How Medical Staff Negotiate Patient-Compliance with the Treatment and Dietary Regimens: A Study of Dialysis Patients in a General Hospital

by

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ABSTRACT

Patients suffering from kidney failure, who do not opt for transplantation, must succumb to long-term dialysis treatment if they wish to remain alive. The nature of dialysis is such that patients are subjected to a wide range of rule specifications and regulations. Patients are required to follow strict dietary and fluid restrictions, and are expected to adhere to dialysis schedules. By virtue of the long-term nature of the treatment, patients learn a great deal about the administration of dialysis procedures. They learn to identify their physiological response to dialysis treatment. Largely through trial and error, they learn how to violate the rules. Unfortunately, not all patients are as shrewd and clever. Many fail to comply with the rules of the treatment and dietary regimens. This has the power to influence staff behavior towards patients.

Failure on the part of patients to adhere to the rules results in a disturbance of ward activities for medical personnel. Attending staff are required to pay "special attention" to patients who have violated the dietary rules; signs of abnormality must be watched for an attended to immediately. Furthermore, non-compliant patients require ultrafiltration in addition to their regular dialysis treatment. As a result, the social order is temporarily disturbed. Because non-compliant patients monopolize beds for longer periods of time, other patients must wait longer before beginning treatment. This means that the technicians schedules will also be disturbed. They must wait until non-compliant patients have terminated their treatment before they can prepare the machines for use by other patients. Finally, nursing staff are forced to reinvoke the rules to patients by counselling them on the effects of over-consumption. This has the effect of putting nurses somewhat "behind schedule".

The treatment and care of dialysis patients, therefore, involves maximizing compliance with the treatment and dietary regimens. To resolve the problem of non-compliance, personnel employ a wide array of negotiation strategies and control tactics in their attempt to maximize patient-compliance with dietary restrictions. They manipulate, cajole, persuade, reprove, bargain, coerce, impose suffering and treat them indifferently. Based on five months of participant-observation of a Dialysis Unit in a general hospital, my aim is to examine how the experiences of dialysis patients are affected by the hospital environment, the nature of the illness, the course of the treatment process and the patterns of behavior of the medical personnel.

RESUME

Les patients qui souffrent de l'insuffisance rénale et qui choisissent de ne pas céder à la transplantation doivent adhérer á un régime de dialyse. La nature de la dialyse est telle que les patients sont sujets à un grand nombre de règlements. Ils doivent suivre des restrictions de diète et de liquide, et doivent adhérer à un horaire spécifié. En vertue de la nature chronique de la maladie, les patients apprennent beaucoup au sujet de la dialyse. Ils apprennent à identifier leur propre réaction physiologique envers le traitement. A la longue, ils apprennent à violer les règlements en sûreté. Malheureusement, tous les patients ne sont pas si sages ni si intelligents. Plusieurs d'entre eux ne suivent pas leur régime. Ceci peut influencer le comportement du personnel envers eux.

La négligence à suivre les règlements de la part des patients, engendre un dérangement d'activités pour le personnel. Le personnel est alors obligé de porter une attention toute particulière aux patients qui ont violé les règlements. Tout signe d'anomalie doit être soigné. De plus, ces patients doivent recevoir l'ultrafiltration en plus de leur traitement régulier. Par conséquent, l'ordre sociale est dérangée temporairement. Parce que ces patients doivent garder leur lit pour une plus longe période te temps, les autres patients schédulés doivent attendre à ce que les machines soient dégagées avant qu'ils puissent commencer leur traitement. Ceci a pour effet de déranger les horaires des techniciens, qui ne peuvent faire autrement que d'attendre à ce que les patients aient terminé leur traitement avant de nettoyer les machines à être utilisées par les autres patients. Enfin, les infirmières sont obligées de réinvoquer les règlements aux patients.

Le traitement des patients en dialyse exige alors une soumission totale au régime de la dialyse. Pour apporter une solution au problème, le personnel emploi une grande variété de stratégies de négotiation. Entre autre, on peut inclure la manipulation, la persuasion, le reproche, la contrainte et l'indifférence. Basé sur cinq mois d'observations d'une salle de dialyse, mon objectif est d'examiner comment les expériences des patients sont affectées par le milieu hospitalier, la nature chronique de la maladie, le traitement et le comportement du personnel.

TABLE OF CONTENTS

CHAPTER ONE

INTRODUCTION

> It's really a matter of life and death. I come here because I have to. I eat what they tell me to because I don't have any choice.... I have to...stated a dialysis patient.

While this patient expresses his distress over the type of lifestyle he is forced to lead, a nurse might be heard to say:

> I honestly don't know what I'm going to do with some of them...Some of these patients drive me absolutely crazy. It seems that no matter what I do, they just don't listen.... I could scream and yell at them until I'm blue in the face and they still don't listen....

What is interesting about dialysis treatment is that patients' survival depends on strict adherence with the dietary and treatment regimens. But what is perhaps most interesting about the treatment process is that staff are dependent on patient compliance to fulfill their role obligations as medical practitioners. More specifically, the maintenance of ward activities and hospital routines is contingent upon patient-compliance with the treatment and dietary regimens. Failure on the part of patients to observe the rules results in a temporary disruption of the social order. Consequently, staff are concerned with maximizing compliance from patients. How do patients deal with the limitations of lifestyle? How do they respond to the tragedy that has befallen them? How does their attitude affect their interactions with the attending staff? How do their patterns of adherence to the dietary rules influence staff behavior towards them?

This is a study of the social dimensions of the treatment of dialysis patients in a general hospital. There are four parts to this introductory chapter. The first describes end-stage renal disease (ESRD), the nature of long-term maintenance dialysis, what happens to dialysis patients once they have been diagnosed as having kidney failure, and who is involved in their treatment and care. The second part reveals the study's contribution to the field of Medical Sociology. Part three looks at the kinds of data upon which this study is based and discloses the methods I employed to collect them. The fourth part describes the general organization of the thesis.

ESRD & MAINTENANCE DIALYSIS

The kidneys maintain homeostasis (state of equilibrium) by filtering out urea, creatinine, uric acid and other waste products from the blood and excreting them in the form of urine. Kidney diseases are serious because large quantities of poisons can collect in the body if the kidneys are non-functional; the final result is death.

ESRD is usually caused by one of a number of diseases which afflicts the nephrons of the kidney. The principal diseases responsible for ESRD requiring dialysis or transplantation are glomerulonephritis (inflammation of the glomeruli) accounting for 50-60 per cent of all cases, and pyelonephritis which occurs in approximately 20-25 per cent

of all dialysis patients (Ledingham, 1979). Pyelonephritis is a disease in which an infection attacks the kidney by way of the ureter (the tube connecting the kidneys to the bladder). Other conditions associated with chronic renal failure are hypertensive nephrosclerosis, polycystic disease and analgesic nephropathy due to drugs (Kennedy, 1979).

In recent years, there has been a definite increase in the proportion of patients with renal failure due to a metabolic illness (Kennedy, 1979). Examples are, in order of importance, diabetis mellitus, amyloid, gout, lupus erythematosus. It should be noted that renal disease is the most common cause of death in patients with diabetis mellitus (Latos, 1980).

Kidney failure occurs with distressing unpredictability. Early signs include nocturia (a loss of urinary concentration ability), edema (a swelling of the ankles and hands, etc.), nausea, dizziness, easy fatigue, general weakness, headaches. Later symptoms of renal insufficiency are loss of memory, impaired cognitive function, irritability, lethargy. In addition, foul-smelling breath, a metallic taste and itching are most common (Latos, 1980; Keer, 1979). As the patient's general condition continues to deteriorate, he becomes increasingly uremic (or toxic). All body systems are impaired and there are marked neurological disorders. The patient's skin becomes excessively dry and sallow and bruises easily. Loss of muscle mass, progressive weakness, anorexia

(prolonged loss of appetite), nausea, vomiting and diarrhea are common to the uremic patient. Generalized seizures may occur, followed by coma or death (Latos, 1980).

The first device incorporating all the basic elements common to today's artificial kidneys was developed in the early 1900's by Abel, Rowntree and Turner at John Hopkin's University (McBride, 1979). However, it was not until the early 1940's that William Kolff, a young physician from the University of Groningen in the Netherlands, developed the rotating-drum device which was successfully used to dialyze patients. (Alwall, 1980). The growth of maintenance dialysis has not occurred evenly throughout the world. Approximately 35 per cent of the total dialysis population is found in Europe, 34 per cent in the U.S.A. and Canada, 21 per cent in Japan and the remaining 10 per cent in all other countries. Kennedy (1979) has shown that the country with the greatest number of dialysis patients per million population is Japan, with an average of 126.2 patients per million.

Maintenance dialysis removes large quantities of waste products and excess fluids from the blood and, as a result, prevents the occurrence of death. Renal failure is therefore a chronic illness.

Once the patient has been diagnosed as having chronic renal failure, allocation to any one of the six forms of treatment is made. Transplantation involves a kidney transfer from one individual to another. Hospital peritoneal or

IPD (intermittent peritoneal dialysis) consists of dialysis through the membranes of the abdominal cavity in a hospital setting; it is accomplished through three weekly sessions, usually ten hours in duration. Hospital hemodialysis also occurs in a medical setting and is managed with the help of an artificial kidney machine; blood is pumped through the dialyzer and waste products and excess fluids are removed. (Murphy, 1980). It takes place two of three times a week and ranges anywhere from four to eight hours in duration.

As its name suggests, home hemodialysis follows the same procedure as hospital hemodialysis with the exception that it is conducted in the privacy of the patient's home. Home peritoneal dialysis is the least common form of treatment because of its high risk of infection. Like hospital peritoneal, it is accomplished through three weekly sessions of 10 hours in duration. C.A.P.D., better known as continuous ambulatory peritoneal dialysis treatment, is much easier to administer. It is conducted three or four times a day in the patient's home and requires only a few hours. This kind of treatment is most commonly used by "people on the go", such as travelling salesmen.

Allocation to any one form of treatment depends on the candidate's age, severity of the illness and the presence or absence of an accompanying disease. For example, patients with a history of heart failure will more than likely be allocated to peritoneal as it exerts less pressure on the

heart. To a large extent, allocation also depends on the physician currently treating the patient. Physicians weigh all the circumstances and choose the form of treatment most suited to meet patients' needs; that is to say, one that will ease their integration into society, handicapped as they may be, and facilitate the leading of a quasi "normal" lifestyle. To a lesser degree, allocation is contingent upon the patient's preference. If patients are clearly opposed to any one given form of treatment, with the help of a physician, together they decide on an appropriate alternative.

Finally, designation to a treatment modality is also based on what is currently available in terms of space. If there happens to be an opening in a certain program the patient will be randomly assigned to it.

The Dialysis Unit is staffed by a multidisciplinary team composed of six technicians, a dietician, chaplain, Head Technician, social worker, unit coordinator, Director of Nursing, two resident doctors four attending physicians, one Chief Physician and as many as twenty-five nurses.

CONTRIBUTIONS TO MEDICAL SOCIOLOGY: The Social Psychology of Compliance.

Nowhere else is non-compliance more vividly illustrated than in a Dialysis Unit, where the major responsibility for feeling "well" lies in the patient's hands. Patients with renal failure are required to follow strict dietary and fluid restrictions (Abram, 1968; Fox, 1974; Blackburn, 1977;

Klenow, 1979; Salmons, 1980; Czaczkes, 1978; Hampers, 1973; Levy, 1974). Failure on the part of patients to adhere to the rules creates an avalanche of problems for the attending staff. Violation of the dietary restrictions causes a disturbance of ward activities. In an effort to pursue their own interests, personnel are therefore concerned with maximizing patient-compliance with the treatment regimen.

Patient non-compliance appears in several studies. In the literature of psychology, Goldstein (1971) claims that non-compliance is a defense mechanism patients use to reduce the anxiety and stress caused by the illness. More specifically, dietary abuse is a way of coping with the constant stressful life situation.

Blackwell (1973) offers a personality sketch of typical non-compliant patients. Such patients are described as immature, impulsive, irresponsible, and do not usually consider the consequences of their actions. Sand (1966) on the other hand, argues that non-compliance is the direct result of competition among patients who want to "get away with the most" on the ward.

Other psychological factors associated with non-compliance are defensiveness and externalization. Research conducted by MacNamara (1969) and Kaplan De-Nour (1974) all focus on theories relating non-compliance to body image. In their view, the body is a medium of expression and may be used to externalize stress and feelings of aggression

and tension. Landsman (1975) suggests that non-compliance is the overt manifestation of patients' conflictual feelings about whether they are well or sick. Patients may feel "relatively well" despite having to succumb to dialysis treatment three times a week and express this conflict through non-compliant behavior.

Though certainly not as well documented as psychological variables, sociology has, however, pointed to the importance of demographic factors in accounting for non-compliance. Studies have shown that women follow medical advice less often than men (Dixon, 1957; Davis, 1968a). Adherence to physicians' recommendations is lower for low-income populations (Becker, 1975), especially older persons (Davis, 1968a), and for those with little or no education (Davis, 1968a).

Research on patient non-compliance has yielded a multiplicity of findings which are generally contradictory and, therefore, far from conclusive. For example, Abramson et al. (1961) maintain that compliance is a function of careful instruction. In contrast, a study of Canadian steelworkers with hypertension, conducted by Sackett (1975:1205) reports that "although men receiving health education learned a lot about hypertension, they were not more likely to take their medicine". In addition, Ambuel et al. (1964) claim that the urgency of the illness determines compliance. A wide variety of studies, however, have shown that there is no association between the severity of the problem and

patient compliance (Becker, 1975; Bonnar, 1969; Charney, 1967).

Other research has examined the influence of family members, friends and significant others in attempting to explain non-compliance. Steidl (1980) reports that there is a marginal relationship between overall family functioning and adherence to treatment regimens for dialysis patients. This finding is consistent with earlier empirical studies (Elling, 1960; Davis, 1968a; Reichsman, 1972).

The problem with all these studies, however, is that they base their findings almost exclusively on patient characteristics in attempting to explain patient compliance. Past research has tended to isolate particular patient characteristics and has failed to treat non-compliance as part of a larger process.

This study will consider patient compliance as part of a process. As such, it contributes to the social psychology of compliance by examining how patients' experiences, attitudes and reactions to their illness and treatment process have the power to influence staff behavior towards them. Furthermore, because patients are not immune to the attending staff, they, in turn, formulate patients' attitudes and ideas and socialize them to occupy certain roles. This study provides an understanding of the reciprocal relationship between personnel and patients.

The need for research in this area is well documented. A few studies have described the importance of investigating the patient-physician relationship to explain non-compliance. Blackwell (1973) reports that a higher rate of patient compliance is found among physicians in private practice than in clinics. Davis (1968a) maintains that a higher compliance rate is shown among populations whose physicians are younger. More specifically, relative to older physicians, younger physicians are more likely to use authoritarian measures to influence patient-compliance.

Very few studies, however, have provided empirical investigation of the reciprocal relationship between patients and medical personnel. Ellis (Davis, 1968a) has perhaps come closest to realizing this goal. In a study of reciprocity between patients and doctors, Ellis has shown that the reciprocal nature of the doctor-patient relationship affects compliance. Similarly, studies conducted by Davis (1963, 1968a, 1968b) point to the salience of cummunication and feedback systems that characterize most doctor-patient relationship and their influence in maximizing patient-compliance.

My aim in this thesis is to apply some of the theoretical models of Strauss (1961, 1963, 1964, 1969, 1978), Ellis (Davis, 1968a) and Davis (1963, 1968a, 1968b) to a group of patients and staff in interaction. In the course of the treatment, personnel socialize patients to occupy certain

roles. These roles coincide with compliance with the dietary and treatment regimens. To the extent that patients violate the rules, and thus disturb ward activities, they are thought of as "non-compliant" and related to as such. This, of course, has the power to influence patients' attitudes towards the attending staff.

My study, therefore, provides empirical support of for the reciprocal nature of staff-patient interactions. I am interested in looking at the effect of the reciprocal relationship on the behavior of staff and in examining the consequences of this relationship on the experiences of dialysis patients.

CONTRIBUTIONS TO THE PRACTICE OF MEDICINE

Over the last few years, there has been a growing interest in the social dimensions of certain chronic illnesses and the techniques which will aid in the delivery and reception of health care. This study will contribute to this major area by responding to at least four needs:

1. The Need for Patient-Centered Research

Although there has recently been a tendency to focus more on patients' experiences, there are still many areas untouched by empirical analysis. This study unfolds from the patients' perspective. It examines patients' experiences and perceptions, and relates them to the attending staff.

2. The Need for Research in an Area where Patients Learn as Much as Personnel About the Treatment

What distinguishes renal failure from other forms of chronic illness is the fact that dialysis patients learn a great deal about the treatment process in the course of their dialysis. At hourly intervals, heparin levels, temperature, weight loss and pump pressure are recorded. Patients either observe as the nurses register the results or are themselves responsible for recording them. In doing so, patients gain much expertise in the administration of dialysis procedures and learn to identify their physiological responses to the treatment. This gives patients a form of operational leverage, or power, in their interactions with staff.

3. The Need for Research in an Area where Patient-Compliance to the Dietary and Treatment Regimens is Crucial

The nature of the treatment is such that patients are required to follow very strict dietary and fluid restrictions. Failing to observe the rules results in patients' deterioration and in a disruption of ward activities for personnel. Research in the area of compliance could disclose some of the strategies and tactics to be used by personnel in the effective management of patients.

4. The Need for Research Adapted to the Changing Nature of Health Problems

In recent years, while acute infectious diseases continue to decline, chronic and degenerative diseases have emerged

as the number-one Canadian Health problem. ESRD is a chronic disease where care is provided in the absence of cure. A study of ESRD will describe staff-patient interactions and should disclose how the patterns of communication between these two social networks can best be improved.

DATA AND METHODS

I began my observations in the month of January 1981 in the Dialysis Unit at the Montreal General Hospital. Participant-observation and informal interviewing were my chief methods for collecting data. Since I am interested patients' hospital experiences, the focus will be on hospital hemodialysis and peritoneal dialysis patients.

For the first three months, my observations focused particularly on the nursing personnel and the management of patients. During this time, I also attended three major conferences. One was from a psychological standpoint and focused on the problem of patient control over treatment in end-stage renal disease. Another explored the biological factors associated with ESRD, while the third examined the policies of Decision-Making in the area of Medical Ethics.

For the next two months, I concentrated almost exclusively on patients' hospital experiences on dialysis. I interviewed patients' talked at length with them and observed their interactions with nurses and other patients.

In an effort to keep up-to-date with patients' progress, I attended the weekly conferences held each Tuesday morning. Conferences are used to stage a review of each patient. If problems arise in the course of a week, they are openly discussed and staff attempt to resolve them.

To collect comparative material, I arranged a visit to the Kidney Disease Centre and Dialysis Unit at the Royal Victoria Hospital. The ratio of patients to nurses if very low - two patients to every nurse, unlike the Montreal General Hospital where one nurse attends every four or five patients. At the RVH, there is much more opportunity to witness nurse-patient interactions. Had I known this at the outset of the study, I most probably would have chosen the RVH instead of the MGH to conduct my study.

While conducting my fieldwork, I was also registered in a reading course which complemented by observations beautifully. I became acquainted with the literature of medical sociology and all its different frameworks. As the semester progressed, my fieldworks and reading evolved hand-in-hand.

GENERAL OUTLINE OF THE THESIS

The study is divided into two main parts. The first looks at the patients' world and examines their experiences on dialysis; the second focuses on the medical personnel and examines their ideological commitment and their approaches to patient management.

In the first part, I look at how the rules and regulations influence patients' lifestyles. In the second, I examine the perspective of the medical personnel. As we shall see, staff are concerned with maximizing patient-compliance to the treatment and dietary regimens. Patients' failure to observe the rules leads to a disruption of ward activities and thus prevents staff from fulfilling their role obligations.

CHAPTER TWO

PATIENTS' WORLD: THE EXPERIENCES OF HOSPITAL DIALYSIS PATIENTS

> There is nothing simple or easy about being a hospital dialysis patient. You exist according to hospital and staff definition. You are assigned some anonymous numerical classification, often deprived of name, given non-descript clothing, exposed to unflattering, and often misunderstood techniques, procedures and time schedules, and shifted around as if you were a piece of baggage, which is continually arriving at the depot five minutes after the last train departed. Your status within the hospital community is clearly at the lowest rung of the totem pole. Decision-making for your care, your treatment, your medications, your meals, your room, your accomodations, even your movements and whereabout rests with others, and you are extremely fortunate if you can only provide partial input into this process. (Schwartz, S., 1980, p. 17).

Chapter two investigates the experiences of hospital dialysis patients. It is divided into two sections. The first section deals with patients' attitudes toward kidney failure and dialysis treatment. How do patients respond to the tragedy that has befallen them? How do they cope with the limitations it imposes?

Part two examines patients' responses to the hospital environment by investigating how their attitudes are translated into patient behavior. How do patients respond to the institutional setting? How do they deal with hospital routines? Given the long-term nature of the treatment, how do they assert their expertise in the treatment process?

THE RULES

LSRD patients on dialysis must follow a wide range of rules. The rules governing patients' lives are very rigid. Patients must adhere to dialysis schedules and dietary and fluid restrictions. Consumption of alcoholic beverages is strictly prohibited. Moreover, long distance travelling becomes almost impossible.

Dialysis schedules must be closely attended to. Kidney failure is a chronic disease which, left untreated, results in death. This means that patients must remain in treatment for life if they wish to remain alive (unless, of course, they opt for transplantation). Patients must present themselves for treatment two or three times a week and remain in treatment anywhere from four to ten hours.

In this respect, treatment and adherence to dialysis schedules are central to patients' survival. They have no other choice but to present themselves for treatment. This necessarily means that an average of three days per week are tied up in treatment sessions. Patients are then no longer free to travel at will. Their lives rotate around dialysis schedules.

The amount of food patients consume is also closely monitored. Patients' daily ration of food consists of two ounces of protein (the equivalent of two eggs), a few meagre slices of bread, one-half cup of natural whole-wheat cereal (oatmeal or cream of wheat), a few pats of salt-free butter, one-quarter of any citrus fruit. Dialysis patients are not allowed to ingest tomatoes or bananas because of the high potassium content of these foods. Patients are deprived of savory homemade soups (because of the high concentration of salt), mouth-watering dishes like chinese food, pizza, lasagna, cold cuts, smoked meat, McDonald's hamburgers and Harvey's delicious french fries. Gone are Schwartz's steamies, Arahova's souvlakies and Dunn's famous cheesecake.

There are also restrictions on fluid intake. Patients cannot drink more than one-half cup of liquid per day, in the form of juice, milk or water. Compounding this, all alcoholic beverages are strictly prohibited.

PATIENT' RESPONSES TO THE DISEASE AND TO DIALYSIS TREATMENT

Some patients see the disease as an invading force with the power to permeate and violate their entire existence. They view themselves as having relatively little control over their lives. For others, life on dialysis has long since become routine. These patients have succeeded in routinizing themselves to an institutional life.

Several themes emerged from my data which clearly reflect the dimensions of patient experience. A brief look at them may provide some insight into patients' attitudes toward kidney failure and dialysis treatment.

A. Restrictions of lifestyle

All patients on dialysis are confronted with the fact that their lives will never be the same. They are "doomed", and one patient said, to "carry the cross for life".

In an effort to ease the burden, several patients find solace in attributing the disease to an act of God:

> I'm very religious...I believe that it was God's Will that I get this disease...I've never done anything bad to anyone...I never criticize anyone...
> (So you don't think that it may be because you've committed some kind of misdeed or something?)
> Oh no! Nothing like that! I think that it's God's Will...I think that He chooses who will get the disease and who won't...I mean, if you look at the people who get it, there are all kinds, right? There are rich and poor, crippled, black, white, blind, diabetic, young and old...No, I really think that it's God Who decides who will have to bear the burden of the disease...who will have to carry the cross...
> But that's life, right? I'll just have to bear it, that's all....

Similarly, another patient said:

> D'après moi, ce sont le Bon Dieu et le Petit Jésus qui décident ça...On ne peut pas faire autrement que d'accepter ce qui nous est arrivé....

For most patients, the most difficult thing is trying to cope day-to-day with the knowledge that their lives have changed so drastically. Patients have no other choice but to accept their fate and to adapt themselves to the dialysis schedules:

> You have no other choice but to accept it. You know that you need it to survive. If I didn't come I could live maybe three weeks at the most...Dr. K. says so - because of all the impurities in my blood I would become toxic and die....

For most patients, having to undergo dialysis treatment is a "real drag":

> Having to come here is a real drag...It's the long hours, you know?

And, more often than not, dialysis is mentally debilitating:

> Je me sens assez fatiguée. Je sui assez tannée. C'est vraiment démoralisant. Imagine-toi, ma chère enfant, être allongée à la journée longue à regarder le placard. C'est fatiguant. C'est démoralisant... Souvent, je pleure....

Many patients report having had to change residence immediately following onset of the disease as they wanted to live closer to the hospital:

> The disease really changes your whole life right around. I became so depressed. It makes things so much more complicated. We had to move out of our beautiful home on the South Shore and into the City to be near the hospital...It was very hard and sad....

Similarly,

> I used to live in Granby. We had a nice little home there. But the travelling was too much for me. Driving to Montreal three days a week like that...So we had to move to Montreal.

For others, beginning dialysis implied sudden limitations of freedom and an inability to travel:

> The thing I find the hardest to accept is the way it changed my life. I used to be so free...If we wanted to go anywhere we could... If we wanted to go down to the States, even if it was just for a hot dog, we could...I have so many good memories (dreaming)...It's the memories that keep me going. If it weren't for the memories, I would have given up a long time ago....
>
> On dialysis you have much less free time. Your whole life becomes very restricted. Almost not like your own anymore...I suppose you could travel if you really wanted to, but it's very complicated because you would have to make all the arrangements first....
>
> When I first found out I couldn't believe it. I didn't want to believe it. I didn't want to come here but, on the other hand, I knew I didn't have a choice. I just couldn't accept what was happening to me. I became depressed! And how my life changed! I use to be such an active person...I used to travel a lot. I could do anything I wanted to do when I wanted to do it...When my husband used to go off to work in the morning, sometimes I would hop on a bus and go shopping for the day. And then things changed...(How?) Well, for one, I can't go out shopping anymore because my legs aren't too good. The disease affected my legs....

Many patients report that performing simple everyday activities became almost impossible:

> Oui, c'est vraiment une maladie qui est vraiment difficile à supporter - physiquement et mentalement. Physiquement, je ne suis plus capable de faire les choses autour de la maison que je pouvais voilà quelques années. Je n'ai plus les mêmes forces que j'avais. J'ai toujours mal aux épaules et au cou. Je me sens moralement complètement démoralisée. Je me sens toujours dépressive. Des fois, je me demande comment je vais continuer à vivre....
>
> Sometimes I feel so guilty about the housework. I can't do it anymore. The house is so dirty. When I get up in the morning and look around the house, I think of all the things I should be doing...Put I just can't seem to make myself move....

For most patients, however, following a set of dietary restrictions is the hardest:

> Oh yes. I have to follow a very strict diet. I can't eat potassium found in fruits and vegetables. I can't drink more than a half-cup of milk a day. Sometimes I get so thirsty... I can't eat more than 2 ounces of protein a day. My potatoes have to be soaked overnight before I cook them. It's terrible!

A patient, complaining that another patient never follows her diet, could be heard to say:

> J. never follows her diet. She just doesn't care! All the patients tell her how dangerous it is! Well tell her, the nurses tell her, but she never listens. She just says: I like to eat! If I want a pizza, I eat a pizza. I don't care. Besides, the nurses will take care of me - they'll fix me up. Do you know how long it's been since I've had a pizza? Not since I first started on dialysis - that was five years ago!
>
> The biggest problem I have found is with the potassium. You must always be careful. The thing I miss the most is grapefruit. I can only have a half grapefruit every second day. I miss the fresh fruits...especially in the summer when there are so many nice fruits in the markets....

> The things I miss the most are bananas and oranges. I used to love to eat an orange first thing in the morning. There is nothing like it then you first wake up. You peel an orange and all the juice come squirting out....
>
> I hate it. I hate this stupid diet. I love to eat and here I am doomed to a life of dieting. There's no justice to it...Especially when everyone around you loves to eat and you have to sit there and watch them! It's so hard when you see everyone around you eating everything they want and nere you are eating only a little bit of this and a little bit of that...Sometimes I get so hungry, I just want to eat everhing in sight!

For many patients, the problem is not in following the dietary restrictions but in adhering to the limitations of fluid intake:

> My problem is not the food - I can easily do without it. I can control myself. The problem for me is with tea. I love to drink tea but I'm not allowed more than a half-cup a day! It just isn't fair! I find it so hard to follow all these crazy rules. Lately what I've done is use a smaller cup - a tiny one - it only holds two ounces of liquid. So in my day I have two cups of tea instead of a half cup. Psychologically, it makes me feel better.

For others, eliminating salt from their diet was perhaps the most difficult thing about starting on dialysis:

> L'affaire que je trouve le plus difficile c'est de suivre la fameuse diète. J'essais mais je ne suis pas capable. I don't have any will-power I guess. For me, to live is to eat! I don't eat to live...I love tomatoes, pizza, chinese food and there's so much salt in all of those kinds of food. That's what I found the hardest when I first started on dialysis - cutting out the salt. You know I used to put salt on my peanuts and potatoe chips before I went on dialysis? And then I had to give it all up completely....

As mentioned earlier, all alcoholic beverages are strictly prohibited. Many patients find this particularly trying:

> You know that you can't drink don't you? It's awful. When my husband gets home from work he immediately pours himself a drink. Of course I can't have any so I just sit there and watch him enjoy his drink. Every now and then, I treat myself to a couple of drinks. It helps me to forget...(forget, forget what?) How awful life can be....

Patients' lives can indeed be "awful". What this woman may be experiencing is a form of isolation from her husband. Many patients claim to have experienced social isolation at least once since the onset of the disease. To them, it is the direct result of the rules and regulations which govern their lives:

> Dialysis really changed my whole life...I lost nearly all social contact. Like this past weekend, my girlfriend asked me to go to her sister's for supper...She was having a cold meal - Tu sais, comme des viandes froides? Comme du salami, du baloni, ces choses là? Mais je ne peux pas manger ces choses là... C'est parce qu'il y a trop de sel dedans... Alors on est allé seulement durant la soirée, <u>après</u> le repas...Et sais-tu que j'ai pris seulement un vers? Eh que c'était dûr!!! This is what dialysis has done to me...It makes me feel like a social outcast...It's made me live in a kind of plastic bubble... (continuing, he said) I can't eat what I want, I can't drink what I want and how much I want to and I can't travel very much...Tell me, is it all worth it???

Another patient, an Italian woman, complained that having to follow a diet runs counter to all her cultural beliefs. Everyone knows that both food and eating are central to the Italian

culture. Sharing food creates social solidarity among family members. It is no wonder, then, that this women experiences a form of isolation as a result of the dietary restrictions:

> I make the sauce on Sundays. I eat just a little bit (pointing to about a quarter inch). Once a week, that's all...And during the week, I make the sauce for my family but I no eat it...I eat only the pasta. I fry garlic in oil put on top of the pasta. Diet - terrible.... Everyone eat and I no eat... Feel terrible....

There are quite few patients who continue to work despite their illness and who receive their dialysis treatment during the evening or overnight. Generally speaking, these patients tend to feel less isolated socially by virtue of the contact they receive at the workplace. However, having to come to the hospital immediately after work and having to spend some eight to ten hours on a dialysis machine is not a fair trade-off for many patients:

> It's hard for me...I work five days a week, nine to five. I enjoy my work...At least I'm with people! But then three nights a week I have to come here...Staying here overnight is no joke, let me tell you. I just can't sleep. At the most, I get maybe two or three hours. It's hard because you know there are people around and some people mumble at night...I get very nervous...because I know I have to get my sleep to feel alright the next day. I have to be at my best and I can't be if I don't sleep. Usually just when I'm finally dozing off, usually around 5 or 6., the janitors come in and on go all the lights! It's maddening....(continuing) A lot of the nurses are really inconsiderate... During the night, when they've finished with the metal clasps, they throw them into the bin... They make a terrible noise...I've tried to tell them about it but they don't listen to me....

B. Feelings of Powerlessness, Dependency, Imprisonment

Several patients have mixed feelings about the dialysis treatment. While they realize they are dependent on the treatment for survival, many feel imprisoned by it. They develop a kind of love-hate relationship with the machine. On the one hand, patients are thankful and indebted for having the opportunity to prolong their lives, but at the same time abhor the type of lifestyle dialysis necessarily entails:

> C'est démoralisant...C'est tellement long... Tu viens ici, et puis c'est donc long...Des fois j'ai envie de tout laisser de côté et de me sauver...C'est drôle eh, mais même si on dépend sur la machine pour notre survie, et on sait qu'elle nous permet de vivre plus longtemps, on se sent quand même emprisonné par elle...On n'est pas libre du tout... C'est comme notre vie ne nous appartient plus... On est attaché à une vie qui se déroule autour des traitements....
>
> It's so hard coming here and being dependent on a machine for your life. I get so restless. Sometimes I feel like giving it all up....

Dialysis treatment involves much more than the long hours patients spend on the machine. Treatment does not end when patients leave the Unit. Survival implies that the restrictions of diet and fluid must be closely attended to both inside and outside the hospital. In this particular sense, treatment is carried over into the patient's "personal" life "outside" the hospital environment and violates his entire existence. One patient described this concern in the following way:

> On sait que ce n'est pas seulement pour aujourd'-hui...Il y a quand même aujourd'hui, demain et après-demain...On sait que ça ne finit pas quand on part d'ici...Il y a toujours la diète à suivre, jour après jour....

Another patient stated:

> The bad thing about dialysis is that you know that you can never fully recover...unless of course you have a transplant...And at my age, I don't see the point in going through an operation like that...Anyhow, as I was saying, once your kidneys die (?) that's it...There's no going back...You know that whether it's two years down the road or even 10 years down the road, you will never get better...So you know that all these things which you must do to stay alive, like coming here, following a stupid diet, starving yourself half to death, you know that all these things, you've just got to keep doing them again and again, over and over....

For some patients, however, following the rules is accepted as a way of life. They have adapted themselves to the constraints of an institutional life:

> At first, I found it a little disturbing. It just takes a little getting used to, that's all....

> Mr. M. Always follows his diet. He never cheats. In all the years that I've known him, I've never seen him cheat...No wonder he's doing so well....
> (How do you mean, "doing so well?")
> Well as far as I know, they've never increased his time. The nurses tell me that he's got good control of his bloods. He tells me that the diet doesn't bother him at all...He said that he used to be a big meat-eater. You know he used to weigh over 200 lbs.? He said that he used to be able to eat these big steaks...now he can only manage a little, bit of chicken or fish..I guess he's really gotten used to it....

> When I first discovered that I had the disease, Dr. K. told me to lead a "normal" life and that I shouldn't let the disease get in the way of anything. He said that I should continue to travel as much as I can, that I should continue to do my exercises...So I do. I lead a very "normal" life...I belong to different clubs, I travel, I exercise....

And in accepting the restrictions, some patients view the time spent on dialysis as a job:

> I treat it like a job. It's like going to work for me. I have to come here, so I do. I'm here three days a week, four hours each time. For me, it's just like having to go to work....
>
> Look at my hair! I've wanted to have it dyed for some time now, but on my days off - look at me saying "my days off" - sounds like a job or something. Anyhow, on my days off, I never really have the time... Hummm...You just made me realize that this place is like going to work for me...The only difference is, I don't get paid for it....

For most patients, however, dialysis has revolutionized their world. Lifestyles which may have previously confirmed a sense of self or a certain identity must be discarded in favor of new ones. One patient, a very wealthy woman, complained that the disease made her feel very poor:

> Depuis que je viens ici, je me sens pauvre. D'après moi, c'est la maladie des pauvres. Je pense que ça, c'est la chose la plus difficile à supporter - à penser que c'est la maladie des pauvres....

Another patient, still quite young, reports that he no longers sees himself as the "swinger" he used to be:

> I used to be very outgoing...Late nights, women, drinking...I was quite a swinger...But I'm not like that anymore...Coming here has turned me into someone very different. I guess I've lost a lot of confidence in myself. No wonder! Having this, (lifting up his arm to show the tubes), wouldn't you feel the same way?

PATIENTS' RESPONSE TO THE HOSPITAL ENVIRONMENT

Dialysis can be accomplished either in the comfort of the patient's home or in the hospital. This choice is usually made for patients by the medical personnel.

Above all, staff are interested in maximizing patient conformity with the rules while minimizing infections. One method employed by medical personnel to achieve these ends is to keep high risk patients (those who fail to adhere to the restrictions and regulations of dialysis treatment) under direct hospital supervision. In other words, hospital dialysis patients are often those who have failed on the home treatment programme and who require very close surveillance.

Keeping this in mind, we will now turn to a discussion of hospital routines. In an attempt to understand what life on dialysis is "really like", I present a detailed account of what patients typically "do" in the course of their treatment. I have divided these activities into three sections. (1) What patients do before dialysis begins, (2) while on dialysis, (3) after dialysis.

1) Before Dialysis

A) Preparing trays: When patients arrive for their treatment, they immediately begin to prepare their own tray. A tray contains all the necessary items patients use in the course of their treatment. Preparing a tray involves securing

the needed items from a larger tray at the centre of the Unit. Patients are responsible for making sure they have enough gauze pads, metal clasps (which are used to block the tubing at measured intervals), cotton swabs, long strands of scotchtape, a thermometer, a needle, seringes, scissors and tiny bottles of heparin (an anticoagulant) and saline solution (used to raise the patient's blood pressure).

Preparing one's tray is symbolic of the underlying staff ideology, namely that patients should be encouraged to participate as much as possible in the division of labor and the treatment process. For patients, it is their way of providing some input into the process. Since dialysis encompasses their whole life, it would only seem natural that patients would experience a need to do so. As one patient explained: "Oh I don't mind...It makes me feel useful...."

> I prepare my own tray when I come in so that everything is ready for the nurses. It saves time....
>
> It's nice to be needed - that's why I do it....

Some patients even go a step further by also preparing the trays of other patients, who may be older or sicker.

> Mr. G. always gets his own tray ready. Mrs. K. gets all those trays over there ready (pointing to about eight or nine trays lined up along a table). She gets at least 8 or 9 ready every time she's in. And on Saturdays, she and Mrs. L. get everyone's ready. (nurse)

From the nurses' point of view, "it really saves a lot of work and time and really helps us out".

Patients do not step into the setting knowing how to prepare a tray. When patients first begin treatment, they are given a set of guidelines detailing all the needed materials. They are encouraged to use the list as a reference point and to "check of all the items just in case they forget something". After a while, patients no longer require the list and simply proceed by memory.

B) Weighing and taking temperatures: Immediately after having prepared one's tray, patients weigh themselves and take their temperature. Many do these tasks simultaneously. Patients then write down their "check-in" weight and temperature on the chart. As we shall see later, patients who have failed to comply with the diet between treatments sometimes attempt to falsify the results.

C) Making beds: The task of making beds customarily belongs to nurses. But the nursing personnel do not always find the time to make up all the beds before the arrival of patients. Therefore, rather than delay the treatment process, patients "pitch in" and make their own beds. While it "helps the nurses out", it also enables patients to feel that they are providing some input into the treatment process.

Occasionally, patients will also make up other patients' beds. This is quite rare and usually occurs only when a fellow patient is "feeling very sick".

D) Deciding on how much to lose: Because patients know how closely they adhered to the dietary restrictions between treatments, they are in a position to judge how much weight they should lose:

> Nurse: Mrs. D. avez-vous pris votre température?
> Mrs. D.: Oui
> Nurse: Et vous l'avez inscrit sur votre feuille? Et puis, combien voulez-vou perdre?
> Mrs. D.: 2.2 Kilos.
> Nurse: Ok. C'est bien.

2. While on Dialysis:

A) Scotchtaping, inserting the needle: For the most part, patients enjoy taking an active role in the treatment process. Many instruct the nurses on where to insert the needle, how to scotchtape the gauze pads and how to position the needle. As one patient explained:

> I try to guide them (the nurses) as much as possible....
> (How)
> Oh I tell them what pressure I need, how to scotchtape, where to put the towel, where to insert the needle, little things like that... I'm sure they appreciate it....
>
> I do everything myself. The nurses are here only to assist me - that's all. Their job is to come only if there is an emergency or something...I do everything myself. I needle myself, I put the scotchtape, I take my own temperature....

B) Taking temperatures: At hourly intervals, patients take their own temperature ane record the results on their chart.

C) Operating the machine: Most patients know how to operate the dialysis machine. As a result, when the machine's alarm goes off indicating some minor problem, patients can immediately identify the source of the problem and remedy it. Patients quickly reach over and press the necessary buttons:

> Bien oui. A chaque fois qu'il y a quelque chose qui sonne sur la machine, c'est moi qui s'en occupe. S'il fallait que j'attende après les infirmières, je te dis que j'attendrais longtemps....
>
> I do everything myself. I see to my own machine.

D) Watching T.V., Reading, Sleeping, Thinking: While on dialysis, some patients watch T.V., while others prefer to read or sleep. Yet others enjoy gazing into space, trying to recapture a distant past:

> (So what do you usually do while you're on dialysis?)
>
> I watch t.v., I sleep, I think, I mostly think...about the past...All the good times... We had such good times...It's so hard coming here and being dependent on the machines...I get so restless...Sometimes I feel like giving it all up....
>
> I never watch t.v. These game shows and soap operas are rubbish. I can't see why people watch them. And besides, I can't see very well because of these glasses so I don't read very much. Once I get some new lenses, I will though...Usually I try to catch up on my sleep....

3. After Dialysis

A) Weighing In: The dialysis now completed, patients weigh themselves one last time and record the results on their chart.

B) Putting the Soiled Sheets in the Laundry Hamper: Just before leaving, patients remove the soiled sheets from their bed and deposit them in the laundry hamper. Several patients, however, fail to observe this tacit rule.

As a rule, nurses do not object to patients who neglect to remove the sheets from their beds. In contrast, patients who fail to adhere to this understanding are met with opposition by those who participate in this activity:

> Il y en a deux surtout qui n'enlèvent jamais leurs draps de leur lit. Ils sont assez pressés de partir...Ils filent dès qu'ils ont fini leur dialyse...Je ne pense pas qu'ils pensent à ce qu'ils font...laisser un tas de boulots comme ça aux infirmières c'est injuste... Franchement, ça ne prend que quelques secondes et ça donne de l'avance aux infirmières...Ca m'enrage de les voir partir avant qu'ils aient fini leurs petites tâches....

DIALYSIS PATIENTS: EXPERTS IN THE TREATMENT PROCESS

By virtue of the long term-nature of the treatment process, dialysis patients learn a great deal about the administration of dialysis procedures in the course of their dialysis:

> A la longue on s'habitue. On vient qu'on sait sait tout ce qu'il y a à savoir sur le dialyse....

> I've been coming here for over 17 years. I've seen a lot of things during that time. I've met a lot of nice people and some not so nice...There's this one nurse that I can't stand...I won't mention names, but I'd just like to tell you that she's terrible... She thinks she knows everything! She thinks that she knows more about dialysis than I do! Doesn't she realize that I've been coming here for over 17 years?

A patient might be heard to say to a new nurse:

> ...6 days? Only 6 days? (voice rising)... You mean to tell me that you've been here only 6 days? Good God, I would never have let you touch me, let alone dialyze me, if I would have known!!!

In the course of learning about dialysis procedures, patients also learn to identify their physiological responses to the treatment:

> I don't mind dialysis too much, as long as I don't get those damn cramps...Then it's really awful! My calf contracts and I could just scream! It's so painful! It usually happens when my B.P. goes down too low and too fast...because of not enough sodium... So they (the nurses) inject me with some saline solution to bring my B.P. up....

Other patients summarized it in the following way:

> I know myself and the machine better than anyone else here...So I do 99% of the work myself. The nurses don't know how I feel just by looking at me! I KNOW HOW I FEEL! So I always do everything myself. The nurses trust my judgement - they know I'm competent!
>
> I know what to do! I know how I feel and I know how "good" I've been between treatments and I know how my body reacts to the machine... I've been coming here so long....

As a result, patients may then capitalize on their ability to identify their physiological responses to the treatment. They learn to devise ways of cheating which pass largely unnoticed by nurses:

> But I'm lucky in a way because I do have low B.P.. I can afford to cheat a little. Every now and then, I go up to the Dorval Shopping Centre and order a smoked meat on rye, french fries and coleslaw up at the Delicatessen there. I need the salt, you know?
>
> When I first started on dialysis, I was very good. I never used to cheat at all... I ate exactly what I was told to. And then, as time went on, I found ways to cheat. What happened was, I would come in and my B.P. would be a little low so when I went home, I ate a little salt thinking that it would be good for me and that it would bring up my B.P.. And it did. The nurses never found out about it. When I would come in the next time, my B.P. would be around normal...But then it got out of hand. I started taking more and more salt, thinking that the nurses wouldn't find out about it... At first it was "just a little" salt, but then it became "oh why not?" and, of course, the nurses soon found out about it....
>
> I don't really follow a "diet" per say. I think I would die if I had to. Oh, I cheat allright!
> (How do you cheat?)
> Well I eat more than they say I should at breakfast but then I skip lunch. I guess it balances itself out because so far they (the nurses) haven't caught on....
>
> I always eat more than they tell me to, but I still try to watch myself....
> (How's that?)
> Well if I know I'm going to cheat at night, I don't eat anything all day. You know, little things like that...For me, it works out fine. And besides, I don't think the nurses even notice....

All these patients have a very clear understanding of their physiological condition and their responses to dialysis treatment. As a consequence, they have learned to "cheat". Although to them it may seem like "cheating", in reality it is not. Patients have simply learned to adjust their eating habits according to the dietary restrictions.

Other patients, however, are not so lucky. They violate the dietary rules and make absolutely no concessions. And by virtue of the close monitoring involved in the treatment process, patients who severely violate the dietary restrictions are always found out. Signs of violation are immediately recognizable by sudden weight gain, a rise in phospherous, sodium and potassium levels and by fluid overload.

In this respect, dialysis treatment is inherently different from any other form of treatment. Patients suffering from a stroke (Hoffman, 1974) for example, and who subsequently undergo physiotherapy, have the power to avoid performing their rehabilitative exercises and still escape the staff's critical eye. It may simply be that the patient is not progressing. Medical personnel may suspect that the patient has failed to follow the rules but cannot prove it.

This is clearly not the case for dialysis patients. Failure to adhere to the dietary and fluid restrictions becomes immediately apparent in sudden weight gain and fluid overload. In other words, the patients' physiological state "tells all". It is impossible to lie or cheat in the true

sense of theword. Sudden fluctuations serve as indicators of non-conformity with the rules and regulations of dialysis treatment.

In an effort to avoid sharp criticism from the medical personnel, patients who failed to comply with the rules sometimes attempt to falsify the results of their chart. Like other patients, they weigh themselves upon arrival but do not record their actual "check-in" weight. The weight they inscribe may deviate from their actual weight by as much as ten pounds. The following experts illustrate this point:

> Looking over the chart of a patient who experiences difficulty in following the diet, the nurse could be heard to say: "Mrs. R. are you SURE this is your REAL weight? To which the patient replied, slightly blushing: "Of course I'm sure!" The nurse then proceeded to guide the patient toward the scale and said: "Well why don't we just check just to make sure?" The patient then stepped up onto the scale, looked at the total and immediately uttered: "I guess I must have read wrong!"
>
> Or sometimes, when patients are caught red-handed and wish to avoid further complications, they may confess as quickly as possible and beg for forgiveness: "Oh please don't be angry at me! I didn't want you to be mad at me...You see, I haven't been very "good" lately, so I thought I'd take a chance....

Many patients justify cheating by saying that were they to follow the diet all the time "religiously", they would certainly "go nuts" or "go crazy":

> I just have to cheat once in a while. To follow that diet all the time would make me go crazy!

Others feel justified in cheating on holidays or when attending weddings, parties or special dinners. Although they may rationalize and excuse their behavior to themselves, patients nevertheless still experience the guilt which usually accompanies the violation:

> Je me sens assez coupable! J'ai triché en fin de semaine et puis j'ai pris 3.4 kilos! C'est parce que je suis allée dans un party samedi soir et dimanche ma fille est revenue d'Hawaii et puis on a fêté...C'est la première fois que je triche comme ça...Je ne sais pas ce qui ma pris....

SUMMARY

In this chapter, I have attempted to disclose what life on dialysis is "really like" by examining patients' responses to the disease and to the hospital environment. Like anyone facing a life of chronic illness, patients are profoundly distressed by the innumerable rules they are forced to follow. Feelings of powerlessness, dependency, imprisonment are most common among patients. In an effort to organize the treatment in a systematic way, treatment activities are highly routinized. Patients have a set of well-defined tasks which they must accomplish during the treatment process. These include the preparation of trays, weighing and taking temperatures, making beds, and placing their soiled sheets in the laundry hamper.

By virtue of the long-term nature of the treatment, patients learn a great deal about the administration of treatment procedures. They also acquire expertise in identifying their physiological responses to the dialysis treatment.

The next chapter consider the staff's world. As we shall see, medical personnel actively engage in negotiation with patients in an effort to pursue their own interests. Above all, staff members are most interested in maintaining the social order. Patients, however, have the power to disrupt the social order by failing to adhere to the dietary and treatment regimens. How medical personnel attempt to

maximize patient-compliance will be the topic of discussion in Chapter three.

CHAPTER 3

IDEOLOGICAL COMMITMENT AND THE MANAGEMENT OF PATIENTS

> The success of the patient resides in his being deceived about certain procedures, because always some of the hospital routine will be dictated not by medical considerations but by other factors, notably rules for patient management that have emerged in the institution for the convenience and comfort of staff (Goffman, 1961, p. 346).

The last chapter described some of the more typical patient reactions to kidney failure, dialysis treatment and the hospital environment. We have seen that the nature of the treatment is such that patients are required to follow a set of specified rules and regulations which must be closely observed both "inside" and "outside" the hospital context. Not surprisingly, patients tend to experience high levels of depression, feel emotionally and psychologically debilitated and sometimes entertain thought of abandoning the dialysis treatment altogether. Renée Fox writes:

> Should physicians invariably do everything they can to treat dying patients by chronic dialysis or transplantation? Is the interlude of survival thus given to patients and their families always sufficiently meaningful and free of physical and psychic suffering to be call a full human life? (1974:377)

This chapter looks at patients from the hospital's point of view by examining the context of the hospital into which patients are admitted. More specifically, it investigates the kind of ideology that is predominant among staff members and how it influences the management of patients. How do members of the Health Care Team define their roles? Are there differences in ideological commitment? If so, how do these differences influence the treatment of patients?

Chapter three is divided into three sections. Part One looks at the underlying ideology and the differences in ideological commitment among staff members.

In Part Two, I look at the importance for personnel of maintaining the social order. In order to fulfill their role obligations, it is vital for them to maximize patient-compliance with the treatment and dietary and regimens.

Part Three is concerned with examining the kinds of problems patients present for staff and the strategies used by personnel in the management of patients. Of particular interest is patient non-compliance and the tactics employed by members of the health-care team in their attempt to maximize patient-compliance with the treatment regimen.

IDEOLOGICAL COMMITMENT: CARE IN THE ABSENCE OF CURE

It has been suggested that there are three types of ideologies which characterize medical institutions. They are cure, care and core ideologies (Mauksch, 1973). Cure is the most traditional ideology and emphasizes recovery. The ideology of care, however, eliminates the possibility of cure and tends to focus on the temporary restoration of health. The third ideology, core, is concerned with maintaining the functions of the institution. Activities include the self-maintenance of the institution, maximum utilization of resources, stability and control. (Klenow, 1979:699)

IDEOLOGY	GOAL
CURE	RECOVERY
CARE	TEMPORARY RESTORATION OF HEALTH
CORE	MAINTAINING THE FUNCTIONS OF THE INSTITUTIONS

Patients must remain in treatment for life or until a transplant is performed if they wish to survive. These considerations suggest that the cure ideology is therefore not applicable to this particular setting. Treatment does not cure; at best, it can only provide a temporary restoration of patients' health. The treatment never removes patients from the sick-role. Rather, it maintains patients in the sick-role for the duration of their lives.

The ideology of care, on the other hand, focuses on the temporary restoration of patients' homeostasis. This ideology, then, characterizes our setting. According to Renée Fox (1974:88) personnel experience the "therapeutic satisfaction of being able to make patients really well", less frequently than is true of other medical practitioners:

> Physicians can seldom cure their patients; more often than not they can only ameliorate their condition and frequently they can do little more than postpone their death (Fox, 1974:41).

In the following excerpt, a nurse expresses her feelings about having to provide "care" for patients in the absence of "cure":

> The fact that I, as a nurse, couldn't cure these patients, but could only care for them used to make me feel very upset. But it doesn't anymore. I guess because I used to work in I.C.U. (Intensive Care Unit). In I.C.U. you see so many patients who never get well. In fact, a lot of them only deteriorate more and more...You see so many that die no matter what you do....

In spite of their inability to "cure" patients, many nurses still derive a sense of satisfaction from knowing that patients are well "cared for":

> In Dialysis, at least you gain a sense of satisfaction in knowing that they (patients) are well "cared for". So OK, so they don't get any better, but at least they don't get any worse! And they do stay well for a long period of time...Some live for years and years... I enjoy my work...It's very rewarding in the sense that I know they are "well cared for" and in the sense that I know that I can help them to live for years and years....

DEFINING CARE

The Dialysis Unit is staffed by a multidisciplinary team, composed of a social worker, psychiatrist, two resident doctors, four attending physicians, one transplant coordinator, a dietician, chaplain, unit coordinator, several technicians, a Head Nurse and several attending nurses.

Dialysis personnel do not constitute a homogeneous group. Strauss et al. (1978, 1964) argue that differences in ideological commitment are common in every social context. "Care", as it is defined and practiced, holds different meanings for each member of the health care team. While it cannot be denied that all staff members aim to provide "care" for

patients, what kind of "care" should be given is sometimes a matter of great disagreement among staff. By looking at some of the occupational groups involved in the "care" of dialysis patients, we can see further evidence of these varied definitions of "care". I would like to consider the nursing personnel, dietician, technicians and physicians.

Nursing Personnel

For most nurses, "good care" means helping patients to follow the dietary restrictions, eliciting "good" blood controls, maximizing compliance with the treatment regimen, minimizing infections and completing the dialysis in the allocated time period. (Kelley, 1980) Central to the role of the nurse is also the comfort and support or patients.

> You can't cure them (patients). At the very best, you can only make them a little more comfortable (nurse)

Dialysis patients, however, are difficult patients to "care" for. Many fail to adhere to the limitations on diet liquid consumption. Consequently, nurses often feel that they cannot adequately accomplish those services to which, as nurses, they feel committed:

> Patients like R. are really terrible to care for. They never do anything you tell them to...R. never follows his diet, he never listens to anything I tell him! He's awful! And when he comes in overloaded, he takes twice as long on dialysis and then the other patients complain...Sometimes this job is so frustrating!...

Dietician

For the dietician, "good care" means helping patients to adhere to the dietary restrictions. The role of the dietician essentially consists of acting as a resource person for patients:

> ...I try to make them see that it is their life that they are dealing with and that refusing to follow their diet is their business, not mine. I try to show them that it is their responsibility and that my responsibility is simply to guide them. I try to make myself very available to them so that they can feel that they can come to me at any time for advice regarding the diet. In other words, I see my role basically as a resource person - not a manipulator. I try to make them realize that they can come to me at any time - that I'm here....

Technicians

To most technicians, "good care" means keeping the machines in proper working order (Kelley, 1980): "Being careful that the machines are always in good working order", "Preventing a catastrophe from happening", "Making sure that the machines function properly".

Physicians

To most physicians, "good care" means making sure that the Unit is adequately staffed, that ward activities unfold in a systematic way with a minimum of disturbances, that infections are minimized, that patients receive proper "all-around" care and that they yield "good" blood controls following adherence to the dietary and treatment regimens.

SPECIAL PROBLEMS FOR STAFF

This section considers some of the problems patients present for staff and how they are effectively resolved. By virtue of the long-term nature of the treatment, patients and staff tend to develop very close ties:

> Here you get to know the patients so well. You develop much closer ties with them. Sometimes that, in itself, can be drawback though...like when you have a patient you don't like or when you have a personality clash with some of them....There's nothing you can do about it....But upstairs, where I used to work in Surgery, at least you knew that it was only for a few short days and then off they would go....You get the satisfaction of knowing that at least they do "get better". But here, the satisfaction comes from the close human contact with patients....(nurse)

> I like working here. It's a nice change from upstairs.
> (Upstairs?)
> On Medicine. You see, upstairs you don't have to deal with the same patients on a regular basis...like here....You don't get to know the patients as well and they don't get to know you as well....Down here it's different...You get to know them and they get to know you - I like that....

Developing close ties with patients creates all kinds of problems for personnel. Such problems include over-involvement or emotional attachment to patients, patient-dependence and problems of trying to be consistent with patients. But perhaps the biggest problem for staff is trying to cope with non-compliant patients. Each of these problems and its solution will be reviewed in detail.

A. Over-Involvement with Patients and Patient-Dependence

Many nurses feel that the kind of relationship they establish with patients is "too close for comfort". Not only do they become overly involved and emotionally attached, but they also worry that such closeness will tend to get "in the way of their work":

> Sometimes I find myself just getting too involved with some patients. You see, you see them day in, day out....You see them go through some real hard times....You see them up, you see them down....You can't help become emotionally attached....Sometimes I worry that it may get in the way of my work....
> (How do you mean?)
> You know, that it may prevent me from doing my work properly....You need the distance....There's got to be some distance, otherwise you wouldn't be able to tell them off when they're bad....
> So if you're too close, you can't tell them off....See?

A few staff members are concerned that becoming overly attached would make them somewhat vulnerable:

> You really have to watch out for these patients though. They can take you for a ride. You have to be careful. It's because they get to know you so well. They kinda get to know your soft spots, you know? For a while there, I was getting too involved with some of them - like R. (a patient) for instance. I felt that he was getting too dependent on me....

Further illustrations of patient-dependence and over-involvement of staff are cited in the following statements by two staff members studied by Sociologist D.J. Klenow (1979:701):

> Well, getting to know them too close. Let's say that they can become overly dependent upon you. They call you all times of the day and night. All kinds of little problems and things like that which can really become burdensome to you. And if you want to, I've never had this problem but I've seen other personnel get very close ties with the patients and the patients dies for no reason or gets in an accident or something and it's almost like having a death in the family.
>
> Myself, I get too involved. Like knowing somebody for a long time and if something happens to them, it gets to you. You work with them day in and day out. You see them go through good times and bad times. To know that something is seriously wrong, it affects you.

B. Consistency Problems

Many nurses experience difficulty in trying to routinely present a consistent image of themselves to patients. More specifically, given the fact that nurses and patients interact two or three times a week, for some 4 to 10 hours in duration, nurses cannot always be consistent in their moods during that time span. There are moments when nurses do not feel at all like interacting with patients. But patients have preconceptions and expectations of the different members of the medical team. As one nurse said:

> You get to know them and they get to know you. You get to know their personality and they get to know yours. They sort of develop preconceptions about you which is not always easy to cope with....

Another nurse said:

> The thing I find the hardest to cope with is always trying to be consistent with patients. For instance, I'm usually quite outgoing and happy-go-lucky. But some days, I just don't feel up to it....I feel tired....And all the patients say: "What's WRONG with you today????" It drives me crazy. It's like they expect you to always be a certain way....And sometimes I just can't....

STRATEGIES OF DISSOCIATION: AVOIDANCE:

The hospital staff cope with problems of patient-dependence, emotional attachment and over-involvement in a variety of ways, all of which are strategies of dissociation. Dissociation allows staff to avoid becoming too involved with patients, since they would otherwise be unable to maximize patient-compliance. Dissociation, as practiced in the Dialysis Unit, is usually in the form of avoidance.

Avoidance is seen in two forms: by minimizing interaction with patients or by requesting a transfer.

1) Minimizing Interaction: Interaction can be reduced to a miminum for medical personnel by a quick greeting or a hurried performance of bedside duties. Avoiding interaction with patients allows staff to exercise more control over them:

> ....And I felt that they were getting too dependent on me....
> (Dependent?)
> Yeah, you know...like always asking me for things. M. get me this, M. get me that....
> So now I don't talk to them nearly as much as I used to be really familiar with all of them. You only get yourself hurt that way....So now I try to put some distance....It helps me deal with them a lot better....

2) Requesting a Transfer: When members of the health-care team find themselves becoming "too emotionally involved with patients", they sometimes ask to be transferred to another shift. Since patients are on fixed schedules, health care practitioners are sure to avoid patients to whom they feel overly attached, by requesting a transfer. Transfer, therefore, provides an emotional escape valve for staff members.

> For a while there, I found myself becoming too involved with W. (a patient). You see, I was working evenings and she comes evenings for her treatment. So I saw her every night for quite a long time. We used to talk a lot. She'd tell me about her husband and the problems she was having at home and how he expected her to do all these things that she couldn't possibly do anymore because of her illness. I'd listen and try to help her out. But I found myself becoming very attached to her....I couldn't deal with it.... You have to think what would happen if a patient like that died! So I asked A. (the Head Nurse) to transfer me onto days. When I saw W. after that, I felt much better....
> (How's that?)
> I felt that I could cope much better....I had more control over my feelings....I didn't feel as vulnerable....

PATIENT NON-COMPLIANCE AS A SPECIAL PROBLEM: STRATEGIES OF MANIPULATION

Perhaps the biggest problem for staff, however, is trying to cope with patient non-compliance. In order to maintain ward organization, medical personnel must maximize patient-compliance with the treatment and dietary regimens.

The hospital staff attempt to elicit patient-compliance in a number of ways, all of which are strategies of manipulation. Manipulation allows the staff to gain the participation of dialysis patients since they play such a vital role in maintaining the social order. The patient's life, then, is highly regulated and ordered according to a disciplinarian system developed for the smooth management of patients by staff. In this particular system, attending staff reward patients for compliant behavior and criticize all behavior which fails to conform to their expectations.

Manipulative strategies are performed individually or in a group in a variety of ways. Part 1 examines the strategies practiced by nurses in their face-to-face interactions with patients on the ward. As we shall see, physicians are not in attendance during most of the treatment process and nurses are granted large spheres of authority. As a result, nurses are the most important figures in maintaining ward organization and in negotiating compliance from patients.

In part 2, I look at the concerted efforts of the health care team in their attempt to maximize patient-compliance to the dietary and treatment regimens.

1) Individual Strategies

The "care" of dialysis patients involves close monitoring and frequent contact between staff and patients. The degree of personal responsibility for minute-to-minute

patient care is higher in dialysis than in most other nursing fields (Gruber, 1980). Physicians are not usually in attendance during most of the treatment process. Since most of the treatment is administered in the absence of physicians, nurses are granted large spheres of authority. Physicians relinquish a lot of control to the nursing staff.

These considerations suggest that nursing personnel are directly responsible for maintaining the social order on the ward. They are concerned with administering the treatment with a minimum of ward disturbances. There is one event, however, which disrupts hospital routine. This occurs when patients fail to follow the dietary and fluid restrictions.

Failure on the part of patients to follow the dietary rules creates at least three kinds of problems for the nursing staff. First, it causes a disruption of the nurses' routine. Nurses are forced to momentarily cease what they had been doing in favor of reinvoking the rules to patients by counselling then on the ill-effects of over-consumption. This lengthy disruption tends to put nurses somewhat "behind schedule". Second, and directly related to this, is the fact that it causes further complications for nurses by requiring them to pay "special" attention to non-compliant patients. Weight, temperature, heparin levels, clotting times, hypotension, signs of chest pain, heart failure, muscle cramps, itching, restlessness and sudden mood changes must be watched for.

Finally, patient non-compliance places nurses in a very delicate position. Patients who fail to comply must receive ultrafiltration in addition to their regular dialysis treatment. While untrafiltration is effective in removing large quantities of fluid, it does not replace dialysis in that it fails to remove waste products. In other words, ultrafiltration does not give non-compliant patients a "good" dialysis. It is not successful in lowering the patient's B.U.N. (blood UREA nitrogen levels) nor in extracting excess potassium and sodium products from the body. These considerations suggest that nurses, therefore, are not successful in their role - that is, they fail to return patients to homeostasis.

All this creates an avalanche of problems for nursing staff. First of all, non-compliant patients monopolize beds for longer periods of time, thus causing treatment delays for other patients. They, in turn, complain to the nursing staff and to other patients about having to "wait around". Secondly, since non-compliant patients are required to receive treatment for a longer period of time, they will often make it known that they are not at all pleased with such an arrangement. They will be a nuisance to the nurses and cause disturbances in the Unit. And, finally, it sets the technicians behind schedule. They have no choice but to "wait around" until non-compliant patients are through before they can prepare the machines for the next patients. And, more likely than

not, the nurses are usually the ones to receive the brunt of these complaints.

1) Redefinition: Transferring Responsibility

In attempting to elicit compliance from patients, many staff members respond by redefining the situation to patients in a more manageable form; that is to say, by transferring responsibility onto patients.

By transferring responsibility onto patients, staff hope to gain patient participation and to maximize patient-compliance with the dietary restrictions. Assuming responsibility for the treatment is insisted upon continually:

> WE do have a few cases that are really difficult. Some simply refuse to comply altogether! They will not hear of it! Like Mrs. S., or R., of J....But I try to make them see that it is their responsibility and their life they're toying with...and that refusing to follow the diet is their business, not mine. I try to show them that it is their responsibility, not mine and that my responsibility is just to guide them....I think that most of them resent having to follow a diet...a lot of them also may subconsciously feel that by not following their diet, they can in some way GET BACK AT ME!... because I am the one who tells them that they must follow their diet...so, in other words, they identify ME as the source of their agony and project their resentment onto me....Let me tell you, it's not an easy job! But, all in all, I try to make them recognize that it's their life and if they don't want to follow their diet, it's certainly NO skin off my teeth! I really do try to make them understand that it's their life they're fooling around with.... (Dietician)

Staff attribute non-compliance to the patient's unwillingness to take responsibility for himself:

> I tell him what to do but he won't listen. He simply won't comply. He refuses to accept responsibility for himself...for his treatment and the disease....(nurse)

> Some of these patients are really hard to deal with. They won't follow the rules....It's as if they're trying to tell me: "Look, I don't care enough about MYSELF to comply..." and that's what really hurts....The fact that they will not take responsibility for themselves... especially when you care for them....It can't be a one-way street. It's got to be a mutual agreement, otherwise, it just won't work....

Interestingly enough, non-compliance is tolerated unless, it disrupts the social order. In the following example, a patient refuses to comply with the dialysis schedule. The attending nurse allows her to get away with this kind of behavior largely because failure to receive treatment does not generate a disturbance of ward activities:

> The nurses tell me it's my life...and that's just about as far as it goes....And it is my life. I remember phoning H. (nurse) up one time and telling her that I just was NOT coming in....You know what she said to me? She said: "F. it's your life....You can choose not to come in, but you must also realize that you can't live without it....You must realize the consequences of your actions....Bye for now F....Hope to see you soon - maybe...." In ten minutes flat I was here....I guess I expected her to bawl me out or something but she didn't.... She just said: "It's YOUR life - You can choose to throw it away if you want to - it's your problem, not mine....

2) Formal Reproof

Patients who fail to comply with the dietary restrictions receive formal reproof from nursing personnel largely because the social order is temporarily disrupted. In the following excerpts, patients are severely reprimanded by members of the medical team for having violated the dietary restrictions.

> The usual dialysis procedures began. Mrs. S.'s B.P. was taken and then she was asked to step up onto the scale. To R's (nurse) horror, Mrs. S. had gained 4.5 kilos. R. was very angry.
> R.: "Mrs. S. you've gained 4.5 kilos!!!"
> Mrs. S.: "I did?" (gulping)
> R.: "What have you been eating, Mrs. S.?" (severely)
> Mrs. S: "Nothing! I've been following my diet! Honest! I eat everything K. (dietician) tells me to....I don't understand how this could have happened!"
> R: "Mrs. S. you obviously did not follow your diet! The facts are here...right in front of you! It's as clear as day that you've not been following your diet! that you've been bad....Now, tell me what did you eat?"
> Mrs. S.: "Nothing out of the ordinary....(afraid)
> R.: "Have you been drinking more than usual then?"
> Mrs. S.: (no response)
> R.: "Well?????"
> Mrs. S.: "Yes"
> R.: "Yes???"
> Mrs. S.: "Yes. I've...I've.... (voice trailing - almost in tears now)....I drank too much tea...that's all....Please try to understand...(begging) I get so thirsty! And it's the only thing that really quenches my thirst...(pleading)....
> R.: "Oh. And HOW many cups did you have? (patiently as if she were talking to a child)
> Mrs. S.: "I don't know....I couldn't tell you.... Maybe 5 or 6...."
> (impatiently now)
> R.: "Mrs. S. you're not allowed to have 5 or 6 cups of liquids, remember?....Remember what K. (dietician) told you? You're only allowed a ½ cup of liquid per day....Remember????"

> Nurse: "And then there's R...he's another classic non-compliant patient. He refuses to follow his diet...he always comes in with very high potassium levels...."
> (So how do you deal with patients who don't follow their diet?)
> Nurse: "I don't stand for it! I get really mad! I scream and yell!"

> Dr. S.: "Greg is a terrible patient. He's disastrous on dialysis. He never listens, he lies, he's a manipulator. Last week, he gained 8 kilos....I tell you, you could scream at him until you're blue in the face and he still doesn't listen....I don't know what we are going to do with him...."
> Nurse: "After he gained that weight, I told him off. We gave him a good going over. After that, at his last dialysis, we saw that he only gained 3 kilos....I think that we just have to show him who's boss."

3) Imposing Suffering on Patients

Another method used by personnel in attempting to maximize compliance is to impose suffering on patients. Staff may do this in a number of ways. Making the non-compliant patient stay on the machine for a longer period of time (ultrafiltration and dialysis) is one mechanism of social control applied by medical personnel.

> A nurse might be heard to say to a non-compliant patient:"...You'll have to try harder next time....Because you see, this puts me out too....Now we're going to have to leave you on the machine even longer....You'll have to get rid of all that extra liquid.... And that's no fun, now is it?..."

Staff contend that making patients suffer will reduce the likelihood of further non-compliance. In other words, it will serve as a future reminder of the many consequences of violating the dietary rules:

> His hematocrit is high. He has a lot of chest pain. He's borderline angina. He's hypertensive. On Friday, I coaxed him into staying on longer to take off more weight. Maybe in the future he'll think a little more carefully before going off his diet like that....(phisician)

Another way to impose suffering on non-compliant patients is to refuse all beverages while on dialysis. In fact, the most opportune time for patients to "cheat" is while they are receiving treatment. But for those who have failed to comply with the treatment regimen, all beverages are strictly prohibited:

> Nurse, please give me something to drink and eat. I'm so thirsty and hungry....
> Nurse: "No. Now you know you can't....You still have 2 litres to lose. You've already been here all day....You must have cheated a lot...."
> Patient: "But please...."
> Nurse: "No, you can't....You don't follow your diet the way you should. You eat too much....No, absolutely not...."

4) Threat

Threat tactics are directly build into staff-patient interactions. Staff threaten patients in trying to maximize compliance with the treatment regimen. Staff regularly tell patients how "dangerous" going off the diet can be:

> (How do you deal with patients who don't follow their diet?)
> Nurse: "I scream a lot and threaten them....I remind them of what may and can happen if they continue to misbehave like that....It's dangerous....Some of them don't understand how dangerous it can be...."

> She's a chronic non-compliant patient. She never listens....I just don't know what to do with her....She's going to have to learn to be more responsible....She doesn't realize how dangerous it can be....(nurse)

Staff also threaten patients with the thought that non-compliance will necessarily entail a longer dialysis:

> If you continue eating and drinking that way you'll be here four days a week, 12 hours a day....

5) Indifference

Patients who regularly fail to comply with staff orders are frequently given the "indifference treatment". This means that patients are simply treated as non-existent (Martin, 1957). Refusing to treat the patient as a person may prevent undesired social interaction. In the following excerpt, a patient fails to comply with staff orders. Eventually, however, she does make an attempt to carry out the order but makes it very clear to the attending nurse that she refuses to be controlled. She ridicules the nurse in a very malicious way. The nurse responds by giving her the "indifference treatment":

> Nurse: "Mrs. L. could you please step over onto the scale?"
> Patient: "No, I don't feel like it....I'm much too tired. Je suis fatiguée...."
> Nurse: "Mrs. L. you have to weigh yourself... come over here onto the scale...here, let me help you" (taking her arm to guide her over toward the scale)
> Patient: "Don't touch me! (brushing her arm away)....I'll do it myself...." (grinning)

> Mrs. L. moved over onto the scale. No sooner had she stepped onto it that she started to waver back and forth. She called out: "I'm dizzy! Help! Someone! I'm dizzy! I'm going to faint! The nurse rushed over to support her before she fainted and gently led her back to her bed. But as soon as Mrs. L. had sat down, she began to laugh hysterically. "Ha! Ha! I fooled you EH?" The nurse gazed at her intently and said: "Suit yourself. If that's the way you want to play the game, go ahead...but just don't inlcude me! You can dialyze yourself..." and then simply marched off.
>
> About an hour later the nurse returned. Mrs. L's dialysis was performed in utter silence. Mrs. L. kept eyeing the nurse suspiciously, shooting side-glances her way. The nurse's face remained an impenetrable mask, opaque, expressionless.... Not one word was said during the entire dialysis.

6) Reinforcement and Approval

Patients who meet staff's approval are reinforced for compliant behavior largely because they assist in the maintenance of the social order:

> Mrs. S. stepped up onto the scale. Observing the check-in weight, the nurse commented: "Mrs. S. your weight is very good! Well done! You've been very good, haven't you? You've been following your diet?" Mrs. S. was all smiles. Straightening her back and extending her chest, she replied: "Yes, I've been very good!"

Many patients thrive on receiving staff approval; they find that complying to their wishes is particularly rewarding. Unfortunately, not all patients are as eager to adhere to the treatment regimen as others.

2) Team Strategies

Goffman (1956) defines a team as a group of people who cooperate in maintaining a given definition of some situation or in "staging a single routine". Team members of the Dialysis Unit meet regularly once a week. These conferences provide staff with an opportunity to air topics of concern, to discuss, negotiate and, perhaps more importantly, to formulate a "fixed front". (ibid:22) Goffman's "impression management" would describe the efforts of hospital staff to coordinate the image of themselves that they present to patients. Their performance in front of patients will tend to "incorporate and exemplify the officially accredited values" (ibid:45) of "care" to which they are committed.

The concept of "front-stage/backstage" is also relevant here. The weekly conference could be described as a "backstage" region. During these sessions, the pecularities of each patient are publicized and given a detailed review. Problems which have arisen during the week are openly discussed. Patients who have failed to comply with the dietary restrictions are severely criticized.

In staging a review of each patient, staff are kept informed of how well or how poorly patients adhere to the treatment regimen. Consequently, they can "manage" their "impressions" accordingly. The essential element in shepherding patients in this way is the coordination of patient

definitions, since staff manage their impressions according to patients' patterns of adherence. In conferences, then, staff unite, organize and rehearse the details of their performance in order to gain maximum compliance from patients.

Not surprisingly then, staff have a vested interest in all aspects of patients' lives. They are concerned with "keeping up-to-date" or "keeping abreast" of all the news so that they can manage patients in such a way as to promote their own best interests and thereby minimize ward disturbances. In trying to elicit compliance from patients, the medical team sometimes pool their resources. This usually occurs when they are dealing specifically with "problem" patients, that is to say, patients who consistently fail to conform to the treatment regimen. If the attending nurses repeatedly fail to elicit compliance from any given patient they immediately bring this to the attention of their colleagues in the context of the weekly conference.

There are a variety of ways in which staff, as a team, manage non-compliant patients. These strategies follow a successive pattern: 1) Higher-level staff solicit the help of an appointed member of the Health-Care Team; 2) If this fails, they request the assistance of specified patients; 3) If all else fails, they request help from the patient's family and friends.

1) SOLICITING HELP FROM APPOINTED MEMBERS OF THE HEALTH-CARE TEAM

Central to this discussion of team strategies is the concept that staff frequently solicit help from certain colleagues in attempting to elicit compliance. Very often, the psychiatrist is appointed Chief Inquisitor; her role is to question the patient in depth in order to gain a better understanding of the non-compliant behavior. Reporting back to the team, they, in turn, will then be in a better position to manage their impressions in such a way as to maximize patient compliance:

> Dr. K: "K. (dietician), have you spoken to him?
> K: "Yes I have. I showed him what he should eat and what he should keep away from but he doesn't seem to want to listen...."
> Dr. K.: "Sounds like another R.M. (patient) to me...."
> Dr. S.: "C. (psychiatrist), why don't you see him and then you could see what kind of a person he really is and then you could report back to us....At least then we'll know how to deal with him...."

The dietician or social worker is often elevated to the position of Chief Inquisitor:

> Dr. L.: "Mrs. M. gained 4 kilos last week. She's not very responsive to the treatment. We drained her and she lost only 1 kilo....
> Dr. K.: "K. (dietician) maybe you could have a word with her?"
> K.: "Fine. Will do. I'll keep you posted."
>
> DR. N.: "Mr. Y. is having a few problems. He seems to be depressed and he hasn't been having very good controls. He doesn't talk very much...he doesn't give us any feedback...."
> Dr. S.: "You're right. He doesn't give you any info. on how he's feeling...."

> Dr. N.: "D. (social worker), do you think that you could speak to him and then get back to us?"

Perhaps most often, medical personnel request the nurse's assistance in their effort to manage non-compliant patients. Higher-level personnel capitalize on the close ties nurses develop with patients:

> Nurse: "I think she's coming out of her depression. She's much more willing to open up now - at least with me she is....We had a long talk the other day and she said to me that she was very depressed about having lost her husband a few years ago....She was very dependent on him for everything...they did everything together....When he died, she felt that her whole world just fell apart...She said to me: "Wouldn't you be depressed too if the man you loved for 50 years died?" I had to agree with her....She said that she's been very depressed lately because she was mourning her husband....You see he died in April and this is April...so during the months of April and May she's depressed - that's when she feels it the most...."
> Dr. B.: "Well K. (nurse), I think you should definitely continue to talk to her....I know that C. (psychiatrist) tried on several occasions but Mrs. P. just screamed until she finally had to leave. Mrs. P. rejected her.... I definitely think that the nurses are doing more good than the psychiatrist....Keep us informed...."

2) <u>REQUESTING HELP FROM SPECIFIED PATIENTS</u>

If soliciting the help of specified members of the health care team proves fruitless and non-compliance persists, personnel capitalize on the close ties non-complaint patients develop with other patients. Non-compliance, in this case, occurs because patients don't understand the importance of

following the rules. In the following excerpt, a Chinese patient fails to comply with the dietary restrictions, not only because she does not understand the language, but also because she is unaware of the effects of overconsumption:

> Dr. S.: "Mrs. L. had a little problem last week. She was a little overloaded. She doesn't seem to understand that she can't drink as much as she likes to. So the plan now is to get Mr. F. (another patient who is also Chinese) to coax her. It seems that Mr. F. and Mrs. L. come from the same town and speak the same language. So hopefully, we'll be able to use him to help her...we'll have to wait and see...."

3) REQUESTING HELP FROM THE PATIENT'S FAMILY AND FRIENDS

If soliciting help from staff or fellow patients proves unsatisfactory, personnel then turn their attention to the patient's family and friends. In the following excerpt, a chronic care patient presented innumerable problems to the attending staff. In fact, the disease had progressed to the point where constant attention and continual treatment were required. This had the effect of disturbing the social order. Nursing personnel had neither the time, nor the inclination to "care" for this patient. There was, thus, a very strong incentive, to discontinue the treatment. The patient's family, had to be consulted first:

> Dr. A.: "Mrs. B. continues to be a problem. It's important to examine the peritoneal fluid....From what I hear it's sterile.... She remains a mess....I really don't know what to do...."

> Dr. S.: "And she doesn't want any tubes in her chest...."
> Social Worker: "Did you tell her that she can't go home?"
> Dr. S.: "Yes...."
> Social Worker: "And?"
> Dr. S.: "Well she emitted a small cry. I couldn't interpret it."
> Social Worker: "I think that it's about time we had a family meeting....Maybe if we got some feedback from the family we could then come to a rational decision....Look, I'll organize a meeting with the family and then I'll get back to you next week...."

LABELLING "NON-COMPLIANT" BEHAVIOR

The label of "non-compliance", as used by medical personnel, does not refer to patients' actions as such. "Non-compliance" is not a valid summary of the characteristics displayed by patients, but refers more specifically to situations where patients have failed to observe the rules.

The management of patients involves the use of a highly complex system of classification. Personnel have a shared language which represent their way of perceiving, identifying and classifying patients according to their patterns of compliance. Implicit in such classificatory processes are staff's evaluations of the degree to which patients conform to the rules of the treatment regimen. Patients who regularly fail to meet staff's expectations are classified as being "bad":

> Nurse: "But even in the best of times, she never was a very "good" patient. She never followed her diet, she never watched her liquids....She never controlled herself.... Her bloods were always up....We would tell her again and again but she never listened...."

> Trying to make some of the younger ones - like R. - realize how important it is to follow the diet is really hard....He's really BAD! He never follows his diet. (dietician)
>
> She's not very compliant. She's a 100% failure....(doctor).

In contrast, patients who observe the rules and assist in maintaining the social order are typically referred to as "good" patients:

> Mrs. K. is such a "good" patient. She never goes off her diet...(nurse).

Similarly, a doctor might be heard to say to a nurse:

> Doctor: "Has C. been "good" or has she been on any binges this weekend?"
> Nurse: "No. She's been good. No binges. She's adjusting very well...."

SUMMARY

Chapter three has been concerned with examining the type of ideology that is predominant among staff members. While "care" in the absence of "cure" constitutes the chief ideology, "care" is defined differently by members of the Health Care Team.

In an effort to fulfill their role obligations as "caretakers", staff are concerned with maximizing patient-compliance with the treatment and dietary regimens and minimizing ward disturbances.

Clearly, the greatest problem for staff is patient non-compliance, the consequence of which is a disruption of ward activities. Personnel cope with these difficulties in a number of ways, all of which are strategies of manipulation. They may be practiced "front-stage" on the ward by nursing personnel, or "backstage" on a team basis in the context of the weekly conference.

These considerations suggest that staff share a highly complex classificatory system in the management of patients. Patients who consistently fail to adhere to the rules of the treatment and dietary regimens are labelled as "bad patients", while those who observe the rules are commonly referred to as "good" patients. This system serves as a directive for group action. More specifically, staff tend to react uniformly to patients in accordance with this classification.

CHAPTER 4

SUMMARY AND CONCLUSIONS

This thesis has attempted to analyze certain dimensions of patients' experiences in a general hospital. We have seen that patients' lives are governed by a wide range of rule specifications and regulations. Patients are required to follow strict dietary and fluid restrictions and are expected to adhere to dialysis schedules. By virtue of the long-term nature of the treatment, patients learn a great deal about the administration of dialysis procedures. They learn to identify their physiological responses to dialysis treatment. Largely through trial and error, they learn ways of violating the rules which may escape the staff's critical eye. Unfortunately, not all patients are as shrewd and clever. Many fail to comply with the rules of the treatment regimen. This has the power to influence staff behavior towards patients.

Failure on the part of patients to adhere to the rules results in a disturbance of ward activities for medical personnel. Nursing staff are forced to momentarily cease what they had been doing in favor of reinvoking the rules to patients by counselling them on the effects of over-consumption. This lenghty disruption tends to put nurses somewhat "behind schedule". In addition, the attending nurse is required to pay "special attention" to patients who have violated the dietary rules. Signs of abnormality must be watched for and dealt with immediately. Furthermore, because non-compliant patients are required to receive

ultrafiltration in addition to their regular dialysis treatment, the social order is temporarily disrupted. Because non-compliant patients monopolize beds for a longer periods of time, other patients scheduled for dialysis must wait longer before starting treatment. This means that the technicians' schedules will also be disturbed. They must wait until non-compliant patients have terminated treatment before they can prepare the machines for use by other patients. The treatment and care of dialysis patients, therefore, involves maximizing patient-compliance with the dietary and treatment regimens.

This study traces some of the manipulation strategies and tactics employed by staff in the management of patients. The staff resolve the tensions caused by non-compliance through negotiation, which may be practiced on the ward by nursing staff or in a group setting in the context of the weekly conference. Threat, persuasion, coercion, argumentation, indifference, reproof, reinforcement and approval are among the strategies used by personnel in a concerted effort to maximize patient-compliance.

RESEARCH CONTRIBUTIONS

I would now like to consider some of areas in which this study contributes to the literature of Medical Sociology.

The Social Psychology of Compliance

This study contributes to the Social Psychology of Compliance by showing how compliance is an integral part of the treatment process. In order to fulfill their role obligations as providers of "care", staff must maximize patient-compliance with the treatment regimen. The study provides empirical support for many of Strauss' theories on negotiation (1978, 1964) and Goffman's theories of "team", "impression management" and "region behavior" (1956). The hospital staff attempt to elicit patient-compliance in a variety of ways, all of which are manipulative strategies. These tactics may be practiced "front-stage" on the ward by nursing personnel, or "backstage" by the Health Care Team in the context of the weekly conference. Staff members subsequently manage their impressions according to the decisions reached through negotiative discourse. Negotiation strategies include threat, indifference, persuasion, coercion, formal reproof, redefinition, reinforcement and argumentation.

The Social Psychology of Illness and Disability

My study examines patients' experiences and perceptions, and relates them to the medical personnel who care for them. As such, it contributes to the growing number of studies on patient reactions to specific illnesses. In the literature of medical sociology, there has been a growing tendency over the last few years to investigate the nature of patients'

experiences and how they are affected by the behavioral patterns of the attending staff. J. Hoffman's work (1974) stands out as an interesting portrayal of hospital life and has suggested to me a number of fascinating comparisons. In her essay "Nothing can be done", Hoffman demonstrated that the organizational, occupational and institutional structure of a general hospital has the power to influence the treatment of patients. It was shown that medical personnel tended to foster a "nothing can be done" attitude towards patients, which was directly translated into the management of patients. Unlike the stroke patients she studied, however, ESRD patients are not merely passive recipients of care, but active participants in the treatment process. Patients are required to adhere to a wide range of dietary rules and regulations.

This study also develops Roth's discussion (1963) of inmates who face an indeterminate sentence. His analysis shows that inmates can influence their timetable through control of their behavior. This, in turn, has the power to influence staff reactions towards them. Roth argues that because the inmate's timetable can be influenced by appropriate behavior, it necessarily implies that there is substantive room for "bargaining". Ward attendants are interested in "bargaining" with inmates in an attempt to maximize compliance and, therefore, reduce their timetable.

In a similar fashion, dialysis patients have the power to influence their timetable by appropriate behavior, namely through control of their dietary habits, and staff "bargain" with patients to make them comply with the treatment and dietary regimens. This observation develops Roth's work by providing empirical support for some of this theories on "bargaining". In addition, it also extends some of Strauss' theories on negotiation (1978) by analyzing how staff "bargain" with patients in an effort to help them reduce their time-table.

The Social Organization of Treatment

The question of information control is directly applicable to my study. Research conducted by Glaser and Strauss (1965) on dying patients has shown that staff have the power to influence patients' awareness contexts. In my study, however, patients are reliable and valuable sources of information for staff. Problems of non-compliance regularly occur with which staff must contend.

The social organization of treatment is functionally adapted to soliciting information from patients. In an effort to maximize patient-compliance, staff are interested in finding out as much as possible about patients and their reasons for failing to comply. Without this kind of information, staff would be unable to fulfill their role obligations. The hospital staff negotiate (Strauss, 1978; Bucker, 1964) and

appoint members of the medical team as "Chief Inquisitors" in the hope of obtaining the needed information.

The social organization of treatment is also adapted to a classificatory or "naming" system developed by Strauss (1969). Strauss emphasizes the salience of language for human action. "Naming", as an act of placement or classification, serves as a directive for group action. My observations indicate that staff employ a highly complex typification or classification system in their evaluation of patients. To the extent that patients comply with the treatment and dietary regimens, they are classified as "good" patients and related to as such. This classificatory system, therefore, serves to direct group action. These observations further develop some of Strauss (1978) and Bucker's (1964) theories by providing empirical support for their work.

Goffman's essays on "Cooling the Mark Out" (1952) and Asylums (1961) also find empirical support in my study. In both instances, the subject, now disabled, must abandon his original self-concept. Similarly, dialysis patients must come to terms with the fact that they will never fully recover the use of their kidneys and that their lives will never be the same. Treatment requires maximizing patient-compliance with dialysis schedules, dietary regimens and restrictions on fluid intake. To achieve this end, patients must relinquish old lifestyles and adopt new ones. Experiences which may have previously confirmed a certain conception

of "Self" must be discarded in favor of new ones. Like the inmate in the "Total Institution", dialysis patients are no longer autonomous, self-sufficient individuals, but are reduced to a life of imposing limits, totally dependent on the life-sustaining machine for survival. But unlike inmates who hold onto a belief in their eventual release, dialysis patients have no such illusions. The disease literally "imprisons" patients in that it permeates their life. There is no way for hospital staff to avoid the "cooling out" process. They have no choice but to make patients fully realize the tragedy that has befallen them. As such, staff attempt to impose a "Situated Identify" on patients. "Situated Identify" refers to the stereotyped Self imputed to persons on the basis of the role they perform in any given social context. The "self" which patients are asked to adopt must be expressed in compliance with the treatment and dietary regimens.

Authority and Control

This study provides evidence for the theory that structure and control are related. Many studies find empirical support in my work. In a study of Decision-Making processes, Simon(1965) reports that the division of labor determines the amount of power that organizational members have. Their power is contingent upon the position they occupy in the hierarchical structure. Belknap (1956), McCleery(1961),

Street, Vinter and Perrow (1966) have shown that personnel with the most patient contact tend to exercise the most control over them. Smith (1965) extended the analysis and concluded that, although "organizational functionaries" or higher-level staff are responsible for making the most vital decisions to the survival of the institution, they are nonetheless unable to exercise their power. More specifically, since lower-level staff are responsible for implementing the decisions issued from higher-level staff, they exert the greatest control over patients. Similarly, in a study of five correctional institutions for delinquents, Zald's analysis (1962) discloses that personnel who perform the most crucial tasks to the survival of the institution tend to exercise the most control over inmates.

My study is concerned with the issue of authority and control and elements of all these studies are present in my data. Following the works of Belknap (1956), McCleery (1961), Street, Vinter and Perrow (1966) and Smith (1965), lower-level staff, namely nursing personnel, tend to exercise the most control over patients by virtue of the frequency of interaction. As we have seen, nurses are the most important figures in negotiating patient-compliance.

This study also supports Lief and Fox's work (1963) on "detached concern". By virtue of the long-term nature of the treatment, staff and patients tend to develop exceptionally close ties. In an effort to maintain control of patients

and to act as authoritative figures, staff tend to minimize their interactions with patients to whom they feel overly attached.

IMPLICATIONS FOR SUBSEQUENT RESEARCH

Several recommendations are possible. The problems of communication and negotiation among staff members and with patients are as multiple as they are diverse. This points to the need for continuing research in the area of Negotiation. Future research could examine staff members' biographies in order to gain a better understanding of the differences in ideological commitment.

Other recommendations are possible. We have seen that staff and patients tend to develop exceptionally close ties. A closer investigation could be made of staff-patient relationships in an effort to examine the depth of these relationships.

Earlier it was briefly mentioned that staff tend to develop an attitude of "detached concern" with patients in order to fulfill their role obligations. Staff need the cooperation of patients. They must function as authoritative figures in order to maximize patient-compliance. To achieve this end, many staff members express an attitude of "detached concern" with patients. Research has documented how "detached concern" is a coping strategy used by medical personnel (Lief & Fox, 1963). Future research could further clarify this issue by showing how such detachment is consistently maintained on the ward by medical personnel.

Other research possibilities include a study of patients on home dialysis treatment. This study examined patients' hospital experiences. One area that was left untouched is home dialysis treatment. A comparative analysis could be made to determine the differences between hospital patients' experiences and patients' experiences on home dialysis.

Another area that calls for study is the influence of the family on the patients' experiences. Further research could investigate how family members deal with chronic illness and the differences in lifestyle it entails.

In the area of patient-compliance, several recommendations are possible. A typology of staff's psychosocial and communication strategies could be developed to determine which tactics are most effective in maximizing long-term patient-compliance.

Additional research in the area of compliance could examine how staff members' beliefs about patient characteristics have the power to influence the way in which staff treat patients. These beliefs could then operate as a self-fulfilling prophecy. Research has shown that if staff expect con-compliant behavior, this attitude will influence their interactions with patients and the way in which they manage them. Patients, in turn, may attempt to meet these normative expectations (Borkman, 1976). Staff's attitudes influence patients in a circular fashion. Further research could consider the reciprocal character of staff-patient interactions.

Future research might also focus on the development of contractual agreements between staff and patients. Research conducted by Susan Boehm Steckel (1977) has shown that the use of "contingency contracting" improves patient-compliance. Based on the systematic arrangement for granting a reward in return for compliant behavior, contingency contracting has proven effective in weight reduction programs and in decreasing blood-pressure. Further research might point to the need for contingency contracting in the treatment of non-compliant dialysis patients.

Subsequent studies might focus on family interactions as possible determinants of compliance. A study conducted by Steidl et al. (1980) of dialysis patients demonstrated that positive family functioning, medical condition and patient adherence to the treatment regimen were significantly interrelated. Further analysis might evaluate the predicted value of these findings by testing them on different target populations.

Additional research in the area of compliance might determine how patients define non-compliance and whether or not deviance is intentional or not. Becker (1963) suggests that non-compliance should be approached in terms of the intentions of the actor. Further research that considers the intentions of "non-compliant" dialysis patients is necessary.

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