meaning of specific symptoms varies from culture to culture (Scheper-Hughes, 1987; Wylan & Mintz, 1976; Murphy, 1974), but the extent of

variation in the meaning of symptoms within one single culture has not yet been documented.

In psychiatric literature, family reactions towards its schizophrenic member is one of the strongest predictors of clinical relapse for schizophrenic patients, known as the relatives' levels of expressed emotion (EE) (Vaughn & Leff, 1976a; Vaughn, Snyder, Jones, Freeman, Faloon, 1984; Karno et al., 1987). EE is a global index of emotions, attitudes and behaviours expressed by family members towards the patients. This global index was originally created in England by Brown and his colleagues (Brown, Birley, and Wing, 1972) and refers more specifically to criticism, hostility, emotional overinvolvement, warmth and positive comments. In a Western setting, scores of hostility and critical comments are highly correlated, and the level of EE is currently calculated on the basis of criticism and emotional overinvolvement. Patients who live in a home environment characterized by a high level of EE are much more likely to experience clinical relapse than those patients who live in homes with a low level of EE. Differences in relatives' EE have been hypothesized to explain the differences in prognosis across societies. For instance, the better outcome for schizophrenic patients in North India has been hypothesized to be associated with the "tolerance" of relatives in that culture towards the illness and its associated disabilities.

The WHO sub-study conducted in Chandigarh (Leff et al., 1990) aimed at testing this hypothesis. The two-year follow-up data did not confirm that global EE predicted relapse over this period. Instead, the authors found a significant association between initial levels of hostility (one factor of EE) and subsequent relapse. Contrary to what has been observed in the West, hostility was not associated with the number of critical comments. Furthermore, very few parents in the Chandigarh study attained a score for emotional overinvolvement. Either higher levels of emotional overinvolvement are practically absent from the Indian context, or if they are present at all, they would be expressed differently when Indian families are compared with American and British families. The authors concluded that hostility, as well as the other components of the EE construct appear to be subject to different social constraints in India, when compared with

American and European cultures. The remarkable difference in cross-cultural levels of EE profiles suggest that distinct family interaction patterns are at play (e.g. particular emotional responses), and that these may affect or are related to the course and outcome of schizophrenia. Two main issues are raised by the Chandigarh study: the cross-cultural validity of the EE construct; and how the emotional temperature in the household may affect course and outcome in schizophrenia.

Others have argued that EE is a narrowly defined empirical construct, that raises the research dilemma of "prediction without meaning" (Jenkins & Karno, 1992; Vaughn, 1989; Greenley, 1986; Koenigsberg & Handley, 1986). This could be another illustration of the bias of "category fallacy" that is so pervasive in cross-cultural research. In other words, most cross-cultural research use notions such as "expressed emotion," "tolerance" or "social support" without questioning their meaning and exploring the conditions associated with their presence in different societies.

Jenkins (1991, 1988a, 1988b) calls for a broad anthropological reformulation of the notion based on her research with families of schizophrenic patients of Mexican-American descent. At a first level, she focuses her analysis on the components of criticism and emotional overinvolvement. She observes that Mexican-American and Anglo-American relatives are not necessarily critical of the same kind of things, and proposes to consider criticism as a negative affective response to perceived cultural violations – which are likely to vary cross-culturally as well. There might be cultures in which kin do not criticize one another at all. She also argues that the emotional overinvolvement component which rates self-sacrificing, overprotective and intrusive

¹ In fact the relationship between EE and actual behaviour remains controversial. On the basis of a literature review, Koenigsberg & Handley (1986) argue that EE reflects particular family interaction patterns, and that it provides a bridging mechanism to explain how the relative's attitude may influence the patient. But it is often overlooked that EE only indicates attitudes about the patient, rather than describing actual behaviour toward the patient. Brown, Birley and Wing (1972) always assumed that EE only reveals a propensity to become critical or overinvolved at times of great family stress. Other authors argue that EE is in fact a response to the patient's behaviour rather than a cause. Other indicators besides EE were also developed to measure family interaction patterns, for example communication deviance (the degree to which a relative's communication lacks clarity), or affective style (relative's emotional and verbal behaviour when interacting with the patient) (Miklowitz, 1994).

behaviours as unusual, depends on the notion of a "bounded" self which could vary according to the cultures, and which should constitute the context under which to evaluate the psycho-cultural dynamic of intrusive and overprotective behaviours. At a second level, Jenkins describes how the Mexican-American family process of identifying the problem as nervios allows relatives to minimize the problems and to claim that the schizophrenic member is "just like me, only more so." The cultural tendency to define the problem as nervios (instead of schizophrenia) would be linked to family efforts to destigmatize the "schizophrenic" condition; it would reinforce family bonds and solidarity by fostering a tolerant inclusion of the mentally ill member within the home. According to Jenkins, since family emotions associated with this folk label mitigate the impact of diagnosis on the personal identity of schizophrenic patients, resorting to this label may influence the course and outcome of schizophrenia.

With the exception of Murphy's work, cross-cultural research has provided little evidence for understanding the social origins of schizophrenia, although it does provide strong support for the hypothesis that social and cultural factors affect the course and outcome of schizophrenia. H.B.M. Murphy (1982) started by comparing societies characterized either by extremely high incidence rates, or extremely low rates, and by observing the changes in psychopathology between historical periods. While comparing Irish and Croatians, both characterized by high schizophrenia rates, Murphy tried to identify what these two societies have in common. He hypothesized that in both locations the high incidence might be related to inescapable, and unsolvable intra-psychic conflicts - whether to emigrate or not. Likewise, both the Achinese and Tallensi - who showed rapid and drastic changes from low to high incidence rates after a stressful process of acculturation, helped Murphy to further define and corroborate his primary hypothesis. This hypothesis correlates high incidence rates with the existence of an inescapable role conflict, for people who are confronted with the necessity to change their role or lifestyle, but lack a satisfying model.

Murphy's in-depth analysis of the Irish society allowed him to further characterize societies with a high incidence rate of schizophrenia. Irish community life

would trap the less verbally capable members in a kind of "cultural double-bind." In other words, there is a style of communication that may burden those who do not distinguish between shades of meaning, "double think and double speak:" "Social situations are schizophrenia-evoking if they persistently confront people with tasks requiring the interpretation of ambiguous, conflicting or otherwise complex information (Murphy 1975:134)." He also drew attention to the general ambivalence about individual autonomy in Irish society, which he traced back to ambivalent relationships between mother and offspring, ambiguity of sexual attitudes in the more traditional communities, and more important, tensions between generations. Murphy (1974) also identified analogous conflicts in a high-risk population of women living in old French Catholic parishes in Canada, who found themselves trapped between contradictory role ideals, and who were without any model available to them, either to recognize or solve the existing conflicts between "traditional" and "modern" expectancies.

Table 1 - Possible socio-cultural factors affecting the risk and chronicity of schizophrenia

Protecting or relieving factors
Liberal and/or modest social expectations
Easy attainability of rewards implied in foregoing expectations
Simplicity and completeness of rules and guidelines for action

Source: Murphy, 1982

Murphy's hypothesis about the "cultural double-bind" encompasses and transcends Bateson's original notion of "double-bind." According to Murphy, family

Limiting the investigation to disordered communication within family settings, Bateson was the first to postulate that when a person is systematically caught in a "double-bind" - a situation in which no matter what a person does, he "can't win" - he may develop schizophrenic symptoms. The essential components of a double-bind situation are:

⁽¹⁾ Two or more persons.

⁽²⁾ Repeated experience.

that may contain "schizophrenia-evoking" stresses for the "schizophrenia-prone" individual - "the evocative role of complex social tasks (Murphy 1975; 1972)." While differences in incidence (risk) are related to the "cultural double-bind," differences in chronicity (evolution) are attributed to aspects of social organization and cohesion (e.g. obstacles culture places in the ways a person with schizophrenia is attempting to resume social roles). Some of the contributing factors to chronicity might include: the nature of social expectations; the attainability of rewards associated with these expectations; the nature of social rules and guidelines for action (see Table 1).

Scheper-Hughes' (1979) ethnography in rural Ireland confirmed that certain family and community dynamics might produce the "double-bind in culture:" What emerges clearly is the generalized family myth of the black-sheep, alcoholic, shy and the incompetent last-born son, who is fated to inherit the family land (since the "pet" son has probably emigrated). Excess rates of schizophrenia in rural Ireland would be associated with postponed adulthood and the later "identity crisis" of the middle-aged Irish bachelor: "the personal history of the schizophrenic reveals the individual's unique interpretation of his dis-ease and his lonely resolution through descent into psychosis (1979:189)." This cultural environment yields a predisposition for the more "psychologically fragile" to resolve conflicts and handle painful interactions by "flight" (withdrawal, delusions and fantasy), rather than "fight." Yet most schizophrenics remain integrated within community life. Often the community shelters the mentally sick by attributing to them a touch of God's blessing mixed in with the "erratic" behaviour: they are not "lunatics," just innocent soul-hearted "fools."

⁽³⁾ A primary negative injunction.

⁽⁴⁾ A secondary injunction conflicting with the first at a more abstract level and, like the first, enforced by punishment or signals that threaten survival.

⁽⁵⁾ A tertiary negative injunction prohibiting the victim from escaping from the field.

⁽⁶⁾ The complete study of injunction is no longer necessary when the victim has learned to perceive his universe in double-bind patterns. (Bateson et al., 1956).

Waxler's (1992, 1979, 1977) research aims at explaining why the course of schizophrenia is better among schizophrenics living in peasant communities in Sri Lanka. Some cultures create a social matrix that produces messages encouraging short-term illness and a quick return to normality. In addition to factors related to family structure and treatment system, she highlights the role of the most pervasive cultural beliefs about mental illness that are considered to be troublesome, worthy of treatment, but not long lasting; since it can be cured. If other episodes of schizophrenia appear subsequently in the person's life, "they are believed to be another illness, not simply the same underlying disease process appearing again after a period of remission (1979:157)." Cultural beliefs would translate into more positive social expectations and a general attitude of tolerance reducing the risk of stigmatization from the disease. Since it is believed that schizophrenia is caused by external events in relation to the sick person, no self-change is pursued during mental illness; mental illness is thought to be a problem of and for the family, not the sick person. Any treatment, therefore, involves the sick person together with the family and the community. More broadly, Sinhalese culture seems to have a different conception of the person, and of what it is to be a person with schizophrenia.

El-Islam (1982, 1979) has reported that in Qatar schizophrenic patients living in extended families show a better outcome than those of nuclear family households. Apparently the extended family shows greater emotional commitment to each other's well-being (even if there is more intra-generational conflict), and is more tolerant of a patient's minor behavioural abnormalities and temporary protective withdrawals. Cohen (1992) argues that hypotheses like the ones defended by Waxler and El-Islam presume an idealization of Third World countries, where the environment for the schizophrenic is always assumed to be "supportive and tolerant, and [with] little risk of prolonged rejection, isolation, segregation and institutionalization (Cooper & Sartorius, 1977:53)."

Murphy, Scheper-Hughes. Waxler, and El-Islam imply at different levels that chronicity is affected by the ways the patient is received into the community, depending on social integration versus exclusion, flexibility or rigidity of role ideals, acceptance of dependency, and other factors. In a similar vein, Warner assumes that social reintegration

of the psychotic depends on whether he or she is "more likely to return to a useful working role and to retain his or her self-esteem, a feeling of value to the community, and a sense of belonging (1983:210)." In his major work, Warner (1985) adopts a political economical perspective to capture cross-cultural and historical variations in the course and outcome of schizophrenia. He raises important issues concerning the effects of social class, unemployment, labour dynamics and the social organization of work on those who suffer from schizophrenia. According to him, unemployment rates may be a predictive measure of schizophrenia prognosis in a given society; in societies where there is high unemployment and low demand for labour, schizophrenics have fewer opportunities to become socially integrated.

Anthropological Approach to Psychosis

One may say that current medical anthropology develops on the crossroads of the "interpretive" and the "critical" traditions which frame the investigation of the social and cultural context of disease. Interpretive anthropology owes a great debt to Geertz's hermeneutics who paraphrases Weber in saying: "[...] man is an animal suspended in webs of significance that he himself has spun (1973:5);" the analysis of culture is understood as the search for those webs of significance. Furthermore, the nature of anthropological understanding is defined by "seeing things from the native's point of view (1983:57);" it is based on a "thick description" of the social and cultural phenomena and aims at providing an analysis of the meaning of people's experiences within local moral worlds. Critical perspectives in medical anthropology are influenced by writers like Bourdieu (1977) and Foucault (1980) who displace the interest from phenomenological knowledge of "lived experience" towards the idea that social practices and power relations produce and reproduce possibilities of knowledge. To reduce the scope of perspectives appropriated by medical anthropology into the "interpretive" and "critical" traditions is a somewhat "artificial" framework that is only being used here for the sake of presentation. Most contemporary medical anthropologists combine the two perspectives, but with a weighting that varies according to the author.

The interpretive tradition in medical anthropology follows a strong interactionist perspective in which biology, social practices and meaning interact in the organization of illness as social object and lived experience. Kleinman (1977) is a leading figure of the "new-cross-cultural psychiatry" which challenges the conventional assumptions of the "old" cross-cultural psychiatry. Kleinman argues that the major shortcoming of "old" cross-cultural psychiatry is its total reliance on Western psychiatric categories that are applied as if they were "culture-free," thus overlooking key local influences on mental illness. Culture shapes the very ways illness is conceived. Culture is not only a form of representing illness, but is essential to its very constitution as a human reality. Another weakness of the "old" cross-cultural psychiatry is that it simplifies the conception of the role of culture in the genesis and course of illness phenomena. Contemporary approaches in medical anthropology speak of the two-way interaction between the person and the social world that is the source of thought, emotion, and action:

Mental illnesses are real; but like other forms of the real world, they are the outcome of the creation of experience by physical stuff interacting with symbolic meanings. (Kleinman, 1988:3)

More recently Kleinman (1995) defined experience as the inter-subjective medium of social transactions taking place in local moral worlds. In other words, experience is not simply a subjective phenomenon, something located in a single person; it is conceived as an interpersonal field shared by, engaged in, and also mediated between persons in a local moral world. Kleinman also argues that an anthropological interpretation of pain, illness and suffering, as well as the biomedical explanation, runs the risk of being experience-distant, thus de-legitimatizing the human dimension of the subject matter. Kleinman claims that the study of illness and suffering calls for an ethnography of experience that is more self-consciously reflective about the human core of human experience. In other words, the complexity, uncertainty and ordinariness of the person's experience "is also missing when illness is reinterpreted as social role, social strategy, or social symbol as anything but human experience (1995:96)." Furthermore, a contextual approach to experience-near categories takes into account that "something is at stake for all of us in the daily round of happenings and transactions (1995:97)." In this kind of ethnography there are at least two experiences to be considered. First, the

anthropologist's own experience in fieldwork as well as his/her understanding of his/her subjects; and secondly, the subjects' experiences of themselves in addition to their experience of the anthropologist working with them (Bruner, 1986; Abrahams, 1986).

Jackson's (1989) fieldwork among the Kuranko, and Desjarlais' (1992), participation in the healing ceremonies of a barefoot Yolmo Tibetan shaman are examples of "ethnographies of experience" in medical anthropology. They give special attention to the interactive and the lived experience of the anthropologist in relation to those he or she studies. The emphasis is put on the ethnographer's awareness of his own reflections, inquiries, reactions, emotions, intuitions and experiences, including bodily experiences during the fieldwork interaction: "Then there is a good case for trying to understand the world through bodily participation and through senses other than sight. Let us not forget the taste of Proust's petite madeleine, nor music, nor dance, nor the sharing of food, the smell of bodies, the touch of hands (Jackson, 1989:11)." These authors use ethnographic reflexivity to talk about the body; the body as an experiencing agent is prominent in contemporary anthropological analysis on the experience of illness (e.g. Csordas, 1994a; Good, 1994; Good, Brodwin, Good and Kleinman, 1992; Kirmayer, 1992; Gordon, 1990; Pandolfi, 1990).

Some interpretive studies in medical anthropology conceive of the body as a subject of knowledge, experience and meaning prior to representation and build on the notion of embodiment as the paradigm for approaching the problematic of illness experience. For instance, Csordas (1994a, 1994b, 1990) discusses the relationship between religious experience and embodiment within Catholic Charismatic healing practices to show how the body is a productive starting point for analyzing culture and self. He attempts to combine Merleau Ponty's (1945)³ phenomenology which situates

³ Merleau-Ponty (1945) introduces the concept of pre-objective to study the embodied process of perception from beginning to end. On this level we "have" no objects, we are simply " in the world:" perception starts with the body in the world. His phenomenology is a descriptive science of existential beginnings, not of already-constituted cultural products. When we begin with the lived world of perceptual phenomena, our bodies are not objects to us. Quite the opposite, they are an integral part of the perceiving subject.

embodiment in the domain of perception (preobjective) with Bourdieu's (1977)⁴ dialectical structuralism that positions it in the domain of practice and interaction with other selves. Such an analysis of perception and practice grounded in the body overcomes the conventional duality between subject and object, by investigating how cultural objects (including selves) are constituted or objectified on the basis of the indeterminacy and flux of everyday life. Hence, the essential characteristic of embodiment is existential indeterminacy.

While the paradigm of embodiment is very significant to contemporary medical anthropology, the interpretive tradition also pays a great attention to the cultural shaping of people's illness experience by investigating the cultural "idioms of distress" (Nichter, 1981) which organize illness experience and behaviour differently across societies. Thus, culture may provide common pathways of behaviour or even construct unique disorders. This approach is particularly evident in Good's (1994, 1977) classic work on "heart distress" in rural Iran. He started with the local categories of distress, and then explored the full range of local meanings associated with them. This allowed him to develop the "semantic network analysis" approach which understands cultural idioms of distress as core symbols in a semantic network which condenses fields of personal experience, particularly stressful experience, and collective representations and values. These networks of words, situations, symptoms and feelings are what give illness, meaning to the sufferer. This approach suggests that networks of experiences, words, symbols, and interpretations "running together" in a particular culture are associated with particular illness forms or metaphors. The meaning of illness is constituted through social interactions to articulate the experience of distress and to organize actions that will relieve it.

⁴ Bourdieu (1977) rejects phenomenology and forges the notion of *habitus* defined as a system of perduring dispositions that are unconscious, and a collectively inculcated principle for the generation and structuring of both practices and representations. *Habitus* synthetizes behaviour and environment in a single term. The intelligibility of social life is grounded entirely on homogenization of *habitus* within groups or classes and individual variation are explained in terms of homology among individuals. Thus, the individual system of dispositions is a structural variant of the group variants, or a deviation in relation to a style. This transposition of different schemes into different practical domains is based on a logical determinacy, which forms the basis for the polysemy and ambiguity that allows for improvisation in everyday life.

Amarasingham (1980) employed the "semantic network analysis" for analyzing a case of madness (*pissu*) and health care seeking in Sri Lanka. She traced the movement of a single patient seeking treatment for *pissu* from a number of healers. This movement of the patient among a variety of treatment systems (Ayurvedic physicians. Western physicians, and ritual practitioners) allows a fluidity of diagnosis that prevents any explanatory system from dominating the patient's perception of her illness. From the patient's point of view the different explanatory and diagnostic frameworks are not conflictive, and have a cumulative effect on her illness. This occurs because the different treatments are linked by an underlying continuity of process: First, a common process of reinterpretation of personal experience in terms of the public idiom of cultural symbols; and second, a continuous theme cut-crossing all treatments, which conceives illness in terms of excess and imbalance.

In their work about the experience of psychosis in South India, Corin, Thara, and Padmavati (in press) suggest that the "semantic network analysis" proposed by Good focuses on coherent associations of symbols and experiences that "run together" in a particular culture. Building on a perspective derived from French structuralism, she emphasizes the polysemic character of cultural representations and symbols, they emphasize which they consider as "chains of associations" that can be appropriated in different ways by singular people:

Rather than insisting on "what typically runs together," the last approach aims at identifying a series of formal oppositions and associations which cross-cut different areas of the cultural frame, are subjected to displacement, replacement, superposition and are mobilized in a variety of ways at both the collective and personal levels. In our research, the series of formal analogies and oppositions displayed in the various areas covered by individual narratives are understood under the background of parallel associations at the cultural level. (in press: 10)

They also hypothesize that the specific way that people experiencing psychosis mobilize the associative chains are in some way marked by the peculiarity of their experience of themselves and of the world. This could translate into a particular way of interpreting cultural symbols, for example in privileging the articulating power of

peripheral or marginal idioms or representations available in their culture; or reinterpreting common cultural items or inserting these into particular associative chains; or giving more weight to certain of the connotations which are particularly resonant with what they experience.

Corin. Thara and Padmavati showed that patients and family members mobilize different representations or activate different associative chains in order to elaborate what is specific in their experience of psychosis. In this study, patients' attitudes and reactions are analyzed at three main levels: a quest for significance; an appeal to religious referents, and the construction of a withdrawn space. Representations, symbols and behaviours pertaining to each of these levels are located in the larger cultural frame.

Other authors have developed other approaches to the cultural elaboration of psychotic experience. One can mention in this context Scheper-Hughes' (1987) work in a community of South Boston. This shows that psychosis affects not only the individual, but also the entire family and the larger social network, because the illness experience intrudes upon and transforms ordinary cultural patterns and relationships. After examining different perceptions and reactions of the individual, the family, and the community towards specific psychotic symptoms, the author concludes that cross-cultural differences in symptom expression can also reflect the kinds of behaviours that are either allowed or disallowed in the family or in the broader community. What is significant in that context are not only the key symptoms of psychosis, but also the way the whole experience of psychosis is structured and its meaning for the actor and significant others.

In her previous work on schizophrenia in rural Ireland, Scheper-Hughes (1979) tried to examine how historical, interpersonal, and intra-psychic processes interact to produce both an "excess" of schizophrenia and a certain "double-bind in culture." In the same line, Jenkins's (1991) work with Mexican-American families, and Waxler's (1977) work in Sri Lanka associate the course and prognosis of schizophrenia with cultural meanings, social response and the social relations in which they are embedded. However, the purpose of these studies is not to investigate the dynamic interaction between the

experience of psychosis and personal, family or community reactions. These three studies like many others remain at the level of identifying possible cross-cultural influences of psychosis (see the previous section).

Another step in the direction of investigating how the experience of psychosis is structured and the meanings it has for actors and significant others is found in Estroff's ethnography Making it Crazy (1981). Estroff investigated the adaptation of psychiatric patients to a community treatment program in North America by asking how someone identified as a "crazy" person might live in the community. Instead of considering mentally ill people as passive victims of discrimination, she indicates how psychiatric patients themselves create, maintain and perpetuate several strategies of "survival" inside the community. From the outside, some of those strategies may appear indicative of nonintegration in community life; propensity toward social withdrawal, indifference to work (preference to receive disability payments), social networks dominated exclusively by other ex-psychiatric patients, etc. From the inside, these behaviours appear as reasonable strategies, since psychiatric patients are enmeshed in a complicated system of social interactions in which their identities or roles as "crazy" people are the means by which they "make it" or survive. For instance, to remain primarily within the psychiatric patients' group may represent a "healthy" choice, because, consciously or unconsciously, patients are choosing to identify with others in terms of commonly held values, resources and experiences. On that basis the author interrogates and re-contextualizes the movement towards social re-integration of psychiatric patients that is being promoted in the context of the trend towards community psychiatry.

Garrison (1978, 1977) examined how the experience of social reintegration back into the community evolves with chronicity. She compared the types of social networks and help-seeking behaviours of Puerto-Rican women selected along a continuum from normal to severely impaired psychiatric patients. She observes that if the process of "social withdrawal" in schizophrenia takes place progressively; the severing of particular social links tend to occur in a particular order where conjugal bonds are severed first, and relationships to nuclear and extended kin (with the exception of parent-child bond) come

second. Dependence upon unrelated persons (friends, neighbours, associates in church affiliations or healing cults) is usually retained, except for those patients with the greatest degree of chronicity who became dependent upon social institutions and their representatives (e.g. police, mental health clinic).

Garrison indicates that neighbours, "good friends," Pentecostal believers, spiritist mediums, and *bodega* proprietors were likely to be participants in re-created "natural support systems" for schizophrenics, even for the foster home placements. Although this study suggests that social networks and help-seeking behaviours change with the evolution of chronicity, the meanings entailed in this process of social integration for patient and significant others still deserves to be investigated.

The experience of social re-integration of patients with schizophrenia differentiated by their rate of re-hospitalization in psychiatry is explored in an original way by Corin (1990,1994,1998). Her study, conducted in Montreal, explores whether there is a specific style of social integration associated with the ability to remain outside of the psychiatric hospital. To understand the strategies developed by schizophrenic patients, she uses an interpretive approach inspired by the perspectives introduced by European phenomenological psychiatrists (e.g. Binswanger 1994a) and by Ricoeur's hermeneutics. For example, signs of "withdrawal," "lack of involvement" or "inactivity" are not interpreted from the outside as signs of "passivity" or as negative symptoms, but as "phenomena" which refer to a basic experience of oneself and of the world. This basic experience may undergo an impressive re-articulation according to its own rhythms and forms, yet it has to be understood for its own sake. This level of phenomenological experience is beyond what a person can explain consciously, even if such a verbal account integrates the experience: "We have to multiply perspectives and move back and

In the current psychiatric understanding the negative symptoms of schizophrenia reflect a loss or diminution of functions that are normally present. Negative symptoms include alogia (marked poverty of speech or speech that is empty of content), affective flattening (diminution in the ability to display expression of emotion), anhedonia (inability to experience pleasure, loss of interest in social interaction), and avolition (inability to initiate or persist in goal-directed behaviour). Positive symptoms include delusions, hallucinations, disorganized speech and disorganized and bizarre behaviour. While these positive symptoms are often colourful and call attention to the patient's illness, the negative symptoms usually impair the person's ability to function in normal daily life (Andreasen et al. 1995).

forth between explicit discourses that describe forms of relationship to the world, as well as activities and behaviours that enact and reveal a specific stance toward the world (Corin, 1990:161)."

Patients with a better evolution (no re-hospitalizations in the last four years) presented a specific pattern of relating to the world which Corin characterizes as a stance of "positive withdrawal," defined as "a position at distance from social roles and social relationships, combined with various strategies for keeping more tenuous links with the social environment (Corin & Lauzon 1992:267)." This position should not be naively misinterpreted as part of a "negative" symptomatology. What appears at the surface level "negative" feature, indicative of "passivity," "lack of involvement," and as a "deterioration," is also part of a larger restructuring process, by which patients reframe in a meaningful way their position towards the world. This general distancing stance was combined in individual narratives with "relating" elements at the levels of behaviours, imagination and symbols. Among the most significant "relating" elements, she identifies a particular way of occupying public spaces such as fast-food restaurants, parks and shopping centres, while remaining at a distance from other people; and resorting to marginal religious signifiers in order to "inhabit" their own position of withdrawal, providing it with a positive and significant meaning. This position of "positive withdrawal" is also articulated with a position of marginality in the cultural and socialstructural environment of North America.

Other authors investigated the subjective experience of psychosis in relation to the concept of person (or self).⁶ Schizophrenia alters the person's whole experience of

⁶ The concept of person occupies and important place in anthropological thinking since the seminal lecture of Marcel Mauss "Une categorie de l'esprit humain: la notion de personne, celle de "moi (1985)." Marcel Mauss (1985) introduces the notion of self as a category of human thought, and describes an historical movement from the concept of person towards the category of the self. He suggests that this last category becomes more and more clearly identified with self-knowledge (la connaisance de soi) and psychological consciousness (la conscience psycologique). Contemporary anthropology identifies a multiplicity of dimensions to the concept of person and/or self (e.g. Harris, 1989, Csordas, 1994c). According to Harris' review, the concept of "self" reveals the human being as a source of experience, including the experience of that human's own someoneness; while "person" pertains to the human as an agent, the author of an action purposefully directed toward a goal. Csordas indicates some methodological implications of

him/herself and of the world, and its effects are more profound than in other disorders, since schizophrenia strikes at the very heart of what is commonly regarded as the essence of the person. One may say that schizophrenia alters and disturbs an individual's common sense of self, the sense of boundaries between self and others, and the ability of the self to relate meaningfully to the cultural world. Culture is most likely to influence the meaning given to this disruption of the self, that is the ways the experience altered by schizophrenia is cognitively structured and interpreted. From that perspective, the interaction between the person and schizophrenia over time is a key phenomenon to be investigated, because individuals have a relationship with the disorder that influences its course and outcome (Corin, 1998; Fabrega, 1989a, 1989b; Carpenter, 1987; Strauss, 1989; Estroff, 1989).

In Estroff's ethnography of psychiatric patients' adaptation to a community treatment program (see above), chronicity in schizophrenia is also interpreted as the relatively permanent shifting of expectations and definitions of the self: "a part-time or periodically patient can become a full-time crazy person in identity and being (1981:223)." This discussion is grounded within the symbolic interactionist perspective which considers "the self as subject and object and as a product of social process; and the interpretation of events, persons and self through interaction with others as a force for maintaining and altering reality" (1981:216) (e.g. Berger & Luckman, 1967; Mead, 1934). Since "crazy" people are not psychotic all the time, two preconditions appear significant for the development and maintenance of a crazy being and identity: a prolonged mutual breaching between crazy people and the others (e.g. normal people); and the fact that denial or rejection of the inter-subjective shareable, knowable reality is incorporated into and separated from the self of the person. In other words, what joins breaching with psychosis is the duration, intensity, and substantive nature of the conflict (or lack thereof) between inter-subjective realities. Identity, or the knowable self is

investigating person and self from the perspective of "cultural psychology" in contrast to "ethnopsychology:" The former approach treats self and person as universal categories allowing the analysis of psychological processes in a cultural context, while the latter concentrates on the "native's point of view" to investigate the presence, nature and cultural consequences of the notions of self and person, as formulated by the members of a specific culture.

constituted by this dialectic between personal and social selves, subjective and intersubjective realities.

In a special issue of Schizophrenia Bulletin that stresses the significance of investigating a patient's subjective experience and sense of self, Estroff (1989) describes how individuals with schizophrenia locate or situate their illness and symptoms in relation to themselves. She also considers that the concept of self encompasses the temporal dimension of personal history (before and after the illness). She believes that Kohut's idea that object relations are located on a continuum between "self \Rightarrow self-object \Rightarrow object" allows the relative impact of schizophrenia on the sense of self for different persons. For some individuals it would be entirely possible to experience schizophrenia as an object, for others schizophrenia is more of a self-object; while for others it is inseparable from the self. This can be exemplified by illness-identity statements where some patients commented "I have schizophrenia," while others make "I am" statements, such as "I am crazy. I'm not crazy. They say I'm crazy. I don't know."

Corin & Lauzon (1994) have explored the self-perceptions that are associated with the different types of evolution of schizophrenic patients in Montreal. Patients' self-descriptions clearly indicate that their self-image is elaborated in an inter-subjective context, and that it develops in relation to, or in tension with, the other's perception of them. Narratives about self-perceptions confirm that the often hospitalized and the not re-hospitalized patients tend to express two distinct modes of being-in-the world at the structural level. Frequently hospitalized patients express a tension between a drive towards involvement in interpersonal and social environments and a feeling of rejection and marginality; by contrast non-rehospitalized patients' discourse and behaviour indicate a relationship to the world dominated by a tendency towards what the authors call "positive withdrawal." At the level of self-perception, a central feature of often hospitalized patients is to constantly refer to attributes commonly associated with normality, even though these conflict with feelings of rejection and uncertainty regarding their own involvement within a normative frame. They also tend to use qualifiers in a more "substantive way," frequently qualifying themselves through personal attributes; in

contrast, the non-rehospitalized patients use qualifiers to resist an "objective" characterization and tend to introduce some space of freedom and contingency within their self-narrative. The latter group also attempts to position itself as a credible source of self-evaluation, by resisting the normality criteria of others. In other words, non-rehospitalized patients resort to "language games" which reintroduce movement and dynamism into their self-perceptions, and elaborate a positive image behind and through apparently negative features. Although these self-image narratives show a basic sense of alienation from oneself and from the world, they also attest to a variety of devices which patients employed to rearticulate a new sense of personal identity.

Barrett (1996) took a critical approach to analyze how schizophrenia is constructed as a pathological characteristic of the "person." He examined various representations of the person with schizophrenia inside a psychiatric hospital, and showed how the "psychiatric model" forms and elaborates a tension between the "subjective person" and the "person as an object." His analysis dissects the institutional practices through which persons are constructed; it reveals the psychiatric discourse within which they are constituted, and explores how they are variously endowed with subjectivity or divested of subjectivity. Initially, the clinicians (psychiatrists, nurses, and social workers) "take" the person and construct layers of clinical assessments and professional definitions until he or she is made into a case. The person with schizophrenia is more like a fragmented object that each different group of clinicians, from its particular perspective, produces into a "segmented case" which mirrors this fragmentation. A "full work-up," or a fully documented case frequently reconstructs the person as an epic of failures, which anticipates the subsequent evolution of schizophrenia. For example, patients are discovered to have "schizoid" traits from their earlier days, for having been loners or very quiet in school. This "full work-up" produces a person with no separation from his schizophrenia; the "whole person" becomes a "schizophrenic." Clinical work is resumed by the process of "seeing patients." "talking about patients" and "writing them up." It often characterizes the patient as being passive, in opposition to his active illness. In certain circumstances, some volitional aspects of the person are also valued: for instance, in a positive way when the patient "goes back to reality" and the disease enters in

remission; or more negatively, when the patient is "putting on" schizophrenia to manipulate others within the psychiatric institution. In sum, there is basic cultural work - internalization, objectification, segmentation, integration, and resubjectification, applied to a person who is admitted to a psychiatric hospital, treated as a case, put back together as a whole person, and then, let go to become somebody again, after recovery.

Besides considering schizophrenia as a pathological characteristic of the person, Barrett (1998) reminds us that it is also located at the margin and at the outer edge of human comprehension and interpretation. Thus, it is not just a marginal category but also an anomaly, because someone categorized as schizophrenic may be simultaneously regarded as a person and not a person. Barrett considers the capacity of interpretation to be a fundamental feature of personhood, and people with schizophrenia may be judged to be both capable and incapable of interpreting other people (usually both at the same time). While in structural terms the category schizophrenia is perceived as a cultural anomaly, in processual terms it may be a culturally specific variant of the liminal persona. In other words, comments the author liminality may also be a tool to examine the practices through which the category "schizophrenia" is constructed and symbolized, and to examine the ways people defined as schizophrenic are then positioned in society. For instance, people defined as schizophrenic are usually considered dangerous and experience social avoidance; they are associated with the notion of "psychic contagion;"

The notion of anomaly is interpreted as irregularity or incongruity that does not fit a system of classification, and is borrowed from Mary Douglas' classical work on *Purity and Danger: "an anomaly is a category that does not fit a given set or series"* (1966:37).

The notion of liminality emerges from the study of rituals in small-scale societies, and is most notably employed by Turner: "The limen, or threshold, a term I borrowed from van Gennep's second of three stages in rites of passage, is a no-man's land betwixt and between the structural past and the structural future as anticipated by the society's normative control of biological development. It is ritualized in many ways, but very often symbols expressive of ambiguous identity are found cross-culturally: androgynes, theriomorphic figures, monstruous combinations of elements drawn from nature and culture, with some symbols such as caverns, representing both birth and death, womb and tomb. I sometimes talk about the liminal phase being dominantly in the subjunctive mood of culture, the mood of maybe, might be, as if, hypothesis, fantasy, conjecture, desire – depending on which of the trinity of cognition, affect, and conation is situationally dominant. Ordinary life is in the indicative mood, where we expect the invariant operation of cause and affect, of rationality and common sense. Liminality can perhaps be described as a fructile chaos, a storehouse of possibilities, not a random assemblage but a striving after new forms and structures, a gestation process, a fetation of modes appropriate to postliminal existence." (1986:40-41)

one's own sanity may be affected if one does not maintain a certain interpersonal distance from the person with schizophrenia.

While Estroff and Corin center on the personal experience of psychosis, the critical approach developed by Barrett rather investigates human reality as a cultural, social and historical phenomenon. Mental illnesses are culturally constructed as are other aspects of social and clinical realities. This critical perspective suggests that representations of illness are actually misrepresentations by those in power and evidence the cultural and social conditions of knowledge production (Good, 1994). Such a "deconstruction" of psychiatry is exemplary of the critical tradition in medical anthropology (Gaines, 1992). In the same line, Young (1995) discussed post-traumatic stress disorder (PTSD) both as a historical product of collective representations and as a new object of psychiatric science. He delineates how PTSD is made "real" through psychiatric practice and science.

A critical approach has also been applied to describe and analyze the epistemology underlying cross-cultural comparisons. Authors commonly contrast between "socio-centric" and "egocentric" notions of the person. Traditional societies would present a relational, context-dependent self which subordinates individual interests to the good of the collective, while in the West what prevails is the concept of an autonomous, bounded and abstract individual existing free of, yet living in, society (Shweder & Bourne, 1984). Lucas and Barrett (1995) suggest that this distinction only reproduces the central categories (concrete versus abstract, relational versus individualistic, fragmented versus holistic) of what they call "psychiatric primitivism" which constitutes the framework within which contemporary research on the cross-cultural incidence and course of schizophrenia shapes its methodology, rhetoric and strategies of interpretation.

⁹ Primitivism is defined as a body of ideas, images and vocabularies about cultural others that is commonly employed to represent non-Western peoples. It fundamentally reveals the ways the West understands itself in opposition to these others. It also corresponds to the source of images used to think about mental illness, and the intellectual traditions that have constituted cross-cultural psychiatry as a comparative discipline (Lucas & Barrett, 1995).

The authors claim that the underlying logic of the debate generates such dichotomies by itself and cannot be rectified by defining these categories with greater precision. They describe the way modern and traditional society are similarly caricatured and contrasted them in opposing ways depending on one's vantage point towards the very notion of "Primitivism". They propose a schema which distinguishes "Barbarian Primitivism" and "Arcadian Primitivism" which leads to opposite assertions concerning the relationship between culture and mental illness (see Table 2).

Table 2 - Interpretations of schizophrenia in relation to psychiatric primitivism

Table 2 - Interpretations of semi-opiniona in relation to psychiatric primitivism		
	Barbarian Primitivism	Arcadian Primitivism
Modern Society	1	3
·	positively valued:	negatively valued:
Traditional Society	progress, science, rationality, control 2 negatively valued:	individualism, disintegration, alienation, division and conflict 4 positively valued
	backwardness, magic and witchcraft, irrationality, superstition, impulsivity	community, integration, involvement, harmony

Source: Barrett, (1998)

From the perspective of Barbarian Primitivism, modern society is positively valued as dominated by progress, science, rationality and control, while traditional society is disvalued as associated with degeneration, disruption and pathogenesis. By contrast, Arcadian primitivism presents a negative image of modern society characterized by individualism, disintegration, alienation and conflict, and a positive image of traditional society depicted in terms of pristine, harmonious and a therapeutic milieu. Although cross-cultural psychiatry no longer depicts traditional society in the negative terms used by Barbarian primitivism (cell 2)¹⁰, it attempts to explain cross-cultural variation in schizophrenia on the negative image of modernity promoted by Arcadian primitivism

The classical example of barbarian primitivism is Kraeplin's belief that children and primitive people exhibited what is general and universal in mental illness, because the manifestations of schizophrenia resemble the signs of an undeveloped intellectual life (Kraeplin, 1992: 519, as cited in Lucas & Barret, 1995).

(cell 3). From that perspective, people with schizophrenia would symbolize the contradictions, paradoxes and ills of the modern society, that of an alienated, fragmented, meaningless and self-absorbed society. Cross-cultural psychiatry is currently dominated by the Arcadian primitivism in which "primitive" (traditional) societies are perceived as providing means to minimize the problem of psychosis while "civilized" (modern) societies would be more "schizophrenogenic." Other authors have also lamented the imprecision of contrasting categories such as "traditional" and "modern," or "developing" and "developed" countries (Edgerton & Cohen, 1994; Cohen, 1992; Hopper, 1991).

More generally, the "critical" tradition appears to be in a constant tension with the "interpretive" tradition. While the interpretive tradition pays careful attention to the experience(s) of those it studies, the critical tradition claims that this approach tends to neglect the social production of knowledge, power relations and the structural framework within which social interactions are embedded.

Several authors open the possibility of reconciliation between the "interpretive" and "critical" approaches. This can be illustrated by Rhodes' ethnography of a psychiatric emergency unit in North America where she pays particular attention to everyday power relations in this setting. Her analysis is influenced by Foucault's notions of power, knowledge, and disciplinary space. From that critical stance, staff, patients, administrators and other institutions are seen as bound together in the same disciplinary space, one in which all are subjects of power. To varying degrees they are all engaged in situations of shifting, reciprocal and multidirectional power relations: "Power as Foucault shows, does not rest in the hands of individuals or groups, rather it is fluid and diffuse, operating in a net-like grid of relationships. This analogy to a net or a web corresponds to my observation to the way the unit worked (1991:6)." Her analysis also takes into account the Foucaultian approach that "where there is power there is resistance" Interestingly, Rhodes defends the thesis that everyday forms of resistance that emerge in the emergency room are also enmeshed in reciprocal and multidirectional ways. She also illustrates how patients are often treated as "objects" whenever the psychiatric diagnosis and treatment decisions are impelled by the need of emptying beds, lack of time, or as a mere

demonstration of clinicians' competence. They need to admit other "more urgent cases" in the emergency room.

Anthropological Approach to Experience: The Role of Narratives

Victor Turner has been a key figure in the formulation of the "anthropology of experience." He built on the concept of "an experience," *Erlebnis*, or what has been "lived through," derived from Wilhelm Dilthey's (1833-1911) hermeneutics (Turner & Bruner, 1986). Turner reminds Dilthey's distinction between "mere experience," which refers to the continuous flux of sensations, feelings and thoughts, and "an experience," which is the inter-subjective articulation of experience with a beginning and an end. While "mere experience" is the passive endurance and acceptance of events, "an experience" is formative and trans-formative, having a temporal or processual "structure" (composed by emotions, thinking and volition):

What happens next is an anxious need to find meaning in what has disconcerted us, whether by pain or pleasure, and converted mere experience into an experience. [...] The point is whether meaningful guidelines emerge from the existential encounter within a subjectivity of what we have derived from previous structures or units of experience in living relation with the new experience. (Turner, 1986:37)

Building on Turner's (1986, 1985) perspective, Bruner (1986, 1984) indicates that experience is by definition self-referential, and only accessible to the person. Even though one can never have complete access to somebody else's personal experience, we can understand experience by interpreting its expressions (representations, performances, objectifications, or texts). However, the relationship between experience and its expression always remains problematic, firstly because experiences do not just exist "out there," independent of their expression in a particular setting, and secondly, because certain modes of expression transform the very nature of the experience. Since in everyday life some experiences are inchoate, a person sometimes lacks performative and narrative resources to understand or fully express what he/she is experiencing; this

leads to inevitable gaps between experience and its symbolic manifestation or expression. One has to distinguish between life as lived (reality), life as experienced (experience), and life as told (expression). Lived experience is always in motion, therefore its expression is never an isolated, static text. It involves a processual activity, a verb form, an action rooted in a social situation with real persons in a particular culture, and in a given historical time. A ritual must be enacted, a myth recited, a narrative told, and a drama performed.

The two major anthropological ways to access the expression of lived experience are the analysis of narratives, and the analysis of rituals. The second perspective (which will be discussed in the last section of this chapter) is especially interesting to explore because rituals create meaning and generate change while communicating the deepest values of the group that performs rituals. When one considers narratives, its essential quality is its unfolding through time, its working through plots. Victor Turner (1981) purports that this structure of narrative time lies parallel to the social process itself; narrative accounts (e.g. story) as well as other social dramas (e.g. religious ritual) are organized in relation to the contradictions embedded within societies and which become evident in moments of breach and crisis. Narratives move through time between the "formed and the indeterminate." Temporality, plot and emplotment are present not only in the structure of a narrative but in its performance. Narratives and social dramas are inter-subjective processes where performers and audiences bring about "an event" within temporally lived experience (Good, 1994).

The notion of emplotment developed by the phenomenological hermeneutics of Ricoeur reveals that the structure of human temporality has a fundamental relationship to the structure of the narrative because both are tied to the structure of the plot. Narrativity and temporality are closely related – as closely as, in Wittgenstein's terms, a language

Narrative theory defines plot as the underlying structure of a story, while emplotment is the activity of a reader or hearer of a story who engages imaginatively in making sense of the story. Mattingly's (1998) anthropological work, for instance, makes extensive use of narrative theory to explore the relationships between story/experience and the use of narratives by occupational therapists as they organize their practices and the experiences of those they treat.

game and a form of life. Indeed, temporality is taken as that structure of existence that reaches language in narrativity, and narrativity as the language structure which has temporality as its ultimate referent. Narrativity is also mediated through notions of permanence and change that contribute to construct the "narrative identity" of the story's character. Historicity refers to the historical condition of a human being who makes, writes or reads these stories. Any text is a "work" of discourse configured into a particular genre with its individual style, while the subject - whether author or reader, is the "playful figure" of the text. It is the complex interplay between belonging and distancing oneself from a text, which is always referred back to its historicity, that forms the matrix of Ricoeur's theory of interpretation (Ricoeur, 1992, 1988, 1981).

Ricoeur's theory of interpretation is based on the comparison of the narrative structures of fiction and history, as distinct from the more chaotic and unexpected realm of everyday actions. In medical anthropology, narratives are explored through the notion of "illness narratives." Illness narratives (e.g. Kleinman, 1988; Good, Brodwin, and Kleinman, 1992) are more specific than a life history because they are focused on particular illness experiences (e.g. disease episode or its origin). Good (1994) describes the "subjunctivizing" function of some forms of illness narratives. In his analysis of illness narratives collected from patients and family members in a study on epilepsy in Turkey, he noticed that the fragmented, contradictory and partial character of illness narratives can be understood as a specific style of narrator which allows the subjects (the "narrator," the "reader," or both) to probe the indeterminacy of reality and to keep open a network of perspectives. This narrative strategy allowed multiple readings of a painful reality. While personal experience was expressed through illness narratives, it was also crossed and permeated by other people's narratives, which modified its meanings and deeper significance. People experience, perceive and express themselves through a vocabulary of feelings, thoughts and behaviours, articulating it with a set of meanings characteristic of a particular socio-cultural setting.

Narratives of illness and healing experiences often provide distinct and competing forms of composing the illness because they usually maintain the quality of subjunctivity

and openness to change. They also represent alternative plots, a telling of the story in different ways and the possibility of an alternative ending to the story. The subjunctivizing elements are also present because the person with the illness, family members and medical professionals are in the midst of the story they are telling. In Good's study, people who told illness narratives of epilepsy were actively engaged in making sense of the illness and in describing a "subjunctive world" in which healing is an open possibility, even if miracles would be necessary. However, illness narratives of tragic or hopeless cases, for instance those of people who are severely mentally retarded show little openness of this kind. The multiplicity of perspectives and the subjunctivity mode is more evident in those illness narratives of people in the early stages or in the "middle" of the story, while they are still re-evaluating the past and seeking to open their future to change. Illness narratives of chronic diseases maintain little multiplicity of perspectives: the disorder is more part of the "horizon" of the experience, instead of a central "theme" of people's lives (Good, 1994).

In her analysis of homeless schizophrenic people, Lovell (1997) suggests that the subjunctive mode of "what happens next," for instance the knowledge which incorporates healing as a potential endpoint, is not what is important for people with schizophrenia. More commonly, narratives of experiences of schizophrenia are characterized by a constant tension within the "who I am" which also represents an existential struggle between annihilation and survival that reclaims a sense of self. The experience of schizophrenia is tied up with the constitution and reconstitution of the sense of self. Other studies of narratives of people with schizophrenia who are struggling to recover from the disorder indicate that a certain movement towards rediscovering and reconstructing an enduring sense of self constitutes an important aspect of improvement (Davidson & Strauss, 1992; Davidson, 1993).

Experience includes not only actions and feelings, but also reflections about those actions and feelings; it refers to an active self, to a subject who not only engages in, but shapes action. In this framework, psychosis is perceived as the illness of a subject who reacts to it and transforms it in a particular way (e.g. the creative ways that patients with

psychosis find to contain or limit the impact of their symptoms). It has spatial and temporal dimensions that contribute to frame, and are framed by the subject's personal lived experience. Narratives are a privileged way in which people express what they experience. What matters, however, is not simply the content of the narrative but also its style. With respect to narrative style, Corin (1998) suggests that an experience is not revealed exclusively by the explicit content of discourses, but also by blanks, contradictions and inconsistencies that permeate lived experience.

Firstly, one has the intricate task of investigating elements of the cultural "web" which are pivotal in affecting the personal experience of psychosis; secondly one has to find an acceptable interpretive frame from which to analyze the temporal flux of a particular person's experience. Corin (1998) suggests three systematic procedures to analyze the notion of experience from the perspective of the person's narratives and discourses:

- (1) By aiming at the deep structure of experience.
- (2) By dealing with issues of continuity and changes in selves and identity.
- (3) By exploring the intentionality of individual narratives, through its embeddedness within a larger life context, and its inter-textual character.

Narratives of Experience of Psychosis in European Phenomenological Psychiatry

Very often, the behaviour and expression of people who suffer from schizophrenia seem to lack the intentionality and meaningfulness of "normal" human activity. For this reason people who suffer from schizophrenia are often perceived as "primitive" and "malfunctioning human beings" incapable of higher levels of purposefulness and self-awareness. Their behaviour is not only difficult to interpret, but in some sense it is perceived as "beneath" any interpretation. The classic psychiatric definitions of

schizophrenia, like the ones proposed by Kraeplin and Bleuler illustrate this position. They represent schizophrenia in terms of "deficit," "loss," "defect" or "failure" (e.g. defective capacity for abstract thinking, impairment of the ability to direct one's attention). In his seminal work *General Psychopathology* (1964) Karl Jaspers' indicates that psychotic experience remains unintelligible, or bizarre not because it is beneath understanding, but because it goes **beyond** interpretation, thus existing in some unimaginable realm outside the possibility of human understanding. In addition, Jaspers' interpretation accepts the possibility of a radical qualitative difference in the nature of the patient's experience. For example, the patient might be manifesting an excess of cognitive functioning, instead of impairment. This approach also opens up the possibility of understanding the nature of individual experience not in terms of "loss" or "malfunctioning," but by emphasizing the active role the person with psychosis might also play while creating his/her "abnormal" world and actions (Sass, 1992).

In the context of European psychiatric phenomenology, other psychiatrists, like Minkowski, Binswanger, Tellenbach and Blankenburg developed a more elaborate interpretation for understanding the experience of psychosis. Minkowski (1970) introduced a further development to psychiatric phenomenology by investigating the structure of states of consciousness in schizophrenic patients. He tried to define the basic disturbance (*trouble générateur*) from which one could deduce the whole content of consciousness and the symptoms of patients. He considers the "loss of vital contact with reality" as the basic disturbance associated with the psychopathology of schizophrenia. This also means that a person with schizophrenia loses his or her "lived synchronism:"

It is evident that the vital contact with reality has a dynamic nature. It is not a question here of either "touching" material reality or of being touched by it or of any other phenomenon comparable to a relationship of this order. What we have in mind is the faculty of advancing harmoniously

¹² Kraeplin stressed the severity and chronicity of "dementia praecox" (schizophrenia). It tends to begin relatively early in life, and to produce pervasive and persistent impairments in many aspects of cognitive and behavioural function. Bleuler superseded the term "dementia praecox" by the "groups of schizophrenias," and tried to identify the nature and characteristics of basic symptoms; among those, the fragmentation in the formulation and expression of thought are considered as the most important (Andreasen et al., 1995).

with ambient becoming, in penetrating it and in feeling one with it. (Minkowski, 1970: 65)

The phenomenological investigation of experienced time is a major concern of Minkowski's work with psychiatric patients. The most immediate and subjective experience of time is the "flowing of life" which has a certain "speed" and meaning; and is structured in past, present, and future. Furthermore, what is called the "meaning of life" cannot be understood separately from the subjective feeling of experienced time. For this reason any distortions of the feeling of time results in distortions of the meaning of life. People with schizophrenia live more in their own personal time than in the world time. Since many schizophrenics experience that time is "fixed" or "frozen" at the present moment, this might eventually evoke in them a strong feeling of immortality. For instance, the schizophrenic patient tells himself that he is "God" or "Jesus Christ," however this thought is confined within this affirmation and goes no further. This idea is sufficient in itself and remains detached from the dynamics of ambient life. The patient therefore seems completely immobilized in himself, and no impelling influence will free him or her from these "fixed" thoughts (Minkowski, 1970; Ellenberger, 1990).

The existential analysis (*Daseinsanalyze*) developed by Binswanger (1994b, 1993) is not limited to the investigation of states of consciousness, but takes into consideration the entire structure of existence of the individual. He also expects that existential analysis will transcend the impasse between the incomprehensible and comprehensible aspects of psychosis. Existential analysis strives to reconstruct phenomenologically the development and transformation of the inner world of experience of psychotic patients. It provides a conceptual framework inspired by Heidegger and Husserl:

Much to our surprise it has turned out that, in the psychoses that were so far investigated, such deviations could not be understood merely negatively as abnormalities, but that they in turn represent a new norm, a new form of being-in-the-world. If, for example we can speak of a manic form of life or, rather, of existence, it means that we could establish a norm which embraces and governs all modes of expression and behaviour designated as "manic" by us. It is in this norm which we call the "world" of the manic. The same holds true for the far more complicated, hitherto

incalculably manifold world-designs of the schizophrenic. To explore and ascertain the world of these patients means, here and everywhere, to explore and ascertain in what way everything that is -men as well as things- is accessible to these forms of existence. For we know well enough that that-which-is as such never becomes accessible to man, except in and through a certain world-design. (Binswanger, 1994b:201)

Existential analysis unravels what it is like to be psychotic and what it is like to change from one mode of being-in-the-world to another. In his first writings, on schizophrenia, Binswanger enumerates four basic aspects constitutive of the particular mode of being-in-the-world of schizophrenic patients, based on his analysis of five detailed case histories (Ellen West, Lola Voss, Ilse, Susan Urban, and Jürg Zünd). The first and major notion called upon is that of breakdown in the consistency of natural experience; it entails inconsistency in the experience or the inability to "let things be:"

What makes the lives of our patients such a torment is that they are not able to come to terms with the inconsistency and disorder of their experience, but, rather, constantly seek for a way out so that order can be re-established. Everywhere we encounter this unquenchable longing to re-establish the disturbed order, to fill the gaps in experience with ever new ideas, activities, undertakings, distractions, obligations and ideals – the longing, in fine, for "peace and harmony" and "home" (Ellen West), or, indeed, for "death as the sole happiness in life (Ellen West), for Nirvana (Jürg Zünd) in the sense of a final ad acta laying aside of things and, in a definitely final effort," the laying aside of one's self. (Binswanger, 1963:253)

This longing for an "end" emerges in the absence of a way out of existence and due to the inconsistency of experience that accompanies it. The second notion describes the splitting off of experiential consistency into alternatives, into a rigid either-or. In this situation the inconsistency of experience emerges under a new gaze because the *Dasein* (being of human existence) appears to be taking a rigid stance in relation to the disorder of experiential inconsistency. The *Dasein* is only being driven from one to the other side of the alternative without resting:

Instead of a free unfolding of experience we find -in all our cases - an 'imprisonment' or 'bondage' in the 'net' or 'fetters' of the rigid alternative. (1963:255)

Covering is the third notion invoked by Binswanger in relation to schizophrenia. It represents the endless effort to conceal the side of the alternative that is unbearable for the *Dasein*. The fourth notion emphasizes the fact that when one's existence is being worn away, the person is no longer able to find a way in or out.

The case of "Lola Voss" gives a good illustration of how these four basic notions together frame a certain world-design in schizophrenia. Lola's entire being is used up by attempts to protect herself from anything that could disturb her existence and call it into question. She then tries to defend herself in a very playful way by consulting an oracle of words and syllables, a ritual that she created. She would always feel compelled to break up the names of things into syllables, to recombine these syllables in relation to her complicated superstitious system, and according to the results of this oracle, she would make contact with the persons or things in question or avoid them like the plague.

"Lola" is only trying to solve her experiential inconsistency by continuously interrogating "fate." Here the either-or alternative is very rigid and insurmountable because she does not find herself in a position to give up the precarious feeling of safety provided through consultation of the oracle. In fact, this position also serves as a protection for existence and the worlds she lives in and safeguard against catastrophe. In this case, the catastrophe is being felt through categories of familiarity and strangeness or uncanniness. Furthermore, the oracle is covering over Lola's helpless state of anxiety concerning what she feels as "the horrible power of the incomprehensible uncanny" that has been constantly threatening and overwhelming her existence. The oracle consultation also reflects how her existence is being worn away because she is withdrawing from any decisional context of life by making all decisions dependent upon one another:

Lola Voss's persecution complex is to be differentiated from mere superstition when she begins to feel herself bound no longer by the decisions of her self-created oracle, but by the decisions of her self created enemies, as in the case of Ilse and Suzanne Urban. We need, finally, to note the displacement that consists in the fact that the blind obedience to the commands and prohibitions of the oracle seems, in her psychosis, still to leave room for a freedom either to obey or run away from the demands of her enemies. This freedom, however, is purchased at the price of a

complete dependence on the enemies, at the price of persecution psychosis. (Binswanger, 1963:262-263)

Binswanger intended to show with this case how "delusions of persecution" appear as another "thin" safeguard or a form of protection in the context of the oracle consultation. He also reminds us that one should pay close attention to what precedes these delusions because they cannot be understood only by investigating the delusions themselves:

We would then surely find that delusions of persecution, similarly to the phobias, represent a protection of existence against the invasion of something inconceivably frightful, compared with even the secret conspiracies of enemies, are more tolerable; because the enemies, unlike the incomprehensible frightful, can be "taken at something" – by perceiving, anticipating, repelling, battling them. (Binswanger, 1994b:208)

Binswanger suggests that it is not sufficient to describe the "delusions" or any other psychotic phenomena in themselves. They also have to be understood in relation to the whole context of the person's biography, for instance to other events of "Lola's" life which could be associated with something "inconceivably frightful." He believes that this kind of approach is the only one to come closer to a systematic understanding of the incomprehensible life of the psyche. Although he reduced the world-design of "Lola" to the categories of familiarity and strangeness because she was feeling constantly threatened by a restless and impersonal hostile power, this is just one of the world-designs that Lola experienced. Binswanger's investigations on schizophrenic processes indicate that one needs to bring into focus the various worlds in which the patient lives, in order to show the changes in their "being-in-the world" and "beyond-the-world."

Blankenburg (1991) published the case history of "Ann" to illustrate the experience involved in pauci-symptomatic schizophrenia. For this author, it is the "loss of the sense of the self-evident," that nurtures one's feeling of inhabiting a familiar world, which represents the basic alteration of the mode of being-in-the world in people with schizophrenia. He describes how this basic alteration emerges in different areas:

- (1) Transformation in the relationship to the world.
- (2) Transformation in temporality.
- (3) Transformation in the constitution of the "I."
- (4) Transformation in the relationship with others.

The transformation in the relationship to the world is reflected in that people who suffer from schizophrenia loose access to common sense and to the "rules of the game" which regulate everyday life. The transformation in temporality constitutes the difficulty to experience a sense of retro-continuity that prevents people with schizophrenia from perceiving that their existence and relationship with the world are also related to the past. This changes drastically the everyday nature of their lives and the possibility to construct a project for the future. These persons experience a transformation in the constitution of the "I" because they cannot rely on a sense of the self-evident quality of their everyday world. There is a lack of basic autonomy, and they are driven towards isolation in order to protect themselves from the exposure to the surrounding world. Their lack of access to common sense evidently affects their relationship with others because people with schizophrenia are unable to master the rules that run through and orient interpersonal relationships.

All these transformations in one's feeling of inhabiting a familiar world produce an aura of strangeness and alienation and transform the "atmospheric quality" of the

¹³ Since Binswanger (1993) and most phenomenological psychiatrists have privileged the investigation of florid psychotic symptoms like delusions and hallucinations, Blankenburg (1991) decided to give more attention to "pauci-symptomatic schizophrenia." This form of schizophrenia corresponds to "simple schizophrenia" (e.g. delusions and hallucinations are not evident) or "hebrephenic schizophrenia" (e.g. disturbances of affect and volition are prominent). See all the definitions of schizophrenia according to the ICD-10 classification in Appendix 2.

world. Tellenbach (1983) paid particular attention to the way this "atmospheric experience" produces concrete changes in the ways people with schizophrenia perceive and give meaning to the world. This "atmospheric experience" gives a new coloration, another tonality, and a new ambiance to existence.

While Binswanger speaks about the desperate attempts of schizophrenic patients to reestablish the "consistency" of their experience; Blankenburg goes further in suggesting that some patients know how to "flirt" with their psychosis, to play with it to a certain degree, even to put it out of play (Blankenburg, 1991: 193).

Being strongly influenced by phenomenological philosophy, the European phenomenological psychiatry aims at identifying the fundamental alteration – what Blankenburg has called *trouble fondamental*, which indicates the basic changes in the modes of being-in-the-word characteristic of psychosis. This approach is radically different from traditional psychiatry, and particularly from North American psychiatry which qualifies itself as being purely "phenomenological." European phenomenological psychiatry considers that abnormal behaviour is a manifestation of the particular transformations of the personal experience of being-in-the-world, including the experiences of time and space. The symptoms of psychosis (e.g. delusions, social withdrawal) are invested with meaning in the sense that they open dimensions of the basic alteration of the experience.

However phenomenological psychiatry remains essentially concerned with the description of "types" that are pathology oriented. Another limitation of its approach is that meaning is perceived as an individual phenomenon of an individual nature, because it refers necessarily to the inner experience of the psyche. Corin (1990) argues that it is necessary to understand how meaning is constructed in a particular setting and how it contributes to the course of psychosis. Phenomenological psychiatry says very little about the basic strategies created by psychotic patients in order to reorganize their experience of themselves and of the world, and of the dynamics and underpinning of these strategies. Corin observes that although phenomenological psychiatrists have made

a great effort to listen to patients' experience, they have shown relatively little interest in the dynamic transformation of the basic psychotic alteration of experience. Moreover, they have not considered how the personal experience of psychosis is also embedded in a larger social and cultural frame that participates in its basic shaping.

What is important to retain from European phenomenological psychiatry is that anthropological investigations of narratives have to take into account that people with psychosis experience a particular mode of being-in-the-world which transforms commonsense experiences of time, space and story-telling. The analysis of narrative strategies that respect the notion of emplotted time in past, present, and future, or the "subjunctive world" in the sense of "what happens next" have to be revisited under this context. If the basic alteration of psychotic experience is not understood by its own sake, the anthropologist runs the risk of considering that patients are beneath any understanding.

Anthropological Approach to Experience: Religious Idioms and the Work of Culture

Although "illness narratives" (e.g. Good, 1994; Kleinman, 1988) are privileged forms of "text" for accessing meaningful interplay among psychosis, personal experience and culture, it would be important not to limit the investigation to what is narrated about experience, but also to attempt to identify those privileged moments or performances which open up the universe of subjective experience (Corin, 1998, 1994, 1985). Performances can be observed in a number of settings, including the performance of religious rituals. The observation of religious rituals also deserves attention because rituals create meaning and generate change while communicating the deepest values of the group performing them (Turner, 1986, 1985).

The approach to personal lived experience through the analysis of rituals has been explored within studies on spirit possession, particularly in the classic work edited by Crapanzano & Garrison (1977). Since spirit possession is considered an unquestioned

given in the world where the "possessed" individual lives, it provides the individual with an idiom, in this case a religious idiom for articulating a certain dimension of his experience. The notion of articulation is understood as the act of constructing an event to render it meaningful. However, this is more than a passive representation of the event, because the act of articulation is in essence the creation of the event. It separates the event from the flow of experience by giving structure to the event. It also gives context, it relates the event to other similarly constructed events, and evaluates this event along both idiosyncratic and cultural patterns. In sum, spirit possession provides a particular idiom which enables the "possessed" individual to articulate a certain dimension of his experience and to give it new meanings:

Once the experience is articulated, once it is rendered an event, it is cast within the world of meaning and may then provide a basis for action. (Crapanzano, 1977:10)

The religious idiom also allows the individual to structure his or her inchoate feelings. This structuring action however only works if the religious idiom is flexible enough to provide idiosyncratic accommodation to the individual and his situation, as well as to temporal or spatial changes in him and his situation. The spirit idiom may be very elaborate, or on the contrary, the spirits may be ill-defined and ambiguous. In both cases the spirits' characters are not as well developed as to discourage individual elaboration and specification. This process of symbolic elaboration and specification results from a complex "negotiation of reality" between the possessed and those around him; no matter how idiosyncratic and fantastical this individual process seems to be. Furthermore, the varied characters of "spirits" are elements within the spirit possession idiom which are in essence polysemic, and they refer to psychological and sociological aspects of human existence.

The dynamics of this process is illustrated by Zempleni's (1977) description of the life history of the traditional priestess Khady Fall. The various ways in which this priestess resorts to beliefs in the *rab* and *tuur* ancestral spirits enables her to articulate and integrate her position within the conflicting demands of the complex lineage-structured world in which she finds herself. For example, determining characteristics of the spirits

inherited by Khady, such as ethnic origin and religion, repeat the essential features of the lineages to which she herself belongs. These characteristics become signifiers of descent and affinity for Khady and enable her to resolve her personal problems on the "demonic stage." In addition, the domestic altars that she creates for these spirits provide a symbolic space on which her family history and her own biography are projected in condensed form. Thus, the *rab* and *tuur* that she evokes occupy well-defined symbolic positions in her life history and carry out specific functions that can be clearly articulated and analyzed. In sum, Khadi's process of solving a personal problem is also expressed in the *rab*'s idiom, or more generally, by the use she makes of **religious signifiers**.

In a clinical setting of Dakar, Ortigues, Martino and Collomb (1967) employed a similar approach to illustrate the particular ways the patient Aminata was able to solve inter-personal conflicts, and to re-organize her initial psychotic state of bouffee délirante by manipulating a series of religious signifiers that involve her affiliation to the Islamic cult of rab, as well as her beliefs in child spirits called nit ku bon, and in maraboutage (magical practices). Aminata associates the origin of her illness with her family-lineage spirits of rab. This interpretation emerged progressively while she was recalling all the worries that she associated with potential sources of her illness: the lost of her child, the loss of her house through a fire accident, the unemployment of her husband, the burden of having a family to feed. She explains that in four successive generations all the women of her family would "fall down" every Thursday and Friday when they neglected the wicked spirits of rab, and this obligated Aminata to worship these spirits. Since the altar that she had at home for the cult of rab was destroyed by fire she concluded that her illness was caused by the rab. Aminata places herself in a position of a follower who is able to overpower and to be subjugated by the rab. She sees herself as being persecuted and/or loved by the rabs, and her illness prompted her to construct a new altar and to fulfil new sacrifices. The development of this interpretation emerged as an active movement made by Aminata and was associated with the improvement of her clinical evolution and recovery.

In his earlier work, Obevsekere's (1970, 1977) interest in the idiom of spirit possession emphasized the ways cultural signifiers are manipulated by the individual to express personal needs and emotions. Crapanzano (1977) perceived this approach as a mechanistic view of psychoanalysis and an excessively "constructed" view of personality development. Even so, Obeysekere was among the first ones to account for the person's spirit possession and the success of the healing ritual in both psychodynamic and contextual terms. He also argues that in many societies mental illness and its symptoms are expressed in a religious idiom that is shared by the community as a whole, for instance the idiom of demonic possession. Since such expressions of illness are related to the larger experiences and worldview of both patient and the community, the illness becomes existentially meaningful to the individual. This common idiom facilitates the communication between patient and the community and the mobilization of group resources, allows for abreactions, and turns away cognitive and perceptual disorganization. ¹⁴ This argument is in consonance with most anthropological literature on non-Western societies where healing rituals orient and maintain the process of recovery developed by patients and their group of reference (e.g. Corin, 1985; Kapferer, 1983).

Later in his work. Obeysekere developed the concept of "work of culture" in the context of his investigation of cultural rituals and healing processes in Sri Lanka. His detailed case studies of ecstatic priestesses in *Medusa's Hair* (1981) describes how the conventional distinction between personal and cultural symbols (or signifiers) is inadequate and naïve. By focusing on the long locks of matted hair that these priestesses always display, he illustrates how this cultural symbol is associated with their critical personal life crises. **Personal symbols** like "matted hair" operate at the psychological and cultural levels simultaneously since the complex personal experiences of the individual are crystallized in this public symbol. These kinds of symbols are both personal and

¹⁴ The sociological consequence of abnormality is one's alienation from one's culture. Spiro (1965) summarized three criteria which constitute the psychological dimensions of abnormality:

⁽¹⁾ A cognitive disorganization; the person cannot think clearly as others in his or her culture do. The person's cognition is private, incommunicable, "a fantasy."

⁽²⁾ A perceptual disorientation; the person's perception of reality is distorted. The person does not see as others in his or her culture do.

⁽³⁾ An affectual disorientation; the person's affects is qualitatively different from others in his or her group (as cited in Obeyesekere 1970:106).

cultural (public), because they allow the expression of unconscious thoughts of the individual and provide a basis for self-reflection (private dimension), as well as for communication with others (public dimension). These personal symbols can also be embedded in two different movements regarding the source of motivation: that of regression and progression. Thus, they can either operate in a progressive way, towards articulation and restoration, or in a regressive way, remaining trapped within repetition and pathology (Obeyesekere; 1990, 1985, 1981).

In *Medusa's Hair*. Obeyesekere still notices that priestesses were most invariably afflicted with an attack by a spirit of a dead ancestor before assuming their priestess role. During the spirit attack they often experienced a sense of abandonment and despair, a form of the dark-night-of-the-soul experience. This feeling of despair has a phenomenological resemblance to the affects associated with depression – abandonment, hopelessness, sadness and guilt. Even though this affliction is often perceived as form of illness, this experience has a cultural meaning entirely different than depression. Removing this set of meanings would do violence to the data. This became an intriguing problem to Obeyesekere because he realized that a similar constellation of affects and behaviours might receive at least two different cultural definitions in Sri Lanka. These behaviours have a phenomenological resemblance with depression:

- (1) As an illness indicative of a spirit attack experienced by ecstatic priestesses.
- (2) As a reference to the Buddhist sense of suffering, experienced as an ontological problem of existence, to be lived through with good cheer.

In addition, the ecstatic priestess "works" to transform private symptoms she experiences into public personal symbols (e.g. spirit attack), by building on the potential of articulation provided by cultural idioms. By analogy with the "dream work" and "mourning work" described by Freud, the author calls this the "work of culture:"

The process whereby painful motives and affects such as those occurring in depression are transformed into publicly accepted sets of meanings and symbols. Thus the constellation of affects that I talked of earlier can, through the work of culture, be transformed in a variety of directions —

into Buddhism and into spirit attack and no doubt into other symbolic forms also (1985:147).

Thus, the "work of culture" is the process whereby symbolic forms existing at the cultural level are created and recreated through the minds of people. It can also be sustained by "myth models," which are "structures on the long run," that operate in Geertz's terms as models of and for reality; yet they get attached to larger narrative forms such as fiction, history or biography (Obeyesekere, 1992, 1990).

For Obeyesekere (1981), unlike Geertz, the personal reality of the afflicted individuals is also included under the term "reality." In this context, spirit attack is both a personal experience and a cultural performance. How can this be related to pissu (or madness)? When the cultural conception of spirits and demons, (e.g. pretas or mala yaka in Buddhist doctrine) acts as a myth model, the members of the community perceive the pissu, that is the bizarre and idiosyncratic behaviour of the afflicted person, through the myth model, and so does the afflicted individual. When the personal (not private) experiences of the afflicted person are understood as the work of a preta and are not considered bizarre, this myth model is also revitalized and rendered real through the behaviour of the afflicted person. This does not mean that myth models always work. They have more chances to fail whenever the behaviour of the afflicted person is unintelligible to the culture. Obeyesekere compares two patients who were exorcized: The first one is a woman who was possessed by a demonic spirit and ran around the ritual arena threatening to tear her clothes off; in this case her behaviour was perfectly intelligible in terms of the preta or demonic myth model. The woman was able to express her inner turmoil in a publicly constituted religious idiom. The other patient was pulling and pinching his skin because he believed that demons were residing under it. He also abused the gods, the spiritual beings who supposedly would help him banish the demons. His behaviour was unintelligible to the exorcist and the surrounding community because in this culture, demons do not get under one's skin and gods are not abused in the ways the patient did. In this second instance, the exorcist concluded that the patient should be taken to see a Western-trained psychiatrist. There are at least two reasons for which the myth models may not work:

- (1) If the patient does not share the myth model, or if subgroups have invented myth models that are not shared by the exorcist.
- (2) If the nature of *pissu* is such that the inner experience of the individual cannot be articulated through the existing myth models.

In ideal circumstances there are two religious pathways to recovery from pissu in Sri Lanka. Most commonly, the exorcist banishes the intruding spirit or demon who aroused the patient's pissu (or madness), to help the person overcome the ego-alien nature of his/her experience and re-integrate within the group. In the second path, the patient tries to convert and elevate the initial possession into divine ecstasy while engaging him/herself in a new mystical and intensely devotional relationship with a deity. In the first path, the Sinhalese belief in demonic possession provides a cognitive and perceptual structure that can serve as a replacement (even if temporarily) for the psychotic fantasy. The psychotic loss of contact with the outside world might be considerably minimized as long as the "cultural constituted fantasy" is a public one. The second path is illustrated by some Sinhalese ecstatic priestesses who also have a psychotic experience and are able to reinterpret it through the "work of culture" while acting as religious healers or ritual experts; they may continue to be symptomatic, yet enjoying an enhanced social role. Although demonic possession, or its opposite, divine ecstasy, involves an ego-alien experience of estrangement, it is radically different from psychotic fantasy because these experiences are not culturally alien. The ideal of a successful exorcism or cure is to abolish the psychotic estrangement, by reworking the original traumatic experience within both ego and culture. In Sri Lanka, therefore, psychotic symptoms can eventually be converted with ease into cultural symbols, and a context is created in which conflict can be resolved and private experience integrated with public meaning.

What is being suggested by all the studies mentioned above is the interest of investigating the personal experience of psychosis from the perspective of the role of cultural idioms, and most particularly religious idioms. One has to consider in which

ways the experience of psychosis is translated into cultural idioms and also the ways the characteristics of different religious idioms come into play with the experience of psychosis. This is even more relevant in Brazil since there is a multiplicity and diversity of religious idioms and myth models through which the experience of psychosis may be transformed and lived through.

Nunes (1999) followed Corin's general perspective when she investigated how the religious idiom of Candomblé (Afro-Brazilian religion) contribute to articulate the experience of chronic psychotic people who live in a small town in Bahia, Brazil. She compared three groups of people, those who were initiated in Candomblé, those who participated in the religious rituals of Candomblé in a marginal way, and psychotics. The initiated tended to perpetuate the religious tradition, the people who were "at the margin" challenged and put it into question, while psychotic people had "broken up" their relationship with Candomblé, even though they continued to refer to its religious idiom. Patients used the religious idioms in a very flexible and idiosyncratic way by creating a bricolage of the religious signifiers that were then re-integrated in their particular mode of being-in-the-world. Since the religious idiom of Candomblé presents a very unclear boundary between the imaginary and the symbolic, patients tend to play with the ambiguity of several religious signifiers in order to qualify their strange experiences. This also allows them to transplant the new meanings they have created within religious interpretations that are accepted. The psychotic experience is then re-situated in a liminal (transitional) space that is invested with personal meaning that has collective echo and resonance.

Previous studies have questioned the possibility of religious healing for psychotic patients within Candomblé (Csordas, 1987; Velho, 1975; Stanbrooke, 1952 as cited in Lewis, 1989). These authors suggest that the behaviour and symptoms of psychotics and schizophrenics are often considered too idiosyncratic and unreliable for these patients to be successfully initiated and absorbed in Candomblé. Normally, cult members distinguish between the religious idiom of possession trance and the psychotic behaviour. In a more recent study, Teixeira (1994) suggested that people who are seen as suffering of loucura

(craziness) have more chances of being healed after elaborating a new religious identity inside the Candomblé centre. However, Nunes argues that a close reading of the narratives analyzed by Teixeira indicates that most cases cannot be associated with psychosis; the term <u>loucura</u> embraces different expressions of emotional disturbances and is not limited to psychosis. These authors restrict their analyzes to the context delineated by Candomblé. When working in a city like São Paulo one has to take into account that people may use several religious idioms and have more liberty to circulate through different religions. A detailed description of the religious terrain of the city of São Paulo will be presented in Chapter 6.

Other studies of the Afro-Brazilian religion of Umbanda (Bourguignon, 1989), Kardecismo and other eclectic spiritist groups (Greenfield, 1992, 1987; Krippner, 1987) indicate that their spiritual healers claim to treat several mental illnesses, including schizophrenia; or that mental illness is not recognized by their adepts as a psychiatric disorder, but only as a state of a possession trance. This also reiterates that certain religious idioms, in this case, possession trance, may have a "family resemblance" in Wittgenstein's terms, with the expression of psychosis.¹⁵

On a general level, certain religious idioms may have more "family resemblance" with psychosis than others. What also remains to be examined is how people with psychosis make use of the diversity of religious idioms and whether this can be related to this family resemblance issue. The few studies of Brazilian religion mentioned above, with the exception of Nunes (1999), focus on religious healing and on the religious idiom of possession trance. What remains to be investigated are the various ways in which the experience of psychosis can be influenced by religion independently of religious healing

¹⁵ Nina Rodrigues (1900) and Artur Ramos (1940), the first scholars to study the Afro-Brazilian religions in Bahia, compared possession and trance behaviour with mental illness. However, this theoretical perspective has been left aside in Brazil, especially after the anthropological works of Bastide (1960) and Herskovits (1941), who emphasized that possession and trance behaviour should first be explained in relation to its ritual and social context, and not necessarily as a case of individual psychopathology (Goldman, 1985). Although this theoretical problem is overlooked within the Brazilian context, the similarities and/or differences between possession, trance and mental illness, especially dissociative disorder, remain a classic debate in North-America between transcultural psychiatric and anthropology. The discussion concerning the inclusion of "possession and trance disorders" within DSM-

and possession trance. The case study of Mr. A. that is described by Corin & Lauzon (1992) illustrates some of the ways religious idioms come into play when articulating psychotic experience. This patient with schizophrenia was able to reframe in a meaningful way his position of "positive withdrawal" especially through the resort to marginal religious signifiers. In addition to giving access to a social support network, some religious groups also provide an idiom that incites the person to elaborate a space of "solitude" where a new coherence of the self can take shape. The possibility of withdrawing was very important to Mr. A in helping him re-frame his position in the context of a larger view of himself and of the world. Whenever he needed peace and quiet he went to his bedroom and sometimes meditated, but more often he listened to the "vibration of silence" of the home, which was like a presence. He learned this technique in a meditation group. He could also concentrate on the light he saw within himself during meditation. It seems that the frame provided by the meditation group allowed Mr. A to "inhabit" and to give a positive value to the negative valence of withdrawal. Mr A was also able to create peace and calm in himself through a reference to God. This helped him build his self-confidence and to envision a more active social life in the future. Therefore, the references provided by the meditation group introduced Mr. A into a new shared symbolic world that helped him to renegotiate his position of distance towards others. They also invited him to construct an inner space from which he could progressively reach out toward a new mode of relating with others.

The particular ways in which Mr. A used religious idioms is characterized by three main features. The first one is related to the characteristics of the idiom conveyed by the meditation group that stresses the experiential dimension of the relationship with God. The second is the distinction between two different positions of relating to the idiom that Mr. A clearly differentiates. One associates an intense involvement in religion with a worsening of symptoms, while the other allows him to articulate his personal and fragile experience in a positive way. The third feature is the freedom taken by Mr. A regarding the religious belief system and his relationship to the group. He did not find himself trapped within a closed belief system, which enabled him to circulate through various

systems of reference that he linked in a kind of *bricolage*. In his case, as in many other cases, the religious signifiers are derived from a religious group that it is very marginal in itself and that does not really create a new articulation between the person and the core society; rather they help him to elaborate his marginal position.

Chapter 3 – The Inside and the Outside

Some mischievous spirit has defined America as a country which has moved from barbarism to decadence without enjoying any intermediary phase of civilization. The formula could be more correctly applied to the towns of the New World, which pass from freshness to decay without ever being simply old. [...] In the cities of the New World, whether it be New York, Chicago or São Paulo (and the last two have often been compared), it is not the absence of traces of the past which strikes me; this lack is an essential part of their significance. Unlike those European tourists who sulk when they cannot find another thirteenth century cathedral to add to their 'bag', I am happy to adapt myself to a system with no temporal dimension, in order to interpret a different form of civilization. [...] In 1935, the citizens of São Paulo boasted that on an average, one house per hour was built in their town. [...] The town is developing so fast that it is impossible to obtain a map of it; a new edition would be required every week. It has been said that if you take a taxi to an appointment made several weeks ahead, you are in danger of arriving before the builders have finished. [Lévi-Strauss, Tristes Tropiques, 1975 (1955)]

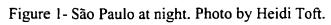
São Paulo just happens to be my home town. Although I have lived away from this megacity quite a few times, I am always puzzled every time I come back to São Paulo because I just have the odd feeling of being a new stranger in my old home town. This feeling was again revived in September of 1997 when I returned to São Paulo to engage in a whole year of anthropological fieldwork. More than 60 years earlier Lévi-Strauss had described the permanence of this city precisely in its lack of temporality: São Paulo as a city which is constantly changing, moving and transforming itself. As soon as I arrived in São Paulo the closest banking machine was not there anymore (it had burned down), the bus line had changed its route, and some streets had recently changed their directions. Suddenly I felt lost: What else would have changed in São Paulo? Would I be able to follow the life experiences of people suffering a first psychotic episode in such a gigantic and confusing city? I will only advance that I often found myself either hurrying through different homes, churches, family dinners, birthday parties and distant neighbourhoods in the East and South regions, also known as the periferia, while other

neighbourhoods in the East and South regions, also known as the <u>periferia</u>, while other times not much seemed to happen, whether I was in the psychiatric emergency room waiting for a "new case" to appear, or whether I spent hours in some interviewee's bedroom trying to engage both of us in any kind of conversation.

Being Poor in São Paulo

The population of the São Paulo Metropolitan Region (SPMR) is estimated at around 17 million with an annual geometrical increase of approximately 1.45% (SEADE and IBGE, 1998). Thus, one out of every ten Brazilians lives in the SPMR. Any other statistical data about this immense population will probably create signs of astonishment and disbelief. Although it is definitively impressive, it can also be illusive to portray the social conditions of the inhabitants of São Paulo with the aid of numbers. Statistics should not be considered more truthful, because a lot might be lost or gained, depending on how the data were collected and have been interpreted or presented. Nevertheless, these numbers may still provide the reader with some useful information which hopefully will exceed the passionate impressions of a person who was born and has lived most of her life in São Paulo.

The centre-periphery pattern of urbanization was consolidated in São Paulo from the 1940s until the 1980s, a period in which the city was transformed into the industrial centre of the country, because the modern heavy industries (e.g. cars) had replaced the traditional textile and food industries. Although this metropolis is nowadays better characterized by its services and terceirization, the new industrialization of earlier decades brought in a flood of migrants especially from the impoverished areas of Northeast Brazil which made the city grow more than 5% a year until the 1960s. For this reason the city area expanded dramatically through the urbanization of the periferia, yet this process of opening up and selling plots of land, together with the expansion of the bus system, was primarily accomplished by private speculators, and with very little control or assistance from the government until the 1970s. These real estate speculators



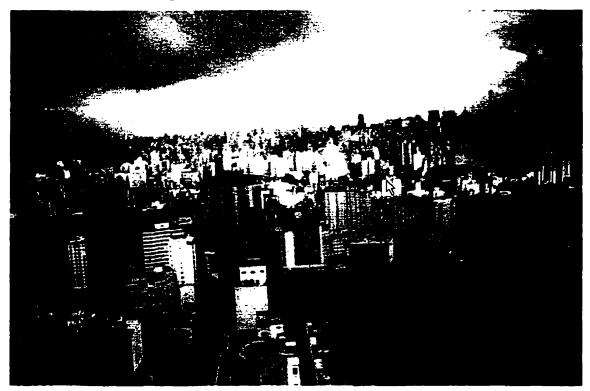


Figure 2- Favela Monte Azul in São Paulo. Photo by Lars May.



were able to create innumerous illegal practices¹ that maximized their profits, from outright fraud to the failure of providing basic urban services. The precarious character of the <u>periferia</u> as a whole, due to the illegality of the land and its buildings, is exactly what made it affordable for a multitude of poor workers who gained a chance to become home owners and solve their housing problems. Frequently, these poor workers were unable to receive any form of government finance to build their own homes, consequently many of them have built their houses in a process called auto-construction: it is a life-long process in which poor families buy a lot and build either a room or a shack at the end of it, so they can move in to avoid rent and afterwards spend decades expanding and improving the building, while furnishing and decorating their homes (Caldeira, 1992; Holston, 1991a, 1991b).

Current government statistics suggest that 78,9% of families live in brick houses, 12,4% live in apartment buildings, 5,2% live in <u>favelas</u>², while 3,5% live inside <u>corticos</u>. In addition, it has been estimated that almost 30% of SPMR's houses are selfconstructed (see Figure 5, 6 & 7). Nowadays, 56,3% of the families own their homes, 34,6% rent it, 12,6% borrow it, and 6,5% have invaded houses and are squatters (SEADE, 1998a). In fact, among the 15 families whom I had the chance to visit at home at least once during fieldwork, 10 families owned their houses (4 were self-constructed, 2 were low-income government constructions, and 4 were precariously built over illegal land, including 1 <u>favela</u>); 2 families rented their homes (1 family lived in a type B <u>cortico</u>), while the remaining 2 families borrowed their houses from other relatives (including 1 type B <u>cortico</u>), and one subject was temporarily living in a type A <u>cortico</u>.

¹ Caldeira (1992) observed that in 1990 São Paulo's Planning Bureau estimated that 65% of the entire city's population lived in residences that were affected by at least one of the various forms of illegality.

² Favela is a set of shacks built on seized land. People normally own their shacks and may transport them around, but they do not own the land which is occupied illegally.

³ I have classified cortico as type A and type B: type A cortico is a kind of tenement housing whose rooms have been rented to different families. In each room, a whole family sleeps, cooks and entertains. The residents of these rooms usually share external or corridor bathrooms and water sources. A Type B cortico is comprised of a common area (quintal) which opens to several houses that follow the bedroom-kitchen pattern.

The wavs in which these 15 families live and appropriate the space of their houses is somewhat different from the typical middle-class model. In the home of 6 families, there was no such place as a living-room, so the kitchen area was considered the central part of the house. In 5 homes, the bedrooms of daughters or sons functioned more as a passage corridor to other parts of the house, instead of being a private and separate room. But in three houses (type A cortico, favela, and one built over illegal land) all family activities were performed in a single room, like eating, sleeping and watching TV. In the homes with no living-room the TV, often considered the most valued household good, was located in the parents' bedroom. A small radio set or an old record player was always present, either to listen to daily religious broadcasting, or to pop music. Only 3 families were able to afford a telephone line. Surprisingly, 5 families owned a car, which was mainly used for weekend outings and emergency situations, but they owned a car, even if only second-hand, old and badly conserved. Although this only reflects my personal values, I was astonished to notice that some preferred to invest in their old car (which increases outside mobility), instead of improving some basic living conditions inside their homes (e.g. confortable chair to sit down).

There is a dramatic gap between the wealthy minority and the majority of the population at the base of the socio-economic pyramid, as seen in Figure 3 which illustrates the distribution of the monthly income of people with an occupation for homogeneous regions of São Paulo during 1997. This figure shows individual incomes, however the total family income is normally composed of the earnings of more than one family member, including the children. The South and East regions are not only the areas where the majority of people live, many in self-constructed houses, they are also the poorest families. Subsequently, these distant regions are precariously served as well, especially concerning public transportation, access to health care, and public education.

Figure 3 - Income of people with an occupation living in homogeneous regions of São Paulo city.

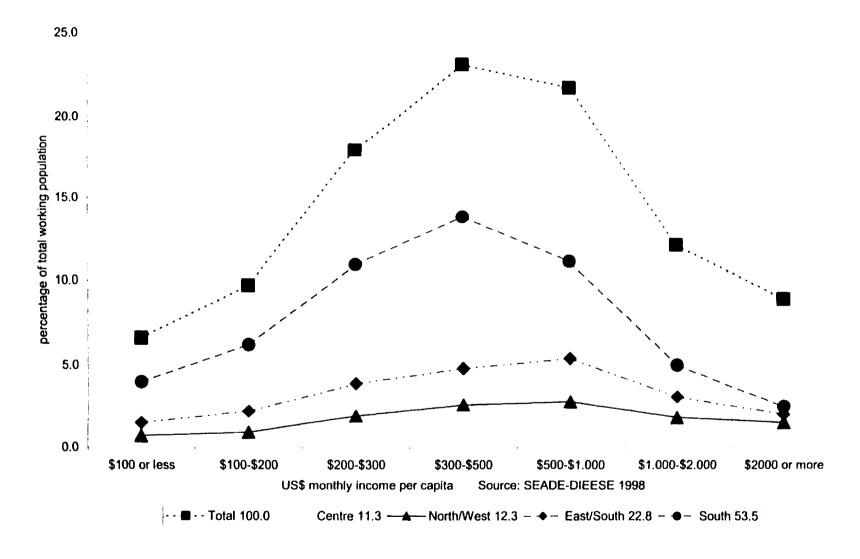
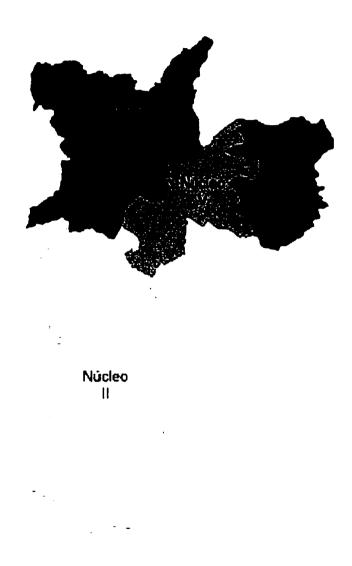


Figure 4 – Map of the city of São Paulo.



Núcleo I = Downtown Area

Núcleo II = South Region

Núcleo III= East Region

Núcleo IV= North Region

Núcleo V = South/East Region (location of São Paulo Hospital)

Although it is difficult to evaluate how many children are being excluded from primary school every year, there is a strong correlation between belonging to the lower social classes, and having less years of schooling. Table 3 illustrates the distribution of the level of education of the head of the family according to different socio-economic classes in the city of São Paulo.

Table 3- Distribution of the level of education of the head of the family in relation to socio-economic classes of the city of São Paulo

Level of Education	Different socio-economic groups*					
	Α	В	C	D	E	Total
Total (in percentages)	100.0	100.0	100.0	100.0	100.0	100.0
I ^{rst} to 4 th grade incomplete	2.0	22.1	28.1	41.9	48.0	22.5
4 th to 8 th grade incomplete	6.2	42.5	42.5	47.2	50.9	34.3
High-school incomplete	7.3	20.5	20.7	9.3	1.1	14.5
High-school complete	23.1	12.9	7.5	1.6	0	12.0
University level	61.4	2.0	1.2	0	0	16.7
Average of school years	12.6	5.8	5.1	3.8	3.1	7.0

Source: SEADE (1998a)

While they are completing the first eight years of elementary school, at least 8% of the students have abandoned school, 32.4% have repeated one school year or more, and 42.3% are delayed in school in relation to their age (SEADE, 1998a). Regarding the 21 patients interviewed, close to half had less than 8 years of schooling (4 males, 6 females), 5 did not complete high school (2 males, 3 females), while only 6 people completed high school (4 males, 2 females). At least 11 persons (6 males, 5 females) needed to repeat one or more school years.

In the past decade the rates of unemployment, pollution, urban violence, criminality, prices and the street traffic have only increased. During the same period migration from other parts of the country have had a much smaller impact on the city's population than before. Thus, the family distribution in relation to the migration status of the head of the family, indicates that 6.4% of the families have been residents for up to 3

^{*} Socio-economic groups A, B, C, D and E follow the general convention: A represents the "richest" while E represents the "miserable".

years, 12.2% from 4 to 10 years, while the great majority of 81.4% have had more than 10 years of residence or were born in São Paulo (SEADE, 1998a). Many residents still hold onto a myth that represents São Paulo as the locomotive of the country and which is always a good place to find a job. Nevertheless, migration to the city has decreased as the rate of unemployment has increased from 10,3% in 1990 to 16,0% in 1997 (SEADE & IBGE, 1998). It took more than a year for 32% of these unemployed people to find another job during 1998.⁴ Another important sign of work instability is the fact that almost 43% of this population with previous work experience changed jobs at least once during the 90's. Table 4 illustrates the magnitude of change in job situations, and its significance for those people who have work experience at one point in their life and live in São Paulo.

Table 4 – Flow between job situations for people with previous work experience in the São Paulo Metropolitan Region (1996)

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Flow between job situations	Percentage
Working with change of jobs	42,8%
Working without change of jobs	20,3%
Working in the first job	6,6%
Working with previous work experience	3,9%
Unemployed with work experience in the 90s	11,1%
Inactive with job experience in the 90s	15,3%
TOTAL	100,0%

Source: SEADE & DIEESE (1998)

The majority of people who have changed jobs (61% of 42,8%), or are presently unemployed (54%) are males; most of them are between 18 and 39 years old; they are equally divided between a group with less than 8 years of education, and another group that completed high-school. Women with little education (8 years or less) are frequently characterized as having no prior work experience, a category which comprises 75% women, of which 61% are between 18 and 49 years old (SEADE & DIEESE; 1998). I have specified these percentages because the 21 patients interviewed are within this age

⁴ According to SEADE & DIEESE (1998) around 29% of the unemployed people (with previous work experience) took up to three months to find another job, while the remaining 40% spent from 3 months up to one year.

range (17 to 27 years), and have been going through very similar work situations (see Table 5).

Insertion of young people into the job market is often hastened by family pressure to raise the level of subsistence for the whole group, or to occupy their spare time that is often spent in the street. Besides increasing the family income, the work of young people allows them to satisfy their personal needs which are not met by the family, like buying new clothes, music tapes, and doing leisure activities. But to be integrated into the work force also means an assertion of their individuality, even though this is considered to be a part of their obligations as sons and daughters; it opens up for them a space of freedom, allowing them access to consumer goods and patterns of behaviour typical of urban young people. Normally the work of young people is only considered a secondary contribution to the total income of poor families. In addition, inside an ideal nuclear family, composed of father, mother, and children, the mother's work outside the home is usually considered as only a small complement to the husband's wage that can serve to buy some extra things. Usually, in Brazil, poor people expect the father to act as the main provider for the whole family (Sarti, 1996; Sposito, 1994; Macedo, 1985; Zaluar, 1982).

Table 5 - Work situation of people during outbreak of psychotic episode

	Male		Female		
Working	7	70%	2	18%	
Unemployed	3	30%	3	27%	
Never worked before	0		6	55%	
Total	10	100%	11	100%	

Nowadays 50% of the families who live in the SPMR follow a typical nuclear pattern with families composed of father, mother and children. The average size of this

⁵ Historically, these poor women always had to work outside the home. Therefore the feminist discourse of "liberation" through work outside the home doesn't carry much meaning to them; because they feel really liberated only when they are able to take care of the house and of their families without the added burden of an outside job (Sarti, 1996).

type of family is around 3.6 people (SEADE, 1998a). However, the father might be unemployed or drinking, the daughter may become a single parent, and the son may get involved with drugs. These are just some commonplace circumstances that shake up the ideal model and demand some family reorganization; they are essentially experienced as disruption and disorder by contrast with the ideal model of family organization which continues to be expected. This model implies that the father is always the main provider and preserves his authority as head of the family, while the mother is the head of the household, and takes care of the well-being of the entire family (Sarti, 1996).

One should not forget the fact that presently in 21% of the families living in SPMR, the mother has actually taken over the role of head of the family due to absence of the father figure, especially through separation or death.⁶ In addition, the family income for 65% of these female headed households is less than USS300 per month (SEADE, 1998a). Beyond the fact that these families are comparatively poorer than the male headed households, the absence of a male provider often means a moral loss that affects the whole family. In this context the mother is likely to assign a significance of "honor" to the paid work she now has to do outside the home, and which makes her proud because it enables her to raise her children as in the male provider model (Sarti, 1996). In this kind of family, the obligations and necessities of daughters and sons to become integrated into the work force is likely to increase, at least this is what has been reported by study subjects. The 20 families⁷ that participated in this study obeyed one of the following patterns:

⁶ Concerning the marital status of the women who are head of the family in SPMR, 34.3% were separated; 33.4% were widowed; and 26.6% were single (SEADE, 1994b).

⁷ One subject has not been counted as the twenty-first family case because he separated from his wife and lived alone.

Table 6 - Family patterns and work situation of head of the family

Family pattern		Work situation of chief-of-the-family
	3	Mothers are working
10 Mother + Children	4	Mothers are retired*
	3	Mothers never worked
7 Father + Mother + Children**	4	Fathers are working
	3	Fathers are retired*
3 Husband-Wife (wife had psychotic episode)	3	Husbands are working

^{* 2} mothers and 1 father have retired due to sickness, but all 7 who are retired receive only a monthly pension of about US\$100.

Pedaços of São Paulo

Most contemporary urban anthropology produced in São Paulo retains a "temptation to the tribe" approach, which means analyzing the neighbourhood, the hospital, the ritual, the party, or religion as if they were closed and auto-centered units. Magnani (1996) argues that the selection of a research topic in the city should not imply cutting all the links that the object of study establishes with the other dimensions and dynamics of urban life. For example, the significance and influence exerted by Candomblé should not be ascribed only to the terreiro (ritual centre) because its rituals overflow the whole city and interact with other social/symbolic spaces (e.g. crossroads dispatches); analogous remarks can be done about other cultural practices in big cities (Gonçalves da Silva, 1996). The ecstatic movement of torcidas organizadas (organized crowds of soccer player fans) in days of "big games" is only one another example about how people might momentarily occupy social/symbolic spaces of São Paulo in different ways (Toledo, 1996).

Lonesome people, anonymous crowds, detachment and fragmented life worlds are the foremost images that come to mind whenever one starts to address issues of sociability within a huge and complex city like São Paulo. It was astonishing to discover how fairly easy it was to record my end-of-day fieldnotes while in the bus or the subway

^{**} In all 7 where the father headed the families, mothers have never worked during the marriage.

(unless it was too crowded), because nobody else around paid much attention to whatever I was saying to my tape-recorder in a low voice. In fact, it was common to see other people listen to their portable CD Rom-players and radios, or to answer cellular phones and pagers while inside public vehicles of transportation. This also suggests that there were some urban spaces which you may pass through relatively anonymous. Yet I was more interested in understanding how "my subjects" reconstructed their own trajectories over the diversity of social/symbolic spaces provided by the city.

When Magnani (1984) investigated how the popular classes living in the <u>periferia</u> of São Paulo filled in their leisure time, he observed a whole spectrum of activities which were not related to the latest novelties of the leisure industry, but were strongly tied with the lifeworlds and traditions of these poor families: circus, baptism parties, birthday parties, marriages, local soccer competitions, male gatherings in drinking bars, charitable bazaars, religious celebrations and rites, collective bus trips to the beach, outings, etc. What distinguished these social activities is that some were practiced inside the home, while others took place outside the home. Furthermore, outside the home activities were subdivided according whether they were done inside or outside the neighbourhood. In his ethnography, the author discloses the importance of a social/symbolic space which is not only restricted to the home, but which informants often call <u>pedaço</u>:

This term designates an intermediate space between the private (house) and the public spaces where a basic sociability is developed; which is broader than the sociability established though family relationships, however it is more dense, meaningful and stable than the formal and individualized relationships imposed by society. (1984:138; my translation)

These <u>pedaços</u> are normally situated within the limits of the neighbourhood and differentiate those people who belong to the network of relationships from the outsiders. People who belong to the <u>pedaço</u> go to the same bus stop, public phone, beauty shop, corner store, health unit, soccer field, etc. They also exchange information or favours, have small conflicts, and participate in neighbourhood activities; in sum, much of everyday life revolves within the scope of <u>pedaço</u>. Some behaviours of loyalty are also

expected from those who belong to the <u>pedaço</u>, but this can also work out as a form of protection. For instance, Zaluar (1994) reported that thieves would never steal from a person who belongs to the same <u>pedaço</u>.

Magnani (1984) transformed the "native" notion of pedaço in a category of analysis which describes a particular form of socialization and appropriation of space (leisure is only one of various forms) that reveals the dynamics of poor neighbourhoods in São Paulo. Pedaço can also be conceived as a space of mediation to DaMatta's (1987) house/street opposition (see description below). Magnani (1996) has also introduced the notion of trajeto (trajectory) to complement the occasionally reified, restricted or extremely "communitary" idea of pedaço embedded in codes of recognition, reciprocity ties, and face-to-face interactions. On the one hand, pedaço functions as a reference point to the lifeworld of the neighbourhood and reinforces the place of origin, family and close network ties. On the other hand, trajeto implies the notion of movement within a field of possibilities (although they are limited) through the other social spaces of the city. For instance, when a person with psychosis is taken to the psychiatric emergency room for the first time, he or she may include this "new" social space into his or her trajectory (and life experience).

House, Street and Other World

Anthropological categories like the house/street opposition have been widely used to explain the social and/or symbolic organization of innumerous societies. I will underscore DaMatta's (1987) interpretation of these categories to suggest how these two spaces interpenetrate each other in Brazil. Initially, this Brazilian anthropologist examined Evans Pritchard's (1940) classic work among the Nuer to remind the readers that every society has a concept of time and a concept of space. In other words, the activities which delineate and mark the time, and provide a basic notion of duration and passage through time, are those activities that occur in distinct spaces in relation to one another. Thus, it is not possible to talk about space without talking about time. Since

people always live "among" or are "in the passage" between social groups, it is possible to feel the time as something concrete, and the transformation of space as something socially important. DaMatta has insisted again and again that several different spaces and temporalities coexist simultaneously within Brazilian society. Obviously some spaces are more individualized while others are more collective, some spaces are permanent while others are transitory (or liminar), and so on.

Before continuing, it is important to emphasize that DaMatta (1997) refashioned the works of Louis Dumont (1970) and Victor Turner (1969) in order to create a useful (albeit disputable) framework for interpreting the Brazilian culture. This author rejects the conventional either/or model (traditional versus modern) by postulating a both/and model, where both hierarchical/personalistic (traditional) and egalitarian/individualistic (modern) codes operate simultaneously throughout the Brazilian society. Whereas many scholars have assumed that traditional elements would progressively be left aside due to the inevitable developments of modernity, DaMatta argues that the non-modern ethic of Brazilian culture may in many situations encompass its more modern alternative. For instance, widespread social dramas like the ethos of jeitinho brasileiro 9, or the authoritarian "Do you know who you are talking to?" 10 not only play out a symbolic inversion, but also indicate how an egalitarian, individualistic situation may suddenly

⁸ Hess & DaMatta(1995) prefer the term "personalistic" because they advocate that "personalism" is more than a cultural system that provides people with a social address in an hierarchical society; it is also a resource that can be used to get around the official rules, e.g. church, state, race, gender of the hierarchical society.

⁹ <u>Jeitinho brasileiro</u> (bending the rules, figuring out a way) is an ethos distinct from corruption that reconciles egalitarian and personalistic principles. For example, a young woman becomes lost in an unfamiliar neighbourhood. She asks for advice from a fire fighter whom she meets on the street. The man explains to her how to go where she wants to go. He tells her to turn left with her car and then give a <u>jeitinho</u> by taking the second left turn and going the wrong way down a one-way street. He explains that this will make things easier for her and that everybody does it anyway (Barbosa, 1995).

¹⁰This situation is hierarchical because implicitly, there are two legal systems, one for the well connected and another for the rest. For example, in case of a parking violation, a well-connected Brazilian might ask the police officer: "Do you know who you are talking to? I'm a friend of so-and-so, who is a friend of so-and-so, who is your boss." The traffic offender might walk away angrily, and a few days later the police officer might actually be obliged to apologize. The parking offender occupies a social position above that of the police officer and has the personal connections to influence the official repercussions of his actions (DaMatta, 1997).

be transformed into a hierarchical, or personalistic one. As a result, Brazil is described as a relational (personalistic) society, one that is neither modern nor traditional, but somewhere in between (Hess & DaMatta, 1995).

DaMatta's interpretation is further developed in calling on the mediations among house, street, and other world (Gods, Saints, Spirits, etc.) which are conceived as fundamental social/symbolic spaces of action and movement for Brazilians. Yet, the meaning of this back-and-forth movement between these three different spaces is broader than merely changing place or contexts, because they are conceived as moral spheres with particular social meanings. Consequently, the house, the street and the other world are spaces with social/symbolic significance that are associated with particular world views and ethics. In support to this argument, DaMatta borrows the notion of double-edged ethics from Max Weber's (1958) analysis of economic exchange because it implies that a society may have codes of orientation and interpretation of behaviour which are contradictory and apply only to certain people, actions or situations. For example, whenever a person buys or sells something from a close relative, he or she may not worry so much about making a profit, but would certainly behave differently, if the transaction had involved a stranger. DaMatta enlarges this notion of double-edged ethics because it might influence other spheres of social life besides economic; and more specifically the house, the street and the other world.

This idea is confirmed when one compares house and street. The home is usually the place where people are hierarchically positioned as "persons" (e.g. father, uncle, mother, son); so they are not "individuals" because everyone relates with each other through family links, or through any other close bond (e.g. sex, age, hospitality). The street, on the other hand, would be a place where people tend to be recognized as "individuals" because they are subsumed under the universal order of the legal system and marketplace. Thus the house is more identified with hierarchical and personalistic moral codes, while the street is usually more egalitarian and individualistic. Nevertheless, some rituals of inversion eventually transform these moral spaces. For instance, the social/symbolic space of the street is transformed during Carnival time, religious

celebrations, political gatherings, or in days of big soccer games. Although the street might be momentarily transformed into these collective spaces, it is also composed of some liminal spaces (e.g. zones of prostitutes and drug dealers), or spaces which are more personal (e.g. where street kids make their home), and so forth.

According to DaMatta, the life worlds of house and street are also mediated by the other world. In this third space of the other world, both moral codes (relational X individual) come together because all people are equal before God, yet they are judged on their individual merits. However, the resolute judgement given by the other world may be mitigated by the intermediary forces of spirits, saints, or the Virgin Mary, who are able to intercede on one's behalf (see description of the religious terrain in Chapter 6). In sum, DaMatta's theory conceives of Brazil as an interstitial culture with a double-edged ethic. Moreover, the heterogeneity of Brazilian society may be exemplified through the fluid and intersecting boundaries between these three kinds of social/symbolic spaces, which can be read as representing distinct worlds, although they also represent complementary values and social strategies within which people move through the day. For this reason the house, the street and the other world are identified as the basic triad that organizes the social/symbolic practices and representations about space in Brazil.

City of Walls and Urban Violence

A redefinition of the meaning of the "street" is underway in Brazil, especially in the big cities, as a result of the increasing violence and unruliness of recent years. Connotations of liberty and encounter once associated with the street space are being gradually replaced by a sense of fear and insecurity (Zaluar, 1993). For example, Caldeira (1992) has described how the fear of crime is creating a new pattern of social and spatial segregation and is changing São Paulo into a city of symbolic and material walls. Everyday talk and rumor about crime have legitimated increasing measures of security and surveillance and transformed streets where children used to play together and neighbours congregated sociably, into empty spaces dominated by high walls, fences, and

in the richer areas, by private guards and security posts. Encounters in the public space are also framed by people's fears and stereotypes in which tension, discrimination, suspicion and violence become the new mark of public interactions. Such "talk of crime" has reinforced symbolic separations by generating stereotypes which label certain social groups as dangerous people to be feared and avoided - especially the poor residents of the <u>periferia</u> – which only increases inequalities and social distance.

If dangerous people are normally associated with the poor, how are the poor people defining themselves? In the poor neighbourhoods of the <u>periferia</u>, the image of the good worker is primarily constructed in opposition to the image of the bandit. Some confusion and ambiguity are attached to the image of the poor, which in some circumstances serves as an unifying function, while in others it serves only to separate the workers from the bandits (Zaluar, 1994, 1985).

This everyday "talk of crime" is nurtured by the fact that urban violence has increased significantly in São Paulo, especially after the 1980s economic recession and the concomitant impoverishment of the entire population. Although the statistics about violent crime¹¹ suffer several distortions, homicide rates for the SPMR have increased from 45.37 (in 1991) to 54.66 per 100,000 population (in 1997). In addition, almost 12% of all male deaths that occurred in 1997 were caused by homicide (SEADE & IBGE, 1998). When one considers the statistics for all violent causes of death, 59.2% of males (4,365) and 29.3% of females (365) died by homicide in 1997. In the same year, the highest proportion of homicides ocurred in the South and East regions of SPMR, corresponding to more than 60% of the violent causes of death (Secretaria do Estado da

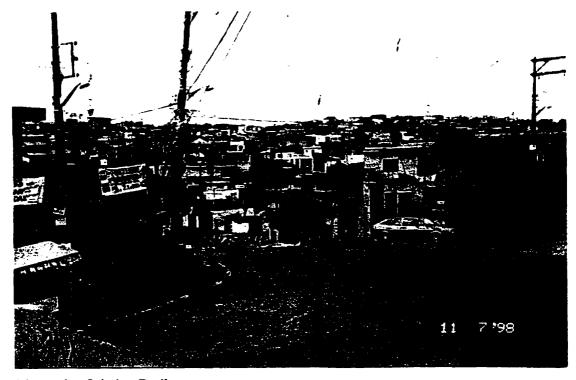
¹¹ Statistics about other types of crime (e.g. theft, robbery, physical abuse) are highly unreported, they will not be discussed here (see Caldeira, 1992). Since all deaths in Brazil have to be reported to the Ministry of Health the numbers are more reliable.

¹² Homicide, traffic accidents, suicides, falls, other accidents and drowning, are the major categories for violent causes of death. Approximately 14% of all deaths that occurred in the SPMR had violent causes (Secretaria do Estado da Saúde SP, 1997).

Figure 5 - Periferia of São Paulo in the South Region.



Figure 6- Periferia of São Paulo in the East Region.



Photos by Cristina Redko

Saúde SP, 1997). Women are more affected by rape and violent aggressions than by homicide. Considering only the police occurrences registered in <u>Delegacias de Polícia de Defesa da Mulher</u> (Police Headquarters for Protection of Women) in 1996, a total of 728 women suffered rape or rape attempt, while 11,597 suffered some kind of violent aggression (SEADE, 1998b). One may notice that the number of women who suffered rape is double the number of women who died by homicide.¹³

It therefore appears that it is the poorest male population who is killed the most often and more violently. Another study about deaths in the periferia carried out by the Núcleo de Estudos da Violência da USP, confirmed police surveys which attest that a large number of homicides occur during weekends around areas of bars where there is a large concentration of men who "drink, fight, and for no reason kill with the aid of a knife or gun" (O Estado de São Paulo, April 26, 1998). More astonishing than the rate of homicides is the number of homicides caused by the police: in 1992, São Paulo's military police killed 1,470 civilians, including 111 prisoners killed inside the city's main prison. During the same year, Los Angeles police killed 25 civilians, and the New York police killed 24 (Caldeira, 1996). One could also expect that the number of people wounded would surpass the number of people who died. This has been shown to happen with the SPMR police, but not merely with civilians: for each policeman who died, an average of 17 policemen were wounded; while for every civilian wounded by the police, there were 3 others who died. This is another indication of the extreme violence practiced by the police, and they are probably using their weapons more than is necessary to subdue suspects (Caldeira, 1992).

After investigating all the cases of death caused by the military police during the 1980s, Pinheiro, Izumino, and Fernandes (1991) concluded that the majority of deaths are acts against poor people, especially young men and black people who live in the poor neighbourhoods of the periferia: 71.5% were men between the age of 15 and 25 years -

¹³ It is well known, although there is no reliable data available that <u>Delegacias de Policia de Defesa da Mulher</u> only cover a small proportion of all the women who suffered rape or some kind of violent aggression, since most of these occurrences remain unregistered (Theophilos Rifiotis, personal communication, August 5, 2000).

which is equivalent to the age range of participants in this study. Even though black and white people who live in São Paulo commit violent crimes in similar proportions, it seems that the black convicts were more persecuted by the police; they also faced more difficulties in having their rights guaranteed by the criminal justice, therefore they had more chances of receiving a more rigorous penalty than the white convicts (Adorno, 1995).

It is a widespread practice of the police who guard the <u>periferia</u> to assess suspect elements by their appearance and certain physical characteristics that are considered marks of a suspect. These characteristics include wearing unconventional clothes, being young, a certain hair and skin colour, and so forth. Other crucial signs are more related with the condition of being a worker, like the <u>carteira profissional</u>, the <u>marmita</u>, and even calluses on the hands (as proof of manual labour). Besides the fact that many poor young people are transformed into suspects without being bandits, the same stigmatizing signs may as well hamper their entrance (or return) to the job market. Thus, the line that separates the image of the poor worker from that of the criminal is very thin indeed (Zaluar, 1994; Caldeira, 1992).

In fact, the *Human Rights Watch World Report 1999* indicates that a whole series of incidents of police abuse (besides homicides) have characterized the transgression of human rights in Brazil. Just an example, often the police practice small rituals of torture as a routine method of investigation in order to extract confessions from defendants – many being shown later to be innocent; and numerous policemen have been involved in corruption, contraband and narcotics trafficking. Although the instances of police brutality are innumerous, police impunity continues to be the rule. According to Zaluar (1994), the negative image which the poor population retains of the police can be articulated in two basic statements:

¹⁴ <u>Carteira profissional</u> is a document that registers a worker's occupational history, and is often the worker's most important proof of citizenship. <u>Marmita</u> is the container in which workers everyday take food to their jobs.

- (1) The police are always chasing the working-class.
- (2) The police force is an agency where impunity and corruption flourishes.

More shocking than the fear poor people often feel towards the police and their lack of faith in the formal institutions of police and justice is the fact that they also expect the police to be violent in order to decrease the high rates of crime, drug trafficking, drug consumption, and other related issues. Thus, it becomes clear that it is not possible to explain the striking increase of urban violence in Brazil with the aid of socioeconomic/urbanization variables alone. For this reason, Caldeira (1992) argued that one should also try to understand the population's support for the use of violence, the status of individual rights, the disbelief in the justice system and its ability to mediate conflicts, and the violent pattern of police performance.

Lived spaces and psychosis

Phenomenological psychiatrists, like Ludwig Binswanger and Eugène Minkowski, pointed out the significance of understanding the psychotic experience in relation to the phenomenology of lived spaces. The most common experience of spatiality is "oriented space"- which has one's body as the centre of reference – which moves along a vertical axis, and along the wide plane of an horizontal axis, which differentiates before and behind, right and left. Binswanger added the notion of an "attuned space" which is a spatial experience determined by one's feeling tone or emotional pitch. At the same time that somebody is experiencing an oriented space, he is also experiencing a special quality of the space in relation to one's own mood. Thus, the pitch or tone of one's inside oriented space may be a feeling of fullness or emptiness, it may be expanding or constricting; while the outside oriented space may have a hollow or a rich and expressive tone (Ellenberger, 1994). Binswanger (1994b) showed that patients with psychosis suffer

¹⁵ Some examples: inside the house, it is often considered a normal behaviour for parents to spank their kids. In the street environment, the violent deaths caused by <u>justiceiros</u> (justice makers) and by lynching of people accused to be criminals are common practices found in the <u>periferia</u> and that are supported by many residents of São Paulo who do not trust the police nor the judiciary system (an they have good reasons not to do so).

a deterioration of their attuned space because it loses consistency, either in a progressive way, or sometimes in a sudden, dramatic way. The excerpts of narratives I have collected also suggest that the alteration of the spatial coordinates also affects the embodied experience of oneself:

During this crisis, I would not remember anyone. Nobody, nobody, and not even where I was. I would lose the notion of space, and even of myself, any physical notion of myself...I lost. I felt that I was very far away. I didn't feel that I was here. I would do things, but for me it seemed that I would not do them! [Eduardo, Charismatic Catholicism]

I thought that the world had ended. Only bad people had remained in Earth, I would see everyone different, I would see everyone in the shape of the Devil. [Mateus, Community of Grace Church]

I would feel, well I would not feel well with myself, felt like I was empty [...] [Feeling empty] inside me, I don't know, inside me I was not feeling well. I was not feeling well at that time, and so I went to a religion because I didn't have a religion. [Maria, Universal Kingdom of God Church]

I know that I became afraid, suddenly I became afraid and I didn't know what to do or where to go. [Leonardo, Return of Jesus Christ Church]

Now my head is more in order... Before it seemed like a fork rotating around [a dish made with] macaroni! And then... I started... the head swollen. [Mauricio, Non-Practicing Catholic].

In Toward a Psychopathology of Lived Space Minkowski (1970:399-432) introduced other distinctions in the experienced spatiality between "clear space," "dark space" and "luminous space." The basic characteristic of "clear space" is associated with an experienced distance in which individuals feel a free space expanding between one another; this enables them to experience distance, extension and fullness of life, that is, a certain life amplitude. Experiencing the obscurity of "dark spaces" goes beyond the mere absence of light; it is associated with the dispersion of experienced distance, so that life amplitude disappears, the vital space is narrowed, and space is de-socialized. For instance, the author associates this experience of "dark space" with delusions of persecution and paranoid hallucinations. The notion of "luminous space" is a way of experiencing spatiality that seems to underlie a number of mystical and ecstatic

experiences where the person would become momentarily blinded by an intense light. Minkowski and Binswanger both argued that psychotic experience is better understood with the knowledge of the spatial experience of the person who is suffering the psychotic episode.

In the narratives I have collected, the affective quality of space is interwoven with the various lived spaces distinguished by Brazilian authors. On the one hand, a first level of analysis builds upon the opposition between house, street and the other world that opens distinct (although pervasive) moral worlds. The notion of pedaço is mediating the life worlds of house and street, while trajeto represents the person's back-and-forthmovement in relation to the amplitude of his or her social interactions (house→pedaço→street). At this first level, reference to the city of walls creates zones of dark spaces within the lively and flowing sociability of pedaços in the periferia. On the other hand, a second level of analysis introduces the personal (and bodily) level of experiencing spatiality that may be more or less attuned to the amplitude of one's life. Since in the case of a psychosis, the quality of "attuned space" is not only affected but often deteriorated, one can wonder how persons circulate between the worlds of house, street and pedaço. And how the affective quality of the lived world reflects or amplifies aspects of the larger lived world marked by poverty, violence and fear. I am interested in the ways in which different spatially and morally structured urban spaces in São Paulo constitute a background against which the alteration of space in psychosis has to be resituated.

Generally, and not only in the Brazilian society, the house is primarily associated with the feminine world, while the street is par excellence the masculine domain. Such meta-categories like the feminine related house, in contrast to the masculine constituted street, often run the risk of reducing and distorting the specificity and richness of individual experiences. However, they may still be useful in helping to illustrate how particular psychotic experiences are not simply embedded in, but also transformed by culture. The beginning of a psychosis is often reported as having been associated with particular lived spaces that are distributed across a gendered line of demarcation.

Table 7 – Anchoring events concurrent with outbreak of psychosis

Street conflicts (10 males)	Theft and/or drugs (4) Police beatings/brutality (1) Street fight (1) Leaving the "street" (4)		
House conflicts (11 females)	Family conflicts (4)* Leaving the house (6)** Tragic death of idolized music band (1)***		

^{*} Some of the most explicit family conflicts mentioned were fights with mother, mother-in-law, husband, siblings, break-up with boyfriend, etc.

Sometimes this broad association gets crystallized around **anchoring events** ¹⁶ that are reported as having happened concurrently with the outbreak of psychosis. Other times the existence of a tension involving a particular lived space is indicated indirectly through the urge to leave a particular kind of place. On the one side, some young men who did not identify any anchoring event directly related to a street conflict, however they still mention that they left the street. On the other side, some young women did not point out a particular house conflict as their anchoring event but they mention a certain urge to leave the house (e.g. to go to church) or actually had to leave it for concrete reasons (e.g. change of address; unexpected family vacation). One could suspect that in these cases, the pressing need to leave the house might indicate some disturbance in their everyday family (house) life. Table 7 shows evidence of this gender differentiation with regard to particular lived spaces, within which occur what I have called anchoring events: young men are strongly connected to the moral world of the street, while the young women are

^{**} Two cases are related to going to church, two are change of address, and the last two are unexpected vacation.

^{***} Singers of <u>Mamonas Assassinas</u> were raised in the <u>periferia</u>, and had tremendous success among young people due to irreverence of their songs. (See also footnote 18).

¹⁶ I have defined anchoring event as the critical event that comes to be associated in the narratives with the outbreak of the psychotic episode. For example, two people have been involved with theft before the outbreak of their psychotic episode, and theft comes to be associated in some way or another with the first outbreak. Since the anchoring event always respects the perspective of the person interviewed, subject and family members may establish different anchoring events for the same psychotic episode.

more associated with the moral world of the house (with the exception of a young woman who mentioned the tragic death of an idolized music band). In fact, José's comments quoted in the next section indicate that the alteration of the lived world often tends to radiate within both types of space.

Dangerous streets

Feelings of fear, and persecution constitute basic signs of alteration of the experience in psychosis. In the case of South India, Corin (in press) has already indicated how a general feeling of fear often colours the whole narrative of people with emergent psychosis. In the case of São Paulo, most people also described fear as encompassing multifarious dimensions of their experience. However, here feelings of fear and persecution are also commonplace experiences of every resident in a city immersed in a world of poverty, urban violence and crime, as described in earlier pages. Consequently, basic signs of alteration of experience in psychosis, in particular fear and persecution, have to be understood through their interaction with more general reactions of fear shared by the entire population.

José's story

José's story is especially illustrative of this particular affective quality of patients' lived world that is concretized through a series of come-and-go trajectories through the urban milieu. In other words, José's unremitting feeling of being chased or of persecution animates the very movement of his inescapable fear and alienates him from every place:

José: Then I noticed that something was disturbing to me. I was already talking outside and I was hearing it inside but this wasn't, it was somebody provoking me from inside, the unconscious, stirring me, you know how this is. Talking and afraid of him, afraid and only taking buses, running I would get into the bus and see one person and see another, and I would say, this person is following me. I would get into the same bus and it

seemed that I saw the same person, I don't know, I would then say that these people were following me. I would get off the bus and onto another, but it seemed that people were following me without stopping, do you understand. Then I would have fear. Oh I went to the airport to catch a plane. I got there, I got there into the airport and I said uhm.... give me... I also said that I was looking very much like Claudinho Bochecha. many people say that.

Cristina: Who is Claudinho Bochecha, I don't know?

<u>José:</u> This is the new <u>dupla sertaneja</u>¹⁷ who sings there. Then I said that they had to call my theatrical contractor because I had to travel to Minas [another state]. I went to the bus station and I bought a ticket, I made my mother give me money, I bought the bus ticket I went to the bus station and then I got afraid of travelling.

Cristina: Why did you want to travel so much?

<u>José:</u> I had fear, I wanted to get out of that place, from home.

<u>Cristina:</u> Were you afraid of your home?

José: I was really afraid of staying at home.

<u>Cristina:</u> Is that so? Was there somebody after you? Did you hear anything?

<u>José:</u> I don't know, because there was also a time when I was caught by mistake, the policemen caught me and beat me thinking I was another guy.

José was actually beaten by the police in his own neighbourhood (or pedaço) a couple of months earlier; a fact depicted as the anchoring event of his psychotic episode. This is not surprising as José is a very poor, black, and unemployed young man who lives in the periferia. His narrative also illustrates the difficulty of drawing a sharp line between reality and fantasy within the lived world of fear and agony. Later in this first interview, José explained how he reacted to the fact of having been mistakenly beaten by the police:

Then after this I started being afraid of going out into the street, [I was] spending some time at home without going out, like my mother told you, after I stayed 7 days at home without going into the street, to nowhere. After the voices started to disturb me is when I began going out at night. [...] There is no way that I would stay at home, I would arrive there and become very terrified, when I arrived in the house I would go in very quickly, and I would not even swallow the food and would go out again.

Musical groups of <u>musica sertaneja</u> are very popular in Brazil. They are normally composed by two men (some are even brothers) who sing country music (often very "soapy") to crowds.

Then I had the idea to tell my mother that I didn't want to sleep at home, that I was afraid of sleeping at home, and so she said that there was a relative who lives somewhere else [the mother was taking José to a psychiatric hospital], so please take me to his house, there is a bunch of people following me, kind of a follower of Jesus Christ, you know that.

Children in a game of hide-and-seek, who are constantly moving in and out of places - either running or standing still - is a good analogy that stands for José's initial experience of psychosis. Yet there are some other ways of reading the same story. First, José's beating by the police transformed his own pedaço into a threatening place, so he avoided the nearby streets, and only remained at home. When José started to hear voices some days later, the home immediately lost its protective atmosphere, and this made him run away from home, and run from his pedaço. In addition, José tried to leave the city by going to the airport and bus station, while wandering through the streets without much direction or sleep. Yet the same incomprehensible fear that drove José to the edge of the city also forced him to stay and not to travel away. While circulating through the city, José continued to be imprisoned by his fear. Second, the violent action committed by the police essentially amplified José's feelings of fear: sometimes it is difficult to discriminate between the fear of police and the fear due to psychosis. Third, José's family shared his fear of police, they took a long time to discover and understand the existence of a fear due to psychosis.

Although José does not appear to have committed any theft or any other crime, in the beginning of his psychotic episode, his family was not really sure whether he did or not. In fact during the days José was ambling in the streets without any bearing, he phone called home from time to time and asked his brother to bring him some clean clothes to the place where he was trying to hide from his persecutors. His brother told me that several times he took clean clothes to the different places where José was trying to hide. His brother added that his own disbelief in the fairness of the Brazilian justice system stimulated him to help José escape from the "police." Only with time did José's brother slowly perceive that there was something strange in José's hiding behaviour; he noticed José's excessive suspicious and fearful attitudes, and all the disguises he created every time the two brothers met.

It is clear that everyday urban violence, especially police violence, resonated with José's psychotic experience. However, José was also living in a moral world that was shared by other poor families of the <u>periferia</u>. Leonardo's story provides another illustration of a blurring of borders between reality and fantasy. It gives evidence of how norms and values governing different social spaces, for example the <u>pedaço</u> versus the street, come into play in that context.

Leonardo's story

Leonardo's first psychotic episode is related to his helping a friend steal a car (theft); and soon afterwards, he felt being constantly persecuted either by the police, theft pals, or simply by "them." These feelings of persecution took a larger proportion as soon as he realized that the car theft happened very close to his home, therefore, close to his private family life. He had broken with the basic logic of <u>pedaço</u> which dictates that people should avoid stealing, or committing other crimes within their own <u>pedaço</u>, a moral space where they would be easily recognized. In addition, Leonardo's fear increased because he believed that this transgression of the <u>pedaço</u> logic would affect the well being of his entire family.

Some revelations can only come in small drops: it took several visits until Leonardo told in confidence that stealing cars was a common practice for him, something he did together with other street friends to raise money to buy drugs (marijuana and cocaine). Suddenly another moral world surfaced, one which characterized his street life: Leonardo didn't see anything wrong in going out to steal a car with friends and have some fun, because he did not make a living out of this leisure activity, and he never killed or threatened to kill anybody, he never used a gun.

Leonardo explained to me how very differently the law, and the police treat those who steal with or without a gun¹⁸. The gun becomes a crucial element of differentiation because people from the <u>periferia</u> consider the act of killing another person, when there is no fair reason to do so, as the worst crime any person can commit. It also makes a lot of sense that Leonardo was feeling very persecuted either by the police or his theft pals, since many of these stolen cars could be easily exchanged for drugs with corrupt elements of the police. In short, the moral world of the street provides some relativization of categories between which no clear boundaries exist: poor worker, thief (with no gun) bandit (with gun), and police (with gun). Furthermore, many young people who are unable to monetarily support their drug consumption behaviour gradually engage in this world of crime and urban violence.

Beyond the fact of not perceiving himself as a thief, Leonardo always succeeded in sustaining the image of a nice, obedient and hard working boy for his family (or inside the home). Several mothers emphasized that what really counted was that their son had correct behaviour when at home, so the mothers remained ignorant about what happened in their street life. Usually, young men attempt to maintain a position that distinguishes the moral worlds of the house from the street. However the divergent worlds of the house and the street often become blurred with the emergence of psychosis. In Leonardo's case for instance, the unbearable fear experienced during his first psychotic episode compelled him to reveal to his parents facets of his previous street life connected with drug addiction and car theft. This revelation caused such a lasting rupture with Leonardo's family and his position as a "good son" that it became impossible to overcome. Several months later - during his

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¹⁸ According to Brazilian laws, theft is always done without guns, so the thieves usually get lesser penalties, than in the case of a robbery (with guns). Several years of ethnographic fieldwork done by Zaluar (1994, 1985) in Rio de Janeiro corroborates the moral world of the street described briefly here through Leonardo's narrative.

second psychotic episode – he ended up being expelled from home by his father.

Hearing voices inside his head was by far the most disturbing sign that changed Leonardo's experience. He also seemed to be caught in a back and forth movement of wanting to run away from home in order to hide from the voices, or to remain always at home in order to watch for the safety of his family against his persecutors, or just because he was too afraid of going out. For a long time, Leonardo's parents prohibited him to get out of the house except to go to church or to psychiatric institutions, in order for him to be protected from the street world of drugs, urban violence and crimes. Thus, his parents considered positively the fact that for a long period of time Leonardo preferred to stay a home. Even when he started to use marijuana again (before the second psychotic episode), his mother overlooked this fact because he was doing it inside the house, where she could keep an eye on him: Nobody knew what could happen in dangerous streets.

All the male narratives, which superimpose experiences of theft, drug addiction, police violence, and street fights, follow a similar direction in the sense that their anchoring events depicted as street conflicts frequently resonate and expand the experiences of fear, terror and persecution associated with psychosis. Thus, Hélio was running away after actually being involved with drugs and robberies (using a gun). I only interviewed him once because he soon disappeared from the city. When I met Hélio, he mentioned that he withheld a series of facts about himself from the emergency room psychiatrist, or lied to her and probably to myself, because he felt terrified that this disclosure would allow his persecutors (police, robbers) to find his whereabouts. One should not be surprised to see street conflicts function as anchors for a series of psychotic episodes, because these are events abound the everyday life of many young males who live in the periferia. The question that remains to be asked is how the same context of urban violence and fear would affect the psychotic experiences of young women.

Normally it is not expected of young women to get involved with the street world of urban violence, crime and drug consumption, although it does happen on a smaller scale. As a matter of fact, the women I interviewed consumed no drugs and usually had no involvement with this kind of street life, despite the fact that some of them lived in very violent neighbourhoods. Even before experiencing psychosis, most young women already lived in a world more restricted to the house, when compared with that of the voung men. I was particularly impressed by a few cases of women who had been living a life of isolation, their social contacts being limited to other family members who lived in the same house. Ironically, girls like Carmen, Kátia, Maria, and Alice only began to have some social contact outside the house through their regular relationship with the psychiatric environment. This was the case of Carmen who for the first time slept outside her home when she was hospitalized in a psychiatric institution. Although the house is essentially considered the moral space of the family, for women in São Paulo it did also work as a sheltered space that protected from the dangers of the street. In all the neighbourhoods I visited, each family spontaneously advised me about the safe time to go back home, or the safer streets where to circulate.

Most young women also experienced feelings of fear and persecution during psychosis, but only a few succeeded in continuing to move back and forth between the inside world of the house and the outside world of the street, as it was the case for several male patients. But for the women this always lasted only for a short time. Although some women experienced a great urge that pushed them outside the house, the basic difference here is probably related to the fact that their families made a bigger effort to keep them inside the house. This family's effort tries to contain the "uncontrolled" behaviour of some young women. To a certain degree, this is related to the family's concern that young women could easily get involved in "undesired" encounters in the street, with the risk of getting pregnant or raped. Families expect the sexual behaviour of young women to be circumscribed within the frontiers of marriage, family life and be limited to their future husband. On the one hand, the sexuality of the potential mother and future housewife always has to be preserved and protected. On the other hand, these young women were considered to be fragile when confronted with the potential dangers of the

male-dominated street. Apparently these worries and fears associated with containing one's sexual behaviour were not only a concern of family members, since they were also expressed without reluctance by some young women during the highest points of their psychotic crisis:

They tried to rape me and I got a trauma from what happened I think I am adopted, something like that in these two years that I've been [systematically] raped, something like that.
[Luana, God is Love]

<u>Cristina:</u> Besides hearing the voices, what else did your daughter feel? <u>Katia's mother:</u> She would feel that they touched, touched her. That somebody was going to relate [sexually] with her, would pass their hands over her, she really started to fantasize sexually. [...] She had her sexual fantasies, like I am telling you, she felt them touching her, she would tell me. [Kátia's mother, Non-Practicing Catholic]

She filled up the closet and all the walls [of her bedroom] with photographs of Mamonas Assassinas. And she would go to sleep after reading them all. And she started to scream. But there is nobody here my daughter. Yes there is, I am seeing them and they want to abuse me [sexually] they are calling me to have sex with them. It happened so suddenly, so she remained the whole night screaming, she remained the whole night because she was afraid, then she came to sleep in my bed and I had to stay with her in the bedroom, she would go to the bathroom and say that they were also in there to get her. And so she said I don't want to stay in my bedroom. I want to go away from this house, this house is full of dead [people], full of people who want to get me. But how they would get you my daughter, this is all from your own head, there is nobody here" [Carmen's mother, NP Catholic]

This fear of being raped or sexually abused may be directly connected with issues concerning their own sexual role. However this fear can also be interpreted as traces that reverberate throughout the general atmosphere of crime and urban violence. Zaluar (1994) reported that while homicide is ranked and perceived by the popular classes as the

[&]quot;Castor oil plant murderers" is the literal translation for the music band Mamonas Assassinas whose members died tragically in 1996 during an airplane accident. The songs played by this music band frequently mocked the poor immigrants from Northeast Brazil, gays, betrayed men, and so on. The most famous song called Vira-vira describes the complaints of a betrayed husband after observing his wife's condition when she returns home from a party of collective sex ("Grupo conviveu com o sucesso por 240 dias" In O Estado de São Paulo, March 3, 1996). You may also return to note in Table 5.

worst crime any person could commit, rape or sexual abuse of another man's woman, usually comes second.

Luana's story

Luana cried out her fear of being raped and adopted the first time she went to SPH's psychiatric emergency. In that day both parents assured the psychiatrist that she was not adopted and had never been raped. They also mentioned confusedly (this episode was a family taboo) that two years earlier Luana had had a serious school fight and had shot and injured another girl, and then she had spent some months in FEBEM (government institution for problematic kids). Luana always avoided talking openly about this episode with me; nevertheless she alluded to it when she claimed that the greatest problem she faced with some female school friends was the fact that they wanted to engage in lesbian relationships with her. In addition, her boyfriend had been in prison for several months because he had robbed a bank to be able to buy drugs. It is easy to imagine that Luana's reference to rape and trauma probably reflected some of her personal experiences with the city's violent milieu.

Kátia and Carmen were comfortable talking intimately with me about their sexual relationships, or their lack of boyfriends. But the terrible fear of rape and sexual abuse they experienced during the psychotic episode were only mentioned de passage, or indirectly. For instance, Carmen mentioned that, "Even now I got this fear of men" when she walked in the streets and noticed that some older man was staring at her. Kátia expressed that "voices" touched her everywhere, then she rubbed her whole body to mimic the reactions she had when these voices wanted to touch her. One may only wonder which other feelings remained concealed or not expressed to the outside world. In the excerpt above, Carmen's mother indicated that her daughter's fear of sexual abuse emerged together with a fear of remaining inside the house, and also inside her the

bedroom. One can wonder how these women resituated themselves within the lived space of the house during their crisis.

Home, Sweet Home

Family conflicts affect both female and male patients. Even so, it was more common to associate a family or house conflict as the major **anchoring event** for a female, than for the males. This is clearly illustrated by Solange's narrative below:

When my husband arrived he whined a lot! So I told him that I was going to build another house to myself. Then like me, he was very nervous too... he never did that. He got a knife and threatened me. I got even more afraid and nervous, but I didn't tell any one about it. From this day it started [the problem]. At least this is what my mother tells me. My mother says that I didn't sleep at night (...), that I broke my home's door lock, but I don't remember. I went to my mother's house and woke her up at 2 A.M. telling her that I was pregnant [but she wasn't]. My mother started to suspect [of something] and I would not sleep anymore. She brought me to São Paulo Hospital. [Solange, 7th Day Adventist]

After the conflict Solange starts to feel even more uncomfortable, fearful and restless inside her own home. Other female patients also reported that in some circumstances they experienced the house as a place that suddenly became "infected":

I woke up, I woke up very agitated, I started to cry and to scream, and so I would sleep here on the bedroom floor, then I started to cry, cry and I didn't know what to do, and then I said that some person had died, and I would say things like that which had no sense. [Luana, God is Love]

I got inside my bedroom and then I became terrified. Because you see a voice but you don't see a face [...]. I was very nervous, I didn't sleep the whole night [...]. I would get scared, so I did a lot of things that I shouldn't have done. [Carmen, Catholic]

There are different ways in which people with psychosis evoke a modification of the "attuned space" inside the home. The space of the house appears as emotionally loaded, either negatively as a place from which one has to escape, or positively as an ultimate space of protection. The patient's "attuned space" is experienced as deteriorated when the house is primarily perceived as an "infected" place, or as a "prison." This lived space might become even darker, when the patient feels imprisoned inside a space which is altered. When the house happened to be infected the patient attempted either to run away or look for some kind of protection inside the house. To go to the parents' bedroom to sleep with them was a common strategy to restore some feeling of protection. In many situations, both female and male patients felt overwhelmed by a feeling of being imprisoned inside the house, or inside an imaginary world dominated by the voice's orders:

It would give me the creeps, give fear, then it was kind of being crazy, it would give fear and [1] would run away from home, and then [1] would return back home, do you understand... Afterwards it would give a big desire to go back home from where... I was very far and it would give me a big desire, but I said no because the 'thing' there wants to get me. [José, Umbanda sympathizer]

I don't have the fear I had before... Before I was even afraid of staying here [own bedroom] lying down [own bed]. [Hélio, Umbanda sympathizer]

But I am still very tightened inside, I always had the need, I never had to go to the shopping centre and come back home. I would go to the movie and go [some place else]. I would go to the shopping centre and do something else. It stayed like very imprisoned inside of me... as if I was unable to go outside. [Eduardo, Charismatic Catholicism]

I was feeling imprisoned inside my dad's house, I didn't like this, I knew that I was incapable of getting out. [Mauricio, Non-Practicing Catholic]

Alice: The person becomes imprisoned, you are a prisoner of something that they [voices] command you to do.

<u>Cristina</u>: Did you feel yourself imprisoned?

Alice: Ah, I would feel [imprisoned], I would feel like not doing exactly everything they [voices] have commanded.

[Alice, Orthodox Catholic & Universal Kingdom of God Church]

Some patients also reported that sometimes they experienced the house as a protective space:

Ya, I was afraid of hearing voices, and things like that, so I would stay in my bedroom [...]. I would stay in the dark bedroom. And I would put a pillow over my head. [Kátia. Non-Practicing Catholic]

<u>Cristina</u>: Do you remember something that would calm you down? <u>Maria</u>: Well, I would remain in my bedroom.
[Maria, Universal Kingdom of God Church]

My agitation is normal. It is like I told you, since I am not getting out of the house, there is no problem, I am peaceful [...] Inside the house I mainly sleep, I remain sleeping. [Jonas, Non-Practicing Methodist]

I don't get out of the house, not even to go to the market, with fear. I only go out if there is somebody else by my side. It seems that I got this fear, that's why I say that it seems to be <u>macumba</u> that was done to me. [Leonardo, Return of Jesus Christ Church]

The fact that the space of the house gets affected in psychosis can be understood in different ways. On a first level, narratives evidence the degree to which the "attuned space" of the house is modified in psychotic experience - as expressed by the terms "infected," "imprisoned" and "protective" spaces. When the house becomes infected the patients tend to leave the house, even though they continue to feel afraid and persecuted; some even attempted suicide while outside the home. As soon as they discover that the outside environment is contaminated as well, they often try to return back home. However the constant sensation of being imprisoned indicates that in some instances they feel trapped and having but few resources to escape from their suffering, felt anguish or pain. Even so, some young people admitted that they were able to find some niches of protection inside their homes. They also tried to diminish the danger in many ways: for instance, by locking themselves inside the bedroom, by engaging in some religious rite, like praying, lighting candles, reading the bible, or fasting (see Chapter 7 and Chapter 8), by hearing or playing music, by controlling the behaviour of other members of the family (e.g. watching who gets in/out of the house), and so forth. But it was usually the young males who eventually felt the urge to "protect" not only themselves but the whole family. This may be associated with the expected masculine role of "bread winner" of the family. In addition, there is not much free space for self-centered behaviours within

these poor families. As a matter of fact most houses are small buildings with little interior space to move around, let alone to withdraw momentarily from family life.

At a second level, one may wonder whether the house conceived of as the moral space of the family, where most of the female life takes place, has been transformed by psychosis. I already mentioned that a series of house conflicts may be the anchoring event of psychosis, especially for young women (return to Table 7). It is evident that family conflicts are mentioned by both male and female patients, however the family conflicts involving female patients appear more emotionally loaded in the sense that women belong more to the sphere of the home, than to the street. In the case of female patients, the family conflicts mentioned more frequently are related to transgressions that they committed in relation to the other family members, for instance, fights with the mother, mother-in-law, husband, siblings, break-up with boy-friend, etc. The same kind of family conflicts were also mentioned in relation to male patients, but in their case, much more relevance was given to "street conflicts". The home is also a place where female patients can preserve their own sexuality from the dangers of rape and violent aggression imagined to be found only in the street environment. Very little is said about sexual abuse and violence inside the home, although this is known to happen.

The strange behaviours that male and female patients start to exhibit have the potential to disorganize the moral space of their families. Besides influencing their usual roles of daughter and son, such behaviours frequently disorganize the daily life of the whole family. For example, the loss of job during psychosis represents less money for the entire family. Added to this financial burden is the habitual family rhythm which has to change to accommodate the behaviour of the ill person: there is no more a right time to eat, to sleep, to carry out household chores, no leisure, decrease of family conviviality, and so on. Chapter 5 will provide more details about these family-related issues.

The major objective of this chapter has been to provide the reader with a general background of São Paulo's urban milieu, and more specifically, to characterize the everyday life of poor families who live in the <u>periferia</u>. Rather than emphasizing the

specificity of the trajectories these young people went through after the outbreak of their psychosis, I argue that the phenomenology of psychosis is always shaped through and interwined with the everyday life worlds of the person. The present context of poverty, high unemployment and urban violence is likely to furnish a distinct frame for the phenomenology of psychosis in São Paulo.

Figure 7- Auto-constructed houses in the South Region.

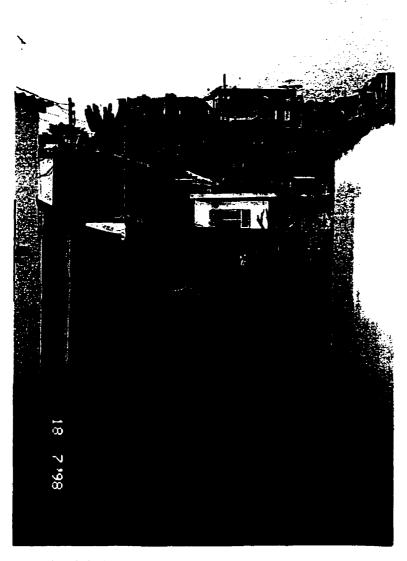


Photo by Cristina Redko

Chapter 4 - Psychiatry, a Space at the Margins

Very early schizophrenia still constitutes a relatively unexplored territory. Entry into this territory calls for new ideas on the social problems involved in bringing the early schizophrenic under treatment, or where the treatment should be carried out and in what it should consist.

[Cameron, 1938: 577]

Getting into the emergency room

It is a very confusing and stressful situation to bring one of your relatives to the emergency room. Families are so perplexed, disrupted and frightened with the odd behaviors expressed by the young person that normally more than one family comes with the patient to the emergency room. For instance, Solange was forced to come to the emergency room by her mother, husband and a close neighbor; Leonardo came with his mother, aunt, and uncle; while Luana and Dora arrived with both parents, besides one or two siblings. Most of the time young people arrived in the emergency room against their will. Eduardo was the only exception because he convinced his family to take him to the psychiatrist when he was feeling suicidal. Since his own father had a long history of psychiatric treatment due to alcoholism, the psychiatric environment was already more familiar to Eduardo. Some of these families sought help in other neighborhood hospitals and primary health units before reaching the emergency room of the São Paulo Hospital. They seemed to be lost in the network of psychiatric services; they were jumping from one place to the other, yet they expected that good care would be provided at the São Paulo Hospital.

Dora's story

Dora's case goes to extremes. Her mother reported that they tried more than nine different psychiatric services before arriving at the São Paulo Hospital. During this period Dora felt very perturbed, suspicious and persecuted by most people, and she was so confused that she "would not talk thing with thing" (não falava coisa com coisa). She was constantly agitated and had no willingness to sleep, consequently the sleep of the entire family was wrecked because they all slept together in one room (they lived in a type B cortico). After the mother started taking Dora to psychiatric services, she not only refused the medication, but stopped eating any kind of food. According to Dora's younger sister she was rejecting the food because she believed that their mother would always mix the medication with food (which she eventually did). Dora's mother explained that they needed to try different psychiatrists because Dora imagined that every physician only wanted to kill her with medication, they were just poisoning her to death.

Dora was extremely thin, dehydrated, withdrawn, and silent when I met her for the first time at the emergency room. I tried to approach her but she only responded: "I don't really know how to talk right." Dora's family was so scared and desperate that they received my presence around them with relief, especially after I decided to sit beside Dora trying to talk with her. At this point Dora's parents were feeling so disheartened that they believed that only through hospitalization they would be capable to force their daughter to eat and be medicated in order to restore her health. Since she was always very suspicious and terrified of every physician she met, the emergency psychiatrist had a very rough time trying to engage Dora into any kind of conversation. This young psychiatrist soon became extremely annoyed with the parents because they really wanted to hospitalize their daughter. After the consultation the psychiatrist expressed

where the patient does not really need a psychiatric hospitalization since Dora was neither acting in "hetero-aggressive" or "auto-aggressive" ways. She anticipated that Dora might end up being hospitalized only because her family was not being "supportive" enough and would not tolerate the situation much further. Attempting to be coherent with her strong position against psychiatric hospitalization (unless there is no other solution) this psychiatrist was still able to convince the family to bring Dora to the Day-Hospital Programme of the São Paulo Hospital. Less than a week later she was interned for a month in a psychiatric hospital on the outskirts of town.

My immediate reaction was to tell Dora that she didn't need "to talk right," we could only try to talk, there was no "right" or "wrong" in the act of talking, but she only replied with more silence. It took me a long time to realize what she was really expressing to me. I had the impression that she sensed that she had lost the "rules of the game" that would allow her to position herself in relation to the others around her, including me. She was terrified about taking medication: she even refused to open her mouth when the psychiatrist tried to talk with her, but it wasn't simply because she abhorred medication and psychiatrists. Beyond that, she was feeling a certain "loss of the sense of the self evident," as described by Blankenburg (1991).

Dora's story was presented here to illustrate the central issues that will be developed in more detail in this chapter. First, it introduces some main reasons that bring these families to the emergency room. Second, it illustrates some common pathways followed by these patients in psychiatric care. Third, it indicates how psychiatrists decide about the treatment that will be provided. Fourth, it exemplifies some of the various meanings that patients and family member associate with psychiatric treatment and how these might diverge from the psychiatrist's orientation. Fifth, it alludes to some major sources of misunderstandings between patients and family members, and psychiatrists and other mental health professionals.

For some months a cluster of signs - sometimes contradictory - evoked a basic alteration of the Dora had of the world and of herself: suspiciousness, withdrawal, persecution, agitation, confusion, lack of sleep, and lack of eating. But it was only after she was losing a lot of weight that her family decided that she should go through some serious medical treatment. A similar situation happened with Maria and Gisela; the main reason for which these three young women were taken to the psychiatric emergency was that they just didn't eat anymore. Table 8 indicates the particular reasons mentioned by family members for taking the young person to the psychiatric emergency; it also mentions the number of those patients who were hospitalized during the outbreak of their first psychotic episode. It is important to highlight that the majority of patients (72%) were not interned in any psychiatric hospital during this period. It is very likely that additional problems existed aside of the core symptoms (from a family perspective), but they were not identified by family members as having induced them to bring the patient to the emergency room. For example, Claudia, Carmen, Solange, and Eduardo all attempted suicide, but they were also agitated, confused, and very afraid. Some of them were having visions and hearing voices as well. For instance, Carmen was hearing voices and having visions related with the tragic death of the music band Mamonas Assassinas, which was mentioned in the previous chapter. On the other hand, Leonardo and Milton also attempted suicide, but this was not the main reason that led them to the emergency room. Drug addiction and bizarre behavior were the dominant signs noticed in Leonardo, while the agitated and violent behaviour were the signs retained for Milton.

Narratives of family members indicate that they seem to have a high threshold of tolerance towards basic alterations involving the young person's relationship to him/herself. Usually the transformation in the constitution of the "I" is only noticed when it reaches a radical level, as the willingness to take one's life away or to starve to death, which can be seen as dramatic expressions of an attempt to destroy oneself. The cluster of signs that lead family members to take the young person to the emergency room are more likely to be aroused by breaking-up the rules of interpersonal relationships (e.g. violent behavior, persecution). For instance, Claudia's mother had to rush to her daughter's work because she was trying to jump from the building. She brought her daughter home and

tried to calm her down with tea and passion fruit juice. During that night Claudia started to scream and became very agitated again. She wanted by all means to go outside, and became very aggressive with her mother. At that time, the family hurried to take Claudia to the nearest emergency room in the middle of the night, instead of waiting for the next day as they had originally planned.

Table 8 – Main reason to go to the emergency room and the number of patients hospitalized

Main reason to go to the emergency room	Number of patients	Hospitalization	
Suicide attempt	4	2	
Fear/persecution	4	1	
Agitated/ violent behavior	4	None	
Not eating	3	2	
Confusion: "não falava coisa com coisa"	3	None	
Drugs/ bizarre behaviour (e.g. "laughs alone")	2	1	
Hearing voices	I	None	
Total	21	6	

During the day, four psychiatrists (including 2 medical residents) are working in the emergency room of the São Paulo Hospital; this number is reduced to two during the evening (including 1 medical resident). I remember that some days, especially if it was raining outside, I would spend most of my time chatting with the psychiatrists because very few patients arrived. Most of the time however these psychiatrists were very busy seeing one patient after the other. I was often bewildered during the hectic periods because I had a hard time to observe with attention all that was happening inside that small psychiatric emergency room. One of the chief psychiatrists always insisted to me that "one needs to forget all the beautiful details that are written in psychopathology books while working at the emergency room." In other words, the emergency room is a place for fast decisions. Fast decisions that have great implication regarding the patient's future but that can be easily questioned; this can be extremely stressful to handle.

During my six months of fieldwork in this setting, I decided to verify the emergency room records to identify which was the last psychiatric decision made for all those patients diagnosed with schizophrenia independently of the duration of their

illness. Table 9 illustrates the recommended psychiatric procedure after the last emergency room consultation in relation to the gender of patients diagnosed as schizophrenic. It is interesting to note that only 11.3% of the patients were recommended for hospitalization and were hospitalized. Most patients were transferred to primary health care units and day-hospitals which are services outside of the São Paulo Hospital (40.5%). The São Paulo Hospital outpatient services absorb 15.5% of the clientele that arrives in the emergency room. These patients are directed either to the Schizophrenia Programme, the Crisis Ambulatory (for acute patients), the Day-Hospital Programme (for outpatients), or the Pedagogic Ambulatory. The proportion of patients absorbed by São Paulo Hospital increases to 19.4 % if one takes into account that during this period 11 female patients were hospitalized in the Female Psychiatric Ward of São Paulo Hospital, although in the Table below they were counted under the general category "hospitalization." The category "go back home" usually represents those patients who are already being treated in another place, and only came in a situation of emergency. Some patients without any evident psychiatric problem in the present, even though they already received a diagnosis of schizophrenia in the past, may fall under this category. The category "return to emergency room" represents those patients whom the psychiatrist wanted to see once more, but who for some reason did not return to this emergency room.

One can wonder how the further trajectories of young people inside the psychiatric services were affected by the decisions made at the emergency room. It is important to highlight that emergency room psychiatrists tried to transfer most of the young people going through a first psychotic episode to other psychiatric services internal to São Paulo Hospital. One can suspect that this is strongly related with the fieldwork I was conducting in that setting. Probably some of these trajectories would have been

¹ I have only considered here those 284 patients diagnosed under the categories F20 (schizophrenia) or F23 (acute and transient psychotic disorders) according to the ICD-10 criteria. I have included the total number of 284 patients in this table because these records do not distinguish in a reliable way those patients who are going through a first psychotic episode from all the other patients with a diagnosis of schizophrenia. The emergency room records cover the period of October 1997 until March of 1998.

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² Out of the 17 female patients under the category "hospitalization," 11 were hospitalized in the Psychiatric Ward of the São Paulo Hospital, while the other 6 were interned in psychiatric hospitals outside of the São Paulo Hospital. All 15 male patients were interned in psychiatric hospitals outside of the São Paulo Hospital, since no Psychiatric Ward for male patients exists in the São Paulo Hospital.

different otherwise. Figure 8 illustrates the trajectories of thirteen patients who were initially transferred to psychiatric services inside of the São Paulo Hospital. Figure 9 shows the trajectories of five patients who were transferred to psychiatric services outside of the São Paulo Hospital. The two most complex pathways that appear in Figure 8 represent the trajectories followed by Leonardo and Carmen. It is likely that if all the patients were followed prospectively for a period of time longer than the minimum of six months that I followed their experiences, their trajectories within the psychiatric services might have been more complicated, as in the cases of Leonardo and Carmen.

Table 9 – Recommended psychiatric procedure after the last emergency room consultation in relation to sex of patients with schizophrenia

Procedure	Female		Male	Total		
	Number	%	Number	%	Number	%
Go back home	7	5.1	8	5.4	15	5.2
Return to emergency room	33	24.1	21	14.3	54	19.0
H.S.P. services	18	13.1	26	17.7	44	15.5
Other services	48	35.1	67	45.6	115	40.5
Hospitalization	I 7	12.4	15	10.2	32	11.3
Evasion	3	2.2	6	4.1	9	3.2
No data	11	8.0	4	2.7	15	5.3
Total	137	100.0	147	100.0	284	100.0

Figure 8 shows that Leonardo was oriented towards the Schizophrenia Programme of the same hospital as six other patients who arrived at the emergency room. During the entire fieldwork these six patients remained in the Schizophrenia Programme, while Leonardo immediately decided to abandon the psychiatric treatment altogether. Several months later, he went through a second psychotic episode and at this time, Leonardo had to be interned in a psychiatric hospital. After a couple of days, he ran away from this psychiatric hospital and went back home, he was then interned in another hospital. After being discharged from the psychiatric hospital for a few weeks he received treatment at the emergency room of the São Paulo Hospital until the day he disappeared from home because his father expelled him from the house (see Chapter 1). Although afterwards she regretted this idea, Carmen told the emergency room psychiatrist that she wanted to be hospitalized. She explained to me that she was trying to escape from the

"voices" and "visions" that were bothering her so much. She was interned in the Female Psychiatric Ward of the São Paulo Hospital for 12 days and then she began to attend the outpatient clinic of this Ward. Since the psychiatrists were not seeing much progress in her they decided to transfer Carmen to the Schizophrenia Programme. Several months later Carmen started to have problems again and as she was too violent with her mother she was hospitalized for the second time. Even though the psychiatrist wanted to hospitalize her in the São Paulo Hospital because she was an ex-patient, the Female Psychiatric Ward had no vacancy that week, and she was interned in a psychiatric hospital outside of the São Paulo Hospital for a period of one month.

A total of eighteen patients are presented in Figures 8 and 9; three additional patients of my group do not appear in these two figures. These three patients made their first contact directly with the Schizophrenia Programme of the São Paulo Hospital, and never went through the emergency room. Mateus arrived at the Schizophrenia Programme just after his first psychiatric hospitalization. Both Claudia and Roseli were advised to go directly to the Schizophrenia Programme through acquaintances who knew psychiatrists who worked in that Programme. By the end of my fieldwork Mateus and Claudia were still being treated at the Schizophrenia Programme while Roseli quit because she preferred to go back to her home town in Northeastern Brazil. The lines in Figure 8 and Figure 9 show the flow of all other trajectories. A small symbol of an ambulance indicates the beginning of these trajectories in the emergency room. When the patient remained in treatment, his or her name appears in the last place he or she was being treated; the polygon indicates that patients abandoned treatment during the follow-up. The boxes represent psychiatric services within the São Paulo Hospital, while the elliptical forms represent psychiatric services outside of the São Paulo Hospital.

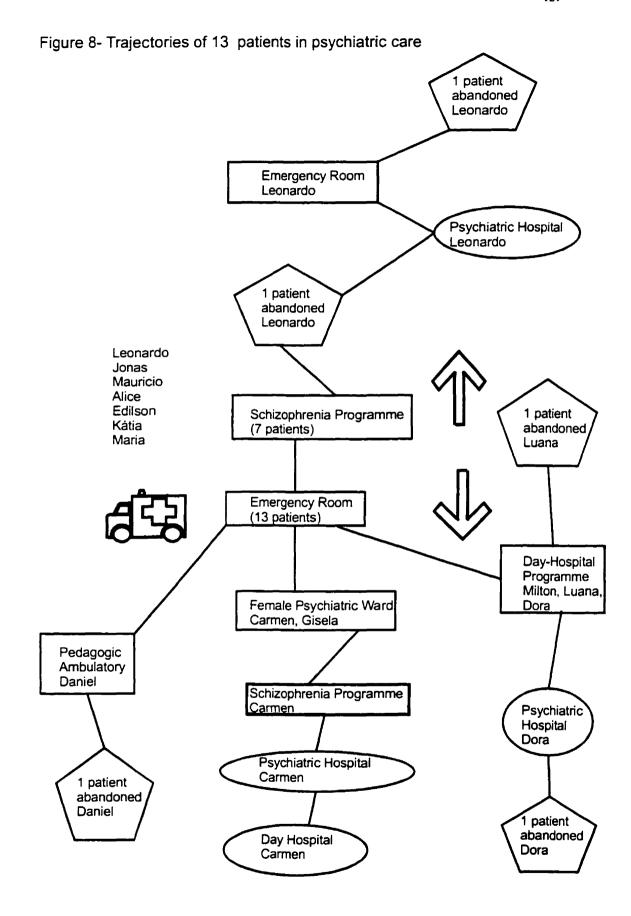
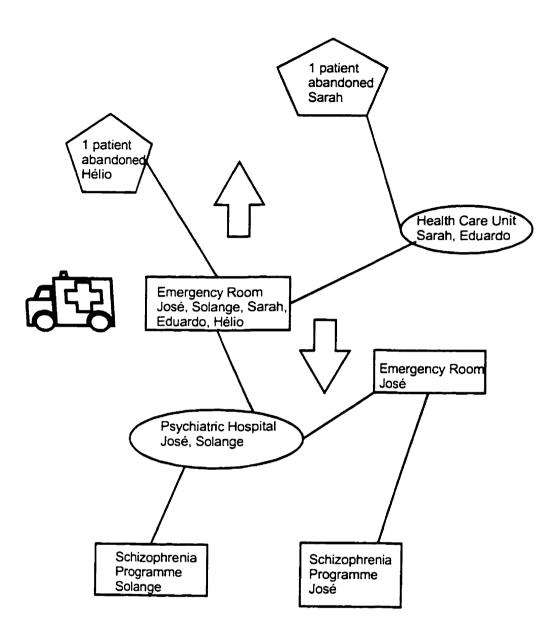


Figure 9 - Trajectories of 5 patients in psychiatric care



During the whole period of follow-up of the twenty-one patients who participated in this study, a total of eight patients (38%) abandoned the psychiatric treatment. Three major reasons account for why these eight patients preferred to abandon the psychiatric treatment:

- 1) Two patients moved out of town (Hélio, M.Roseli)
- 2) Three patients quit while being transferred to another psychiatric service (Leonardo, Sarah, Dora)
- Three patients questioned the very need of the psychiatric care (Luana, Gisela, Daniel).

I do not know whether any epidemiological study has been conducted to describe the different trajectories of psychotic patients within the psychiatric services of the city of São Paulo. Yet recently, a prospective study was conducted in Campinas, which is an urban center not so far away from São Paulo. Amaral (1997) indicates that almost 50% of the patients who are discharged from psychiatric hospitals have not turned up at the primary health care units to follow their psychiatric treatment. Of those who showed up at the health care units, 45% had a diagnosis of psychosis, but 52% of all these patients abandoned their treatment at the primary health care unit at the end of four months (independent of psychiatric diagnosis). In addition, ¼ of the patients (24.7%) who continued their treatment at the health care unit returned to the psychiatric hospital within the first four months, and most of them had a diagnosis of psychosis. There is no reason to expect very different conditions for the psychotic patients of São Paulo since the psychiatric services of both cities are organized in a similar way. These figures illustrate that psychiatric patients are used to discontinuing psychiatric treatment, especially when they have to switch from one psychiatric service to another.

During my fieldwork at the emergency room, I noticed that several patients who were advised to return to the emergency room did not do so. It is not possible to know whether these patients have actually abandoned the psychiatric treatment altogether or whether they preferred to seek help from another psychiatric service. That they did not

come back as recommended indicates resistance and discontinuity with the treatment that was being offered at the emergency room. For this reason I checked the emergency room records for the 284 patients who received a diagnosis of schizophrenia to verify which proportion of these patients followed the recommendation to return to the emergency room. Table 10 indicates that 44.4% of the patients with a diagnosis of schizophrenia were asked to return to the emergency room for at least one additional consultation. This kind of advice is normally given to patients who are not already followed-up in some other psychiatric service of the city. However this does not mean that those patients who were not asked to return to the emergency room are already being treated elsewhere. The major reason for which almost ½ the patients (49.7%) were not asked to come back is because they were immediately re-directed to another psychiatric service after their first consultation at the emergency room.³

Table 10 – Proportion of patients with schizophrenia asked to return to the emergency

room after the first consultation									
Patients with schizophrenia	Female		Male		Total				
	Number	%	Number	%	Number	%			
Patients asked to return to ER	59	43.0	67	45.6	126	44.3			
Patients who received a different orientation	66	48.2	75	51.0	141	49.7			
No data available	12	8.8	5	3.4	17	6.0			
TOTAL NUMBER OF PATIENTS	137	100.0	147	100.0	284	100.0			

Table 11 presents the total number of patients who were asked to return to the emergency room and those among them who did not come back (42.9%). Such a refusal is significantly higher for the female patients (55.9%) than for the males (31.3%) (Pearson Chi-Square = 7.746, df =1, α < 0.05). Although one cannot assume that all patients who refused to return to the emergency room also abandoned their psychiatric treatment, these patients tend to be very refractory to follow the psychiatric recommendations from the beginning. It remains to be investigated whether the female

³ The small number of patients that appeared in Table 9 under the category "go back home" are also included here under the category "patients who received a different orientation."

patients are more resistant to psychiatric treatment than the male patients, or if they only switch psychiatric services more often, instead of quitting the psychiatric treatment.

Table 11 - Last known destination of all the patients with schizophrenia asked to return to the emergency room after one or more consultations

Patients asked to return to the emergency room	Female		Male		Total	
	Number	~~~ ~~~~	Number	%	Number	%
Have not returned to ER	33	55. 9	21	31.3	54	42.9
Re-directed to another service after returning	26	44.1	46	68.7	72	57.5
Total of patients oriented to return to ER	59	100.0	67	100.0	126	100.0
TOTAL NUMBER OF PATIENTS	137		147		284	

Besides describing the different trajectories that psychotic patients might follow inside the psychiatric services, these tables illustrate the importance of a discontinuity in psychiatric treatment and this is clearly a topic that deserves further investigation. Considering the nature of the data I have collected during my fieldwork, I can only explore this topic from a qualitative perspective. One could hypothesize that two important factors that may contribute to the discontinuity of treatment relate to the meaning that patients and family members associate to the psychiatric treatment and to a problem of communication with mental health care professionals.

Before discussing these two factors in more detail let us turn to the factors associated with a recommendation of hospitalization. Menon (1994) conducted a study on psychiatric emergency room records in 1989 for the São Paulo Hospital. She also interviewed a representative sample of patients, and identified the most important factors that influence the decision for psychiatric hospitalization. Patients are more likely to be hospitalized when:

- 1) They receive a diagnosis of non-organic psychosis.
- 2) There are important difficulties in their social and family relationships.
- 3) They are reticent to cooperate or refuse the psychiatric treatment.

Psychiatrists of the São Paulo Hospital tend to hospitalize less those patients who have never been hospitalized before, while those patients who have been hospitalized before are more likely to be hospitalized again (Menon, 1994). This suggests that psychiatrists try to avoid as much as possible the hospitalization of those patients going through a first psychotic episode. Even though they have to take into account the shortage of psychiatric beds available, I observed during fieldwork that most of them believe that psychiatric hospitalization is the most drastic *rite de passage* with a potential to reinforce stigmatization and to augment the likelihood of future hospitalizations.

In order to decide whether it is possible to avoid hospitalization, the patient can remain in observation in the emergency room for about 72 hours (in acute cases) or the psychiatrist may ask the patient to return frequently for a few additional consultations. Since in most cases the patient is not going to be hospitalized, the psychiatrist has to find the most adequate service for this patient. Besides considering the characteristics of the patient and of his/her family, this decision also seems to be based on characteristics of the psychiatrists themselves in conjunction with the characteristics of the services available.⁴ More generally patients who trigger more positive feelings from the psychiatrist or those who present some kind of academic interest have more chances of being transferred to a psychiatric service internal to the São Paulo Hospital, rather than to psychiatric services outside of the Hospital. Another element that is taken into consideration is the quality of treatment offered by particular psychiatric services within the network of psychiatry; as their quality varies to a large extent from place to place. The psychiatrist usually selects what is considered the "best" service available in the region where the patient lives, particularly for patients at the beginning of a psychiatric trajectory. For instance, I observed that the match making between patient and psychiatric hospital obeys a tacit rule. In those cases where the psychiatrist is obliged to hospitalize a patient going through a first psychotic episode, he always tries to select a "better" hospital for this patient, while chronic "revolving-door" patients tend to be directed to the "worse" hospitals.

Characteristics of the psychiatrists and characteristics of the services being offered are variables that Menon (1994) did not include in her model to explain the most important factors influencing psychiatric hospitalization. For example, it has been shown elsewhere that psychiatrists with longer experience tend to hospitalize less, and that patients seem to be hospitalized more when there is more vacancy available (Streiner, Goodman, Woodward, 1975).

Psychiatrists believe that those patients who go to the "worse" hospitals are more likely to enter a life long career of psychiatric hospitalization.

Dora's story

Back to Dora's story. It was very hard for me to understand why the resident psychiatrist perceived the family to be so "non-supportive" while the whole family was there accompanying Dora to the psychiatric emergency room. The psychiatrist seemed to feel confronted by the parents whom had already decided by themselves that they wanted to hospitalize their daughter. In that contact, the psychiatrist overlooked that Dora was refusing any medical treatment, which is normally considered a good reason for hospitalization. Furthermore, the psychiatrist gave more weight to the fact that Dora was not expressing any kind of aggressiveness and that she was very withdrawn, although this was not the behavior that she seemed to have at home. After many visits to Dora's home, the mother reported that quite often her daughter was behaving in very agitated and aggressive ways. The whole family was in desperation, yet they still tried to remain at Dora's side all the time:

It was so much suffering, I am just so tired, so crazy, she stayed without eating prostrated in bed, without bathing, we would bathe her, we would open her mouth with a spoon to give food to her, we would brush her hair, brush her teeth, and then she got better, and so she didn't want to take any medication any more. Then she started, every time she would bite me, when I gave her medication she would bite me, she would say that she was going to pick up a knife to kill me and to kill her.

[Dora's mother, Adventist 7th Day]

While the psychiatrist interpreted in a snapshot that this was a typical case of a "non-supportive" family, I would rather have the opposite interpretation. I believe that most of the time Dora was receiving a superabundance of support from her family. One would think that she sometimes reacted aggressively because she was feeling engulfed by all the attention and support given by her family. But within the confusing and pressing

context of the emergency room the psychiatrist often can only capture a very small and partial portion of a more complex case story. Unfortunately, they are urged to make difficult treatment decisions having only these partial elements at hand.

Frequently, psychiatrists have to base their diagnosis and treatment decisions primarily on the information disclosed by the family. Some patients are extremely withdrawn or what they are able to express makes very little sense. It may also be very difficult to distinguish the psychotic symptoms from the "real" facts of everyday life. I have mentioned elsewhere that Luana entered the emergency room in haste and anguish because she thought that she had been raped and sexually abused. The psychiatrist discarded the possibility of a rape episode only after talking with Luana's parents. Solange's mother had to explain that her daughter was only fantasizing that she was pregnant. Leonardo's uncle needed to reassure the emergency psychiatrist that his nephew's feelings of being persecuted by the police were not "real," even though he actually had stolen a car. In some circumstances, family members may also prefer to omit or deny some information. For instance, one teenage girl tried to express all her fear towards sexual abuse while suffering her second psychotic episode. Many months afterwards, I discovered by chance that this girl had in fact been sexually abused by her step-father several times, but the mother withheld this information for a long time because she was very ashamed to discuss this issue with psychiatrists. Probably she didn't want to be questioned since her partner still lived with her, despite all the sexual abuses.

In some circumstances, I had the chance to observe how easily psychiatrists believe in the whole content of the stories told to them. They also feel pressured by the little time they have to take a detailed clinical history. Consequently, psychiatrists sometimes forget that besides the family, the patients are also "negotiating" with them the treatment decisions from their own perspective. For example, Hélio disguised a series of meaningful information about himself to the psychiatrist because he imagined that this information would enable his "persecutors" to find him. Leonardo played out the stereotype of the "poor young boy" to convince the psychiatrist to give him all the medication he needed for free, since he was very terrified of the idea of asking his father

to pay for his medication. The unbearable fear of becoming too costly to his family dominated Leonardo's interactions with the psychiatrist. As soon as José was discharged from the psychiatric hospital he returned to the emergency room and faked to the psychiatrist that he was still very sick because he wanted another hospitalization. Since José arrived alone, the psychiatrist managed the situation by telling him to come back only with his mother and after that he was directed to the Schizophrenia Programme. Some weeks later José explained to me that suddenly he had this "silly" impetus to be rehospitalized because there was no food in his home that week, while the psychiatric hospital provided five meals a day. Apparently Leonardo emphasized his condition of poverty to protect himself against the "fear of being too costly" and against the reactions of his family, while José tried to play with psychosis to protect himself from his poor living conditions (lack of food on the table).

Playing stereotypes is a common strategy on the side of psychiatrists as well.⁵ The type of questions that psychiatrists ask, the attitudes they have, the ways they perceive the patient and family members, and the subsequent decisions they make are strongly influenced by the images and stereotypes they have developed in their previous clinical experience. Social class differences play an important role here, particularly in relation to the low level of education and conditions of poverty experienced by most families: "they are ignorant and poor, that is all." This is one of the most typical off-hands comments that I heard from psychiatrists. Very often they suspect that patients and their families have great difficulties to understand what was being advised. But similar comments are also triggered by situations where psychiatrists themselves found the interaction with their clientele incomprehensible, confusing, and complicated.

⁵ The notion of stereotype takes into account that human perception is always selective: "People all over the world do seem to group phenomena into categories and to exaggerate the differences between categories. Second, when these categories involve human beings, they may serve to define the boundaries and relations between groups. The perceived, exaggerated differences between two groups help to justify the behaviour of people in one group toward the other group. The exaggeration of stereotypes thus can

Eduardo's story

I remember that the emergency room psychiatrist who was seeing Eduardo took almost two months before deciding for a psychiatric diagnosis. He had to pull out the facts from Eduardo, yet his responses were usually very evasive: "I was a little bit confused, I don't know how to explain, but my mother can explain. I was feeling different from everyone else." In addition, the psychiatrist complained to me that Eduardo's mother was so confusing (and ignorant) that she was incapable of informing in a consistent way what was happening to her son. He even insisted that the mother invite some other member of the family, or some of Eduardo's friends to come to the emergency room for the next consultation. Although nobody else came, the psychiatrist hoped that in this way he could obtain more reliable information about what Eduardo was going through.

After several consultations, the psychiatrist concluded that Eduardo was really experiencing psychotic symptoms besides being extremely depressed, for instance "hearing voices," "fear," and "thought transmission." At this point, both Eduardo and the mother became attached to this psychiatrist because of all the attention they were receiving. For this reason they heard with a lot of disappointment that the psychiatrist decided to transfer Eduardo to the neighborhood health care unit instead of continuing the treatment in the São Paulo Hospital. Some months later I mentioned to this psychiatrist that I was still visiting Eduardo in his home. He had totally forgotten about this case even though he saw the patient almost weekly for more than two months (which is very unusual for the emergency room setting). He added that this case had "not touched him in any way."

I wondered why he had this reaction since most emergency room psychiatrists, including him, have a special interest for cases with a first episode psychosis because they believe that they have more chances to intervene in a positive way. What counted most in this case seemed to be the constant interaction difficulties that probably influenced the psychiatrist's decision to transfer the case to another place. Qualifications such as "ignorance" and "poverty" certainly play an important role in the way psychiatrists deal with patients and their families. In sum, psychiatrists tend to admit the more interesting cases (from the academic perspective) to the outpatient services of the São Paulo Hospital in addition to the less troublesome ones.

It is a common practice for psychiatrists to ask the most underprivileged patients to bring in the medication in order to check if they are taking the "right" amount at the "right" time or whether they are really taking it. They assume that the low level of education of these patients and their families strongly affects the compliance towards psychiatric treatment. This stereotype only repeats itself. Psychiatrists perceive that some families are just too ignorant to understand the medical prescription, or that they are simply too complicated and confusing to follow the medical orientations correctly. In a certain way they are deprecating these families, but families can react with deprecation as well. It was José's mother who first brought this idea to my attention. One day José's mother was outraged that every time she went with her son to the Schizophrenia Programme, the psychiatrist would ask them to bring the plastic bag with the medication that was being taken. She interpreted that this psychiatrist was being very irresponsible to forget all the time which medication should be prescribed. Why would she not simply check the annotations made in the patient's records file? Did she really know what was her son's sickness?

Although psychiatrists perceive that "ignorance" is the primary factor in the case of "confusing" and "complicated" families, they also associate these last two attributes to broader family dynamics. The dominant stereotypes emerge from the vulgarization of psychoanalysis and consider family dynamics as extremely noxious to psychotic patients;

"the mother has a symbiotic relationship with the patient," " the family is sick, the patient is only the scapegoat," "the mother manipulates the medication because she doesn't want the patient to heal," "the family is too complicated to give medication properly," and so forth. These off-hands comments gain more strength when psychiatrists realize that the patient is not improving; they immediately associate the persistence of the sick condition with an inappropriate intake of medication that has been left in the hands of such "defective" families. Once a young psychiatrist gave vent to her feelings in a very explicit way: "I have a lot of pity of those patients who do not have a supportive family. The patient suffers so much already, and when his family is crazy, the situation only worsens." It seems as if they always wanted to maintain a position on the patient's side, and prefer to perceive the patient as the "innocent victim" of the whole family. Thus, while many families blame themselves as being responsible for the sickness of the reputedly most frail family member (see the next chapter), psychiatrists often blame these families for being too ignorant, malfunctioning, and uninterested to follow the medical treatment.

The Meaning of Medication

Listening to the narratives of psychotic youth and their families, it becomes clear that their relationship with psychiatrists is primarily mediated through the medication and related issues. It is important to remember that some new brands of anti-psychotic medication (e.g.: Risperdal) cause very little side-effects (e.g. trembling, stiffness, etc.) in comparison to the more traditional brands (e.g. Haloperidol). However during the period of fieldwork the new brands were still very expensive while the more traditional brands were provided for free by the Ministry of Health. In the emergency room setting, psychiatrists were obliged to use the cheaper brands, and very few families were able to afford the top-of-the-line medication to give continuation to psychiatric treatment.

Positive aspects of medication

Even though most young people are very disturbed when they arrive at the emergency room, their families are not expecting to see them following any type of psychiatric treatment. However these families notice the positive impact of medication when they observe the patient becoming more tranquilized after taking strong doses of medication that they associate with <u>calmante</u> (popular name for sedative medication). A certain satisfaction that they feel towards the positive impact of medication is mainly captured by their tone of voice:

When we got there [emergency room] the doctor gave a <u>calmante</u>, then she slept, came home and slept the rest of the night. Yet, the next day I had to take her to another hospital. [Claudia's mother, Umbanda sympathizer]

They said that it would go away and they stayed with him in observation and gave an injection for him to calm down... we soon returned home. When he takes these injections he calms down. [Milton's mother, Catholic]

Only after the hospitalization, when he returned that I am telling you that he became calmer. [José's mother, Universal Kingdom of God]

Some young people recognize the positive effects of medication; they have the impression that anti-psychotic drugs are helping them to improve and feel better, at least in the initial phases of treatment:

When I was feeling better, I took a lot of injections there [psychiatric hospital] to become calm, they would measure my blood pressure, then I realized that it was a week that I was there tied [in bed], I remember that. [Solange, Adventist 7th Day]

Then I had to stay home taking medication and feeding myself. Then I felt like going back to work to distract myself and not think in any thing else. Only in helping my family, to come back to work, to come back after all, after the medication. With this medication that I am taking now I am feeling better. [Milton, Catholic].

They [voices] talked about everything I was doing. I don't know if it is still like this now... everything I did they would hear. Everything I said, everything I thought the spirits, these macumbeiros, would hear

everything! They remained chasing me. Now I am not sure if they still are because the doctor passed some medication to me so I have been able to forget more. I have been able to divert my thoughts from what was happening. Now I have been improving! [Leonardo, Return of Jesus Christ Church]

Negative aspects of medication

It is uncommon that the act of taking medication be experienced as a straightforward process towards "improving" and "feeling better." Psychiatrists usually take some time until they find the best anti-psychotic for a particular person and the most adequate dosage; medication frequently bring about side-effects, and the family starts to believe that these medications are only doing more harm than good:

Sleep, sleep, she never had any problems to sleep, she slept well, but in the first time she took the medication she had a reaction so she remained the whole night awake saying that it was very loud [voices]. It was desperation that night that I spent with her to calm her down. But then she said that it was getting even louder, that it was giving her no tranquility, thus she was getting desperate, even me, I got afraid too, reacted and got worse. [Kátia's mother, Non-Practicing Catholic]

Thanks God she didn't have these crises anymore after taking the medication. But each medication makes her have a different behavior. Sometimes it seems that she is invalid because her arms and her neck become very stiff and she walks crooked. Lift your body Maria, she lifts her head, and in a while it happens again so she walks with her legs kind of stiff. This medication is now affecting her differently, she is more quiet, silent, but she speaks little, she speaks less. There are times that she is more conscious, but there are times that she is just like this. [Maria's mother, Adventist 7th day]

My son came here, and I didn't even know that he was so bad, it was when he stopped talking and he had a sort of faint, a kind of faint and he remained all stiff. And so this happened when every one cried and became terrified, to live here with this boy. The doctor said this is called impregnation, and for us to put him and turn him around to put him into the car, and he was stiff, and he was carried like this by the arms. [Eduardo's mother, Charismatic Catholic]

Atrophied because she trembles, she would tremble while holding a cup of milk, she would eat but the food would fall from the fork. I told the doctor, doctor this girl is becoming atrophied with the medications that you give her, 'ya but these are the side-effects'! [Carmen's mother, Non-Practicing Catholic]

Stiffness, "impregnation," trembling, and changes of behavior are some common side-effects of anti-psychotic medication. Very often, families are more scared and concerned with the side-effects than with the symptoms of psychosis. When the psychiatrist is able to reduce the side-effects it is more likely that families will continue to accept the psychiatric treatment. But they also understand better why some patients prefer to refuse the medication. They are caught in the middle. Sometimes they make an alliance with the psychiatrist and insist on the medication, other times they make an alliance with the patient and create no objections when the medication is refused.

Young people themselves are already feeling very strange as a consequence of psychosis. When they take the medication and experience the negative side-effects, it seems that they are only reinforcing this strangeness even further:

I felt well, I felt a little motionless, I never took <u>calmante</u>. I would feel a little motionless, very odd, very strange. [Maria, Universal Kingdom of God]

Then the doctor said the medication you are taking is too strong. I felt that it was the medication that was too strong... the medication was making me feel annoyed only in one place. I was just walking back and forth, back and forth, and I would not remain calm at home not even a minute.

[José, Umbanda sympathizer]

Having experienced too much discomfort from these added feelings of strangeness, Leonardo and Luana confessed to me that they decided to test how they would feel if they stopped taking the anti-psychotic medication. While Luana received the active support of her parents to quit medication, Leonardo's parents only supported him by not making too much opposition to his decision. Both of them abandoned the psychiatric treatment after stopping the medication. Both of them emphasized that they

were only searching for their own self, they wanted to return back to their "normal" self without the effects of any medication:

I feel bad with medication, I become very agitated, I feel disturbed, I don't want to take this medication anymore! It was my father, my father, let me see, it was yesterday that I stopped taking [medication], I believe it was yesterday that I stopped taking. My mother is going to make a test with me during a whole week, I will remain without medication to see if I return to normal. I remain walking from one side to the other, I remain very agitated with medication, that is why I don't want to take it anymore. It is damaging me, this medication is damaging me. Now that I stopped taking it, I am normal. Now I can speak to people. Before I would remain trembling, I would not stop to tremble with the medication. Now I am normal and I am able to talk with people. Even some friends of mine came here vesterday and they talked with me. [Luana, God is Love]

I am well now, I don't need it [medication] anymore. I thought I needed to see how it is, because it seemed that I was hiding myself behind the medication. [...] I stopped taking it [medication], then I came back to normal. It is coming slowly, it is not 100% yet. Now I am more peaceful after I stopped taking the medication. I believed that the medication too did it [illness]. I felt that I was retarding, I don't know, in my way of talking, in the way when I had to talk it disturbed, it seemed that I was slow, sick, my body was heavy. Ah so I am not taking this medication anymore, pimples started to grow in my face. [Leonardo, Return of Jesus Christ Church]

In some cases young people who reject medication only become worse. Apparently they are going through a "loss of vital contact with reality" (Minkowski, 1970); in some ways, they do not appear to worry about becoming worse. Parents become panic-stricken and try whatever means they have to give medication to the patient. Patients might fake in pretending they swallowed the medication, or they throw it away. Sometimes parents try to mix medication with the food without the patient's awareness. The food tastes awful. Then the patient might start rejecting the food as well. This is what happened to Dora and Milton. They were being deceived to take the medication with food and became more aggressive with their families. In that context, the only solution is to take the patient to the doctor, then to church, then to another doctor, and so forth. Milton told me that when he arrived at the São Paulo Hospital he liked the way the psychiatrist

approached him, and my presence there in the emergency room. He went back home convinced to take his medication again. His parents were relieved because they didn't want to hospitalize their son. Dora didn't have the same luck.

I heard several complaints from young people that taking neuroleptics is much worse than consuming drugs. like marijuana⁶, cocaine⁷, or LSD. ⁸ Five young male patients reported to me that they smoked marijuana during the outbreak of their psychotic episode, although they also had long periods when they simply avoided the drug. It is more likely that they avoided marijuana when the drug was accentuating some of their psychotic symptoms (e.g. altered perceptions, paranoia), and that they consumed it when it produced in them some sense of alleviation. But the hypothesis that they eventually continued to use marijuana even when it only accentuated some of their psychotic symptoms should not be discarded. They may suddenly find themselves "stuck" in a "whirlwind" movement hoping that if they take a little more of the drug they just consumed they would finally attain some relief.

The effects of cannabis (marijuana) normally last a couple of hours and range from stimulating to mellowing immediately after taking the first hit. Most people feel "high", more relaxed and talkative, and less concerned about what they say or do. However it can also make some people nervous, dizzy and upset. Later on the person may become reflective and sleepy. Physically the person will feel the eyes redden, acceleration of heartbeat, and an enormous increase of appetite. Cannabis can also affect the person's balance, judgement, memory, reactions, and perceptions, especially when used together with alcohol. In fact, large amounts of cannabis can cause hallucinations and paranoia. Regular use of cannabis by people with mental illness can bring on their symptoms or make them worse (Addiction Research Foundation, 1997a).

Cocaine overworks the person's body and brain. The heartbeat, blood pressure and body temperature is boosted. The action in the brain makes the person feel energetic, more sociable, confident and in control. The feeling is so powerful and pleasurable that many users immediately want more cocaine. But some people will feel withdrawn, anxious or even panic-stricken. Taking more cocaine makes the pleasure (or the panic) stronger. When the person uses cocaine often and long enough, the "high" gives way to paranoia, hallucinations and a unwell feeling because the person can't sleep and doesn't feel like eating (Addiction Research Foundation, 1997b).

b LSD is a type of hallucinogen that mainly affects the way the person thinks feels and acts. It bends one's mind in such a way that the person has hallucinations so he or she sees and hears things that don't really exist. Sometimes hallucinogen users have a "bad trip." They suddenly feel paranoid and extremely anxious about losing control. These feelings can lead to bizarre and even violent behaviour because hallucinogens are very powerful and unpredictable (Addiction Research Foundation 1997c).

Joints, marijuana cigarettes, are the most popular way of smoking marijuana in Brazil (and in North America). Normally it is a social event where the joint is always passed in a circular fashion to all those present. But while Jonas was withdrawn in his bedroom he smoked marijuana by himself. The other patients have also mentioned occasions when they smoked marijuana or used other drugs in a solitary way. In fact, psychiatrists frequently distinguish those patients who are "truly" psychotic from those patients who have a psychotic episode induced by drugs by asking them whether they prefer to consume drugs alone or only in social situations (Cíntia Camargo, M.D., personal communication in August 1998). The reader will discover in Chapter 5 that Jonas believed that he was improving when he started to go out again to meet his friends in the bar to drink and "get stoned."

Leonardo's narrative below exemplifies that these young man often associated drug addiction with a period of their lives when they were feeling quite "normal" and had more control of themselves. In this context the experience of drug abuse is perceived as extremely good and it is very different from the symptoms of psychosis:

Before when I used marijuana it seemed that I was kind of crazy. I am not really sure because when I did things I would do them with more attention because I knew that I was drugged. Now I try to do things with attention but it seems that... Before [with marijuana] it seemed that things got right! It seemed that everything turned out well. I didn't seem, everything really went well, in the ways I planned and wanted things to happen. Then after I stopped [with marijuana] is when I started to feel strange things [psychotic symptoms]. [...] Even while being crazy [by smoking marijuana] I would do things right, I would not do things wrong! I was perfect. But now I have to be calm, to do things with more calmness... because before I could think... and now I cannot even think right. Just pay attention to the way I talk, I am talking in a confusing way, I am saying things that... [Leonardo, Return of Jesus Christ Church]

With the progression of the psychotic episode some young men inferred to me that going back to their previous drug use habits strongly indicated that they were improving and that they were coming back to some kind of normalcy.⁹ For instance, one

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⁹ The medical literature hypothesizes three different models to explain the high prevalence of drug abuse among schizophrenic patients: the "vulnerability model" suggests that drug abuse may cause schizophrenia

day Mauricio told me that he was very anxious to use marijuana again because then "I feel crazy, but at least I relax." When Leonardo started smoking marijuana again he explained that he was avoiding smoking it whenever he had to do something that demanded a lot of attention or something very "heavy" that would make him feel lazy to accomplish. Their comments were very slippery regarding cocaine or any other drugs. I suppose because none of them felt very comfortable in talking about it with me.

Ways of taking medication

A person who does not take the medication as prescribed or refuses it is regarded by the psychiatrist as a non-compliant patient. This is perceived as challenging the presumed authority of the psychiatrist over the patient, and that often results in interactions that force the patient either to do what the psychiatrist says or to suffer the consequences. However, various authors have demonstrated that a patient's non-compliant behavior cannot be understood outside the context of the person's life and specifically outside the context of the person's health-seeking process and treatment expectations (e.g. Kaljee & Beardsley 1992; Hunt, Jordan, Irwin, Browner, 1989; Conrad, 1985).

Fieldwork indicates that families often expected anti-psychotic medication to have the "aspirin effect": take the pill for the "headache" (illness) to pass away. It seems that they perceive medication as a "magic pill" that would provide immediate results. Furthermore, the narrative of Carmen's mother illustrates some lay conceptions towards anti-psychotic medication that seem to underlie the behaviour of many other families:

or increase the likelihood of its expression in individuals who are already vulnerable to the disorder. The "self medication" model postulates that schizophrenic patients may be self-medicating their symptoms when they engage or re-engage themselves in drug abuse. Schizophrenic patients often report that they use drugs to get "high," to alleviate "depression" and to relax in addition to their desire to diminish the negative symptoms, that is to increase emotions, talk more, and to increase their energy. It is well known that depression is very difficult to distinguish from akinesia (side-effect of neuroleptics) and the negative symptoms. The most preferred drug, marijuana, is both anxiolytic and activating (increasing energy), while alcohol shares the anxiolytic effect and cocaine the activating one. The third related model hypothesizes that drug-abusing schizophrenic patients try to self-medicate the uncomfortable side effects of neuroleptic medication (Buckley, 1998: Dixon, Haas, Weiden, Sweeney, and Frances, 1991). These models have the potential to further explore why some of the young men who participated in this study presented a back-and-forth movement between drug abuse and abstinence.

Ah then this medication is worthless! Because when the medication is good to heal a certain illness, it should have effect only over that illness, and it should not act upon another organ of the human body. This is my way of thinking. I am right or I am wrong? I don't understand much but I believe one thing, shoes are made for you feet, so you should not wear them in your hands. You should not walk wearing shoes in your hands, gloves are made for your hands. Now when a medication for a certain illness harms another organ of the body it does not serve for that illness nor for any thing else! [Carmen's mother, Non-Practicing Catholic]

These families currently imagine that every illness has a corresponding medication to heal that specific problem (the shoes and gloves analogy). Furthermore, the medication which produces side-effects is worthless since it is doing more harm than good and because people expect that any medication always promotes good health and well-being. Besides being very concerned with the side-effects, they also believe that if the person takes this medication for a long period of time the "drug" would accumulate in the body and this would cause irreversible "dependence" over time. Persons who depend on medication are not considered healthy. Some young people also expressed with indignation that they consider anti-psychotic medication the real "drug;" to be dependent on this type of medication would be much worse than any drug addiction problem. In addition, while being medicated they cannot act or be their "true selves" anymore, as it was suggested by Leonardo's and Luana's narratives. Therefore it becomes easier to understand why the relationship patients have with anti-psychotic medication fluctuates over time.

I have noticed during my fieldwork that very few young people take the medication exactly in the ways prescribed by the psychiatrist. It is not unusual to see the patients and/or their families report to the psychiatrist that they are taking the medication as was prescribed, when they are taking very little medication or no medication at all. Even so, some patients would rather continue to go to see the psychiatrist week after week, instead of taking the radical decision of quitting the medical treatment. I suspect that in this case the patient needs to be periodically reassured by the psychiatrist that they are still progressing well, even though they have discontinued the medication without the

psychiatrist's awareness or approval. Leonardo and Carmen employed this kind of strategy (see also Chapter 1).

Some families explained to me that they were trying to diminish the anti-psychotic medication without the psychiatrist's awareness in order to avoid the accumulation of too much "drug" in the body, "dependence" or because they wanted to reduce the side-effects. If the medication is reduced little by little, they believe the person's body would slowly get accustomed to less medication until it becomes totally unnecessary. For example, Luana's mother only administered medication to her daughter when her irritability intensified. But this is far from being a linear process because some patients might suddenly decide to take much more medication than needed hoping that this will rapidly lessen some symptoms. Eduardo and José had the common habit to take more medication than prescribed when they were feeling restless or had difficulties to sleep. Therefore, the various ways the young people deal with their medication are more related with immediate meanings and needs associated with this medication, than with the original medical prescription proposed by the psychiatrist. Ultimately, it is the person who decides (sometimes together with the family), but never the psychiatrist, what sort of medical regimen will be followed.

Sometimes it is hard for the young people and their families to understand why the psychiatrist is changing the type of medication or the dosage. I heard a series of complaints from family members because they frequently assume that when psychiatrists constantly change type or dosage of the medication they are not being competent enough to solve the patient's problem. Some families suggested that psychiatrists were not really knowledgeable about the illness; they were simply testing different medications until finding one that would work. For instance, José's mother believed that psychiatrists should never prescribe a medication until they were certain about which illness they were treating. In other words, families consider that different medications may be a strong indicator that psychiatrists ignore which illness they are treating. It also gives the impression to patients and their families that the person is only being treated as a "guinea pig" and not as a human being.

Grounds for Misunderstanding

Difficulties in the physician/patient relationship is a traditional topic in the medical anthropological literature (e.g. Hahn & Gaines, 1985; Kleinman, 1980). This topic is too vast to be covered in detail here. For this reason the discussion that follows is restricted to the key sources of misunderstandings that I had the chance to observe during my fieldwork. A major source of conflicts between psychiatrists and their clientele is that they hold different representations of mental illness. Another common source of misunderstanding is related to the notion of stigmatization. These two elements contribute to diminish the significance of psychiatric care in the context of incipient psychosis.

Representations of mental illness

Carlos's story 10

Carlos spoke very little, was very withdrawn and stiff in his posture, and remained most of the time standing quiet. His mother reported in a confusing way to the psychiatrist that in the last three months her son began to isolate himself from other people, and that recently he attempted to commit suicide by drinking cockroach poison. She also carried in her hands the tin containing what was left of the cockroach poison. A few weeks earlier Carlos had remained hospitalized for seven days due to this poison intoxication. From time to time Carlos suddenly cried out loud to the psychiatrist: "I am going to die, I am going to die, I am catching all sorts of disease." When the mother started desperately to scream, the psychiatrist asked me to keep her company outside of the room for a few minutes to enable him to talk with Carlos with more tranquility.

This was the only time I had some contact with Carlos and his mother because they did not come back to the emergency room of the São Paulo Hospital. I did not invite them to participate in the study because the two emergency psychiatrists were in doubt about the psychiatric diagnosis. It could either be a second psychotic episode (initially this would not fill the selection criteria) or some kind of personality disorder.

While we were both waiting in the corridor, Carlos's mother in a thrust and disturbed way explained to me that her son was not louco (crazy), yet she could not understand why he started behaving strangely so suddenly. Then she said: "this is coisa feita [black magic], it can only be coisa feita." Her husband had also been fighting with her because he insisted that their son needed to have a chapa da cabeca¹¹ done. For this reason she had already taken her son to another hospital that morning, but since the physicians there refused to perform the chapa da cabeça exam. they immediately came to the emergency room of the São Paulo Hospital with the same request. Even though the emergency psychiatrist tried to explain several times that this type of problem cannot be viewed through the chapa da cabeça because only the bones are seen in this exam, she was still not convinced. She was absolutely certain that her son's problem was related to some spiritual problem. Probably the coisa feita made by some envious neighbors was intended to harm her, but had affected her son instead. In the sixth day that Carlos was hospitalized to eliminate the cockroach poison intoxication, she had a consultation with an Umbanda spiritual healer. This spiritual healer explained that her son was being possessed by some encosto (leaning spirit), and that he would die from some fatal disease if she did not take him out of the hospital immediately. In the seventh day when she was going to demand that her son leave the hospital he was coincidentally discharged. She believed that this sudden discharge was affected by some good spiritual influence. Before entering the emergency room, while they were waiting their turn to talk with the psychiatrist, a follower from the Universal Kingdom of God Church suggested that they should go to her church. This other person had already suffered from a similar problem and was only healed in this Neo-Pentecostal church. When the psychiatrist called us back in the room, Carlos's mother expressed to him all her rage that he also had refused to do the chapa da cabeça exam. She screamed at the psychiatrist that they

¹¹ Popular name given to the X-ray exam or electro-encephalogram (brain scan.) The literal translation

were leaving the emergency room but would go directly to the Universal Kingdom of God Church even if they would have to return home only after midnight that day. She also anticipated that her husband would be very mad with her in case the <u>chapa da cabeça</u> was not done. Some minutes afterwards I saw the mother desperately asking a taxi driver parked in front of the hospital to take them to the nearest Universal Kingdom of God Church.

Despite all their desperation, anguish, and feelings of helplessness, the families usually listened very carefully to the advice given by the emergency room psychiatrist. The situations that were most likely to generate turbulence in the emergency room cluster around three topics:

- 1) Refusal of medication by the patient.
- 2) Decision to hospitalize or not.
- 3) The chapa de cabeça exam.

So many people request the <u>chapa da cabeça</u> that psychiatrists even have rehearsed responses to tackle this issue. Most times they don't sound convincing. The urge to have a <u>chapa da cabeça</u> done indicates that families hold a representation of mental illness as something concrete and with a specific localization in the brain. When they seek help in a medical setting, they are expecting to find some "material illness" that would explain the patient's problem. The widespread notion of "material illness" is always considered in opposition to the notion of "spiritual illness": "material illness" is for physicians to handle, while the "spiritual illness" is a problem for religious healers (see also Chapter 6). Furthermore, positive results in the <u>chapa da cabeça</u> exam would rule out the presence of some "spiritual illness." It is very difficult to know beforehand whether the illness belongs to the "material" and/or the "spiritual" domains. When the psychiatrist tried to explain in simple terms to Carlos's mother that this exam is useless because the <u>chapa da cabeça</u> would only show the bones, this probably reinforced her

suspicion that her son was suffering from some "spiritual illness." In fact, many other families have gone to a variety of physicians because they wanted to have this exam done. In situations like this, family complaints that psychiatrists "just do too much talking, but do not solve nothing" were very frequent.

Besides this representation of mental illness as something very concrete located in the brain, a whole series of lay assumptions emerge which associate mental illness with the permanent loss of memory and conscience. Therefore, several family members attempted to minimize the extent of the patient's problem by emphasizing that they have noticed no loss of memory or consciousness, only some loss of personal control. Furthermore, the patient's uncontrolled behavior can be easily perceived as a reaction to evil influences from the spiritual world, in other words, as some kind of spiritual problem:

Oh, I don't really know. I imagine that Leonardo's problem is spiritual because if it were a problem for physicians, he would lose his memory he would lose his conscience. But this is a problem that he only has once in a while, it is not a problem that he has all the time, that's why the problem is a spiritual one. [Leonardo's grandaunt, crente]

This could only be a coisa maligna [malignant spirit] that would lean over her to make her see things, and to make her say nonsense. Because whatever she saw and whatever she did she still remembers today. But if she really had some perturbação [disturbance] coming from her head that was not spiritual, she would not remember. She would not be able to remember if this had come from her head, from her mind, she would not remember. It is just like she told you, she told you what she was seeing [visual hallucinations]. Yet she was unable to control herself not to do certain things, not to say certain things. Whatever she was feeling like doing she would do. She just wasn't able to control herself not to do it, do you understand? But whatever she saw before she recalls everything today. If we ask her she will tell. [Sarah's mother, Assembly of God]

More often than not these families interpreted that the young person's illness pertained to both "material" and "spiritual" domains, instead of privileging one or the other. This also helps to understand why psychiatric sources of help were rarely discarded because people privileged religious source of help. Gisela's story is the only exception; she abandoned the psychiatric treatment after she realized that Umbanda

therapies made more sense to what she was experiencing (see Chapter 7). But most commonly, people resort to psychiatric care and to religious sources of help simultaneously. In other words, psychiatric help is most often abandoned because families believe it is no longer needed and not because "religion" has taken its place. Religion will always be there.

Daniel's story

Daniel's mother was extremely upset to be forced to come to the emergency room during the evening together with her son because the psychiatrist wanted to talk with her. She already made her own conclusions about Daniel's problem. Since he was examined by the chapa de pulmão (chest X-ray) and the chapa de cabeça and nothing appeared, the mother was absolutely sure that Daniel's problem only had a "spiritual" origin. When one of the psychiatrists explained that night that her son was only a little bit "disturbed" and "obsessed," the mother sighed in relief. Since she associated these words with the "obsessive spirits" that were "disturbing" her son, she imagined that this time the psychiatrists finally discovered the right diagnosis. In the past few months, Daniel had taken all types of medications and gone to several health care services, besides becoming involved into his mother's church. He was desperately searching a solution for his problem. He had become a very quiet and fearful person who remained most of the time lying down on his bed. It had been a couple of years since he quit school because he had difficulties to learn. He also had many terrible and scary thoughts that disturbed him constantly. He heard voices in his head. He was frightened and worried that he would die at any moment. Frequently his heart suddenly accelerated and the fear only intensified. Besides several psychiatrists, he also consulted a cardiologist. He was feeling completely "intoxicated" after taking so much medication.

simple schizophrenia, Paranoid schizophrenia. obsessivecompulsive disorder, panic, and mental retardation - these were the different psychiatric diagnoses attributed to Daniel at the São Paulo Hospital. The psychiatric resident started to follow Daniel at the Pedagogic Ambulatory. Since Daniel would come to the hospital whenever he felt like coming, but never during his weekly appointments, the psychiatrist began to refuse to provide care outside of the appointment time. Daniel quit the São Paulo Hospital before the psychiatrists had the chance to reach a final agreement in relation to the psychiatric diagnosis. Daniel stopped searching for psychiatrists, even though he continued with his back-andforth movement between different hospitals, until the moment he was told that his "problem" was more related with the heart. The SCID-DSM-IV psychiatric interview indicates a diagnosis of panic disorder.

I preferred to interrupt following Daniel in his daily life due to this controversy between psychiatric diagnoses. I had no solid ground to determine whether this case could be defined as a first psychotic episode. Even so, I had the chance to go to his baptism ceremony (see Chapter 7) and he also accepted to be interviewed with the TPI and the SCID-DSM-IV. Daniel's story is included here because of its relevance from an anthropological perspective. It illustrates clearly how a psychiatric diagnosis can be socially and culturally constructed (e.g. Young, 1995; Gaines, 1992; Kleinman, 1988). But this is the everyday reality of the emergency room. There are many other cases that defy psychiatric classification, and this certainly has great implications towards the future life experiences of these patients. Daniel is a very poor, mulato, and non-educated young man who had tremendous difficulty to express in an intelligible way to the psychiatrists what was his problem. Yet the psychiatrists don't stay behind; they were not really able to understand Daniel's experience in another way than translating it into several psychiatric diagnoses. They only played back-and-forth with different labels to his mental illness, all of them corresponding to representations covered and legitimated by scientific standards of psychiatric classification. I also believe that Daniel's case transcends the inevitable

issue of misdiagnosis. No psychiatric classification is "perfect," and psychiatrists will always commit some mistakes. There are two other possibilities to be considered:

- 1) Daniel never had a psychiatric problem but whenever someone decides to seek help in psychiatric settings, this is already a strong indicator to psychiatrists that this person has a mental health problem.
- 2) Daniel has a psychiatric problem that does not "fit" well in any category of psychiatric classification. Consequently, the case becomes too complicated to be treated and Daniel is expelled from psychiatric care in a very surreptitious way.

Representations about stigmatization

I have noticed that psychiatrists and other health care professionals usually act with the best intentions to provide the most adequate care. Notwithstanding, they are often able to grasp only a small portion of the patient's problem or they hold a distorted perspective of the patient's reality. I share with these health care professionals the preoccupation towards avoiding social stigmatization of the person who suffers a psychotic episode. Yet what we consider to be stigmatizing does not necessarily correspond to the perspective of psychotic people and their families. This conflict of interpretations is most evident in issues related to unemployment and sick leave payments. Very few young people were entitled to receive sick leave payments from the government. Their major problem was to prove that they had worked at least for a whole year before the sickness, so that they would have paid some previous contribution to the government. Most often, they had no means to prove this since those who worked had primarily worked in sideline jobs, or their previous work experience reached less than one year.

José's story

After attending the Schizophrenia Programme for more than six months José and his mother thought that it was a good idea to ask the

psychiatrist to provide José with a written proof that confirmed the diagnosis of schizophrenia. After taking possession of this proof José would be able to apply for a steady monthly allowance due to illness disability given by the Ministry of Social Welfare. This strategy was already being used by José's mother herself who was considered disabled by the government's social insurance due to heart problems. This was her basic way to guarantee a small but secure family income every month. Even so, the money she gained cooking and selling tapioca on the streets or by keeping an eye over other people's parked cars were substantial additions to the family budget. The first reaction of the psychiatrist was to deny the written diagnosis of schizophrenia to José because she judged that this would stigmatize him forever and would impede him to look for jobs in the future. José and his mother felt very outraged by the psychiatrist's attitude, and I still remember very clearly how they left the consultation room screaming and calling him bad names. But they did not give up so easily. Some weeks later they had an appointment with the social worker of the Schizophrenia Programme. She then acted as the intermediary between them and the psychiatrist who was then convinced to render the diagnosis of schizophrenia official. The social worker paid more attention to basic issues related with patient's rights and minimized the significance of stigmatization as a consequence of psychiatric diagnosis. José was very happy to receive this written proof of schizophrenia diagnosis because he was having great difficulties in finding a job; the money that he eventually earned in keeping an eye over other people's cars on the street was just too little. Neither José nor his mother made any association between his difficulties in finding a new job and the psychotic episode he had just suffered.

The divergence of perceptions between José and the psychiatrist can be interpreted in the following manner. On one level, José imagined that the psychotic episode would never come back because he perceived it as one unique and temporary

event. This differs from the widespread perception of health care professionals who see a first psychotic episode as a sign of a condition that will develop further and only deteriorate with time. On another level, since José's two brothers and sister were unemployed for a long period as well, the whole family linked the problem of unemployment with the country's economic crisis. Consequently, no association was made between his lack of job and the possibility of stigmatization due to psychosis.

Even though the problem of stigmatization associated with schizophrenia is already well documented in the anthropological literature (e.g. Barrett, 1996; Estroff, 1985; Waxler, 1977) one still needs to put this notion into context in relation to the specific social-economic realities lived by the psychotic patients. I was surprised to hear Jonas tell me with satisfaction that he preferred to continue receiving the sick leave payments by the Ministry of Social Welfare instead of finding a new job because he was receiving much more money than in the previous temporary jobs he was working in. Yet this strategy requires the psychiatrist to maintain and perpetuate the diagnosis of schizophrenia for a longer time. It is important to mention that the Ministry of Social Welfare demands that every patient return to a medical consultation with his own physicians once or twice a year. This periodical medical consultation is done to decide whether the person still deserves to continue receiving the sick leave payments or the disability allowances for another period.

Dora's story

I became very concerned one night because Dora had left a message on my pager informing me that she needed to talk with me urgently. I hurried to her house the next morning to discover what was happening. I was particularly worried because she had abandoned the psychiatric treatment as soon as she was discharged from the psychiatric hospital after one month of hospitalization. Thus, she never showed up at the local primary health care unit as recommended. Several months had passed since her psychiatric hospitalization, yet she was still having a hard

time to find a new job. Since she used to receive a reasonable salary, her contribution represented a substantial part of her family's budget. Her family also associated the outbreak of her psychotic episode with the day that they had to move from a two bedroom apartment to a type B cortico in order to spend less money because Dora had been unemployed for several months.

When I arrived at Dora's home the next morning, she was already out in the streets looking for jobs. Her mother told me that they phoned because Dora needed to pass through the medical examination of the Ministry of Social Welfare in order to continue receiving the sick leave payments. For that, they wanted me to arrange a psychiatric prescription with the emergency room psychiatrists of São Paulo Hospital. Dora needed this prescription to present as proof of sickness to the Ministry of Social Welfare, however she vehemently refused to see any psychiatrist again. I explained to the mother that the psychiatrists who I knew certainly would not accept to write any prescription without seeing the patient in person, and that I was in total agreement with this kind of ethical attitude. I apologized but I would not be able to help them out in this way.

Some weeks later Dora told me how she managed to pass through the medical examination of the Ministry without going first to the psychiatrist to get a prescription. She used the old prescription that she had received in the psychiatric hospital; when she had to be examined by the Ministry's physician she acted in a very crazy and foolish way. She also faked that she had some memory impairment but she found this performance very easy to do because the whole medical examination took only a few minutes. She commented that it was "good to be sick" but she immediately corrected herself by saying that it would be good if she could continue to fake mental illness in order to continue receiving money in such an easy way.

José, Jonas, and Dora were much more concerned with immediate solutions to deal with the situation of unemployment than with the possibility of being permanently stigmatized by mental illness. The financial difficulties of the immediate present are more urgent than any prospects about their future life. Since they are not feeling so stigmatized in the present it becomes difficult to imagine why that would happen in the future. But the different ways patients and their families interpret the problem of social stigmatization traverses other social spaces besides work related issues.

In the early stages of disease, "schizophrenia" is often a less charged notion to these families than the condition of mental illness (doença mental) since this psychiatric terminology is not popularly known. I have noticed this particularly during some group family meetings organized by the Schizophrenia Programme to provide basic educational information to help families to cope with the burden of living with a mentally ill patient. Some parents would feel extremely relieved to discover that the illness was not exclusive to their children, and that they could even call it "schizophrenia." The young people are not "crazy" (louco), the problem they have is called "schizophrenia."

With the progression of my fieldwork a total of twelve patients were receiving psychiatric care at the Schizophrenia Programme. Very few patients were receptive to engage themselves in some of the activities of the Programme (e.g. occupational therapy, group therapy) besides the periodical medical consultation. The psychiatrists complained that some patients and families even skipped the medical consultations, although they would come quickly if the condition worsened, if the medication was provoking side-effects or when they needed a new prescription to buy medication. Once more the significance of psychiatric care revolves around medication issues. In the context of incipient psychosis, young people and their families hope to abolish the medication (and the psychiatric treatment) as soon as possible. Thus, any type of psychiatric care is likely to be discontinued as soon as the medication loses its central importance. These families strive to forget that the psychotic episode ever did happen. They will rather reject participating in any extra activity furnished by the Programme, because it implies continuity of psychiatric care, instead of the desired discontinuity.

Some mental health professionals realized that the main problem was that they were "mixing" the patients: patients with early psychosis and their families were being asked to participate in the same activities than those families and patients with chronic illness. They realized that young people with early psychosis and their families have needs and concerns that are very different from the chronic cases. The interaction with the chronic patients can be extremely painful, especially when young people identify these patients as a reflection or a mirror of themselves. This also occurred in those situations of psychiatric hospitalization. By the time I was finishing my fieldwork mental health professionals from the Schizophrenia Programme were tailoring activities specifically for the first-episode cases.

Apparently the few families who showed some interest to participate in the activities of the Schizophrenia Programme found a new space for socialization in this psychiatric setting. This often happens because they lack other space where they could meet people. Families tend to participate more actively when the problem has become chronic. But in this case too, the psychiatric setting gains more importance as patients and families begin to exclude themselves from other social spaces. What remains to be questioned is whether there is a possibility to create new spaces of socialization without the connotation of "medicalization" that is so inherent to the psychiatric setting. There are already a few self-help groups organized in São Paulo that are directed to psychiatric patients and their families and that function outside the psychiatric environment. But usually these self-help groups are formed primarily by middle-class and upper middle-class families and reach a minority of people. One can wonder what could be done to meet the problems and concerns of these families, and more specifically the less privileged. Meanwhile, it should not be surprising to observe these families keeping the space of psychiatric care at the margins of their everyday lives.

Chapter 5 - Social Reactions Towards People with Psychosis

Madness affects not only the individual, but the entire family, and larger social network, its symptoms producing and reproducing distortions in human relations so that after many years after dealing with psychosis both the individual and their significant others are radically changed. We are not dealing than with norms, but rather with cultural patterns and beliefs as they are refracted through and changed by one of the most devastating assaults in personhood: psychosis. Nevertheless, there is no doubt that cultures provides some guidelines and social scripts for how to behave when crazy and how to respond to madness in others.

[Scheper-Hughes, 1987:56]

The radical changes mentioned by Scheper-Hughes develop slowly, but some initial signs and contradictions inherent to the changes experienced by psychotic people and their families are already evident during the outbreak of the first psychotic episode. Furthermore, the role played by the family is a central issue on several studies that deal with the social and cultural factors that influence the perpetuation of schizophrenia. The idea that levels of family members' "expressed emotion" influence the clinical relapse of people with schizophrenia is the most widely established "fact" in the literature. I have already suggested elsewhere that the expression and cluster of emotions that correspond to "expressed emotion" seems to differ cross-culturally (see Chapter 2). Authors like Jenkins (1988b) have argued that what triggers family reactions might differ as well. In addition, these reactions reflect a broader understanding regarding the notion of person and of the expected ways to react to particular attitudes and behaviour. For instance, core North American values such as autonomy, independence, responsibility, and initiative are involved in the elaboration of the notion of person in the United States. Jenkins observes that criticism in Anglo-American families tend to be triggered by behaviours interpreted as indicative of "laziness;" these families are more likely to react in a blunt or vitriolic way when they describe the illness of the schizophrenic member. By contrast, Mexican-American families are more worried by a disrespectful attitude towards elders or authority figures in the family; their way of understanding the problem leads them to express both

anguished and tender feelings towards the schizophrenic member, as well as a desire to shelter him or her.

Scheper-Hughes' (1987) examined individual, family and community differences regarding perceptions and reactions to psychotic symptoms in a community of South Boston. She observed that Irish-American families are more likely to complain about the inappropriate appearance or behaviour of psychotic patients, but that they often overlook the patient's lack of contact with reality (e.g. hallucinations, delusions, nonsensical language or other cognitive symptoms of psychosis). Some families would even interpret symptoms of psychotic ideation as signs of creativity and genius, rather than madness. In addition, some Irish families who participated in the study moved from a position of denying the "problem" to one of denying the "person" with the problem. By contrast, families from an Anglo-Italian background seemed to have greater tolerance towards signs of psychotic affect (e.g. mood swings, emotional outburst, acting out) when compared to patient's signs of lack of contact of reality.

Murphy (1974) observed that French Canadian families are more community-oriented and family-oriented than British Canadian families who, conversely, give more emphasis to individualism. A natural consequence of this is that schizophrenic patients from a French Canadian background are more likely to suffer and be more concerned with the loss of social ties (whether real or imagined), than patients from a British origin. One could hypothesize that patients with a French Canadian background will put more effort into maintaining their social ties, whether they are psychotic or feeling well. In addition, French Canadian schizophrenics are highly concerned and perhaps "delusional" regarding their interpersonal relations, while the British Canadians are largely indifferent to them. Consequently, the typical French-Canadian schizophrenic tries to maintain his or her involvement in interpersonal relationships, and expresses less signs of "social

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¹ Scheper-Hughes (1987) also makes reference to Opler & Singer's (1956) study. These authors investigated ethnic differences in behaviour and psychopathology among Italian- and Irish-American schizophrenics. Italian schizophrenics exhibited many schizo-affective features marked by a tendency towards talkativeness, hyperactivity, excitement and mood swings when compared to the Irish-Americans. By contrast, the Irish-American schizophrenics tend to be more delusional, hallucinatory and fantasy-indulging, in addition to being more guilt-ridden and conflicted by sexuality.

withdrawal" when compared to the British-Canadian schizophrenic. Murphy also suggests that French Canadian families are more tolerant and take a longer time to label the odd behaviours of its member as a "schizophrenic patient" or "mentally ill person," when compared to British Canadian families. Murphy further hypothesizes that this high level of tolerance can also convert to relatively high intolerance once someone exceeds a certain level of permitted deviancy, since the degree of irritation produced by extreme deviancy is much greater when social contacts are close than when they are loose.

It is a commonly accepted assumption in the cross-cultural epidemiological literature that family environments in Third World countries are more "supportive and tolerant." Consequently people with schizophrenia would have little risk of prolonged rejection, isolation, segregation and institutionalization. Other authors have objected about the process of homogenization and essentialization underlying this kind of assumption (e.g. Edgerton & Cohen, 1994; Cohen 1992). They argue that different family dynamics and reactions may occur across families or within the same family within a particular society. Notions such as "tolerance" and "social support" normally have more than one dimension. For example, the mother can try to be more tolerant, while the father is not tolerant at all, meaning that attitudes of tolerance differ among different family members. In some circumstances, a particular family member may be more supportive than in others, or he or she can gradually become less or more supportive. Reactions have to be understood in a broader context, including the problems that are evolving and may eventually become "chronic." Attitudes and behaviour are also affected by larger circumstances that concern the whole family life, as global conditions of poverty or events touching other family members.

The first part of this chapter compares the kinds of behaviours and manifestations that were mentioned the most regularly by patients and family members. It describes their impact on family life and the basic type of reaction they evoke. Some of these reactions are directly related to specific behaviours and disturbances while others are more broadly evoked by the whole situation. The first set of reactions is particularly expressed when people describe how the problem started and attracted their attention. Family members

then describe how particular signs or behaviours first triggered their attention as indicating the existence of a problem. The second part of the chapter emphasises that reactions also vary and change in relation to the social role of each family member and the family dynamics at play. More generally, narratives indicate that reactions work in a kind of "feed-back loop," since family reactions modify the subjective world and reactions of patients, while patients' reactions modify family's attitudes and behaviours. The last part of the chapter describes the fear of loucura and stigmatization manifested by patients and family members in the broader context of community life.

Signs of Disturbance and Family Reactions

Jonas's story

<u>Cristina</u>: When did you first notice that something was kind of different or seemed kind of strange, that something was changing in you?

Jonas: Practically it was at my job while I was answering the calls and suddenly I started to believe that the whole world was watching and keeping an eye over me, something like that. Afterwards it became very heavy.

<u>Cristina</u>: What kind of calls you were answering?

Jonas: They are pager phone calls.

Cristina: Yeah.

<u>Jonas</u>: Suddenly I got some kind of fear, and I started to think that everyone was talking about me.

Cristina: Yeah.

<u>Jonas</u>: And this started to destabilize me, and so I thought that something was really wrong.

Cristina: What these people were talking about you?

<u>Jonas</u>: Ah it was some sort of fun that they were making out of me, and they would observe me working.

Cristina: Hum.

<u>Jonas</u>: But theoretically they did not imagine that I was going to discover. <u>Cristina</u>: Hum.

<u>Jonas</u>: And they played games, and they began to touch on behaviour issues.

Cristina: Kind of...

Jonas: Kind...let's say, some kind of joke, as if they were making jokes out of my face, more or less like that. I don't believe it is exactly this, but it is almost like this. Then after some time I started to have problems to go out

in the street, I started to have problems to stare at people, it was something in evolutionary scale.

Cristina: You were afraid of going out in the street?

<u>Jonas</u>: I have this fear, but this is not so much a fear of going out in the street, but it is a fear of staring at people.

Cristina: Hum.

Jonas: To make contact with people has not been very easy for me.

Cristina: Hum.

<u>Jonas</u>: This is a strange thing because I have always been a very communicative person, I have always talked a lot and suddenly this problem came and I stopped.

During this first interview Jonas's described his fear by stressing that: "I lost the way in how to stare at people...I have unlearned it." However he felt incapable of identifying the source of this fear which was disturbing him tremendously. When he first told his mother and sister what was happening they paid no attention to what he said. But the fear only increased and increased so that Jonas started to make up excuses for not going to work and remained most of the time locked in his bedroom. Jonas's mother and sister became progressively more irritated and nervous with him because they imagined that he was only faking some disease in order not to work anymore. Jonas lost his job. Initially Jonas's girlfriend thought that it was quite normal that Jonas had some conflicts with his coworkers because provocations, envy, and gossips are likely to occur in any job. Some weeks later she began to worry because Jonas was always avoiding to go out with friends during the weekend. She mentioned that Jonas's bedroom was totally dirty and messy and that most of the time he remained lying down in bed with the lights off and windows shut. His mother even wanted to clean Jonas's bedroom but his sister opposed this because he was doing absolutely nothing the whole day. Jonas's girlfriend decided to intervene. She asked her brother to accompany her and they both convinced Jonas to consult a physician because of all the stress and tension that he was going through. They also forced Jonas to take a bath, while in the meantime they cleaned his bedroom.

Jonas had already consulted a physician, a psychologist and tried some acupuncture before going to the emergency room of São Paulo Hospital, always supported by his girlfriend. Only then he started to take neuroleptics. His mother and his sister continued to complain about Jonas's laziness and the climate of tension exploded when the sister lost her job as well. Jonas was very upset because he felt that his family was doing him a great injustice. His girlfriend begged for the mother and sister to go to the emergency room so that the psychiatrist could explain them how serious Jonas's problem really was. After this talk his mother changed her attitude completely while his sister chose to ignore the situation even more. The mother started following Jonas to all psychiatric consultations in addition to seeking eagerly for religious sources of help. Jonas was transferred to the Schizophrenia Programme. The mother called her exhusband who started to visit his son after many years of absence; confronted by the situation, he decided to provide some financial assistance to the family as well. Finding a temporary job out of town provided a good reason for the sister to continue spending most of her time outside of the home (and its problems). She was extremely annoyed by all the especial attention her mother was now giving to Jonas. Although he had always been the favourite son, the mother's protection became even excessive in the sister's eyes. More than ever Jonas was being spoiled.

The mother started to keep a close eye over all Jonas's movements, feelings and desires from the moment she discovered through the psychiatrist that her son had suicidal thoughts. She cried and cried. The girlfriend too. But they always avoided crying in front of Jonas since they did not want him to notice their deep preoccupation. Jonas's father phoned one day to inform the family that he did not have enough money to continue providing financial support. The girlfriend believed that this affected Jonas so much that his condition worsened. After the psychiatrist changed the medication, Jonas started slowly to feel better. He even

ventured a part time job for a short period of time. He was entering data in a computer for a friend. However most of Jonas's friends had disappeared from the house. In the first few months when he felt a need for solitude, he rejected most visits of his friends. The mother accepted Jonas's position and asked all of Jonas's friends not to come anymore. This also allowed her to dismiss some of Jonas's friends that she considered "bad company." She regrets that she accepted Jonas's request to send away the church people whom would always come to pray and bless Jonas and the home.

When Jonas began to feel better, he started missing the company of his friends. He was not much concerned with any job hunting because he was receiving sick leave payments from the Ministry of Social Welfare. He started to go out in the evening to spend some time with friends in a bar. He always went there because he liked to recognize the people who regularly attended the bar. He was very glad to be able to stare and talk with these people without any fear. For him this was the real sign of his improvement. Sometimes he would come home drunk. His mother and girlfriend became very apprehensive when the psychiatrist told them that Jonas was not supposed to mix the neuroleptic medication with alcoholic beverages. They started to have constant fights with Jonas but that did not stop him from going out to drink. He also began to consume marijuana more often. He felt that marijuana helped him to be more creative. He wanted to be very creative now that he had improved from his sickness. The last time that we met he mentioned with a certain satisfaction that he had read somewhere that people who have mental problems are more creative than normal people.

Jonas's story illustrates how family reactions both transformed according to the evolution of the problem and were influenced by the broader family life context. It indicates that some signs of psychosis attract the immediate attention of family members, more than other manifestations. In addition, other kinds of problems will be reviewed

which tend not to be considered as so disturbing by family members even if they are considered as psychiatric symptoms from a psychiatric perspective. Family reactions also illustrate the influence of what I have described as the "personalistic" orientation of the Brazilian society on family's perception of the interaction and its way to react to it.

Reactions to particular domains of disturbance

Narratives indicate that symptoms of psychosis can be a way for the patient to express and react to a perceived altered world; their perception of the reactions of others contribute further to their altered world. One could therefore say that patients' symptoms integrate a larger feed-back loop of actions and reactions between their particular mode-of-being-in-the-world, and the reactions that they trigger in family members. The excerpts below illustrate that several young people were worried by a kind of escalation of a feeling of nervousness which they present as one of the preliminary changes in their mode-of-being-in-the-world during the outbreak of psychosis:

Ah the thoughts, thoughts of pessimism, morbid [thoughts] you know, bad thoughts. Bad thoughts about what was going to happen to me. During the crisis I was nervous too, when my mother talked to me and my father [talked] I would get very nervous too. I would get nervous and I did not want to say anything, it seems that I did not want to talk to anyone. [Eduardo, Charismatic Catholic]

My mother was worried to see me always tense, always nervous, I was holding myself not to explode! [short silence] I don't like to be... to be... I don't like to feel myself watched out... I don't like to feel myself like an animal. I was feeling myself an animal. [Mauricio, Non-Practicing Catholic]

I would get very nervous. It was not my way of being the things I did. A lot of nervousness. I was kind of scared. I never was like this, why I was doing this. Icch I would hit things and kick things. Like there is garbage pail near the front entrance of my home. I will show you all that I hit it because I was enraged. Because they [voices] would say that everything that I did, I am not sure if it is still like that, everything that I did they [voices] would hear. Everything that I said, everything that I thought these macumbeiros [people who practice black magic] would hear! They [voices] were persecuting me. [Leonardo, Return of Jesus Christ Church]

I went into my room, then I started hearing voices and I became terrorstricken because you hear a voice but you don't see the face. The voices told me to be calm. But I got very nervous and I did not sleep the whole night. [...] I was very scared so I started doing things that I should have not done. I almost cut my wrists, you cannot see it anymore. I almost cut my wrists and I threatened to throw myself. I went to my mother and said that I was going to church and I went to take a bus to throw myself from the bridge on the Tietê river. Afterwards I ran away from home. [Carmen, Catholic]

Being nervous also seems to express that these young people were feeling endangered in their own existence. Eduardo tried to paralyse his personal interactions because he was very doubtful about what was going to happen to him next. In our conversations he explained to me that his doubts oscillated between the fear that he was already dying and the desire to kill himself. Mauricio was incapable of escaping from the thought that he was being chased, in the same way that animals are hunted. Hunted to be killed? Leonardo suffered because the "voices" interfered with all his actions including "listening" to his thoughts. Nervousness and rage were reactions to his feeling of being annihilated by the "voices." Carmen was extremely nervous and disturbed by her imagined threatening "voices," and she thought that her only way out was to take her life away.

During this initial period family members are not always aware that the young person might be hearing "voices," or is feeling completely trapped. They are more likely to react when they start to observe incessant changes in the emotional quality of the patient's mode of being. Family members become progressively worried when they notice that that the person starts to have difficulties to control the feeling of nervousness and is unable to calm down. They might try to offer water with sugar, passion fruit juice, or even make some prayers and blessings. When nothing seems to bring some sense of relief to the young person, family members begin to feel very hopeless and often react themselves in a nervous way.

Nervousness is an emotional sign of disturbance frequently mentioned by patients and family members. Even if patients and family members appear to use this term to

characterize particular attitudes and behaviours of the patient, one can wonder how far it also relates to the multifold constellation implied in the idiom of <u>nervoso</u> (nervousness), described in the literature as a culturally meaningful way to express different forms of distress in Brazil. Duarte (1986) resorted to the idiom of <u>nervoso</u> to interpret his observation of the everyday life of two communities of blue-collar workers in Rio de Janeiro. Duarte indicates that the idiom of <u>nervoso</u> not only reveals a distinct conception of the person, but can also be expressed through a diversity of psychological/psychiatric, religious, or physical/moral categories (See Table 12). <u>Nervoso</u> is a widespread idiom of distress that can also be associated with mental illness in some situations. It also gained especial popularity in the North-American anthropological literature.²

Table 12- Some examples of categories for the idiom of <u>nervoso</u> in Brazil

Psychological/psychiatric	Doença dos nervos [nerves illness];
	Maluco, louco, doido [crazy];
	Doença mental [mental illness];
	Hysterical, seizure, psychological trauma
Religious	Encostado [caused by a "leaning" spirit];
	Possessed by Devil, by spirit;
	Obsesso [caused by "obsessing" spirit];
	Affected by spell, evil-eye, or witchcraft
Physical/moral	Crise de nervos [nervous crisis];
	Ataque de nervos [nervous attack];
	Acesso de nervos [nervous outburst]

Adapted from Duarte (1986).

According to Duarte (1986), the very rich semantic language of <u>nervoso</u> is expressed mainly in two different modes: <u>estar nervoso</u> (the condition is transient) and <u>ser</u>

² According to the North-American anthropological literature nerves, nervios, and ataque de nervios are culturally shaped idioms of distress that often serve as a legitimating explanation for several forms of suffering: marital or social conflict, expression of grief and anger, stress response syndrome, etc. (e.g. Low, 1994; Guarnaccia, DeLaCancela, and Carrilo, 1989). It may also occur in the context of individual psychopathology, and cuts across several conventional psychiatric categories, including anxiety or depression (e.g. Nations, Camino, and Walker, 1988), seizure like episodes (e.g. Guarnaccia, 1993), panic (e.g. Guarnaccia, Rubio-Stiptec and Canino, 1989), dissociative experiences (e.g. Oquendo, Horwarth and Martinez, 1992), or established psychotic disorders, such as schizophrenia and bipolar disorders (e.g. Guarnaccia, Parra, Deschamps, Milstein, Argiles, 1992; Jenkins, 1988a, 1988b; Swerdlow, 1992).

nervoso (the condition is permanent).³ There is a gradation between these two conditions: estar nervoso expresses a state of disturbance which is lighter and more transient, and which is often attributed to an external cause. Ser nervoso can be associated with the notion of "nervous temperament" and denotes a more intense and permanent condition indicated by the "internal" qualities of the disturbance. Since the polarity between the two modes is not rigid, this allows multiple nuances for the idiom of nervoso. What I want to highlight from Duarte's classification is that religious idioms of distress (e.g. possesed by Devil, encosto) and the idiom of nervoso may interpenetrate each other. This has also been observed by Villares (1996) when she interviewed family members of chronic schizophrenic patients in São Paulo.

In her study of Mexican-American families with a schizophrenic member, Jenkins (1988a, 1988b) indicated that resorting to the idiom of nervios reflects a broader understanding of the problem and has implications at the level of family's reactions. Problems are understood as beyond the control of the individual. As nervios is broadly applied to people who are distressed over difficult life circumstances, it is not restricted to psychiatric disorders. Such labelling allows Mexican-American relatives to identify themselves with the schizophrenic member; adopting the culturally accepted idiom of nervios can be seen as a strategy to maintain strong self-other connections within the family context. In this case, resorting to the idiom of nervios reinforces family bonds and solidarity and fosters the tolerant inclusion of the patient within the home. Furthermore, most Mexican-American families have difficulty in applying the term mental illness or "crazy" (loco) to their relative's condition because this implies that the person has lost all reason, is completely out of touch with reality and out of control, besides being potentially unpredictable and violent. They normally perceive that this stereotypic description of "craziness" (locura) does not exactly correspond to the attitudes and behaviours of their ill member. By contrast, Anglo-American families prefer to use the term "mental illness" or diagnostic labels such as "schizophrenia." Correlatively, mental health professionals tend to explain schizophrenia to the families as a "biochemical

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³ Estar (to be, to be in) denotes a transient condition in the sense that it describes a continuing action (e.g. she is sleeping), or it denotes proximity in time (e.g. the lease is about to expire). By contrast, ser (to be) denotes an inherent quality or permanency of state or condition.

imbalance." Such information is often received as guilt-allaying, since it helps parents to discard the fear that they may have "caused" their son or daughter's problem.

I did a computer search of all the instances where the label <u>nervoso</u> appeared in the narratives of patients and family members. When the patients talked about their own nervousness they always employed the expressions <u>estar nervoso</u> or <u>ficar nervoso</u> (become nervous) which emphasize the transitoriness of the condition. As the only exception, Maria attributed the source of her irritability (<u>nervoso</u>) to her temperament (<u>ser nervosa</u>). When parents talked about the patients they also gave preference to the transient condition of <u>estar nervoso</u>. But when mothers talked about themselves, some of them also employed the expression <u>ser nervosa</u>. One could hypothesize that they were trying to exculpate both the patient and themselves, and to put the main burden on themselves in saying that they would easily react in a nervous way to the patient's difficulties because this was part of their own temperament.

That both parents and patients prefer to use the expression estar nervoso when they referred to the patient's mode of being suggests that they perceive the problem as a transitory condition instead of a permanent and inherent quality of the person. But they also have some divergences regarding the meaning of transitoriness. Family members perceived the problem as coming only from the outside and they always expected the nervoso to disappear. Patients however, identified nervoso as a transitory reaction to the strangeness of their experience. During the outbreak of psychosis, both patients and family members speak of the transitoriness of nervoso; nervoso appears closer to a "symptom," rather than to the whole idiom of nervoso as such which can condense diagnostic labels, etiologies, particular modes of being and indicate some awareness of treatment.

Some patients' narratives describe the increasing importance of <u>nervoso</u> and its progressive association with screaming, aggressivity and destructive behaviours in their account of how the problem erupted and became manifest. One may imply that <u>nervoso</u> indicates a preliminary perceived change that may eventually be transformed into

aggressive reactions that reflect the patient's increasing absorption within the ongoing psychotic process:

I took out my tooth and afterwards I felt kind of strange, I did not even know what was happening to me... I would get nervous, I was nervous, then my mother told me that I would spank, that I have spanked her, that I spanked my other sister, I also wanted to spank my father. [...] I got very agitated, I started to call names, I started to say a lot of things that I did not do, and so I would say... I went to my sister's house, and she told me that I wanted to kick, to kick the chair, that I wanted to spank her, I wanted to do many things that it was not really myself. I have destroyed my teddy bear that I loved, I tore him, I tore him entirely apart, I don't know what was happening to me... I only know that I was nervous, so I had to discount it over some toy, something like that, I had to discount my rage. [Luana, God is Love]

I became... I was already a little nervous. Then I became... it aggravated my nervous system even more. I am not really sure but I became a little bit aggressive, the nervous system was stronger... at least my mother told me that I would get very nervous and I would break things. But I don't remember. [...] I would start to break things. And when I started to talk I talked a lot, I would not stop talking, I would shout, and then my mother noticed that I was not feeling well. My mother told me that I would attack her! [Maria, Universal Kingdom of God Church]

I was not quiet. I was getting very nervous. I would listen to loud music... Then I did not have what to do, and the family doesn't even let you listen to loud music. Then I started to break a lot of things there [home]. The radio... and I almost broke the TV. This was recent because I was not hearing anything and this would make me lose my head! [Milton, Catholic]

Luana, Maria, and Milton clearly recognize that their behaviour was aggressive and destructive, but they are not really sure why they behaved like that. Most often they only described a feeling of strangeness in relation to themselves because they felt obliged to behave in such uncontrollable and unexpected ways. What they experience seems to defy any possible explanation. The excerpts below illustrate some of the reactions reported by the mothers of these three patients:

She started to have visions of dead... of dead people, she had a lot of fever, 'don't you come close to me', and she was getting very afraid of seeing those coisa ruim [evil spirits]. [...] Sometimes she would shout 'don't you come close to me, just go away'. I would pick her and say ah my daughter

stay calm there is nothing here, don't do this, keep quiet, she is already gone [spirit of dead friend]. I would explain things to her, and then she would pick up things and started to destroy them. [...] And she would not say things with sense. From Sunday to Monday she was aggressive, she even wanted to be aggressive with my husband, she would speak in a very altered way with us. When Monday came we took her to the psychiatric emergency. [Luana's mother, Assembly of God].

Maria's mother: One day we started hiting each other because I was trying to calm her down, and I held her by the shirt collar like this: keep quiet for God's sake, keep quiet. She thought that I was being aggressive with her, 'Look mother, you want to fight with me, you want to hit me', 'No I am not going to hit you, I want you to stay quiet', but the more I said this the less she accepted it. She grabbed my hair and when she grabbed my hair, I grabbed her hair and we rolled on the floor.

Cristina: How did this end?

Maria's mother: It was possible to separate [one from the other], because the neighbour who lives close heard the noise and the screaming and then she came, she gave a lot of water with sugar to her, took her to her house and calmed her down. [Maria's mother, 7th Day Adventist]

He arrived home and started to call everybody names, he scolded everyone in this house. He wanted to spank his brother. This happened a week before we took him to the psychiatric emergency, he was only searching for things to break up. As I told you he wanted to spank his father, spank his brother, and we were not used to this since he would react like this when he had some small problem, but never so aggressive! [...] I believe that he was suffering a lot because now that he is getting better he says 'mother, how I feel myself to be another person, I am more calm now, my head is lighter', this is what he says. This means that he has been feeling a lot of confusion in his head. He doesn't tell this to me, but I imagine that this is not possible to be expressed. I believe that these confusions [in the head] sometimes do not allow him to express himself [in a proper way], it remains only with him. [Milton's mother, Catholic].

The narratives indicate the main family reactions triggered by the patient's behaviour and the ways mothers tried to explain the strange and uncontrollable aspects of their child's odd perceptions and behaviours. These interpretations influenced their own reactions which then impacted on the patient's own behaviour. At the level of family reactions, the narratives suggest that mothers try their best to talk to the patients to calm them down. But in some circumstances they also react with aggressiveness in response to the patient's aggressiveness. Most family members regret this afterwards, suspecting that it may have accentuated the patient's problems, including his or her aggressiveness. They

had the impression that they had no other choice because the young person was also transgressing fundamental moral codes of the family life. Although people tolerate seeing siblings fighting with each other once in a while, they expect the young person to respect and obey parents unconditionally. Spanking the parents is decisively forbidden. Parents were trying to put limits on the patients' transgressions. Both sides feared what could happen next.

Family members sometimes prefer to tolerate some transgressions committed by patients when they fear the consequences of any reprimand, as illustrated by Milton's mother. The family was preparing to visit a religious healer while the mother was in the kitchen washing some dishes. Her son suddenly grabbed her by the back and tried to rip her clothes apart. She managed to escape from him without screaming, but the idea that her son wanted to rape her never abandoned her thoughts. She never mentioned this episode to her husband because she believed that he would become furious to the point of "killing" their son.

If one pays close attention to the narratives of Maria's, Luana's, and Milton's mothers, they mention that patient's aggressive behaviour was stimulated by some kind of misperception and/or unexplainable mental confusion. Maria was feeling very threatened by her mother even though the mother swears that she had no intention to harm her daughter. One may say that Maria could have lost the "rules of the game" that would allow her to distinguish whether her mother was really going to spank her. I would also not discard the possibility that the atmosphere of mutual fear experienced by both of them accentuated Maria's aggressive impulses.

On another occasion, Luana's mother complained that her daughter's aggressiveness was related to her being very frightened because she was having visions of "evil spirits." In fact, it could be the case that Luana may have at some moment associated her strange experiences with the presence of evil spirits surrounding herself. Both of them are very religious and accept as fact the interference of the "other world" (DaMatta, 1987), of spirits within their everyday life. One possible interpretation is that

Luana's imagined visions reflect and translate an altered perceived world into the language of the spirits idiom. One could also wonder how far such frightening visions could not reflect her actual perception of her relatives dressed in front of her. Luana's aggressive and destructive behaviour could also be a way for her to introduce some kind of distance between herself and the appalling visions in which she was engulfed.

Milton's mother's narrative manifests some understanding of her son's reactions and feelings of strangeness towards what he was experiencing. She comments that it was almost impossible for her son to express in words some of the "confusions" that were going on in his mind: He remained very quiet without expressing them. She also tries to encapsulate the aggressive behaviour of her son by emphasizing its alien character to her son himself. Her current description can be seen as a kind of inner rumination about the puzzling past behaviour of her son. She imagines that he regrets his violent behaviour towards her, but that he doesn't know how to say it.

Aggressive and destructive behaviours never come alone. They are always embedded in a larger range of behaviours and attitudes. They however appear to be given a pre-eminent place in the manifestation of the first psychotic episode or at least in its recollection. This is likely to be related to the degree of threat involved in the patient's aggressive behaviour and to the implication of a transgression of basic family norms and behaviours. Aggressive behaviours attack the very foundation of family life, and turn family relationships upside down. Other signs of disturbance, including nervoso, seem to be minimized or tolerated for a much longer period of time than aggressive behaviours. The manifestation of aggressive behaviours could also be perceived at a more implicit level as an ultimate call or as a way for the patient to express feelings that his or her life is endangered.

At the emotional level, sadness is a sign that calls for the especial attention of family members:

She started to become more calm and to talk normally, she was only very sad. [Sarah's mother]

When she saw something or thought something sad then she would say "I am going to die mother, I want to die, I am going to die." [Maria's mother]

He started to become very sad, he would come, I tried to talk to him and he would remain silent. It seemed that he was crying but he did not want to express it. [Milton's mother]

I don't understand why he fears people, why he doesn't feel like doing anything, but most importantly why he is so depressed, because he was a person that you would never see sad or in a bad humour. [Jonas's girlfriend]

These expressions of intense negative feelings is a great source of concern to family members. I recall their helplessness because they were unable to stimulate the patient to have more positive feelings. Although nervousness and sadness are highlighted by family members, these emotions are often complemented by expressions of despair, fear, distress, irritation, agitation, restlessness, and other kinds of emotional disturbances.

Family members were also perplexed and disturbed to notice what they perceived as a patient's lack of emotion. Some were shocked when they noticed that the young person was not even able to cry when a close relative died. Leonardo's father had difficulties understanding why his son was having problems with the neuroleptics while his son was only laughing. Families were also perplexed when patients showed no emotions in situations that used to touch them. For example, Eduardo's parents were bewildered to see their son watching the soccer game at the TV without vibrating together with the whole family. Maria's mother was upset to hear her daughter say that she was not able to love her (the mother) anymore. Relatives were worried when patients expressed either too much emotion (e.g. sadness), or to its opposite, too little emotion.

A parallel concern was also expressed by patients when they noticed that they were no longer feeling emotions in the same way, or when they tended to withdraw from activities they used to enjoy:

I like to go out with friends. What I am complaining is that now I still go, but it is not the same as before. Ah I don't know the things that I told you...

I tell you that with me now things are different. Moments of pleasure. I don't have the same pleasure as before. [Eduardo, Charismatic Catholicism]

I don't feel emotion. I don't feel emotion in the same way that you people feel emotions. If I go out for a walk I just go out. But if I don't go out I don't feel any emotion as well. [Maria, Universal Kingdom of God Church]

I used to be very happy, very lively and talkative, I talked about several subjects. Now I feel myself slow, very discouraged and quiet. I am afraid... [to talk to people]. I am afraid that I will not find any work anymore... because of my condition... because I am just like a snail, slow, I don't know how to deal with people anymore. I am afraid. I don't really know but I don't have that [emotional] contact with people anymore. [Dora, Adventist of 7th Day]

Patients were feeling different. This often created an aura of strangeness and alienation around themselves, but most importantly it permeated their interpersonal relationships. One may hypothesize that their social withdrawal could be a reaction to their impression of losing their usual way of relating with other people. I had the chance to ask both Dora and Jonas if they felt the same difficulties in relating with me. They both responded that they felt no problems with me because I was already "familiar" to them. It seems that to deal with "strange" people is what affected them the most. One could think that their accentuated difficulty of interacting with unfamiliar people is heightened in the context of the "personalistic" orientation of the Brazilian society described by DaMatta (see Chapter 3). Interacting with people from the "street" could accentuate an experience of anonymity, of being an anonymous individual, rather than feeling recognized as a "person" in the space of the "house." Contacts with people who are "familiar" could help patients to diminish their sense of strangeness and alienation. On another side, patients also "aspire" to a certain space of strangeness by attempting some form of contact with people who are not very familiar to them. One may wonder whether this could not allow patients to relieve themselves from the emotional load of interacting with people who are extremely familiar to them.

Fear, hallucinations and delusions of persecution are also described as enmeshed with the everyday experiences of these young people. Family members often overlook the significance of these signs when they first start occurring. Jonas was feeling persecuted by his co-workers, however this a common problem in every job situation. José was running away from the "voices" but his family sometimes questioned whether he was not really running away from the police. Kátia believed that she was being spied on through the wall, yet her mother interpreted that she liked to make-up childhood stories. Sarah felt persecuted by the Devil in a context where her family believed that everyone can be molested by the Devil. It is mainly the persistence of these perceptions or increasing levels of fear, anguish, persecution, and the morbid emotional quality of patient's experience (e.g. "they want to kill me") that call the attention of their relatives.

From another perspective, one can say that family members paid more attention to the alteration of interpersonal relationships than to the more personal unusual experiences of patients (e.g. delusions and hallucinations). The most common way they referred to the patient's behaviour can be resumed by the expression "não falava coisa com coisa" ("did not talk thing with thing"). This means that their talk was very confusing and difficult to understand, and that it affected the possibility of interacting with the patients because when they talked they only talked nonsense. When I asked family members what kind of nonsense patients uttered, they often were not able to remember. Or such nonsense talk was most likely to be associated with talking alone, or only saying absurdities. But what family members overemphasized was that patients often confused the identities of people, or were momentarily unable to recognize people:

Oh he would remain the entire day in front of the house gate. My neighbours... I wouldn't see much because I did not have much time to keep an eye on him, but my neighbours would notice because sometimes they would pass by and greet, and he would do like this with his arms in a way that suggested that sometimes he was not recognizing [the person]. Sometimes my neighbours would talk with him, 'Leonardo I am so and so', he would not remember the person's face and would start to talk alone

⁴ It has been documented cross-culturally that family members prefer to deny or minimize the presence of hallucinations and delusions as important signs of disturbance of their psychotic relative. For instance, this attitude has been observed among Mexican-American families (Jenkins, 1988a), the Chinese (Lin & Lin, 1981, as cited in Jenkins, 1988a), and the Irish (Scheper-Hughes, 1987).

with himself. Then he would sing church hymns, he would pray and kneel down, that is how he was. That is when everyone said that he should go to São Paulo Hospital. [Leonardo's mother, Return of Jesus Christ Church]

She was like this, she would not talk thing with thing, things that made no sense, she would talk about. When I arrived there the first thing that she talked about I laughed. When I was lying down, because I was lying down with her in her bed... 'no, no, don't turn off no because I am adoring my mother' [mother being confused with the Virgin Mary]. And I replied 'my daughter don't say something like that for God's sake. We can only adore God because He is the only one who is worthy of all adoration', she said 'ok I did not know'. There were times that she was irritated and nervous, but other times she would remain in silence, without talking to anybody, it was like that. [Sarah's mother, Assembly of God]

He was not talking thing with thing. It seemed that that he was talking to himself. I don't understand. On this day he was saying that he was going to buy a car to go to work with this car [the son was unemployed]. [Eduardo's father, Non-Practicing Catholic]

She went to the bank to receive her money, but on this day she went home not talking thing with thing. She did not talk thing with thing. My grandson that has I year and six months was hospitalized because he had bronchitis. And she started to find him [grandson] strange. [...] She would push me and say that I was not her mother, that I was her aunt, then she said 'ah I want to meet my father'. But 'it is not long ago that he died' and she knew who her father was. She would say 'my father is very black'. And I would say 'as far as I know he had my colour' [mulata] and she has one [photograph] but she would say 'but I want to meet him.' [Solange's mother, Assembly of God]

This emphasis on interpersonal behaviours is another indication of the "personalistic" orientation of the Brazilian society and of its influence on family members' reactions. People I interviewed seemed to be most concerned with the patient's not following common-sense rules that orient interpersonal interactions and by the quality of the exchange. In many cases, what the patient actually did or said seemed less important than "familiar" people not being recognized as persons. This context contributes to explain why family members usually gave less importance to the patient hearing "voices" and having "visions" (auditory and visual hallucinations), or reported

other types of delusions and unusual perceptions.⁵ In addition, patients themselves appeared to find very difficult attributing meaning to their unusual experiences, or preferred not reveal their details to other people, including relatives. Their narratives presented a series "blanks," doubts or interruptions reflecting that they could not tell much more of what they had experienced. For instance, some patients only referred very briefly to certain unusual experiences such as telepathy, hypnotism, the feeling that TV or radio were talking about them, or that everyone else knew what they were thinking. Then the narrative silenced or changed. This might also explain why family members had difficulties understanding patients beyond that he or she "não falava coisa com coisa."

The modification of self-care behaviours is also an important part of the global alteration associated with a psychotic episode. Narratives identify an alteration of basic activities of self-care as signs of disturbance, most particularly in the areas of eating and sleeping. Parents become progressively concerned when they notice that the young person is not eating, looses sleep, forgets to bath or dresses up carelessly. I was also amazed to observe that some mothers appear to give more importance to problems associated with the food intake of the sick person than to any other sign of psychosis.

In relation to food, most young people appear to eat very irregularly; others would only accept certain kinds of food, while others reject to eat any kind of food. They called to the following reasons for justifying why they were not eating properly:

- (1) They radically adopted the religious ritual of fasting.
- (2) They attempted to control their body image and/ or health.
- (3) They wanted to avoid neuroleptic medication (suspected to be mixed with food).

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⁵ Psychiatric classification identifies different types of delusion. For instance, delusion of persecution (delusions that others are trying to harm or kill, that there is a plot or conspiracy), delusion of reference (delusion that the individual is referred to through TV, radio, newspaper), and control, somatic and fantastic delusions. The following are some examples of unusual perceptions or experiences: depersonalization (feeling that one is not a real person), de-realization (feeling the world is unreal), thought disturbance (external influence over one's thoughts, such as telepathy and hypnotism), thought broadcasting (thought seems public not private), thought blocking (thoughts stops suddenly, mind is a complete blank), thought insertion and thought control (Corin, Lesage, King, and Van Haaster, 1996).

There is a transformation in the constitution of the "I" in the sense that persons perceive themselves or the world around them in a distorted way. They imagined that they were preserving themselves by rejecting the food. For instance, some young people saw religious fasting as a sign of devotion to God. When they felt extremely disturbed they could experience an urgent need to be consacrated by God, which often compelled them to exaggerate with fasting, perceived as the way to feel better. Dora's case is slightly different. She avoided eating because she suspected the food to be causing all the changes she was experiencing: "I don't really know, I was feeling very strange. I was getting very big. I felt myself very big. I wasn't even able to sleep, I would wake up all the time." She also suspected that the food was harmful to the point of killing her because it was poisoned with medication.

When parents notice that the young person is constantly rejecting food, they usually try to offer them food in a very caring way. Sometimes however they have to control their own reaction of irritation in face of the systematic rejection of food. For instance, Milton's parents tried to offer their son all kinds of food, but he repeatedly gave them the same response: "I am nauseated." In the cases of Dora, Gisela and Maria, they lost a lot of weight before their families realized that insisting any longer was no more possible. The only alternative left was to bring them to the emergency room. The excerpt below describes how Maria's mother interpreted the behaviour of her daughter:

She was baptized in the Universal Kingdom of God, she started to read the bible, too much, too much, and she would pray, pray, pray without stopping. This was affecting her head more and more, and so she stayed without eating, she wouldn't eat anything. She started to get worse and worse. She did not want to eat, she did not want any thing, she locked herself up, she would stay locked up in her bedroom, and she would get out only to go to church, she would not watch any TV. [...] When she got really worse I brought her to the hospital, because she was out of herself. She wanted to die, she did not want to eat, to feed herself, she became only skin and bones, she arrived in the hospital just skin and bones. I believe that all the [bad] things she would say to me, all that [strangeness] that she would feel was caused by her weakness [of not eating].

[Maria's mother, 7th Day Adventist]

It is true that Maria was also acting very aggressively with her mother and that she was having suicidal thoughts. But she was very confused. Sometimes she wanted to die, other times she imagined that she was already dying because she felt that her head was "empty." Maria searched desperately for religion and she exaggerated with fasting and lost more than 25 kg. Initially, Maria and her mother understood the problem in contradictory ways. While Maria was struggling to feel better through religious fasting, her mother believed that her daughter's strange and aggressive behaviours were the direct consequence of excessive fasting. Maria's mother only emphasized what many other mothers explained to me: they strongly believe that proper eating is essential for the recovery of health because the lack of eating only brings weakness and sickness. Lack of eating is not only perceived as a sign of the problem; it is also its source. Like most other mothers, Maria's mother expected that by feeding her properly, her daughter would stop with her strange and aggressive behaviours. It did not happen quite in this way.

Food is one of the principal ways through which the urban poor think about their life conditions. This fact is even more so for the mothers, since one of their major roles is to guarantee the well-being of the whole family by always providing them with good and sufficient food (Zaluar, 1982). In addition, the significance of proper eating can be understood against the background of broader cultural representations of health and illness which were documented in a study conducted in Campinas, São Paulo. In this study, poor families defined health in terms of one's disposition to work followed by a disposition to go out for a walk. Eating properly, sleeping, feeling well, and the absence of pain were also considered important markers of good health. For the people interviewed in the Campinas' study causes of illness cluster around three main directions:

- (1) The nervousness of the person (especially in women).
- (2) The fatality of one's destiny.
- (3) Insufficient food intake, lack of hygiene or climatic conditions.

At a smaller scale, pollution and some social problems like drinking alcohol are also included in this list (Queiroz, 1991). My own interviews add the idea of illness being

caused by spiritual problems; this will be explored in more detail in the next three chapters.

Sleeping well is considered a marker of good health. During the crisis many young people were unable to sleep. They were restless, anxious, and agitated. One night after the other, they would walk back and forth inside the house, make noises, turn the lights on and off, talk alone, and disturb other people's sleep. This behaviour slowly affects the sleep of the other family members in the house. The worry, restlessness, anxiety, and agitation therefore diffuses to the other members of the family and nobody is able to sleep well anymore. Often when family members are already very tired and irritated with their own lack of sleep, they start to be more concerned and worried with the consequences of such strange behaviours manifested by the patient. Especially when these behaviours continue to build up, they begin to dread what the young person might do during the night when everyone else is sleeping: They might harm themselves and any other person of the family. Family members become more alert (and tired) and impose on themselves an attitude of constant vigilance in relation to all the patient's movements. More than being a marker of bad health, the lack of sleep deeply affects the interpersonal relationships of the entire family in a negative way.

He was not sleeping, he would not sleep, he would remain [awake] during the night. We were not able to keep with him so we would take a little nap and when we would wake up he would be there moving things around, would take the blankets away from his brothers, trying to push them out of bed, like that, he would come to the living room. [Milton's mother, Catholic]

She would not sleep and I was giving <u>calmantes</u> [sedatives] to her because she was getting <u>maluca</u> [crazy] because not even me nor her would sleep. There were nights and nights without sleep because she would not let [us sleep]. If she was the type that would wake up without disturbing, but she would not let us sleep any more. She is that selfish type, if I am not well nobody else can be well, then she would not sleep and would not let anybody else sleep. I am going to get <u>maluca</u> if this continues because I work the whole day and during the night I can't sleep! A lot of medication to sleep I was giving her, but it would solve nothing, so I believe that she got a trauma from all this. [Raquel's sister, Catholic]

During the night I would not sleep anymore, she would wake up and call, mother, mother, she did not want anything with her husband, everything was the mother. Then she woke up, she woke up and climbed to the top of the roof... and so at midnight I would be calling my neighbour to help me for God's love, for God's love, because I could not handle her, she almost died, me and her, she climbed on top of the roof.

[Solange's mother, Assembly of God]

During the night he would not sleep and would remain walking throughout the house. We were not able to sleep as well, worried with him. I did hide everything that I was able to hide from him. [...] During the night I would not sleep. Sometimes me or my husband we would keep an eye on him during the night afraid that he would do some crazy thing. It is like I explained to you, I did hide everything because everyone hides what is there to hide. I would hide the knife, the scissors, everything that was pointed, because the despair was too much, the pain was too much, and because one of these times he could do some crazy thing. He would beat his head over the wall, he did beat his head so much, that I don't understand how he did not blow up his head with so much pain. [Leonardo's mother, Return of Jesus Christ Church]

Other self-care behaviours like bathing, brushing one's teeth and dressing up call the attention of family members in the sense that such carelessness affects negatively the presentation of oneself towards others. This self-presentation is particularly important while the young person leaves the space of the house and goes to the street. It is believed that when poor people are careless in their self-presentation they are easily confused with beggars, vagrants, thieves, prostitutes and other dangerous people. Very often, these young people ignored family complaints regarding self-care behaviours. In this case, family reactions fluctuated between forcing the young people to take more care of themselves and just letting them do as they wanted. It is more strategic sometimes to tolerate some unacceptable behaviours in order to moderate the level of stress and tension experienced by the whole family.

Narratives indicate that a transformation of <u>nervoso</u> into aggressiveness, polarized expressions of emotions (too much/too little), confusion about other people's identities, and self-care behaviours are the signs perceived as most disturbing by relatives. Most frequently these signs trigger reactions on the side of family members, and depending of these reactions, patients may respond with another kind of reaction. Now, other signs of

disturbance did not attract too much attention of family members, such as behaviours diagnosed as "cognitive deficits" in psychiatry, or the issue of social withdrawal. At least in the beginning, theses signs tend not to be isolated as indicating a mental problem.

Kátia's story

Katia has always been a shy girl and she had difficulties making friends. The mother believes that Kátia's shyness is a consequence of family problems because her father was an alcoholic and she was not allowed to bring any friends home. The mother was the only one working because the father was too sick. Kátia dropped out of school. She was finding it very difficult to understand what was being taught. When the teacher noticed that Kátia was not following the classes she advised the mother to take Kátia out of school so she would not feel frustrated to repeat the school year for the second consecutive time. Her mother accepted the fact as kind of normal because she knew that her daughter never liked to study. Kátia started to attend a course in basic computer skills because that would facilitate her to find job afterwards. She was very distracted during these classes as well. Several months later Kátia started "hear voices." Her mother only told her that "it is all your imagination." Kátia was terror-stricken because the "voices" wanted to kill her. She tried several strategies to get rid of these voices. She isolated herself in her bedroom more and more. She would lie down in bed while keeping the room in complete darkness and covered her head with pillows. She put also cotton balls in her ears, or to loud music in the radio, yet the voices continued to disturb her. She felt touched by the voices. The mother interpreted that this was some kind of sexual fantasy that adolescents always have. The father thought that Kátia only wanted to call the family's attention because she was a very lazy and spoiled girl. The grandmother agreed with the father.

Kátia's behaviour oscillated between restlessness, agitation and social withdrawal. Her feelings of fear and persecution only increased because the voices still wanted to kill her. She also felt that some neighbours were spying on all her movements through a hole in the wall. Kátia insisted that her mother take her to some spiritual centre because she wanted to free herself from the voices and such intolerable fear. Kátia's mother rejected her daughter's request because she doesn't believe in religion. Kátia's father execrated psychiatrists because of his alcoholism. The mother had many conflicts with the father and the grandmother since both of them were against the idea of taking Kátia to the psychiatrist. After some months of psychiatric treatment the voices disappeared. The mother was relieved that her daughter was not hospitalized in a "place for crazy people." Kátia's father died. Kátia did not cry because she did not get along well with her father. Some time after Kátia went walking in the park and met an older guy who soon became her first boyfriend. Now she goes out with her boyfriend often and they also have sexual relations. Kátia still hates to study, yet she preferred to go back to school because she wanted to feel occupied. The mother truly believes that Kátia's illness made her daughter wake up to life.

Comparing Kátia's story with other cases reveal some common patterns regarding family reactions. In face of problems of cognitive functioning, for instance learning difficulties, the family only worries much later, most frequently when the person is already under psychiatric treatment. When other signs of cognitive functioning call the attention of family members during the psychiatric treatment, for example a lack of concentration and distractibility, families usually interpret these signs as an effect of neuroleptics. Learning difficulties and the repetition of a school year is a widespread problem in São Paulo, especially for families of low-income (see Chapter 3). Families accept as a fact of life that some youth repeat the school year, and/or that they prefer to abandon school to join the work force. More money is always needed inside the house. Class repetition is often associated with a lack of interest in studying, and people are

aware that not every child will have the chance to study to become a "doctor" one day. Learning difficulties, social withdrawal, fear, persecution, "hearing voices," agitation, and restlessness are signs of the disturbance that accumulated over a long period of time before Kátia's mother suspected that her daughter was having a real problem.

During the onset of psychosis, social withdrawal also tends to be disregarded by family members. Families tend to account for it in terms of the patient's personal characteristics to explain it as related to generational issues or other concurrent events, therefore minimizing the importance of social withdrawal. According to her mother, Kátia was always a very quiet and introverted girl, she also added that "young people always like to live in their own world separated from family life." Eduardo's isolation from family life was understood as a form of rebellion because he was extremely critical of his parents' attitudes towards his other siblings. Claudia's social withdrawal was associated with her previous introversion and with the fact that her boyfriend broke up with her. José was beaten by the police and this explained why he remained several weeks locked in his room.

Jonas's story, described in the beginning of this chapter, illustrates that each family member may give a different meaning to social withdrawal, depending on a broader context. His mother and sister knew that Jonas used to fake sickness to skip work. They needed his work, and used to accuse him of laziness and irresponsibility. Jonas's girlfriend considered the situation from a different perspective. That Jonas stopped working did not affect their relationship as much. She always praised Jonas as being very intelligent, so she believed that the type of work he was doing was extremely boring for him. What immediately called her attention was when he started avoiding all his friends and did not want to go out with her anymore. Kátia's father was shocked that her daughter did not want to study and wasn't working. For him she was simply a lazy girl spoiled by her mother who approved her inactivity.

In a series of cases, signs of social withdrawal were not even mentioned, either because families neglected the issue or some patients did not show any significant indication of social withdrawal. I would also propose a third interpretation. Some patients may have tried to create a space of withdrawal but were impeded to doing so by the living conditions of their families. Jonas and Kátia had their own bedroom that allowed them to seclude themselves and remain unperceived by their families. Most other young people had to share their bedroom with some other family member or the bedroom served more than one house function. For instance, Milton shared his bedroom with two brothers, and this room was actually the "corridor" that linked the kitchen with the living room. Luana shared her bedroom with two sisters, and this was also a "corridor" that linked the kitchen with their parent's bedroom. Dora's family slept all in one room that had a small kitchen attached. In the previous chapter the emergency room psychiatrist was perplexed by Dora's position of social withdrawal while the family only highlighted her aggressiveness and refusal to eat. I suggest that Milton, Luana, and Dora found less moral and physical space for developing a position of withdrawal, than Kátia and Jonas.

Comparing specifically the cases of Kátia and Milton, both of them were very disturbed by the "voices" they were over-hearing. Sometimes they had sudden impulses to listen to loud music. Eventually the sound of loud music gave them some sense of peacefulness that may have buffered the disturbing voices. But it was much easier for Kátia to shut herself up in her bedroom to play loud music without molesting other people, than for Milton. Besides annoying his family by playing loud music, Milton had several aggressive conflicts and broke household objects when he demanded that the family keep completely silent. Often he felt that his family was making too much "noise." One could suspect that he sometimes was unable to distinguish the unbearable "voices" he was over-hearing from the everyday talk of family members. It appears reasonable to infer that patient's aggressiveness or constant conflicts with other family members may eventually function as markers to separate personal lived spaces which are "blurred."

What I have affirmed regarding family reactions towards social withdrawal may sound paradoxical in regard to the "personalistic" orientation of the Brazilian society is taken into account. One could easily hypothesize that the "personalistic" orientation would incite relatives to notice social withdrawal as a grave problem and to react against

it. Murphy (1974) suggested that schizophrenic patients from French-Canadian families express less behaviours related to social withdrawal when compared to patients of English-Canadian families; French-Canadian families tend to be more family and community oriented. In the case of the families who participated in my study, I would like to reiterate that some signs of disturbance are more acceptable than others, like nervoso, unusual experiences (delusions and hallucinations), cognitive deficits, and social withdrawal. One possible interpretation to the tolerance for social withdrawal is that this behaviour creates much less anxiety among family members than some other behaviours (e.g. lack of eating, aggressiveness, suicide attempt). It is evident that social withdrawal affects in different ways the interpersonal relationships both within the family, and with the community. Within the family, generational problems and some kind of distancing may partially explain family tolerance towards social withdrawal because this sign of disturbance lowers the direct confrontation between the patient and his or her family members. When the patient keeps an attitude of social withdrawal towards community life, this may be perceived as positive by family members, especially when the isolation of the patient inside the home helps families to avoid feelings of shame or the fear of stigmatization, since the patient's problem is not being openly expressed to the eyes of the outsiders.

Global family reactions

In addition to reacting to particular signs of disturbance, family members reacted in a more global way to what was happening. Most commonly, family members first experienced a deep suffering after the outbreak of the psychotic episode. Strong feelings of despair, helplessness and fear before such difficult situation left mothers, fathers, siblings and other relatives with little choice besides crying out their pain, sadness and sorrow:

Oh Virgin Mary, I would cry night and day I would cry, I would cry a lot. It seemed that I was even going to die, and my husband too, because we don't even talk something like that, you see a child with health, with life, that never had nothing and suddenly stays like this, it is not easy, it is not

because I did not have any children that I don't know how it hurts. [Carmen's grandmother, Catholic]

Everyone here got terrified, Eduardo was very bad, and the crisis that he had would make us terrified. Here the only person who resisted with equilibrium was me because the rest oh Virgin Mary was everyone terrified, everyone would cry... scream and cry. [...] They were terrified but it could not be in front of him. It had to be discreet, it could not be in his front. It was very hard to control this family because it was not to show in front of him what we were feeling, and sometimes he would do things that. [Eduardo's mother, Charismatic Catholic]

Ah they [brothers and sisters] cried a lot. Particularly the one who was just here [...] He [younger brother] would cry a lot because it is very sad. My children they are like this, they do not have much communication between themselves. The three of them are introverted, but when there is a problem that happens with one of them, the other one gets immediately desperate, including the day that he had the crisis, everyone was crying because nobody had seen it before. [Leonardo's mother, Return of Jesus Christ Church]

And the neighbours here knew, everyone from the street knows the suffering that I suffered because there were times that I cried a lot. Then I would cry out of nervousness, I would cry for his medical treatment. I don't know why God has put me in this world to suffer like this. After I started going to church, thanks God, God has given me peace and is giving me life. [José's mother, Universal Kingdom of God Church]

Everyone cried. Sometimes it was difficult to figure out who in the family needed more support. These emotional reactions erupted with more strength when families noticed that the young person was remaining very disturbed even after having received psychiatric help and/or religious support. Family members were extremely concerned to hide these crying out reactions from the psychotic person because they imagined that it could affect the patient in a negative way. They were not always able to control themselves or other family members. Some patients reported to me their huge discomfort and sadness when they noticed family members crying and suffering because of them.

Families also tried to control their own behaviours while they interacted with the patient. During my home visits, I noticed a series of attitudes to avoid imposing pressure on the person suffering psychosis. Several times parents advised the other children to be

more patient and to make small concessions towards the patient. For example, Luana's parents repressed their younger daughters every time they tried to react to Luana's nervousness and aggressive behaviour. Parents also tried to please the person by preparing their favourite food or, sometimes, they allowed patients to behave as they wanted inside the house. They believed that pressure or direct disagreement had the potential to exacerbate the person's problems. For instance, Milton's parents started to buy bottled spring water and soft drinks in great quantity because that was the only liquid that their son would drink. Claudia was allowed to stay the whole day listening to loud music and dancing alone. Parents also made huge efforts to tolerate some of the strange conversations in which the patient engaged. Sometimes they preferred not to pay much attention to what the patient was telling them, while other times they tried to find a way not to encourage his or her strange thoughts. Mauricio was very upset with his mother because he waited for her the whole night in the shopping centre but she never arrived to meet him. He had communicated with her through "telepathy" to arrange this meeting. His mother preferred to apologise that she had forgotten to meet him in the shopping, instead of disagreeing with him by saying that he was only "imagining things." Leonardo's mother tried all the arguments she could find to explain to her son that he had not sinned just because he looked at the beautiful girl who was crossing the street.

As the problem evolve, most of the narratives also mentioned the tremendous effort made by the whole family to keep an eye over all the movements of the patient:

If we allowed she would go out, but we did not. She would not be left alone not even one second. We were scared. Because in all these places [religious sources of help] that I went they said that if we neglected her she would disappear and only would come back pregnant. So, I became terrified. I am so terrified that I don't leave her alone not even one second. No way! It is very difficult to live and not being able to do other things, and have to keep this vigilance all the time. [Claudia's mother, Umbanda sympathiser]

Now I am mixed-up because after she got sick I am in a wretched situation because I cannot go out I cannot do any thing else because she takes all my time, all the time she called me, all the time she called me, all the time giving her medication: "Please mother stay with me that I am afraid of

being alone, mother stay with me." [Carmen's mother, Non-Practicing Catholic]

Every one has fear, every one gets tired, but my daughters are dealing with him, they get tired to remain with him the whole day, because he has delusions and talks things. [...] There are some days that it is very difficult to hold him, afraid of going out... of getting involved. The psychiatrist scared us when he told to keep an eye over him, to take care of him, and he [the son] gets very disturbed with this. [...] I told him that I was going to start working again and that I would leave early in the morning, so he had to stay making company to his grandmother because she stays very alone. I inverted things by saying you cannot stay alone! He should make company to his grandmother, because his sister would be here and his nephew too. I have been telling him not to be worried with his sisters, because each one has her own life. You complain that people are keeping an eye over you, and in the end you are doing the same thing with your sisters. [Mauricio's mother, Non-Practicing Catholic]

I have mentioned earlier in this chapter that this attitude of constant vigilance often begins when the young person becomes agitated, restless, and is unable to sleep. This vigilance increases tremendously when families are advised by psychiatrists or religious people to keep a close eye over the patient. The fear that their relative might harm him or herself or other people is the major justification for so much vigilance. Families also mention that since patients lose common sense notions of time in relation to everyday activities, they also demand constant attention. Besides giving medication to patients, mothers also have to convince them to eat, wake up or go to sleep. In some occasions the patient only feels "safe" and "secure" while a family member keeps remaining around them. Several mothers described to me how the patient resembled a little child because he or she became much more dependent of them during the psychotic episode. Sometimes patients only wanted to sleep in their mother's bedroom, while other times they asked to be constantly hugged and cuddled. Another protective attitude is to maintain the patient inside the house as much as possible. Often this excess of caring and vigilant attitudes disrupted everyday activities of family members who spent most of the time with the patient. Claudia's boyfriend and Solange's mother ended up losing their job. After some weeks, the caring person normally feels extremely burnt out by the whole situation. Many mothers complained that they have lost a lot of weight and sleep during this period.

During that period of extra vigilance and protection, the patients' behaviour usually oscillates. Although patients usually express a desire for being protected by their families, they also frequently feel extremely burdened by all that protection. That the patient often preferred to sleep in the parents' bedroom during the episode is an overpowering example of his or her desire for "protection." However, a thin line divides what a family member considers basically as a caring attitude, and what is perceived as excessive vigilance from the patient's perspective. More details from Mauricio's mother narrative illustrate this dilemma. Mauricio started to feel that the whole world around him was very "wrong." He also thought that his neighbourhood was very bad because it was full of drug dealers, sexual abusers, thieves, and drug addicts. Being the only male among three sisters, he decided to protect them from the "wrong" world outside the house. He kept an eye over all their movements and tried to prohibit them to go out. At the same time, his sisters received the task to keep an eye over Mauricio when the mother was not home. Conflicts between brother and sisters became unbearable. The mother attempted to alleviate the atmosphere by telling Mauricio that he needed to stay home to take care of his grandmother, while it was in fact the opposite. Mauricio's fear, suspiciousness and persecution in relation to the "wrong" world only intensified with the constant protection (vigilance) of his family.

When the patient is recovering, a common family attitude is to find small activities for them to do. They think that if the patient keeps his or her mind "busy" with some activity, they would be able to obliterate the "bad" thoughts disturbing them. Some patients would take a computer course to learn basic skills. Others were invited to help with the family work. Patients were unable to do the work appropriately but parents usually disregarded the fact. Kátia's mother asked her daughter to help her sewing. Leonardo joined his father in the construction of the house. Edilson started to work in his uncle's car mechanics business. In a certain way, patients continued to be sheltered among the family.

Crying, protection, vigilance, conflicts and despair: a whirlwind of turbulence seems to hit family life while the patient is under psychiatric treatment. Collective

suffering, worry, anguish and fear, added to the disruption of the everyday routine, make the entire family live the individual's psychotic crisis together. It is only when the patient gives indices that he or she is feeling better that the whole atmosphere slowly settles down. At this stage most families try to forget the episode ever happened or avoid talking about it in front of the patient. Once more, they make an effort to protect the patient's feelings by erasing his or her problem from family's memory. They all want life to come back to the normal.

The Significance of Social Roles in Family Reactions

What is the problem? Who is to blame? Which is the solution? Questions like this invariably emerge among family members during the outbreak of a psychotic episode. Misunderstandings between family members are very frequent because their reactions towards the problem are influenced by their own social role within the family. In this context, the role of the mother is extremely important because among the urban poor, family life revolves around the mother figure. She is also the main person responsible to maintain the well being of the entire family. My study also shows that the mother's significance increases more because of the father's figure absence in ten families (see Table 6 in Chapter 3). More often than not, the mother is the first family member who takes the initiative to seek help (psychiatric and/or religious); she also acts as the most constant caregiver of the patient. Mothers may complain that all the strain associated with the problem is "on their shoulders;" they receive this as a part of their mothering role.

In their narratives mothers often value the self-sacrificing behaviours required for them to be able to raise their children properly, in spite of all the family problems. But mothers were also questioning where they had failed. They were feeling staggered by the young person's strange behaviours. They had a hard time to understand why the patient started to misbehave or was having constant conflicts with them, which is even worse. They blamed themselves. Other family members blamed the mother as well. Once I heard a fight between Jonas's mother and her ex-husband who complained that she never had an

"active voice" with their son, according to him, it was this reason for which Jonas was not recovering. The significance of the mothering role transform mothers in an easy target for blame. This only deepens their sorrow and feeling of guilt. But mothers also questioned whether the accumulation of family problems, including more specifically marital problems (e.g. alcoholic husband, husband's violence or betrayal, divorce) could have contributed to precipitate the patient's problem.

Some mothers tried to transform their own behaviour to better deal with the patient:

Initially I only attacked him, but now I started to talk more. [Jonas's mother].

It was her sickness that woke me up in the sense of giving more attention to her and to help her more... to talk more with her. [Kátia's mother]

I changed with him, I always talk with him now and I try [to be caring]... I already talked with him today, my son let's go to church. [Leonardo's mother]

He gets sad... I say we have to be more caring with him, we have to be more caring, and that is all. [Mauricio's mother]

Mothers' feelings are mixed-up and contradictory. At the same time that they try to be more caring because their child is in crisis they suspect that they have raised their child in a too "bounded" or even "dependent" way. Carmen's mother feels sorry that she always tied up her daughter's shoe laces, and never expected her daughter to heat up a cup of coffee. Kátia's mother regrets that she never allowed her daughter to choose her own clothes, she would always pick her up after school, and sometimes she even did her daughter's homework. Mauricio's mother recognizes that she always protected her son more because he was much more dependent than her daughters. This kind of criticism also comes from other members of the family: Milton's father is shocked that his son tells everything to his mother including his outings with prostitutes. Claudia's sisters complain that their mother always spoiled their younger sister too much. Jonas's sister feels left aside because her brother was always the mother's favorite.

When the patient seemed almost to have recovered, some mothers tried to decrease their protective behaviour and expected to "fix" the problem by forcing their child to be more independent. For instance, Kátia's mother stopped doing everything in place of her daughter. Carmen's mother forced her daughter to go out to work and to help in house chores. Dora's mother stopped to give a privileged treatment to her daughter. This whole process led mothers to reflect upon their expected social roles as mothers. Some of them felt very strained because they now questioned whether the over-protective and self-sacrificing behaviours they always valued so much were also what provoked the psychotic episode. In these cases, the families' belief that the mother/patient relationship crossed the boundaries of normalcy converged with the psychiatrists. This does not mean that I have the intention to revive old-fashioned psychoanalytical theories about the "schizophrenogenic mother." Narratives only suggest that cultural features of the mother's role in Brazilian society can turn out to be perceived as problematic.

On the side of siblings, the patient's problem triggered a fear they had that the patient would become crazy forever. For instance, Dora's sisters only visited Dora once in the psychiatric hospital and they never had the courage to come back. Afterwards they asked me several times whether their sister was really crazy like the other patients. José's sister also asked me: "Do you think that he is going to come back to what he was before... or he is going to be always crazy like that?" Mauricio's mother had a terrible time to diminish the conflicts between her children. One of her daughters was so terrified that she wanted her brother to be sent to a psychiatric hospital for the rest of his life. When Mauricio improved from the psychotic episode, his mother decided to remove her son out of the house temporarily by asking him to attend a course for waiters in another town. Her strategy had a double intention: to guarantee a profession to her son since the high unemployment makes reinsertion in the job market difficult for anybody, and to alleviate the lasting tension between siblings.

Some fathers also gained their share of the blame, more particularly those who were separated from the mothers. Like Jonas's father, they usually tried to participate in

solving the patient's problem, but their sudden presence was commonly received with uneasiness, both by the mother and the patient. In general, the behaviours of fathers who lived with the family oscillated between supporting the mother in caring for the patient and taking some strategic distance from the entire problem.

One can also notice that before the onset of the psychotic episode, some patients were invested with especial tasks or socials roles because of external circumstances. For instance, Jonas, José, Maurício, Mateus and Dora were the main "bread-winners" of the family. When psychotic problems prevent them of accomplishing their usual tasks, family members and particularly the other siblings have difficulty accepting or understanding it. In addition, siblings have to assume extra house chores, find a job themselves, or help the mother to take care of the patient. They were extremely distressed themselves, and also wanted to be treated fairly. For some of them it was very difficult to accept the especial treatment received by the patient. They also had a hard time understanding why sometimes parents created such a positive image of the patient that was not consonant with the patient's actual behaviour. During the crisis, they were the "good children" who collaborated with the family, not the patient. I suppose that parents sometimes needed to valorize the image of the patient in order to cope with the problem. Some siblings tried to keep a distance, while others had more direct conflicts with the patient or the parents.

The intensity of family conflicts that may arise during the outbreak of a first-psychotic episode sometimes gave me the impression that these families were living inside a "kettle with burning water that was about to explode." I find this metaphor useful because it indicates that these families also tried to contain the conflicts within the family environment as much as possible. They also made all possible efforts to keep the patient inside the house. But for that to occur, they had to find a way to buffer some family conflicts and simultaneously display some attitudes of tolerance towards the strange behaviours manifested by the patient.

In two cases only, the intolerance towards the patient became so extreme that he or she was expelled from the house. Sarah lived with her husband and her father-in-law in

the North of the country. The family collected Brazil nuts for living. Sarah's mother was suddenly requested to bring her daughter and granddaughter back to São Paulo because according to her father-in law. Sarah had disgraced the honor of the whole family by her strange behaviours. The father-in-law paid the mother's trip and justified that in the South of the country Sarah would find better medical treatment. Sarah's mother understood that her daughter's problem was a blessing from God: it imposed the reconciliation between Sarah and her parents because some years earlier, before coming back in her family, she had run away from home to live together with her boyfriend.

Leonardo's father initial reaction was to move with the whole family to live in another neighbourhood since his son dishonored the whole family with his strange behaviours and drug addiction. For several months, the mother was able to manage the irreconcilable tension between father and son by convincing her husband of the rightness of the religious message that only a lot of parental understanding could solve the problem. I have already mentioned elsewhere that after the second psychotic episode and the first psychiatric hospitalization, Leonardo's father expelled his son from the house. He became so enraged when he saw his son smoking marijuana again that he forced the mother to chose between having him or their son leaving the house. This feeling that the patient dishonored the entire family by his strange behaviours was extreme, not a frequent reaction. More than being the problem of the patient, the psychotic episode affects the moral life and the well being of the whole family.

At the beginning of this chapter, I questioned the significance of variables such as "tolerance" and "social support" for defining family's reactions towards persons with schizophrenia in Third World countries. I suggested that one needs to take into account the different family reactions that occur within the same family and that they transform with the progression of the problem. During the first psychotic episode however, families generally tend to tolerate the problem and to provide social support to the patient. But "tolerance" and "intolerance" also seem to fluctuate in the context of each family. This may be affected by how each family member reacts to different signs of the disorder, the

family dynamics, social roles at play and their social-economic conditions over the course of time.

The Fear of Loucura and Stigmatization: Life in the Community

Even if patients and family members try to de-dramatize the long-term significance of the problem, the possibility of craziness always remains rampant. When it becomes explicit, the label of <u>loucura</u>, tends to come from outside of the family:

She [neigbour] knew that I was getting <u>louco</u>! [crazy]. [Leonardo, Return of Jesus Christ].

My friends would say that I <u>estava louco!</u> [was crazy]. What have I done to stay like that... because I would not talk thing with thing.
[Mateus, Community of Grace Church]

Everyone would say that I <u>estava louca</u>, that I <u>estava louca</u>. But I don't really know myself if I became <u>doida</u> [crazy] in the way I have told you. [Claudia, Congregation Virgin Mary]

I asked my mother to take me to a place... of spirits or something like that. 'No. no let's see what this is or isn't in the physician'...if it was coisa da cabeca [problem in the head]. I imagined that it was loucura [craziness]. I did not think it was normal to hear voices. I imagined that only a crazy person would... [Kátia Non-Practicing, Catholic]

After going to São Paulo Hospital I heard a voice 'this guy is <u>louco!</u>' That I was <u>louco</u>, the voice told me that I was <u>louco</u>. The voice told me that I was <u>louco</u>. I stayed in the hospital then the doctor was giving medication and I became calm. [José, Umbanda sympathiser]

Patient's narratives suggest that they were uncertain whether their strange behaviours could be associated with crazy people's behaviour. In fact, some patients asked me whether their unusual experiences really happened or if it was something that was only being created in their mind. In parallel, insinuations made by other people or heard in the social space they participate in also trigger an association with <u>loucura</u> [craziness]. For instance, Kátia only started to question the possibility that she might be crazy when her mother decided to take her to the psychiatric emergency, instead of a religious place. José heard "voices" in the psychiatric emergency room telling him that he

was crazy. What is not very clear is the source of these voices. It may have come from the other people in the room who commented on his aggressive behaviour. It may have been the same "voices" that constantly threatened to kill him.

Family members suggest that the first reference to <u>loucura</u> (craziness) come from outside the family, for example, from friends, neighbours, schoolmates and fellow workers. It is only in situations of extreme conflict and tension that family members dare to say that the patient is getting crazy. They prefer to avoid any reference to <u>loucura</u> and rather told that the patient was not feeling very well. They had some doubts as well. Several parents explained to me that the patient's problem could not possibly be <u>loucura</u> since crazy people continuously demonstrate strange behaviours, which was not the case for their child. By contrast to the polysemy of the idiom <u>nervoso</u>, the expressions <u>louco</u>, <u>louca</u>, and <u>loucura</u> represent a condition of extreme disturbance and indicate an absolute alteration of the person (Duarte, 1986).

Mauricio's story

It was Mauricio's birthday that night. He still manifested the effects of neuroleptics because the birthday party happened less than two months after he started the psychiatric treatment. When I arrived there everyone was already celebrating and chatting: the mother, three sisters, the grandmother, the aunt, the mother's boyfriend, Mauricio and his sister's friends. Everyone was eating one appetizer after the other and the background music was very soft. One of Mauricio's sisters baked a huge strawberry cake to sing the "happy birthday." Just before cutting the cake Mauricio excused himself to go out and invited some other friends (young men who live in the neighbourhood) to share his birthday cake. A real commotion happened while everyone was singing "happy birthday." I was also very astonished to hear that the young men were shouting da lua, da lua ("from the moon") while we were all singing. This alludes to the name of a well-known personage from a famous Brazilian T.V soap opera. Even

though <u>da lua</u> represented a silly and disturbed young man, everyone loved him than the "hero" of the story. Later Mauricio explained to me that sometimes his male friends would also jocosely call him <u>jamanta</u> (devilfish). This was the name of another mentally disturbed personage from the soap opera that was passing on television at the time. Mauricio gained these nicknames after the outbreak of his psychotic episode. He also believed that his friends were not trying to offend him by calling him with these nicknames. He even found them funny. What I had interpreted as pejorative nicknames were being employed in a playful way to allude to the strange behaviours manifested by Mauricio during that period.

One may wonder what Mauricio's friends gossiped about him when he was not around. Among the youth however, in some circumstances the condition of craziness receives a positive meaning. People who break normal patterns of behaviours and try to be different, even if that is associated with drug consumption, may feel comfortable in identifying themselves as crazy. When patients interacted with me, they referred to the words louco and loucura with a certain anguish, uncertainty and fear. Often they interrupted the narrative before taking the risk of using these terms. Very much like their family members they normally associate this condition with people who are locked in psychiatric hospitals for the rest of their lives. Particularly those patients who went through psychiatric hospitalization always tried to explain to me that they were somewhat different from the other crazy patients inside the hospital. The distinction between estar <u>louco</u> (transient condition) and ser louco (permanent condition) also indicates the nuances they were trying to introduce. Many years ago, I observed similar ideas while doing fieldwork in a female psychiatric ward of the Juqueri asylum in Franco da Rocha, São Paulo. Although the women whom I interviewed were chronic psychiatric patients with no chances of social re-integration, they also created a series of representations to discriminate themselves from most other women in the ward, and whom they considered as being the real "crazy" patients (Redko, 1991).

Popular images of hospitalized chronic psychiatric patients are terrifying. Their evocation in association with the patient's behaviour compelled family members to react. It is also a strong indicator that the situation became out of control and has expanded outside of the home sphere. The same strange behaviours also have the potential to evoke religious representations associated with "evil spirits" and encosto (leaning spirit). When this is the case, some people from the community may feel the moral obligation to invade the space of the home to offer help (see Chapter 7). Although both interpretations are threatening and confusing, they also trigger family members to search for different kinds of help.

Mauricio's story illustrates that in some circumstances the denomination of <u>louco</u> is also avoided by community people or is associated with less negative interpretations. A study conducted in Embu, <u>periferia</u> of São Paulo by Quirino dos Santos, Miranda, Leite, and Pereira (1992) indicates that people are more likely to say that psychotic people who circulate daily in their community only commit "acts of craziness," instead of stigmatizing them with the term <u>louco</u>. Community reactions have to be understood in their context. One could think that the behaviour of crazy people who circulate in the same <u>pedaço</u>, week after week, is perceived as less threatening than when a co-worker, schoolmate, or close friend commits sudden "acts of craziness." People from the neighbourhood seemed to be more scared when José's psychotic episode first exploded than afterwards, when he returned from the psychiatric hospital. As in Mauricio's story, neighbours also used playful nicknames to allude to José's strange behaviours. José was not bothered by this kind of reaction while he circulated in the neighbourhood. Most of the time he was playing dominoes in the neighbourhood bar or matches of soccer with other neighbours who were unemployed just like him.

Family members always tried to explain that to me that "there are neighbours and neighbours." Families were very concerned to avoid the majority of "bad" neighbours because they only gossip and envy people, while the "good" neighbours circulated in their homes just like family. These "good" neighbours often gave them a hand during the outbreak of the first psychotic episode. They helped to give medication to

the patient, they helped to separate a family fight, they cried together, but most importantly they brought religious messages of hope and consolation. Some supposedly "good" neighbours also revealed to be "bad" neighbours because they preferred to keep a distance from the problem. In some cases neighbours were the first people to draw the attention of family members to the patient's problems because he or she was interacting with them in strange ways. Relationships with the extended family are not much different. Only those few relatives who were always very close to the family eventually provided some support during the crisis, while all the other relatives were more avoided than usual. Some mothers confessed to me that they were very ashamed to interact with most of their relatives because they had a person in the home who was having mental problems.

Most patients were already out of school when the problem occurred. Most of them had abandoned school while a few others had already completed High School. Only six patients were attending school during this period. Luana and Edilson only missed a few weeks of school while Carmen and Claudia had to repeat the school year. The mothers of Carmen and Claudia preferred to transfer their daughter to another school after the psychotic episode. They hoped that the new environment would be more stimulating for their daughters because they were going to meet different school friends. They were trying to protect their daughter from the frustration of repeating another school year, but they also wanted to avoid any gossip and intrigues with previous school friends and teachers. Siblings who went to the same school as the patient refrained from talking with the patient's schoolmates. They also wanted to buffer any gossips since they felt very uncomfortable with the idea that the patient was having some mental problems. Some teachers provided advice to the patients and asked them to consult the school's social worker or psychologist. Before Carmen's second psychotic episode, a school teacher also advised her mother to take her daughter to a religious group that helped problematic youth (see also Chapter 1). Some parents were persuasive and convinced teachers to facilitate the patient's school obligations while they had to stay at home. Alice was allowed to do some school exams at home while Milton received his high-school diploma without doing the final exams. Milton was very proud that he was going to receive his diploma yet he was very worried to sign the diploma because he trembled all the time due

to side-effects of his neuroleptics. Once he showed me a scrapbook full of signatures because he was training to sign his name without trembling. The family was also extremely proud of Milton's innate drawing abilities. The living room of their house is decorated by some drawings that Milton made when he was a teenager (see Figure 10).

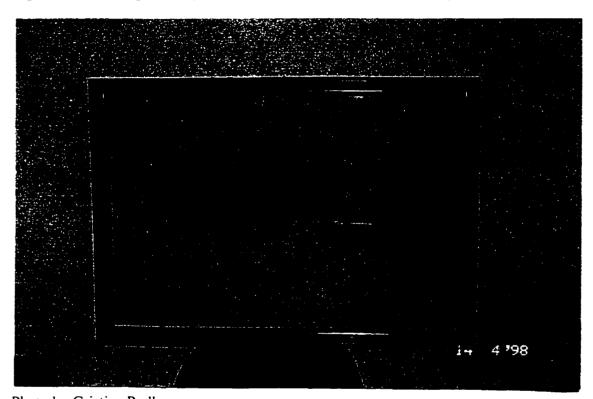


Figure 10 - Drawing made by Milton and which is hung on the living-room wall.

Photo by Cristina Redko

The majority of patients (75%) had some work experience. Several patients however, were unemployed or only held occasional jobs. All the patients who were working lost their jobs during the outbreak of the psychotic episode. The only exception is Milton because his father worked in the same factory for many years and was able to guarantee his son's position. However, Milton's father preferred not to receive any visits of co-workers at home while the son was sick. Jonas's story mentioned at the beginning of this chapter illustrates that patients often started to have problems in the work environment and were dismissed for this reason. This kind of problem is not much

tolerated by the co-workers. After loosing their job, patients also loose contact with all the people who worked at the same place. For the patients who were already unemployed, it is difficult to determine whether the unemployment relates more to the economic recession of that year or if these persons already displayed some signs of disturbance. In some cases, both factors reinforced each other: A similar reasoning applies to patients who had abandoned school. Patients usually abandoned school after they started repeating the school year. Only a few patients abandoned school a short time before the outbreak of their first psychotic episode.

Many patients surprised me in emphasising that they did not have any friends. The only exceptions were Jonas, Mauricio, José, and Eduardo. Curiously the four exceptions are males for whom it is culturally acceptable to maintain a "street" life outside of the "home." All the other patients explained that schoolmates, co-workers or the people with whom they eventually went out with (e.g. to dance, to the church, to consume drugs), were only acquaintances. Often only parents, brothers and sisters were perceived as the people with whom they could really maintain a close relationship of friendship: only the family members are trustworthy. One may wonder whether they hold a very rigid and restricted definition of friendship, so that most people are unlikely to fit in this category. Another possible interpretation is that they only maintained very tenuous interactions outside the family environment. I often heard psychiatrists make hasty conclusions about this topic. When patients mentioned that they had very few friends or that they never had a boyfriend or girlfriend, this was primarily interpreted as a pre-morbid characteristic of the person. It is very likely that these tenuous interactions are also affected by the general climate of urban violence and fear in addition to the confusing rhythm of modern life in the metropolis where people have less chances to consolidate relationships of friendship. The behaviour of youth in São Paulo is also changing. For instance, a well known contemporaneous phenomenum is called "ficar com" ("to be with"). This expression indicates that youth seldom have stable boyfriends and girlfriends because they often switch their relationships very quickly.

The circulation of the family inside the community undergoes some changes with the outbreak of the psychotic episode. Some people of the community disappear, while others are avoided. Only those few people who offer some social support or tolerate the problem, and most particularly people or activities that offer some religious source of respite, become more present during this period. In a certain way, families also slowly withdraw from the everyday life of the community. In some cases, I was practically the only "visitor" that these families had some disposition to receive in their homes. I suspect that this gradual isolation of the family responds to a double movement. Their time for socializing becomes more restricted because they try to provide unremitting attention to the person who is suffering of psychosis. Yet they try to stay away from any gossip or stigmatisation that might easily come from outsiders. Family reactions are often ambiguous. While they try to affirm that the problem is only transitory and that life is coming back to normal, they feel threatened by any community reaction that suggests that it may not be so.

Chapter 6 - Religions, Healing, and the Evil

Everything will turn out right

If we put our faith into action And have confidence and pray God will listen and answer And everything turns out right

REFRAIN

Everything will turn out right Everything will turn out right If we put our faith into action Everything will turn out right

I know that life is not only made of good moments
And that there are difficult times
Life is just like this
But if we put our faith into action
Everything will turn out right

(Hymn 106 from Universal Kingdom of God Church; my translation)

Mapping Out the Religious Terrain

It is almost impossible to describe the worlds of everyday life of São Paulo's residents without discussing religion. Religion is everywhere. Although religion is an important part of any culture, it seems to be even more so in Brazil. Furthermore, the recent increases in poverty, violence and daily hardships caused meaningful changes in the religious landscape. Particularly in the life of poor people such changes have greatly affected their lifestyle and their culture in general. In order to understand the everyday life worlds of these people, it is important to describe the present religious landscape and how people have been relating with the "other world," to use DaMatta's (1987) term. The larger religious background described in this chapter is supported mainly by the

discussion already found in the literature, while the analysis of the ways in which such diversity of religious experiences contribute to articulate the psychotic experience is reserved for the next two chapters.

Brazil is known as a quintessentially Catholic country. While in the Census of 1960 more than 90% of the country's population defined themselves as Catholics (Camargo, 1973), the religious field has been going through significant changes, and today only three quarters (74.9%) of the population still consider themselves Catholics (Pierucci & Prandi, 1996). In the last couple of decades other competing religions have significantly increased their number of followers, especially the various forms of Protestantism and the Afro-Brazilian religions (Umbanda and Candomblé), to name the most important. In this context the first question to be asked is what it means to be Catholic in Brazil. Camargo (1973) inspired by Weber and Geertz¹ makes a crucial distinction between "internalized" and "traditional" Catholicism:

The notion of internalization refers to the way in which the faithful person participates in the religious life by adopting its values, norms and practices in a very conscious and deliberate manner. It contrasts with traditional religion that is commonly implanted in societies where sacred institutions legitimate the social order and penetrate the whole network of human relations. Brazilian rural Catholicism is a typical example of this traditional religious life that establishes a mode of religious behaviour and social life called cristandade by theologians. The urban Catholicism that prevails in the country has an impoverished religious content and very few social functions, thus it does not induce awareness of the meaning of the ritual with which it maintains itself. Thus, urban Catholicism is maintained as a traditional form of religion, despite the drastic loss of a great part of its functions. [1973:77; my translation]

Nowadays the great majority of Brazilian Catholics are "traditional" (61%); most of them go to church only sporadically, and for special occasions like baptisms, marriages, and funeral rites. These people usually call themselves "non-practicing Catholics" and only keep religion as an indicator of their social identity. This group also includes some people who attend mass regularly, but who do not become involved in any

¹ Especially the paper by Geertz (1973) called "Internal Conversion in Contemporary Bali."

Catholic movement that proposes the revitalization of Catholic life. Popular religion also integrates a larger range of practices that constitute Traditional Catholicism, like the devotion to saints, <u>promessas</u> (promises), miracles and pilgrimages to sanctuaries. In São Paulo State for instance, there is the gigantic sanctuary of <u>Nossa Senhora de Aparecida</u>, who is the patron saint of Brazil.

Although "traditional" Catholics represent 61% of the entire adult population in Brazil, another 14% of the population experiences Catholicism in a more internalized way that involves a personal movement of reorientation and a real commitment to religion. These Catholics are the ones who participate in several religious movements of which "Christian Base Communities" (CEBs) and "Catholic Charismatic Renewal" are the most representative. The "internalized" Catholics differ from the "traditional" because to them religion always means an option with values and attitudes that are emphasized and outspoken in the community. By contrast, the so-called traditional Catholics normally follow the religion in which they were raised (Prandi, 1997).

The "Christian Base Communities" is an internalized form of Catholicism that has to be situated in the context of the rise of liberation theology² movement in the 60s. In this movement several Catholic priests started to preach the Gospel as a call for social justice, levelling of religious authority, and as a response to the Catholic Church's growing commitment to a "preferential option for the poor." In Brazil the Christian Base Communities are characterised by the creation of small reflection groups where participants read the Bible together, with the help of liberationist study guides and pastoral agents, discuss its implications for their everyday lives, and are thereby inspired to fight for social justice. CEBs have been a significant political movement that promoted a variety of forms of the struggle for social justice, and thus motivated many people to become involved in neighbourhood organisations, land reform movements, labour unions and political parties. Paradoxically, some studies also indicate that most CEBs

² Liberation theology is a set of ideas that attempts to reconceptualize religious symbols by setting them "free" to perform a mobilizing rather than hegemonic role. This conscientization based on religious themes is thus intended to lead the poor to class-based awareness and political action (Berryman, 1987).

participants remain uninterested in social movements and other political matters (Drogus, 1997; Burdick, 1993; Macedo, 1986). Nowadays the CEBs' movement appears to be declining in Brazil, although 2% of the entire population still follow it (Prandi, 1997).

On the other side, Catholic Charismatic Renewal is a movement that began in Pittsburgh, USA, but is presently gaining strength in Brazil, having reached 4% of the adult population. In contrast to CEB participants, the Charismatics focus their religious practice in the private and intimate domains of everyday life, and show no interest in collective problems that involve political participation. The message transmitted by the world wide Catholic Charismatic Renewal is very similar to Pentecostalism in the sense that some of the followers also "speak in tongues" (or glossolalia) during meetings. practice touch-healing, believe in the gift of the Holy Spirit as a spontaneous experience rather than as a ritual sacrament delivered by some authority of the Church, and emphasize that people have the chance to change their lives by "accepting the Holy Spirit." A primary characteristic of Charismatic Renewal in Brazil is the devotion made to the Virgin Mary, which is also found in traditional Catholicism, but does not exist in Pentecostalism. Internally the Charismatic Renewal represents an opposition to "liberation theology" Catholics; while externally it competes with Pentecostals to convert people who desire a religious experience characterised by a feeling of sacred immanence (Machado, 1996; Lehmann, 1996; Prandi, 1997).

In parallel to Catholicism, various forms of Protestantism have conquered a significant portion of the population in contemporary Brazil. It is a form of religion practised by 13% of the adult population (Prandi, 1997). Its various forms can be classified in "Historical" and "Pentecostal" Protestantism. Historical Protestantism was established by the early European immigration, and is composed of denominations such as Lutherans, Baptists, Methodists, and 7th Day Adventists which together represent 3% of the adult population (Prandi, 1997). According to Aubrée (1987) Pentecostalism is distinguished from other forms of Protestantism by two main elements:

- (a) The doctrine of predestination, which encourages the follower to withdraw from community life since the non-Pentecostal way of life is full of damnation and pitfalls that detract from the path towards salvation.
- (b) The implementation of the gifts of the Holy Spirit.

Pentecostalism underscores the emotional experience of glossolalia and the gift of healing. This is reflected in the description of conversion to the "Assembly of God" in Northeast Brazil:

Three moments are necessary for someone to belong entirely to Pentecostalism, and the first one consists of a declaration made in a loud voice to the neighbourhood's community that one 'accepts Jesus' (as the Saviour). There is no chronological order for the other two moments. one of them is the "baptism in water" (through immersion), a collective celebration that happens once or twice a year, depending on the number of new adepts, representing the official recognition of the new adherent by the sect. The other moment is the 'baptism by fire', or the irruption of glossolalia (a type of verbal trance characterised by the spontaneous emission of a sound sequence more or less longer that makes no sense outside this mystical arena). Glossolalia signifies the recognition of the adherent by the divinity. Glossolalia comes about according to individual dispositions, sometimes immediately or only a long time after acceptance of Jesus'. However, glossolalia is a prerequisite to having access to one or the other of two kinds of hierarchy that intersect within the sects. The first hierarchy can be analyzed as "spiritual", and corresponds to the accumulation of the gifts of the Holy Spirit over the crente.3 It is considered by the Pentecostals as the divine reward for the respect of prohibitions and the enactment of the commandments; consequently, it is a proof of "sanctification", and those who obtain several gifts are very respected by others followers. The second hierarchy has a temporal dimension, and allows a sect (especially when it expands) to function efficiently. The different degrees of function are the positions of assistant, deacon, vicar, and pastor, and the parallel function of evangélico. Almost always the assistants are women who practice charity, while the other positions are remunerated. [Aubrée, 1987:264, my translation]

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³ <u>Crente</u> (believer) or <u>evangélico</u> are colloquial names for the people who follow any one of the Protestant denominations. Furthermore, there are eight gifts of the Holy Spirit in increasing order of importance: it is the gift of tongues (glossolalia), the interpretation, evangelization, healing, prophecy, wisdom, gift to discern the spirits (read thoughts), and the gift to make miracles.

Development of Brazilian Pentecostalism can be divided into three waves: the first decades of the 20th century, the 1950s and early 1960s, and the late 1970s and 1980s. In the first wave the "Christian Congregation" arrived in 1910, and the "Assembly of God" in 1911. The "Christian Congregation" continues to be identified with Italian immigrants and has remained relatively limited in scope, while the "Assembly of God" (AG) has expanded to become "the" national Protestant church in Brazil (and the biggest AG in the world, according to the number of followers). Since the influence of the North-American AG has always been very limited, the growth of the Brazilian AG has gone through an autonomous development, like most other Pentecostal sects (Corten, 1995; Freston, 1994).

The second wave reinforced autonomous ⁵ Pentecostalism besides introducing an extensive use of mass media (especially radio at this point), and "new" secular locales for religious rallies (stadiums, gymnasiums, and cinemas). The three largest churches originated in São Paulo: "Four Square Church" in 1951, "Brazil for Christ" in 1955, and "God is Love" in 1962; the last two of these churches have Brazilian founders and emphasize divine healing and exorcism.

The third wave or Neo-Pentecostalism represents the era of the "Electronic Church:" the two most significant groups are the "Universal Kingdom of God Church" founded by Edir Macedo in 1977, and the "International Grace of God Church." The "Universal Kingdom of God Church" is an exemplary case since it makes extensive use of television in order to divulge the "exorcisms from demon possession" and the theology of "rapid prosperity" which is interpreted as the outcome of real work of God in one's life. Many Pentecostal churches have gone through divisions into smaller sects that represent a common form of proliferation.

⁴ It is estimated that in Brazil the "Assembly of God" has 5 million followers although some studies calculate up to 8,5 million. In contrast there are 2 million AG followers in the USA, 500,000 in Mexico and 300,000 in Argentina (Corten, 1995).

⁵ Rolim (1992) defines autonomous Pentecostalism in opposition to classic Pentecostalism. The former, he explains, is developed around strong leadership, yet is dissident from the classic that originates from the Pentecostal churches of North American missionaries, and is very uncommon in Brazil. Healing, exorcism, and prosperity are the most significant characteristics that define "autonomous" Pentecostalism in Brazil.

In sum, while the emphasis of the "Assembly of God" is on "baptism in the Holy Spirit" as certified by "speaking in tongues" (glossolalia), "God is Love" is characterized by divine healing, and the "Universal Kingdom of God Church" stresses exorcism from demon possession. The evil that needs to be expelled through exorcism is particularly related to Afro-Brazilian cults such as Umbanda, or to vices such as alcohol and drug addiction (Prandi, 1997; Mariano, 1996a; Corten, 1995; Freston 1994). The "Assembly of God" (first wave), "God is Love" (second wave), and "Universal Kingdom of God Church" (third wave) are the most representative Pentecostal Churches sought out by the people who participated in this study.

Parallel to the various Catholic movements and Pentecostal Churches, the Brazilian religious field also includes more local forms of religion, mainly Kardecismo, Candomblé, and Umbanda. Kardecismo (or Spiritism) comes from a reinterpretation of the work of the French Spiritualist Allan Kardec, and was introduced in Brazil at the turn of the last century. Since then it has had a significant influence especially among intellectuals and urban middle-classes. Kardecistas compose 3% of the adult population; however they are more concentrated in big cities like São Paulo where Kardecismo attracts 8% of the urban population (Prandi, 1997). Kardecismo followers value the intellectual and spiritual progress of the individual and advocate social mobility through formal education. Its system of practices resumes in three interrelated principles that contribute to the "spiritual evolution" of the person: development of spirit mediumship, the study of books about Spiritualism, and works of charity (Aubrée & Laplantine, 1990).

Candomblé is a religion of spirit possession with an African origin; it is followed by at least 0,5% of the adult population. The deep penetration of Candomblé in Brazilian culture enhances its visibility in the national religious arena, even though the greatest proportion of followers still live in Salvador (Bahia) where they constitute 2% of the population. Until the 1960s this religion was restricted to black people. Afterwards, its rapid spreading in São Paulo and Rio de Janeiro has opened Candomblé to people of all colours and social classes (Prandi, 1997, 1991; Gonçalves da Silva, 1995). Umbanda is a religion of spirit possession derived from the confluence of Kardecismo, Candomblé, and

Traditional Catholicism. It is followed by 1% of the adult population. Most people are first attracted to Umbanda to obtain a spiritual consultation in order to solve their everyday problems like illness, unemployment, family conflicts, or love affairs (Brown, 1994; Montero, 1985; Camargo, 1961). In 1989 Negrão (1996) found 14, 601 Umbanda centres, 2539 Kardecismo centres, and 1421 Candomblé centres officially registered in the city of São Paulo.

Table 13: Religious affiliation of adult people according to sex in Brazil⁶

	Percentages (%)	Male	Female	Total	Cases
CATHOLICS	TOTAL	50.4	49.6	100.0	15.707
	Traditional	52.9	47.1	100.0	12.874
	Charismatic	29.7	70.3	100.0	799
	CEB's	45.6	54.4	100.0	371
	Other movements	42.5	57.5	100.0	1659
PROTESTANTS	TOTAL	47.1	52.9	100.0	2.791
	Historical	46.3	53.7	100.0	720
	Pentecostal	47.4	52.6	100.0	2.070
KARDECISTAS	Spiritism	46.0	54.0	100.0	736
AFRO-	TOTAL	46.0	54.0	100.0	279
BRAZILIAN	Umbanda	45.8	54.2	100.0	192
RELIGIONS	Candomblé	46.5	53.5	100.0	87
OTHER RELIGIONS		48.4	51.6	100.0	417
NO RELIGION		63.8	36.2	100.0	1.036
Total number of cas	es (100%)	50.4	49.6	100.0	20.966

Source: Pesquisa DataFolha (1994), as cited in Pierucci & Prandi (1996).

Two percent the adult population belong to a variety of religions like Judaism, Buddhism, Messianic, Mormonism, Jehovah's Witnesses, as well as some esoteric sects. However, 5% of the adult population declared that they have "no religion," a proportion that is higher in cities like São Paulo (6%), Salvador (7%), and Rio de Janeiro (11%). That a greater proportion of males are found within the "no religion" or the "traditional Catholics" groups is not surprising and confirms the largely accepted idea that women are

⁶ Data presented in Table 13 and Table 14 integrate a national survey related to the presidential elections of 1994. It is probably closer to reality than the IBGE Census of 1991 because the sociologists Pierrucci and Prandi were careful to design a research methodology that would avoid the automatic answer "I am Catholic" since the same person might have other religious affiliations as well. However their sample is composed only with people over 16 years old.

usually more frequent participants in religion than men. Table 13 illustrates the religious affiliation in Brazil according to sex, while Table 14 compares the religious affiliation of the adults who live in the cities of São Paulo, Rio de Janeiro, Salvador, and for the whole of Brazil.

Table 14- Religious affiliation of adult people in three big cities of Brazil

	Percentages (%)	São Paulo	Rio	Salvador	Brazil
CATHOLICS	TOTAL	65.2	59.3	65.3	74.9
	Traditional	58.9	52.3	56.4	61.4
	Charismatic	2.0	0.9	2.5	3.8
	CEB's	0.8	0.7	1.8	1.8
	Other movements	3.5	5.3	4.6	7.9
PROTESTANTS	TOTAL	13.5	14.8	13.2	13.3
	Historical	2.3	4.7	3.8	3.4
	Pentecostal	11.3	10.1	9.4	9.9
KARDECISTS	Spiritism	8.0	7.5	7.5	3.5
AFRO-	TOTAL	3.7	4.9	2.7	1.3
BRAZILIAN	Umbanda	2.5	3.3	0.6	0.9
RELIGIONS	Candomblé	1.2	1.6	2.1	0.4
OTHER RELIGIONS		3.4	2.3	4.1	2.0
NO RELIGION		6.2	11.1	7.2	4.9
Total number of case	es (100%)	1437	899	244	20968

Source: Pesquisa DataFolha, (1994), as cited in Pierucci & Prandi (1996).

The hegemony of Catholicism is being shaken, and religious pluralism has become a reality in Brazil, especially in the urban areas of the <u>periferia</u>, where religious migration has often been the norm, not the exception (Burdick, 1993). Pierucci & Prandi (1996) conducted a representative survey in the city of São Paulo in 1995; it indicates that 26% of the adult population has converted to another religion. Around 40% of the people who converted had done so in the previous three years (or less). Although people from all religions may eventually convert to another faith, 58% of the converted were originally Catholics. Furthermore, this recent religious conversion is highly associated with poverty and marginality, except in the case of conversion to Catholicism. This survey also confirmed that the main reason for recent conversion to Catholicism involves the "Charismatic Renewal," which is known to be a middle-class phenomenon that affects particularly women. In the remaining religious groups (Historical Protestant,

Pentecostalism, Afro-Brazilian and Kardecismo) the people who were raised in these religions always enjoy better life conditions than those people who have recently converted. In addition, people with low income and low level of education prefer to convert to Pentecostalism. Afro-Brazilian religions, or Historical Protestants, in this order. Table 15 shows that marginality and poverty (indicated by low levels of education) are associated with religious affiliation.

Table 15- Colour and school level in different religions of the city of São Paulo⁷

	Religions					Pentecostal		
	Catholic %	Kardecist %	Afro- Brazilian %	Total Protestant %	Total Pentecostal %	Assembly of God %	Universal Kingdom of God Church %	
COLOUR								
White	60	73	54	52	50	53	48	
Mulatto	29	22	32	32	36	28	37	
Black	11	5	15	16	14	19	15	
TOTAL	100.0	100.0	100.0	100.0	100.0	100.0	100.0	
SCHOOL LEVEL								
8 th grade	54	26	58	69	76	78	88	
High-	33	40	29	26	23	21	11	
school								
University	13	34	13	5	2	l	1	
TOTAL	100.0	100.0	100.0	100.0	100.0	100.0	100.0	
1.500								
cases								

Source: Pesquisa DataFolha (1995), as cited in Pierucci & Prandi (1996)

Table 15 illustrates that Pentecostalism attracts the urban poor more than any other religion. Pentecostalism appears to perform an important role as a cultural strategy for coping with urban poverty. It succeeds in part because Pentecostalism fosters a sense of closeness to God, enhances self-esteem, develops leadership skills, promotes literacy, provides support networks, and encourages a sober and ascetic style of life. Although

⁷ There are no available data for São Paulo regarding the total number of Protestants in the major churches; in the city of Rio de Janeiro 31% of all the Protestants are from the Assembly of God, while 16,5% belong to the Universal Kingdom Church of God Church (Fernandes, 1998).

In fact, a survey done in the city of Rio de Janeiro in 1994 indicates that around 60% of the Pentecostals receive a monthly wage of USS200 or less. Every year more than 80000 people convert to Pentecostalism in Rio (Fernandes, 1998).

Neo-Pentecostal Churches explore popular notions of magic and miracles, the rational dimension of life of the Pentecostal worldview is what is most appealing to the poor. They already had access to magic, miracles, and emotions in their previous religions (Mariz, 1994a).

Religious conversion in Brazil has been interpreted from three major perspectives: "free market" perspective, "common shared beliefs," and the construction of a "religious identity." The first perspective is advocated by Pierucci & Prandi (1996). These authors conclude that the concept of religious conversion as a unidirectional process has weakened since it is very easy to switch religions without making any dramatic biographical or life change. The religious field would resemble the free-market of consumer goods. The person is now allowed to consume different religions in succession or at the same time, and this would not require actual conversion: religion has become only a matter of "prêt-à-porter" individual choice. Pierucci & Prandi argue that "religious conversion" without internalization is less meaningful. However, they have not analyzed it from the perspective of people's subjective experience.

The second perspective, called "common shared beliefs", emphasizes that in everyday life people may mix practices and religious beliefs from diverse origins according to a logic determined not so much by a single church dogma, but rather by people's concrete living conditions. These "plural" religious identity and religious conversion are both facilitated since Brazilian Catholicism, Pentecostalism, Afro-Brazilian religions, and Kardecismo hold a common ground of shared beliefs: spiritual healing, belief in sorcery and witchcraft, moral definitions of good and evil, and so forth. These religions provide a framework of popular understanding that is embedded within popular consciousness, which transcends any particular religious affiliation. However, the

^a The notion of individual choice emerges with the idea that secularization has been taking religion away from the collective and public domains to the private sphere. This phenomenon is called "privatization" of religious life because it is limited to individual and autonomous religious practices that mainly incorporate the sacred to serve immediate needs. Ribeiro de Oliveira (1994) illustrates this "do-it-yourself ethics" within Traditional Catholicism, Mariano (1996b) and Campos (1997) within Neo-Pentecostalism (third wave).

fluidity of boundaries between different religions goes against more rigid notions of conversion conceived as a unidirectional process (Oro, 1994; Brown, 1994; Fonseca, 1991; Brumana & Martinez, 1989).

The third perspective centered around the notion of "religious identity" considers that the situation is much more complex than what is suggested by reading the religious trajectories as purely opportunistic efforts to solve "concrete problems." Regardless of their "concrete problems" people often refuse to consult certain religious specialists or resist affiliating with specific religious groups. Authors working in that perspective see religious conversion less as a mark of opportunism than as corresponding to ongoing "dramas of conscience" interwined with the complex construction of a religious identity. This approach aims at understanding the specific factors that makes the person choose one religion over another, while the second perspective is more concerned with interreligious similarities (Burdick, 1993; Fry & Howe, 1975).

Although the discussion above helps situate some transformations that are happening within the religious arena, it is insufficient to convey the diversity of people's life and world experiences. People in the same structural position may choose different religions: they may also develop specific practices that are not structurally predictable. Also, the same religion may generate different subjective experiences and consequently distinct behaviours. Different religions may also produce similar experiences in different individuals. Thus it is important to understand the role of each religious group in people's everyday lives, as well as in their popular use (Mariz, 1994a; Rostas & Droogers, 1993).

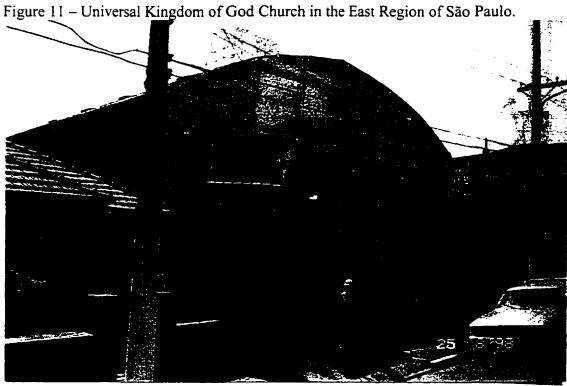


Figure 12- God is Love Church in the South Region of São Paulo.



Photos by Cristina Redko

Religious Healing Practices

People experience "possession" and the presence of "spiritual beings" as a natural occurrence in their lives. Every individual is conceived as a person with at least some tenuous link to some "spirit." Consequently, the existence of "spirits" and the possibility of "spiritual healing" is not even questioned, although these spirits assume different identities in the each religion: The Spirit guides in Kardecismo or Umbanda, the Holy Spirit in Pentecostalism, and the saints in Catholicism. In addition, most forms of spiritual healing presuppose that the person's body functions as some kind of "lightning rod" that attracts spiritual energies. This conception is much more evident in Pentecostalism and Afro-Brazilian religions because they conceive the body as a "horse" ridden by different spiritual entities that manifest themselves in order to practice good or bad actions. The body has no value by itself. Besides receiving the soul that gives identity to the person, the body may also receive good or evil spirits. Another element that eases the mediation between the different religions is that some of their rituals have the analogous purpose of expelling or taking out from the person's body the supernatural source of evil. Thus, rituals of exorcism and purification also operate as a gateway to religious conversion (Campos, 1997; Birman, 1997a, 1996; Boyer, 1996).

In short, the body is normally perceived as being inseparable from the person's "soul." This also explains the widespread practice of resorting to religious sources of help in parallel to seeking specialists "of the body" (physician, pharmacist, herbalist) whenever somebody is sick in Brazil. Healing might need to cover both aspects of the person (body/soul) in order to be effective because most people acknowledge the distinction and refer to different dimensions of doença material (material illness) and doença espiritual (spiritual illness). In fact, it refers to different dimensions of the illness reality grounded in practical experience. Thus, most illnesses can be classified simultaneously in both categories, or may be transferred from one category to another according to:

- (1) Diagnostic and therapy provided by each healing specialist (religious healer, physician).
- (2) The family's help-seeking decision to resort to a specialist "of the body" or to a specialist "of the soul."
- (3) The decision to resort to these specialists at the same time or in succession (Ngokwey, 1995, 1988; Queiroz, 1991; Loyola, 1984).

The essential effect of religious healing is to alter the meaning of illness for the sufferer; it is also considered a form of persuasion that changes a person's assumptive world. In other words, there is a transformation of the suffering and experience through the transformation of the self. Therefore, what is regarded as healing does not necessarily include the removal of symptoms; it can refer to the meaning the person attributes to his or her illness or to a change of lifestyle. Although religious healing is not defined in terms of faith, a component of faith plays a part in most therapeutic encounters (Csordas 1994b, 1988; Bourguignon, 1976). A brief description of the world views and main approaches to religious healing provided by the most representative religions found in Brazil are presented below.

The system of representation in Kardecismo assumes constant communication between the "visible" and the "invisible" worlds (composed by higher-level and lower-level spirits). It also gives an important place to the Hindu notion of individual Karma and reincarnation. Human beings are believed to be spirits temporarily embodied in a material body. Spirits would return to the material world to be exposed to challenges from which they may learn lessons that may contribute to their moral advancement. Yet both embodied and disembodied spirits are able to advance spiritually by doing good works. Spirit mediumship presupposes the study of books on Spiritism which leads the individual to practice charity (mediumship in action), and both practices develop even further the person's own spirit mediumship (which can also be developed due to a previous incarnation). That is how spirit mediums gain the ability to communicate with the "higher-level spirits" (more advanced) in order to transmit their messages through a variety of forms. Psychographic mediums allow the spirits to write with pen and ink by

directing the medium's hand. But literature, paintings, music and sculptures are also transmitted through mediumship. Clairaudient mediums hear information, while clairvoyant mediums see spirits and look into the spirit world. Healing mediums act as receptors for various types of "energy" using it to heal by means of magnetic passes that cleanse a client's energy field. (Aubrée & Laplantine, 1990; Krippner, 1989; Greenfield, 1992).

Kardecismo sessions are commonly performed at a centre of Spiritism or at someone's home. There are several categories of sessions or meetings, such as doctrinal study, development of mediumship, works of charity and the healing ritual called desobsessão. In the study and development sessions Spiritists normally read and discuss Kardec or another Spiritist writer. Sometimes students are encouraged to relate the passage of the book discussed to problems in their everyday life, very much like Bible study groups of CEBs and Protestant churches. During the development sessions when the lights are turned out and people concentrate, some of the mediums-in-development receive spirits, but not every medium needs to receive a spirit. Both types of sessions usually begin and finish with a kind of laying-on of hands called passes, and in some circumstances people drink water that has been spiritually cleansed with passes. These passes represent a mode of communication between the sender (disembodied spirit or spirit of the medium) and the receiver; they dissipate the negative energy while transmitting positive energy (or fluids) to the individual; sometimes with a healing function (Hess, 1991; Aubrée & Laplantine, 1990; Camargo, 1961).

According to Kardecismo "obsession" is a pathology caused by disturbing "obsessing spirits" (disincarnate lower-level spirits in search of a body where they can introduce or fix themselves). The perturbations from "obsessing spirits" can be mild (e.g. sadness, nervousness, irritability, domestic conflicts), but in severe cases, they may provoke some physical or mental illness. Several individuals who suffer "spirit obsession" are considered to be "ill" mediums, because they are unable to control their mediumship, and allow themselves to be guided by the obsessing spirits. A session of desobsessão is conducted by a group of incarnate spirits (mediums) who are guided by a

group of higher-level spirits of light. It aims to provide help for both suffering spirits (the "obsessed" and "obsessing"). Often the session begins with some reading, an initial prayer, and some cleansing passes. When participants find themselves under the protection of the spirits of light, they then demand the obsessing spirit to manifest itself. Normally the obsessing spirit is desperate and crying while being received by the medium of incorporation. Another medium in direct contact with the spirits of light, the medium of clarification starts a dialogue with the obsessing spirit to indoctrinate and enlighten this lower-level Spirit, until he expresses remorse for his actions. The obsessing spirit will likely resist being indoctrinated; when he finally relents, he promises to leave the body and the incarnate Spirit of the victim in peace. The session then ends with another series of passes to evacuate the accumulated tension and restore the energy (Aubrée & Laplantine, 1990; Greenfield, 1992, 1987).

Kardecismo's therapies are primarily composed of the resort to <u>passes</u>, <u>desobsessão</u>. Hahnemann's homeopathy, spiritual surgeries, and regression to past-life. This is usually achieved by the joint action of higher level spirits (specially the Spirits of disincarnate physicians) and the medium that receives the spirit's message (e.g. a homeopathic prescription). The existence of natural or material illness is not neglected by Kardecistas, yet the etiology of spiritual illness is explained through the relations the individual maintains with the Spirit world. This etiology expands in three main directions:

- (1) Karmic illness is a consequence of the faults committed by the incarnate spirit in previous lives.
- (2) Illness can be due to the bad actions accomplished in the present reincarnation.
- (3) Illness may be caused by others, e.g. the individual is victim of black magic, or is influenced by Spirits with low spirituality or retarded entities (Aubrée & Laplantine, 1990; Hess, 1991; Greenfield, 1987; Warren, 1984).

Umbanda is a spiritual possession religion based on a karmic model of spiritual purification. The image of the world as lying beneath an astral plane and stratified in numerous levels of increasing spiritual purity is central to Umbanda's cosmology. The

person's place after death in the astral plane is determined by the good actions accomplished during his or her life, which tells how quickly he or she will become a spirit of light. If persons are still burdened with social debts after death, they will continue to wander on the earth as a spirit without light. All the spirits have the opportunity through reincarnation and the performance of charity to increase their purity and rise to the astral plane. Umbanda's cosmology distinguishes the spirits of light and the spirits of shadow. The possessing spirits, or guides (caboclos, preto velhos, exus)¹⁰ descend to earth to purify themselves in the form of advice, divinations, purification, protection, cure and justice. Because the guides are trying to purify themselves they do not fit into neat categories of good and evil, but along a moral continuum. In other words, all these spirits can do either good or bad, since what is understood to be black magic by some may be perceived as "white magic" by others. People from all social classes consult Umbanda practitioners in order to solve their everyday problems. This occurs during public rituals of charity, where the individual has the chance to speak directly with the guide. The guide who acts through the body of a trained medium diagnoses the causes of the consultee's complaint, performs immediately some ritual treatments, recommends additional treatments and gives practical advice. These consultations provide the basis for continued participation and are the main source of recruitment of clients to take more active roles in Umbanda, as members or mediums (Brown, 1994; Burdick, 1993).

The typical treatments offered by Umbanda are summarized in Table 16. They can be grossly divided into two main categories: Those which focus on the relationships between individuals and the spirits, and those treatments which only act on the spirits themselves. Although these treatments often intend to heal, frequently the term illness can be applied to personal and social problems other than a biological sickness. Beliefs and ritual practices associated with "illness" vary enormously across Umbanda centres. Camargo (1961) listed the most commonly recognized etiology as follows:

¹⁰ <u>Cablocos</u> (deceased Brazilian Indians), and <u>preto-velhos</u> (deceased old-black slaves) are considered spirits of light while the <u>exu</u> (or the female <u>pombagira</u>) would be spirits of shadow. Yet the <u>exu's</u> identity is a little more complex because it is associated with the image of the marginal black, the trickster or what Brazilians call <u>malandro</u>. Thus, the <u>exu</u> is a subversive guide who often works on the basis of negative reciprocity. Unlike Candomblé, the great African deities (or <u>orixás</u>) no longer descend to visit Umbanda

- (1) Sickness as consequence of religious negligence or ignorance.
- (2) Magical etiology of illness (e.g. <u>coisa feita</u>: a "thing done" by a <u>exu</u> spirit's work of black magic).
- (3) Pertubations provoked by spirits (e.g. encosto: a "leaning" spirit or "obsessing" spirit agitates the person).
- (4) Karmic illness (concept borrowed from Kardecismo).
- (5) Illness resulting from undeveloped mediumship.
- (6) Illness caused by the evil eye (suggested by Pressel, 1974).

Table 16 - Frequent magical/religious therapies employed in Umbanda

(A) Treatment acts on the individual

EXORCISM THERAPIES

- 1- Rituals of <u>desobsessão</u> rituals (medium pulls away the maleficent forces or obsessing spirits which inhabits the person's body)
- 2- <u>Passes.</u> blessings and fumigation (medium pulls off the bad influences from the person.)
- 3- <u>Banhos de descarrego</u> (person takes ritual discharge baths with special plant mixtures.)

ADORCISM THERAPIES

- 1- Development of mediumship (individual learns to control the possession by spiritual entities.)
- 2- Infusion (mixture of special herbs with <u>cachaça</u>, a sugar cane rum).
- 3- Practices of irradiation (transmission of "positive energy" to individuals).
- (B) Treatment acts on spiritual forces: "dispatches" and offerings to spiritual entities (e.g. orixás, preto velho, exu)

Adapted from Montero (1985).

Unlike in Umbanda, in Candomblé the client is not able to communicate directly with the spirits when making a consultation. In Candomblé, consultation is private and made through the oracle: the jogo de búzios (cowrie shells game) played out by the pai or mãe-de-santo (medium leaders). Besides revealing one's own Orixá (spiritual deity), this

centres because they have no need to purify themselves. Thus they send the <u>cablocos</u> and <u>preto velhos</u> as messengers or intermediaries (Burdick, 1993).

consultation provides a "diagnosis" of the problem affecting the consultee's life and prescribes the sacrifices that are necessary to solve it. The most common ritual sacrifices are the <u>ebó</u>, <u>bori</u> and the religious initiation. <u>Ebó</u> is a type of ritual sacrifice that purifies and discharges (descarrego) by transferring the evil that inhabits the person's body to food and sacrificed animals. Bori is the most common form of healing therapy, but it is also used as the first ritual of initiation. After a series of ebós and ritual baths the person has to be secluded in the terreiro (spiritual centre) up to seven days for the bori ceremony, and during this period a series of foods and sacrifices are offered to mark the beginning of the person's alliance with the Orixá. Nowadays in São Paulo bori has become an autonomous rite that can delay initiation indefinitely, since it can be carried out and renewed several times. This also allows more followers to join Candomblé since it gives them more freedom in relation to final conversion completed only after many long, complex, and costly rituals of initiation. Olubajé is a collective ceremony performed annually to enhance the health of the whole community, and is dedicated to Obaluaiê: the Orixá that rules smallpox and other contagious diseases (Gonçalves da Silva, 1995, Teixeira, 1994; Prandi 1991).

Although most religions recognize the possibility to encounter the supernatural through trances or trance like states, they differ in the manners in which the person communicates with spirits. While in Pentecostalism the person is able to enter in direct contact with the Holy Spirit (or God) with no intermediaries, in Umbanda, Candomblé, and Kardecismo the contact with any spirit is usually mediated through another person (the spirit medium). Furthermore, religious knowledge is accessible to anyone who follows Pentecostalism through the study of the Bible, whereas this sacred knowledge is a secret available only to the leaders of Afro-Brazilian religions. Since any participant can bypass the mediation of priests and saints in order to communicate directly with God, this helps them to feel competent to interpret the Bible, preach or become leaders. The prophetic orientation and the egalitarian possibility of revelation to all followers is what best distinguishes Pentecostalism from Afro-Brazilian religions. Among Pentecostal groups the power of the words (read in the Bible) replaces the power of Catholic saints

(or other spiritual beings) and their intermediation in Catholicism (Mariz, 1994a; Prandi, 1991; Lehmann, 1996).

In the different Pentecostal churches, faith healing (or divine healing) is usually accomplished by blessing through the laying-on of hands on the person's head. The pastor and his assistants bless each person after having stimulated the entire congregation through music and impassioned prayer to ask the Holy Spirit to flood the whole place with a current of healing power. This gift of healing through the laying-on of hands sometimes incites the faithful to "become enraptured in the Spirit," the ritualized emotional experience of direct contact with God. 11 In most Pentecostal churches (excluding the Assembly of God) the divine healing power evoked can be directed beyond the walls of the church to afflicted family members or friends who are not present at the service. This also gives continuance to widespread practices of Traditional Catholicism and Umbanda in which the faithful place photographs of the ill, bottles of water, cooking oil, carteira profissional, flour and salt, and pedidos de oração (prayer requests) on the altar to be blessed during the ceremony. 12 Charged with prayer, these objects facilitate the healing of people whom are absent since they function as spiritual conductors. Furthermore, the purity symbolised by water, the purification and anointment by heat, fire or oil are some ritual elements derived from the Judaeo-Christian tradition that are abundantly employed as well (Chesnut, 1997; Lehmann, 1996; Corten, 1995).

Faith healing surpasses glossolalia as the most common gift of the spirit in Brazilian Pentecostalism including the Assembly of God. Besides speaking in tongues and faith healing, revelation is the only other spiritual gift of practical significance to followers of both Assembly of God and God is Love. Prophecy tends to become lumped under this rubric of revelation, but it is essentially women crentes who have the ability to

¹¹ To become enraptured in the Spirit or to be "resting in the Spirit" is a reaction to the laying-on of hands where the individual falls down backwards (with the help of one or two assistants), and remains in the lying down position followed by a deep sensation of psychic and moral well being. Most people have described this experience as one of abandonment, where they lose consciousness of their egocentric self, and submit themselves either to God or the Spirit, having sensations of warmth and of loss of gravity, soon followed by a feeling of happiness and peace (Gondin, 1981 as cited in Corten, 1995).

¹² <u>Pedidos de oração</u> (prayer requests) recalls the ubiquitous Catholic practice of petitioning of saints and the Virgin Mary (Lehmann, 1996).

reveal God's divine messages through their dreams and visions. Since baptism in the Holy Spirit is not as universally experienced as faith healing, those who have not experienced it may have doubts about the vitality of their faith (Chesnut, 1997; Corten, 1995).

Life histories of people who converted to the Assembly of God in North of Brazil narrate a message of faith healing closely related to their condition of poverty. Ultimately people are being healed from the maladies of poverty; illness can be interpreted as having a physical, social or supernatural sense (spiritual illness). Life histories of affliction are often characterised by the intersection of these three illness types, which in turn prepare poor people to accept the Pentecostal message of faith healing. For instance, Brazilian women are usually responsible for the health care of the entire family. Thus, it is not surprising to observe that almost half of the women who converted to Pentecostalism for reason of physical illness have not converted because they have cured themselves, but through the cure of another person, normally a family member. The major reason that impels Brazilian men to convert to Pentecostalism is the desire to be cured from alcoholism. After physical illness, domestic strife is the social illness that most frequently instigates people to convert to Pentecostalism. In this context conversion is also a strategy for bringing peace to one's violent environment (Chesnut, 1997).

The metaphor of illness is only a necessary, but not sufficient condition for conversion to the Assembly of God. The person usually goes through the following steps: a sudden crisis, faith healing and subsequent affiliation with the Pentecostal community. The healing force of the Holy Spirit is more evident in the ecstatic worship (gifts of the Spirit, and baptism in the Holy Spirit) and the mutual aid networks that are created among Pentecostal followers. Pentecostal theology helps to elaborate a moral asceticism and a stark polarity between church/home and world/street that persuades followers to put their faith into practice and renounce the earthly vices (e.g. partying, drinking, gambling, adultery) that often culminate in illness. Furthermore, the experience of healing in most Pentecostal Churches is indelibly linked to the once-and-for-all experience of religious

conversion, while followers of the Afro-Brazilian religions or Kardecismo may undergo any number of cures (without any conversion) (Chesnut, 1997; Burdick, 1993).¹³

There are some rigid codes of behaviour to be followed by the Assembly of God members in order to keep the evil world away while creating a sense of group solidarity and distinctiveness. For instance, followers have to be careful about how they present themselves; women only wear skirts or dresses and waist-length hair, and reinforce this ascetic apparel with no make-up or jewellery. However, God is Love imposes much more rigid rules of withdrawal from community life when compared to the Assembly of God. For example, God is Love's members are not allowed to watch TV; it is considered diabolical but they listen to religious programmes on the radio. In addition, they have to obey many more legalist prohibitions to avoid being punished. But such rigidity of rules reached its limits because lately God is Love has been losing many followers. In contrast to most Pentecostal churches the Universal Kingdom of God Church specifies no interdictions in relation to self-presentation or modes of behaviour (Chesnut, 1997; Campos, 1997; Boyer, 1996; Freston, 1994).

The most popular form of faith healing that emerged with Neo-Pentecostalism (third wave) is the cult of <u>libertação</u> (liberation or exorcism) that occurs in the Universal Kingdom of God Church. Here the rituals differ from other Pentecostal churches because the pastors always evoke and provoke the evil personified in the figure of the Devil to manifest itself; therefore the act of exorcism is not only a possibility, but an

¹³ For example, Mariz (1992) posits that the ascetic behaviour of Pentecostals stimulates them to avoid the consumption of alcoholic beverages, which can consume up to 30% of the household budget of poor families.

Some examples of God is Love's legalist rules are: children above 7 years cannot play ball games, men cannot wear red colours, women cannot take contraceptives nor wear high heels. Furthermore, people are separated by gender while attending any church meeting. Punishment is severe and frequently related to a suspension of privileges as a church member. For example, the person who masturbates will be temporarily dismissed from church for a whole year, if she is married for two years, and if she is obreira (pastor's assistant) for three years (Freston, 1994).

The word <u>libertação</u> has double meaning. On one hand there is the 'liberation' of individuals from the Devils possessing them. On the other hand, there is the 'liberation' of the evil spirit within the individual from the body that in some sense imprisons it (Lehmann, 1996:139).

obligation. In this context, participants do not make much distinction between exorcism and the gift of healing through laying-on of hands, the ritual gesture that incites the manifestation of the Devil. Since collective exorcism precedes the conversion ritual (through baptism in the Holy Spirit), it becomes the starting point for a healthful life. Although the cult is divided in three parts – laudation, exorcism and consecration of offerings – the fight against the Devils occupies a significant part of the whole liturgy (Campos, 1997; Corten, 1995).

More recently, some Brazilian authors like Oliva (1997) and Campos (1997) have analyzed the ritual of exorcism as it is performed in the Universal Kingdom of God Church through the perspective of René Girard's (1996, 1977) mimetic theory which relates violence with the sacred. From that perspective the person who is being exorcized personifies and manifests symbolically all the violence of everyday life. The Devil is thus considered the symbolic scapegoat and origin of all evil. The Devil also represents the bad violence projected outside the person, while the good violence (or the blessed sacred) is the unanimous violence the audience discharges over the person who is being exorcised (or the sacrificial victim). It seems like a symbolic lynching in which the Devil is blamed, vituperated, trampled upon, punished, ridiculed, and finally expelled. But the target of so much collective rage is not the victim because the ritual of exorcism only rejects the invisible entity that has been possessing the person's body. The catharsis created by this ritual of exorcism (or sacrifice) ends up bringing a sense of relief, peace, and happiness to all participants (including the exorcized victims). This process has to be

¹⁶ Although there is a difference between the "demonic force" that possesses (or 'rides') the person, the acts of exorcism, and the receipt of the Holy Spirit as a gift (e.g. glossolalia, " resting in the spirit"), one might consider them as separate moments within the same ritual. Goodman (1988, 1972) suggests that what physically happens to the individual who "speaks in tongues" or expresses "possession by the demon" is very similar and corresponds to an universal state of ecstasy, or ecstatic experience.

¹⁷ In sum, René Girard presupposes that interdictions, rituals and myths are the foundation of religion (and of human culture) because they have the function of controlling the essential violence. The evolution of this mimetic scapegoat theory has three different phases. First, human beings are mimetic or acquisitively imitational creatures. This will potentially bring people into conflict, even violence, because they might be competing for the same objects of desire that they have learned or imitated from each other. The second moment is the scapegoat mechanism because the oldest way of being released from the (potential) violence that mimesis produces is through non-conscious convergence upon a victim. Third, the Bible discloses the hidden scapegoat mechanism of human cultures (Girard, 1996).

repeated indefinitely because the Devil survives every one of its victims and will soon reappear by possessing somebody else (or the same victim). For this reason the ritual may bring relief, although it does not heal. In addition, the victim surrenders in two different moments: through exorcism and during the collection of the <u>dízimo</u> (tithe) or spontaneous offerings.¹⁸

The temples of Universal Kingdom of God Church are often seen as convenience-churches or spiritual emergency rooms because according to the propaganda there are always a pastor and a miracle just waiting for you. Furthermore, the rituals are performed within a weekly sequence of correntes (or circles) and seasonal campanhas de fé (faith campaigns): every miracle, religious conversion or exorcism represents one more victory of God over the diabolic forces. Correntes are organized around a weekly cycle, where each day corresponds to the discussion of a particular topic: the prosperity or entrepreneurs (Monday), health (Tuesday), Holy Spirit (Wednesday), family (Thursday), evil spirits or libertação (Friday), youth (Saturday), and love (Sunday). Although Fridays are especially dedicated to exorcism, expelling evil spirits may also be performed any other day. Followers are persuaded to attend one specific corrente once a week for a fixed period, let's say seven weeks - this also resembles a Catholic novena - to fulfil a vowel or achieve a goal, or simply to devote themselves to their own salvation. Campanhas de fé explore one major topic for several consecutive days, for example the campanha de Israel.

A major element of Neo-Pentecostal rituals is the <u>desafio</u> (defiance or duel) the faithful makes towards God. This defiance has to be spoken out with great determination

Still following Girard's theory (1996) the basic function of religion is to maintain social peace, and this is achieved through sacrifices because it solves the essential violence. This essential violence is generated through people's frustrated mimetic desires. Furthermore, the sacrificial ritual expels the violence away from the group while transforming it into sacred influence (or good violence). Thus the sacrifice propitiates the sacred because it keeps away the bad while attracting the good influences.

¹⁹ In the <u>campanha de Israel</u> people write down their <u>pedidos de oração</u> (prayer requests) in special blank forms that will be burned in a "saint camp fire" and the ashes will be taken to Israel to be thrown away in places of strong emotional identification with Christian life after the bishops have prayed over them (Campos, 1997).

and faith followed by monetary offerings or the <u>dízimo</u>. In addition, the notion that "who gives, receives back" completes this defiance because God then becomes indebted in function of the offerings (monetary sacrifices) made by the faithful. In other words, the follower needs to put his faith into action (defiance) by making an alliance with God (offerings). This is called theology of prosperity that holds that as partners of God or the financial supporters of divine works, the faithful are destined to become wealthy, healthy, happy and victorious in all their endeavours. The relationship with God is marked by the conviction that it is a good investment. This theological tendency clearly negates the typical asceticism of Pentecostalism and has tarnished the public image of many Universal Kingdom of God Church participants. Nevertheless, to consider the <u>dízimo</u> exclusively as a matter of financial exploitation promoted by Neo-Pentecostal Churches is to lose sight of the mechanics of popular religiosity in Brazil. Material investment in the sacred, whether in Umbanda, Catholicism or Pentecostalism is a routine part of the religion of the poor (Campos, 1997; Chesnut, 1997; Lehmann, 1996; Mariano, 1996b; Almeida, 1996).

Very much like the Universal Kingdom Church, the God is Love Church emphasizes the significance of the <u>dizimo</u> and practices particular forms of <u>correntes</u> where the person fasts and goes to church for seven consecutive Saturdays (or Tuesdays, etc.) in order to solve some problem (e.g. quitting a vice, getting a job). The Assembly of God is not systematically organized around <u>correntes</u> as the Universal Kingdom of God Church. However it provides regular study and prayer sessions as well as the monthly <u>Santa Ceia</u> (Last Supper). ²² I have also observed through fieldwork that <u>crentes</u> from

²⁰ According to the Universal Kingdom Church of God's founder bishop Macedo, this alliance with God means that everything that belongs to ourselves (our lives, strength and money) starts belonging to God, and what are God's belongings (blessings, peace, happiness) begins to belong to ourselves. Furthermore, "God never looks at the amount (of money) that people bring in their hands, but in what is still left in their pockets" (Macedo, 1990:106, as cited in Campos, 1997).

²¹ For example, for a short period in 1992, Bishop Macedo was arrested after being accused of swindling, shamanism, charlatanism, scorn of religions, and supposed involvement with drug traffic. He has been liberated from most judicial processes due to the intervention of important politicians whom are also linked with this church (Almeida, 1996).

The <u>santa ceia</u> is also celebrated in other Pentecostal Churches like the Universal Kingdom Church of God and the God is Love. The rigidity of the latter also appears here because God is Love members have to

several Pentecostal churches (except from Universal Kingdom of God Church) promote a whole series of <u>campanhas de oração</u> as another form of faith healing. Often the relatives, neighbours, or friends who follow Pentecostalism come several times to the person's home to sing and pray for the <u>libertação</u> (or healing) of the person, for example during seven different occasions. The person who is the target of these prayers does not have to be present, or to have any participation in these small and home based prayer circles (Lehmann, 1996; Freston, 1994).

Prayer groups inside the church (or person's home) and seasonal circles (religious gatherings in big spaces like soccer stadiums) are common rituals in Charismatic Catholicism Renewal; they may include sessions of faith healing. However healing also takes place during meetings and masses carried out with this main objective. Repentance is usually the first step of the prayer while the group recites the rosary. Sometimes, contrition is guided by a leader who asks the participants why they are there and what are the life transformations that the Holy Spirit might provide them. This brief questioning is followed by a prayer of gratitude and laudation to the Holy Spirit who brought the participants to gather together. Nothing is said or done without making immediate reference to the Holy Spirit or Jesus; this always has a strong emotional tone just as in Pentecostalism. After this meditation, a long period of intense singing worship and laudation hymns replaces the silence of the prayer. This moment of effusive happiness is followed by the sadness of the confession period. It is followed by the interpretation of a biblical text, and more singing. At the end of the ceremony some people give their testemunho (conversion testimonial) about the changes the Holy Spirit brought to their lives, as in most Pentecostal Churches. The testemunho is celebrated by all participants who sing and praise the Holy Spirit in order to reaffirm their personal faith (Prandi, 1997).

Prayers, blessings, and faith are common healing actions practised in Traditional (or Popular) Catholicism as well. I want to emphasize however the underlying logic of

prove that they are up to date with their tithe records as a condition for taking part in the santa ceia (Lehmann, 1996)

promessa (vow), pilgrimages and the working of miracles in relation to healing. The promessa illustrates the strong exchange that exists between the devotee and the Catholic saints. When a person's wish is accomplished, such as the cure of a sick son, he or she has to express gratitude in a ritual act of sacrifice, normally a procession or pilgrimage. The vow is often considered a miracle, particularly after its accomplishment. Actually, supplicants believe that saints grant miracles not in exchange for the promised deed, but as a reward for the good will, suffering and patience that have preceded it. Belief in miracles can be interpreted as symmetrical and opposite to belief in sorcery, witchcraft, and coisa-feita.²³ Belief in miracles serves to explain the resolution of negative events that break up the continuity of everyday life (e.g. a sick son). Similar to witchcraft, the explanation for the miracle is sought in past events and refers to a moral system. By contrast, the magic spells or coisa-feita are employed to explain the bad outcome of events like an illness, accident, death, and so forth. Besides being a moral explanation, the sorcery (coisa-feita) is also associated with the existence of a conflict involving the person who has suffered. Both sets of beliefs deny the possibility of life events happening at random because they call to past actions for justifying the present situation. In addition, most people believe in the idea of destiny (Chesnut, 1997; Burdick, 1993; Zaluar, 1980).

At another level of comparison, the <u>coisa-feita</u> or <u>mal-feito</u> is opposed to <u>mal de Deus</u> (God's evil). God's evil is perceived as a kind of <u>castigo divino</u> (divine punishment) because all the evil that afflicts people is interpreted as due to the suffering the person still has to go through during this life world. Even if people believe that suffering is inherent to the human condition, the person is also responsible for his or her actions; suffering can be a probation for those people who have committed bad actions during their life. In Traditional Catholicism however, the notion of divine punishment is used more frequently in relation with the non-fulfillment of the individual's obligations towards the saint, or due to a breach in the relations of reciprocity between the saint and the individual (Zaluar, 1980).

²³ I agree with the position of several authors who prefer to make no distinction between witchcraft and sorcery since the greatest concern is the witch's malificence and not the ways the action was put forward. See for instance Thomas, 1997; Souza, 1986; Pocock, 1985; Brumana & Martinez, 1989.

Notions of Evil

God's evil, evil spirits, God and the Devil, good and evil. Different religions are also defined through their representations of evil. These concepts of evil may shift from absolutist to relativist perspectives. Defilement, guilt and sin are just some of the various ways in which evil can be experienced, symbolized and judged.²⁴ Some differences between Catholic and Protestant views illustrate some unresolved mystery associated with the necessity of evil that no religion has yet solved. Each religious worldview seems to have a distinctive approach to the necessity of evil (Parkin, 1985; Taylor, 1985).

Catholicism tends to be ambivalent with the regard to the necessity of evil. Sin is conceived as an expression of evil and one must distinguish between Original Sin and the sins committed by individuals.²⁵ Evil conceived as Original Sin or impurity is judged inherent to the human condition because everyone is born with this stain (defilement). Only baptism viewed as a purification ritual can wash it away. When evil represents breaching one's relationship with God, this evil is not conceived as inevitable. One can always turn back and ask for the grace of God, for instance during the Catholic Mass. In addition, confession and the recitation of prayers (Sacrament of Penance) are available to enable the person who sinned to restore his or her relationship with God. Confessions and penance are important because the forgiveness of sins does not remove the guilt attached to some offence.

In addition to dealing with a whole series of spiritual beings, including the evil, Catholicism acknowledges the evil through the doctrine of Original Sin and the practice of confession. By contrast, as a result of the Reformation, Protestantism has removed the

Ricoeur (1969) created an evolutionary typology of evil and showed how it moves away from a symbolism of defilement towards a symbolism of sin. The movement starts when man experiences communal sin and it progresses to individual guilt. In the first phase man is burdened with fault or defilement, while in the other man suffers guilt as the author of sinful deeds. Other authors have argued that defilement, guilt and sin are indeed basic forms for experiencing the evil cross-culturally, as long as the notion of evolutionary typology is left aside. See for instance Birman, 1997; Taylor, 1985; and Overing, 1985.

²⁵ Original Sin corresponds to the breach in the relationship between Adam and God as told in the myth of Genesis (Taylor, 1985).

invocation to saints, angels and spiritual beings. Protestantism eliminates the Catholic idea that all beings are situated hierarchically on a chain between the Supreme Being (God) and the most inferior beings in the realm of matter. According to Protestantism, God and men are related directly to each other and not by a "chain" of different spiritual beings; their relationship builds exclusively on God's grace and man's faith.

Protestantism rejects the doctrine of Original Sin. People sin because all creatures are imperfect and it is in their nature to sin. Thus baptism is not so important as a purification ritual. Protestantism emphasizes the idea that baptism as a confessional ritual confirms the person's decision to renounce the Devil and commit him or herself to Jesus Christ as his saviour. Several Protestant Churches insist upon adult baptism, since only adults have the ability to make a confession. Confession is both the acceptance that one is a sinner and the declaration of commitment to Christ. Through baptism, the person is placed in the right relationship with God, despite being a sinner. No institutional place is usually provided for confession since the sins have to be confessed individually in the relationship between the sinner and God. In some Protestant sects, people publicly known to have sinned are expelled from the religious community because sin is not allowed inside the congregation. The world is often perceived as separated in two parts: the world of sinners outside the congregation and the world of non-sinners (saints) who remain inside. Protestantism recognizes that sin is necessary because of the human condition, but that it can be avoided if the person strongly keeps her faith in God (Taylor, 1985).

Although still insignificant in the Old Testament, the Devil became very important after having been elevated by later Judaism and Christianity to the position of God's grand cosmic antagonist. The Devil then became an omnipresent force, always

²⁶ This is also called the "Great Chain of Being," a pre-Enlightenment concept which provides a static view of the universe. There is a specific place on the chain reserved for each type of being. For instance, man is placed between the angels and the animals because he is considered part spiritual and part physical. The Devil is placed as a rogue angel who keeps wandering between angels and human beings and entices men to sin. As a sinner the human being becomes a witch and practices witchcraft on behalf of the Devil upon the innocent (Taylor, 1985).

ready to tempt men into paths of evil. The Protestant Reformation only strengthened this idea of the Devil's personified reality and immediacy; in addition, the inevitability of human sin produces a sense of powerlessness in the face of evil. The Protestant emphasis on the single supremacy of God in contrast to the Catholic idea of a graded hierarchy of spiritual powers slowly dissolved the belief of a world full of spirits by entrusting all supernatural acts to a single source. The notions of God and Devil reflect a Manichaean vision of reality. At the same time the victory of monotheism is required to explain why evil exists in the world if God was good. One can say that the Devil helps to sustain the existence of an all-perfect God (Thomas, 1997).

Historically, in Brazil the Devil never possessed the omnipotent presence attributed to it in the old European Protestantism, except under the circumstances of colonial catechizing when the Catholic Jesuits terrified the Native People by creating an intolerable image of the Devil. During this period the Natives were so terrified by the image of Devil that many of them preferred to die, rather than be converted to Catholicism. Nevertheless what has reigned over everyday life ever since are notions of Heaven and Hell, sacred and profane, Native, Black, and European magical/religious practices that may sometimes converge, while at other times they are kept apart. The dynamic reality of everyday life in colonial Brazil is more characterized by fluidity than by rigid dichotomies. This is expressed by the old popular saying: "If somebody lights up a candle to God, another candle has to be lit for the Devil." One could say that the Brazilian Devil has lost most of the lasciviousness, arrogance and aggressiveness found in its European counterpart. The Brazilian Devil may have different shapes and figures in the same proportion that multiple forms of diabolic action are possible until today (Souza, 1986; Oliva, 1997).²⁷

More recently, the significance of the Devil's figure has radically changed, particularly under the influence of Neo-Pentecostalism; it has become the absolute

²⁷ The different characters that may be assumed is illustrated through the 96 different terms found in the "Aurélio" Dictionary to define the Devil: diabo, demônio, Satanás, Lúcifer, espírito maligno, espírito das trevas, capeta, exu, coisa-má, coisa-ruim, and so forth. Most terms however describe the Devil with disdain (Oliva, 1997).

incarnation of "all evil that exists in the world." According to Zaluar (1997), the undeniable growth of the Devil's importance is associated with the recent increase in violence, crime and poverty in urban Brazil. She suggests that such precarious life conditions generate extreme experiences of fear and terror that have stimulated the urban poor to perceive their life worlds only in absolute terms. Neo-Pentecostalism is the religion that puts most emphasis on this strong evil image of the Devil. According to Sanchis (1994), this is accomplished through the development of a "polycentric discourse on evil" in the sense that a whole series of spiritual beings now become identified exclusively with the Devil, particularly those entities originating in the Afro-Brazilian religions. This commands a "Theology of Spiritual War" which corresponds to the insistence on the necessity to fight Afro-Brazilian religions through Neo-Pentecostal preaching and its curative practices. Events perceived as evil are not considered extraordinary or inexplicable, they are immediately associated with witchcraft (ruled by the Devil) or with the insoluble antagonism between God and Devil. In this sense the evil (Devil) becomes omnipresent and banal; it is considered the source of most events that disturb everyday life, like illness, fights, unemployment, alcoholism, divorce, financial problems, etc. (Birman, 1997; Mariz, 1997, Soares 1993)

There are several ways in which the Devil can affect a person. One of them is demonic possession, which according to Bishop Macedo can be caused by: heredity, direct or indirect participation in Afro-Brazilian religions and Kardecismo, Devil's wickedness, involvement with people that practice any Spiritual religion, sacrificed food, and by rejecting Christ. Most of the time demonic possession happens without the person's knowledge or consent. Macedo also gives a list of ten symptoms that indicate the presence of the Devil: nervousness, headache, insomnia, fear, faint of attack, desire of suicide, illness of which physicians ignore the cause, visions and hearing voices, vices and depression (Macedo, 1990, as cited in Mariz, 1997). It is important to notice that

²⁸ Since the accusations of "diabolical" made towards other religions integrates the "Theology of Spiritual War" which is found in other Neo-Pentecostal Churches around the world, this is not an original creation of Brazilian Neo-Pentecostalism (Mariz, 1997; Campos, 1997).

some of the symptoms associated with demonic possession can also be found in people who are suffering a psychotic episode.

This "polycentric discourse on evil" nurtured by Neo-Pentecostalism is quite distinct from the syncretic religious practices that usually permeate popular Catholicism. For instance, the Catholic Church has always tolerated their followers worshipping saints and spirits; its relationship to evil is ambiguous and it allows some room for the action of witchcraft.²⁹ While Neo-Pentecostalism reinforces a Manichaean morality separating good from evil, the notions of good and evil are more ambiguous and overlapping in Traditional Catholicism.

In a way similar to Traditional Catholicism, Afro-Brazilian religions conceive of a diversity of origins for the evil. The Devil is not perceived as the only source of evil, and does not embody the absolute evil. While the Pentecostal world view is based on a rigid opposition between good and evil, each one corresponding to discontinuous and irreconcilable levels of reality. Candomblé and Umbanda, conceive good and evil as situational and relative realities. For example, exu may be either good or evil, depending on the circumstances. The world is viewed as one continuous flux of exchanges where the adept needs to maintain a favourable balance between received benefits and its repayment. A constant effort to make and maintain alliances is fundamental to guarantee one's advantageous position. Kardecismo differs from the other religions because it creates an opposition between good and evil according to an evolutionary perspective: following a continuous evolutionary line, the evil corresponds to lower levels of existence. Access to sacred power happens through personal development (Rabelo, 1993).

Table 17 at the end of this chapter summarizes what has been described for each religion as the generic and social origins of evil, the types of agents more likely to be accused, and the magical/religious healing offered.

Popock (1985) indicates some basic characteristics of "witchcraft" found in several cultures: "Understandable malice is related to jealousy (the desire to preserve) and envy (the desire to possess). [...] The relation between jealousy and envy in cultures where misfortune is preferably explained by human malice explains how it comes about that some misfortunes – indeed, the greater part of them – are regarded as understandable, which is not to say that they are forgivable" (1985: 44-45).

The few recent studies that compare the religious experience in different religions actually focus on people who have already consolidated their belonging to specific religions (e.g. Mariz 1994a, Burdick 1993). Such a focus on people well integrated within a particular religious tradition, leads to the disregarding of the experience of people whom only have a marginal religious participation. One could suspect that religious experience is not necessarily coherent or homogeneous. A comparison among people from different religions tends to underestimate the fluid and paradoxical aspects of one's religious experience. I would argue that the recent phenomenon of widespread religious migration is still poorly understood. Data that will be presented in the next chapter suggest that the process of migration and conversion to another religion might be more complex, fuzzy, and full of back-and-forth movements than what has been described in the literature. Furthermore, contemporary studies that touch on the issue of religious healing (Chesnut 1997, Teixeira, 1994, Montero 1985, Loyola 1984) are not very specific. These studies primarily valorize the importance of "healing" in several religions, but it is not very clear what kind of "illness" is being healed.

The next two chapters focus on the religious experience of people who suffer a first psychotic episode and their families. They examine the ways people confronted by such an extreme experience of psychosis, personally or through a relative, move within the religious field, and whether and how they appropriate it in their quest for healing. Such data do not allow the interpretation of broader social and symbolic processes that characterize the religious arena in São Paulo city and its transformation. These chapters rather aim at exploring in detail the interactions between religious experience and psychosis. However these data contribute to undermine the idea that religious experience is a coherent and unidirectional phenomenon.

Table 17- Generic and social origins of evil in relation to agents mostly accused, and magical/religious healing

RELIGIOUS GROUP	GENERIC ORIGIN OF EVIL	SOCIAL ORIGIN OF EVIL	GROUPS OR AGENTS	MAGICAL/RELIGIOUS
			MOSTLY ACCUSED	HEALING OF EVIL
"Official" Catholicism	God (as a test of faith to the	Supernatural or ethical: it is	There are no specific	Religious conversion of
(O.C.)	faithful)	either produced by a supernatural	accusations because	the person; faith; prayers;
	Devil and his emissaries	agent, or by sins of the faithful	terrestrial powers over evil	Catholic exorcism;
			are not recognised	priest's blessings,
m the town	C.I. D. IV. O.C.	S and add diff of	NA	sacraments
Traditional or Popular	God or Devil (as O.C.)	Supernatural or ethical (like O.C);	Macumbeiros, Umbanda,	Religious conversion, faith, prayers, blessings,
Catholicism (T.C.)	Wandering or death souls, sub-natural beings and entities	Catholic agents, specially the malignant mediums.	Candomblé, other domestic agents of evil, sorcery,	Catholic healing, resources
(1.0.)	from Afro-Brazilian cults.	manghant meaturns.	envious people with power	from beneficent mediums.
Protestantism	God or Devil (like O.C), but	Supernatural or ethical (like O.C);	There are no accusations	Like O.C., but
	giving more emphasis to issue	no social possibility for someone		emphasising ethical
	of faith.	being evil's agent		conversion and
				transformation of person,
				exorcism, blessings
Pentecostalism	God or Devil (like O.C)	Supernatural or ethical (like O.C);	Macumbeiros, Umbanda,	Conversion, prayers, faith,
	Any malignant force is	malignant spirits of T.C.,	Candomblé, sorcery, agents	divine healing, Neo-
	identified and an effect of the	Kardecismo, and specially from	identified or working for the	Pentecostal exorcisms,
	Devil	Afro- Brazilian cults	Devil	miracle blessings, spiritual
., .				treatments.
Kardecismo	spirits of shadow, encosto,	Supernatural: the spirits	Umbanda, Candomblé,	Desobsessão, passes given
	spirits of dead people (e.g.	themselves, malignant spirits, also	domestic agents of	by mediums, spiritual
	relatives)	from other possession cults.	malignant possession	healing, development of mediumship.
				i mediumsinp.
Umbanda and	Orixás, deities and	Supernatural: spiritual beings,	Black-magic, malignant	Fight among Orixás, des-
Candomblé	supernatural beings, guias,	other Umbanda and Candomblé	domestic sorcerers ("the	incorporation of malignant
	several types of (malignant	centres, domestic agents	left-side")	spirits, dispatches.
	spirits		,	

Source: Brandão (1986)

Chapter 7 - Religious Pathways in Help-Seeking

Wait for God in your battles when with evil you struggle with. Trust God He is faithful. God is the sustenance of my life. God the consolation during all life. God invites you to rest with Him. Oh, my soul have faith in God. Why my soul is afflicted? God consoles you, remain trustful. Only Him protects and sanctifies. Rely on Him that He is faithful. Rigour and grace is only God who concedes. Remain confessed and ask Him. Jesus the just will intercede for you, Yes my soul to the faithful God (Pentecostal hymn recited by Claudia; my translation)

Personal and Family Significance of Religion

Claudia's story

During the time Claudia was suffering her first psychotic episode she started, under the influence of her boyfriend, to regularly attend a Pentecostal Church. For a short while she appreciated the ambiance of the church. She told me that church followers were very tolerant with her since they would not be bothered by her walking restlessly inside the church, or that on one occasion she suddenly interfered with a baptism ritual in order to be baptized herself. Claudia loved to sing the hymn quoted above every time she went to church. She would call for this hymn over and over again for everyone to sing it together: "Why is my soul afflicted?" I have the impression that this hymn encapsulates through its

religious idioms (evil, God, soul) some of the feelings that Claudia was experiencing during her crisis. She was also very pleased to hear me when I accepted to recite this hymn to her in our first encounter. Later that same day in her home, she abruptly put her veil over my head to see if I would look beautiful dressed in the veil that she wore in church and during her nightly prayers. The bible (a gift from her boyfriend), the veil, and the recitation of religious hymns were powerful elements that composed my first encounter with Claudia, much more than what she has ever told me through words.

For all the people interviewed in this study religion is normally lived as a family matter. The initial religious option of each person is strongly framed by the family's previous religious background, more frequently by the mother's; thus it is rarely experienced as a matter of individual choice. In seven of the families when the father is still present, he seems to expect the mother to be in charge of the religious life of the whole family; fathers therefore do not participate very much. Table 18 shows the religious affiliation that predominated in each family before the outbreak of the psychotic episode.

Table 18 - Dominant religious affiliation of each family (mother)				
CATHOLICISM (10)	8	Traditional Catholics		
		(3 non-practicing; 3 Umbanda sympathizers)		
	1	Charismatic Catholic		
	1	Orthodox Catholic		
PROTESTANTISM (11)		Historical Protestantism (4)		
	2	7 th Day Adventists		
	I	Methodist		
	1	Baptist		
		Pentecostalism (7)		
	3	Assembly of God		
	2	Universal Kingdom of God Church		
	1	God is Love		
	1	Other Pentecostal Churches		

Although this affiliation sets the initial religious background for each family, it tells very little about the meanings of religion in people's lives. This is particularly evident in those families who have Catholicism as the dominant religious background. Families who consider themselves non-practicing Catholics are not as much engaged in religious life as the others. Their religious experience is not "internalized" (Camargo, 1973) in the same way that those Catholics who orient their lives by religion. Catholic families are also more receptive to participate simultaneously in other religious milieus, for instance Umbanda, Kardecismo, and even Pentecostalism. In the case of Protestantism the families often participate more in the everyday religious life of their own congregations. But this does not imply that they restrict themselves to their own church, or that they would not try out other religious options in situations of deep crisis. Such a fluidity of boundaries between the different religious domains is further cross-cut by a common ground of shared elements already mentioned in the previous chapter: spiritual healing, belief in sorcery and witchcraft, and moral definitions of good and evil.

Table 19- Levels of religious participation before and after psychosis

	Level of	BEFORE F	SYCHOSIS	AFTER PSYCHOSIS	
	Participation	Person	Mother*	Person	Mother*
10 young	Active	2	7	8	8
males	Not active	8	2	2	1
11 young	Active	6	6	9	8
females	Not Active	5	4	2	2

^{*} Information for the mother of 1 young female and 1 young male is unknown.

Although people may change their original religious background, the notion of religious affiliation remains insufficient to understand how religion affects everyday life for two major reasons:

- (1) People often have different levels of religious participation over time.
- (2) People make use of a variety of religious signifiers independently of active religious participation or affiliation.

Table 19 gives a rough picture of the level of religious participation presented by the young people in comparison to their mothers before and after the outbreak of the psychotic episode. It becomes clear that women (mothers or their daughters) are usually more actively involved in collective religious activities than the young males. In addition, most people become more involved after the outbreak of the psychotic episode. Nevertheless, even if some people are not actively involved this does not exclude that they may also use religious signifiers, which then constitutes their basic religious experience.

I decided to include the religious affiliation beside the name of each patient or family member's narrative in order to situate the reader regarding the most significant religious background of the person during the outbreak of psychosis. For instance, Alice's original religious background is Orthodox Catholic, however it was the Universal Kingdom of God Church that affected her the most during the outbreak of psychosis. In those cases in which the person tried several religious pathways to help without giving pre-eminence to one of them, I maintained their original religious affiliation. For instance, Jonas was involved with Regression to Past lives, Umbanda, Neo-Pentecostal healing practices, Reiki, etc., although he was raised in a Methodist environment. The decision to include the religious affiliation does not mean that it plays a major role in most of the areas examined. This remains an empirical question to be investigated.

Claudia's story

To continue with Claudia's story: like her mother, Claudia never showed much interest in participating in any kind of religious activity until the time she became ill. The family's original religious affiliation is Traditional Catholicism. Claudia's mother sympathized with Umbanda since the time her own mother (Claudia's grandmother) began to go to Umbanda centres, even though she was not an adept herself. During the outbreak of Claudia's psychotic episode her mother's first initiative after going to the psychiatric emergency was to take her daughter to an

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¹ According to Negrão (1996) most spiritual leaders from Umbanda centres also perceive themselves as fundamentally being Catholics.

Umbanda centre. In addition the mother also took Claudia to consult a card reader, and to participate in some Kardecismo sessions. Claudia's mother declared repeatedly to me that only God (independently of any religious background) was empowered to solve her daughter's problem. However Claudia explained her sudden religious participation because "everyone has to have a religion." Since Claudia's boyfriend belonged to a Pentecostal Church he told Claudia's mother that if Claudia started attending his church, she could possibly be healed. Although Claudia's mother believed she had no vocation to become a <u>crente</u> herself, she easily accepted her daughter going to the Pentecostal Church with her boyfriend. For some months Claudia attended the Pentecostal Church together with her boyfriend because "I like to go," and during this period she believed that "I was born to be crente." She also began to learn how to play the church's organ because she imagined that this would be one of her mother's dreams. Even though Claudia herself suddenly joined a collective Pentecostal baptism ceremony, she did not feel this baptism healed her. However she acknowledged that her mother (and boyfriend) took her to "every place, even macumba: she has already done everything for me to heal."

Dora's story

Dora was brought up in a Protestant household. With the exception of her father, everyone in the family adopted the Seventh Day Adventist Church several years previously when they lived in Northeast Brazil. Dora's mother explained that she raised her kids in this religious environment since in the neighborhood where they lived, people who attended the Seventh Day Adventist Congregation were "better off in life" than her own family. She also wanted her children to have more contact with this religious milieu for them to follow the examples of these "good people." Dora's mother considers herself a very religious woman and she

never fails to go to church, especially on Saturdays, when the Adventists dedicate the whole day to God and spirituality. Dora's mother believes that this life is no longer of use because the Judgement will soon arrive; therefore only God is able to bring salvation² to those who follow His words and have been completing His work. Since everyone's destiny is under God's hands, He is the one who always "opens [or closes] the doors" to people's lives. Like many other people who participated in this study, Dora's mother unconditional trust and faith in God is strengthened by the belief that "God is only one," regardless of the person's original religious background. This probably enabled her to seek help in different churches, more specifically in several Pentecostal churches, during her daughter's psychotic episode. This peregrination through different Pentecostal churches was also nurtured by the crentes' explanation that her daughter was sick because some espírito maligno (malignant spirit) was disturbing her. Even though Dora's mother gave preference to Pentecostal forms of healing, she also tried to give several "discharge baths" to Dora with special infusions of plants mixture prepared in bottles (garrafadas).

Since childhood, Dora had enjoyed going to the Seventh Day Adventist Church and for many years she was educated in the church's school. After finishing High School she migrated to São Paulo in search of better job opportunities. There she continued to remain involved in that religion and her closer circle of friends were Seventh Day Adventists. Almost a year before Dora's family realized that she was going through a psychotic episode, she made a trip back to Northeast Brazil to visit her parents. Her mother still lived there and only migrated to São Paulo some months later when she decided to separate from Dora's father. During

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² The notions of Judgement Day and salvation are crucial to Seventh Day Adventists all over the world, however they do not receive as much emphasis in the Brazilian Pentecostal Churches (Oliveira Filho, 1972; Pierucci & Prandi, 1996).

Discharge baths (with water, herbs and/or salt) is a very common practice in Umbanda to protect and cleanse the soul and body of the person. This protection is often reinforced by Catholic prayers and by lighting candles to different orixas, and to the person's guardian angel (Brumana & Martinez, 1989).

Dora's trip to Northeast Brazil her mother was astonished to observe that her daughter had suddenly become very religious. She spent most of her vacation walking in and out of churches carrying a bible to tell everyone that Jesus was coming because the Judgement Day had arrived. She was so excited and joyful with this fact that she distributed all her belongings to needy people, which her mother saw as an act of benevolence. After returning to São Paulo, Dora slowly began to feel very frightened and persecuted and eventually ended up avoiding the Seventh Day Adventist Church altogether. However she remained to some extent committed to this church and always felt like going home the few times her mother managed to take her inside any Pentecostal church: "This is not my church, I am an Adventist." After Dora was discharged from the psychiatric hospital, she stayed for two weeks in one Adventist spiritual retreat located in the country with the intention of cleansing herself from the anti-psychotic drugs taken in the hospital. During this retreat she ate only natural food as a means of pursuing a healthier life style.

More broadly, the stories of Claudia (Catholic background), and Dora (Protestant background) exemplify that long before the psychotic episode religion already played a significant role in the life of their families and that this role is only intensified with the outbreak of psychosis. Families with a Catholic background are more readily open to try out a diversity of religious help-seeking options than are Protestant families. Nevertheless, most Protestant families also looked for religious sources of help outside their own church congregation, even though they gave precedence to Pentecostal churches. Although religious affiliation is the first factor to influence the direction of religious help-seeking trajectories, it is not the only factor. Claudia's mother's first initiative was to take her daughter to an Umbanda centre because she was already a Umbanda sympathizer. Claudia felt particularly uncomfortable with the Umbanda rituals, especially when popcorn was thrown all over her body. Thus, both of them abandoned Umbanda and started trying out other religious options. Dora's mother easily accepted

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that her daughter try some alternative religious sources of help outside the Seventh Day Adventist Congregation.

The role played by religion is itself multi-layered expanding in several directions in people's lives. According to the mothers, religious beliefs and practices provide them and their families with a new space of moralization, reinforce social links and help to tolerate human suffering.

Some mothers purposefully raise their children in a religious milieu with the hope of imbuing them with good values and a morale that would prevent them from choosing the dangerous side of street life:

I was very afraid that they [children] would get involved with bad company [in the street] and this and that so I raised them inside the church. [Jonas's Mother, Methodist]

Many years ago it was very different - the ways of behaving in this world, because nowadays it is just too much! To raise children today is not easy - no. Ten years ago, my sons were very innocent compared with all the knowledge there is today, everything is very advanced. [...] Today you see a 15 year old boy and what he will not do? Even a father he becomes. Ten years ago a young boy was not like that. He was more withdrawn and lived more inwardly. They didn't have what they have today: the knowledge, that everything is liberated in schools, they use... My sons were raised since they were small in a Christian home; they were raised in church because my husband was evangélico, they were accustomed to church, with Sunday school [...] I have been evangélica for many years now. [Mateus's mother, Universal Kingdom of God Church]

Mothers also report having found moralization and reinforcement of values for themselves. Religion always teaches them some rules of good living that enables them to change themselves, and to re-organize their own family life:

I suddenly felt like going [to church]. I wanted to be a <u>crente</u> myself... After I went [to church] I separated from his father because of all the fights, and the drinking, and betrayals [...] A lot has changed in my life, a lot has changed. Now I have a will to live, and the way we live today, I am not the person I used to be. Now I am a happy person; I was not happy

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before. I also feel that since I started to be a <u>crente</u> my life has changed: I have also received several cures. [Daniel's mother, God is Love]

Before I used to be like this, whatever I had in my hands I would throw [over people], and when I had to spank [one of my kids] I would really spank them, you would feel pity. Now I have modified myself a lot. The church teaches you a lot, it teaches you how to take care of your kids, and how you should not be... Before I would call many bad names inside my home, and I was very attached to saints, candles, and macumba. [Leonardo's mother, The Return of Jesus Christ Pentecostal Church]

But I am not all that violent now you know. I used to fight [with people] all the time. [...] Thanks to God it has been 10 years since I began to calm down a lot; it is also my age and because I am always sick... I believe it is my religion [that calmed me down] because it has been a long time that I have been going to church and listening to the word of God. I was just not baptized before. And at the time that I used to be violent I would go to Umbanda a lot [...] And I would drink a lot! [...] After I was healed from my stomach problem while going to church I promised myself that I would never go back to Umbanda again. And I never did. And now my children too, thanks to God, one by one I am taking them to church to see if we can improve our living conditions. Before I would buy 30kgs of rice and it would not be enough for the month. It seemed that something was eating all the rice; I would cook a big pan to leave in the fridge. [...] But at lunch time when I would hunt for food it just wasn't there anymore. Now I only buy 20kgs and it lasts the whole month, thanks to God. God has been blessing me. [José's mother, Universal Kingdom of God Church]

Religious participation also works out as a strategy to endure the violence, fear, dangers, and uncertainties of everyday life:

I go to church because I like to go! [...] Our God is only one and we are doing no harm to anyone because in this world there is a lot of violence, in this world we only live with fear, when we get out of the house we don't know whether we are coming back. The day does not belong to us; it belongs to God. [Solange's mother, Assembly of God]

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⁴ In this context <u>macumba</u> is only being used in a pejorative sense to refer to Umbanda or Candomblé. Historically <u>Macumba</u> was a marginal Afro-Brazilian religious practice among the urban poor of Rio de Janeiro and São Paulo. Since the beginning of this century Umbanda has progressively substituted Macumba, but still today Umbanda and Candomblé practitioners are sometimes called <u>macumbeiros</u> (Negrão, 1996; Brown, 1994; Brumana & Martinez, 1989).

In providing spaces of sociability and in strengthening links of solidarity with other participants, religion provides a feeling of reassurance among the urban poor and contributes to the creation of adherents of a new ethos. This is particularly significant in overcoming the distrust produced by life hardships and violence of everyday life.

It is really beautiful! It is very beautiful, their baptism! So I went there and I decided to be baptized myself! It is a long time that I have been baptized. I even have the membership card! And then there is the participation in the activities: I participate in the choir, in the prayer circle, in singing hymns. I never miss it! I go almost everyday. [...] Like today, today we are going to make a visit to another church in Diadema... We are leaving in a bus and we are going to visit the church.... to visit churches that are in festivities. They invite other churches, and our church has been invited. [Luana's mother, Assembly of God]

In the churches I have been going to if you have a problem all the church brothers will help you out. If you see that a church brother is having a problem, that he is hungry, the church brothers will help him out.[...] I like many things you know, the conviviality with the church brothers, the doctrines: it is not only my son that they help out, it is everybody, and if there is someone sick, oh we will all go [to his home] and pray for him. [Leonardo's mother, The Return of Jesus Christ Church]

I observed throughout fieldwork that the spaces of sociability created by Pentecostal Churches include some forms of leisure like charitable bazaars, home visits, picnic, music, and dancing, that are common among the urban poor, although they are embellished by a strong religious connotation. One day I visited Luana's home and felt the impulse to dance together with Luana's little sister and her friends to a religious music in a modern pagode⁵ rhythm that praised God. While this popular music style is appropriate for dancing and usually manifests strong erotic connotations, the religious version transforms the erotic character into a laudation to God:

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⁵ Pagode is a type of <u>samba</u>, while <u>samba</u> is the music of carnival and is taken as one of the key symbols of music expression in Brazil. The recent trends of <u>samba</u> have incorporated the beat of the funk to that of reggae, and other strong African rhythms like the <u>lambada</u> and <u>axé music</u>. The rapid growth of a cultural industrial market dedicated to gospel music that borrows from varied rhythms of <u>samba</u> deserves further investigation in Brazil.

Hallelujah, hallelujah, hallelujah Hallelujah, hallelujah, hallelujah [refrain] Right hand, left hand With the two hands we praise the Lord [refrain] Clap your hands, bump your feet With our body we praise the Lord [refrain] Giggle, ha ha ha, dance With our body we praise the Lord [refrain] Give one glory, another glory, Glory to God With our mouths we praise the Lord [refrain] Hop once, hop twice With three hops we praise the Lord [refrain] (song and music by "Radicais na Fé," my translation)

Moralization and socialization is a *sine qua non* quality of religious participation for those families with a Protestant background, particularly for the followers of the Pentecostal Churches. Similar comments were reported by the two families who practiced a more internalized form of Catholicism (Charismatic and Orthodox.). For other families classified as Traditional Catholics, religion looses significance as a tool for constructing new spaces of sociability, solidarity and moralization among the urban poor. In this case, however, Catholic beliefs continue to provide a basic framework that helps people deal with existential angst and human suffering. All religions examined here enable the person to transform suffering into something more bearable, supportable, or as Geertz (1973) would say, more sufferable. This is primarily achieved through the instilling of hope, comfort and faith in God.

Religious faith becomes even more important when these families perceive themselves to be suddenly engulfed in a chaotic situation after the outbreak of a psychotic

episode. Hope and faith allow these families to face personal strain and the burden entailed by the patient's problems:

We [family] are all Catholics thank God. I have the intention of dying as a Catholic, and so we try... at least this is how I see it... if it is God's wish, because an illness is not a misfortune. God allows it in the sense of a probation to prove our faith. If we love God we need to have probations in this world because our life is not a smooth sea, do you understand? [Raquel's sister, Catholic]

Only God could have given me the strength to endure this! Because it is hard! It is hard, hard, hard. You have only one daughter inside your home and your hopes are all in her. [Claudia's mother, Umbanda sympathizer]

God is going to bless. I have faith in God! I have the conviction that God has opened a door, I have a lot of faith! My daughter has to get better. [Dora's mother, Seventh Day Adventist]

I would only cry, my business was to cry and cry. And pray for God. It was because of my son [that I cried]. There was a day that I was just so desperate that I even said to God... I said that if it was [fate] for my son to suffer like this, God take him away. I know that I am going to suffer, but I prefer to suffer seeing God taking him away from me, than to see my son suffer like this, and nothing could be done because the crisis was just very strong! [Leonardo's mother, The Return of Jesus Christ Church]

Hope and faith in God traverses most narratives regardless of the family's original religious background, level of religious participation, or the actual situation being faced by the mother or the patient. This widespread faith in God is also very clearly depicted by Mauricio:

To believe in God, a religious person is who believes in God, and it doesn't matter who that God is.... You search for God when you are in despair, lately I have been doing this, searching for God when in despair. [Mauricio, Non-Practicing Catholic]

Every time these families (Catholic or Protestant background) talked about religion, the idea of an omniscient, omnipresent, omnipotent, and all-perfect God pervaded their narratives. God always protects and gives strength to endure adversity,

God shows which path to follow, only God is trustworthy; God has the power over life and death; God is able to accomplish whatever men cannot do. Thus, to talk about religion is to talk about one's love and unconditional faith towards God.

I selected José's mother's religious trajectory, to be described below, to illustrate the fluidity, contradictions and *bricolage* involved in the construction of one's religious identity and experience, and how this construction is also closely related to the hardships of everyday life. In addition, religious signifiers from different religions may interpenetrate each other, gaining more or less significance.

José's mother story

One sunny afternoon, while talking in the kitchen with José's mother, I suddenly realized how the meanings constructed through religion are frequently much more complex and fluid than the mere adoption of the worldviews provided by the person's current religious faith. This becomes clear in the ways José's mother continually valorizes, manipulates, maintains or changes religious signifiers from distinct religions throughout her religious trajectory.

Like most people who decide to convert to Pentecostalism, José's mother initially stated that her recent conversion to the Universal Kingdom of God Church, by transforming and "healing" her, has improved the life of her whole family (similar narratives are systematically evoked in the social sciences literature on Brazilian Pentecostalism).⁶ At the beginning of my work with José's mother I had some difficulty in understanding these declarations as I observed the precariousness of her living conditions, in addition to the fact that her eldest son had just gone through

⁶ I was equally astonished when similar perceptions regarding personal conversion to Pentecostalism were disclosed by Sarah's mother (Assembly of God), Luana's mother (Assembly of God), Solange's mother (Assembly of God), Daniel's mother (God is Love) and Mateus' mother (Universal Kingdom of God Church). For further examination of the social sciences literature, see for instance Chesnut 1997; Lehmann 1996; Machado 1996; and Mariz 1994..

his first psychotic episode. But listening to the narratives of all the mothers who converted to Pentecostalism, I came to understand how their lives became filled with renewed hope and meaning, even when there is no food on the table, or one of the children is terribly sick.

For several years while raising her five kids, José's mother used to regularly attend Umbanda rituals where she would incorporate spirits (gira). During this period her house was often full of sick children who would come with their parents to be blessed and healed by her spiritual powers. She felt capable of helping these sick children no matter how her own family life was falling apart. She was living with a violent husband (later they separated) who spent all the money she earned after a lot of hard work in the small bar they owned. So much unhappiness and despair transformed José's mother into an alcoholic and very aggressive person; she also began to have stomach problems. She searched for medical treatment in vain, and then began to attend the distant Catholic Charismatic Church of Father Francisco, that was known to make miracle cures. After feeling cured of her stomach problem, she progressively abandoned her drinking, her violent behaviour, and most Umbanda activities.

Some years later, her oldest and married daughter (José's twin sister) was unemployed and extremely sick. Very worried, José's mother sought help in the nearby Universal Kingdom of God Church. In her opinion it seemed close to the approach towards spiritual healing she had experienced earlier with Father Francisco. The sick daughter accompanied her mother to this Pentecostal Church until the daughter was finally "liberated" from the "demonic possession" she was suffering. Both daughter and mother are very confident that only this "liberation" allowed the daughter to be healed and to find a good job. After this "liberation" the daughter attended church only sporadically, but José's mother continued to

participate every week in religious ceremonies to receive benefits for all her other children and to improve their family life.

José's mother felt very lost and desperate with the outbreak of her son's psychotic episode. Sometimes she believes that José was obsessed by some espírito maligno (malignant spirit). Other times she relates that the psychotic episode was caused by one of her ex-boyfriends. He fell into a rage after she expelled him from her home, and in revenge performed some macumba to reach her, but this coisa feita affected José instead, who she considers to be "weaker," and thus more vulnerable to witchcraft or evil spirits. Umbanda therapies would be very effective to eliminate any of these causes; however she preferred to take José to the Universal Kingdom of God Church, as she did with her daughter. José tells that his mother forced him to accompany her twice, afterwards he refused categorically to go to church again. This impelled José's mother to go through "baptism in water" at the Universal Kingdom of God Church because she expected that her personal conversion would slowly help her son recover from his crisis. All the other five mothers who converted to Pentecostalism did so long before the outbreak of their son or daughter's psychotic episode.

Many times José's mother mentioned to me her disappointment with the lack of interest that her son demonstrated towards church. Nevertheless, this is not a source of conflict between them because in Pentecostal churches the religious conversion of the mother frequently goes beyond a personal solution; the benefits of her own church membership would be extended to the whole family. In this case, José might be eventually "healed" because his mother went through conversion (baptism) and was exorcised. Often this theological model implies that the source of evil circulates through the family while inhabiting the woman's body, and through a woman's condition of wife and mother. During her "spiritual liberation" (exorcism) the pastor proclaims the power, authority, and the blood of Jesus, and in the name of Jesus he demands the evil entities to

leave the person's life. Even if the exorcized woman's child maintains a distance from church, this does not invalidate the mother's approach (Birman 1997a; Lehmann 1996). Several other mothers made numerous attempts to take their psychotic son or daughter to Pentecostal rituals, however they also accepted their offspring's lack of desire to frequent the church, and would attend only by themselves.

Nowadays José's mother associates her previous immersion in Umbanda with the violent behaviours she had during the same period. This is congruent with the ordinary discourse of Neo-Pentecostal Churches that always associate Umbanda practices with the works of the evil (or Devil) that can only be eradicated through the direct contact with God. It seems to indicate that she internalized the discourse. This tries to convince the follower to abandon all magical/religious practices outside the scope of this church. It also reiterates the "polycentric discourse on evil" in relation to Umbanda, but it does not mean that José's mother has totally abandoned the worldviews once provided by this Afro-Brazilian religion. Although José's mother abandoned her major Umbanda practices (e.g. incorporating spirits, fulfilling "offerings" to the deities) after her Pentecostal conversion, she stills keeps a series of marginal beliefs and practices which do not confront so directly the Manichaeist worldview emphasised by Neo-Pentecostalism. For instance, the following photo illustrates that in order to protect her whole family from other people's "envy" and "evil eye" José's mother maintains the green plant "comigo ninguém pode" ("nobody can harm me") at home, which she relates with the Afro-Brazilian orixás Ogum and Oxum. In addition, the plant vase sits just in front of a picture of São Jonas, who is the Catholic saint whom Umbanda followers associate with Ogum.

Apparently "spiritual healing" is the key element in triggering changes in José's mother's religious trajectory. This story also indicates how the personal construction of religious experience is an ongoing process that condenses all of the three perspectives discussed in the literature: "free market," "common shared beliefs," and the "construction of a religious identity." From a "free market" perspective, José's mother could have taken her daughter to be healed at the Charismatic Catholic Church or to any other religious place, but she preferred to go to the Universal Kingdom of God Church since it was much

closer to her home. As in most other narratives, distance and the money spent with spiritual healing plays an important part in the choices that are made.



Photo by Cristina Redko

Neo-Pentecostal Churches require exclusivity by rejecting most beliefs and practices from Umbanda and other popular religions. Nonetheless, the presences of exu and pombagira are invoked by the pastor during the rituals of exorcism. The existence of spiritual entities coming from the Afro-Brazilian religions is still recognised. Although Neo-Pentecostal Churches always confront Umbanda practices, a dialogue still remains between them because the reality of the Afro-Brazilian spiritual entities is not questioned. This is facilitated by the "common shared beliefs" that people who follow these two religions have. According to some authors, the rotation of clienteles between Pentecostalism and Umbanda is also explained because no significant social/cultural difference exists between agents or clients of the two cults: they share the same employment opportunities, the same urban areas, even belong to the same families. In

addition, both cults allow devotees to elaborate the marginal positions they occupy in society at the religious level (Soares, 1993; Burdick, 1996; Brumana & Martinez, 1989).

However, José's mother's conversion to Neo-Pentecostalism does not erase completely her previous Umbanda belief system. She still believes in macumba, evil spirits and so forth; therefore "all the evil" is not necessarily related with the Devil. Her own religious belief system resembles a bricolage of elements emerging from distinct religious experiences. Thus, the construction of José's mother's "religious identity" is much more complex than simply abandoning Umbanda in order to privilege the religious beliefs and practices of Neo-Pentecostalism. Analysing the way she herself differentiates the two religions would provide important clues to understand the construction of one's religious identity. Often these differences are not easy to detect. This might be explained by "common shared beliefs" (similarities) and that the bricolage of religious experience frequently overshadows the differences. This pattern reflects what is described in the social sciences literature on Brazilian religions, which emphasizes similarities rather than differences. José's mother mentions no major difference between the various religious frames beyond that Neo-Pentecostalism is associated with the general re-organisation of family life, while Umbanda did belong to a period of life where her family was very disorganised.

Contrasting with the mothers' narratives, most young people have not given much thought to the ways religion might have influenced their personal experience before the outbreak of their psychotic episode. Their previous religious experience is described in general terms: "I have always believed in God," "I am very attached to God," "I have always liked this religion," "I have faith, you need to have faith," "I like to go to

⁷ It is hard to find studies that try to investigate the differences. The possibility that this position could be determined by cultural ideologies is not in the scope of the present thesis. Fry & Howe (1975) are an exception and discuss the differences between the social experience of people who are attracted to Umbanda and those who prefer Pentecostalism. The authors suggest that Pentecostal Churches attract more people who have significant experiences with impersonal relations, while Umbanda is more attractive to people whose daily life is based in the constant "manipulation" of strategic persons and who find inconvenient an impersonal mode of ordering social relations. This model is consonant with DaMatta's interpretation of Brazilian culture where both "impersonal" and "personal" moral codes operate simultaneously. Fry and Howe recognise that their model is a crude simplification of the multifaceted social/religious experience that traverses everyday life.

church," "I have always been attached to religion, but after this problem (psychosis) I started to go to church more often." Religion seems to have been part of their family life: these young people were raised in a religious environment and have "inherited" religion from their parents (usually the mother). Comments of many young people are summarized by Claudia's position: "Everyone has to have a religion," with no perceived need to establish which religion that should be. Even for those who are not actively involved in religious life, a minimum "faith in God" appears to have an important value. Religion is also presented as a matter of "calling", especially when these young people become actively involved.

Religious Help-Seeking and Psychosis

Religious sources of help are by far the most prevalent in the help-seeking trajectory, besides the psychiatric services. "Spiritual healing" is a key motive that induces families to search for religion as a source of help (and treatment) after the outbreak of the psychotic episode. In this context "healing" often becomes one of the most meaningful aspects associated with religion. In this chapter I explore the importance religion acquires for family members and patients as a source of help and treatment, while the next chapter explores how religion is itself a source of meaning in the context of a psychotic experience, both for patients and their families. A few questions have to be addressed: Which are the steps leading towards religious sources of help? What is the range of religious help-seeking strategies? How does the family's help-seeking strategy involving religious sources of help differ from that of the person suffering psychosis? Are religious sources of help compatible with psychiatric care?

Before starting my fieldwork I suspected that resorting to psychiatric care would not exclude the call to religious sources of help. This impression was based on the general importance attributed to "spiritual healing" by the Brazilian population, as it has been documented in the literature, and most people believe that healing has to involve both bodily and spiritual aspects of the person in order to succeed. Even so, I was

surprised to discover that out of the twenty-one families that participated in this study, only Kátia's family (Catholic background) did not resort to any type of religious source of help, and relied exclusively on psychiatric care. Indeed, most families (76%) tried more than one religion as a source of help.

Table 20 gives a general idea of the different types of religious sources of help sought in relation to the original religious background of each family. It is worth mentioning that families usually resorted to religious sources of help that belonged to their own religious background, before trying anything different. All the families with a Protestant background went to more than one Pentecostal Church: "Universal Kingdom of God," "Assembly of God," and "God is Love" were their favourite places. One has to notice that attending simultaneously different Pentecostal Churches (including Charismatic Catholicism) is an accepted common practice, especially among crentes (Mariz & Machado, 1996). Independently of their religious background, most families resorted to Pentecostalism (76%), and, in second place, to Umbanda (52.3%). However, families of a Catholic background explored a wider range of religions, especially Kardecismo and Esoteric practices, when compared with Protestant families who privileged Pentecostal Churches and did not resort to Catholicism, even though some of them tried Umbanda healers. The Catholic families who resorted to Catholicism privileged vows to Nossa Senhora de Aparecida, prayer requests left in the church, and a significant increase of private prayers at home. The most common form of Esoteric practice sought is "card reading" as a divinatory practice. Pentecostalism is discussed in more detail in this chapter because the majority of families sought this religious source of help more frequently, and the abundance of data allows a more solid comparison between different families and patients versus the family perspective. I also give particular attention to Umbanda, since half the families have also tried this pathway to help-seeking.

Table 20 - Family's original religious background in relation to religious help-seeking

	trajectories			
Family's original religious	10 Catholic	11	Total= 21	100%
Background		Protestant		_
Family help-seeking trajectories				
Pentecostalism	5 families	11 families	16	76%
Umbanda	6 families	5 families	11	52.3%
Catholicism	7 families	None	7	33%
Neo-Esoteric ⁸	2 families	3 families	5	24%
Kardecismo	2 families	None	2_	9.5%

Relatives' perspective

I observed that family members felt very confused, lost and helpless during the outbreak of psychosis. They would try whatever was within reach to solve the problem. However, members from the extended family, neighbours and friends would visit the home to offer some religious help:

Only God to give some mercy in a time like this, because I believe there is no spiritual centre, no Church, there is only God to help us! If you go to a [religious] place they tell you something, you go to another, they will tell you something else, and your mind stays in a way that you don't know where to go anymore. Many people have come here [home], and they would say you should do this. I think I have some 50 addresses [religious places to consult]. Ah you take her to that spiritual centre because that one is good. Ah you take her to the other one that is also good. And you just don't know anymore where to go. It is only money, if you have money, it is only money that goes. I didn't go to any places anymore, because I don't have money, because if I had money I would have gone more.

[Claudia's mother, Umbanda sympathizer]

Then the <u>crentes</u> would ask, can we come to your house <u>senhora</u> to make prayers for your son. We would accept that because we were so desperate with him, then they would come here [home] and pray. [...] Ah, I was so very sad, because my son is not like this, I want to see my son liberated from all this and what kind of help can I offer to my son? I was feeling

The term "neo-esoteric" was first adopted by Magnani (1996b) to designate all types of "alternative practices" found in São Paulo that have some relation with "magic," for instance, card reading and other divinatory practices, meditation and relaxing techniques, shamanic sessions, oriental therapies and so forth.

very worthless myself. Because everything that we were trying because people would say try this, people would say try that, and we were not obtaining any solution. [Milton's mother, Catholic]

Even before the family had the chance to consider existing sources of religious help, these would often "knock at the door." Neighbours, friends and the extended family would come to suggest names of incredible spiritual healers, or they tried to attract the family to their own church or spiritual centre. But the most common form of religious help was the visits of crentes from different Pentecostal Churches that came regularly to pray, bless the person and the whole family (campanha de oração). Although this phenomenon is certainly more intense during the first weeks of the crisis, I observed it happening throughout the time. Like the two excerpts above illustrate, the mothers sometimes felt overwhelmed with the abundance and diversity of religious help offered to them. In this situation, religious help is just one more "added burden" to the problem for the family. There is no doubt that these "knocking at the door" visits have also stimulated families to step outside the house to find alternative forms of help.

One might suppose that most families struggled to take the patient to several religious places due to some "lack of efficacy" of the previous religious option. That was not always the case. This could be a too superficial or instrumental kind of explanation. Narratives of two mothers from a Protestant background illustrate the kind of motives that trigger continuous family efforts for a fluid religious help:

I am evangélica... from the Baptist. Yet I took him [son] to the Church of Grace because the God who is in my church is inside all the others. I have faith that God has operated in his life, and that God has helped in his [psychiatric] treatment, and is still helping. We did prayers. But it was not only in one church; it was in several churches that we prayed for him.... Assembly of God, God is Love, the Baptist too... We did campanhas de oração. When the person has a problem we do this campanha praying together for 6 days, for 7 days always at the same time, to talk with God about that topic. And thanks God, God has been operating [over my son]. [Edilson's mother, Baptist]

I believe it was God [who healed my daughter]. In part it was the physicians' help, but in another part it was God through the prayers and the search for (God)... We did...I did two <u>campanhas</u> here of fasting and

prayers. I would always search and meet people in churches, and when the people got acquainted with her they would always pray and fast for her. In four churches I have taken her in this way... Trombetas, Assembly of God, Celestial Arc, God is Love... they are all good, all of them have the correct doctrine to be followed [...] But I believed just like in the words of... the more prayers, more power, like they say. So if I go there in somebody's church than in somebody else's church, then the church sisters will help more, they are going to see her situation, and mine, that I am fighting with her, and they will pray more for her and look more for [God], so God will liberate her [spiritually] even faster, that's why I did like this. [Sarah's mother, Assembly of God].

These narratives claim a kind of "added efficacy": the more religious places one goes to, the more God's power one attains to solve the problem faster. Be it expressed within a language of "added efficacy" or "added burden," the basic reasoning remains the same. Most families strongly believe that religious resources are an essential complement to the treatment provided by psychiatric care:

There is the spiritual part and the material part. The spiritual part belongs to the church while the material part belongs to the medical specialities.
[Mateus's mother, Universal Kingdom of God]

There is a part that was done by the physicians, but there is another part that was done by God plus the power of prayers and [spiritual] healing. [Sarah's mother, Assembly of God]

Ultimately, God's power in combination with spiritual healing transcends the work of physicians, since these physicians would also attain their power through God's will. However, physicians remain important since they take care of the "material part" of the sick person, while God looks after the "spiritual part." Sarah's mother was not able to determine whether her daughter suffered from a "spiritual" or a "material" problem. That is why Sarah was treated in several Pentecostal Churches in addition to going to the psychiatric emergency room. Since the efficacy of "spiritual healing" is ultimately certain most families prefer to try another religious place whenever the help currently provided does not solve the problem (which happens quite often). Spiritual healing always remains an open possibility. Moreover, the cumulative effect of caring for the sick person's

spiritual well being might generate more results than finding the "optimal" religious place to begin with.

Milton's story

People from the Assembly of God (first wave) and God is Love (second wave) visited Milton's home several times to pray a campanha for him. In addition, a family cousin phoned to take Milton to another church. But the phone call was so rushed that only when they arrived did they discover the cousin was taking them to the Universal Kingdom of God Church (third wave). Milton's mother felt disconcerted and betrayed because she strongly believes that this last church was against Catholicism since the occurrence of the "chute da Santa", while she and her son are impassioned Catholics. She began to cry and prayed to the Virgin Mary because she imagined they were transgressing their Catholic faith. She also believed that her son was very uncomfortable with the exorcism rituals since he was extremely nervous and compulsively wanted to drink water when they left the church. Her son then confided that he "didn't like it." Milton's mother recalls that she shivered every time the Devil was evoked inside the church. Even so, she always tried to hide from the cousin that they were very upset to have gone to the Universal Kingdom of God Church because the cousin was only trying to help her son. She felt obliged to accept the assistance offered by most Pentecostal people because they only wished to bring some comfort and prayers. However she did not let go of the family's Catholic faith, so they promised to make

Other mothers have mentioned to me their own indignation towards the "chute da Santa" ("kick on the Virgin Mary") episode: on October 12th, 1995, which date is the celebration of Nossa Senhora de Aparecida (Virgin Mary), the patron Saint of Brazil. One bishop of the "Universal Kingdom of God" inadvertently kicked the image of the Virgin Mary during the broadcast of TV Record's religious programme (owned by the Universal Kingdom of God). The rival TV Globo (most powerful TV station in Brazil) showed and repeated the "chute da Santa" several times in their news programme; and the divulging of this episode provoked a series of popular acts of indignation, redress and violence, coming specially from the Catholic faithful (Almeida, 1996). For this reason most Catholics reject the "Universal Kingdom of God Church," yet they show tolerance towards other Pentecostal Churches.

a pilgrimage to the sanctuary of Nossa Senhora de Aparecida after resolving Milton's problem.

While buying dog food in the neighbourhood of the family home. Milton's father told the store owner that they had already gone to the doctor, but that their son was still having problems. Since the store owner saw an analogy between what the father was describing and a problem she had had before, she suggested the address of the Kardecismo centre where she was "healed." After Milton was examined by a "spirit medium" from this Kardecismo centre, the parents were eager to bring their son to six consecutive sessions, once a week. They were also advised to continue with Milton's medical treatment because these sessions would only heal the "spiritual illness," but not his "material illness." During the sessions the mother enjoyed the advice about "ways to act in this world" given through the readings of Kardec's books. At the end Milton and every person present would receive passes individually while being surrounded by three different mediums. The mother believes that since she is the mother, and her husband the father, both of them had to receive passes to collaborate with their son's "spiritual healing." The whole family stopped going to Kardecismo after the six sessions that were initially recommended. The mother regretted the interruption but the centre was very far from their home and they could not afford to pay the cab driver's ride every week. Although the father also blamed their lack of money, he thought that these sessions were not really helping his son in any way. Very frequently families who participated in this study preferred to go to religious places that were far away because the recommendation came from a reliable person, so they believed the place more trustworthy.

Milton felt happy and relieved every time they attended the Kardecismo sessions. He also liked to keep at home one of Kardec's book. Besides reading this book from time to time, he often drank the tea that

was given by a Japanese spiritual healer. Yet the Bible was another source of reference that soothed him. But what he appreciated most were the few times his uncle asked the family to go to the Charismatic Catholic Church of Father Marcelo. Milton himself loved to sing and to participate in the "liberation" mass. He felt relaxed and more capable of speaking freely. It was also easier for him to avoid "falling into temptations." Apparently he relates his suffering with some loss of control over "temptations." However, the first time we talked he mentioned immediately: "When I felt the problem, my problem, I believe that my problem is spiritual... because I felt something strong calling me." Much later I understood that he was only questioning himself as to whether his problem resembled something "spiritual," instead of providing any certainty about what caused it.

Milton's father declared that as parents they became very confused with so many "knocking at the door" visits because some people would say that their son's problem was caused by <u>macumba</u> (black magic), while others related it with <u>coisa do diabo</u> (thing from the Devil) or <u>encosto</u> (leaning spirit). Milton's father was very skeptical towards these explanations because he thought that only the psychiatrists would be able to heal his son. Milton's mother was more receptive to religious explanations, but these were no less frightening than the psychiatric diagnosis. Initially she refused all the indications to take her son to Afro-Brazilian religions because she associated them with "black magic." However they consulted a Japanese spiritual healer who played the jogo de <u>búzios</u> (cowrie shells game) and made "dispatches," but she ignored whether this healer adopted Umbanda or Candomblé. Nevertheless, her expression of relief, contentment and satisfaction was intense when she

¹⁰ According to the printed media Father Marcelo is provoking a revolution inside the Catholic with the rapid growth of the Charismatic Movement. Every week the three "liberation" masses given by the priest receive around five thousand people, a collective commotion that affects the region's street traffic (ISTO É, 1997).

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revealed to me that this spiritual healer confirmed through the divination game that her son was not being disturbed by any kind of encosto.

The first time I met Milton and his parents in the emergency room the mother was desperately explaining to the psychiatrist that they were already doing everything possible but their son was not getting any better. She also took out of her purse all the medical prescriptions including the schedule of the next Kardecismo sessions to prove all their efforts to the psychiatrist. My first impression was that they were the typical Catholic family who would try every religious source of help available to solve the problem. I only discovered afterwards that they also had some restrictions or divergent opinions regarding religious sources of help. While the father became progressively more skeptical towards spiritual healing, the mother insisted continuously. They were also extremely confused with the different religious sources of help because they often provided new interpretations (or cultural etiologies) to the problem: macumba, coisa do diabo, encosto, and so forth.

The religious help provided through <u>campanhas de oração</u> (Pentecostalism) promote spiritual healing through the blessing and prayers. Although this resource was used more abundantly by Protestant families, it was not rejected by Catholic families. Most families (Protestant and Catholic) agreed with Milton's mother that words of comfort and prayers always alleviated the problem, regardless of their healing potential. Prayers and blessings were always welcome. Particularly in this case the notion of added efficacy or cumulative effects is extremely important. Prayers were the most frequent resource of respite that mothers appealed to whenever they found the time to do it at home or dropped by the church to pray. Since Eduardo's mother belonged to the women's Charismatic Catholic prayer circle of the building where they lived she intensified the prayers in support to her son. The act of making <u>promessas</u> to a particular Catholic Saint were also very common. Besides Milton's family, two other Catholic families temporarily tried the religious help of Kardecismo. It is possible that other families have not considered this source of help because it reaches more the upper and middle-classes.

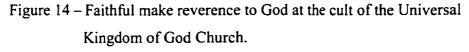




Photo by Folha Online

I have also observed a whole series of secondary religious rites performed primarily by the mother in order to benefit her sick son or daughter. Pedidos de oração (prayer requests), in which the faithful brings objects (e.g. photo, piece of clothing, document) of the sick person to be blessed during the religious ceremony, happened quite often. Another common practice is to take back home some of the objects that have been blessed. For instance, Leonardo's mother would always return home from the Pentecostal church with "blessed bread" or "anointed oil." She mixed a little piece of bread each day in her own cooking and spread small drops of oil all over the place to bring spiritual cleansing and protection for the whole family.

Some families were also caught in ambiguous situations, especially when the religious help offered was against their values or faith. Besides the Catholics, some Protestant families rejected the Universal Kingdom of God Church (third wave) as well. Some were against the "theology of rapid prosperity" because they imagined that this church only exploited the poor, while others believed that the teachings from the Bible

were completely distorted in this church. Family reactions varied. While in some cases these families simply avoided going to this church, in others they accepted this religious help in the same way as the help provided by other Pentecostal Churches. But they never remained very long (except two mothers who already followed this church). This is also probable because the patients most often rejected going to this church.

Umbanda generated some ambiguous and contradictory reactions among family members as well. However there were different levels of acceptance and rejection that varied according to the type of religious therapy, religious background of the family, or the position of the family member. Thus, discharge baths with special infusions of plants mixture prepared in bottles (garrafadas) given to the patient at home were more accepted than taking the patient to Umbanda religious rituals. Families of Pentecostal background demonstrated much more opposition towards Umbanda than the Catholic families. This is also probably related to the exclusivity of faith demanded by Neo-Pentecostal Churches that associate any other religious practices, for instance Kardecismo and Umbanda with the works of the evil. While certain families tried out Umbanda therapies at least once, others were totally against it. In some of these cases it was only one member of the family, usually the males who are less committed to any religion, for instance Solange's husband, who made strong opposition to the other family members, or who took the patient in secret, without the knowledge of other family members:

You see two of my daughter's colleagues who said that they were her friends, they wanted to take her to the macumba center, to take out the coisa ruim [evil spirit]. They imagined that it was work of macumba that was made against her. I said: "no, not my daughter, I am not going to take her to the macumba center, because I am from the church and I have faith that Jesus will heal her, so I do not have to take her any where else besides the church." Then the girls insisted: "no but we will take her and they are only going to do her good, they are not going to do any evil things to her, they are going to try to take it out [evil spirit] from her." I replied: "no, there is no need, I am already taking her to church and there with the prayers she will get well," and I started to take her to church quite a lot! And the church sisters are making campanha de oração here at home too! Monday it will be seven days that we are making this campanha!

[Luana's mother, Assembly of God]

But I reacted [against daughter's husband], and he got very upset. He wanted to take her to a certain place... <u>macumba</u>, [tells in tone of confidence] he really took her to a <u>macumba</u>, and we [the family] didn't like it! (...) I said to my daughter: "Look don't get too revolted with your husband because he didn't really know what to do and he believed in the neighbor's talk, and so he spent 250 reais [US\$250] without being able to." [Solange's mother, Assembly of God]

Some families sought for some forms of help-seeking that were more related to Neo-Esoteric practices and not necessarily classified as "religious." Going to card readers who predict the future was the most common resort. However Jonas's family also accepted to have one of his friends to come over to his home to apply some Reiki healing sessions of energization. Jonas by his own initiative also went to some acupuncture11 sessions, and tried Past Life Regression (the forms of help seeking that Jonas experimented will be discussed in more detail later). Another example of "Neo-Esoteric" practices is the "power of the mind" group which offers a course to which Mauricio's family attended. It was the boss of one of Mauricio's sisters who suggested the family to frequent this group. Family members emphasized that this was not a religious group, although the group reiterated the "power of God" and respected all religions. They also believed that this form of help was very important because it strengthened people's mind. The objective of this "power of the mind" group is to conduct the cosmic integration of the individual at the mental, physical and spiritual levels and the people interested are trained in courses given by physicians, physiologists, psychologists and philosophers. The intention is for each individual to learn to capture the surrounding energetic vibrations in order to reach the "cosmic consciousness." With the amplification of one's cosmic consciousness the person is able to know the absolute Truth, Justice, Liberty and Peace. This group also applies principles that come from astronomy, the energetic power of the pyramids, "psychogalvanometry" (instruments that detect small electric currents in the brain) and "kirliangraphy" (photographing one's aura) (Charuri, n.d.). Mauricio told me

¹¹ Since Jonas's father is of "Japanese" descent I speculate that this allowed for Jonas to become more familiar with acupuncture as a form of alternative medicine with its millenary origin in Japan and China. Furthermore, this was also a form of help-seeking that Jonas searched out by himself, that is, without his mother's influence (she is divorced from the father).

about this group with a lot of excitement because he wanted to learn how to strengthen his mind with the hope to rid himself of his psychotic symptoms forever. He also showed several pamphlets about the "power of pyramids" and he wished he had the money to buy one for himself. I suppose that the whole family attended the courses for two reasons: they wanted to support Mauricio and because each one of them expected to strengthen their own minds in order to be protected from problems like the one Mauricio was having.

It is clear that the significance of religion for the family intensifies with the outbreak of the psychotic episode of one of its members. Families are desperately searching for forms of "spiritual healing", and this is likely to be related to the widespread belief that the person's body is composed of a "spiritual" part and a "material part", and that both of them have to be "healed". Another plausible explanation is that some of the symptoms of psychosis are easily associated with signs of spiritual possession, or some other kind of spiritual disturbance (see also next chapter). A new space of sociability and solidarity is also created when religious people try to aid family members to tolerate the chaotic situation they are engulfed in during the psychotic crisis. In this context messages of hope and faith are extremely significant; sometimes even more important than expecting that the psychotic patient will be cured through religious healing. As I mentioned before, the cumulative effect of caring for the spiritual well being of the psychotic patient may be more meaningful than finding the "optimal" religious therapy. It is more common to see religious sources of help as a complement to psychiatric helpseeking, than as the main option. Nevertheless, many family members emphasized that ultimately God is the only one who has the "real" power to heal and that physicians can only act through God's will.

I also suggested how family members sometimes feel lost in a back-and-forth movement between distinct religious places. This movement may be ambiguous and contradictory, and may also transgress some of the family's previous religious beliefs and faith. For instance, when Milton and his mother were taken to the Universal Kingdom of God Church without knowing to which church they were going. The contradiction and ambiguity may also be generated because distinct religions give different definitions and

solutions to the problem, even though there is a large space for fluidity and common shared beliefs between these religions. Thus, family members may either apprehend different religious meanings and signifiers through a process of *bricolage*, although a cleavage might also occur in relation to a previous (or present) religious identity, belief or the involving religious context. For instance, even though Milton's mother is a fervent Catholic, and totally against Umbanda practices, the whole family made a consultation with a folk-healer, who discarded the possibility of Milton's problem being related to encosto. What I also want to emphasize is that each person may use the diversity of religious signifiers in a particular way, which may either correspond to the collective meanings attributed to the signifier or diverge from it. Now it is time to explore the patients' perspectives in relation to religious help-seeking.

Patients' perspective

Leonardo's story

Leonardo's involvement with Pentecostalism emerged with psychosis. Contrary to Jonas's indifference, Leonardo created a space of contact with Pentecostalism that oscillated between strong fanaticism and frank rejection. His mother also became involved with the intention of stimulating her son's participation in the Pentecostal church, and to receive some support herself. For the time being I will describe only the campanha de oração that occurred while I was visiting the home. Leonardo was heavily sedated with anti-psychotics that day since he had been recently discharged from psychiatric hospitalization. This event also allowed me to observe very closely Leonardo's reactions in relation to the ambience generated by the ritual. This campanha de oração is the most frequent form of religious help accepted by the families I have contacted. As with Leonardo, other patients experienced some momentary relief and peacefulness after the campanha.

Late in the afternoon I was talking with Leonardo in his bedroom when three followers and the pastor from the Return of Jesus Christ Pentecostal Church arrived to continue the campanha de oração which had started during the hospitalization period (without Leonardo's presence). After everyone gathered in the family kitchen, "sister" Jandira asked why there were no more birds inside the cages located near the front door. Leonardo's mother explained that as soon as he came back from the hospital, her son wanted to free the birds from the cages, but as she was worried the birds would die of hunger, she gave them to her neighbors. Leonardo added: "I myself would have freed the birds from their cages because nobody should be imprisoned." Sister Jandira replied: "Even the birds praise the Lord and make songs to Him, it is not only we human beings who do that, because it is such a simple thing to praise the Lord." Although Leonardo was indirectly expressing his indignation towards psychiatric hospitalization, "sister" Jandira did not pay attention to this dimension of Leonardo's words and instead referred to the birds in praise to introduce the religious singing that was about to happen.

The pastor, two church "sisters," one church "brother" (ex-drug addict), Leonardo's mother and grandmother, his younger brother, Leonardo, and myself participated in the <u>campanha</u> that lasted less than half an hour. After singing two hymns to praise the Lord, everyone kneeled down in a different spot in the kitchen to start praying individually. These prayers were performed out loud with different rhythms, timings and tones producing an atmosphere of thrilling commotion. Leonardo remained very quiet and a little distant, only listening to other people's prayer. Then the pastor asked Leonardo to come closer so that he could apply the "blessing prayer" over his head in order to take all the "evil" away. Leonardo immediately warned the pastor not to touch his shaved head with his hands; he allowed the pastor to put his

hands over his shoulders, but not over his head. The pastor replied that "where" he is going to put his hands is not so important, only the presence of Jesus is important.

Before starting the "blessing prayer", the pastor told a long story (looking particularly at me) about his previous religious life as an Umbanda pai-de santo (medium leader), a position which provided him with enough experience to discriminate between "a problem for doctors" and "when it is not for doctors, it is only a spiritual problem." Only prayers and blessings would solve "spiritual problems" like Leonardo's. The pastor continued by mentioning the good example provided by another church "brother" present, and who succeeded in "liberating" himself from a previous life of drug addiction and drug trafficking after making contact with God. It is interesting to note that to guide his present religious work, the pastor also builds on his previous experience as an Umbanda medium. This illustrates once more the fluidity of boundaries and the existence of shared elements pertaining to the spiritual domain.

Afterwards "sister" Jandira asked Leonardo to open up any page of the bible by chance to read a paragraph. She interpreted what Leonardo read in the following way: "The doors are all open for you, they are not closed [...] yes Leonardo you were elected by God, you are one who was elected by God now." Leonardo felt some satisfaction in hearing these words, so he stared back and replied: "Your crown in front of God is huge, while my crown is still very small." The pastor then took the liberty to disagree with Leonardo: "To you the crown is very big as well." These comments seemed to comfort Leonardo, who turned to his mother to say that now he wanted to attend church once more, and would accompany her tomorrow evening. The pastor proceeded with Leonardo's "blessing prayer," but at the end the grandmother was in tears, so she asked the

pastor to be blessed as well: "Let the evil leave your body, so the voice of Jesus can enter our heart."

Jonas's story

The Methodist Church was part of Jonas's everyday life until he was 15 years old. Afterwards his mother and sister were the only ones to continue to attend church. Nowadays Jonas perceives himself to be a "spiritualist," without belonging to the Methodist faith. During his first psychotic episode Jonas secluded himself at home, spending most of his time in his bedroom. Some acquaintances from the Methodist Church soon came to pray for Jonas, at the mother's request. Jonas's mother noticed that her son became increasingly nervous with the prayers, blessings and testimonies. When the church "sister" declared that once she was very "depressed" herself, she had even tried to jump from her apartment building, and that only these prayers healed her, Jonas became so irritated with this testimony that he preferred to return to his bedroom. He also repudiated the pastor wanting to lay hands over his head. The church people reacted by explaining to Jonas that they had to bless his bedroom as well. Jonas refused to have any participation in these final blessings, withdrawing to his mother's bedroom instead. While they went in Jonas's bedroom the church people commented that there must be some espírito maligno (malignant spirit) hauling around the room that needed to be expelled. Several weeks later, devotees from the "Assembly of God" visited Jonas's home as well, but Jonas always avoided participating in the rituals.

Jonas's friends also attempted to give him some religious help. One of them tried a series of Reiki¹² healing sessions in order to bring Jonas's

¹² Reiki in Japanese means "universal life force energy," and is a widely known form of healing though the direct application of Chi, or a force very similar to Chi. Chi is the term used by Chinese mystics and martial artists to define the underlying force the universe is made of. Reiki is a system of channelling that energy to

"energy" level back to equilibrium. Another friend convinced Jonas to take a series of "discharge baths" (Umbanda) at home. Without understanding the real significance of these Chinese and Umbanda rituals, Jonas's mother accepted these forms of religious help until her son decided to avoid these friends every time they came back to visit. She was even feeling positive about the "discharge baths" because it forced Jonas to bath himself (which he was not doing) before the ritual bath. Jonas explained to me that he began to avoid any contact with these friends and the church people because he was feeling very indifferent to their religious help. But in parallel Jonas created on his own some private religious rituals that I will describe in the next chapter.

What is important to retain from these two cases is the space of negotiation created between the patient, the people offering religious aid, and the family members. Leonardo and Jonas experienced in different ways the religious help that was being offered to them. Leonardo liked to participate in the campanha, and on this particular day, he felt some comfort in hearing that he had been "elected by God," although he paid very little attention to what the pastor tried to emphasize in his blessing or preaching. Jonas progressively disengaged himself from the rituals, yet religious people continued to come, although less frequently. It is important to note that both of them felt very uneasy with the pastor's gesture of laying-on-hands over their heads. While this was a sufficient reason for Jonas to reject any further participation in the Pentecostal ritual, Leonardo was able to negotiate with the pastor to be blessed without being touched on the head.

My impression is that Leonardo also felt some sense of empowerment associated with his "shaved" head and requested it not to be touched by anyone. However his reaction could also have other meanings. Days earlier Leonardo had mentioned to his cousin that he had shaved his head during the psychiatric hospitalization because he

someone for the purpose of healing. It is believed that it was first discovered by the Japanese Dr. Usui in the late 1800's, a teacher and minister of a Christian school in Japan. In its simplest form the healer uses Reiki by placing his or her hands on the patient with the intent of bringing healing and willing for Reiki energy to flow (Herron, D., n.d.).

wanted to look just like a "policeman," a powerful figure always present in his previous experiences as a car thief to buy drugs. Just before this campanha, Leonardo told me that he had hated the psychiatric hospitalization because it was worse than a prison, and he recalled that several times in his life he had bribed the police to avoid going to prison, thus the hospitalization was for him intolerable. His younger brother also confided to me about feeling very scared to see Leonardo burn a whole bunch of personal photographs earlier that day, "just like a macumba's black-magic." It is well known that "spiritual guides" enter the medium's body through the head. Indeed the process of developing mediumship is often called "breaking the head." For this reason mediums regard their head as sacred, and will remain forever vigilant as to who touches it: they will often try to avoid crente healers, for they know they seek to lay hands upon their heads (Burdick 1993). One may also suspect that Leonardo's feeling of empowerment emerges from his beliefs in macumba. Apparently for him a meaning of "empowerment" is enmeshed with the figures of the "police" and Umbanda "medium."

The two stories above portray positive and negative reactions of patients to the religious help offered at home. Narratives collected from patients also shed some light on their reactions towards the various steps taken by them or their family in order to obtain religious help outside the home. In many occasions, attending church rituals appear to bring comfort and relief to the patient:

When my mother doesn't go to church, I go by myself or my father takes me to church. Ah, there I feel well, I feel well... The voices inside the church I do not hear the voices! Not inside there, not inside!

[Leonardo, The Return of Jesus Christ Church]

I would feel well [inside the church] but I always liked to go to church. When my mother would say 'I am going to take you to my church today, don't you want to go?' I replied that I wanted to go, then she would take me to church and everything. There were the prayers, everyone making prayers to me, my aunts and every one else, and so I am better now, thanks God. [Luana, God is Love]

There were times that I would go in the afternoon, in the evening, in the morning, it would depend. I liked to go because I would feel very well

[inside the church]. Ah I would feel a relief! [...] I would feel well, I would feel myself lighter... but it was not totally... I would also feel that I was not totally well. [Maria, The Universal Kingdom of God Church]

I was particularly surprised the first time I interviewed Leonardo and Maria because they were very emphatic in affirming that while inside the church they felt that some of their psychotic symptoms (e.g. "hearing voices," "emptiness in the head") disappeared. However, on other occasions they both revealed their doubts in relation to this, or even exhibited negative reactions towards church attendance, just as some other patients. In many circumstances, the person manages a kind of inner distance towards the religious ritual. It was striking to notice how the five young people (Luana, Sarah, Gisela. Dora, Daniel) whom I have actually accompanied to a religious ritual always maintained a certain position of distance and detachment in relation to the general commotion of the rituals. Luana was very distracted and paid little attention to The God is Love cult. She also had a hard time remaining seated and praying together with the other attendees. When we left the church that night she insisted to me that she always felt very well when going there. My impression was that most of the time the patients were participating in the religious ceremony without really being there. One may suppose that whenever the patient is able to maintain a "free" circulation and tenuous links with the religious ritual he or she experiences it in a positive and soothing way. However, during fieldwork, it was far more common to arrive at the family's home, and then to discover that the patient preferred to postpone "our" visit to a religious place for another day. Patients also mentioned that most church rituals provoked an exacerbation of fear, persecution, and alienation:

Suddenly I became like this... very quiet. Very quiet and only thinking that people were persecuting me. Inside the church I thought that people were getting together just because of me; they would make church meetings just because of me. [Dora, The Seventh Day Adventist]

I would feel very weak when I had to go to church, I would feel very bad. I was not even able to get inside the church, I was very afraid! [...] I thought that church people were possessed by the Devil. I would not let them put their hands over my head, because I thought I was healed. In my mind I was feeling well... the unusual things which I would see is because I really believed that it was the end of the world, so that was normal for me. I had

to search for the salvation of souls and preach to the people, this is what I thought. [Sarah, Assembly of God]

No I can only be very thankful to the pastor and all the other church brothers. The only issue is that I was not feeling well inside the church: sometimes the pastor would be there giving his sermon, while I only wanted to run away from the church.... The pastor would be talking up in front but I would not be paying any attention. I was not really feeling well inside the church [Leonardo, Return of Jesus Christ]

More generally, religious ceremonies and references often seemed to be loaded with ambiguity and paradoxes. If the reader recalls Dora's story described at the beginning of this chapter she began to act differently when she visited her parents in Northeast Brazil and started to preach for the salvation of all souls because the Judgement Day had arrived. Her parents were not particularly worried with her sudden fanaticism because she was also extremely joyful. Several months later in São Paulo, after her family recognized her psychotic episode, Dora refused categorically most of her mother attempts to take her to Neo-Pentecostal churches. Even though she justified that attending to Neo-Pentecostal churches was completely against her Adventist faith, she also started to feel very uneasy inside the Seventh Day Adventist Church, as evidenced in the excerpt above. Thus, she maintained a position of withdrawal from the church meetings because she could not escape from imagining that the faithful were articulating some conspiracy against her.

Dora's narrative evokes a possible convergence between personal experience and some aspects of a particular religious idiom. In her case, one could think that the Seventh Day Adventists' message regarding "the end of the world" resonated with her own quest for the meaning of life and death, for what would happen next (in the Judgement Day). In a similar way, Sarah relates the eclosion of her psychotic episode to the "end of the world;" her immediate reaction to all her unusual perceptions and experiences, was to pray for the salvation of all the souls. In her own understanding this reaction seemed reasonable because she was only trying to escape from the "end of the world." It is interesting to observe that both Dora and Sarah see their own unusual experiences reflected in the world around them, which they can only interpret as "ending." However,

they also attempted to distinguish themselves from all the other people since they had the impression they had a mission to accomplish while preaching for the salvation of all souls. In this context, they were often aware that what they perceived was not being perceived by the people around them.

Sarah always insisted in telling me in a very eloquent way that she was only "liberated" from psychosis after going through several faith-healing rituals of Pentecostalism. This perceived healing function Sarah attributes to religious rituals have to be situated in a context where religious signifiers permeated Sarah's psychotic experience. According to Sarah, the "liberation" was not achieved through personal conversion (baptism), but with the aid of campanhas at home and the correntes inside the church. Only the persistence of these prayers gradually made her feel better. However, Sarah did not always perceive prayers in a positive way. Sarah agreed with the Pentecostal faith that all "evil" must be eliminated; yet her awareness regarding the presence of "evil" (or Devil) operated in unstable ways. In the excerpt above, this is exemplified by the fact that Sarah sometimes confused and misinterpreted the religious signs and gestures that she received from the other church people. She would also become very frightened when she inverted the religious signs. While the pastor tried to exorcise the "evil" from her body, in several occasions she rejected this ritual gesture of laying-on of hands because she felt that all other church people, including the pastor, were "possessed by the Devil," except herself. On other occasions, Sarah received well the church prayers and blessings, although sometimes questioned whether she was being possessed by the Devil herself.

One can say that in Sarah's perceived world, religious signifiers were thrown into the turmoil of references she was experiencing. Sarah was often unable to distinguish the people around her from the frightening image of the Devil (evil). For instance, in some circumstances her mother only personified the Devil, while in others she associated her mother with the image of the Virgin Mary. Sarah seemed to be permanently caught up in deep contradictions of this kind. Frequently she also felt impeded of making sense of such unusual experiences. Was she being faithful to God? Was she being possessed by the

Devil? How could she trust herself? How could she trust a pastor who looked like the Devil? Why did the confidence she deposited on her mother makes her mother resemble the Virgin Mary? One may say that Sarah was constantly struggling to find some "holding point" (either in her or other people) each time the religious signs she experienced played out contradictory or ambiguous meanings.

Leonardo's attendance to Pentecostal churches was full of ambiguities as well. Initially he felt in peace every time he went to church but progressively his lack of attention towards the pastor's preaching and church rituals was transformed into a sudden urge to run away from church. This feeling was followed by extreme fear because he felt chased by the "voices" again, even inside the church. Inside the church the "voices" gained a religious connotation: "evil spirits" and macumbeiros were disturbing him, instead of the "voices" of the "police" and "car thieves" who had disturbed him before. Unlike Sarah, he preferred to abandon the Pentecostal church, although he returned several months later, after his second psychotic episode.

It seems that patients' experience in relation to religious attendance evolves between two opposite polarities which can transform into one another or combine in paradoxical ways: On the one side, religious attendance may bring some kind of relief and respite to the patient; on the other side, it may evoke negative feelings, such as persecution, which may exacerbate the patient's insurmountable and original fear.

The shifting boundaries between these two extreme experiences can be exemplified in the following case: the patient starts to feel persecuted by "evil forces", or hears demanding "evil voices" and decides to seek some religious source of help as way to escape from the "evil". Although the continuous religious attendance may bring some sense of peacefulness and safety, this may be slowly transformed in negative feelings (e.g. everyone inside the church "looks" like the Devil). In addition, a paradoxical backand-forth movement between positive and negative feelings may also emerge leaving the patient entrapped in deep and apparently unsolvable contradictions.

As it was the case for the parents, patients' narratives show that there exists a difference between searching for, or accepting to receive, religious help and religious conversion. Normally, the <u>campanha</u> at home and regular church attendance is supposed to lead to conversion (baptism) to Pentecostalism. While seventeen young people (76%) received <u>campanhas</u> at home, only twelve of them (57,1%) tried to attend at least to one Pentecostal church, and only nine (42.8%) were motivated to attend church more regularly during some period. Among these nine people, only four (19%) aimed at being baptised within Pentecostalism, while the other five refused. Two major reasons were involved in this refusal. Three people considered that baptism was unnecessary, because they had been previously baptised within Protestantism (Mateus, Luana, Edilson). The other two people however, felt that they were not yet prepared for the "straight path" that all <u>crentes</u> should follow (Sarah, Leonardo).

Claudia, Maria, Alice, and Daniel tried to receive baptism within Pentecostalism, but were not successful for different reasons. The young women involved themselves in rituals of baptism but this was much more a sudden decision they made while watching the ritual, hence with no previous approval from other church members. However church members did not prohibit their action, and they allowed them to join the ritual. Daniel's case was different, as explained below. Some time afterwards they all abandoned the Pentecostal faith; and the significance of their "baptism in the waters" was not sustained.

Daniel's story

Daniel was very proud to invite me to attend his "baptism in the water" in The God is Love Church. When we arrived at the place of the ceremony. ¹³ Daniel discovered that he could only be baptised after his 18th

¹³ This ritual is held only a few times during the year in a church property surrounded by a lake in the outskirts of the city (Bororé island). It is a big celebration where hundreds of people are "baptised in the water" at the same time, and they usually bring their families to see the ceremony, listen to the preaching and to socialise with other church members (see Figures 15 and 16).

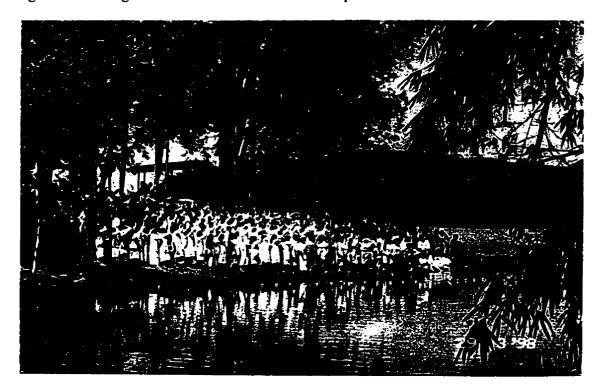
birthday, which would only happen some months later. 14 Daniel felt very ashamed to have invited me to a baptism that did not happen. However he felt very relieved to maintain his position of "new-converted" (person who adopts the faith but has not yet been baptised), because he also believed that he was not prepared to follow the "straight path" that all baptised crentes pursue. He thought that this would still be very difficult for him to undertake because he would have to give up cherished behaviours that constituted his youth identity. It was still hard for him to accept that after the conversion he would have to avoid listening to popular music on the radio (only religious music is allowed), and would not be able to wear jeans any more (only social clothes).

The ascetic behaviours required to frame one's life after conversion to Pentecostalism kept young people in the mediating position of "new-converted," or led them to abandon the faith. This strategy to maintain a position "betwixt and between" a previous "lay" life and religious conversion may be a common behaviour of youth, therefore not necessarily linked to the experience of psychosis. However in the case of psychotic patients, one may suspect that the strictness and a certain rigidity (e.g. you can only listen to religious music) of the rules imposed by conversion to Pentecostalism ascetic behaviours may be too hard and overwhelming to follow for those patients who have lost access to the common sense "rules of the game" that regulate everyday life.

¹⁴ Pentecostals insist on baptism being a unique personal experience of the Holy Spirit and one which can only occur after the age of reason and as a result of personal conversion while the Catholic Church practices it as a sacrament and a ritual which can and should be administered to infants (Lehmann, 1996).

1

Figure 15 and Figure 16 - God is Love Church "baptism in the waters".





Photos by Cristina Redko

Although most young people were first taken to the Pentecostal Church by their parents, some of them also expressed a personal desire to attend the church ceremonies, although for a short period of time. I would like to draw closer attention to Mateus and Leonardo's stories in contrast to Maria and Alice's. Both young males joined the Pentecostal Church immediately after the outbreak of psychosis. They associated this membership primarily with an attempt to fight their drug consumption habits. Both young females joined the church long before their family noticed they were having psychiatric problems and the psychotic episode is interpreted to be something related to their excessive religious involvement.

Mateus's story

Mateus was raised in a Pentecostal family and attended church assiduously. Even his father (who also had psychotic problems) seemed to be a very active crente while he was alive. Like many other male teenagers, Mateus became disinterested with religion and chose a more "rock and roll" lifestyle when he became older. Mateus's began to have some strange experiences, and one month later just after a long Carnival trip with friends where they consumed drugs excessively (marijuana, cocaine and LSD) he reported signs of a modification of his experience. His mother's first reaction towards his restless and strange behaviours was to take Mateus to the Universal Kingdom of God Church she attended. Every time they went to church, the pastor was unable to calm down Mateus and his behaviour only became more out of control. Mateus's stepsister decided to interfere because she immediately associated her stepbrother's behaviour with the schizophrenia of their late father. She and the mother convinced Mateus that they had to visit some distant relatives out-of-town but they actually took Mateus to the psychiatric hospital where the father had been interned several times. As soon as Mateus was discharged from the psychiatric hospital he decided to avoid his previous friends and engaged himself in the Pentecostal Church:

I go to church every Saturday and Sunday. Ah, feel well. Ah, the <u>espírito</u> <u>do bem</u> [spirit of goodness] because I am not using drugs anymore. [...] Ah I feel well because it is an environment where there are no drugs, no cigarettes, and there are a lot of youth looking for Jesus. Well the majority of young people I know are all drug addicts, everyone I know is addicted and mean! [Mateus, Community of Grace Church]

Leonardo's story

After the outbreak of his first psychotic episode Leonardo was so terrified by the "voices" which persecuted him that he was compelled to confess to his parents about his drug consumption habits (marijuana and cocaine) and his involvement in a car theft. His parents decided to send Leonardo to his grandmother's house so he could hide more safely from the other "thieves" and the "police" (voices). Leonardo imagined that the "voices" would invade the house at any moment to kill him and his whole family. Leonardo's mother however believed that her son was being persecuted by the "thieves," but she also wanted to alleviate the climate of tension between her son and her husband after Leonardo's confession. Both parents were enraged and worried with Leonardo's drug consumption. In addition, they could not forget that one of Leonardo's closest cousins had recently been murdered because of drug addiction and involvement in the drug traffic. The mother frenetically searched for a drug addiction centre to hospitalize Leonardo, but she was soon convinced by her sister-in-law and some other neighbours to take her son to a Pentecostal youth retreat instead. Leonardo readily accepted the idea of the retreat because he imagined that it would be a good place to hide from the "voices" and he hated the idea of being hospitalized. There was no vacancy in the retreat, but the church counsellor suggested to Leonardo that he attend a Pentecostal Church in his neighbourhood because he would be "close to God" in the same way. Leonardo then frequented the Pentecostal Church almost every day:

After I got into church I stopped smoking marijuana, I stopped going out in the night, every Saturday and Sunday I would go out [at the night]. Now I ask God to give protection to my family, protection to myself, to help me out and never let anything fall short in my home. I pray to my neighbours, I pray to the guys who persecute me. The difference now is that I look for God... in peace [...] I was such a fool. I would make a lot of disorder [street night life], I would do lots of wrong things. Not so wrong, just to have fun! [Leonardo, Return of Jesus Christ Church]

Some months later Leonardo stopped attending the Pentecostal Church and his mother condoned that he started to consume drugs again. During this period he mentioned to me that some young men from his previous street nightlife decided to convert to the Pentecostal Church in order to stop smoking crack. I asked him whether they were being successful and Leonardo exclaimed that it is very hard to quit crack, even though his friends diminished their consumption after the religious conversion.

These two stories are consistent with the fact that the most important reason that impels Brazilian males to go to the Pentecostal Churches is the desire to rid themselves of commonplace "vices" like alcoholism and drug addiction. Mariz (1994b) has argued that Pentecostal doctrines and worldview provide a frame that is helpful to fight against these "vices" and poverty, particularly alcoholism. Conversion to Pentecostalism would give the person a new sense of dignity, power, and lawfulness. Since alcoholism is basically conceived as the "work of the Devil," people are not considered responsible for their addiction, they are only victims; this diminishes their feeling of shame for their alcoholism. According to Mariz, this perspective connects alcoholism with sin, but it also frees the person from guilt or regret. The Pentecostal discourse emphasises that people are "liberated" from alcoholism, instead of making them feel any guilt or regrets for their sinful actions. This is achieved by "over-emphasising" that alcoholics are isolated from the church, doctrines and the power of God, so they have no autonomy and become an easy prey of "malignant forces." Paradoxically, it would be precisely this minimization of guilt, shame and regret that increases the person's ability to deal with these feelings. Even if these people are not held responsible for their addiction, they are expected to be

responsible in expelling the "evil" away through religious conversion and "spiritual liberation" (Mariz 1997, 1994a). I would rather say that Pentecostalism both accentuates a feeling of guilt and shame and offers a way to get rid of it.

Returning to Marcelo's and Leonardo's stories, it is clear that both young males became involved with the Pentecostal Church to escape from the "evil world" in which they were living before (e.g. drugs, police, street violence). Through participating in the Pentecostal community, they were also protecting themselves against the modes of life in which the "people of the world" live. Pentecostal followers often distinguish themselves from the inclusive society by calling every non-Pentecostal "people of the world," those who are liable to commit evil and sinful actions. They reject "the world" in such a way that a social withdrawal within their religious community protects them from the "malignant forces" that dominate the external world (everyone outside the religious community). Within the religious community a "private" morality is created because you may keep an eye on the other followers, but they watch your acts as well (Prandi, 1992; Machado, 1996). For instance, crentes easily recognize each other by the way they dress-up and the discrete way they always behave in public places (not religious places). They are also more confident to interact with the other crentes because they are reassured that these people are not affected by "evil forces" like every one else would be.

Although some did it more openly than others, five (out of ten) young males talked with me at some point about their drug consumption habits. The preferred illicit drugs were marijuana and cocaine, but alcohol and tobacco are consumed as well. It is important to note that all eleven young women denied any type of drug consumption. However the young males never expressed any feelings of guilt, regret or shame for having consumed drugs. Quite the contrary, drug consumption seems to compose the "ethos" of male youth while they participate in the "street-life." Thus, the widespread Pentecostal discourse that relates drug consumption with sinful action does not affect them. I have observed for instance, that during Leonardo's campanha (described

previously) he paid absolutely no attention to the "conversion testimonial" ¹⁵ given by the church brother who insisted to Leonardo that he was "liberated" from drug addiction only after he accepted Jesus as his Lord and saviour.

Leonardo and Mateus gave more weight to their escaping primarily from the "evil world" outside the Pentecostal community. They hardly expressed any feelings of guilt, shame or regret towards their drug addiction. This might run against Mariz's generic assumption that Pentecostalism helps people deal with their feelings of guilt, shame, and regret, even if only through "denial." For the time being I only suggest that in the case of the young people I have interviewed these are not the kinds of feelings that bothered them the most. I would suspect that it would also be the case for the other young people from the same environment.

I have noticed that religious conversion tends to remain unstable in the patients I have interviewed. This could be partly explained because the world space created inside the religion community comprises two main facets: On the one side, the faithful feel protected among the other <u>crentes</u> yet separated from the "evil" that affects all the "people of the world;" on the other side people from the same religious community are allowed to keep an eye on each other.

In the case of patients this vigilant behaviour might eventually exacerbate the initial feelings of persecution that probably influenced them to look for "protection" inside the religious community in the first place. Furthermore, the strictness and ascetic behaviour required in most religious communities after conversion makes most young people quit such "straight path."

¹⁵ According to Chesnut (1997) the "conversion testimonial" is one of the most effective techniques to attract people to Pentecostal faith. I heard a whole series of "conversion testimonials" during fieldwork. Often people gave these testimonials expecting to persuade me to convert to Pentecostalism as well.

Maria's story

Maria's first contact with the Universal Kingdom of God Church was through its TV programme broadcast every night until dawn. She was feeling very "empty" herself and thought that through religious participation (since she had no religion) she would feel better. Maria started attending the Universal rituals (correntes, libertação, baptism) in a very fanatic way and against her mother's will. Initially she felt very relieved to participate: "I would feel good inside, I talked with God, even though I would not have visions of spiritual things." Some months afterwards, Maria's mother (Seventh Day Adventist) had the impression that her daughter was being influenced by a neighbour who was a crente and convinced Maria that she was being possessed by some "evil" spirit that should be exorcised in the church. Once Maria tried to run away from home to exorcise the "evil spirit" in church, yet her mother was able to hold her "possessed" daughter with the help of some neighbours. They forced Maria inside the car to take her for the first time to the emergency room.

Alice's story

After having interviewed Alice and her mother at the Schizophrenia Programme I lost contact with them for several months. Alice's mother thought that their participation in this study could be prejudicial to her daughter because we talked a lot about Alice's involvement with the Universal Kingdom of God Church. Her mother was very concerned that continuing with this kind of talking would only produce another psychotic episode. Both of them believed the outbreak of psychosis to be mainly a consequence of Alice's sudden and fanatic involvement with this church:

When I got to know this religion I began to get involved not for the... but involved in the fanatic side... fanaticism, that means to be very attached to religion... and to do those things that they tell you to do. To do everything right; that is how I felt... not exactly obliged to do everything they demanded. It was not compulsory, but I would feel a force inside of me that a coisa ruim [bad thing] was coming out, a coisa ruim coming out [from me]. At the moment they talked about liberation, this liberation started to get me, how can I explain this, it could get you and start to affect the spiritual side of the person. They thought that... the person would go to church to be liberated and to expel the Devils from the person's body, and so I started to have epileptic attacks. [...] I thought that this was some spiritual thing because it did not depend much on me, it did not depend on me, because I would faint spontaneously, no it was not so spontaneous, but a force that would make me faint. Every time the pastor would say ha, ha, ha, to liberate he expelled the Devils, and so he said to get it, for it to go out from the person's body. Then it would get out of my body, and I would feel that it was little by little getting out from my body but this did affect my mind. It would get out from my body. This is what I felt, this is what I felt because it was not me doing it spontaneously. I would not know if this was some kind of hypnosis that happened to me too because everything depended on the pastor's voice.

[Alice, The Universal Kingdom Church of God]

Alice's mother started to find her daughter's behaviour very strange because she would come home from church very nervous and disturbed, she would not sleep nor eat, and was desperate to assimilate what was written in the bible all at once. The mother judged that Alice was totally "robotized" by the church's fanaticism. For example, one day she arrived home so agitated by the Universal Church that she automatically threw away the images of Virgin Mary and Jesus Christ that her grandfather kept in the house to pray:

I started to throw images through the window, Saint images through the window... I would start to talk alone during the evenings, and to prayalone. [Alice, The Universal Kingdom of God Church]

This action of throwing away the images of the Catholic Saints gains a special meaning because Alice tried to imitate the polemic and widely known "chute da Santa" ("kick in the Virgin Mary") episode. Thus, Alice agreed with her mother that she was "robotized" and could only keep thinking of the bible. Yet she also explained to me that

she needed desperately to read the bible because this would give her some sense of security, and because she wanted to understand a little better what was happening to her. It is very likely that this incomprehensibility about her own existence is what triggered her to go to church in the first place.

While Leonardo and Mateus expected to find some "protection" inside the religious community, Maria and Alice were searching for some "answers" in relation to their own existence. I suspect that all of them were unexpectedly attracted towards Pentecostalism because it provides very simple and repetitive messages to deal with most problems of everyday life. Any existential anguish may be easily resumed into a "battle" between good versus evil. God versus Devil. Another plausible interpretation is that such straightforward messages are so appealing because patients are themselves feeling engulfed in confusion, uncertainty and chaos. However their involvement in a religious frame is not always perceived positively by their family. In the case of the two young women the families progressively associated their "religious fanaticism" with the idea of excess and perceived it as increasing the risk of some medical problem (or relapse).

The religious membership of acute psychiatric patients who were consecutively admitted to a psychiatric unit in Southeastern Brazil was compared according to the diagnosis of psychosis in an epidemiological study (Dalgalarrondo, Caetano, and Laurito, 1994). Although the authors make no firm conclusion because of the possible non-identified selection factors in health seeking and hospital admission processes, they were still surprised to find a significant over-representation of psychosis diagnoses among Pentecostal patients when compared to Catholic patients. The authors wonder whether affiliation to Pentecostalism is a risk factor predisposing to psychotic breakdown or if pre-patients are more likely to join a religious church. Leaving aside the "chicken-orthe-egg-who-came-first" character of this question, which remains without answer, I would like to discuss a little further why psychotic patients are suddenly attracted to Pentecostalism and why afterwards they may reject it very abruptly.

Let's go back to Maria and Alice's stories. I hypothesize that they were searching for answers of the type "that is the way the world is" which are provided by Neo-Pentecostalism, rather than looking for some form of religious healing, at least in the beginning. Neo-Pentecostalism's position toward the world was also experienced by them in a very rigid way because gives no leeway for interpreting "the world" in a way different from what they claim. In addition, Maria and Alice were also "seeking for a way out," to use Binswanger's terms, in the sense of re-structuring their own existence. Their subsequent participation in religious healing rituals could arise out of this quest for "seeking a way out." However, it is also very clear in Alice's narrative that she abandoned herself to the religious rituals to the point that she felt "imprisoned" and would repetitively and excessively do only what the pastor said. Maria also became "stuck" in a movement of running to church all the time and at any time in order to take away all the "evil" that overwhelmed and encompassed her existence. Their over-involvement with Neo-Pentecostalism could be suspected to have accentuated their experience of psychosis and their perception of the world as divided in a very rigid way between good versus evil. It is of no surprise that they suddenly decided to abandon it, and that they themselves question whether Neo-Pentecostalism was what made them feel even worse. In many circumstances their unbearable dread of the evil world dominated their feelings towards the world.

Umbanda is the most common source of help sought by patients and families after Pentecostalism. However all the young people (with the exception of Gisela) have rejected Umbanda therapies after some try-out:

My mother went with me everywhere... even <u>macumba!</u> They gave me <u>passes</u> because they threw popcorn over me like this! I felt just the same. I got out of this, I only went once, I hate <u>macumba!</u> My mother has done everything for me to heal [Claudia, The Congregation of the Virgin Mary Church]

On another occasion when I talked to Claudia she expressed once more her aversion towards Umbanda: "Ah, I didn't like it, I got very anguished, I only got worse."

But she was unable to explain what exactly she didn't like about it. The most common

justification I heard is that these young people "felt just the same" or they experienced only a momentary relief after undergoing some Umbanda therapy. I suggest however that two other elements may have contributed to enhance their rejection of Umbanda: the context of the help-seeking initiative, and of the healing ritual itself. As was mentioned before, the individual's/family's resort to Umbanda was normally veiled from the other members of the family. For instance, the father would take the young person without telling him or her where they were really going and without the mother's knowledge or will (Eduardo, Edilson) The three young men (Leonardo, Daniel, Hélio) who resorted to Umbanda on their own initiative, did so secretly. They also preferred to keep secret most of what happened with them there. Most often the young people and their families regarded Umbanda with suspicion and mistrust right from the beginning. This character of secrecy is also related to the ambiguous place occupied by Umbanda in the religious scene of São Paulo, especially for those people with a Protestant religious background.

People came to take us to the Umbanda center, and I said that I would not take my daughter. I only took her because my neighbor insisted too much. No, that was not an Umbanda centre, but a woman [Umbanda healer] who would consult at home. Then the woman boiled some herbs and gave a discharge bath on my daughter and everything else. But my daughter didn't want to take off her clothes because she gets embarrassed, she is shy. My daughter didn't want to take off her clothes and the woman got mad at her and everything, so I went only once and never got back, I said I am sorry because... I didn't like it, and my daughter didn't like it either. [Carmen's mother, Non-Practicing Catholic]

This initial shared attitude of suspicion, mistrust and secrecy helps to create an atmosphere of incredulousness even before the start of the Umbanda therapy. In addition, the two excerpts above indicate that Claudia and Carmen were also feeling very uncomfortable in participating in the healing therapy itself. It seems that Umbanda healing practices have more potential to reinforce fearful rather than soothing experiences.

Solange's story

Curiously, Solange did not even recall the episode when her husband took her to an Umbanda centre. She became very rebellious and enraged with her husband when she discovered it. Her sister-in-law tried to reconcile them by telling Solange that while she was in the Umbanda centre nothing bad happened to her because she would only say: "I have faith in God and there is no person better than God." Her mother explained to her that Solange's husband didn't really know what to do to help her out, so he followed the advice of a neighbour and spent a lot of money that he didn't have to pay for the Umbanda ritual. Although the mother was also trying to bring some conciliation to the climate of intrigue, she believes that her daughter only came back worse from the Umbanda centre. In addition, she disapproved of her son-in-law's attitude from the beginning because it was against her Pentecostal faith.

Leonardo's story

One week before Leonardo started to attend the Pentecostal Church regularly, he asked a close neighbour and old friend of his mother who makes dispatches of <u>macumba</u> to help him out. He commented that many members of his extended family believe and eventually use <u>macumba</u>. He assumed that I was going to recriminate with him in some way because of this dispatch of <u>macumba</u>. Thus, he emphasized to me that he had no intention of doing any "black-magic," but that he only wished to keep away the guys (voices) which were persecuting him. He bought the material (e.g. candles, chicken) including some clay for the neighbour to mould the image of the <u>capeta</u> (exu, or Devil) but he did not have to pay any money for the dispatch itself. The neighbour also asked Leonardo to mark down the names of the people (voices) who were persecuting him, but since he didn't know the names he invented some. He decided to give

the names of some people who had teased that week. He saw her doing the dispatch of <u>macumba</u>, although he refused to tell me any more details about it. He reiterated that he only felt a momentary relief after doing this dispatch because soon afterwards the voices started to disturb him again.

While Umbanda dispatches or consultation rituals seem to be ineffective for most patients, the major distinction between the stories of Solange and Leonardo is that the former was taken to the ritual without being aware of it, while the latter searched for this form of help-seeking on his own. Furthermore, Leonardo only tried to do the dispatch with a close friend of his mother that he trusted completely. Gisela's story described below is more complex because she tried out different folk healers.

Gisela's story

Gisela had passed through several <u>benzedores</u> (folk healers, some from Umbanda) before she was admitted in the psychiatric ward of the São Paulo Hospital for twenty-one days. After being discharged Gisela still went weekly to see the psychiatrist for a couple of months. She and her husband became progressively annoyed and unsatisfied with the psychiatric treatment received there because in their perception the psychiatrist would only increase the dosage of neuroleptics without solving the problem or giving any concrete or sensible explanation about what was Gisela's illness. Thus, she decided to quit the psychiatric treatment at her own risk and she started to feel better without taking any anti-psychotic medication. Simultaneously Gisela found some help and respite with the spiritual treatment offered by another Umbanda healer they discovered:

I thought I was well already, in this part [material illness] I did not take any more medication, everything that he [psychiatrist] prescribed because when I was sick and I would go and consult with him, he would always prescribe and increase the pills. No, now you are going to take this one [pill]. And he would always increase the pills and I would see no result.

After I started to go to a folk healer is when I got well, when I stopped with all the medication and I didn't take it anymore. [Gisela, Umbanda sympathizer]

She told me that only this last Umbanda healer was capable of solving her problem. But this is not what happened with some previous Umbanda healers she consulted. She recalled that one of these previous healers forced her to participate in the ritual sacrifice of ebó in which all sorts of foods and beverages are thrown over the person. She became extremely irritated with the ritual and didn't like the fact that she got very dirty: "Ah. I got very disgusted and enraged because I told him that he wanted to kill me with a bowl full of things... Uhhh!" The last Umbanda healer seemed to be less affronting to Gisela although he asked her to take some garrafadas in "discharge baths", and to go by the sea to do some dispatches to Yemanjá to ask for protection. Even though her husband had to spend a lot of money - he paid USS100,00 monthly, and which totaled more than \$1.000.00 - to buy the material for the dispatches and discharge baths, he believed that it was worth all the debts he made because his wife finally got healed.

Gisela always gave me the impression that she maintained herself at some distance and expressed a certain feeling of alienation when she tried to engage herself in these Umbanda consultation therapies. This impression was only confirmed when I accompanied her to her spiritual healer. She justified her invitation to visit him by the fact that he would be the only one capable of explaining to me what she went through: both in relation to her illness and the religious therapies. She explained to me that she herself didn't remember what happened to her during her illness and that she was not able to explain the kind of Umbanda therapies she went through. She seemed to be somewhat disinterested in the meanings or the reasons she went through these Umbanda therapies. What was most important to Gisela is to feel reassured that she was definitely healed.

When we went together to talk with the Umbanda healer I noticed that Gisela felt very afraid and trembled when the Umbanda healer changed his voice tone, because he was incorporating the spirit of the tranca-rua, 16 and started to talk and give advice to each one of us (Gisela, her husband and myself). We all prayed together the "Hail Mary" and the "Our Father Who Art in Heaven", and this was the part of the ritual that Gisela seemed to enjoy most. 17 Before the advice was given tranca-rua asked each one of us to drink a whole glass of vermouth (which I hate!) in one sip, although he gave Gisela only a small dose. What tranca-rua basically told Gisela is that she should continue to come and see him every two weeks to be blessed and to be ascertained that she continued to have her corpo fechado. 18

Since I visited Gisela some other times after this event I was able to notice that she was not going as frequently to the Umbanda healer as in the beginning of her therapy. She commented that one of the reasons that she was not going to the Umbanda healer so often anymore was because she was having constant fights with her husband regarding the envy and conflict with her sister-in-law. She would only go to the Umbanda healer in the company of her husband because she avoided to circulate in the city by herself. The last time I visited Gisela she told me that several times in the past few weeks she was feeling persecuted by the image of some "person". This made her go back to the Umbanda healer, and he calmed

¹⁶ <u>Tranca-rua</u> is a common name given to the spirit of <u>exu</u> (both in Umbanda and Candomblé). I have already mentioned in Chapter 6 that the <u>exu</u> often can provoke negative and positive effects, just like a trickster, even though he is more associated with the negative and evil.

¹⁷ I would like to add that Gisela considers herself an ardent Catholic, and she keeps a huge image of Nossa Senhora de Aparecida on top of her night table, although she doesn't attend Catholic Church as often as she wanted.

¹⁶ Corpo-fechado (closed body) is a popular term used by Umbanda healers which means that the person's body and soul are protected of the influence of malignant spirits, dead spirits, or vagrant spirits. When the person has corpo aberto (open body), he or she is more susceptible to receive the influences or incorporate one of these evil spirits. Umbanda therapies such as discharge baths and dispatches are helpful to protect the person in order to regain a corpo fechado

her down by explaining that what she was seeing was a "dead spirit" who used to live close to her house, and that this was only happening because she was still a little bit "weak" (body and soul). Since she was being blessed by him (Umbanda healer) this time, the "dead spirit" was not going to disturb her or incorporate in her body. He also promised to go to her house to fumigate ("spiritual cleansing") the place.

I have not followed Gisela's story any longer since I went back to McGill a couple of days later. I am not certain whether she continued to go to this Umbanda healer or whether she searched other religious sources of help, or whether her feelings of persecution increased with so much intensity that she had to see the psychiatrist again. What I can say is that the moral and religious universe of the Umbanda healer was much closer to Gisela's worldview (e.g. beliefs in encosto, "dead spirits", coisa feita) than to the responses of the psychiatric resident who would never give her any plausible explanation about what was happening to her, in addition to prescribing neuroleptics that only made her feel worse.

Religious Help-Seeking: an Ambiguous Quest

Reflecting about the patients' perspective towards religious help-seeking I would like to highlight three major issues that traverse what I have described so far. The first issue is related to the attendance of religious rituals; it seems that patients feel a certain sense of peacefulness when they are able to maintain a certain distance from the "main stage" and general commotion of the rituals. In this case Pentecostal rituals often allow some space for the patient to circulate without being the focus of direct attention. One may wonder whether this "free" circulation within the "protected" ambience of the religious setting may be a contributing factor to the building of feelings of trust and relief.

The most common behaviour of patients is to participate in a marginal way in the religious healing rituals; or alternatively, they may elaborate their experience of psychosis

by making a profuse use of religious signifiers or in some cases they may create their own private rituals (see the next chapter). Patients seem to resist becoming normal followers by playing or remaining at the margins. In this sense the modes of behaviour expected in religious rituals are played out in a very flexible way by patients. This is exemplified by their going to church only when they wanted to do so, or by the fact that Claudia, Maria, and Alice decided on their own to "baptize" themselves.

I suspect that the directness of the one-to-one interaction between an Umbanda healer (or Pentecostal pastor) and the patient, which may occur during some forms of religious healing is what is most often rejected by the patients. One can remember here the pastor's gesture of laying-on-hands over the patient's head to expel the evil spirit away from the patient's body. I would say that this gesture entails a very powerful meaning since it represents the direct contact with the evil (or Devil) that has to be exorcized from the patient's body in order for the patient to enter in direct contact with the Holy Spirit. One can only speculate about how patients have experienced this ritual of a direct contact between the Holy Spirit and evil forces. I would not be surprised if they eventually confused the meanings attributed to the "power" of the Holy Spirit and the "malignant power" of the evil (or Devil). Furthermore, these therapeutic rituals may "invade" bodily frontiers of the patient which are already "blurred".

The second major issue takes into account that that patients' positive feelings and reactions towards religious healing and religious help-seeking are constantly shifting or infiltrated by negative ones. Patients appear to be thorn between contradictory stances. They tend to feel immersed within a threatening world and surrounded by threatening forces. This general feeling gives a particular quality to their lived world and can permeate the religious sphere. Nonetheless, they search for benchmarks and reassurance, thus churches or religion can provide them with a possibility of faith and trust, and give them some sense of certainty, peacefulness, and security. More commonly, these two sets of attitudes are in parallel or in alternation. Consequently, they move back and forth in the religious world in a constant quest for stability and significance.

The third issue is related to the flexible, shifting and ambiguous nature of religious signifiers. I suggest that this aspect surpasses the "common shared beliefs" quality which pervades most religious idioms. The flexibility of religious idioms enables patients and family members to play with religious signifiers from distinct religions without being reproached. However, patients and family members can play with religious signifiers in particular ways which are not totally congruent with the collective meanings given to these religious signifiers. Furthermore, patients may be torn by a paradoxical position in relation to religious signifiers or their religious involvement. It is particularly evident through the stories of Maria and Alice described above, that they also experienced their devoted religious involvement in a very rigid way. When this happened they found no other "way out" besides abandoning their fanatic participation at the Universal Kingdom of God Church. I further hypothesize that when patients are able to maintain a certain position of marginality towards religion, this may contribute to the reorganization of their inner psychic space, since it allows them to move back and forth in a restorative quest towards self-preservation.

One may conclude that in most cases Pentecostal rituals and Umbanda therapies were not completely effective in terms of "healing" psychosis. If patients and family members gave preference to Pentecostal rituals this can also be related to Pentecostalism being the form of religious help that was "most at hand" for them. In addition, the resemblance of some psychotic symptoms with recognized signs of "demonic possession" (see also the next chapter) may have influenced families to search Pentecostal religious sources of help. One also has to take into account that 52.8% of the families who participated in this study had a Protestant religious background, and therefore, they were more liable to resort to Pentecostal forms of religious healing to begin with.

By contrasting patients' attitudes towards religious help-seeking in relation to their families, it is evident that patients presented more ambiguous, contradictory and paradoxical reactions than the families. This is likely to be related to the interactions between their psychotic experience and religion; thus their resort to religion is most often associated to a quest of significance in relation to themselves and the strange and uncanny

experiences they were having. However, family members also presented ambiguous and contradictory reactions, but they also demonstrated the clear intention, faith, and hope to cure the patient through religious healing.

Chapter 8 - Religious Construction of Psychotic Experience

VOICES

Voices, voices, I can't get rid of them telling me where to go what to do I can't hear you God I'm drowning in confusion the cacophony of voices is enough to make me crazy I need your still small voice I can't hear you I plug my ears and the noise gets louder I try to listen to you but shrill voices are all that I can hear God. God. I can't hear you I can't find you I can't follow you I'm too busy listening to everyone else I want to hear your voice I want to know you I want to hear your voice I can't stand confusion I'm so lost I need your voice

(Poem by Katy Schrader, n.d.)

Religious Shaping of Experience

In the previous chapter I have emphasized the overall significance of religious strategies of help-seeking and healing after the outbreak of a first psychotic episode.

Nevertheless, the role of religion as a potential source of help and healing is only one of the ways through which religion affects the experience of psychosis. Religion also has a more direct impact on the articulation of experience for people with psychotic problems. My analysis is inspired by the perspective developed by Crapanzano (1977) in his studies on spirit possession. I retain particularly the notion of articulation of experience by which cultural idioms represent a matrix of meanings and provide a basis for action both at the idiosyncratic and cultural levels. For instance, spirit possession provides a particular idiom which enables the "possessed" individual to articulate a certain dimension of his or her experience and to give it new meanings. The complementary notions of cultural idioms and of articulation of experience allow the reposition of religious signifiers within the larger religious frame to which they belong and to pay attention to the ways they are borrowed, used and transformed by singular persons.

One could say that I am interested by the "work" of religious signifiers following Obeyesekere's (1990, 1985) notion of "work of culture," in order to elaborate the inner experience of the person suffering psychosis. We will see that a particular religious signifier may be interpreted or used differently by patients and significant others, or by patients in different contexts or at different periods of their lives. In his work Obeyesekere was particularly interested by the way collective symbols are appropriated by singular persons and used to express, transform and to communicate personal experiences of distress and suffering. His notion of "personal symbols" expresses the idea that some symbols operate simultaneously at the personal and cultural levels; they allow the expression of the unconscious thoughts of the individual and provide a basis for self-reflection (private dimension), as well as for communication with others (public dimension). Since these "personal symbols" are public and private at the same time, they provide the person with option, choice and the leeway for manipulation. In addition, they may operate either in a progressive way, towards restoration and elaboration, or in a regressive way, remaining trapped within repetition, personal conflicts or problems

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¹ Obeyesekere (1990: xix) has defined "work of culture" as "the process whereby symbolic forms existing on the cultural level get created and recreated through the minds of people." For more details refer back to Chapter 2.

(Obeyesekere, 1990, 1981). From that, I retain that the resort to religious signifiers does not necessarily have a healing function. As seen in the previous chapter, they can also reinforce fear and confusion, depending on the position a patient adopts towards them.

I selected the most prominent religious signifiers that emerged from the narratives of patients and family members. These religious signifiers originate from the diversity of religious idioms that traverse Brazilian culture; most frequently from the Catholic, Protestant and Afro-Brazilian religions. Basically, there are two sets of key religious signifiers: those signifiers belonging to mainstream religions, more specifically God, the Devil, the Holy Spirit and the Bible; and those signifiers that are broadly associated with a range of supernatural beliefs, like witchcraft, macumba or coisa feita, "spirits of the dead," encosto (leaning spirit) and other types of spiritual entities (usually with an evil connotation). I will also mention less typical religious signifiers that only have been used by specific patients when these appear particularly significant to the personal experience of a person. See for instance, the case of past life regression (Neo-Esoteric religious idiom), reincarnation, and incense (religious signifiers) described in Jonas' story below.

The relevance of analysing religious idioms and signifiers is to unravel in which ways these cultural elements orient and organize practices, explanations and meanings on the side of particular patients and family members. Some religious signifiers have the potential to embrace and condense different functions or levels of meaning. This is particularly the case with macumba that appears to fulfil various functions in the narratives I have collected. I have already mentioned that several young people were confronted with these when being led by their families to participate in some work of macumba (or Umbanda therapy) to counteract possible noxious effects. Macumba can also be evoked as a causal explanation or manipulated as a religious signifier with the sole intention of transforming psychosis into a more comprehensible experience. The term macumba is also used to refer to some personal (and idiosyncratic) rituals that some young people create for themselves in order to cope with psychosis. Referring to macumba tells little of the particular meanings, uses, and connotations that are attached to particular practices in these various settings.

In this chapter, I first illustrate the place and the ambiguous function played by religious references through discussing a few idiosyncratic religious rituals elaborated by patients. In order to explore the significance of religious signifiers for articulating the interpersonal and personal experience of psychoses, I then take two broad perspectives: First I consider the place of religion in the broader context of cultural etiologies resorted to by relatives and patients; and second, I focus on the ways patients use and appropriate a few key religious signifiers from within the experience of psychosis. In both approaches, religion is discussed from a perspective close to what Weberians call the problem of meaning. One may also say that psychosis often involves the construction – or better, the creation of a world that makes sense for the subject who is experiencing psychosis, but does not make sense for others.

Jonas' story

Jonas' initial awareness of the outbreak of his psychosis is associated with his solitary effort to conduct a past life regression therapy done through hypnosis while repeating the orientations of a TV program he watched one night.² He explained that he tried this regression to remember past facts about his own life that remained blocked in his mind. He would talk and answer back to his own unconscious mind in order to

According to Inessa King Zaleski, a hypnotherapist who lives in North America, past life regression therapy is an effective way to discover the reasons for current fears, recurrent dreams and personality tendencies by understanding them, learning from them in order to let them go forever through the exploration of the person's past lives. For example, a man had an unexplainable and severe fear of large bodies of water but he never lived next to one in his life. When he was regressed to a past life he found himself 8 years old and the only witness to his parents drowning in their little boat filled with water while he was running back and forth helplessly on the beach. Age regression is the process of going back to a previous life in your current life to discover repressed memories that affect your subconscious actions and reactions. Future life progression is a progression into a future life. Past life regression is based on the belief system of reincarnation present in Buddhism, Hinduism, and Islamism which states that people have lived many times before and that their spiritual development evolves with each lifetime. When one experiences past life regression the person is led back to a different time through hypnosis and feels that he or she is in a different time and space from where the person can talk and answer questions about his or her experience. This experience is most effective when guided by a therapist even though it can also be successful when guided by a recording. (Zaleski, n.d.). I would add that reincarnation is a very popular religious signifier in Brazil that has been largely spread by Kardecismo.

return to his childhood (age regression) and start using what was useful then, but which was presently blocked. He expected that this access to the blocked information of the brain would help him analyse some present problems related with unemployment, high debts, and a difficult relationship with his mother and sister. Through the explanations of the TV program Jonas understood that all the burdens from previous lives are found in the cells of the person because each cell has a "memory." Much later. Jonas questioned whether this regression contributed to the emergence of his problem (psychosis), even though he also perceived it as the best form of support he encountered to face his troubles. Curiously, he made no direct causal link between the social and family problems he was facing and the outbreak of his psychotic episode. In addition, he associated the deposit of past lives problems in the "memory" of one's cells with a genetic mode of transmission.

When Jonas first told me about this regression I only imagined that he was interested in learning some neo-esoteric practice since during the same period he also attended some acupuncture sessions. However Jonas' mother and the emergency room psychiatrist immediately interpreted the regression as a sign of psychosis. They also blamed Jonas for trying the past life regression by himself without the proper guidance of a hypnotherapist. As long as he persisted talking about regression this also indicated to them that he was still not feeling very well. He was so driven by this frame of reference that he tried a few times to hypnotise his mother to force her to solve her problems through regression. Besides this regression, Jonas also performed idiosyncratically another private ritual in his bedroom. Most of the times he left his bedroom in the dark with the windows shut to burn incense.³ He also transformed the bedroom into a

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³ The use of incense is a very ancient religious custom employed by Egyptians, Hindus, Buddhists, Chinese, Japanese and the Catholic Church. The early Egyptian used incense as a basic ingredient for sacrificial rituals to counteract disagreeable odours and drive away demons because it was believed that incense both manifested the presence of the Gods (fragrance being a divine attribute) and to gratify them. Hindus burn incense for ritual offerings and for small offerings in their own homes. Buddhists burn it during daily rites,

small "sanctuary" by always keeping the Bible visible with a cigarette on top of a page that he opened at random. His mother imagined that to keep this cigarette on top of the Bible symbolised some <u>pedido de oração</u> (prayer request) that Jonas was making. She innocently believed that her son was asking God to help him quit smoking. It is understandable that Jonas created a "sanctuary" out of his bedroom since this is the place where he remained withdrawn most of the time.

One may say that regression and the "sanctuary" are two private rituals that Jonas created for himself while attempting to cope with psychosis, most specifically while dealing with the terrible fear he was experiencing. Past life regression can also be considered part of a religious idiom since it is based on the belief system of reincarnation and one's spiritual development. In this case Jonas used at different levels this religious idiom of past life regression. He perceived it as a help-seeking pathway to solve his personal problems, and the contrary, he also wondered whether the past life regression was what triggered his problem (psychosis). One may say that while Jonas was borrowing the religious idiom of past life regression and its signifiers, he also transformed it and subverted it. For instance, Jonas did the regression alone, without the aid of a hypnotherapist. He also attempted to hypnotise his mother only through his "thinking", since they were often not in the same room. Jonas felt empowered enough to hypnotise himself and other people (even without their knowledge). Thus, past life regression retains an ambiguous and contradictory position in Jonas' experience, working simultaneously as a perceived cause, as a form of expression, and as a way to cope with his problem (psychosis). For instance, he interpreted that his problem was related to some kind of "mind block", therefore the practice of past life regression seemed to be so important.

festivals and initiations. Chinese burned incense during processions to honour their ancestors and household Gods while in Japan incense is incorporated in the rituals of the native Shinto religion. The Christian church started to use incense in Eucharistic ceremonies since the 4th century to symbolize the ascent of prayers and the merits of Saints. The symbolic meanings of incense include purification and prayer, and it is also perceived as having special powers such as the ability to rise to the sacred realm and reach the divine beings of one's religion. Because of the widespread belief that incense is close to the divine most people use it for private prayer or to feel closer to the Gods. Other may use it for relaxation, for some kind of holistic therapy or simply to achieve spiritual peace (*The Spiritual History of Incense*, n.d.; *The Incense Story*, n.d.).

With regard to what I have called the "sanctuary", I have mentioned before that Jonas preferred to spend most of the time in his bedroom because it was the place where he found some peacefulness and could deal better with his fear by avoiding contact with other people and by sleeping most of the time. Jonas' girlfriend was particularly concerned that Jonas kept his bedroom disorganised, with the mattress on the floor, clothes all over the place, dirty, and dark all the time (with the windows shut). Jonas' mother however paid more attention to the fact that Jonas constantly burned incense and that he carried the family's Bible up to his bedroom and left it open at different pages always with a cigarette on the top. One possible interpretation is that the Bible, the incense, the cigarette, the dark room, and the strange ways the other bedroom objects were ordered at the same time expressed Jonas' "disorganised" experience but also allowed him to create some kind of "sanctuary" and a more peaceful atmosphere. Although this private ritual is much less elaborate than the regression, it probably had some special significance for Jonas. However, Jonas never mentioned to me that he was keeping the Bible in his bedroom. He only talked about the incense without giving it any spiritual connotation. He explained that to burn incense was the easiest way he found to hide the smell of marijuana smoke from his mother.

One can wonder whether marijuana was just another element (veiled) that composed Jonas' "sanctuary" ritual, or whether Jonas attributed some spiritual or religious meaning to smoking marijuana alone in his bedroom. But the fact that he always left a tobacco cigarette on the top of an open Bible suggests some kind of association between the act of smoking and the spiritual realm. Ironically, while Jonas is manipulating a series of religious signifiers to cope with his suffering, more specifically the regression and the "sanctuary," these are often viewed as "pathological" or negative signs by the outsiders (mother, girlfriend and psychiatrist).

Several other young people I worked with created such kinds of "private religious rituals" during the outbreak of their psychosis. Frequently they repeated or transformed portions of some well-known religious ritual, alone and idiosyncratically. Often the idiosyncratic, persistent or displaced character of these religious performances was what

first alerted family members to the existence of a problem (psychosis). Narratives mention numerous examples of "private rituals". For example, one can mention Alice's "robotized" behaviour while she reads the Bible continuously and throws away all Catholic Saint images that she finds in her way; Maria's intransigent fasting and sole attempts of exorcism when she cries out loud "burn the Devil, burn the Devil" while kneeling down over her bed; Leonardo's simulated work of macumba while he burns his photos and other personal objects in a campfire lighted up in the backyard; or Dora's unremitting preaching and Bible reading around the town on behalf of the salvation of all souls.

The young people described to me these idiosyncratic "religious rituals" very en passant or it only appeared in "bits and pieces", fragmented throughout the narratives. One may wonder whether this is related to their going through their first psychotic episode, and whether with the progression of the illness they may have more chances to elaborate and increment these personal rituals. This kind of elaboration is exemplified by the case history of Mr. A. described by Corin & Lauzon (1992) and summarized by me at the end of Chapter 2. These authors argue that these "private rituals" and the space of "positive withdrawal" contribute to create one of the basic ways patients attempt to cope with psychosis. One may suspect that the young people I interviewed diminished the importance of these behaviours or they preferred to conceal their practices. Another hypothesis is that the young people had very few chances to create a space of solitude allowing them to carry out these private and idiosyncratic rituals. Various factors may have diminished the opportunity to construct a "living space" of "positive withdrawal:"

- (1) Lack of concrete space in the household where they could be alone by themselves, due to their life conditions (see Chapter 3).
- (2) The constant presence of family members who kept the patient imprisoned within a web of "protection" or of "vigilance" (see chapter 5).

⁴ This is a common expression employed by pastors of Neo-Pentecostal churches during rituals of exorcism

(3) The fact that most common religious idioms in Brazil do not encourage the person to remain alone for long periods of time, like in meditation, private retreats, or renunciation to the world.

These private and idiosyncratic rituals evoke different kinds of reactions from family and community members. I suggest that these reactions can be separated into three different phases, even if they do not always follow a sequential order. At the beginning of the problem when the patient starts to pray, read the Bible, or goes to church more often, this is usually positively perceived by family members, especially the mother. From the perspective of family members, it is only when such praiseworthy behaviours like praying, reading the Bible and fasting become eccentric, exaggerated or excessive that they lose their positive value. Young people themselves normally overlook or may even be unaware of the exaggerated, excessive and odd character of their religious behaviours, particularly because they are feeling so desperate and anguished that they continuously search for alternative ways to cope with their problem:

Since the surgery was so purulent, I started to read the Bible a lot. I started to meditate a lot about God's words. [Sarah, Assembly of God]

There is no condition to reduce the fear. So I pray a lot. [Hélio, Umbanda sympathiser].

The church helps a lot to release your speech. So I prayed a lot. [Milton, Catholic]

Whenever I feel like it, I kneel down, I kneel down and pray. I pray to ask God... for God to liberate me from this illness. This can only be an illness. [Leonardo, The Return of Jesus Christ Pentecostal Church].

During this second phase, patients may be intensely involved in religion as their symptoms worsen; sometimes they may be able to elaborate through the religious idiom their personal and fragile experience in a positive way. What I am calling the third phase is more likely to occur after several psychotic episodes. During this period, family and community members may sometimes "normalize" or accept more easily some odd and idiosyncratic religious behaviours manifested by patients because they have already acted in this way before. This generalized acceptance can provide more freedom for patients to

behave idiosyncratically; although the passage of time also allows patients to accommodate their experience of psychosis within their life world. Their unordinary experience may become more closely related to the religious world, and most importantly, with their particular and idiosyncratic ways of resorting to it. This is illustrated by Nunes (1999) who investigated the ways the religious idiom of Candomblé contributes to the articulation of the experience for chronic psychotic people. She observed that although these chronic psychotic people have "broken up" their relationship with Candomblé, they continue to refer to its religious idiom. Furthermore, they apparently use the religious idioms in a very flexible and idiosyncratic way by creating a bricolage of several religious signifiers that are then re-integrated in their particular mode-of-being-in-the-world.

Most of the time, the young persons' and family members' perceptions differ in what concerns the significance of these religious behaviours and their interaction with psychosis. Since they are experiencing deep contradictions within themselves and in their surrounding world, patients often manipulate the religious signifiers in ways that are much more complex, open, and shifting than what has been described so far. Before exploring in more detail how religious idioms and signifiers can be incorporated in their experience of psychosis, I will discuss the role and significance of cultural etiologies for patients and family members, and leaning the focus more specifically to religious etiologies. I will describe in which ways these "causal explanations" can affect the personal and interpersonal experience.

Cultural and Religious Etiologies

Anthropologists pay great attention to cultural etiologies which are being defined here as "causal explanations" that people give to what they are experiencing in terms of illness. Regarding the experience of the first psychotic episode discussed in this work, cultural etiologies may have a relationship with some "anchoring event" which occurred at the time of the outbreak of psychosis (see chapter 3), but that is not always the case.

The notion of cultural etiology implies an explicit relation of causality, which is different from attributing meaning to what one is experiencing. For instance, the patient may be seeing dreadful images or hearing threatening voices that he or she immediately associates with evil spirits, without thinking that his or her problem is due to spiritual causes.

A careful reading of illness narratives indicates that cultural etiologies invoked by both family members and patients frequently lack the logical and causal coherence often expected by anthropologists. Young (1982b, 1981) argues that inconsistencies in cultural etiologies can be understood in terms of multiple types of knowledge structure or styles of reasoning.⁵ Young claims that illness narratives reveal at least three distinct forms of knowledge at play in people's explanations:

- (1) Formal and informal models derived from explanatory models based on causal logic.
- (2) Knowledge based on prototypical experiences of patient and significant others and which are called upon analogically through images and metaphors.
- (3) "Chain complexes" which link present experiences to other experiences metonymically, through the recollection of sequences of events without implying causality or logical implication.

Only the first type of knowledge is explicitly causal while the other two contribute to narrative accounts of symptoms and illness experience. These three forms of knowledge presented either by the patient, family member, physician or anthropologist, are not only comparable to cognitive structures (e.g. causal models, classificatory schemes), but are also embedded in actions, social relations and material equipment. Table 21 shows the main features of these three types of knowledge or cognitive schema.

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⁵ Young's argument is also a criticism to the "rational man approach" in medical anthropology and to the "Explanatory Model Approach" (EMs) introduced by Kleinman, Eisenberg, and Good (1978), which provided the authors a frame for analysing transactions between patient and physician in health care settings.

Young's argument suggests that cultural etiologies that emerge from the narratives of patients and family members are likely to be inconsistent and do not always present a logical causal sequence. However Young's analysis focuses on the cognitive production of knowledge associated with "causal explanations." Here, I rather want to pay attention to a broader network of links and associations embedded in the subjective experience of psychosis. I will try to identify which categories come to be cristallized in cultural etiologies, and which illustrate the polysemic character of cultural signifiers. Singular people may mobilize different representations or activate different categories both at the personal and at the collective level, in function of the peculiarity of their experience of themselves and of the world.

Table 21 - Types of knowledge structure underlying illness narratives

	Explanatory models	Prototypes	Chain complexes
Structure	Logical	Analogical	Metonymical
Production System	Propositional logic	Images and metaphors	Contiguity
Representation	Causal sequences	Exemplars	Events
Mode of Elicitation	What caused your symptoms?	Have you ever had/felt anything like this before?	What happened before you developed your symptoms?

Adapted from Kirmayer, Young, and Robbins (1994).

Mothers' perspective

The two examples below illustrate the way mothers mention several possible causes for their child's problem without integrating them in a coherent dialogical scheme:

Jonas' mother story

When I interviewed Jonas' mother for the first time I began with my traditional triggering questions: "When did you notice that something was changing with your son?" "When do you believe that your son's problem started?" She felt the urge to tell and reconstruct Jonas' life since his childhood, so we remained talking for a couple of hours. She recalled that Jonas was always a headstrong minded and rebellious boy and that she always made a lot of effort to discipline and educate him. That is why she introduced both her children to the Methodist Church, although she added that sometimes she had no alternative other than spanking or punishing her son (e.g. prohibit to watch TV) to guarantee some respect and discipline. She interprets Jonas' rebellious behaviour as a reaction to the fact that her husband abandoned the family while the children were still very young. When her son was five years old she remembers that he fell from a bicycle and that this required stitches to his head. At that time no chapa de cabeça exam was made, so the mother wonders whether this fall did also affect Jonas' mind and his later psychotic episode.

When Jonas was 9 years old another important event deranged his life. His favourite grandfather died, and even though the extended family tried to hide from the children that he had committed suicide, one of the cousins showed to Jonas the tree where the grandfather hung himself. After that Jonas presented a behaviour simultaneously very introverted and disturbed; he would run away from the house, and he began to have learning difficulties and problems of social adaptation at school. Jonas' mother still feels very guilty in remembering the day when Jonas exploded crying: "Only my grandfather loved me, nobody else." She thinks that her son was extremely attached to his grandfather because she had to work outside of the home all the time and had very little time to spend with her children. The schoolteacher asked the mother to take Jonas to a

psychiatrist and after a couple of months he recovered his school performance.

When Jonas was 15 years old he started to hang out with friends, to smoke and drink, and sometimes would not even sleep at home. It is just a typical behaviour of young men around this age. He also abandoned the Methodist Church and started to work in a bank. Jonas' mother became constantly worried and wondered whether her son was going out with "bad companies"; however, her greatest dislike is that he smoked tobacco cigarettes (she ignores that he also uses other drugs). She has a firm belief that excessive smoking and the smoke of cigarettes can affect a person's mind, and thinks that it is an additional element that contributed to induced Jonas' psychosis later on.

Two years before the outbreak of Jonas' psychosis he felt very bored and constant martyrdom in continuing to work in the bank, because of that he resigned from this position. Since he had worked in the bank for 10 years he received a good amount of money (legal benefits) when he resigned. However Jonas spent all this money partying, paying for beer and drugs for himself and his friends; soon he started borrowing money from a loan shark in order to cover all the debts that he was making. He started to become nervous because he was unable to pay back the loan shark. His mother believes that: "This was accumulating, accumulating, so this debt money [and the previous events] disturbed his life, affected his mind." The mother and the sister were very upset with Jonas' behaviour since all the money he spent was enough to make a down payment to start buying a house.

Jonas remained unemployed for a long period of time. However, less than two months before the outbreak of his psychotic episode, Jonas found a night shift job in a pager service business. His mother believes that

the stress of the night shift also affected her son. She holds an image of her son as a very intelligent and easygoing person who is loved by everybody. She imagines that he quickly made friends with the boss and that his other co-workers were jealous about it. For this reason she still wonders whether her son was actually being persecuted and had conflicts with his coworkers or if these tensions only existed in his imagination. When Jonas started to feel very frightened even to go to work, his mother and his sister started to pressure him not to be so lazy, and the mother thinks that this pressure could be another element responsible for his psychosis. A couple of weeks before the outbreak of psychosis, she found very strange that he insisted for her to go through a past life regression. When a psychiatrist told Jonas that he should not continue doing past life regression by himself, the mother assumed that the regression collaborated to trigger the psychotic episode as well. His friends also started to keep away from Jonas because they thought that he was becoming crazy with his "obsession" towards past life regression. Yet Jonas believes that the regression enabled him to find the job in the pager service. Once the mother went to walk in the park with Jonas to ask him why he wanted to do past life regression and he answered that he was missing his grandfather and he wanted to meet him again through the regression.

Jonas' mother also believes that all the time he remained locked in his room and the smoke of incense were deleterious for him. In addition, the previous tenant of the house was a Mason (which suggests a mysterious atmosphere) and died in Jonas' room, and his mother wonders whether his "dead spirit" would not continue to haul around and disturbing her son. This explanation was reinforced by members of the Pentecostal Church who visited them several times to bless Jonas and the house. The church people believed that some "spirit of dead person" or "evil spirit" moving around the bedroom needed to be eliminated through prayers (campanha) to aid in Jonas' healing. Finally, the mother prefers to

associate Jonas' extreme fear with "panic attacks" and "depression", since the idea of a psychotic episode is too threatening.

Jonas' mother's narrative indicates that in her attempt to account for her son's problem, she reviewed the whole life of her son and explored several explanations that may have contributed to the outbreak of psychosis. Some of these explanations run in parallel, and she is convinced that it is an accumulation of social situational events that triggered the psychotic episode: night-shift job, conflicts with co-workers, family pressure, past life regression, "spirit of dead person" in Jonas' bedroom. All these events were occurring around the time of the psychotic episode itself. Other events that she recalled happened earlier in Jonas' life: her own divorce, suicide of Jonas' grandfather, falling off a bicycle, debts with a loan shark, and so forth.

Maria's mother story

Years before her daughter's psychotic episode Maria's mother noticed that her daughter had learning and memory problems. At that time, she decided not to pressure her to continue going to school or to find another job because she believed that this pressure would only impair Maria's mind even more. The mother perceived that Maria's greatest problem is that she is an adopted child. It was a cousin who revealed to Maria that she was adopted, soon after the death of Maria's adoptive father. Her mother believes that the concomitance of both events: father's death and the discovery of being an adopted child shook Maria's emotional and mental well-being permanently and influenced the outbreak of her psychotic episode several years later. That her daughter was adopted leads her mother to wonder whether her daughter's various problems (e.g. head problem, learning and memory difficulties, nervousness, inconstant temperament, psychotic episode) can be attributed to hereditary or genetic issues. In this context, the possibility that she could have "something" in the brain or that she suffers from <u>loucura</u> (craziness, mental illness) is not

discarded by Maria's mother. She also associated the psychotic episode both with a "panic attack" (ataque de pânico) because her daughter was afraid of boarding the bus, and with "depression" (depressão) because her daughter cried all the time and wished to die. Her narrative also indicates a constant tension between an explanation in terms of a problem derived from hereditary factors and a supernatural causation:

I told the psychiatrist that I was in doubt. I was thinking about the spiritual issue. A spiritual thing, well it is not this, but I did think about it. Other people have said that when my daughter went to the Universal Kingdom Church of God they said that there was something there because she took the Holy Communion but she was not prepared to take it... Then my daughter wanted to take the spirit out... it seemed that she was completely possessed, so this is something that made me think about it [...] I thought that this could only be a temptation [from the Devil], I thought that because she talked too much, she called names to me, she called names to everybody, then she talked and talked and I had to get away from her, I could not stay there close to her. [Maria's mother, 7th Day Adventist]

In this portion of her narrative, Maria's mother is convinced that her daughter's psychotic episode erupted due to Maria's religious fanaticism, developed while she was attending the Universal Kingdom of God Church. In this context religious overinvolvement is perceived in a negative way. Maria's mother also mentioned that her daughter's physical weakness was caused because she avoided eating; it is not clear whether her mother thought that this was a consequence of exaggerated religious fasting, or if physical weakness was seen as a major cause of her daughter's problem (psychosis). One can say that Maria's mother's position regarding religious etiologies condenses a combination of various levels of explanation. Three events that Maria's mother mentioned suggest that she associated her daughter's difficulties (psychosis) with supernatural causation:

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[&]quot;The ethnopsychiatric terms "panic attack" and "depression" are popularly used, and do not necessarily correspond to the psychiatric definitions found in the ICD-10 or DSM-IV. I observed that these two terms can be associated with schizophrenia in the sense that panic is a name for describing the insurmountable fear that the patient is experiencing; and that depression is related to deep sadness and apathy.

- (1) The strangeness of Maria's behaviour resembles the behaviour of people who are possessed by the Devil.
- (2) The pastor and other acquaintances confirmed that her daughter was being possessed (the spirit is incorporated) or tempted (the spirit surrounds or leans over the person) by the Devil or evil spirits.
- (3) Maria told her mother that she was being punished by God because she drank during the <u>Santa Ceia</u> (Last Supper) Pentecostal Church monthly ritual when she was still not allowed to do so.

In addition, Maria's mother also mentioned the possibility of magical causation. She remembers that several years ago, a friend of her niece came to live with them for a short period of time, but that she did not get along with Maria. This friend liked to play with <u>macumba</u>; Maria's mother is certain that she prepared a work of <u>macumba</u> which affected her daughter.

A comparison between the two mothers' narratives suggests that particular circumstances or events lead to a different weight to the specific components of etiological forms. Maria's mother appears to give a prominent place and a special significance to "natural causation" because Maria is an adopted child. Thus, Maria's problems can be easily associated with a "bad" genetic inheritance from her unknown biological parents. Genetic or hereditary causation is mentioned very infrequently by family members. The only mention of this level of etiology is done in case of adoption, as in Maria's and Carmen's case, or in a few other cases when the mother remembers that a close or distant relative also suffers from "mental illness". But I have illustrated that this genetic hypothesis does not close the quest and does not prevent the mother to look for other causes.

By contrast, Jonas' mother emphasized the role of social situational events as possible causal explanations to her son's problem. Maria's mother also gave attention to social situational events, but in this case she interpreted Maria's school and working difficulties as a personal problem caused by her daughter being an adopted child. Maria's mother understood that it was not her daughter's fault, that she may have inherited "bad" genes. Jonas' mother also tried to avoid blaming her son by putting more emphasis on the influence of "bad" relationships that her son acquired with the people in the "street world". Both mothers, like all the others, are also inclined to associate "family conflicts" and "religious etiologies" with the outbreak of psychosis.

Like most other parents, Jonas' and Maria's mothers are in a constant quest for cultural etiologies that may help them to explain the problem (psychosis). The etiological categories they mobilize have a different weight according to gender, life histories, and possible influences of community members. Since these categories are also context-dependent, they may also change their position and significance with the evolution of the problem. For example, after a lengthened contact with psychiatric care patients and family members may eventually give more value to the opinion of mental health professionals, even though these opinions are often re-interpreted.

A whole series of causal explanations apparently have no religious connotation, or they are not framed within a religious background. They refer to nervousness, family or social conflicts, drug addiction and heredity, among others. Nevertheless, these events can also be linked to the religious world. For example, one of the most common effects of encosto (leaning spirit) over the person is to provoke nervousness, while drug addiction and personal conflicts can reflect the influence of Devil possession or a work of macumba, and heredity may be simply a question of God's destiny. It is more common to hear family members elicit different causal explanations throughout their narratives, however they also pay particular attention to religious etiologies (or supernatural causation). This probably echoes the widespread popular belief according to which most illnesses present a "spiritual" dimension (supernatural causation) and a "material" dimension (natural causation).

Besides the urge to exculpate their offspring, the parents resort to cultural etiologies indicates that they recognize that their children's problems have to be situated within a larger context. Families usually build on the notion of "causal explanation" by reasoning that psychosis and its outcome can be a consequence of previous life disturbances or evil events that have accumulated through time. Most parents however have also expressed their deep uncertainty when they elicited these causal explanations to me. In this context, the accumulation of several cultural etiologies (which have no preponderance among themselves, or which keep shifting their importance) can also be interpreted as another sign of uncertainty from the parents' perspective.

I have already mentioned that religion offers a parallel and complementary frame of explanation for parents in search of causes. The notion of religious etiologies has to be taken in a very broad sense including black magic, witchcraft and various Neo-Esoteric groups. In the mothers' narratives, the idea that their child's problem could be due to some religious "cause" was often initially suggested by followers of a particular religious group:

They would pray and pray, they would come home, a whole bunch of religions. They would pray here, they would pray and stay here with my daughter. No, they would just pray and go away. They arrived, prayed and then would say that it was a coisa feita made to her, that it was a encosto that she had, that it was who knows what. [Claudia's mother, Umbanda sympathizer]

In the Assembly of God the spirit manifested in a woman. I went together with my son, my daughter [who had psychosis] didn't go. When the spirit manifested the woman came running into our direction saying that my daughter was not well because she envisioned one espirito maligno [evil spirit] running and pushing and wanting to rip apart there and they took it away. I felt very bad with this, I felt very bad. [Dora's mother, Seventh Day Adventist]

No it has been a long time that my son had this [encosto]. But he was calming down because when he was like that he would not even let me work, he would persecute me inside and out. I thought that my son had some encosto as soon as he started to tremble, his body had something there. Because the man, I had separated from my husband so the man I lived with, no I lived alone, he would only come every 8 to 8 days. But he was a macumbeiro and I didn't know. He told me that if I left him he

would throw me sick in bed, but I told him that I had a lot of faith in the Holy Spirit so he would not throw me down. That is, he did not throw me down, but he threw my son down. [José's mother, Universal Kingdom Church of God].

Explanations in terms of encosto, espírito maligno, or evil spirits are generally well accepted by the mother because they resonate with their own observation that the patients expressed signs of nervousness, fear, insomnia, fainting or nervous attack, visions and hearing voices, which are popularly associated with signs of spirit or Devil possession. These signs of disturbance or strange behaviours may also be the consequence of some kind of malice, "black-magic" (or coisa-feita) committed by some other human or spiritual being to harm the patient. José's mother is the one who explores this notion more clearly, because when she separated from her ex-partner, she believes that he threw a work of macumba over her, but it affected her son instead in the form of encosto (since she considers José's spiritually "weaker" than herself).

For family members religious explanations allows some benefit by removing the blame from the patient and shifting it to spiritual entities or acts of sorcery perpetrated by other people. This process allows parents to keep a positive image of their children as individuals who have not failed, nor sinned, and who cannot be made responsible for their sudden bad, unexpected or unexplainable actions.

Patients' perspective

After reading the narratives, going through my field notes and listening to some tapes over and over again, I had finally to accept that it is unlikely for patients to mention a "causal explanation" to their problems (psychosis), even if they seem inhabited by a deep questioning regarding the meaning of what they are experiencing. Even when I asked them explicitly questions about their way of explaining their problems, their most immediate answer was "I don't really know" or "I am not sure." In some instances, they wondered whether their problems were related to some problema da cabeça or to some kind of spiritual problem. Previously I mentioned that Jonas attempted to do past life

regression after he suspected that he was undergoing some kind of "mind block." When I asked him explicitly for a causal explanation he emphasized his uncertainty; he also told that he only started to understand his problem a little better when the emergency room psychiatrist gave him some kind of explanation:

Cristina: Did you find some explanation for this that happened to you?

Jonas: Ah I don't really know... I was only able to see something when the doctor told me. She said that it was a "malfunction of perception."

[Non-Practicing Methodist]

In several occasions patients asked me whether they were having some kind of problema da cabeça. I remember feeling disconcerted because I was not sure what was the best way to answer them. For instance, Mateus questioned me whether the strangeness of his recent experiences was real and truthful or only a product of his mind and imagination. He was expecting some feeling of reassurance from my response that he was incapable to find within himself. Leonardo reacted in a similar way although he also wanted to understand why he was being persecuted by the "voices" and what was their potential danger:

I would like to ask you if when I was in that way [psychotic episode] if that was something from my head... or if it was true the things I was seeing? They could have been true. [Mateus, Community of Grace Church]

Now I don't know why they [voices] are persecuting me, what they want, what they are doing. Or if this is also something from my head... I don't really know [interrogative tone]. Is it really something from my head? I imagine that is something that... Do you think that is possible for them to come and kill my family?

[another interview]

I don't really know. I think that if I had something [in my head] it ended. But I don't know if it happened because of the drugs or if it happened... I don't know... persecution... I don't know. This thing I imagine that it was something from my head, but now it is going away.

[Leonardo, The Return of Jesus Christ Church]

The deep anxiety and uncertainty that several patients manifested in relation to what they were experiencing, often lead them to formulate vague religious hypotheses:

I don't really know, I believe it had to happen... Something that came from... God [fate]. Is it something like that or it isn't? [Claudia, The Congregation of the Virgin Mary Church]

I have got so much fear... this seems to be a <u>macumba</u> that was done to me! [Leonardo, Return of Jesus Christ Church]

My problem, I imagine that it is a spiritual problem because I felt something very strong calling me asking if it was for me to come to work or to come home. I left my work and came home. [Milton, Catholic]

I have asked my mom to take me to places where there are spirits and things like that. [Kátia, Non-Practicing Catholic]

But most patients do not accept easily the religious hypotheses of causation suggested by their entourage. Their relationship to broad religious signifiers appears much more fluid, shifting and paradoxical than what is included under the term "religious etiology". José's mother was convinced that her son's problem had a supernatural causation (see her previous excerpt in this chapter, and her story in Chapter 7); this motivated her to take José to be exorcized at the Universal Kingdom of God Church. However this only confirmed to José that his problem was not related with the supernatural:

José's story

José-After I have heard the voices my mother took me to church to see if I would get better and to check if it was something, some evil spirit. She took me and I felt well there, I didn't see anything [of importance], I saw people fall down but I didn't fall down. When the pastor said whoever is hearing voices, evil things, things from the Devil, things from Lucifer, you burn now! I remained normal, I felt I was there normal, the pastor came to bless me, I believe I have nothing to do with the supernatural.

<u>Cristina-</u> So, do you think that your problem has nothing to do with Lucifer?

<u>José</u>- No, no it has nothing. I have always been a Christian, thanks God. (...)

<u>Cristina</u>- But why do you believe that your problem is not related with sorcery?

<u>José</u> – I don't think it is... My problem is because I am hearing voices. I have already gone to church and nothing happened to me there. I don't

really know. I went up there and I didn't fall down [sign of Devil possession] and the prayers there were very strong!

In the excerpt above when José rejected a supernatural cause to his problems he noticed that he was not possessed by the Devil like some other people in the church (who fell down). Thus, he discards any relation between the voices he was hearing and signs of Devil possession. He even feels himself protected from the malevolence of the Devil because he considers himself to be a Christian. But in most occasions, José used religious signifiers ("something spiritual," "something supernatural", God) to give shape and try to understand the significance of the unnatural, ambiguous, and exceptional quality of what he was experiencing:

<u>José-</u> I was running in the roadway and there was a guy following me. It seemed like an animal thing.

Cristina- Like what?

<u>José</u>- It seemed that it was something spiritual, who knows something sent by God.

<u>Cristina</u>- A spirit ... why do you imagine that God would send something like that?

José- I don't know why.

<u>Cristina</u>- You don't have to know but maybe you have some idea.

<u>José-</u> Ah I am, I am, I have a lot of faith in God, but I don't know what it is. Maybe it is somebody who is coming to give some message.

<u>Cristina</u>- What I am trying to ask is if you have any doubts in this sense <u>José</u>- I don't know, I don't really know how to explain it, it is something supernatural, it seems to be supernatural.

I also had the chance to observe a dialogue between José and Kátia while both of them were waiting in the hallway for their psychiatric consultation at the Schizophrenia Programme. Although Kátia is very shy and always talks very little, José tried to flirt with her during their conversation. In very few words Kátia expressed that she always felt very frightened with the voices because she imagined she was hearing the voices of some evil spirit. José partially agreed with the resemblance because he replied that these voices which disturbed each of them could only be the voices of a very knowledgeable being, and there is no more knowledgeable being than God. Later that day, José explained to me that the voices could only represent a very wise being such as God because they were very powerful voices that speak within the person, and for him this indicated a wisdom

beyond the human limits. In this context he appears to give a positive connotation to the "voices." In another occasion, when José participated in the clinical meeting of the Schizophrenia Programme, his response to psychiatrists inquiring about the "voices" illustrate how supernatural references seem to permeate his whole experience:

Psychiatrist A – How were these voices?

<u>José</u> - They were irritating, the voices would say 'I want to kill you'. I would run, get in the bus, call another bus, and would pass under... you know, under the ratchet [for not paying the bus fare].

Psychiatrist B – Under the ratchet or under the bus? [teasing tone]

<u>José</u> - Then the voices disturbed, the voices disturbed straight away. I would run, I would run more and more, running and hearing the voices I want to kill you, then I would go to the shopping. Then I left the house, I stayed nine days outside of the house.

<u>Psychiatrist B</u> – What were you doing then?

<u>José</u> – I would walk in the street back and forth, I would walk the whole night.

<u>Psychiatrist B</u> – Do you remember the places were you went?

<u>José</u> - Once I walked from the Pinheiros roadway until the Paes Mendonça supermarket, I would walk.

Psychiatrist B – Weren't vou afraid?

<u>José</u> - I felt fear... like this, when I arrived in the place. Once I arrived at Paes Mendonça and the guy said you should leave at this time. It was three in the morning.

Psychiatrist B - Who said that?

<u>José</u> - The security guard. I said I wasn't going to leave. It was the fear, fear, fear, really very irritating. Fear of something from the past.

<u>Psychiatrist B</u> – What from the past?

José - I don't even know what to say.

(...)

Psychiatrist A – Do you have any idea about what were these voices?

<u>José</u> – I imagine that they are people who have died already. All people who have died already. All acquaintances that I had and who have died... a long time ago, so they started to chase me.

Psychologist - Who were these acquaintances?

<u>José</u> – A guy who lived near my house and he was a very good friend. Then he died, then I started to hear his voice, their voices, voices of dead people and people who are alive too.

<u>Psychologist</u> - Besides his voice did you recognise some voice of some other acquaintances you have?

José - I recognized the voice of Piui who lives in the villa.

Psychiatrist B - Who is Piui?

⁷ Paes Mendonça is a giant supermarket where José eventually found some temporary work packing the clients' groceries.

<u>José</u> – And the voice of a murdered one who died too, this Piui and a guy called Pita.

Psychiatrist B - He died too? He died of what?

<u>José</u> - One of them was shot, and the other died a normal death, a motorcycle driver, and as he was crossing the street, an Opala car came and ran over him, so he died.

<u>Psychiatrist B - But this is not normal, it was an accident [laughs]. What did Pita die of?</u>

<u>José</u> - He was shot, and the other died in the motorcycle, and the last one was shot.

Psychiatrist B - Is it very violent where you live?

<u>José</u> – It is the South region there, it is very dangerous. The place where I live is not so violent, Parque Santo Antonio is more violent because there dies one every day. The place where I live is more calm.

<u>Psychiatrist B</u> – Do vou see murdered people there?

<u>José</u> – I see. You always see dead people, all the time, not all the time, but almost all the time there is death there.

<u>Psychiatrist B</u> – Is it because of drugs, robbery?

<u>José</u> It's drugs, robbery, fights in the family; the guy gets the gun and he shoots and he doesn't even care. It is a place that gives you fear to live there. I am used to it, I like to live there, but sometimes I feel like moving.

If one takes into account the different excerpts above, José makes allusion to the supernatural realm in different ways and contexts, in order to try to describe his experience of psychosis. It is very clear that he vehemently rejects the idea of spiritual causation, especially after he goes to the Universal Kingdom of God Church with his mother. Nevertheless, when he talks to me about the unexplainable quality of what he was experiencing (second excerpt); he makes an association with "something spiritual" or "something supernatural". It is interesting to note that José is probably not speaking of the same kind of voices because he suggests qualitative variations within his experience of "hearing voices". For instance, he tries to convince Kátia about the positive quality of the "voices", while she only associates the voices she hears with the negative quality of "evil spirits" and expresses to José all her insurmountable fear. Throughout my fieldwork I noticed that other patients sometimes attributed positive and soothing qualities to the "voices" they were over-hearing, even though most of the times the negative, threatening, and uncanny aspects of these voices dominated their narratives.

While being interviewed by the psychiatrists. José seemed to provide a phenomenological description of what he experienced. It is important to retain here that José's narrative is impregnated by his experience of living in a violent environment. In this context the "voices" irritate and frighten him because "they" say "I want to kill you." or because he progressively associates these voices with "something from the past." "people who have died already". "voices of dead people" (dead spirits), "voice of a murdered friend." and "voice of a dead friend."

On another occasion I had the chance to talk with José and his mother regarding the interview he had given to the group of mental health professionals. I began our conversation by joking with José, because I believed that he exaggerated the image of "a poor black boy who lives in a slaughtering and violent environment" to the mental health team. He only laughed back at me with a certain malicious expression on his face. At this point José's mother joined the conversation to explain that their neighbourhood was extremely violent a couple of years before, but that now the violent atmosphere "calmed down" after the construction of a police station. Yet she emphasized several times that it was very likely that many "spirits of dead people" from the previous violent period remained wandering around in their neighbourhood. In this occasion, José completely agreed with his mother's beliefs.

What they were telling me is congruent with the popular religious belief that "spirits of dead people" (e.g.: evil spirits, encosto) may exert some malevolent influence over the "living" people. But they may also only be the spirits of significant others who remain wandering around in the world of living people with no "evil" intentions (see also Table 17, Chapter 6). It is not surprising that José and his mother believe that since the neighbourhood where they live used to be extremely violent and dangerous, it remains constantly surrounded and infested by the spirits of people who have died or have been killed there. Several other people whom I interviewed believe that it is more common to find spirits of "dead people" around the place they have died. Furthermore, when these people did not die of a natural death, but were killed or have suffered an accident, it is

more likely for them to remain some period of time wandering around the world of the living, since they were not prepared to die so suddenly.

Taking this into account one may suspect that cultural signifiers such as "dead people" flourish in the narrative José gave to the psychiatrists in ways that may open up multiple interpretations. Voices that tell "I want to kill you" are very threatening and evil. One may hypothesize that when these are transformed into voices of "dead people" who were close acquaintances while alive; they may seem less evil. In other words, when the source is recognized the voices may become "more friendly" and "less frightening". Yet some of these voices belong to people who not only died but they also did it in a violent way. Would they have been "evil" people while alive (e.g. drug dealers, thief)? Would these voices only want to kill José because they have been "killed" in the first place?

On the same occasion I also asked José why he imagined that one of the voices who was chasing him was the voice of a "dead" friend. He then attributed a sense of revenge to this "persecution" because of a terrible fight that happened between him and his friend just before his friend's death. José is trying to connect the voices with negative facts that have actually occurred in the past. Thus, the possible meanings for "something from the past" unfold in a kind of centrifugal spiral: "past" fight with friend, spirit of "dead" friends, spirits of "dead people" (unknown to José). "Something" could also have other meanings unknown to me.

One still needs to compare convergence and divergences between José and his mother regarding religious explanations and signifiers. José's mother usually manipulates the religious signifiers in a more focused and affirmative manner, while her son uses them in a more dispersed and interrogative way. I also had the chance to observe over time a series of conflicts between José and his mother regarding their interpretations to religious signifiers. Both of them share the same popular religious beliefs; they strongly believe that evil spirits or macumba may have caused the problem. When José discards this kind of explanation as applying to him, an ever-lasting conflict is then established between him

and his mother because she insists in vain for her son to participate in practices of faith healing at the Universal Kingdom of God Church.

According to José's interpretations the voices and visions cannot be the result of spirit possession or macumba, yet in different circumstances they resemble voices of evil spirits, dead spirits, or God. He is primarily alluding to the unexplainable and exceptional quality of what he is experiencing, although he begins to reject conceiving himself as the "carrier" of these spirits. José is apparently mitigating the problem by separating the source of the voices from himself. However, his mother still associates the "voices" José overhears with the spiritual realm. In addition, she tries to exculpate José by believing that her son's problem was caused by macumba or encosto. The mother expresses some relief when she resorts to these religious signifiers, and it seems that she is removing any possibility of blame, guilt, or fault from her son. She is also trying to reintegrate him within a shared social space by exculpating his present "bad" or "strange" actions. For him it is not enough to have these accusations of social blame removed, while the voices continue to disturb him. He seems to resort to religious signifiers primarily to frame his feelings of strangeness and alienation in relation to the voices and the social environment.

I want to reiterate that José keeps changing the qualifications he gives to the voices and visions he has experienced: "animal thing," "something spiritual," "something supernatural," "message sent by God," "God," "friends who died," "dead people," and so forth. This also strongly suggests how José feels increasingly unstable and uncertain regarding his own feelings and perceptions. José is being affected and interacting with different audiences while he associates this or that quality to "psychotic symptoms". For example, he clearly exaggerated to the psychiatrists the image of a slaughtering environment for the neighbourhood where he lives.

The incessant change of quality attributed to voices or visions indicate that José was constantly struggling to understand what was happening to him. It also reflects the uncertain and drifting quality of his perceived environment. Furthermore, the fear generated through psychosis becomes enmeshed with the widespread fear of wandering

"spirits of the dead" and of urban violence. I would also like to emphasize with José's story that religious signifiers are embedded within broader everyday life experiences.

The multiple and paradoxical ways that José plays back and forth with cultural signifiers indicate that voices and visions usually transmit negative feelings ("I want to kill you"), but sometimes they can also be positive or neutral ("message sent from God"). I was astonished to discover that most patients experienced similar movements oscillating between positive and negative connotations, in a kind of pendulum movement where the negative often prevails. I will argue later on that this movement may in some situations reveal a permanent struggle to preserve "life" or one's existence, which represents a positive connotation, against threatening and negative feelings of imminent "death."

Binswanger assumes the existence of as many forms of being-in-the-world as there are psychotics. But he recognizes two fundamental modifications of "world"-formation for those people who are called psychotic: one characterized by "leaping" (ordered flight of ideas) and by a "whirl" (disorderly flight of ideas), and the other characterized by a shrinking and simultaneous narrowing of one's existence. The latter modification can also be understood in the following terms: "the freedom of letting 'world' occur is replaced by the unfreedom of being overwhelmed by a certain 'world-design'" (1994b: 194-195).

I would like to suggest that the ways José plays back-and-forth with religious signifiers correspond to "leaping" especially in the long excerpt when he was speaking with the mental health professionals, and corresponds to a "whirl" when he associates multiple meanings to the "voices" that either bother or bring some comfort to his mode-of-being-in-the-world. The concept of shrinking and simultaneous narrowing of one's existence is best portrayed in Chapter 3, when José feels trapped by the "voices" that want to kill him and he keeps running away from home and from the "voices." Furthermore, the vague and leaping way by which José resorts to religious idioms and signifiers seems more related to his attempt to put words to and to qualify his shifting and uncanny experience, than to provide an explanation as such. Maybe because the

enigmatic quality of his experience is so overwelming that it focuses all or most of his interest. What I have commented about José's experience in relation to his resort to religious idioms and signifiers also recurs in other patients' narratives, even though these narratives can be very fragmented and full of "blanks".

Macumba, witchcraft, and "coisa feita"

Witchcraft, <u>macumba</u>, or <u>coisa feita</u> are very popular explanations for why something is going wrong in a person's life (e.g. sickness, drug addiction, marital betrayal, etc.). Sarah and Gisela talked the most explicitly about <u>macumba</u> and acts of sorcery as one plausible explanation for their problem. Both of them were married and believed that whoever threw the work of <u>macumba</u> over them wanted to wreck their marriage. This hypothesis involving <u>macumba</u> emerged with a particular strength when other religious people insisted on this kind of explanation, but the few young people who mentioned it as an etiology, only did so when the psychotic episode was already over:

<u>Sarah</u>: I don't know how to explain it. I only remember that after this, going back to the subject of the Devils in the church it was revealed that it was witchcraft that was done to me.

<u>Cristina</u>: Do you know who might have done this witchcraft to you?

<u>Sarah</u>: I have a suspicion, but I can't talk much about it. It is because I cannot judge other people. Don't judge in order not to be judged.

[another interview]

Sarah: In fact it was revealed that it was work of macumbaria that was done to me. This was revealed in the church. [...] The Holy Spirit reveals to people [about macumba]. Normally it is envy or things like that... a lot of my clothes disappeared... I think it was the cousin of my husband... I am not sure; I am not judging her. It could have been any other person.

Gisela: It was witchcraft. The folk healer told me that who did this to me did not like me and wanted to see me far away. The first time the witchcraft was done it was to have me and my husband under a rock [dead]. But they were unable to do it because I am very strong, the folk healer said that my Saint is very strong. This time they tried even harder, but they didn't get me because I am very attached to God and nothing gets on me [...].

Cristina: Do vou suspect somebody?

<u>Gisela</u>: It is not only this... there is a slut... there is this girl that liked my husband before we got married

More often the mention of macumba and witchcraft allowed patients to connect the evil meanings associated with it with all the evil they were experiencing during the psychotic episode; they probably had a very hard time to express it in other terms. In spite of this, most patients often doubted whether their problem was the result of a work of macumba. Family members are much more receptive than the patients to the idea that macumba and sorcery could be responsible for the problem. As suggested by Sarah's and Gisela's narratives, it is more likely that patients mention causal explanations only after the psychotic episode is over rather than when they are experiencing it. I decided to transcribe Mateus's mother's narrative below because she raises two very important issues which were also touched on by other mothers. The first one is that some family members only began to suspect macumba, witchcraft or some kind of "spiritual problem" not only because of the patients' strange behaviours, but because patients mention (often in a very confusing way) these terms to their families. The second issue is related to the notion of "frailty" or "weakness" which may refer to the fact that people with a very strong faith in God are less likely to be affected by macumba, witchcraft or evil spirits. This "weakness" can also be associated to a feature of the person's character. In this sense strong faith would transmit to the person the invincible power of God.

I believe there is some spiritual problem. When you are a Christian for so many years, you already have your own experience in this part. Now my son dated a girl who belonged to a Candomblé or Umbanda centre. I don't know these things, I just hear about them. This girl, she must be a witch... now this is a fact! He dated her and insisted to me "mother I suspect that she did macumba to me, she did it!" "Leave off my son, you should not think these things. You are a Chistian for so many years, you have faith in God, and God is superior to all. Just have faith in God that the macumba won't get you" But since he is frail... He is a person that is not smart to escape from macumba. Because when the person has moral fibre, he sees and tries to get out of it but Mateus is a very standstill kind of person! [...] The girl did the macumba because he quit his job, he lost two jobs, and would only drink a lot of beer, he drank a lot of beer. And all these things started to affect his head. Mateus is very frail. You need a lot of spiritual strength to liberate vourself from the filth of the world, because there is a lot of filth. But if you really have faith in God, the evil repels away. [Mateus's mother, Universal Kingdom of God Church]

I preferred to focus my discussion on only a few cases in order to explore in more detail relatives' and patients' perceptions and resort to cultural etiologies, and more specifically religious etiologies. Looking at all the narratives, it becomes clear that families assign more importance to cultural etiologies than patients, although their narratives are also permeated by uncertainty. Patients' narratives are still more immersed in uncertainty, however their overwhelming uncertainty is more related to the nature of what they were experiencing. Young's distinction between "prototypes" and "chain complexes" (see Table 21) helps to differentiate between the ways patients and family members make use of such diversity of cultural etiologies. Since patients are desperately questioning about the nature of what they are experiencing, one may say that they are looking for "prototypes" to understand (not necessarily to explain) their altered experience. Family members are more keen in searching for causal explanations than patients. I have illustrated in many different ways in the previous chapters how the experience of living together with a person who is going through a psychotic episode is extremely overwhelming and anguishing. Taking this into consideration, one may say that family members build numerous "chain complexes" in order to understand and explain the problem and difficulties associated with psychosis. In their attempt to account for the situation "chain complexes" emerge more frequently than "rational" causal explanations. I believe this to be very clearly demonstrated in the description of Jonas' and Maria's mothers narratives above.

I have provided little emphasis here to the ways that family members use more conventional religious etiologies because this was implicit in the previous chapter on help-seeking. I reiterate that religious etiologies are evoked with uncertainty, doubts and ambiguities, even though at a different level than other cultural etiologies. I also hypothesize that religious etiologies are very significant because they provide focus and cristalization, in other words, they provide a bounding frame for family members without supressing other cultural etiologies. These more conventional religious etiologies trigger a much more active movement, compared to explanations which evokes causes that cannot be changed (e.g. problem of adoption, "persecution" of co-workers).

Religious Signifiers in Psychosis

Even if they tend not to give an important place to religious etiologies as such, most patients resort to and manipulate religious signifiers during their psychotic episode. I argue that in the case of psychosis, the significance and the role of religious signifiers goes well beyond the realm of etiology or explanation. One has to adopt a broader perspective and try to identify core religious signifiers that are mentioned in the patients' narratives and to examine their meaning for a particular person in a particular set of circumstances. For each of the core religious signifiers, I will situate the sets of meaning evoked by the patient under the background of its more normative significance as expressed in family members' narratives.

The Bible

Family members mention the Bible as a very important tool to learn the words and the "gifts" of God. The Bible also functions as a vehicle to search for God's presence and to ask for His protection, forgiveness, or help in solving concrete problems. Some mothers told me that all is written in the Bible, and that I should go and check it out (e.g. "God created the physicians to heal diseases," "the Bible recriminates macumba"). The Bible appears invested with a symbolic meaning and integrated in a global relationship to God. However, people also appear to read the Bible very literally and search for sentences that fit with their vision of the world. For example, even if macumba is not explicitly mentioned in the Bible, its close association with evil, particularly from a Pentecostal perspective, leads them to think that the Bible condemns macumba. In the next section Sarah's story will illustrate how her attempt to make a "literal" reading of the Bible accentuates the feeling of being engulfed within psychosis.

The mothers' excerpts below also illustrate that reading the Bible is only one element among a broader range of religious behaviours:

We make some intention with God, "Oh Lord, I will start to fast until a certain time and the intention is for you Lord to liberate me from this." I

establish a period of time that I tolerate staying without eating, and during that period, you keep yourself connected with heaven, you read the Bible all the time, in order for the malignant and negative thoughts not to affect your mind. You remain praying, reading the Bible or singing some hymn until the moment that you kneel down, ask for God's forgiveness and deliver your fasting as your intention to [solve] the problem. [Sarah's mother, Assembly of God]

Now that I am in [the Pentecostal] church I have changed a lot. Before I had a lot of fear of the spiritual guides from Umbanda. I had fear of some spiritual guides. The guide would say "do this" and I would take the money from any where to do it [make the dispatch]. I imagined that if I didn't do it, something worse would happen, and if something else happened I imagined that it was because I haven't done what the guide demanded. I was like this, but when I returned to church, we start to learn in the Bible, it explains to you how things are, and now I have lost my fear. [Leonardo's mother, The Return of Jesus Christ Pentecostal Church]

Several young people gave the Bible a particular and more exclusive significance during their psychotic episode. I already mentioned Jonas' "cigarette and Bible ritual." After the outbreak of psychosis, José wanted always to sleep with a Bible under his pillow, although he does not like to read it. After returning from a youth retreat of Charismatic Catholicism, Eduardo started to claim obstinately that: "The Bible is the most right thing that exists because Jesus is very righteous, so you really have to express thanks." The girlfriend of Eduardo's brother commented that Eduardo truly believed in what he was saying about the Bible and Jesus but that he would also change his mind about it. She also thinks that he does not follow the Bible properly, although he believes in it. Eduardo's mother added that her son would read the Bible constantly, and that for a good period of time he passed whole days only reading the Bible. Once Eduardo told to me that he was avidly looking for some "answer" in the Bible, even though he was unable to tell what kind of answer he was searching for:

Eduardo: Now I have been reading a lot the Bible because I get interested in the topics, so I read the Bible. I have always read a lot. I used to be very curious. And now I am reading the Bible to see if I find the answer... there are beautiful things in the Bible.

<u>Cristina</u>: What kind of answer you are looking for? <u>Eduardo</u>: I don't know... an answer... I don't know.

Milton was particularly explicit regarding the role he gave to the Bible as a way to cope with psychosis:

No because afterwards I need to read [the Bible] and so I go back to read the Bible... because the Bible helps you a lot. The Bible that I gained, I don't know who in my family gave it to me, thus I am reading this Bible now. It helps for you to have faith and not get very tempted... for you not to make disorder, not to break anything, not to break this table. [Milton, Catholic]

In other cases, the patients' resort to the Bible appeared more confused and unstable. Alice's narrative illustrates how the Bible appears to be absorbed into the "delirious" quality of her lived world. Alice establishes a contiguous relationship between herself, the Bible and a lit candle on her neighbour's window. When she reads the Bible or talks about it, the flame of the candle seems to respond, and she interprets this as a work of macumba. Her reactions towards the candle's flame then become exacerbated: she feels the urge to talk even more about the Bible, she kneels down in a praying position, and she faints in the floor as if she had abandoned herself to the Holy Spirit. The Bible occupies an ambiguous position in her world: Alice reads the Bible incessantly to counteract what she names as a "work of macumba," but this experience also presents a negative side because she feels her reactions become exaggerated and "out of control." But at the end of her narrative Alice also gives a positive value to the Bible, when she explains that she uses it in her search for some feeling of safety while facing a very unstable reality, and in her incessant quest for the significance of such incomprehensible experiences:

Ah, I would start to talk alone in the evening, to pray alone. Oh I would pray, I don't know if... if it was the Bible, I was talking... I was in my kitchen. I was talking the Bible, and I was feeling very pressured by the shadow, no it was some kind of shadow, no it was some kind of candle that was in the neighbour's window. Then I felt very uncomfortable with that because it seemed that it was something like some macumba that was being done to me... the candle in the neighbour's... the candle remained lighted the whole night. Now the candle it was just like [macumba], the more I talked about the Bible, the candle would respond, it would respond like this, the candle would light up even more, the flame was blazing even more. And so I thought: Why that was happening to me? Then I was

talking in the kitchen, every time that I talked about the Bible, that I started talking I would feel. I would faint on the floor, or I would kneel down. In other occasions I would raise, I would raise because I didn't accept that, once more I would talk and I would even be... there were days that I would not sleep well. I was unable to sleep well because I would only think in the Bible. [...] That candle it was something like... like a macumba. Macumba because every time I said anything and read the Bible, then I would begin... when it responded the candle would light up even more, but then I would fall down on the floor, I would fall down and would remain kneeled. And so I thought: why all that was happening? I remained a long period like this, without... I saw shadows during this period too. And so I imagined that it was that candle that was contributing for all this that was happening.[...] Other times it was like... I would feel more safe because I was able to read the Bible. I would feel more safe, and I had the urge to read it to learn more... the religious teachings, I felt like reading it to understand better what was happening... what is the difference between one religion and the other? What religion we were following? [Alice, Universal Kingdom of God Church]

One could say that there are convergences between the manner that family members and patients refer to the Bible: "one has to read the Bible all the time," "the Bible explains to you how things are." "I lost the fear by reading the Bible." This seems to be the accepted frame of reference shared by patients and family members. In other words, patients also resort to the Bible like any other person who seeks some kind of religious consolation and reassurance. The divergences between patients and family members rather rest with the excessive and contradictory ways patients manipulate and attribute meaning to the Bible. For instance, in the context of a prayer request one is supposed to read the Bible until the prayer and fasting is finished. But Alice was incapable of stopping to read and talk about the Bible. She also mixed the sequences of events, and reading the Bible, kneeling down, and praying was usually done in a disorganized and confused way. One may also associate her experience of the Bible with a "whirlwind," the disordered flight of ideas described by Binswanger. When Alice manipulates the Bible in a very distorted and idiosyncratic way, it becomes evident that her religious experience not only interacts, but becomes enmeshed within her psychotic experience.

God and the Holy Spirit

The conception of an omniscient, omnipresent, omnipotent, and all-perfect God dominates the narratives of both patients and family members. This unconditional faith, trust and love toward God may coexist with the possibility that God could also punish them in some circumstances, while in others they receive His grace and forgiveness. This ambivalent representation of God as a punishing/rewarding figure is anchored in Popular Catholicism; this ambivalence was particularly mobilized in the patients' narratives:

I don't have any nervousness. I was never afraid of anything! I am only afraid of God! I have fear of God. The only person that we have to fear is God. Exactly, I fear the <u>castigos de Deus</u> [God's punishments]. We all have to be afraid of God's punishments. You have to have... respect towards God. [Hélio, Umbanda sympathizer]

In the first place who is keeping vigilance over me is God! (...) Now this is a good thing. But before I was feeling worried, I didn't like it [he gesticulates with the body his fear of God]. But now I don't have fear of God. I know what is good for me, and what is not. [Mauricio, Non Practicing Catholic]

There [Universal Kingdom of God Church] I started to manifest the Devil... it is the process of liberation, that is how they call it. I thought that it was not going to be good for me, but after I left the church, after some months it [psychosis] got worse. Now I only pray and I only believe in God. I only pray for Him, I only pray for Jesus and for the Bible, pray for the Bible. When I threw the images of the Virgin Mary and of Jesus Christ out of the window, I didn't know that this was going to harm me. Then it [psychosis] started, it was just like... my mother says... this was a castigo de Deus. Because I was not supposed to do that [throw the images] and it started to take hold of me... I threw the images and it started to harm me. It started to harm me like this: I was having "epileptic attacks" and I started to see shadows. [Alice, Universal Kingdom of God Church]

The narratives above indicate that the ambivalent representations of God are related to the fearful and "delirious" mode-of-being-in-the-world that these young people suddenly feel engulfed. Hélio associates his insurmountable anxiety of feeling persecuted with his fear of God's punishments. Only those who truly respect and believe in God can

liberate themselves from this fear. But at the same time, fearing God is also a way to show respect towards Him. Mauricio connects his fear of God with the sensation that God is keeping an eye over him, but it is not clear for him whether this vigilance is good or bad. He assumes that to be watched over by God should always be a good thing, but he simultaneously mentions that he felt very afraid and worried when that happened. He associates this fear of God to the extreme confusion he experienced during the outbreak of psychosis; a period when he was incapable of distinguishing good from bad.

Being originally an active Orthodox Catholic, Alice sees the psychotic symptoms ("epileptic attacks," shadows) she was experiencing as a result of God's punishment due to her "sinful" behaviours, when she threw the holy images away and incorporated the Devil while inside the Universal Kingdom of God Church. This punishing God coexists with the image of a praiseworthy Being that is deserving all love and prayers. It is interesting to note that besides praying to God and Jesus, Alice also prays to the Bible. One may wonder what special meaning she associates with the Bible, which receives the same kind of devotion she directs to God. Like a few other patients, Alice also gave me the impression that to "talk with God" and to "talk with the Bible" could sometimes have the same meaning. To talk to God appears directed towards a key stable person (figure) when everything else is shifting. I will come back to this idea in more details later on in this chapter.

More often than not patients intensify to unimaginable limits, their faith, love and devotion towards a powerful and benevolent God that supersedes the figure of the "punishing" God. This is often a personal God with whom they can talk with and receive messages. For instance, Mauricio explained to me that he preferred to talk with God in a personal way, because he didn't really know how to pray to God. This attitude is in line with the popular religious belief that one is able to "talk with" God or to "see" God as a "human being;" however, He usually manifests Himself only to give very special messages. During fieldwork, the most impressive description I heard about God was a testimony given at the Assembly of God Church where Sarah had invited me to accompany her. On that afternoon the church ceremony ended up with a very long

testimony from a woman who used to be a Umbanda <u>mãe-de-santo</u>, but who suddenly decided to convert to Pentecostalism after a personal encounter with God:

When I opened my mouth and said aha there was a man dressed in white in the middle of the church sisters. I saw Him with the eyes that Jesus has given me. I looked at Him and when I looked at that man dressed in white His clothes would come down to the middle of His hands, to the middle of the palm of His hands. His clothing was very white, very white. I looked to His feet, and when I saw His feet, when I saw His face I was afraid of looking at Him. His feet and His hands are not like our feet and hands. The hands of Jesus have a bronze colour, the hands of that man who came to talk with me had a bronze colour. Have you my church brothers already seen lightning in the ski? That was the colour. His feet were also different from our feet. I would say that sparks of fire would come out from the hands of that man. He was in the middle of the church sisters, and He came close to me. He said some words to me. I am going to tell you everything that man told me because thank God until today it is being fulfilled. It was really Jesus that came to talk with me in person. That man told me, the words that he said: "Woman I am your Lord, I am the Holy Spirit and I came directly to talk with you here in Earth. I came to tell you that is enough! Here in Earth I am closing the doors of the Umbanda centre so vou will not work for Satan anymore. Beginning today you are going to work for me but before this happens, several events will occur in your life for you to be sure that I am God and entering with providence in your life. For you to know that I am God, Hallelujah." That man would say in a very powerful way that He was the Holy Spirit, but I am going to tell you that I was afraid. My hair would stay on its end and I became very hispid and frightened. My heart was beating so fast, it seemed that it would come out from my mouth. I wanted to run away but I couldn't, and that man kept saving to me that He was the Holy Spirit. I feared Him, I maintained my head down because the Devil always turns down his head to Jesus, and that man disappeared.

The idea of having acquired "special powers," or in some way of having become a very "special person" is quite common among psychotic people. In psychiatric terms, it is qualified as a feeling of omnipotence. However, this kind of idea resonates with religious beliefs claiming that the faithful have been "elected by God." Like some other patients, Sarah seems to have experienced this sense of being special in a positive way. Yet in some circumstances, having the same special powers can also be very terrifying (see a more detailed description of Sarah's in the last section of this chapter). For example,

Sarah was very reluctant to tell her mother about her personal "fight against the Devil" because she imagined that the power of this revelation could kill her mother. She comments that she finally lost these special powers when she abandoned herself to God. thus allowing God to carry on with the fight against the Devil. Eduardo was also very frightened with the idea that he could injure his mother only through his thoughts. Mauricio also believed that he had special powers because he was able to perceive all the "wrong things" that were happening in his surrounding world. He was anguished and perplexed to see so much "wrongness" in the world. These "extra-sensorial" perceptions sometimes became very threatening, particularly when Mauricio imagined that he had such powerful telepathic thoughts, that he could even kill his mother just through his thinking. Having "special powers" therefore appears to carry ambiguous meanings: by feeling so "special" patients may attempt to form a positive image of themselves that may help them to tolerate the uncanny and incomprehensibility of what they are experiencing. Only people with "special powers" would be able to overcome so much anguish and terror. However these "special powers" are also limitless, which makes patients experience that they are also able to harm other people besides the "evil world" they are trying to fight against.

Such a feeling of having been transformed into a very special person can take an extreme form and lead to the impression of having become identified in some way with God:

When I started to go to church it seems that... The Spiritism started to chase me, with voices and doing macumba to me... They are spirits... I am the 'Holy Spirit', and they are the 'spirits of evil' [voices]. They do macumbaria,, sorcery, this kind of stuff. [...] And so people say that I dribble... that I listen to the voices... and then I dribble the spirit... that I was going to die, that they [voices] wanted to kill my family [Leonardo, The Return of Jesus Christ Church].

In a way similar to Sarah who tried every strategy possible to deceive the Devil. Leonardo attempted to dribble⁸ the spirits of evil. Identifying himself with the Holy Spirit gave him some sense of "power" which helped him to deal with the unbearable persecution where he found himself caught in. I suggest that this new sense of empowerment is what allowed him to "dribble," irritate, and fight back the voices that had been disturbing him. One may hypothesize that "dribbling" these voices placed him in an active stance (by provoking the adversary) and gave him some sense of self-control (by controlling the "ball") towards his own existence. This is specially the case in those occasions when the voices were there "playing the soccer game" against him. It could also be possible that a patient's insurmountable fear and anguish is metamorphosed into some kind of power that "dribbles" psychotic symptoms. In any case, Leonardo preferred to keep secret about how he managed to dribble these evil spirits.

Narratives indicate that the figure of God on whom patients rely is always that of an omnipotent God. Patients derive some sense of stability from believing that they have been "elected by God," or even that they have become God, but this kind of perception may also remain entrapped within psychosis. Thus, a very thin and flimsy line appears to separate one's experience of God from oneself. One may question whether this close association between aspects of the psychotic experience and one's experience of God weigh up in the religious experience towards the negative or towards the positive, as the only "way out" for patients to cope with psychosis.

Devil and evil spirits

Once José's mother decided to take me to the main Universal Kingdom of God Church in town, rather than to the neighbourhood's church she attended more assiduously. I was immensely excited that night to hear a long sermon given by Bishop Macedo (who is the founder of the church) and to observe dozens of faithful falling into a trance because they were being possessed by the Devil. At the end of the ceremony the

⁸ Dribble is a slang term used in soccer games which means that the soccer player is able to fool his adversary by provoking him through body movements to keep control of the ball to run with it or to pass it over to another player.

pastor exorcized the Devil from each one of them through the gesture of laying-on-hands: "I demand in the name of Jesus and of the Holy Spirit for you the Devil to leave the life of this person, get out, leave, leave! Burn, burn, burn!" What I want to emphasize here is rather the explanations the pastor gave about the Devil. Before starting his sermon, Bishop Macedo asked all the faithful to sing two hymns: "His Name is Jesus" and "The Prudent Man." Afterwards he asked everyone to open the New Testament to Matthew Chapter 12, but he only read a small excerpt beginning at verse 43:

When the unclean spirit has gone out of a man, he passes through waterless places seeking rest, but he finds none. Then he says, "I will return to my house from which I came." And when he comes he finds it empty, swept, and put in order. Then he goes and brings with him seven other spirits more evil than himself, and they enter and dwell there; and the last state of that man becomes worse than the first. So shall it be also with this evil generation. [Bible, Revised Standard Version, pp. 941]

Bishop Macedo re-interpreted this passage from the Bible by focusing on the notion of "unclean spirit." He explained that the "unclean" or "evil spirit" always needs a human body to express and to manifest itself, yet the spirit is incapable of manifesting itself in a dead body. Since the "unclean spirit" always needs a living human body to manifest itself any person can be possessed by evil spirits. According to him, "obsessing spirits," "evil spirits," the Devil, and so forth are only different names given to the same phenomenon. There would be two main reasons for a person to be possessed by the Devil: the effects of witchcraft (or macumba) or a complete lack of knowledge of God. He added that the evil spirit "lodges" itself in the heart of the person because the heart is the centre of life, the centre of decisions and the centre of emotions. But it is only the "boss" of the evil spirits that lodges itself in the heart of the person. From this moment on, the "boss" starts to call other "evil spirits" to come inside and possess the person as well. One evil spirit arrives and lodges itself in the head of the person so the person begins to have incessant headaches. Another spirit comes and lodges itself in the leg of the person, so the person is unable to move his or her leg; another one lodges itself in the stomach and the person starts to feel unbearable pain or gets sick on the stomach, and so forth.

Afterwards Bishop Macedo declared that after people come to the Universal Kingdom of God Church and go through the process of liberation they then feel themselves liberated, they feel healed; they feel much better. But when no change happens in their lives, no prosperity, it is because they have not yet pulled out the "boss" of the evil spirits from their hearts. The "boss" of evil spirits only leaves people when they start to rebel against their wretched and miserable life. The person has to rebel, to fight, and demand from God: "God I do not accept my situation anymore!" To become determined, rebellious and to show what one really wants is also part of the process of liberation. People have to conquer this by themselves, thus they cannot expect the pastor to accomplish this miracle for them. It is very important to always carry a pocket version of the New Testament, so the person can always read it during free time. He added that all that he was saying was written in the New Testament: these are the words of the Lord, one only needs to follow what is written there.

José's mother and Leonardo's mother were the two persons who invited me to go to a Universal Kingdom of God Church. At these occasions I also had the chance to discuss with them what they thought about the Devil and evil spirits. Leonardo's mother basically agreed with Bishop Macedo that the Devil, evil spirits, obsessing spirits, encosto, exu, are only different names for describing evil manifestations. In fact, Leonardo's mother believed that demonic possession is analogous to the possession through which people participate in Afro-Brazilian rituals and receive spiritual guides. When we talked about this Leonardo and another cousin were present in the kitchen and they vehemently disagreed with Leonardo's mother (even though both of them follow Pentecostalism). They perceived the process of liberation in the Universal Kingdom of God Church as only a simulation, and thought that no Devil was being exorcized. While many mothers follow the opinion of Leonardo's mother, others attempt to make a certain distinction between evil spirits and the Devil because they conceive the Devil to be the worst and most destructive evil spirit:

<u>Macumba</u> is just like a "prayer request," if the person doesn't like you the person throws a <u>macumba</u> over you. The <u>macumba</u> calls the evil spirit. I throw it over you to disturb your life or to kill you. Then you are in a car

or walking in the street and something happens [e.g. accident]. There are all kinds of things that can happen. The spirit of death doesn't move [when possessing the person], he remains stretched out and falls down, he remains there like dead. And there is that one who wants to destroy everything, he is going to destroy. There is the one who gets angry and teases you from the back, he has a lot of strength... that is the Devil. [José's mother, Universal Kingdom of God Church]

I imagined that now with the end of the world coming [apocalypse], the enemy [Devil] is circling everyone, looking for a breach to incorporate [in people]. Since my daughter gave motive, she opened a breach for Him [Devil] to incorporate, this is what I was thinking. Temptation from the enemy. He is the big boss. We have this tempter which is our rival. We have to be very attached to God to free ourselves from the claws of the Devil. Haven't you ever seen a demoniac person incorporating an evil spirit? [Maria's mother, Seventh Day Adventist]

Family members may find some "family resemblance" between the patient's odd behaviours, signs of demonic possession or some other spiritual disturbance. This is not surprising since some of the symptoms that Bishop Macedo associates with demonic possession can also be found in people who have psychotic symptoms: nervousness, headache, insomnia, fear, attacks of faintness, desire for suicide, illness of which physicians ignore the cause, visions and hearing voices, vices and depression (Macedo, 1990, as cited in Mariz, 1997). I also observed that families preferred to avoid using the term "Devil" whenever they could. I suspect that this term has such a powerful meaning, that not to mention the Devil may be an attempt to keep distance from His evil actions.

On the patient's side, many of them seem to share the opinion that the Devil or any other type of evil spirit represents the encompassing presence of the uncanny and terrifying evil in their existence. Curiously, a few patients reminded me of another popular religious belief concerning the Devil, exu, or evil spirits. They attributed to the D/evil the quality of trickster. In other words, the Devil can initially fool the person and be very good with him or her with the sole intention of seducing the person. After that the person becomes dominated by the Devil and is obliged to fulfil all his desires and evil intentions:

This cousin of my husband knows people who do <u>macumbaria</u>. One of her legs was healed, I believe by the Devil... the Devil heals! He heals so people will always make his desires. In fact he remains behind the images of Saints to listen to the spirit of people and their prayers so he can effectuate their desires. [Sarah, Assembly of God]

Only Maria and Alice mentioned to me very rapidly that in some situations they imagined that they were incorporating the Devil during the outbreak of their psychotic episode. This occurred more frequently during the period when they fanatically attended the Universal Kingdom of God Church – which is the Neo-Pentecostal Church that most insists on the exorcism of Devils and other evil spirits. It is possible that other patients did not find the courage to tell me that in some circumstances they felt themselves like an evil spirit. However, it is more likely that patients projected all the evil they were experiencing to their surrounding world. In other words, they tried to distinguish themselves from the evil in order to feel some sense of "empowerment" providing them some "way out" of psychosis. This discussion will be further developed in the next section.

Fighting Against the "Evil"

The previous section was built around a few prominent religious signifiers (Bible, God and [D]evil). It is important to realize that the various religious signifiers are integrated and interplay within singular narratives. One religious signifier may also have a variety of meanings within the same given time. Singular narratives are shaped by the shifting meaning that religious signifiers can take in a person's discourse. Sarah's narrative below demonstrates how she colours and perceives herself and her surrounding world through the messages she reads in the Bible in such a way that she does not differentiate the frontiers between the imaginary and the real. It also indicates how she tries to hang on to religious signifiers that always appear to be absorbed within her distorted vision of herself and of the world.

Sarah's story

<u>Sarah</u>: I would read the Bible about every thing that I wanted to know I would go there [and read the Bible]. There is one verse in the Bible that says that somebody died afraid of bugs because he has not glorified God.

Cristina: Ya.

<u>Sarah</u>: Then the bedroom where I was would be full of bugs and mosquitoes.

Cristina: Uau.

<u>Sarah</u>: With bugs, with mosquitoes. So I would start glorifying the name of Jesus, glorify.

Cristina: What do you mean by glorifying Jesus?

<u>Sarah</u>: Give glory to God. <u>Cristina</u>: You would say...

<u>Sarah</u>: Give glory to God, alleluia. Then I started to feel peace inside of me. It was such a great peace... until the day I went to look at myself in the mirror. I went to look myself in the mirror and I saw myself transparent in the mirror.

[...]

Cristina: So you were not eating...

<u>Sarah</u>: Even so they [family] would always make me eat anyway. But I was not hungry to eat no.

<u>Cristina</u>: What other changes did you feel in yourself? <u>Sarah</u>: I felt that I was not the same Sarah as before.

Cristina: What was different then?

Sarah: I was ... I was feeling pure, kind of pure of heart.

<u>Cristina</u>: Hum. <u>Sarah</u>: [pure] of soul.

Cristina: Hum.

<u>Sarah</u>: And I was feeling kind of different [points to her own nose].

Cristina: Your nose?

<u>Sarah</u>: Very big [nose]. I would look in the mirror and after looking I would see myself transparent. There was one day that I even saw my soul getting out of myself.

Cristina: Yah.

Sarah: I would do this and I would see my soul outside of myself.

Cristina: you would look at the mirror and would see your soul outside

<u>Sarah</u>: No, no, that was without looking at the mirror. I would only see look at my hands [shows hands] I would see two hands, one going out of me, do you understand?

Cristina: Hum... I understood.

[...]

<u>Sarah</u>: I was walking [in the sense of behaving] very correctly. I was walking in the straight path. Since the Bible says that we have to walk in straight paths. Very correct, never fail, never lie. That means that I was becoming a biblical person.

Cristina: Yah.

<u>Sarah</u>: Without failing. I used to be very nervous and so I became calm, passive. Because the Bible says that we need to become the model of Jesus. Just like a sheep.

Cristina: And so you were passive just like a sheep?

<u>Sarah</u>: That's it. So I was following everything that was written in the Bible, following correctly. Afterwards I started seeing Devils

Cristina: Where would you see the Devils?

<u>Sarah</u>: And the Devils used the people themselves, people from my family to try to kill me.

<u>Cristina</u>: Where would you see the Devil... in your husband... your father-in-law?

<u>Sarah</u>: That's it. In my father-in-law, in my mother-in-law I would see him. <u>Cristina</u>: And how would you know that they had a Devil inside of them?

Sarah: Inside of them, ah?

Cristina: How would you distinguish it? How would you know?

<u>Sarah</u>: When they were possessed by the Devil their ears would become thinner, they would become pointed.

Cristina: Their ears, hum hum.

<u>Sarah</u>: One day I even had a premonition when I touched my husband's ears it was perforated just like thorns in his ears.

Cristina: Ah...

<u>Sarah</u>: Just like needles. I touched his ear and I picked up a thorn. Once my husband was talking to me and he maltreated me, he maltreated me very much... He spanked me, he pushed me through the throat... he forced me to put a piece of wood outside.

Cristina: Ah.

<u>Sarah</u>: But I knew that this was not him. In his shadow I would see the shape of a death's head, in his shadow.

<u>Cristina</u>: It was during the same period or before? It was during the period you were seeing the Devils with horns or a little before?

Sarah: It was during the same period.

<u>Cristina</u>: And wouldn't he say to you that there was no death's head, that there was no Devil... how would he react?

<u>Sarah</u>: He would laugh. He would tease me. He... I didn't tell that I was seeing those things, you know.

Cristina: So you kept it to yourself?

<u>Sarah</u>: I kept it to myself. I knew that it was not him who was maltreating me, that I knew.

<u>Cristina</u>: What did you try to do to solve this problem of the Devil?

<u>Sarah</u>: Everything that the Devils asked me I would do the opposite.

Cristina: What do vou mean?

Sarah: They would ask me to take a shower, I would not take it.

Cristina: What else did they ask you?

<u>Sarah</u>: Once I... they wanted to arrest me inside my bedroom.

Cristina: Hum

<u>Sarah</u>: I would make noise. I would sing and kept giving glory to God and this irritated, this irritated them a lot.

Cristina: Hum.

<u>Sarah</u>: But I never tried to disobey them. I always tried to obey their wishes. Even so I tried to glorify, I only spoke about the name of God and I sang very loud!

Cristina: Hum... which music did you sing?

<u>Sarah</u>: [starts to sing]: Ah my God is the one...It is beautiful yes it is beautiful the place that God prepared for us. I repeated this several times: It is beautiful yes it is beautiful, it is beautiful the place that God prepared for us. And this irritated...

Cristina: This irritated?

<u>Sarah</u>: It irritated them. They could not hold themselves when I acted like that.

Cristina: Oh vah.

Sarah: They got mad and rebellious against me, so they tried to kill me.

<u>Cristina</u>: Did you go back to church again, did you do something else; did you ask for somebody's help?

<u>Sarah</u>: Me, while I tried to read the Bible they would hide the Bible from me... They would take it from me, they would not let me go to church.

Cristina: Hum... you were not able to go to church?

<u>Sarah</u>: No I was not able. I was only able to follow the right path of Jesus, to obey and being obedient. But at the same time I was disobedient because I obeyed God but not the Devil.

Cristina: Hum.

<u>Sarah</u>: I soon knew that it was the Devil who was using (me). Besides, in the church here God used a vase to tell my mother that I was fighting against the Devil face to face.

<u>Cristina</u>: Ah what do you mean that he used a vase...explain to me what you mean.

<u>Sarah</u>: A vase? A person who follows Jesus here... here on Earth. A person who follows all commandments of Jesus is a vase. That means that everyone of us is a vase, a <u>senhora</u> is a vase. Now in his way and in God's way he saw the use. Everyone of us is a vase.

Cristina: Ok. Oh a "vase" here in São Paulo told that to your mother?

<u>Sarah</u>: It was a person who told my mother that I was fighting with the Devil face to face, front to front... and this is true.

<u>Cristina</u>: So since you were seeing yourself fighting the Devil how did you end up here in São Paulo, what made you come?

[Sarah was living in Pará with her husband before her mother brought her back to São Paulo].

Sarah: I myself concentrated very deeply on God.

Cristina: Hum.

<u>Sarah</u>: I did make her come, it seems that I did make her come. I read a verse from the Bible and I asked help for my mother.

Cristina: Hum

<u>Sarah</u>: I remembered that she... no I was not remembering that well. I remembered that she was a member of the church, so I asked for God, for God to help me.

<u>Cristina</u>: Did she go [to Pará] to bring you or did you come by yourself? Sarah: She went to fetch me.

Cristina: Ah.

<u>Sarah</u>: When she arrived there they [husband's family or Devil?] did everything to hide from her what was really happening to me.

Cristina: Hum.

<u>Sarah</u>: They even made me believe that my mother had a heart problem. Feeling the heart tum tum and snoring because they say that when a person snores too much this indicates a heart problem. Did you know that?

<u>Cristina</u>: No I didn't. You are the one who is telling me that... but I snore. <u>Sarah</u>: [laughs]. Ah I would feel... I would tremble that my mother could have died in case I told her, she gets very terrified. They did it, the Devil made me think like this for him... what I did to help me. Oh... God helped me in such a way that I even had powers.

Cristina: What do you mean?

<u>Sarah</u>: I would look like this to the light, the Devil would turn off the light, and I would turn the light back on with my eyes.

Cristina: OK, so did you have more powers than the Devil?

<u>Sarah</u>: Hum... I made the sky and earth... die the sky and earth with my faith.

Cristina: Uau.

<u>Sarah</u>: With my faith with my faith I was able to move the skies and earth fighting against the Devil.

<u>Cristina</u>: How long did you keep fighting with the Devil... are you still fighting with the Devil?

<u>Sarah</u>: No, thanks to God no. Now I left the fight to God, I have abandoned myself to God.

Cristina: And so you mother went [to Pará] and brought you back?

<u>Sarah</u>: When my mother arrived her face shone like the face of an angel.

Cristina: Ya.

<u>Sarah</u>: It shone, the most beautiful thing in the world.

<u>Cristina</u>: Hum. <u>Sarah</u>: Her eyes.

Sarah understands her psychotic episode as related to talks with God (especially through the mediation of Bible reading) and fights against the Devil. "God," "Devil" and the act of "Bible" reading are the basic religious signifiers used by Sarah in her attempt to make sense of psychosis. She reads the Bible always looking for orientation to deal with her feelings of strangeness in relation to the environment, other people, and herself. Apparently, resorting to Bible reading keeps a double meaning throughout the narrative.

On the one hand, it helps Sarah to cope with the enveloping strangeness. On the other hand, it exacerbates her feeling of strangeness in relation to the transparency of her body that can be associated to "soul loss" and to other body distortions (e.g. big nose).

Sarah depicts a series of self-perceptions that have a religious connotation: pure of heart \rightarrow pure of soul \rightarrow biblical person \rightarrow calm and passive like a sheep \rightarrow model of Jesus \rightarrow person with special powers. This succession of qualifications suggests that Sarah attempts to accept the odd transformations she has been observing in herself (e.g. nose gets bigger, soul leaves body) in a positive and religious way. One may also suspect that body transformations and "soul loss" are very frightening experiences. Sarah seems to counteract these strange perceptions by constructing an image of herself as a person "pure of heart and soul," who is more likely to become a "biblical person," who follows the words of God and becomes the "model of Jesus." Only a "biblical person" allied to God would be able to win the fight against the "Devil."

For Sarah the act of reading the Bible seems to be absorbed in the "delirious" quality of her world. Everything becomes replete with religious meaning; because the Bible is representative of the eternal truth, it hypothetically contains all the answers that people need. In addition, the Bible is taken as the core symbol to reveal "the origins" of human existence. Most young people I interviewed continuously searched for answers concerning their own existence. Patients question the meaning of life, of their existence, and the very certainty of reality, destabilizing everything that is taken for granted in their common world. While they are immersed in uncertainty, the manipulation of religious signifiers potentially provides them certainty and truth.

Sometimes patients associate the act of reading the Bible to their "talks with God." The faithful as well equate words written in the Bible with personal talks with God. This can generate confusion between the words of God (written in the Bible) and one's reality: people talk *about* God and *with* God simultaneously (Cesar, 1996; Mariano, 1996a). "Talks with God" may be perceived positively, and may help to fight against the negative influence of the "Devil". Sarah describes a constant sensation of being trapped

with a pressing need to obey the Devil because he only intends to kill her. Nevertheless, she slowly discovers some strategies to deceive and disobey the Devil, for example, to sing religious songs out loud and to glorify God. She is trying to find a "way out" of the evil world where she imagines herself to be engulfed. However, when she starts to glorify God uninterruptedly, she remains trapped in her endless fight against the Devil. The tension between the repetitive acts of glorifying God to eliminate the presence of the Devil only contributes to exacerbate her problem. The perceived omnipotence and omnipresence of the Devil only aggravates Sarah's anguish and perplexity. This experience is also very confusing and chaotic because the same person, for instance Sarah's mother, may acquire the qualities of the "Devil" or the "angel" interchangeably. She behaves in function of an imagined "reality" which seems contradictory to outsiders. One may also associate the range of contradictions expressed in Sarah's narrative with the "whirlwind" world formation described by Binswanger.

Sarah feels that her faith gives her the power to "move the sky and earth" and this is mobilized in her fight against the Devil. Besides indicating the tremendous effort she is investing to eliminate the Devil, her struggle also puts her in a very special position of "superiority" in relation to the Devil. I imagine that these grandiose feelings eventually express some resistance towards a complete entrapment within psychosis. Sarah often prefers to keep secret many feelings she was experiencing. For instance, she did not tell her husband that he resembled the Devil, even though she interacted with him as if he was, or that she had suddenly gained the strength of God's power in her hands. This appears to indicate a certain awareness that psychotic perceptions and feelings take place in a parallel space which does not coincide with ordinary life. This parallels other people's opinion, but patients frame it differently, as for them, their perceptions are "real".

However, keeping secret about these disturbing feelings may well be another strategy to fool the Devil. It is also a form of prudence as she is not sure whether her husband is the Devil or not, or whether she really acquired God's power. According to Corin, Thara, and Padmavati (in press) keeping things secret may well be part of a

general intention to protect a private space necessary for taming and elaborating what is occurring. The secrets that patients maintain can also contribute to build an inner psychic space, sheltered from the intrusion, malevolence, curiosity or adverse reactions of other people. In this context, the external observer is not always in a position to grasp the underlying meanings of Sarah's chaotic behaviour. Since every signifier is susceptible of being re-signified in the patients' own imaginary, they are allowing themselves some "distance" from the "real" world while they keep secrets.

Mateus's story

While I was interviewing Mateus, he gradually introduced religious signifiers to describe modifications in his experience. Initially he was very amazed that his girlfriend was aware of what he was dreaming even when she was very far away from him (in another State). He immediately interpreted that his girlfriend could only be clairvoyant or a medium:

She would read my thoughts. She was able [to do it]. I thought that this was the work of the Devil because something like that is not possible something like that, a person to read the thoughts of another person [...] And this continued, even after smoking marijuana because we smoked everyday, things like that seemed to happen. It seemed that when she smoked marijuana and I smoked it her head would become linked with mine. [Mateus, Community of Grace Church]

That his girlfriend could read his thoughts and have her head connected to his own head were the first signs to Mateus that he was losing his personal sense of boundaries with the outside world. He also interpreted that she was the pivot of the crisis because she had the habit of making macumba and other acts of sorcery. Later Mateus explained that his girlfriend had no real intention of harming him since she was only being used by the forces of evil. Mateus also anchored the outbreak of psychosis into a trip with a group of friends during Carnival holidays and during which he consumed LSD:

I thought that the world had ended. That just bad people remained on earth. I would see everyone different, I would see everyone in the shape of Devil. [...] Nothing was real, it was something from my head, nothing was true. It was something from my head because it is not possible people remain in the way I saw them, of hearing voices... hearing... ah [the voices] would say that I went to Curitiba and spend Carnival there. The voices would say that I would remain there and that I would never see my mother again, that I would remain there, that the world had ended, it was horrible! [Mateus, Community of Grace Church]

Expressions like "forces of evil," "the world had ended," "just bad people remained," and "everyone in the shape of Devil" only reiterate the deterioration of Mateus's experience. These signifiers are primarily employed to label and describe his unusual experiences. They also indicate that Mateus was struggling to keep some sense of permanence in his own existence, by contrast to the unstable and unreal changes that he was experiencing. With the association of people looking different and "bad" with the figure of the Devil, he transformed the indescribable experience into something more intelligible. This likely applies also to Sarah when she assumed that the people around her represented the figure of the Devil.

Referring back to several patients' narratives described in this chapter, it is more evident now that the world around them seems to be dominated by the "fixed" feeling of evil. Oppositions between God and Devil, good and evil can also refer to existential questions concerning "life" and "death." For instance, Sarah constantly asked her husband whether she was dead, as she also believed that she had the power to make the sky and earth "die," and that she was able to put an "end" to the whole world. This kind of perception appears as a more active version of Mateus' "paralysing" mode of being-in-the-world when he imagined that "the world had ended."

In the two stories above, Mateus and Sarah attach religious signifiers to their strange experiences and this helps them to describe and name their unusual experiences. One could also hypotesize that they are also trying to protect their precarious sense of self in projecting the deterioration of their experience to the outside world. While Mateus seems to remain blocked at that level, Sarah also moves into something else in creating

positive religious self-perceptions about herself, like being a "Biblical person," and "pure of heart".

Both patients also made a whole series of allusions to their missing a personal sense of boundaries in relation to themselves, other people or the outside world. Their sense of self seems to be constantly dissolving and changing its own limits or boundaries. They might have lost the "illusion of wholeness" that permeates the self in all societies:

In all cultures people can be observed to protect multiple, inconsistent self-representations that are context-dependent and may shift rapidly. At any particular moment the person usually experiences his or her articulated self as a symbolic, timeless whole, but this self may quickly be displaced by another quite different self which is based in a different definition of the situation. The person will often be unaware of these shifts and inconsistencies and may experience wholeness and continuity despite their presence. [Ewing, 1990:251]

The model offered by Ewing indicates that one may shift and change through dialogue and conversations with another self, while also de-emphasizing the parallel existence of aspects of the self in order to elaborate a sense of a personal identity with its own history and permanence in time. I hypothesise that beyond loosing the "illusion of wholeness," the two patients above have been affected in their different modes of permanence of self through time. What seems to be very difficult for most patients is to maintain this feeling of permanence of self because they seem to be absorbed within constant changes. In other words, they seem to be experiencing a dialectic process between permanence and change of self, which is often weighted towards the second. More than looking for a sense of personal identity, patients are also asking two fundamental questions: "Who am I?" and "Do I exist?" Such an existential perspective provides some access to the experience of psychosis; it helps to understand the meanings given to the "disruptions" of the self described in the literature, and the ways the experience, altered by schizophrenia, is cognitively structured and interpreted.

What I have discussed in relation to Sarah and Mateus is exemplary of the experience of most patients who participated in this study. What may differ is their degree

of involvement with religious idioms and signifiers, and the particular ways they capture these signifiers and try to make sense of their experience. There are different levels of reality taking place. It seems that these young people manipulate religious signifiers at three different levels. First, religious signifiers are useful to label or describe what they have been experiencing. After analysing the case of Ellen West, Binswanger (1994c) concluded that it can be a very superficial explanation to say that people with schizophrenia have difficulty in finding words to express what they are experiencing:

The truth is rather that the schizophrenic has so much difficulty finding words for his experiencing because his "world" is so novel, so altered, or even disintegrated, that he no longer finds "holding-points" to which he can "affix" his language. (1994c:321)

Second, the religious signifiers indicate continuous attempts or strategies of coping with psychosis or in finding a "way out" of psychosis. One may suspect that these religious signifiers eventually function as the "holding points" in which people with psychosis adhere to in their novel mode-of-being-in-the-world. Third, they reflect the quest for comprehensibility necessary to perpetuate and reassure one's own existence and sense of self. There can be a convergence of religious idioms with ones' own experience and quest. Thus, patients appropriate some religious signifiers more than others because they converge with their reality more easily. Religions also have the potential to provide a set of representations and meanings which contribute to insert a personal and alienating experience within a stable frame of reference; it equips psychotic people with a range of notions and symbols that they can appropriate for their own quest for significance.

My own work with psychotic people has indicated the important role of religious signifiers that can be borrowed from religious groups or reworked in an idiosyncratic way. At some level my findings converge with Corin & Lauzon's (1992) work with psychotic people in Montreal and Corin, Thara and Padmavati (in press) work with psychotic people in South India. In both cultural settings, patients resorted to religion often as an attempt to escape from the tremendous sense of confusion they were experiencing. They also borrowed elements from a variety of philosophical and religious conceptions and adapted these to their personal world. I would like to argue that religious

signifiers in Brazilian culture interact with the experience of psychosis in ways that also differ from the effects of religious signifiers in the experience of psychosis in Montreal and South India.

Both in Montreal and South India, the potential role played by "solitude" or a certain "solitary retreat" seems to allow psychotic patients to renegotiate a new relationship between themselves and the world. The case of Mr. A in Montreal (which is described in Chapter 2) evidences how certain religious and cultural signifiers provided by a meditation group helped him to elaborate his experience of withdrawal in a manner significant to him. In South Indian culture, renunciation is considered a supreme value, and it is common to see wandering ascetics of all ages, travelling from temple to temple to sacred places. In this context, detachment is perceived as a compromise between renunciation and involvement in the world, and people are allowed to live in the world under the Hindu philosophy of renunciation. Religion legitimates relative isolation; in this context Hindu psychotic patients may be allowed to construct a position of social and personal withdrawal within a religious frame that allows and supports their movement of retreat.

By contrast, the narratives I have collected suggest that the relational aspect of the religious experience is more developed in Brazil. First, this echoes the fact that most religious rituals and practices emphasize collective emotion and outwardly expressiveness and seem to provide very little space towards a movement of "renunciation" or "retreat." What I have observed among the patients who participated in my study is that the most prominent religious idioms and signifiers, especially Neo-Pentecostalism and the Afro-Brazilian religions, furnish them with very little opportunities to construct a "living space" of "positive withdrawal", unless they use the signifiers in a very idiosyncratic way. Furthermore the "relational" co-existence of "the other world" even in the smallest everyday actions and reactions of people generate a particular quality and bloom to the meaning of religion and religiosity. For instance, the widespread belief in "evil spirits" seems to be independent of any current religious affiliation or involvement. Finally, the personal articulation of religious idioms and signifiers condenses three main functions in

relation to one's experience of psychosis. They help to communicate, to elaborate, and to transform the experience of psychosis.

Through the notion of "work of culture" Obeyesekere (1985) has suggested that some cultures offer a greater potential than others for a personal elaboration of psychiatric disorders, including psychosis. Considering the "work of culture" in relation to the inner experience of psychotic patients, this author noticed that religious and cultural signifiers may operate both in a "progressive" way, towards restoration and elaboration of one's mode of being-in-the world, or in a "regressive" way, leaving the person trapped within repetition, personal conflicts or problems. Narratives indicate that patients and family members often gave more weight to the "regressive" elaboration of the experience in relation to these signifiers, rather than the "progressive". I am not saying that patients' resort to religion is merely "regressive", but that they have paid far more attention to this aspect of their religious involvement during the outbreak of psychosis. I believe that many patients were so absorbed in their own "delirious" experience, that together with their family members they were often impelled to emphasize the "regressive" aspects. The "progressive" elaboration of the experience was also present, but less evident. However, one has to take into account the fact that I met patients and families during the very outbreak of psychosis and just after, so that time had not yet allowed for the elaboration of more stable strategies to cope with psychosis.

In addition, to talk in terms of the "regressive" or "progressive" elaboration of experience is also a value judgement. This became evident when I tried to discriminate in which situations patients were able to cope with their psychosis through the use of religious signifiers, and when they were not able to do so. I recall Leonardo's initial involvement with Neo-Pentecostalism when he would go to church every day. He was feeling a sense of protection inside the church, because he would not hear the "voices" during the rituals. This illustrates a way in which religious idioms and signifiers helped Leonardo cope positively with psychosis. However, Leonardo also created a series of idiosyncratic macumba rituals during both psychotic episodes that he went through. To the eyes of outsiders these idiosyncratic rituals were only indicating a worsening and

accentuation of psychotic symptoms. Why did Leonardo insist on the rituals? Maybe this was the only way he found to "cope" with the strangeness and dreadful experiences he was going through.

I would like to conclude that religion occupies an important and irreplaceable space in the experience of psychotic people and their significant others in Brazil. It provides support through the religious web to overcome and accept such overwhelming and anguishing experiences even when religion is taken out of context, and is mainly absorbed in the "delirious" quality of the psychotic experience. Which other cultural signifiers could carry out the same "function" in the sense of elaborating one's experience in relation to oneself and the world?

Chapter 9 - Conclusion

Ballad of the Crazy

They say that I am crazy To think like this If I am very crazy Since I am happy More crazy is who tells me And is not happy, not happy If they are beautiful I am Sharon Stone If they are famous I am a Rolling Stone More crazy is who tells me And is not happy, not happy I swear that it is better Not to be normal If I can think That God is myself

[Lyrics and music by Rita Lee/Arnaldo Baptista; my translation]

When I was about the same age as the young people who participated in this study the "Ballad of the Crazy" was a Brazilian rock music hit. This music was praising the happiness of "breaking-up the rules," of being subversive in the moral sense, and a plea for freedom of thinking, rather than making an allusion to psychosis. Breaking up the rules or subverting the world order is closely associated with adolescence and young adulthood behaviour in the Western world. In a certain way the three themes developed in the song may also be seen as echoing aspects of the psychotic experience. However, in the last case they take a different quality. This attitude also takes an additional meaning in the Brazilian context. In the context of the psychotic experience, breaking up of rules and the subversion of the world order enacted in the behaviour and speech of patients frequently presents a constraining character. It is not so much an issue of questioning normalcy, as in Rita Lee's song or in the young adulthood behaviour, but an indication of

the difficulty in mastering the rules that run through and orient interpersonal relationships. As Blankenburg (1991) suggested, people with schizophrenia often loose access to common sense and to the "rules of the game"; they cannot rely on the self-evident quality of their everyday world. Breaking up the rules can be related to the ethos of the jeitinho brasileiro that was first discussed by DaMatta and is mentioned in Chapter 3.

Freedom of thinking is a very fervent and deep-seated issue in Brazil that has arisen after several decades of military dictatorship. When patients find themselves entrenched and entrapped in psychosis, most of the time they cannot experience any freedom of thinking. When the schizophrenic "voice" decides, persecutes and commands it allows no freedom to reflect. While Rita Lee's song calls for freedom of thinking in the sense that one can even believe that one is God and escape from the norm, this is not exactly what happens in the psychotic experience. To outsiders, patients may be perceived as people who escape from normalcy and break up the "rules of the game". But to patients themselves, in most circumstances they may find no other "way out" besides behaving and thinking in the way they are behaving and thinking. It is in this context that religion may come into play.

Religions provide cultural idioms that tackle the uncanny and unexplainable aspects of human experience. They help people contend with existential angst including life and death issues. European phenomenological psychiatrists view psychosis from the perspective of the alteration of the experience of being-in-the-world. As is the case for all people, but particularly for psychotic patients, this experience is also threatened by "non-being," death and existential angst that are frequent themes in the narratives I have collected, and are the most common forms of threat to "non-being". In my research, patients usually resorted to religion in their quest for the significance to the unexplainable mode-of-being-in-the-world in which they felt engulfed. Most commonly they commented that what they were experiencing often "seemed like something spiritual, or supernatural". I tend to agree with Binswanger (1994c) that this resort to alternative signifiers may have a deeper meaning than simply finding words to express the radical

(sometimes paradoxical) alteration of the mode-of-being-in-the-world which a person with psychosis is experiencing. Patients move through an incessant quest for significance due to the constant change or the temporary absence of "holding points" which could enable them to experience a certain sense of stability in their own mode-of-being-in-the world. In this context, their reliance on religious signifiers may be a way for them to seek "holding points" in which to "affix" or express their altered experience.

Most importantly, patients may manipulate the fluid semantics of religious signifiers from one or more religions to play with psychosis, or even to put it out of play (Blankenburg, 1991). In this context, the diversity and ambiguity of religious referents allow patients to cope with psychosis. Nonetheless, the opposite movement is also likely to happen. The ambiguity and diversity of religious signifiers may momentarily accentuate the "absence" of "holding points" in which one could sustain one's sense of being-in-the-world. When religious signifiers and "holding points" are continuously being re-signified the psychotic person not only experiences a lack of stability, but a deterioration of his or her position within the surrounding world. A good example is Sarah's long narrative described in the previous chapter regarding her "fight against evil," while I would also interpret it as her "fight against psychosis." This does not mean that patients are always coping with psychosis in what psychiatry conceives as a "positive" way. For instance, "If I can think that God is myself" is a common thought that helped several patients create some kind of "protection" against the "evil world" in which they felt themselves engulfed. From a psychiatric perspective this attitude only reveals the prominence of psychotic symptoms.

The crucial question that remains to be answered is whether the religious idioms and signifiers that patients use have the potential to help them find a "way out" of this "whirlwind" movement, or whether they tend to exacerbate the symptoms of psychosis. The outbreak of a first psychotic episode is such an unstable (and usually rapid) experience that sometimes it is difficult to distinguish the "positive" effects of religion from its "negative" or "neutral" effects. Evidently, certain religious idioms and signifiers have more potential to help the person muddle through his or her existential angst than

others. This is also pungently dependent on the particular ways that each person reinterprets and makes sense of the variety of religious idioms and signifiers that are available to him or her. For patients, a fundamental aspect of this resort to religion is associated with an attempt to seek a "way out" of psychosis in order to preserve and safeguard their own existence. One may wonder what patients would do instead if religion did not exist as some kind of "holding point," even when it works only temporarily. Family members resort to religion from a slightly different perspective. They are primarily seeking alternatives, but most often complementary forms of "healing" the patient. The despair, confusion and anguish of family members may become insurmountable, and this may precipitate a back-and-forth help-seeking movement between a diversity of religious therapies and religious signifiers. The fluid semantic and ambiguity of religious idioms and signifiers unfolds alternative ways of solving, explaining or coping with the patient's problem while family members may also find themselves burdened by the variety of possible "solutions" they can follow.

I have suggested that patients and family members may diverge in the meaning they are attributing to religious idioms, religious signifiers and help-seeking pathways (including psychiatric care). This divergence is also a consequence of the polysemic quality of religious idioms and signifiers; particular people may manipulate the same religious idioms and signifiers in different ways. Furthermore, the quest for significance that characterizes the inner mode-of-being-in-the-world of psychotic patients is not experienced nor perceived in the same way by their family members. Family members are only able to react and re-interpret what patients are trying to express, and not necessarily what patients are experiencing. I have also suggested that the behaviour of patients, family members and significant others (e.g. neighbours, mental health professionals) work in a kind of "feed-back loop" that modifies the subjective world and reactions of patients, while patients' reactions modify attitudes and behaviours of family members and significant others.

In addition, I have insisted throughout this work that the phenomenology of psychosis is always shaped through and intertwined with the everyday life world of

patients and their significant others. In this context, religious idioms and signifiers are not the only elements that influence or elaborate the experience of psychosis. All this suggests that the influences which "culture" casts over the evolution of the psychotic episode is much more complex, slippery, and difficult to determine than what is traditionally discussed by "cross-cultural" psychiatry.

I would like to exemplify this complexity by discussing once more the issue of "social withdrawal." I mentioned in Chapter 3 that Minkowski (1970) argues that every person experiences a type of "experienced distance" which is like a "free space" that people feel around themselves, and which gives them a feeling of "amplitude of life," but this is deeply missed by many psychotic patients. Minkowski associates the experience of schizophrenia with the experience of "dark spaces," since the obscurity of "dark spaces" goes beyond the mere absence of light; it is associated with the dispersion of "experienced distance," so that "life amplitude" disappears, the vital space is narrowed, and space is desocialized. People who do not suffer any kind of mental problem usually experience a "clear space" in which individuals feel a "free space" expanding between them and others; this enables them to experience distance, extension and fullness of life, which corresponds to the feeling of "amplitude of life."

I have argued that in Brazil patients have few chances to find a "lived space" where they can feel at peace or isolated. The physical space of the home is often small, family members create a never-ending web of protection (or vigilance) around them, and the majority of religious idioms and rituals provide scarce opportunities for them to create a space of solitude, and of freedom of thinking. I argue that in this context "a position of withdrawal" surfaces in patients' marginal participation in most religious rituals, through which they may be trying to maintain some distance or boundaries between themselves and the surrounding world. This may often be their only "way out" to mark a certain "distance" between themselves and other people; especially when patients have a hard time to differentiate the frontiers between the imaginary "evil world" they are fighting against and the "real" world. I suspect that whenever psychotic patients attempt to mark some "distance" between themselves and other people, they are also seeking for some

kind of "free space" which helps people to experience an "amplitude of life." This may also explain why some patients try to maintain a position of withdrawal in relation to the world. Another attitude relevant in this context is the recurrent need that patients have for keeping secrets from other people. This need for keeping secrets, in addition to participating in a tentative withdrawal, may allow these patients to have some space for "freedom of thinking", and a space for "living."

I suggest that the best way to account for the manners which patients grasp and manipulate cultural idioms and signifiers; and above all, how they manage to preserve their being-in-the world is by borrowing the analogy of "bricolage," first used by Lévi-Strauss (1966). The "bricoleur" is adept at performing a large number of diverse tasks, but the universe of instruments which is available to him is limited, thus the rules of the game are to always make something with "whatever is at hand." He uses a set of tools and materials which is always finite and is also heterogeneous, but which is the contingent result of all the occasions he had to renew or enrich the stock, or to maintain it with the remains of previous constructions and destructions. The set of tools and materials the "bricoleur" uses cannot be defined in terms of a project; it is only defined by its potential use. The creativity of the "bricoleur" consists in making new and unexpected arrangements with the elements that he has "at hand." He rarely becomes tired of ordering and re-ordering these elements in his quest to find a "meaning" (or use) for them. This can also be interpreted as a liberating action since the "bricoleur" often protests against the idea that anything can be meaningless. I would like to conclude by saying that the "bricoleur" or psychotic patient, like every other human being "not only contains numerous possibilities of modes of being, but is precisely rooted in the multifold potentiality of being" (Binswanger, 1994b: 197).

Lévi-Strauss (1966) applied the analogy of "bricolage" to characterize some features of mythical thought, and to distinguish it from scientific knowledge. Although I have chosen to use this notion, I have absolutely no intention of associating the particular mode-of-being-in-the-world of psychotic patients with mythical thought.

APPENDIXES

Appendix A

The ICD-10 Classification of Mental and Behavioural Disorders

F20-F29: Schizophrenia, schizotypal and delusional disorders

Introduction

Schizophrenia is the commonest and most important disorder of this group. Schizotypal disorder possesses many of the characteristic features of schizophrenic disorders and is probably genetically related to them; however the hallucinations, delusions, and gross behavioural disturbances of schizophrenia itself are absent and so this disorder does not always come to medical attention. Most of the delusional disorders are probably unrelated to schizophrenia, although they may be difficult to distinguish clinically, particularly in their early stages. They form a heterogeneous and poorly understood collection of disorders, which can conveniently be divided according to their typical duration into a group of persistent delusional disorders and a larger group of acute and transient psychotic disorders. The latter appear to be particularly common in developing countries. The subdivisions listed here should be regarded as provisional. Schizoaffective disorders have been retained in this section in spite of their controversial nature.

F20 - Schizophrenia

The schizophrenic disorders are characterized in general by fundamental and characteristics distortions of thinking and perception, and by inappropriate or blunted affect. Clear consciousness and intellectual capacity are usually maintained, although certain cognitive deficits may evolve in the course of time. The disturbance involves the most basic functions that give the normal person a feeling of individuality, uniqueness, and self-direction. The most intimate thoughts, feelings and acts are often felt to be known to or shared by others, and explanatory delusions may develop, to the effect that

natural or supernatural forces are at work to influence the afflicted individual's thoughts, feelings, and actions in ways that are often bizarre. The individual may see himself or herself as the pivot of all that happens. Hallucinations, especially auditory, are common and may comment on the individual's behaviour or thoughts. Perception is frequently disturbed in other ways: colours and sounds may seem unduly vivid or altered in quality, and irrelevant features of ordinary things may appear more important than the whole object or situation. Perplexity is also common early on and frequently leads to a belief that everyday situations possess a special, usually sinister, meaning intended uniquely for the individual. In the characteristic schizophrenic disturbance of thinking, peripheral and irrelevant features of a total concept, which are inhibited in normal directed mental activity, are brought to the fore and utilized in place of those that are relevant and appropriate to the situation. Thus, thinking becomes vague, elliptical, and obscure, and its expression in speech sometimes incomprehensible. Breaks and interpolation in the train of thought are frequent, and thoughts may seem to be withdrawn by some outside agency. Mood is characteristically shallow, capricious, or incongruous. Ambivalence and disturbance of volition may appear as inertia, negativism or stupor. Catatonia may be present. The onset may be acute, with seriously disturbed behaviour, or insidious, with a gradual development of odd ideas and conduct. The course of the disorder shows equally great variation and is by no means inevitably chronic or deteriorating (the course is specified by five-character categories). In a proportion of cases, which may vary in different cultures and populations, the outcome is complete, or nearly complete, recovery. The sexes are approximately equally affected but the onset tends to be later in women.

Although no strictly pathognomonic symptoms can be identified, for practical purposes it is useful to divide the above symptoms into groups that have special importance for the diagnosis and often occur together, such as:

- (a) thought echo, thought insertion or withdrawal, and thought broadcasting;
- (b) delusions of control, influence, or passivity, clearly referred to the body or limb movements or specific thoughts, actions, or sensations; delusional perception;

- (c) hallucinatory voices giving a running commentary on the patient's behaviour, or discussing the patient among themselves, or other types of hallucinatory voices coming from some part of the body;
- (d) persistent delusions of other kinds that are culturally inappropriate and completely impossible, such as religious or political identity, or superhuman powers and abilities (e.g. being able to control the weather, or being in communication with aliens from another world);
- (e) persistent hallucinations in any modality, when accompanied either by fleeting or half-formed delusions without clear affective content, or by persistent overvalued ideas, or when occurring every day for weeks or months on end;
- (f) breaks or interpolations in the train of thought, resulting in incoherence or irrelevant speech, or neologisms;
- (g) catatonic behaviour, such as excitement, posturing, or waxy flexibility, negativism, mutism, and stupor;
- (h) "negative" symptoms such as marked apathy, paucity of speech, and blunting or incongruity of emotional responses, usually resulting in social withdrawal and lowering of social performance; it must be clear that these are not due to depression or to neuroleptic medication;
- (i) a significant and consistent change in the overall quality of some aspects of personal behaviour, manifest as loss of interest, aimlessness, idleness, a self-absorbed attitude, and social withdrawal.

Diagnostic guidelines

The normal requirement for a diagnosis of schizophrenia is that a minimum of one very clear symptom (and usually two or more if less clear-cut) belonging to any one of the groups listed as (a) to (d) above, or symptoms from at least two of the groups referred to as (e) to (h) should have been clearly present for most of the time during a period of 1 month or more. Conditions meeting such symptomatic requirements but of duration less than 1 month (whether treated or not) should be diagnosed in the first instance as acute

schizophrenia-like psychotic disorder (F23.2) and reclassified as schizophrenia if the symptoms persist for longer periods.

Viewed retrospectively, it may be clear that a prodromal phase in which symptoms and behaviour, such as loss of interest in work, social activities, and personal appearance and hygiene, together with generalized anxiety and mild degrees of depression and preoccupation, preceded the onset of psychotic symptoms by weeks or even months. Because of the difficulty in time onset, the I-month duration criterion applies only to the specific symptoms listed above and not to any prodromal nonpsychotic phase.

The diagnosis of schizophrenia should not be made in the presence of extensive depressive or manic symptoms unless it is clear that schizophrenic symptoms antedated the affective disturbance. If both schizophrenic and affective symptoms develop together and are evenly balanced, the diagnosis of schizoaffective disorder (F25. -) should be made, even if the schizophrenic symptoms by themselves would have justified the diagnosis of schizophrenia. Schizophrenia should not be diagnosed in the presence of overt brain disease or during states of drug intoxication or withdrawal. Similar disorders developing in the presence of epilepsy or other brain disease should be coded under F06.2 and those induced by drugs under F1x.5.

Pattern of course

The course of schizophrenic disorders can be classified by using the following five-character codes:

F20.x0 Continuous

F20.x1 Episodic with progressive deficit

F20.x2 Episodic with stable deficit

F20.x3 Episodic remittent

F20.x4 Incomplete remission

F20.x5 Complete remission

F20.x8 Other

F20.x9 Period of observation less than one year

F20.0 - Paranoid schizophrenia

This is the commonest type of schizophrenia in most parts of the world. The clinical picture is dominated by relatively stable, often paranoid delusions, usually accompanied by hallucinations, particularly of the auditory variety, and perceptual disturbances. Disturbances of affect, volition, and speech, and catatonic symptoms are not prominent.

Examples of the most common paranoid symptoms are:

- (a) delusions of persecution, reference, exalted birth, special mission, bodily change, or jealousy;
- (b) hallucinatory voices that threaten the patient or give commands, or auditory hallucinations without verbal form, such as whistling, humming, or laughing;
- (c) hallucinations of smell or taste, or of sexual or other bodily sensations; visual hallucinations may occur but are rarely predominant.

Thought disorder may be obvious in acute states, but if so it does not prevent the typical delusions or hallucinations from being described clearly. Affect is usually less blunted than in other varieties of schizophrenia, but a minor degree of incongruity is common, as are mood disturbances such as irritability, sudden anger, fearfulness, and suspicion. "Negative" symptoms such as blunting of affect and impaired volition are often present but do not dominate the clinical picture.

The course of paranoid schizophrenia may be episodic, with partial or complete remissions, or chronic. In chronic cases, the florid symptoms persist over years and it is difficult to distinguish discrete episodes. The onset tends to be later than in the hebephrenic and catatonic forms.

F20.1 – Hebephrenic schizophrenia

A form of schizophrenia in which affective changes are prominent, delusions and hallucinations fleeting and fragmentary, behaviour irresponsible and unpredictable, and mannerisms common. The mood is shallow and inappropriate and often accompanied by giggling or self-satisfied, self-absorbed smiling, or by a lofty manner, grimaces, mannerisms, pranks, hypochondriacal complaints, and reiterated phrases. Thought is disorganized and speech rambling and incoherent. There is a tendency to remain solitary, and behaviour seems empty of purpose and feeling. This form of schizophrenia usually starts between the ages of 15 and 25 years and tends to have a poor prognosis because of the rapid development of "negative" symptoms, particularly flattening of affect and loss of volition.

In addition, disturbances of affect and volition, and thought disorder are usually prominent. Hallucinations and delusions may be present but are not usually prominent. Drive and determination are lost and goals abandoned, so that the patient's behaviour becomes characteristically aimless and empty of purpose. A superficial and manneristic preoccupation with religion, philosophy and other abstract themes may add to the listener's difficulty in following the train of thought.

F20.2 - Catatonic schizophrenia

Prominent psychomotor disturbances are essential and dominant features and may alternate between extremes such as hyperkinesis and stupor, or automatic obedience and negativism. Constrained attitudes and postures may be maintained for long periods. Episodes of violent excitement may be a striking feature of the condition.

For reasons that are poorly understood, catatonic schizophrenia is now rarely seen in industrious countries, though it remains common elsewhere. These catatonic phenomena may be combined with a dream-like (oneiroid) state with vivid scenic hallucinations.

F20.3 - Undifferentiated schizophrenia

Conditions meeting the general diagnostic criteria for schizophrenia (see introduction to F20 above) but not conforming to any of the above subtypes (F20 – F20.2), or exhibiting the features of more than one of them without a clear predominance of a particular set of diagnostic characteristics. This rubric should be used only for psychotic conditions (i.e. residual schizophrenia, F20.5, and post-schizophrenic depression, F20.4, are excluded) and after an attempt has been made to classify the condition into one of the three preceding categories.

F20.4 – Post-schizophrenic depression

A depressive episode, which may be prolonged, arising in the aftermath of a schizophrenic illness. Some schizophrenic symptoms must still be present but no longer dominate the clinical picture. These persisting schizophrenic symptoms may be "positive" or "negative", though the latter are more common. It is uncertain, and immaterial to the diagnosis, to what extent the depressive symptoms have merely been uncovered by the resolution of earlier psychotic symptoms (rather than being a new development) or are an intrinsic part of schizophrenia rather than a psychological reaction to it. They are rarely sufficiently severe or extensive to meet criteria for a severe depressive episode (F32.2 and F32.3), and it is often difficult to decide which of the patient's symptoms are due to depression and which to neuroleptic medication or to the impaired volition and affective flattening of schizophrenia itself. This depressive disorder is associated with an increased risk of suicide.

F20.5 – Residual schizophrenia

A chronic stage in the development of a schizophrenic disorder in which there has been a clear progression from an early stage (comprising one or more episodes with psychotic symptoms meeting the general criteria described above) to a later stage characterized by long-term, though not necessarily irreversible, "negative" symptoms.

F20.6 – Simple schizophrenia

An uncommon disorder in which there is an insidious but progressive development of oddities of conduct, inability to meet the demands of society, and decline in total performance. Delusions and hallucinations are not evident, and the disorder is less obviously psychotic than the hebephrenic, paranoid, and catatonic subtypes of schizophrenia. The characteristic "negative" features of residual schizophrenia (e.g. blunting of affect, loss of volition) develop without being preceded by any overt psychotic symptoms. With increasing social impoverishment, vagrancy may ensue and the individual may then become self-absorbed, idle, and aimless.

F20.8 - Other schizophrenia

F20.9 – Schizophrenia, unspecified

F23 – Acute and transient psychotic disorders

Systematic clinical information that would provide definitive guidance on the classification of acute psychotic disorders is not yet available, and the limited data and clinical tradition that must therefore be used instead do not give rise to concepts that can be clearly defined and separated from each other. In the absence of a tried and tested multiaxial system, the method used here to avoid diagnostic confusion is to construct a diagnostic sequence that reflects the order of priority given to selected key features of the disorder. The order of priority used here is:

- (a) an acute onset (within 2 weeks) as the defining feature of the whole group;
- (b) the presence of typical syndromes;
- (c) the presence of associated acute stress.

The classification is nevertheless arranged so that those who do not agree with this order of priority can still identify acute psychotic disorders with each of these specified features.

It is also recommended that whenever possible a further subdivision of onset be used, if applicable, for all the disorders of this group. *Acute onset* is defined as a change from a state without psychotic features to a clearly abnormal psychotic state, within a period of 2 weeks or less. There is some evidence that acute onset is associated with a good outcome, and it may be that more abrupt the onset, the better the outcome. It is therefore recommended that, whenever appropriate, *abrupt onset* (within 48 hours or less) be specified.

The *typical syndromes* that have been selected are first, the rapidly changing and variable state, called here "polymorphic", that has been given prominence in acute psychotic states in several countries, and second, the presence of typical schizophrenic symptoms.

Associated acute stress can also be specified, with a fifth character if desired, in view of its traditional linkage with acute psychosis. The limited evidence available, however, indicates that a substantial proportion of acute psychotic disorders arise without associated stress, and provision has therefore been made for the presence or the absence of the stress to be recorded. Associated acute stress is taken to mean that the first psychotic symptoms occur within about 2 weeks of one or more events that would be regarded as stressful to most people in similar circumstances, within the culture of the person concerned. Typical events would be bereavement, unexpected loss of partner or job, marriage, or the psychological trauma of combat, terrorism and torture. Long-standing difficulties or problems should not be included as a source of stress in this context.

Acute polimorphic psychotic disorders with or without symptoms of schizophrenia include bouffée délirante..

Complete recovery occurs within 2 to 3 months, often within a few weeks or even days, and only a small proportion of patients with these disorders develop persistent and disabling states. Unfortunately, the present state of knowledge does not allow the early prediction of that small proportion of patients who will not recover rapidly.

These clinical descriptions and diagnostic guidelines are written on the assumption that they will be used by clinicians who may need to make a diagnosis when having to asses and treat patients within a few days or weeks of the onset of the disorder, not knowing how long the disorder will last. A number of reminders about the time limits and transition from one disorder to another have therefore been included, so as to alert those recording the diagnosis to the need to keep them up to date.

The nomenclature of these acute disorders is as uncertain as their nosological status, but an attempt has been made to use simple and familiar terms. "Psychotic disorder" is used as a term of convenience for all the members of this group with an additional qualifying term indicating the major defining feature of each separate type as it appears in the sequence noted above.

Diagnostic guidelines

None of the disorders in the group satisfies the criteria for either manic (F30.-) or depressive (F32.-) episodes, although emotional changes and individual affective symptoms may be prominent from time to time.

These disorders are also defined by the absence of organic causation, such as states of concussion, delirium, or dementia. Perplexity, preoccupation, and inattention to the immediate conversation are often present, but if they are so marked or persistent as to suggest delirium or dementia of organic cause, the diagnosis should be delayed until investigation or observation has clarified this point. Similarly, disorders in F23. - should not be diagnosed in the presence of obvious intoxication by drugs or alcohol. However, a recent minor increase in the consumption of, for instance, alcohol or marijuana, with no

evidence of severe intoxication or disorientation, should not rule out the diagnosis of one of these acute psychotic disorders.

It is important to note that the 48-hour and the 2-week criteria are not put forward as the times of maximum severity and disturbance, but as times by which the psychotic symptoms have become obvious and disruptive of at least some aspects of daily life and work. The peak disturbance may be reached later in both instances; the symptoms and disturbance have only to be obvious by the stated times, in the sense that they will usually have brought the patient into contact with some form of helping or medical agency. Prodromal periods of anxiety, depression, social withdrawal or mildly abnormal behaviour do not qualify for inclusion in these periods of time.

A fifth character may be used to indicate whether or not the acute psychotic disorder is associated with acute stress:

F23.x0 Without associated acute stress

F23.x1 With associated acute stress

F23.0 - Acute polymorphic psychotic disorder without symptoms of schizophrenia

An acute psychotic disorder in which hallucinations, delusions, and perceptual disturbances are obvious but markedly variable, changing from day to day or even from hour to hour. Emotional turmoil, with intense transient feelings of happiness and ecstasy or anxieties and irritability, is also frequently present. This polymorphic and unstable, changing clinical picture is characteristic, and even though individual affective or psychotic symptoms may at times be present, the criteria for manic episode (F30.-), depressive episode (F32.-), or schizophrenia (F20.-) are not fulfilled. This disorder is particularly likely to have an abrupt onset (within 48 hours) and a rapid resolution of symptoms; in a large proportion of cases there is no obvious precipitating stress.

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F23.1 - Acute polymorphic psychotic disorder with symptoms of schizophrenia

An acute psychotic disorder, which meets the descriptive criteria for acute

polymorphic psychotic disorder (F23.0) but in which typically schizophrenic symptoms

are also consistently present.

F23.2 - Acute schizophrenia-like psychotic disorder

An acute psychotic disorder in which the psychotic symptoms are comparatively

stable and fulfil the criteria for schizophrenia (F20.-) but have lasted for less than 1

month. Some degree of emotional variability or instability may be present, but not to the

extent described in acute polymorphic psychotic disorder (F23.0).

F23.3 - Other acute predominantly delusional psychotic disorders

Acute psychotic disorder in which comparatively stable delusions or

hallucinations are the main clinical features, but do not fulfil the criteria for schizophrenia

(F20.-). Delusions of persecution or reference are common, and hallucinations are usually

auditory (voices talking directly to the patient).

F23.8 – Other acute and transient psychotic disorders

Any other acute psychotic disorders that are unclassifiable under any other

category in F23 (such as acute psychotic states in which definite delusions or

hallucinations occur but persist for only small proportions of the time) should be coded

here. States of undifferentiated excitement should also be coded here if more detailed

information about the patient's mental state is not available, provided that there is no

evidence of an organic cause.

F23.9 - Acute and transient psychotic disorder, unspecified

Includes: (brief) reactive psychosis NOS

Appendix B

Table 22- Comparison of psychiatric diagnoses given in the emergency room (ICD-10) in relation to diagnoses provided by the SCID-DSM-IV after 6 months to patients who participated in this study:

Name	Emergency room diagnosis (ICD-10)	SCID-DSM-IV diagnosis after 6 months or more
Alice	Acute polymorphic psychotic disorder with symptoms of schizophrenia	Schizophrenia residual type
Carmen	Acute polymorphic psychotic disorder with symptoms of schizophrenia	Schizophreniform disorder
Claudia	Acute and transient psychotic disorder	Psychotic disorder not otherwise specified
Daniel	Paranoid schizophrenia	Panic disorder without agoraphobia
Dora	Acute schizophrenia-like psychotic disorder	Bipolar I disorder, most recent episode depressed
Edilson	Acute schizophrenia-like psychotic disorder	Schizophreniform disorder
Eduardo	Schizophrenia, unspecified	Bipolar II disorder, most recent episode depressed
Gisela	Acute polymorphic psychotic disorder with symptoms of schizophrenia	Major depressive disorder
Hélio	Other acute predominantly delusional psychotic disorders	Patient abandoned treatment
Jonas	Acute schizophrenia-like psychotic disorder	Schizophrenia paranoid type
José	Acute polymorphic psychotic disorder with symptoms of schizophrenia	Schizophrenia paranoid type
Kátia	Acute schizophrenia-like psychotic disorder	Schizophrenia residual type
Leonardo	Schizophrenia, unspecified	Patient abandoned treatment
Luana	Acute schizophrenia-like psychotic disorder	Patient refused to be interviewed
Maria	Hebephrenic schizophrenia	Schizophrenia residual type
Mateus	Acute and transient psychotic disorder unspecified	Substance-induced psychotic disorder
Maurício	Acute polymorphic psychotic disorder with symptoms of schizophrenia	Substance-induced major depression and manic episode
Milton	Paranoid schizophrenia	Patient refused to be interviewed
Raquel	Paranoid schizophrenia	Patient abandoned treatment
Sarah	Acute schizophrenia-like psychotic disorder	Schizophreniform disorder
Solange	Acute and transient psychotic disorder unspecified	Adjustment disorder unspecified

Appendix C

Informed Consent Form (Portuguese):

Carta de Informação

Convidamos você a colaborar com este estudo sócio-cultural que investiga a experiência de vida das pessoas que estão recebendo um primeiro atendimento psiquiátrico. Este estudo também investigará que outras fontes de ajuda a pessoa vem procurando para aliviar ou tentar solucionar o seu problema. Por exemplo, a pessoa frequentemente busca apoio ou ajuda junto à família, amigos, vizinhos, comunidades religiosas ou alternativas, além de ter procurado o tratamento psiquiátrico. O principal objetivo será observar de que formas estas diferentes fontes de ajuda (incluindo também o apoio psiquiátrico) podem influenciar ou modificar a experiência de vida da pessoa com problemas psiquiátricos. Uma melhor compreensão de como se desenvolve a experiência de vida das pessoas que sofrem problemas psiquiátricos pode futuramente beneficiar outras pessoas que sofrem de problemas semelhantes.

A sua participação neste estudo consiste primeiro em responder a um questionário sobre saúde cujas perguntas serão feitas por um psiquiatra. Numa outra ocasião você terá a oportunidade de contar para a pesquisadora sobre as diversas circunstâncias ou problemas da sua história de vida pessoal até o momento em que você acabou procurando a primeira ajuda psiquiátrica. A pesquisadora também pedirá para entrevistar um dos membros de sua família (uma outra entrevista independente da sua) para que ele ou ela também possam contar qual é a visão deles sobre esses problemas que você tem enfrentado. Para algumas pessoas que tenham maior interesse em continuar participando neste estudo a pesquisadora pedirá para observar mais de perto como se desenvolve a experiência de vida destas pessoas nos primeiros 6 meses após o início do atendimento psiquiátrico. Caso você queira continuar participando da pesquisa, este acompanhamento será feito através de conversas informais e também de visitas junto com você para conhecer os ambientes e as pessoas mais importantes do seu dia a dia.

A sua participação neste estudo é voluntária e caso queira, você pode desistir de participar neste estudo a qualquer momento. Caso recuse em participar, esta decisão de modo algum irá afetar o atendimento médico que você esteja normalmente recebendo. A pesquisadora também tomará todas as medidas necessárias para garantir neste estudo a sua anonimidade e a das pessoas que lhe são próximas.

Consentimento pós-informado
Eu, li atentamente a carta de informação
referente ao estudo antropológico que investiga a experiência de vida de pessoas que
recebem pela primeira vez um atendimento psiquiátrico e tive a oportunidade de fazer
todas as questões que desejasse. Eu entendo que se eu tiver qualquer dúvidas referentes
ao estudo eu posso contactar a pesquisadora Cristina Redko.
Minha participação neste estudo é voluntária e eu posso retirar o meu consentimento e
abandonar o estudo a qualquer momento. Minha decisão de participar neste estudo ou
desistir de participar nele em nenhum momento irá afetar ou prejudicar o tratamento
médico que eu venha a receber normalmente no Hospital São Paulo da UNIFESP -
Escola Paulista de Medicina.
Eu concordo em cooperar totalmente com a investigadora neste estudo sabendo que todas as medidas adequadas para garantir a minha anonimidade neste estudo também serão tomadas.
Assinatura do participante (ou da pessoa responsável)
Nome completo do participante:
Data:

Investigador:....

Appendix D

Glossary

Banho de descarrego: Ritual discharge bath in Umbanda or Candomblé with special plants mixture.

Benzedor(a): Folk healer, from popular Catholicism, Umbanda or Candomblé.

Bori: Most common healing therapy in Umbanda and Candomblé, but it also considered to be the first ritual of initiation.

Cablocos: Possessing spirits of deceased black Indians in Umbanda.

Cachaça: White rum made of sugar cane.

Calmante: Tranquillizer

Campanha de oração: This is a typical form of religious healing in Pentecostal Churches. Often the relatives, neighbours, or friends who follow Pentecostalism come to the person's home to sing and pray for their <u>libertação</u> (or healing).

Campanhas de fé: Faith campaigns in Pentecostal Churches that explore a specific topic during a certain period of time.

Capeta: Devil

Carteira profissional: This document registers a worker's occupational history, and it is often the worker's most important proof of citizenship.

Castigo de Deus or castigo divino: Divine punishment from God.

Chapa da cabeça: Popular name given to the X-ray exam or electro-encephalogram (brain scan).

Chapa de pulmão: Chest X-ray

"Chute da Santa": Episode that occurred in October 12th, 1995, which is the celebration of Nossa Senhora de Aparecida (Virgin Mary), the patron Saint of Brazil. One bishop of the "Universal Kingdom of God" inadvertently kicked the image of the Virgin Mary during the broadcast of TV Record's religious programme. The rival TV Globo (most powerful TV station in Brazil) showed and repeated the "chute da Santa" several times in their news programme; and the divulging of this episode provoked a series of popular acts

of indignation, redress and violence, coming especially from the Catholic faithful (Almeida, 1996).

Coisa da cabeça: Mental problem or disturbance in the head.

Coisa do diabo: Evil provoked by the Devil.

Coisa feita: A "thing done" by exu or through the work of black magic

Coisa maligna: Malignant spirit, Devil.

Coisa ruim: malignant spirit, disturbance, Devil.

"Comigo ninguém pode": Green plant called "nobody can harm me" which is associated with the Afro-Brazilian orixás Ogum and Oxum.

Correntes: A ritual which followers of Pentecostal churches attend once a week for a fixed period of time, for example seven weeks, to fulfil an obligation or to achieve a goal, or simply to commit themselves towards their own salvation.

Cortiço: A type of tenement housing where rooms have been rented to different families. In each room, a whole family sleeps, cooks and entertains. The residents of these rooms usually share external or corridor bathrooms and water sources. But a cortiço can also be comprised of a common area (quintal) which opens to several houses that follow the bedroom-kitchen pattern.

Crente: Believer or <u>evangélico</u> - colloquial names for the people who follow any one of the Protestant denominations.

Desafio: Defiance or "duel" the adept makes towards God in the Universal Kingdom of God Church.

Descarrego: Act of purifying the person through spiritual religious rituals.

Desobsessão: Healing ritual of Kardecismo that aims to expel the "obsessing spirits".

Dízimo: Tithe paid monthly to the church by its adepts.

Doença espiritual: Spiritual illness.

Doença material: "Material" illness not caused by spirits; it is for medical doctors to heal.

Doença mental: Mental illness.

Doido(a): Crazy.

Ebó: Type of ritual sacrifice in Umbanda or Candomblé that purifies and discharges by transferring the Evil which inhabits the person's body to food and sacrificed animals.

Encosto: Leaning spirit who agitates the person.

Espírito do bem: Spirit of goodness

Espírito maligno: Malignant spirit.

Estar nervoso: Being nervous (transitory condition).

Estar louco: Being crazy (transitory condition).

Evangélico: Crente.

Exu: Orixá in Candombé and spirit of shadow in Umbanda.

Favela: A set of shacks built on seized land. People normally own their shacks and may

transport them around, but they do not own the land that is occupied illegally.

Ficar nervoso: Estar nervoso.

Garrafada: Special infusions of plants mixture prepared in bottles to give discharge

baths.

Guias: Spiritual guides in Umbanda, for instance, preto velho and caboclo.

Jeitinho brasileiro: Bending the rules, figuring out a way; this is an ethos distinct from corruption that reconciles egalitarian and "persona. stic" principles in Brazilian society.

Jogo de búzios: Cowrie shells divination game in Candomblé and Umbanda.

Libertação: Ritual of "liberation" or exorcism that occurs in Neo-Pentecostal Churches.

Louco(a): Crazy.

Loucura: Craziness.

Macumba: It is usually used as a pejorative name given to Umbanda and Candomblé

practices.

Macumbaria: Act of macumba.

Macumbeiros: Pejorative designation for people who practice macumba.

Mal de Deus: God's Evil.

Maluco(a): Crazy.

Marmita: A container in which workers take everyday food from home to their jobs.

Mulato(a): Mullato.

"Não falava coisa com coisa": Expression which means that the person is only talking nonsense and makes no sense.

Nervoso: Idiom of nervousness.

Nossa Senhora de Aparecida: Virgin Mary; she is also the Patron Saint of Brazil.

Novena: Resembles the Pentecostal <u>corrente</u>, but is practiced in Catholicism.

Obaluaiê: The orixá who rules smallpox and other contagious diseases.

Ogum: The <u>orixá</u> who rules the forest and the iron, he is a hunter, a fisherman and a

fighter.

Olubajé: Collective ceremony performed annually in Candomblé to enhance the health

of the whole community, and is dedicated to Obaluaiê.

Orixá: Spiritual deity in Umbanda or Candomblé.

Oxum: A female orixá who rules fertility and reproduction, she is very seductive and

conceited.

Pagode: A type of <u>samba</u>, while <u>samba</u> is the music of carnival and is taken as one of the key symbols of musical expression in Brazil. The recent trends of <u>samba</u> have incorporated the beat of the funk to the reggae, and other strong African rhythms like the lambada and axé music.

tamouda and and music.

Pai/mãe de santo: Medium leaders in Umbanda or Candomblé

Passes: A kind of laying-on-hands practice in Kardecismo.

Pedaço: This term designates an intermediate space between the private (house) and the public spaces where a basic sociability is developed; which is broader than the sociability established though family relationships, however it is more dense, meaningful and stable than the formal and individualized relationships imposed by society (Magnani, 1984:138).

Pedido de oração: Prayer request.

Periferia: Suburbs of the city of São Paulo.

Perturbação: Disturbance that may or may not have a spiritual origin.

Pombagira: Female exu.

Preto velhos: Possesing spirits in Umanda of deceased old-black slaves.

Problema da cabeça: Problem in the head or mental problem.

Problema de nervoso: Problem of nervousness.

Problema espiritual: Spiritual problem.

Promessa: Vow.

Santa Ceia: Last Supper

Senhora: Madam.

Ser louco (a): Being crazy (permanent condition).

Ser nervoso (a): Being nervous (permanent condition).

Terreiro: Sacred space in which the Candombé or Umbanda centre is located.

Testemunho: Conversion testimonial normally practised in Pentecostal Churches.

Torcidas organizadas: Organized crowds of soccer player fans.

Trajeto: It implies the notion of movement through a diversity of social spaces of the city within a field of possibilities (although they are limited).

Yemanjá: The mother of all orixás; she also governs the sea.

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