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Comprehensive Care:

Shaping the Moral Order in a Japanese Institute for the Treatment of Epilepsy

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July 1992

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements of the degree of Master of Arts

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SHORTENED VERSION OF THESIS TITLE:

Shaping the moral order in a Japanese epilepsy center

Abstract: This thesis is about how medical knowledge is constructed by staff for patients and their families in a Japanese 'comprehensive care' facility for the treatment of epilepsy (the JEC). The thesis sets out to explain the possible reasons for differences between the number of surgeries for epilepsy performed at the JEC and the number performed in a Canadian institute. I will argue in the thesis that the fundamental difference between the two institutes lies in cross cultural and cross institutional differences in the uses and interpretations of the polysemic phrases 'comprehensive care' and 'quality of life'. They are ideological constructs embedded in a social process of knowledge production. Uncritical acceptance of these institutional objectives has significant ideological consequences in that it (1) justifies the unequal distribution of services, (2) legitimates the treatment program's objectives, and (3) masks the social relations out of which authoritative knowledge about epilepsy at the JEC is produced.

Résumé: Cette thèse regarde la façon dont le personnel d'une institution Japonaise (le JEC) construit le savoir de l'épilepsie pour ses patients et leurs familles. La thèse tente d'expliquer les raisons pour les quelles il y a une différence entre la frequénce de la chirurgie pour l'épilepsie effectué au JEC et dans une institution Canadienne. Je vais demontrer que les différences fondamentales entre les deux institutions sont sur leurs interpretations et usages des phrases 'la qualité de vie (quality of life)' et 'le soin complet (comprehensive care)'. 'La qualité de vie' et 'le soin complet' sont des constructions idéologiques enfoncés dans un processus social de la production du savoir à le JEC. L'acceptation sans discernement des objectifs institutionnels a des conséquences ideologiques importantes parce que les objectifs institutionnels (1) justifient la distribution inégale des services medicaux; (2) légitiment les objectifs du programme de traitement; et (3) masquent les relations sociales à partir de quoi le savoir autoritaire sur l'épilepsie au JEC est représenté.

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Support for the research on which this thesis is based was provided by a Friends of McGill Fellowship, McGill University (1990-1992), a McGill Summer Bursary (1991) and a YKK Fellowship from McGill University (1991). Many thanks to Margaret Lock, Allan Young, Roger Keesing, and Richard Scott for stimulating discussions and/or careful readings of drafts of this thesis. Thanks also to Dr. Frederick Andermann and the staff and patients at the Montréal Neurological Institute. Special thanks must be reserved for Dr. Masakazu Seino, Dr. Kazuichi Yagi, and the staff and patients at the National Epilepsy Center of Japan for all that they taught me during my field work in Shizuoka.

Table of Contents

1. Introduction

1.1 Comprehensive care in the treatment of epilepsy

This thesis is about how medical knowledge is constructed by staff for patients and families in a Japanese 'comprehensive care' center for the treatment of epilepsy (the JEC).[1] My primary aim in the thesis will be to discuss the possible explanations for puzzling differences in the types of therapies practiced and number of surgeries performed at the JEC and at a Canadian institute (the MNI). The two institutes ostensibly have the same treatment goals: improving the 'quality of life' of their patients through 'comprehensive' care.

I will suggest that while there is no immediately obvious reason for the differences between the two institutes, fundamental differences in institutional objectives shape practices and knowledge at the two institutes. These differences, I will show, are based on historically and culturally distinct uses and interpretations of the polysemic phrases 'comprehensive care' and 'quality of life'. I will argue in the thesis that the knowledge and practices at the JEC are ideological constructs embedded in a social process of knowledge production.

* * *

'Comprehensive' care, an idiom used to describe the treatment program at the JEC, is also used to describe treatment programs for epilepsy worldwide. Broadly speaking, institutionalized programs for the treatment of epilepsy have shifted from primarily providing life-time *custodial* care in convalescent homes for people with epilepsy, mentally handicapped people, or people with psychiatric problems to that of providing shorter term care which has as its express purpose the *normalization* and *social reintegration* of people with epilepsy (cf. Brulleman 1972; Commission for the Control of Epilepsy and its Consequences 1978; Deboer and Donkers 1972; DeGraaf 1972; Grant 1981; Gummit 1990; International League Against Epilepsy 1937; Japan Epilepsy Association 1986; Leichtenworthel 1900; Lund 1972; Lund and Randrup 1972; Menardi 1972 of Epilepsy

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[1] The JEC is a pseudonym for the Japanese institute in which I conducted research. It will be referred to as 'the JEC' or as 'the Center' throughout this thesis.

Centers 1990, 1991; Reid 1972; Schou 1937, 1938; Seino 1974; Teglbjaerg 1939). It is this trend towards normalization in the politics of therapy for epilepsy and disability related to epilepsy, as played out at the JEC, which will concern me in this thesis.

* * *

The trend to treat patients with epilepsy under the objective of social normalization began in the 1950s with (1) the closing of a number of custodial care facilities in the United States and (2) a concomitant reshaping of epilepsy treatment programs in Europe (Grant 1981). It was fueled later (1) by international conferences of specialists in the treatment of epilepsy (cf. Proceedings of the 4th European Symposium on Epilepsy 1972) whose contributors advocated the importance of this shift in treatment goals and (2) by widely cited investigations sponsored by the governments of Britain and the United States whose investigators argued for the necessity of a shift to the goal of social reintegration (cf. Reid 1972; Commission for the Control of Epilepsy and its Consequences 1978). The internationally sanctioned shift to this broadly defined treatment goal made its way into the Japanese politics of epilepsy and disability related to epilepsy in the 1970s. In 1974, a prominent neuropsychiatrist who drew from these sources lobbied the Japanese government. He argued for the establishment of specialized facilities which would address the rehabilitative needs of people with epilepsy (Seino 1974).

Thus, by the early 1990s, treatment methods in many institutes around the world had as their main objective the social reintegration of people with epilepsy. Their programs were categorized under the overarching umbrella of 'comprehensive care'. Medical specialists generally describe 'comprehensive care' as a program designed to facilitate the aforementioned social normalization through psychological, social and medical management (otherwise known as 'medical' and 'paramedical' management) (cf. Brulleman 1972; Commission for the Control of Epilepsy and its Consequences 1978; Deboer and Donkers 1972; Degraff 1972; Grant 1981; Gummit 1990; International Bureau for Epilepsy 1972; Japan Epilepsy Association 1986; Lund 1972; Lund and Randrup 1972; Menardi 1972; National Association of Epilepsy Centers 1990, 1991; Reid 1972; Seino 1974). In academic papers and lay journals, proponents of 'comprehensive' therapy have cited high unemployment, low educational levels, economic (i.e. cost-benefit) concerns and psychological problems which lead to social disability as compelling reasons for adopting this therapeutic framework (cf. Yagi 1989, 1991a, 1991b, 1991c; Asano et al. 1986; Yagi and Ohnuma 1986; Grant 1981; Proceedings of the 4th European Symposium on Epilepsy 1972; Commission for the Control of Epilepsy and its Consequences 1978; Gummit 1990).

Programs for the treatment of epilepsy world-wide now (in 1992) bear outward similarities in their use of the rhetoric of 'comprehensive' care to describe their methods of patient management (cf. Seino 1974; Kokuritsu Ryooyooso Shizuoka Higashi Byooin 1975; Grant 1981; Gummit 1990; National Association of Epilepsy Centers 1990; Commission for the Control of Epilepsy and its Consequences 1978). However, similarities between the treatment programs stop at the level of the organizing principle of 'comprehensive' care and the abstract goal of social normalization for patients with epilepsy. Beyond the overarching framework of social reintegration through 'comprehensive' care , I suggest, are distinct assumptions about which signs are to be interpreted as symptoms in need of treatment. I contend that the disabilities that 'comprehensive' therapies have been designed to ameliorate and the form and content of the treatment programs used in particular societies and institutes are not universal and found in *nature* but are products of historically and culturally specific struggles and processes (cf. Young 1988; Comaroff and Comaroff 1991; Lock ms). Although I will concentrate primarily on a Japanese example in the thesis, I will draw briefly on examples from European and North American settings for comparative purposes.

1.2 The emergence of the problem

I first became interested in the relationships between ideology and medical knowledge and practices related to epilepsy while doing research on the institutional treatment of epilepsy in Canada in preparation for my field research in Japan. In an interview, Dr. F. Andermann, the neurologist under whom I conducted field research at the Montréal Neurological Institute (MNI) in Canada, mentioned that while approximately 100 surgeries for epilepsy were performed at his institute each year, only 12 per year had been performed at a similar institute in Japan in the mid-1980s. He reported that he could not explain the differences between the practices at the institutes as being technological, for Japanese physicians had access to the same technologies (and more) than their Canadian counterparts.

Further investigation revealed to me that only 50-60 surgeries were performed in all of Japan each year in the 1980s, fewer than were performed at the single center in Canada in which I was conducting field research. Moreover, I found that although the MNI was perhaps one of the better known centers for the surgical treatment of epilepsy in North America, the number of surgeries for epilepsy which were performed at the institute was not exceptionally high (for the level of specialization of the institute). Surgeons at other North American centers performed approximately the same number of surgeries as were performed at the MNI.[2]

Only when I had been conducting field research for a few months at the MNI, however, did I realize the significance of Dr. Andermann's observation. The MNI was a hospital for the treatment of neurological disorders in which only 15 beds were devoted to the 'seizure service' (epilepsy service). It was not a center devoted expressly for the treatment of problems related to epilepsy. Nonetheless, 100 patients received epilepsy surgery at the MNI each year. Most patients who were admitted to the MNI had been examined by their local physicians and referred to the hospital's physicians as being possible surgical cases. In addition, before admission, many of the MNI's patients had either been screened for surgery by neurologists who staffed the MNI or were in the process of being screened for surgery during their stay. It seemed, from my observations, that the MNI effectively operated as a surgical center for most of its in-patients with epilepsy (with the exception of the patients admitted with status epilepticus and other emergency problems). What I had assumed, before

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[2] Surgery for epilepsy has become an increasingly popular intervention since the 1980s. Although the MNI is world renowned for surgical treatment, the number of surgeries for epilepsy performed at the institute is comparable to other institutes in North America and Europe. According to the plan for the National Association for Epilepsy Centers, for example, the fourth level treatment center is described as a *surgery center* (National Association of Epilepsy Centers 1990, 1991). Several centers in the United States function at this level.

conducting field research, was a dramatic procedure performed only on people with extremely severe cases of epilepsy seemed common, almost mundane at the MNI.

The staff of the MNI held weekly 'seizure seminars' which the center's specialists attended. During the seminars, psychologists, EEG specialists, residents, neurologists, neurosurgeons, and psychiatrists presented analyses of admitted patients and discussed particular patients' suitability to receive surgical treatment. Patients and their families were brought into the seminar room and interviewed in front of the people attending the seminars. They were asked to describe seizure events in detail and answered questions posed to them by the audience, questions which were usually about particular aspects of their seizure episodes.

Patients did not generally stay in the hospital for extremely long periods of time (over 3-4 months) (those who received surgery were discharged 10 days after surgery). During the day, when they were not receiving individual counseling or medical tests, the MNI's patients were free to do as they pleased and spent their time reading, knitting, or conversing with staff, other patients, or people who had come to visit them.

In other interviews and conversations, Dr. Andermann expanded on his confusion about the low number of surgeries performed in Japan. He asserted that the Montreal Neurological Institute's policy to treat patients with epilepsy with surgery regardless of age, occupation, or gender seemed reasonable, He stressed the importance of medical intervention for the control of seizures in-patients with epilepsy.

This importance of this goal -- seizure control through epilepsy surgery -- at the MNI became even more apparent after I observed more 'seizure seminars' and rounds at the hospital and read papers about surgery for epilepsy written by MNI staff members. I learned that patients with a great variety of backgrounds and personalities were admitted to the hospital for surgery: included among the surgical candidates at the MNI were well-educated adults who were employed, children, and people who were considered 'slow' (i.e. they had made low scores on the IQ tests given to them by the hospital's neuropsychologists). Discussions during seizure seminars centered mainly on gaining consensus from the various medical specialists on the localization of seizure onset. 'Risky' candidates were those in whom a single defined seizure origin could not be easily found. At the MNI, ideal surgical candidates appeared to be those in whom physicians could easily find the onset of seizures.

Furthermore, in papers by MNI staff members, the success of surgery was described in terms of the degree of seizure control attained after surgery. In these papers, emphasis was placed on the importance of improving the 'quality of life' of individuals through seizure control (cf. Andermann 1977, 1991; McNaughton and Rasmussen 1975). In a 1991 review of criteria for patient selection for epilepsy surgery at the MNI, for example, Andermann argues that patients with mental retardation, psychosis and other personality problems are all eligible for surgery, since seizure control which might result from performing surgery may improve patient (and family) 'quality of life' (Andermann 1991: 31). He supports this proposition with results from papers which relate seizure control to the improved 'quality of life' of individual patients, children and the improvement of psychiatric symptoms in individual patients (cf. Andermann 1977; Falconer 1972; Rasmussen 1980; McNaughton and Rasmussen 1975; Savard et al. 1985; Jensen and Larsen 1979).

Andermann also stresses in his article the relationship of individual goals to social rehabilitation and social disability. He writes, "Some seizures are more socially disabling than others. The person's aspirations and expectations, intelligence, motivation, occupation and environment must be considered in addition to the seizure pattern and frequency" (Andermann 1991: 21).

According to Andermann's paper (1991), other papers by MNI staff members, and my observations at the MNI, ideal surgical candidates therefore appeared to be people whose seizures would probably be controlled by surgery. In other scientific papers I read, interpretations of the efficacy of surgery were based on how much seizure frequency was reduced after surgery (cf. Rasmusssen 1983). In addition, my observations suggested to me that at the MNI, surgery was perceived as an important means by which individual lives would improve, since seizure control would help people reach personal goals (Andermann 1991: cf. also Rasmussen 1983). This implied a goal of controlling seizures which would ultimately lead to (1) the improvement of individual lives and (2) the fulfillment of individual goals and aspirations.

Hence, after preliminary observations at the MNI, discussions with patients and staff, and a brief examination of papers written by the staff of the Montreal Neurological Institute, I was left with the impression that the improvement of the individual lives of patients with epilepsy through seizure control was the MNI's main treatment goal. Surgery, being an option which had brought about successful control of otherwise intractable seizures, was an intervention which was often performed and recommended by the hospital's staff.

Armed with these impressions about the institutional treatment of epilepsy (highly interventionist, surgically oriented techniques with the primary aim of seizure control set in an acute care, university affiliated hospital), I left for my field work in Japan at the JEC, with the puzzle about the differences in rates of surgery unsolved. Given that (1) diagnostic technologies and classification schemata for epilepsy had been internationally standardized in the 1960s (cf. ILAE 1964, 1969, 1970, 1981, 1985, 1989; Gastaut 1969; Dreifuss 1990)[3] -- physicians world wide participated in international conferences and contributed papers to journals discussing the biological phenomenon, epilepsy; and (2) no *significant* epidemiological differences in the rate of occurrence of epilepsy in Japan and North America had been documented (JEA 1986),[4] it would seem to have followed intuitively that all

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[3] The World Health Organization organized the first international classification of epileptic seizures and of epilepsy in 1969 (Gastaut 1972; ILAE 1964, 1969, 1971). This classification remained the same until 1981, when a new international classification for epileptic seizures was proposed (ILAE 1985). In 1985, a new international classification scheme which has gained some international acceptance for the *epilepsies and epileptic syndromes* was introduced. It was revised in 1989 (ILAE 1985, 1989; Dreifuss 1990).

The director of the JEC now serves on international committees which produce classification criteria for epileptic seizures and syndromes. In addition, at the JEC, all staff physicians are given a handbook describing the epileptic syndromes. The handbook is used as a reference for making diagnoses -- it is a direct translation of the international criteria published by the ILAE (Kokuritsu Ryooyooso Shizuoka Higashi Byooin 1990; ILAE 1989).

[4] Epidemiological research on the incidence of epilepsy has been riddled with methodological problems. A discrepancy between the incidence of epilepsy in North America and Japan *has* been reported in the past, but some of the differences have been described the artifact of particular methodologies. Epidemiological studies from the 1960's and 1970's, for example,

institutes in technologically equipped countries world-wide would provide the same biomedical interventions with approximately the same frequency. This, however, was not the case in the treatment of epilepsy in Japan and North America. Each year, surgeons at a single institute in a country with a population of 24 million (Canada) performed almost twice the number of surgeries performed in all of Japan, a country of 120 million people.

Moreover, the differences between the Japanese and Canadian institutes could not be attributed to crude economic interest in either setting. Physicians in the Japanese and North American contexts I was studying were salaried employees, and the frequency with which surgery was performed therefore did not effect their salaries directly.

I was not able to solve the puzzle about the differences in the numbers of surgeries performed in the two institutes immediately upon my arrival in Japan. However, I gained insight into the possible reasons for the differences between the two centers after (1) careful examination of some papers written by the JEC's staff and (2) a brief examination of the historical circumstances surrounding epilepsy surgery in Japan and at the MNI. I searched for and found papers in a Kyoto medical library which might clarify which forms of intervention for the treatment of epilepsy were practiced (and therefore considered significant) at the JEC and how their use was justified.

A number of articles written by staff at the JEC were particularly illuminating in this regard. Rather than concentrating on seizure control (which would then result the improvement of the 'quality of life' of individuals) as the single goal of medical intervention, as the staff at the MNI seemed to, the authors of many of the papers I read discussed social rehabilitation under a 'comprehensive care' plan. They described seizure control and social

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reported rates of 1.0-1.4/1000 in the general population of Japan. Other studies have reported the ratio to be 3.8/1000 in North America and Europe. Other rates of occurrence in various populations which are frequently cited are 1.7/1000, 3.5/1000, and 4.8/1000 (Livingston 1954; Shin-chuo et al. 1985; Hauser 1978 -- cited in Tsuboi 1988). In a 1988 paper, Tsuboi suggests that some of the variation from study to study is an artifact of differences in the methods by which epilepsy is defined and identified in each of the studies. He goes on to suggest that, according to his study, the prevalence of epilepsy in Japan ranges from 1-11/1000 (Tsuboi 1988). Because of differences in methodology from study to study, one can only suggest that though variations in the prevalence of epilepsy in Japan and North America may exist, *significant* variations probably do not exist.

rehabilitation as necessary and interdependent therapeutic goals in the treatment of epilepsy. Staff members at the JEC, like those at the MNI, wrote about improving 'quality of life'. Yet their descriptions of 'quality of life', rather than concentrating strictly on the improvement of individual lives through seizure control (as at the MNI), primarily stressed the goal of social rehabilitation through behavioral reform (cf. Yagi 1989, 1991a, 1991b, 1991d; Yagi and Ishida 1991; Yagi and Ohnuma 1986; Yagi and Seino 1990; Asano et al. 1986; Mihara 1989, 1990, 1991; Mihara et al. 1990; Mihara et al. 1985; Mihara et al. 1989).

The 'comprehensive care' program at the JEC, it appeared from these articles, was a special social rehabilitation program whose ultimate goal was the improvement of the *quality of life* of people with epilepsy. According to the articles, social rehabilitation entailed increasing a person's ability to contribute to society. Some authors made specific statements about which behaviors were seen as particularly important for social rehabilitation. They argued that although seizures did effect social disability, they were only one of many factors which influenced high unemployment among people with epilepsy (cf. Yagi 1991a). The authors described various personality problems such has poor 'interpersonal relations' and excessive aggression and dependence as other factors which led to 'poor social status' (i.e. lack of employment) (Asano et al. 1986).

Similarly, with respect to surgery, the authors of one paper described the goals of surgical intervention not simply in terms of seizure control, but rather in terms social rehabilitation (i.e. eventual ability to contribute to the work force) (Mihara et al. 1990). The authors of the article reported that their patients were selected very carefully using strict criteria devised following the 'comprehensive care' plan. They had performed a limited number of surgeries (appx. 60 over a 5 year period) on a select group of candidates. The selection criteria espoused the ultimate goal of social rehabilitation in the selected surgical candidates. Two-thirds of the recipients of surgery were well-educated males with fairly good employment prospects.

In addition, further investigation and discussions with the staff of the JEC revealed historical reasons for the low number of epilepsy surgeries performed at the JEC. The JEC's director said that in 1975, lay interest groups who were lobbying against psycho-surgery forced all Japanese neurosurgeons who were trained to perform epilepsy surgery to sign an agreement to stop.[5] Neurosurgery for epilepsy was not re-instituted in Japan until 1983.[6] Those patients on whom surgeries *have* been performed since 1983 are selected using strict criteria. The number of surgeries performed has been limited by the staff at the

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[5] In the 1970s, Japanese neurosurgeons who specialized in surgery for epilepsy were identified as performing psycho-surgery because in Japan, epilepsy was treated by neuro-psychiatrists (psychiatrists with special training in neurology). In addition, some of the surgical treatment of epilepsy which was performed in the 1960s and 1970s had as a main goal the amelioration of behavioral problems (cf. Sano 1960; Narabayashi 1976).

Furthermore, according to staff members at the JEC, though staff are quick to categorize epilepsy as a neurological disorder, its categorization as a neurological and not mental (psychiatric) problem is not so clear among lay people. One indicator of this is that since 1976 the Japanese lay organization sponsored a campaign against popular sentiment that epilepsy is a psychiatric illness ('Epilepsy is not a psychiatric illness' campaign) (Seino, personal communication).

The unclear boundaries between epilepsy as neurological or psychiatric disorder in public sentiment, no doubt, had some influence on the call for neurosurgeons to cease performing surgery for epilepsy. In 1991, neuropsychiatrists at the JEC were very sensitive about this issue and were quick to point out that epilepsy was a *neurological* disorder if mention of these unclear boundaries was made.

[6] The JEC was not alone in beginning to perform epilepsy surgery in the 1980s. There has been major growth world-wide in interest in surgery for epilepsy since the beginning of the 1980s. For example, the number of surgeries performed in centers in North America has increased 10 fold in the past 10 years (Mihara, personal communication). In addition, since the 1980s, there has been a flood of publications, lay and academic, concerning surgery for epilepsy (cf. Spenser and Spenser 1991; Lumina 1991; Nami 1991; Elger 1991).

For an European example, surgery for epilepsy has been performed with increasing frequency in Germany recently. Surgeons perform approximately 200 surgeries there each year. A number of surgery programs were started there in the late 1980s. These programs will soon reach capacities of 80-100 cases/year.

This dramatic increase in surgery in Germany is attributed to an increase in the number of surgeries performed in North America which resulted in an urgent call for surgical centers in Germany by the Minister of Social Affairs. These centers have been structured as surgical centers and were set up in close collaboration with North American clinics -- one was set up following the example of the MNI, while another was set up in close collaboration with the Cleveland Clinic Foundation in Ohio. An increase to 350 surgeries/year in Germany is predicted for 1993-4.

One report attributes the relatively low number of surgeries in Germany in the past to (1) the treatment of epilepsy by neurosurgeons alone rather than neurosurgeons in cooperation with neurologists, electrophysiologist and epileptologists (the conditions under which surgery is performed today) and (2) a low success rate (Elger 1991).

treatment centers in which they are offered (Seino, personal communication; Seino and Mihara 1991).[7]

By contrast, epilepsy was treated by neurologists in North America. As a result, interest groups who lobbied against psycho-surgery in North America in the 1970s did not pressure neurosurgeons who performed surgery for epilepsy to stop. Thus, because North American surgeons of epilepsy, unlike the Japanese neurosurgeons, did *not* agree to quit performing surgery in the 1970s, the number of epilepsy surgeries performed in North America in the 1970s did not drop dramatically to zero, as it did in Japan.[8]

Other historical reasons for the differences between the MNI and the JEC became apparent to me after an examination of the MNI's history. Unlike the JEC, the MNI's seizure service had functioned as a surgery center for epilepsy since it opened. Wilder Penfield, a man who is regarded as one of the pioneers of neurosurgery, was affiliated with the institution from the time that it opened in 1936. He performed his first temporal lobe surgery in 1928 (Rasmussen 1983). The center itself serves as an important training ground for the

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[7] Before the 1970s, most surgery for epilepsy was performed at university medical centers. In describing the history of surgery for epilepsy in Japan, Seino and Mihara specify that most surgery is now performed at "comprehensive" care centers (rather than university hospitals) and are integrated into the comprehensive treatment programs. The authors of the article are careful in specifying the care which is now taken in choosing the patients on whom the intervention is performed and in integrating the surgery into the treatment programs (Seino and Mihara 1991).

[8] While some of the neurosurgeons and staff members at the MNI are very well-informed about the popular struggles against psycho-surgery, surgery for epilepsy was not, in North America, categorized with psycho-surgery. Andermann (personal communication) is quick to distinguish surgery for epilepsy from psycho-surgery, emphasizing the neurological and physiological aspects of surgery. Surgeons at the MNI, too, are quick to distinguish the treatment of epilepsy as that for a *neurological* not *psychiatric* problem.

Furthermore, in contemporary Japan, unlike some of their predecessors who attempted to use surgery for epilepsy to relieve behavioral problems (i.e. aggression et al.), the new generation of neurosurgeons in Japan, many of whom were trained in North America rather than Europe, perform surgery with an express goal of controlling the physiological manifestations called seizures. Those surgeons with whom I spoke emphasize this point and stress that they do *not* use surgery as a form of behavioral control and were not trained to do so. The Japanese neuro-psychiatrists with whom I spoke were also quick to isolate the biological phenomenon of epilepsy from other "mental health" problems *(seishin byoo)*, emphasizing that their interpretation of epilepsy was drawn from the discipline of *neurology* and not psychiatry.

surgical treatment of epilepsy, and between 1936 and 1980, 1210 patients received surgery for temporal lobe epilepsy at the MNI.[9]

Were these the reasons for the comparatively low number of surgeries performed at the Japanese institute? The historical agreement by Japanese neurosurgeons to stop performing epilepsy surgery and the historical association of the MNI with new technologies related to surgery for epilepsy partially explained this paradox. Moreover, though social rehabilitation through 'comprehensive care' as a primary goal did not explain differences in the numbers of surgeries performed in the Japanese and Canadian institutes, it did suggest to me that differences between the institutes were deeper than simple technical differences.[10] It suggested that differences between the JEC and the MNI might be related to the *goals* of medical intervention at each of the settings. The differences between the institutes' goals appeared to result in distinct rules. The rules justified a particular distribution of medical services and choice of therapeutic methods at the JEC and another set of strategies at the MNI.

This was simply an impression gleaned from observations at the MNI, my review of papers written by staff of the JEC and a brief review of the histories of the institutes. Only when I arrived at the JEC, had gone on a tour of its facilities, and had spoken with its staff did I realize the significance and the depth of the differences between treatment strategies at the two locations.

My initial tour of the JEC consisted not only of visits to the center's out-patient clinic and epilepsy and 'disabled children's' in-patient wards, but also of a visit to its classroom facilities and its occupational and recreational therapy building. In contrast to the Canadian

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[9] While it appears that the MNI represents a very special case with respect to numbers of operations performed, only in the past was the volume of surgeries performed at the MNI extraordinary. In recent years, surgery for epilepsy has become increasingly popular, and a number of centers around the world now provide the same volume of surgeries for epilepsy as the MNI. See footnote 6 above for a more detailed description of changes in the volume of surgery for epilepsy performed around the world.

[10] In other words, there are few trained professionals and training programs for neurosurgery for epilepsy in Japan.

center, the staff of this hospital treated only people with epilepsy.[11] The JEC had 200 beds for patients with epilepsy (100 children's beds and 100 adults' beds), as opposed to the 15 allotted to the seizure service at the MNI.

It appeared, from my observations, that what was being taken as *disability* at the MNI and at the JEC differed significantly. At the MNI, *disability* related to epilepsy seemed to be associated largely with seizures and physiological function. However, at the JEC, it appeared that staff associated the *disability* they were treating with both the *physiological* problem of having seizures *and* behavioral problems. The therapies at the JEC targeted behavioral and personality problems. The staff of the JEC said that these problems influenced social well-being and social functioning[12]

I learned in my first few days that daily life for patients at the JEC did not simply consist of individual counseling, testing and therapy sessions interspersed with free time to read, write letters, watch television, and socialize with staff, other patients, visitors and family as daily life for patients did at the MNI. Life at the JEC consisted of a daily schedule of activities which began at 6 am and ended at 9 pm daily. All of the JEC's adult patients walked about freely. They were required to participate in organized athletic and occupational therapy activities and to manage and clean the hospital ward in which they lived. Hence, daily life, treatment goals, *and* the treatment interventions chosen at the Japanese and Canadian institutes differed significantly.

Cross-cultural and cross-institutional differences in treatment strategies, such as those described above, are commonly acknowledged by anthropologists and physicians alike

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[11] At the Montreal Neurological Institute, only one neurologist treated patients with epilepsy, and its out-patient epilepsy clinic was held only two days a week. By contrast, at the JEC, 5 physicians who treated over 130 patients with epilepsy each week staffed the out-patient clinic.

[12] This is not to say that a black-white distinction between the institutes exists. For example, at the MNI, it was recognized that there were major social and social-psychological problems associated with having epilepsy. However, the institute's goals were limited to physiological therapies and social and psycho-social problems were not dealt with except in special cases. At the MNI, there were no therapies integrated into daily life to treat psycho-social disabilities.

(cf. Young 1982; Littlewood 1990; Seino, personal communication; Andermann, personal communication). More interesting is the second observation which led to my interest in the relationships between ideology and medical practices and knowledge at the JEC. I found, after further research, that the terms which were used to describe the JEC's treatment program (i.e. 'comprehensive care' and 'quality of life') were terms used internationally to describe programs for the treatment of epilepsy. 'Comprehensive' care was a term used by specialists in the treatment of epilepsy world-wide, and had been in use in Europe since the late 1960's (cf. Brulleman 1972; Lund 1972; de Boer and Donkers 1972; Lund and Randrup 1972).

During my field research, I learned that the staff of the JEC did not write and speak about the JEC's treatment program as being inspired by indigenous methods. Instead, they described the inspiration for the program as being centers in the United States and Europe. For example, in papers, staff constantly referred to the 'Comprehensive Epilepsy Program' and 'National Association of Epilepsy Centers' (NAEC), two American programs (cf. Yagi 1991c; Wada 1981). The guidelines drafted under the American plans for 'comprehensive' treatment, however, describe 'comprehensive care' for people with epilepsy as consisting of high-tech, highly interventionist methods. Under the NAEC guidelines for epilepsy centers, the fourth level of care is a 'surgery center', the description of which shows similarities to what I had learned about the MNI's institutional goals and plan (NAEC 1990, 1991).

In addition, the JEC's staff described their center as being modeled after European centers for the treatment of epilepsy. The authors of scientific papers have described most of these epilepsy centers as being essentially rehabilitation/medical treatment centers for people with epilepsy (cf. Proceedings of the 4th European Symposium on Epilepsy 1972). In one discussion, for example, the JEC's director told me that impressions from a tour he took in the early 1970s of European epilepsy treatment centers inspired the JEC's treatment framework. He wrote in a paper that while Europe had a 100-year history of the institutional treatment of epilepsy, Japan had yet to offer a single institutionalized treatment program for people with epilepsy. With this comment, he suggested that the treatment of epilepsy in

Japan was not as advanced as that in Europe, i.e. that people with epilepsy in Japan were not receiving the treatment and attention (1) that they deserved and (2) that people with epilepsy in Europe were receiving (Seino 1974).

I compared the treatment programs at the JEC with those in Europe. All of the terminology staff at the JEC used to describe its rehabilitation facilities and plans (day-care, occupational and recreational therapy, etc.) appeared to be direct translations of terms used in institutes in Switzerland, Norway, Sweden, the Netherlands and Denmark (cf. Proceedings of the 4th European Symposium on Epilepsy 1972). Photographs of activities at a European center and drawings by children who were patients at that center decorated the waiting room of the JEC's out-patient clinic during the summer of 1991. Despite the similarities between the JEC and centers in other countries and conscious efforts to emphasize these similarities, however, close examination of descriptions of the European institutes also showed differences between their treatment objectives and those of the JEC (cf. Proceedings of the 4th European Symposium on Epilepsy 1972).

'Comprehensive' care therefore appeared to be an idiom used around the world by a wide range of medical (and 'paramedical') specialists. It appeared, from my readings of scientific articles, that this type of care was supposed to bring about the rehabilitation of people with epilepsy. Consequently, the 'quality of life' of people with epilepsy was supposed to improve. Yet, the way in which 'comprehensive' care was implemented by medical professionals varied from society to society. 'Comprehensive' care ranged from highly interventionist, surgically oriented methods (primarily to bring about seizure control) in North America to the use of behavior modification methods to bring about *social rehabilitation* in the Japanese context. Though different standards held in each of these contexts, the therapies were described by staff in both settings as oriented towards improving the 'quality of life' of individuals with epilepsy.

A third group of observations led to my interests in the ideological nature of medical knowledge and practices at the JEC and the ways in which they maintained their authority. As I spent more time at the JEC, I noticed differences between the accounts staff and patients gave of hospitalization and its effects. While these differences also existed at the MNI, the remainder of the thesis will be devoted to an analysis of the JEC. I will therefore concentrate strictly my observations of incidents at the JEC in this section.[13]

First, what staff of the JEC described as the treatment program's ultimate goals often differed significantly from what patients described as wanting from treatment at the JEC. In discussions and conversations, most staff members spoke in abstract terms about the program's goals. They said that they were treating patients with comprehensive care so that they would rehabilitate and participate fully in society. They did *not* speak in terms of being able to cure the biological phenomenon of epilepsy.[14]

On the other hand, patients rarely spoke in these theoretical terms about rehabilitation, and most patients who were admitted to the JEC expressed hopes that their epilepsy would be *cured*. They said that having epilepsy prevented them from being independent, being able to drive, being able to marry, and having interesting jobs. Very few patients, if any, expressed any interest in social rehabilitation.

Second, not only were there obvious discrepancies between what staff and patients said they expected from the center's treatment program, but what became apparent during my field research was that the program might not be accomplishing what it claimed to be

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[13] The problems described in this section are not uniquely Japanese problems. The observations I describe in this section, however, emerged during my field research at the JEC.

[14] From my limited observations at the MNI, I believe that at the MNI there were also differences between what patients and physicians described their goals. One young woman with whom I spoke, for example, had particularly severe problems with her memory, which she described as resulting from her problems with epilepsy. The results she said she hoped her surgery would produce was an improvement in her *memory*. (I found later that many patients who took the medication she was taking experienced memory problems as a side-effect.) Her physician, on the other hand, said that her memory would not improve after surgery, and in fact, that her memory might worsen rather than improve after surgery. However, he thought her seizures would be well controlled through surgery. Though both parties made their hopes clear to one another, the young woman received surgery.

accomplishing with its therapies[15] It was not clear to me whether the changes produced in the context of the JEC actually helped unemployed people find employment. Moreover, the behavioral changes which patients seemed to undergo while at the JEC seemed to me simply to be products of the institutional environment and therefore only temporary.

This paradox became apparent to me after I had performed my field work for a short while in an adult ward of the JEC. Almost half of the patients who visited the out-patient clinic were under 15 years of age (Kokuritsu Ryooyooso Shizuoka Higashi Byooin 1988), and the number of hospital beds were divided evenly between adult and children's beds. However, adults generally had to wait much longer than children for admission to the JEC. Adults waited for approximately six months for a hospital bed, while children waited only 1 month. I learned during my stay that one reason that adults waited to be admitted so much longer than children was that once *in* the hospital, adults stayed for much longer than children. They stayed between 3 months and 2 years. Children stayed for 1 to 6 months. Furthermore, I learned that *despite* full seizure control, many adult patients were *readmitted* for 'psychiatric' or other reasons on their own accord (or by family members) after they were discharged. Other patients who were hospitalized refused to be discharged despite nearly complete seizure control.[16]

Staff reported that they were aware of problems with the program, and some even emphasized in discussions that many patients who appear to improve while hospitalized

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[15] With respect to the MNI, as seizure frequency was considered its primary goal, the success of the program was measured according to the degree of seizure control attained. While staff described the purpose of surgery in papers as being the improvement of 'quality of life' through seizure control, they only spoke of it abstractly. They equated it with greater seizure control. Patients' subjective interpretations of 'quality of life' were not included in these evaluations and it was not always apparent that the 'quality of life' of particular individuals had subjectively improved. One woman, for example, had returned to the MNI after having overdosed on her anti-epileptic medication. She had received surgery two years previous to the overdose and her seizures were subsequently fully controlled. However, after receiving surgery, her life did not necessarily improve. She quit her job, began living on disability checks and was living alone. (Her son rarely visited her.) She refused to leave the hospital during the period when I was conducting my research.

[16] This was true of patients at both the MNI and the JEC. Physicians are aware that many patients refuse to be discharged from hospitals in both Japan and Canada. It is viewed as a prevalent problem in Japanese psychiatric institutions and has been classified and given two names (hospitalism and institutionalism) in Kondansha's Comprehensive Dictionary of Psychiatry (1984) (Kondansha 1984; Seino, personal communication).

revert to their pre-admission habits after returning home. They also suggested that adults who were admitted probably represented a group who had suffered from the symptoms of epilepsy (seizures) much longer than children who were admitted. According to staff accounts, the reason that adults stayed in the hospital longer than children was that they had psychological and social problems more serious than the ones children had. Staff also said that adult in-patients had types of seizures which were probably more resistant to pharmaceutical intervention than children.

In other discussions, staff members noted that, unlike children in-patients, who attended school and therefore had something to do *in society*, adults who were admitted generally did not have a stable position in society (i.e. work). They said that adults therefore had less incentive to leave the hospital. In addition, they noted that physicians were more willing to devote more in-hospital time to attempting to produce seizure control in adults than in children. The physicians maintained that finding work while one had uncontrolled seizures was more difficult than staying in school with uncontrolled seizures.

Staff members told me that another complicating factor for many adult patients was that families often put pressure on the hospital's physicians to provide complete seizure control (almost impossible for some patients) before discharge. This demand often resulted in extremely long hospital stays for some adult patients.

Patients also expressed an awareness that they did not necessarily leave the program with the prospect of having improved lives. Many patients who had had the diagnosis of epilepsy for a long while and had been admitted to the JEC many times said that they did not expect the program to change their lives. They also said that upon returning home, they would be surrounded by the same environments and have the same problems that they had previous to admission.

Despite the differences between the patient and staff accounts described above *and* awareness among staff and patients of the hospital's problems, the center continued to run smoothly and *flourished*. In 1991, the list of adults waiting to be admitted into the hospital numbered over 40 patients at all times.[17] One hospital administrator and one physician said in discussions that despite the long wait for admission to the adult wards, most patients were willing to wait to be admitted.[18] The out-patient clinic was extremely busy, so busy that patients had to schedule appointments with out-patient physicians far in advance.

To sum up, the reasons for my interest in the ideological bases of medical knowledge and practices and the ways in which the authority of that medical knowledge is maintained were three fold. First, I was struck by differences in the biomedical interventions for epilepsy used in the Japanese and Canadian institutions in which I chose to do field research. Second, though the institutional framework of the two treatment programs was defined in both societies as 'comprehensive' and as leading to the improvement of *quality of life*, the therapies which staff used to improve *quality of life* were distinct at the two institutes. At the Canadian institute, 'comprehensive care' which staff used to improve *quality of life* indicated high priced (although covered by the health insurance system),[19] high-tech, surgically oriented methods which would ameliorate the physical symptoms associated with epilepsy quickly. On the other hand, in the Japanese institute, it indicated longer hospital stays in a rehabilitation and activity-oriented center. The staff's stated objectives at the Japanese institute were to prepare people with epilepsy for participation in society.

I found that the differences in treatment options chosen in the two contexts could be explained in part historically. In Japan, for example, the treatment of epilepsy was associated with neuropsychiatry, an association which led lay interest groups to pressure Japanese neurosurgeons to stop performing surgery for epilepsy in the mid-1970s. On the other hand, in North America, epilepsy was associated largely with neurology. Lay groups in North

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[17] Approximately 10 children were usually on the waiting list.

[18] In other words, patients were willing to wait and *wanted* to be admitted into the center despite awareness that there was very little evidence that the center did, indeed, help ameliorate their symptoms or problems.

[19] Surgery for epilepsy is covered by provincial Medicare in Canada. In Ontario, costs to the province for patients who receive surgery have been estimated as being approximately $1400/day (Canadian). Most surgical patients are hospitalized for 20-30 days (Lumina 1991).

America did not force neurosurgeons who were trained to perform surgery for epilepsy to stop.

Finally, not only were there differences in the interpretations of suitable treatment methods for epilepsy in the two locations, but in the example which I discuss in the remainder of the thesis, the JEC, (1) the institutional goals differed from what patients said they expected from the treatment program; (2) the efficacy of the program was dubious, i.e. the treatment program did not appear to me, to staff, or to patients to be accomplishing what institutional descriptions of its activities said it was; and (3) patients and staff were aware that the program did not produce the results that 'comprehensive care' should have. Despite awareness of these contradictions, the program continued to function and flourished.

1.2 Medical knowledge, ideology and resistance

After a selective review of the literature on the comprehensive management of people with epilepsy, a review of anthropological literature on Japan, extensive observations, interviews, and casual conversations with staff and patients at the JEC, I have concluded that the types of medical intervention and treatment programs offered at the JEC were not arbitrarily chosen, but are ideological. They are ideological for these reasons: (1) They naturalize particular knowledge about epilepsy and disability related to epilepsy while subverting or devaluing other ideas. (2) In naturalizing this knowledge, they convince people to act in ways which they may not have otherwise chosen. (3) Finally, they serve specific interests, interests which are identified by the hospital's directors and staff (cf. Young 1988:14).

While the knowledge at the JEC is *ideological* in the sense described above, patients and staff at the JEC are aware of the contradictions inherent in the institution's therapeutic program. How, then, does this ideological knowledge maintain its authority? Many recent social theorists have attempted to explain how particular knowledge maintains authority despite the existence of social contradictions.[20] It became apparent to me when I was

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[20] A few examples of work which has addressed this issue are: Comaroff and Comaroff (1991), Willis (1977), Abercrombie et al. (1980), Williams (1977), and Scott (1985, 1990).

conducting my field research in Japan that the maintenance of the authority of ideological knowledge at the JEC did not depend on *ideological incorporation*, as some might argue (cf. Comaroff and Comaroff 1991). Moreover, patients and staff did not appear to comply with the JEC's treatment program simply out of necessity. They did not seem to express their opposition to authority by producing 'hidden' transcripts of official events, as others might argue (cf. Scott 1985; 1990, esp. pp. 90-107).

Both of the viewpoints mentioned above rely on a fundamental assumption that the authority of ideological knowledge is maintained, for the most part, through individual consent. They account for the continuation of oppressive practices via individual acceptance or rejection of the practices, or through the *consciousness* of individuals. In the former case, belief in a system will allow for its continuation, and critical consciousness of contradictions in the system will galvanize people into political action (cf. Comaroff and Comaroff 1991:24).[21] In the latter case, individuals who are aware of contradictions inherent in a particular system will not publicly oppose particular oppressive practices. Instead, they will subvert or reinterpret oppressive practices *unofficially*. Thus, in the latter case, individuals *consciously* allow ideological practices to maintain their dominance (cf. Scott 1985, 1990).

While the accounts described above are useful, my observations suggest that the maintenance of the authority of ideological knowledge at the JEC relies more heavily on *social processes* and a particular division of labor between staff and patients than on the conscious acceptance or rejection of that knowledge by patients or staff. Based on my observations and discussions with patients and staff at the JEC, I have concluded that the social order and, thus, the authority of ideological knowledge at the JEC are maintained largely through (1) a social process of knowledge production embedded in the daily life of the

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[21] The Comaroffs use the model of a *chain of consciousness* to describe changes in critical awareness which will lead either to a rise to political action or inaction. It seems that their understanding of the maintenance of conditions of inequality relies most heavily on an individual's (or a group's) complete acceptance of these conditions. They do not discuss factors outside of the individual consciousness which may prevent political action (Comaroff and Comaroff 1991).

institute (Young 1980, 1988, 1990) and (2) particular social processes which are used in many Japanese institutions to preserve social order (Rohlen 1989; Peak 1987).

The knowledge production process at the JEC resembles a labor process whose main product is medical knowledge. In the knowledge production process, the definition and interpretation of bodily processes rests on a strict division of labor between professionals and patients. First, medical professionals appropriate and interpret bodily knowledge about patients (self knowledge and other physiological signs). They then re-appropriate and inscribe the knowledge in official documents. Finally, they appropriate and reinterpret the knowledge once again for publication in scientific papers (Young 1980:138-140; 1988:10-12). The process of knowledge production does not always move in the direction described above, and each of the levels in the knowledge production process is mutually interdependent. Nonetheless, the authority of institutional knowledge and practices is usually maintained in this process.

While the social process of knowledge production provides a sound explanation of the maintenance of ideological knowledge in general, it does not provide an explanation for the particularities of the case of the JEC. Recent ethnographic studies on Japanese social institutions reveal historically and culturally specific ways in which social order and authority are maintained in Japan (Rohlen 1989; Peak 1989). In one paper, Rohlen argues that order in Japanese social institutions rests not on direct control or coercion, but on decentralized authority. This operates in direct interdependence with the social relations encouraged by a type of moral education found in all facets of Japanese public life: learning the behaviors and practices fitting of 'life in a group' -- *shuudanseikatsu*. The qualities which are deemed necessary for *shuudanseikatsu* are: humility, eager participation in group activities, and smooth and harmonious interaction with others (cf. Peak 1989:94; Lock 1991: 520-521).

Following Rohlen's ethnographic description of the preservation of order in Japanese society, I will take the stance that at the JEC, authority is maintained through (1) a social process of knowledge production; (2) the constant encouragement of behaviors fitting of 'life in a group'; and (3) the reinforcement of practices which allow authorities to control situations without the appearing to assert direct rule.[22]

Thus, the authority of dominant medical practices and knowledge is preserved through a social process of knowledge production. These medical practices exist in a setting in which authorities control situations without appearing to assert direct rule. How, then, does change occur, and how can one account for opposition and resistance to authoritative knowledge? It is now a commonplace in anthropology that while cultures and ideologies maintain some fundamental coherence, they are under constant revision and are constantly being challenged by internal and external oppositions and resistance (cf. Lock 1988; Young 1988; Scott 1985, 1990; Ong 1988; Abu-Lughold 1990; Keesing 1992; Comaroff 1985; Comaroff and Comaroff 1991). Following this observation, I will take the position in this thesis that

> the medicalized body . . . is not only the product of changing medical knowledge and practice, but is at the same time a manifestation of potent, never settled, partially disguised political contests which contribute to the way in which the . . . body is 'seen' and interpreted (Lock ms: 1-2).

I will therefore suggest in this thesis that the form and content of authoritative knowledge about epilepsy and disability related to epilepsy at the JEC is also shaped by everyday struggles and challenges, or *resistance* (cf. Young 1988).

I define resistance here, following Young, as an every day act or behavior which displaces or impedes the flow of the production of medical knowledge (Young 1988: 11-14; cf. also Keesing 1992:451). *Resistance* is *created* [23] daily at the JEC and includes refusals to collaborate in the *knowledge production process*. Generally speaking, it can be found in two forms in daily life at the JEC: (1) resistance which is easily appropriated and re-integrated into the production process and (2) resistance which is not so easily assimilated into the

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[22] This is discussed in greater detail in Chapter 2.

[23] Allan Young, personal communication, May 1992.

production process and must be overcome (Young 1988:11-12). Resistance at the JEC is usually easily subverted and re-integrated into the knowledge production process.

With respect to the Japanese case, Rohlen's discussion in a recent paper is essential to an understanding of the specific characteristics which resistance (in the political sense -- cf. Keesing 1992) takes on at the JEC. His discussion concerns the cultivation of personality features important to 'living with the group' *(shuudanseikatsu)* in schools and businesses.

According to Rohlen, teachers and business managers in Japan maintain their authority and control acts of resistance by encouraging personality characteristics necessary to 'life in the group'. He asserts that they manage resistance to authority not through direct discipline or coercive methods, but rather by peer review and techniques which produce self-realization in resistors. These techniques allow authoritative figures to effectively reduce resistors to no-win, self-defeating situations in which they have no opponents (cf. Peak 1989; Rohlen 1989). Based on my observations, these practices provide the basis for the subversion of resistance and the maintenance of what appears to be order and group harmony at the JEC (cf. Rohlen 1989; Peak 1989).

In summary, I will argue in this thesis that the medical knowledge and practices at the JEC are ideological in that (1) they function to naturalize particular ideas about epilepsy and disability related to epilepsy while subverting other ideas and (2) they represent the interests of particular groups (the directors and staff) at the institute. At the JEC, medical knowledge maintains its authority via a social process of knowledge production. The hierarchical relations of knowledge production are upheld in an environment of decentralized management (Peak 1989; Rohlen 1989). Resistance to the flow of knowledge production occurs daily at the JEC, but is usually manipulated in indirect ways and (re)absorbed into the process or overcome. It, nonetheless, may also provide the impetus for social change (Lock 1991, n.d.).

1.3 Settings

'Comprehensive care', medical management and therapies which staff of the JEC use in an effort to improve the *quality of life* of people with epilepsy, was the organizing framework of the institute in which I conducted field research between May and September of 1991.

The JEC is located in the outskirts of the medium-sized city of Shizuoka, Japan (population: approximately 3.6 million inhabitants). Shizuoka is located approximately halfway between the major urban areas of Tokyo and Osaka. On one side of the JEC is the Shizuoka Prefectural Children's hospital and on the other sides of the hospital are rice fields and hospital dormitories. The nearest grocery store and neighborhood are approximately 1/2-3/4 mile from the hospital, within easy walking or biking distance.

As one enters the hospital compound after passing through narrow roads which divide rice fields, one is greeted by a small blue sign with bold white lettering which reads *Kokuritsu Ryooyooso Shizuoka Higashi Byooin (National Convalescent Hospital, Shizuoka East Hospital).* Small letters below the sign announce the presence of a *Tenkan sentaa (Epilepsy Center)* on the premises.

Just beyond the parking lot is the hospital, a low (4 story), white building. To the right of the hospital entrance is a fenced-in baseball field in which the hospital's patients play baseball. Festivals are held in the field, and sometimes staff teams also gather to play baseball there. In front of the hospital are a few waiting benches and a public pay telephone. A few of the hospital's patients might be playing on the playground equipment in front of the hospital. Dormitories which house the hospital's nurses and doctors and their families are situated across the parking lot.

Around the corner of the main hospital building is a small greenhouse and outside garden plot. Parts of the garden are labeled with numbers and names of plants. In the morning, around noon, and in the late afternoon, one might find a few of the JEC's in-patients (dressed in street clothes) weeding the garden or conversing near it.

Between the garden and the hospital is a rectangular area of concrete over which a series of clothes lines hang. On sunny mornings, one will find the hospital's patients in street clothes hanging their clothes to dry and, before dusk, gathering them.

On a typical summer day, the parking lot might be half full. A taxi cab or two might be waiting at the taxi stand in front of the hospital. Some patients might be outside the hospital sitting in a shaded area, while other patients' parents might be accompanying them on walks or waiting with them to be called for their appointments.

On the surface, the JEC appears simply to be a cross between a dormitory and a hospital. However, closer examination suggests a striking congruence between 'comprehensive care' practices as they are carried out at the JEC and commonsensical assumptions about individuals in relation to society which permeate Japanese institutions. The practices reinforce particular ideas about the *shakaijin* (social being, adult) (Lock 1988, 1991). The idealized *shakaijin* is humble, participates eagerly in group activities, and interacts smoothly and harmoniously with others (Lock 1991).

1.4 Methods

What were the conditions under which JEC was established, and what do the Center's staff members describe as the major influences on the treatment program? How is the authority of the medical knowledge and practices established and enforced at the JEC? Are there similarities between the practices at the JEC and in other Japanese social institutions? How do physicians at the JEC account for the efficacy of the treatment program? Do patients and staff accept these interpretations of the program's efficacy?

I will attempt to answer these questions in the body of the thesis by examining the history of the development of the JEC, its rehabilitation program and its stated goals for adult patients. The information used in this thesis is drawn primarily from observation in and interviews conducted while in residence at the JEC between May and September 1991. I will also draw from observations at and interviews with patients and staff at the Montréal Neurological Institute in Canada which were conducted between 1990-1991.

My research at the JEC was divided into (1) interviews, casual and formal, with the institute's staff and patients, (2) close examination of patient charts and records, and (3) daily observations in the out-patient clinic, of daily physician rounds, of consultations in one ward, of grand rounds in one ward, of one adult ward of the hospital, of all meetings of physicians at the hospital and the staff of one ward, and of the formal therapy activities conducted at the center.

I also participated in therapy activities and went on recreational outings. I attended one of the JEC's festivals, after-hours dinners and celebrations. Finally, I translated the hospital's information guides. I collected staff interview schedules for patients, patient evaluation forms of all types, and documents which had been produced about the hospital.

I informed patients and staff about the purposes of the research project both informally and formally. To clarify my research aims for the hospital staff, I described my purposes in two papers I presented to the JEC's physicians and in one paper I contributed to one of the hospital's publications.

I did not tape-record interviews. Because I was living in the hospital and saw the same small group of people daily, I felt that taping scenes or interviews would make the people I observed or with whom I was speaking uncomfortable. This, I felt, would lead to a stilted, flattened view of life at the center. Unlike an acute care center, where there might be a high turnover of staff and patients and in which daily life is extremely busy for patients and staff, the JEC functions at a slow pace, much like a chronic care center. During the months I spent in the hospital, there was very little turnover in the staff. Although some new patients were admitted and other patients were discharged during my stay, most were in the hospital for the duration of my stay. I was therefore able to have sustained and daily contact with a number of the institute's patients and many of the institute's staff members.[24]

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[24] My reservations about recording interviews and conducting strict, closed interviews with patients were reinforced when, in my first day observing in the adult ward at the JEC, one physician, trying to be helpful, called a patient into a consultation room, flipped through his chart in front of him, asked him a few cursory questions about his life history and his ideas about epilepsy, and then left him in the consultation room with me. He directed the patient to answer any questions that I asked him. What resulted was that after the physician left, the

With respect to the interviews, because I was interested in understanding why particular events at the hospital were or were not significant to the staff, I structured conversations with staff members around events which had occurred or problems which the staff had at the hospital. My discussions with patients covered areas ranging from why they had come to the hospital, their expectations, what they would do after being discharged from the hospital, to their frustrations.

I took detailed notes by hand on conversations, events, activities, problems I witnessed, the ways in which problems were resolved and the ways in which people described the resolution of problems. I also examined patient charts for the ways that daily events and patient information were recorded. I took verbatim notes on clinical encounters I observed at the JEC's outpatient clinic. Finally, I took notes on my computer which recapped daily events and conversations I had with the staff and patients.

Because my contact with the patients and staff of the hospital was not only made up of interviews, but also consisted of participation in activities, I cannot say that the information on which I base this thesis is derived strictly from interview material. It is drawn from an eclectic collection of notes, papers, memos and observations gathered while living in the hospital. All of the examples I use in the thesis are drawn from this information.

In the body of the thesis, previous work by anthropologists on children's educational institutions and adult institutions in Japan will be used as a foil with which to compare the practices at the JEC. I will use case histories of the ways in which resistance to authority is dealt with and authority is enforced at the JEC to examine the ways in which the authority of particular forms of knowledge is maintained at the center. Finally, I will explore claims about the program's efficacy and their relationship to the social processes at the institute.

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patient appeared very nervous and answered my questions with short answers in the most polite form of Japanese.

What I retained from the initial interview was an uncomfortable feeling and the memory of the patient's deference to me. I found it much easier and informative to spend time doing the activities that patients were required to do, becoming friends with patients, and speaking with them informally.

2. Maintaining the social order

In this section, after an historical discussion of the purposes and development of the 'comprehensive' care system at the JEC, I will describe the JEC's resulting therapeutic framework. I will contrast it with descriptions of practices in other Japanese social institutions. It will be my contention that although the JEC was established by groups fighting for social change, the comprehensive care therapies reproduce conventional knowledge about the social order in Japan.

2.1 The establishment of a comprehensive care center in Japan

The struggle to establish the JEC

The campaign for the creation of the JEC began in June and July of 1973. At this time, two informal support groups, one whose members consisted of parents of children with epilepsy, the Association of Parents of Children with Epilepsy, and the other of adults with epilepsy, the Volunteers Association for People with Epilepsy were founded. In the early and mid-1970s, members of these groups, working in conjunction with several prominent Japanese neuro-psychiatrists,[25] lobbied for the opening of a specialized center for the treatment of epilepsy. Because the two groups had overlapping members and interests, physicians at the National Center for the Treatment of Nervous and Mental Diseases in Tokyo brought them together (Seino, personal communication 1991). The resulting group was called the Japanese Epilepsy Association. It was founded to represent the interests of people with epilepsy and their families (Matsutoma 1980).

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[25] In contemporary Japan, adults with epilepsy are treated primarily by specialists called neuropsychiatrists, physicians trained to treat disorders which are classified in North America as psychiatric and also those which are classified in North America as neurological. Increasing specialization in Japan specifically, and in biomedicine generally, has led to the creation of a world-wide recognized subspecialty called 'epileptology'. However, those trained in the subspecialty in North America are first trained in neurology while those trained in Japan are first trained in psychiatry. Other specialists in both Japan and North America who treat epilepsy include pediatricians and neurosurgeons.

In 1974, the neuropsychiatrist who was later to become the director of the JEC, M. Seino, wrote a paper in an effort to rally support for the opening of a specialized epilepsy center. In the paper, he described the medical facilities and services available to Japanese people with epilepsy as far behind those available in Europe. He noted that although institutional care for people with epilepsy was available as early as 1860 in North America and Europe, this type of care had never been available in Japan. He argued that the "500,000 people of Japan [with epilepsy]" should have facilities which would meet their needs. The facilities, he continued, should be similar to institutes for the treatment of epilepsy in the West (Seino 1974).

The lay epilepsy organization has taken a similar tactic when describing the aim of its campaigns (the establishment of the JEC was one of them). Its charter consists of an appeal to the public and the government to address the *sufferings* of people with epilepsy. The *suffering* that people with epilepsy endure in their daily lives, according to the lay organization's charter, does not simply consist of suffering associated with seizures, or *biological* problems. It also consists of suffering which results from society-wide prejudices against people with epilepsy.[26] The organization's aims stress the fundamental need for "sufficient medical services, education, and welfare for [people with epilepsy]" (Matsutoma 1980). It aspires "to abolish ignorance, prejudice, and discrimination toward people with epilepsy" (Matsutoma 1980:443). The establishment of a facility for the treatment of epilepsy would therefore be a movement towards reaching these goals: (1) increasing public support and (2) attaining adequate medical and social service facilities and government funding for people with epilepsy.

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[26] These prejudices are reinforced in policies which, for example, place employment restrictions on people with epilepsy. People with epilepsy are prohibited from being licensed (and therefore employed) as cooks, barbers (hairdressers), interpreters/guides, x-ray technicians, sanitary workers, while they are restricted from becoming, for example, public health workers, physicians, dentists, dental hygienists, nurses, masseurs, physical/occupational therapists, pharmacists, technicians dealing with poisonous drugs and veterinarians. People with epilepsy are strongly recommended against becoming teachers, fire fighters, lawyers, tax collectors, governmental employees, social insurance service workers, and architects (first and second class). In 1991, a photocopy of the restrictions was pasted to a desk at the JEC's out-patient clinic, and all staff members were familiar with the restrictions. In all, 16 prohibited professions, 12 restricted professions, and 15 'strongly recommended against' professions are listed.

At approximately the same time that the two epilepsy interest groups and the physicians began lobbying for the opening of an epilepsy treatment center, the number of patients going for treatment at tuberculosis centers in Japan was decreasing. One tuberculosis treatment center was located in the outskirts of Shizuoka, a medium sized city halfway between the urban centers of Tokyo and Nagoya. During the seasonal rains in the early 1970s, the hospital was badly damaged by floods. Severe water damage in combination with the decreasing number of patients visiting the center provided an incentive for government officials to close the hospital.

In 1975, in response to the demands by the epilepsy interest groups, the Ministry of Health and Welfare re-designated the Shizuoka hospital as one for the treatment of epilepsy. The ministry gave the physicians who were most deeply involved in the lobbying efforts for a center for the treatment of epilepsy the responsibility of organizing the JEC. Because the JEC was to be the first center in Japan devoted expressly to the care of patients with epilepsy, its directors were given the task of creating a unique program which would treat what they saw as the most debilitating problems of epilepsy.

In summary, the JEC, a comprehensive care center for the treatment of epilepsy, was established only after physician and lay organization lobbying of the Japanese Ministry of Health and Welfare. These groups described problems with discrimination, employment and lack of access to medical services in the lives of people with epilepsy. They identified these as *needs* for which the Japanese government should take responsibility. The Ministry responded to these demands by allocating funds and one hospital facility (a defunct tuberculosis center) for the establishment of a specialized center for people with epilepsy.

Comprehensive care at the JEC

The *needs* of people with epilepsy about which Dr. Seino wrote in his 1974 appeal for the establishment of an epilepsy center were to become much more clearly articulated after the composition of the proposal for the institute's treatment program.[27] In 1975, the JEC's organizers constructed a document which described the objectives of the institute.

In the document, they proposed the creation of a center which not only provided biomedical treatment for epilepsy but which also provided social rehabilitation services for its patients (Shizuoka Higashi Byooin 1975). In an article in *Iryoo*, a weekly journal published for Japanese medical practitioners, Wada, the first director of the institute, described the hospital as one conceived of as a 'comprehensive treatment center'. Specialized paramedical and medical workers would come together in this center to treat people with epilepsy (Wada 1981).

The guidelines for the JEC and later amended guidelines bear similarities to the guidelines for epilepsy centers provided by the National Association of Epilepsy Centers in the United States (drafted in 1988) and the plans for Northern European institutes described in the symposia papers of the 1971 meeting in Europe (NAEC 1990; Proceedings of the 4th European Symposium on Epilepsy). Although the institute's directors have described American and European sources as providing the inspiration for the center, the directors do not endorse the highly interventionist, high-tech approach and emphasis on surgery described by the NAEC in its guidelines for epilepsy centers in the US (NAEC 1990). A closer model appears to be the European one.

The initial proposal for the Center suggested that 6 departments be included in the hospital: a medical department, a rehabilitation department, a nursing section, a research department, a training department (primarily for the training of nurses and physicians), and a service department. Each of these departments was further divided into sub-departments (Shizuoka Higashi Byooin 1975).

The initial plan placed great emphasis on social rehabilitation services. Seven areas in which to offer such services were proposed: in-hospital classrooms, occupational therapy, physical therapy, a half-way house, a workshop, a school for the training of special

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[27] Dr. Seino was one of the main collaborators in the production of the institute's therapeutic guidelines.

education teachers, and a section which would house mothers and children. By the early 1980s most of the departments which the hospital's organizers described in the original 1975 plan for the institute had been added to the hospital.[28]

This 'comprehensive care center', in addition to providing biomedical services for in- and out- patients, houses a day-care center for recreational and occupational therapy, classrooms for school-age in-patients, a research laboratory, a pharmacy and departments of social work and neuro-psychology. 132 non-medical personnel, 28 staff physicians (neuro-psychiatrists, pediatricians, and neurosurgeons) and approximately 150 staff nurses work at the hospital.

The in- and out- patient clinics

The JEC has been highly successful since its out-patient clinic opened in May 1975. Admission to the Center's in-patient facilities began in December 1976, after the first 100 beds for epilepsy patients were added. In 1978, classroom and therapy rooms in which children now attend class were added to the institute. The Center's Day Care building, in which occupational and recreational therapy sessions are now held, was not completed until 1980. Finally, two children's wards were added in 1982 and 1983 (Kokuritsu Ryooyooso Shizuoka Higashi Byooin 1989, 1991b, 1991c).

Of the Center's 360 in-patient beds, 160 beds in four wards are devoted to the care of the severely handicapped, many of whom have seizure disorders. The remaining 200 in-patient beds are allotted to patients with epilepsy.

The Center's epilepsy beds are divided evenly between the two adult and two children's wards and are usually filled to capacity. The waiting list for adult in-patient beds is long. Approximately 40 patients are normally on the list. Those on the list must wait for

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[28] The only service of the original 'comprehensive care' plan which was not yet incorporated into the Center's comprehensive epilepsy care in 1991 was a 'half-way house', which was primarily to function as a 'stopping over' place for people who had problems in society but were not having physiological problems severe enough to warrant hospitalization. Another purpose of the 'halfway' house would have been to serve as a buffer between hospital admission and society. Because a halfway house does not classify as a medical facility, the hospital was not able to attain funding for it

anywhere between one month to 6 months for a bed. The waiting list for the children's wards is shorter, with approximately 5-10 patients at a time waiting for an average period of less than a month. The average stay for adult in-patients is reported as a little over three months. The amount of time patients spend in the hospital, however, ranges from a few days to several years.

Children stay in the hospital for a much shorter time period. Most stay for under three months and almost all for under 6 months. They are usually admitted to the hospital together with their parents. In extreme cases, such as when an infant's parents cannot stay in the hospital with him/her for financial or other reasons, the child is admitted into a severely handicapped children's ward. According to some staff members, these children usually stay in the hospital longer than those admitted to the epilepsy wards.

130 patients pass through the out-patient clinic daily. In 1990, approximately 39,450 people were seen by the JEC's out-patient physicians. Appointments to see out-patient physicians (either as a new or continuing patient) must be made well in advance (Kokuritsu Ryooyooso Shizuoka Higashi Byooin 1989, 1991a, 1991c).

The patient population

Patients who go to the JEC for its out- and in- patient services are of all ages and come from all areas of Japan. In 1988, 92% of the hospital's outpatients were under the age of 35, with 48.5% under the age of 15 and 43.5% between 15 and 35 years of age (Shizuoka Higashi Byooin 1988).[29] Over 74% of the patients come from the Kanto and Chuubu regions of Japan.[30]

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[29] This description of differences between numbers of patients above 15 and below 15 is not arbitrary, but drawn from the hospital's practices concerning patients above and below the age of 15. Excepting special cases, patients 15 years of age and under are treated as children and receive treatment from pediatricians. They are admitted as in-patients into one of two children's wards. Those over the age of 15 will most likely receive treatment from a neuropsychiatrist and, if admitted, be admitted into an adult ward.

[30] The area in which the hospital is located is called Chuubu. 46.9% of the JEC's patients came from Chuubu. The Tokyo area, a little over one hour from Shizuoka by 'bullet train', is called the Kanto region. 27.4% of the hospital's patients come from this region. 13% of the hospital's out-patients come from the Kansai region of Japan (including the urban centers of Kyoto, Osaka, and Nara). Although 56.4% of Japan's population lives in within a 400 kilometer radius of Shizuoka, 81% of the hospital's patients come from this area.

The JEC is not the only epilepsy center in Japan, although it was the first center devoted solely to the treatment of epilepsy to be established in Japan. Other epilepsy clinics are located in urban areas like Tokyo (at the National Center for Nervous and Mental Diseases) and Pushi. In the early 1980s the Kansai Regional Epilepsy Center (National Utano Hospital) and another National Epilepsy Center (Teradomari Hospital) in Niigata Prefecture were established. However, according to staff members of the Shizuoka hospital, the Shizuoka center is unique in its emphasis on 'comprehensive care', i.e. in its treatment methods.

Staff members report that the other Japanese epilepsy centers do not do nearly as well financially as the Shizuoka hospital. One such center, the Teradomari Hospital, opened as an epilepsy center in the mid 1980s, but is in danger of closing down because of a lack of demand for services. The Shizuoka center, on the other hand, is extremely busy, so busy as to be constantly short of physicians and other staff members. Staff members attribute much of the center's success to the ideal location of the center -- a few hours' train ride to the most densely populated areas of Japan -- and the mild weather in Shizuoka (snow rarely falls during the winter).

Although other epilepsy centers have been established in Japan, the Shizuoka center is considered the 'final stop' hospital. It is a center to which physicians at other epilepsy clinics refer patients who have problems they cannot treat. Most patients who go to the center are referred by their local physicians, and a few are self-referred. Those who are self-referred have found out about the center through word of mouth, advertisements for the center, or media (newspaper, magazine or television) reports about the center.

In July 1991, the Japanese Ministry of Health and Welfare designated the Center as a 'referral center' -- an officially recognized specialized tertiary center for the treatment of epilepsy. This designation changed practices at the hospital in three ways: (1) it raised the center's status to that of a fourth-level, specialized hospital; (2) it allowed physicians to bill more for writing return letters to patients' regular physicians; and (3) whereas before the designation, the fee patients paid for their initial visit to the clinic was dependent only on the type of health insurance coverage they had, under the change of status, insurance will not cover patients who were not referred to the hospital by other specialists. In other words, the patient without a referral must pay in full for the first visit. The cost is ¥4200 (appx. US$31)[31] for people aged 6 and over and ¥4700 (appx. US$35) for people under 6 years of age. This is a base fee and does not include the cost of required tests or medication.

The initial visit to the clinic is by far the most expensive. In addition to the flat physician's fee, staff perform a number of required tests on all patients (the EEG, the CT scan and blood level tests). Before the hospital was re-designated as a 'referral' hospital, all patients who were covered under the National Health Insurance Plan (70% coverage) could expect to pay in the range of ¥8,000-15,000 (appx. US$59-111) on the initial visit. Policy holders of the employees health insurance plans and their family members would, respectively, expect to pay one-third and two-thirds of the above-mentioned figure. Under the new 'referral' designation of the Center, those who come in without a letter of introduction must pay a little over three times the figure above for their initial visit. Successive visits are covered by insurance.[32]

The government places a nation-wide ceiling of ¥57,600 (US$422) on the amount that a hospital can accept from its in-patients each month during the first three months that patients reside in the hospital. Patients are reimbursed for any amount above the ceiling that they pay. With respect to transportation and other medical costs, the government provides a

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[31] The scale used to convert Japanese Yen to US dollars is ¥135:$1.

[32] Since a health insurance plan instituted by the Japanese Ministry of Health and Welfare in 1961, nearly all of Japan's population has been covered in one way or the other by health insurance (Steslicke 1982, 1987). This system has developed into one in which there are primarily two types of health insurance available to Japanese people: (1) insurance coverage through employers *(kenkoo hoken)* (people who work for large companies, are government employees, seamen, and teachers among others) and (2) national health insurance (kokuho) which includes all people not covered by the first category (farmers, the unemployed, small business owners, part-time workers, etc.). Payment for the first form of insurance is extracted from the salaries of employees while there is a nominal monthly payment for the community based (national health) insurance.

Coverage is not equal under both forms of insurance. The first provides 90% coverage for all medical expenses for the main policy holder and 80% coverage for the policy holder's family members. With the second form, coverage is limited to 70% for the policy holder and his/her family members. For a more complete description of the Japanese health insurance system, see Steslicke (1987).

tax deduction of up to ¥100,000 (US$741) to families of patients who visit the JEC. Because epilepsy is not considered a 'major illness', however, the government does not cover hospitalization and medication costs in full.

2.2 Early education and becoming an adult: Japanese social institutions

> It should be a basic principle that moral education in the school should be provided throughout all the educational activities of the school. Therefore, propose instruction for moral development should be given not only in the hours for Moral Education, but also in the hours for each Subject |sic| and Special Activities |sic|, in conformity with their respective characteristics.
>
> In carrying out moral education at school, due consideration should be given to establishing close human relationships between teachers and pupils and among pupils themselves and to guiding thoroughly the practice of moral codes in the basic behavior of everyday life in cooperation with the home and the local community concerned.

--Educational and Cultural Exchange Division, UNESCO and International Affairs Department, Science and International Affairs Bureau, Ministry of Education, Science, and Culture, Government of Japan. Course of Study for Elementary Schools in Japan (1983: 1).

Though the staff the JEC describe international influences, particularly European and American, on JEC's institutional framework, its treatment goals articulate strongly with the stated goals of other Japanese social institutions, particularly with the goals of educational institutes and businesses (as quoted above). The goals have been described elsewhere as upholding ideals in which individual preferences and goals are suppressed "for the sake of group harmony, cohesion, and advancement" (Lock 1988:406). They have been tied to the Japanese government's efforts to create suitable workers and therefore produce a more competitive work force through reforms of its educational system (Lock 1991).

In which other Japanese institutions are these objectives endorsed? How do they maintain their dominance in these institutions? The following is a brief examination of the conditions surrounding the emergence and maintenance of order in Japanese institutions. I will concentrate specifically on practices related to early socialization. The description will clarify (1) the ways in which practices in other social institutions in Japan articulate with those at the JEC and (2) how authority is maintained in these institutions.

In a review of parenting practices in Japan, Rohlen has suggested that in contrast to North American parents, who tend to encourage independence and verbalization in their children at a very young age, Japanese parents encourage openness, receptivity to adult guidance, and dependence in their infants at home (Rohlen 1989). Japanese parents, Rohlen suggests, control (mis) behavior in their young children not through the assertion of authority, but rather through appeals to feelings and the "utilization of a close emotional bond" developed between mother and child. Parents rarely use direct discipline with infants and young children. Only in extreme cases of misbehavior do they use it (Rohlen 1989).

The behaviors encouraged in young Japanese children in early socialization contrast with those expected of children once they are in pre-school. Japanese parents who have been interviewed report that entrance to pre-school marks for their children a significant transition into public life, describing it most commonly as a place where children must learn skills which are important to 'living with the group' *(shuudanseikatsu).* This entails willing and enthusiastic participation in group activities, making individual desires and goals secondary to those of the group (showing *enryo*), and striving for smooth and harmonious interaction with the group. The behavioral characteristics teachers encourage by 'living with the group' are usually subsumed under the general objective of preparation to become an adult, a socialized person, *shakaijin*, who will contribute fully to the work force (Peak 1989).

In a study of Japanese pre-schools, Peak has found that teachers use highly effective methods of indirect manipulation to enforce the authority of ideas about behavior fitting of 'life in a group'. She notes that the teachers she studied use the same methods to discipline or modify behavior. Peak found that pre-school teachers do not meet resistance to authority with direct opposition. Rather, they appear to ally themselves with students who oppose them. The result of teacher-student struggles in these situations is that (1) children, having no apparent opponent, are manipulated into conceding defeat and (2) teacher intervention and direct control are not readily apparent in the enforcement of authority (Peak 1989). As with the enforcement of authority at home, in elementary schools, teachers direct behavior not through enforcement of rules, but rather through practice, gentle persuasion and encouraging self-knowledge in their students (Rohlen 1989; Peak 1989).

How are desired behaviors (those fitting of 'life in a group') encouraged in schools and adult institutions? Both Rohlen and Peak note that in school children are taught to act in ways fitting to *shuudanseikatsu* not by means of rules and precepts, but rather by keeping them on a regular schedule of group activities. Daily schedules for pre-schoolers are fairly loose. However, as children progress through elementary school, highly standardized routines are added, to the extent that days are "under the jurisdiction of. . . an intensively routinized order" (Rohlen 1989:21). Teachers enforce routine and discipline not only through repetition, but also through modeling of proper and improper conduct. Students, rather than teachers inspect conduct (1989:21).

Practices in adult institutions in Japan (i.e. businesses) show fundamental similarities to those in schools. In Japanese businesses, much emphasis is placed on decentralized authority, peer review, strictly routinized days, and cooperative management (Rohlen 1989). As in Japanese schools, co-workers share housekeeping chores, must comply with dress codes, and participate in group discussions. Again, these activities standardize practices important to *shuudanseikatsu* ('life in a group') and reinforce "individual understanding of social necessities" (Rohlen 1989: 27). This, in turn, encourages the fulfillment of the requirements of being a socialized person, *shakaijin*, who will contribute fully to the work force. As in elementary schools, authority is enforced not through direct, coercive measures but through apparently decentralized management and peer review (Rohlen 1989).

In summary, particular practices which encourage behaviors suitable for 'life in a group' *(shuudanseikatsu)* dominate Japanese institutions, among them schools and businesses. These practices, for the most part, emphasize the importance of group cooperation, interdependence, and peer review. Teachers and parents describe these characteristics as necessary for preparing to become a fully socialized adult in Japanese society, a *shakaijin*. Patience, privileging the goals of the group over one's own goals and aspirations, and humility also fulfill this ideal. While on one hand this may suggest a 'harmonic' picture of Japanese society, the practices, on the other hand, can be seen as enforcing an ideal in which the goals and desires of the individual are sacrificed for the fulfillment of the goals of the group (cf. Lock 1986, 1988).

The analyses discussed in this section (esp. Rohlen 1989; Peak 1989) add insight into the question of how cohesion is maintained in Japanese social institutions. They suggest that the authority of the knowledge and practices in Japanese schools and adult institutes is maintained not through direct coercive force but by decentralized management. This results in limited (almost non-existent) intervention by authority figures, peer review, and the encouragement of behavior modification through self- knowledge and self-reflection. According to these researchers, though appearances suggest harmony and autonomous personal decision making, ultimate power to manipulate resistance remains in the hands of those in authority.

2.3 Claims about the 'comprehensive care' program's effects

Judging from the stated goals of the therapeutic activities practiced at the JEC, the JEC's therapies are successfully changing (or curing) bad habits and personality traits in dysfunctional people. They are preparing healthy, productive, group oriented people to enter the work force. This conclusion is supported by the Center's staff in their papers about comprehensive care, rehabilitation, and surgery. In these papers, changes in behavior and 'employment status' are used as evidence of the positive effects of the JEC's treatment program. Yet, claims about the efficacy of the program are problematic. In this section, I will delineate problematic aspects of claims about the efficacy of the treatment program both from the perspective of an outsider and also from the perspectives of patients and staff at the JEC.

In a 1989 paper, Yagi, the JEC's deputy-director, concludes that occupational therapy at the center's Day Care center was considered effective for "at least 50% or so of unemployed patients" (1989:191). The reference from which he draws these conclusions is a

1986 article which he co-authored with a social worker employed at the JEC (Asano and Yagi 1986).[33]

Similarly, in papers concerning the efficacy of surgery performed at the JEC, the hospital's staff describe three major types of positive changes exhibited in post-surgical patients. These changes are in: 'occupational status', intelligence and memory quotient (based on the neuro-psychological testing), and seizure frequency. In the most recent of the papers, Mihara finds that two years after surgery, 74% of 43 people were either completely seizure free or had auras but no seizures. Of the remaining 26%, 12% had seizures approximately once/year, 7% had an approximately 10% reduction in seizure frequency and 7% experienced no change in seizure frequency at all.[34]

With respect to changes in intelligence quotient (IQ) and memory quotient (MQ), Mihara reports an average increase of 6 points in both areas two years post-surgically compared to the results of the same tests performed shortly before surgery, during Step I.[35]

Finally, the authors report that most of the people who underwent surgery improved their 'occupational status'.[36] Using a chart with which they compare improvement in seizure frequency and occupational status, the authors attempt to demonstrate a relationship between

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[33] The authors of the 1986 paper described patients who had a "more volitional and less hesitant attitude. . . compared to [unsuccessful group]" (1986:483) as having successfully completed the program. Other behavioral changes in the successful group were: greater attentiveness and patience, less 'rejective' [sic] and 'intrusive' attitudes in interpersonal relationships, and decreases in aggressiveness and haughtiness.

[34] This paper was the most up-to-date in September 1991. Previous to this paper, at least 4 papers were published by JEC staff members who drew from the same data . The first paper of the series, the 1989 paper by Matsuda et al., describes follow up data from only 23 patients.

[35] Keep in mind that by the time the patient undergoes the two-year battery of neuropsychological tests, he/she has undergone the same battery of tests three times.

These results agree with what is currently accepted by specialists in the study of epilepsy as the standard increase in IQ after surgery.

Specialists in North America and the Montreal Neurological Hospital cite an approximately 10 point increase in IQ after surgery (cf. Spenser and Spenser 1991). Although neuropsychologists perform these tests, the numbers are widely recognized by surgeons and neurologists as positive results. Neuropsychologists, however, are reluctant to accept these results as indicative of positive changes in brain function which result from epilepsy surgery.

[36] The authors divide 'occupational status' into 6 categories: (1) full time employment (2) part time (3) unstable work/ "occasional work" (4) self-employed (5) unemployed and (6) employed.

decrease in seizure frequency and rise in 'occupational status' (Mihara et al. 1989; Mihara 1991).

* * *

Although the reports described above appear to confirm that the comprehensive care program at the Center has been successful, evidence that the treatment program has been directly responsible for positive changes in either the social rehabilitation of its patients or their 'mental' abilities (IQ and MQ) is problematic. First, some of the patients the authors studied appear to have become employed after discharge from the JEC. However, in both discussions about surgery (Mihara et al. 1989; Mihara 1991) and the discussion about Day Care (Asano and Yagi 1986), the authors find a significant number of people who have not benefited from the therapy, that is, patients who have not, subsequent to treatment, become gainfully employed.

For example, the author of one paper concerning surgery finds 5 such cases. Mihara, the institute's surgeon writes:

> Those people whose complex partial seizures are reduced to less than one time a year stand a great chance of finding employment. However, 5 of these cases [of those that we are reviewing] were involved in unstable part time work or lower [after two years]. Before surgery, none of these people were interested in finding work. They either possessed very dependent personalities or their social skills were not adequate to conduct necessary interpersonal relations smoothly (Mihara 1991).[37]

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[37] This is my translation of a Japanese-language source. A similar paper written by Mihara et al. in 1990 (published in English) reads as follows, "Three patients had no complex partial seizure for two years post-operatively and yet their social adjustment never improved because of an apparent tendency toward dependent character traits and/or interpersonal difficulties. To some extent, such psychological disorders are common in patients with intractable seizures who are surgical candidates. Complicated psychological conflicts are thought to persist before and after surgery and are never overcome by amelioration of the seizures themselves. Unlike patients who are operated on for common disorders, these patients tend to overestimate the surgical procedures, and the post surgical reevaluation. Appropriate consultation and exploration are needed until the candidates become confident; otherwise they may be psychologically burdened, making the post operative social adjustment difficult" (1990:280).

According to Mihara, those patients with dependent personalities or poor social skills did not re-integrate into society successfully. He and his colleagues come to similar conclusions in other papers in which they discuss people who have not become engaged in full time or stable work since receiving surgery (cf. Mihara et al. 1990; Matsuda 1989).

Similarly, in their discussion about changes brought about by rehabilitation practices in the Day Care center, Asano and Yagi conclude that the personality changes they describe are elemental to improving "the patient's ability to cope with the job situation" (1986:484). However, they also find that nearly half of their sample failed to rehabilitate successfully (i.e. become gainfully employed). In the article, the authors attempt to distinguish between those patients who successfully rehabilitate and those who fail. They suggest that differences between the personality types of patients in the successful group and patients in the unsuccessful group are significant. They use 'cost-benefit reasoning' to argue that Day Care services should be provided for people with personalities or character traits which most closely approximate the characteristics of the patients in the successful group. The authors end the article by advising that although rehabilitation activities may be important in bringing about 'normalization and social adaptation', selection of suitable (i.e. easily rehabilitated) candidates to attend Day Care is equally important (Asano and Yagi 1986).

With respect to 'mental' improvements, a close examination of the distribution of changes in the IQ and MQ test scores of patients who received surgery suggests that claims about causal connections between the increases in scores on memory and intelligence tests and surgery is at best risky, and at worst misleading. Many patients who were tested (16/37, or 43%) received the nearly the same score on the IQ test pre- and post- surgically. A few patients' scores dropped, and three patients had score increases of greater than ten points. The distribution of score changes in the memory test is distributed fairly evenly between those who scored lower, the same, and higher on the test two years post surgically.

Finally, not only are claims about the program's efficacy weak upon external examination of the premises of the claims in papers, but in discussions and casual conversations, staff members express an *awareness* of the weakness of claims about the treatment program's efficacy. Nurses and physicians note that most people do not change during the course of the Center's therapeutic programs, and that those patients who start out with problems will most likely, when they leave the structured life of the institute, have the same problems they had before admission. Others report that although people might change while they are hospitalized, their home environments will not change. They assert that people will revert to their pre-admission habits upon their return home. Some staff members who have been working at the Center for many years report that their greatest hope is that the Center's patients might take with them, after discharge, a tiny portion of what they have been taught at the Center.[38]

Patients also express an awareness that the changes effected by the treatment program are only superficial or temporary, but their accounts differ somewhat from the staff accounts. Their accounts do not concentrate on behavioral problems, but on social problems. For example, one young woman, Noriko, a university graduate, expressed deep concern in ever being able to be married or being able to continue on the career path that she had chosen. She had a type of seizure that no one in the hospital could understand or treat, and had been admitted three times already, each time for long periods. She had been told that she would have to be in the hospital for at least one year for the medical staff to be able to understand and treat her seizures.

In one conversation, she said that she had tried to overcome her problems with epilepsy and in society in many ways. She had joined self-help epilepsy groups and tried to be active in society. Noriko stressed that though her family was not religious, she had chosen to join a Christian church because she thought that it would provide her with emotional support. She felt that these organizations helped a bit, but what she wanted most of all was for her epilepsy to be cured. She said that though her seizures were not of the type which could be treated through surgery, had pleaded with her physician to allow her to have surgery because it could control seizures successfully.

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[38] This is accepted to such an extent that those patients who *do* change are teased by staff members and reminded of these changes.

Noriko had been admitted many times, and the problems with her life had not improved through hospital care. However, she continued to utilize the facilities of the JEC, because, she said, this was the most specialized institute for the treatment of epilepsy in Japan. She stressed that she had no other alternatives. This case is only one of many examples of patients' accounts of the problems they were having, what they wanted therapies at the JEC to address, and their awareness of problems with the treatment program.

During the summer of 1991, a number of patients returned to the JEC after their seizures had been controlled through surgery.[39] The returning patients included people who had returned to work after surgery and had problems adjusting to work or to the outside world. One example from my field research is that of a man who was readmitted post-surgically, seizure free, to the JEC, Yamaguchi san.[40] He said that his life had not improved since having surgery and that he, in fact, still had as many problems in society now as before surgery. He was still taking anti-epileptic medication and the hospital physicians had stressed to him that he still had epilepsy. However, he had not told his employer that he had epilepsy, out of fear that he would be fired or he would be treated differently. Though his insurance plan, a company plan, would have covered this admission, he was paying *in full* for the hospital stay, because he did not want his employers to know where he had gone.

Yamaguchi san had progressively been having more trouble at work and empathized with other patients who did not want others to know they had epilepsy. He stressed that letting people know one had epilepsy had significant consequences for employment, marriage and family. Many other patients at the JEC described problems which were similar to Yamaguchi san's.

Other patients at the institute, particularly those who had been admitted to the institute repeatedly, refused to be discharged. They refused because they were aware that the changes

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[39] In charts and discussions, staff described the reason these patients were re-admitted as 'psychiatric'.

[40] This is a pseudonym. The suffix -san is used after names in Japanese and is usually translated to the more formal 'Miss' or 'Mr.' In Japanese, however, the use of this suffix does not carry the formal connotations of 'Miss' and 'Mr.' It is used regularly among acquaintances.

effected by the institute were only temporary and were largely an artifact of the institutional setting. Though patients expressed an awareness that very little would change in their lives as a result of their hospitalization, they continued to use the hospital facilities and many even returned several times.

* * *

While it might first appear from descriptions of the institutional goals of the JEC and in papers about the JEC that the treatment program has brought about major changes (esp. social rehabilitation) in those who are being treated, it seems that the effects of the JEC's therapy on the lives of patients have yet to be shown. First, the authors of the scientific papers discussed in this section do not make the reasons why patients were classified as unemployed before treatment clear. For the most part, the selection process in place at the JEC allows access to these therapies only to patients who are considered 'employable' (easily rehabilitated). If the patients chosen for these therapies (especially surgical therapy) are largely considered 'employable' before therapy, then conclusions about the efficacy of comprehensive care (i.e. gainful employment post-discharge) in these papers are problematic in that they are based on the self-fulfilling prophecy that those people who are *proper* from the beginning will rehabilitate well.

Secondly, the authors of these papers use evidence of the efficacy of 'comprehensive care' to support the validity of the criteria used to select candidates for these therapies. Where problems with rehabilitation *do* occur, individual patients, not the therapeutic methods or framework of the JEC, are described as faulty or improper candidates. Justification for the unequal distribution of services appears to follow this curious logic: because the effects of comprehensive care on people who do not possess the proper social skills, personalities, etc. are not clear, the only way that the goal of producing patients who will rehabilitate well (in their terms) can be met is through the distribution of scarce resources to candidates who *already* possess 'good' qualities. Finally, both staff and patients agree with these observations. Many patients say that the JEC's therapies do not address the problems which they find most important.

The treatment program therefore does not appear to address the problems which first fueled the efforts to establish the JEC. The evidence provided in staff papers about the efficacy of the comprehensive care system does not support the conclusion that the Center's comprehensive care services are efficacious. Rather, it seems only to justify the differential distribution of services based on particular personality or behavioral characteristics.

2.4 Ideology and the production of knowledge

If it is not clear that the comprehensive care program at the JEC is rehabilitating people as documents describing it say it is, *and* patients and staff are not convinced of the program's efficacy, what, then, is happening? Following Young (1988), I would like to suggest that the main product at the institute is not 'productive bodies' for the work force but a *knowledge product* which is produced at the JEC. Social order is enforced and the authority of this knowledge maintained at the JEC through decentralized management practices which characterize many other Japanese social institutions (Rohlen 1983, 1989; Peak 1989).

The dominant practices and ideas at the JEC, the *knowledge products*, are ideological in that (1) they force people, through the division of labor in the production of knowledge, to act in ways that they may not have otherwise chosen; (2) they naturalize particular historically contingent ideas about the individual in relation to society (cf. Lock 1986, 1988; Rohlen 1974, 1983); and (3) in doing so, they justify (a) a decidedly inegalitarian distribution of health care resources (i.e. 'efficacious' therapies) and (b) the isolation of particular behavioral characteristics as symptoms in need of treatment.

The knowledge production process at the JEC occurs in several stages. The first stage consists of the initial clinical visit, during which the patient is seen by a medical resident and the JEC's director. Imaging studies, EEGs and blood tests are taken, and personal, family and seizure histories are elicited from the patient and his family. During this stage, the patient's and family's accounts of the illness are taken up by the hospital's physician, who searches for clues in the descriptions about the patient's seizure type(s) and etiology. The physician takes up specific parts of the patient's description and combines it with other information she gleans from EEGs, imaging studies, and the patient's past physician's diagnosis and description of his condition. She combines this with other impressions from the visit to compose the JEC's first official diagnosis of the patient's condition.

In the second stage, admission to the hospital and hospitalization, information inscribed in out-patient charts informs staff members about the patient's histories, diagnosis, and possible problems (<u>before</u> the patient is admitted). Staff members representing separate fields of specialization in the 'comprehensive care' team read the patient's out-patient chart and are responsible for particular aspects of the patient's treatment and evaluation. During the patient's hospitalization and upon discharge, representatives from each part of the 'team' reinterpret/evaluate particular aspects of the patient using categories provided in hospital documents. These staff members then enter their evaluations into the patient's chart.

In the third stage, the interpretations of epilepsy produced in the documents in the first two stages are taken up by the hospital's staff. They are used in scientific papers about epilepsy and disorder related to epilepsy. Aspects of epilepsy which the staff members choose as salient are documented and discussed in these publications.

The staff's choice of issues about which to write is not arbitrary, but is embedded in existing international and local debates and historical circumstances. It is limited and shaped by particular technological factors. For example, in the past 30 years, 'comprehensive care' has become an increasingly important descriptive term in international discussions about the management of people with epilepsy. However, the objectives of and practices included in the comprehensive care treatment program at the JEC have been subject to the influence of local, historically specific practices and ideals. Another example is the surprisingly low number of surgeries performed at the JEC in comparison to other institutes in North America. The number is low because surgery at the JEC has been integrated into its treatment program and, as such, is only offered to people who the staff feel will benefit from the surgery. The low number also results from the lack of neurosurgeons in Japan who perform surgery for epilepsy, as all Japanese professionals trained to perform epilepsy surgery quit in the 1970s.[41]

In scientific papers, staff discuss the efficacy and benefits of the treatment program. This gives authority and shape to the JEC's treatment program. The content of the issues discussed in the papers is under constant revision and exists in interdependence with (1) the events at the JEC and (2) current debates among professionals.

While the processes described above lend authority to particular knowledge and practices about epilepsy, at the JEC, the maintenance of authoritative knowledge at the JEC is not due simply to the division of labor in the process of knowledge production. At the JEC, the knowledge about epilepsy and disability related to epilepsy maintains authority both through the hierarchical process of knowledge production described above and enforcement of order which occurs in an environment of *decentralized authority* (cf. Rohlen 1989).

At the JEC, patients and staff at the JEC are strongly encouraged to participate cooperatively in every-day decision-making processes at the institute. Despite this emphasis on decentralized management, however, institutional imperatives, as dictated by the comprehensive care framework, usually gain authority via staff manipulation (cf. Peak 1989; Rohlen 1989).

Two significant ideological consequences result from the social processes described above: (1) particular groups in the hospital are empowered to define disorder and disability and (2) the distribution of services at the Center is skewed to favor highly educated, 'proper' people over others. Historically contingent medical ideas and practices are given an autonomous and timeless character as things-in-themselves in this knowledge production process (cf. Lukács 1971; Taussig 1980; Young 1980).

The next sections will be devoted to detailed descriptions of therapies and practices at the JEC, their goals, and the ways in which their authority is maintained.

2.5 Institutional practices and daily life at the JEC

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[41] This is discussed in the introductory chapter and in the section on surgery below.

A day in an adult ward at the JEC

Though the JEC is a hospital which offers biomedical services, observation of the daily life in one of the adult wards would leave the casual observer with the distinct feeling that she was not in a center for the treatment of sickness and disability (epilepsy) but rather at a summer camp. The observer would be left with an impression that the center was one in which organized activities were interspersed with brief periods of relaxation.

On a typical day, one might see some of the nursing staff wearing white uniforms (other nursing staff members cannot be distinguished from the patients, as they wear athletic outfits), physicians in white coats, and some medical equipment in the adult wards. However, most of the people in the ward wear regular day clothes and move about freely.

The day room, the area directly to the right of the opening of the stair well, is a large room with a number of windows. It is filled, cafeteria style, with long rows of wooden tables and chairs, a large refrigerator at one end, and a set of couches and a coffee table in front of a television.

On the left of the stairway entrance is the nursing station. A sign-in/out book and a row of handicrafts with patients' names on them-- vases, bead work, traditional Japanese boxes, etc. -- are displayed on the wooden counter of the nursing station.

After wake up at 6 am, morning stretching exercises to the radio *(rajio taisoo)* at 6:30 am, and breakfast at 7 am, there is great amount of activity in the large day/eating room of the ward. A few people might be found watching television from the couches in the day room, or knitting, doing embroidery, reading the morning newspaper, socializing or playing with a puzzle. In the same room, other people might be sitting at one of the long, wooden tables used at meal times writing letters, making paper figurines *(origami)* or playing cards. Others might just be returning from a morning jog around the rice fields surrounding the Center. Still others might be signing out for a walk around the center, while others might be carrying laundry to the laundry machines on the floor or going outside to hang their clothing out to dry. One or two nurses or nurses' aides might be sitting in the day room socializing with the patients.

The day room and nursing station are situated in the middle of the hall. Down the hall one way is a special group of rooms. Among them are two private rooms, usually empty or only occupied for short periods of time. The people who occupy these beds are those who are admitted into the ward as 'emergency' cases or those who have just undergone surgery of some sort.

Two other rooms are located across the hall from these single rooms. One of these is a large room with two beds, curtains between the beds, and video and EEG equipment behind the beds. From time to time, people with white lab coats, technicians or physicians, enter the room and study the video monitor or the EEG readings which have been recorded. The people occupying the beds have elaborate bandages on their heads with wires of different colors protruding which are connected to a box. This box, in turn, is connected to another box with wires which connect it to the monitoring machines. Both beds have camera monitors directly above them whose images can be seen both in the nursing station and the EEG/video area just behind the beds.

The people who occupy these beds, unlike those in the day room, usually wear pajamas. Because they are being monitored, they are allowed to leave their beds only for short periods of time. They are allowed to go to the washroom or smoke a cigarette in the day room, for example. They often occupy their time either by watching television (each bed is equipped with a television), playing video games, writing letters, doing crossword puzzles, or socializing with nurses, physicians, or other residents of the ward who stop by to visit them.

The final room on this side of the hall is the only room in the ward with large windows facing the hall. In it are four beds each of which has a set of curtains which can be drawn for privacy. These beds are reserved for people either about to receive surgery or those who have already undergone surgery.

Doubling back past the day room and nursing station and along the hall to its other end are the ten other rooms in the ward. Although two of these rooms are semi-private, with only two beds each, the remaining rooms have four to six beds apiece. They are usually filled to capacity. Venturing into one of the rooms, one might first see a hanging embroidered or hand-lettered sign on the outside of the door warning the visitor to 'please knock!'. Entrance into the rooms reveals in each room small, twin sized beds with lockers on either side and small cabinets above them. Some of the lockers have calendars hanging on them, while still others might have cards from schoolmates or pictures from home pasted up. Many of the beds have portable CD-radio-cassette players on the shelves beside them. The beds do not have curtains which can be closed for privacy around them.

Before 9 am on any given morning, only about half of the floor's residents are in their rooms reading, writing letters, tidying up, or listening to music on headphones. The other residents of the floor can be found in the day room or doing their laundry. Others have gone out for unsupervised short walks or jogs together.

At 9 am every morning except Sunday, a nurse makes an announcement for patients to return to their rooms to await morning rounds by their physicians. The room becomes deserted almost immediately after the announcement. On Monday, Wednesday, and Friday, patients leave the ward immediately following rounds for occupational therapy or school, many carrying bags, and some with school books. By 10 am, the ward is almost completely empty, save a nurse's aide or two, a few physicians and a few nurses.

The patients' weekly schedule, posted above a blackboard at the nurse's station, reads as follows:

<u>Morning</u> / <u>Afternoon</u>

Monday: occupational therapy *(sagyoo chiryoo)* / director's grand rounds
Tuesday: bath / exercise therapy *(undoo chiryoo)*
Wednesday: occupational therapy / exercise therapy
Thursday: linen change, living guidance (instruction)/ exercise therapy
Friday: occupational therapy / exercise, lecture or patient meeting
Saturday: exercise therapy / bath

Patients are kept on a daily schedule which is set up to keep them occupied from wake up at 6 am until lights out at 9 pm.

For the in-patients of the JEC, life in the adult wards is one of strictly controlled daily activity with only brief interruptions (periodic blood level checks and other medical tests, physician consultations, and daily medication for all) which remind them that their stay is a *hospital* stay. Nonetheless, the activities which permeate everyday life at the JEC are part of a deliberate therapeutic system ('comprehensive care'). This system was initially constructed in response to calls to address the social *needs* of people with epilepsy. The sections below will be devoted to a discussion of the processes by which the JEC's planned activities and their goals, couched in the language of biomedicine, rehabilitation, restoration and social well-being, are naturalized and made relevant in the out-patient clinic and in every day life at the JEC.

Admission into the hospital

The patient's first contact with the JEC and its comprehensive care treatment program is through the out-patient clinic. The selection of patients for hospital admission may at first glance seem to be a neutral process through which patients' *needs* to be hospitalized can be evaluated by staff using objective, universal instruments. However, at the JEC, the selection of patients for admission is decidedly *particular* to the institute and affected deeply by its 'comprehensive care' framework and its orientation toward social normalization.

Patients may be selected for hospitalization in two ways. First, many patients (or their parents) come to the hospital for the express purpose of being admitted into the hospital (more often than not, the patients' parents provide the impetus for admission into the hospital). These people make their requests clear either at one of their interviews or on a questionnaire supplied to them by the hospital. Many have either been advised about admission to the JEC by their local physicians or have heard about in-hospital stays for seizure control through the media or friends, acquaintances or family.

Second, patients who are new to the clinic and who have not yet received the diagnosis of epilepsy are put on the waiting list for admission for observation, diagnosis, and pharmaceutical intervention. Patients who live close enough to visit the clinic monthly or bimonthly and would like to (or who the physician would like to be observed) are assigned a regular physician at the clinic. Others, who return to their home clinics, are given written responses to give to their regular physicians and are told that they may return to the JEC in the event of an emergency. Social workers give potential in-patients literature on the cost of staying in the hospital. They also advise them on financial and other matters. Physicians tell most patients that they will probably stay in the hospital for approximately three months.

Physicians at the JEC admit most patients for 'seizure control' and 'pharmaceutical therapy' *(yaku butsu chiryoo).* They admit a few patients for surgical therapy. Finally, some patients are admitted because they have overdosed on their medication, experienced sudden complications or status epilepticus, or have encountered other emergency situations.

When I performed my field research in 1991, physicians admitted some patients whose seizures were not controlled by medication, ostensibly for seizure control. According to the staff, these patients were also admitted because the physicians suspected they were non-compliant with their medical routines or were keeping irregular habits. Though the patients were told that they were receiving 'adjustment of medication' treatment, staff described their treatment plan as two-fold. They expected that these patients, after being admitted to the hospital, would learn from the routines in the hospital, change their poor life-style habits, and thus attain reasonable seizure control. These changes in habit, staff said, were as important as pharmaceutical therapy in many cases.

This stance is exemplified by this narrative, which details the selection of one young man for admission. After the patient's clinical visit one resident said in an informal conversation, "That patient was a strange character *(kawatta hito)* wasn't he. . . he's been put on the waiting list to be admitted because we suspect that his seizure control problem isn't with the inefficacy of his medication, but is in his life-style. We hope that once he is in the hospital, he will be put on a regular schedule, his seizures will be controlled, and he will see that it is his life-style that is aggravating his seizure problem."

The patient being discussed had visited the out-patient clinic because his seizures were not controlled. Briefly, the process by which the decision to admit this patient to the hospital went as follows (the visit described below was a 20 minute visit):

* * *

The physician walks into the clinic and silence falls over the residents. Before he enters, the residents have been leafing through the DSM-IIIR handbook and talking excitedly. The physician sits down and the resident reads the patient history she took before the session as the physician flips through the EEG report. The resident begins, describing the incoming patient as a young man, aged 26, whose seizures started at the age of 17. His 'educational history' is read -- he dropped out of junior high school and his grades were not good. During junior high school, he was caught smoking and drinking. Family history -- there is no record of seizures. He has one older brother who lives at home. He drives (eyebrows raise around the room, because it is illegal to have a driver's license if one has epilepsy). He has had one car accident. He has a motorcycle and still rides it now. The physician listens and folds pages of the EEG over, marking them for future reference. The resident continues, "before, the patient had seizures every six months but the seizures have recently increased to occurring one or two times every month."

The physician tells the resident to call the patient in. She calls the patient in. The patient walks in with his mother and older brother. The patient is dressed in blue jeans, a T-shirt and black boots, has longish, unkempt hair and dark skin. His mother is a small woman wearing a dress, and his brother has shorter hair and is wearing tan cotton pants and a dress shirt. There are 3 patient chairs in the out-patient clinic and a larger physician's chair directly facing the chairs. The residents sit behind a table watching the physician's interview of the patient and his family.

After the patient enters the room, the physician begins asking him questions.

What kind of work do you do? -- Part-time work *(arubaito)*

How long have you been doing this? -- For about six months.

What other kinds of work have you done? -- Other part time work.

How long have you stayed at these positions? -- This is the longest I have stayed at one job.

Have you ever been fired because of epilepsy? -- One time, I quit on my own because of seizures, and another time I was fired. I quit because I was weak in the morning and could not work then.

Do you like to drink liquor? --Yes.

The physician looks at the observers and says, "People who like to drink alcohol are usually not compliant. . ."

He then asks the patient about his driver's license, about driving, and about his motorcycle. The patient says that he has a driver's license. The physician then asks the patient if he knows that it is illegal to have a driver's license when one has a seizure problem. The patient does not respond.

The physician describes the legislation which prohibits people diagnosed with epilepsy from having driver's licenses. He then asks the patient if he has ever had an accident while driving. The patient says that he only has seizures when the car is stopped. The physician asks him if it is at signals (at flashing lights). The patient says, "No -- only when the car is stopped."

He goes on to tell the patient that driving is dangerous because he might have a seizure.

The physician then moves on to the issue of school and asks the patient questions about school. Why did you quit school -- was it because of epilepsy? -- No. I quit because I didn't like it. Epilepsy didn't happen until after I quit.

Have you been to prison before? Have you been arrested before? Handcuffed?

-- Yes, a few times. I think it is because of my hair and my looks.

. . . Just because of your looks and hair? You weren't doing something else then?

Well....

What about drugs? Do you inject yourself with drugs?

Pause. Well, marijuana. I've smoked it before

How many times? A few? How much does it cost? Tens of thousands of yen for a little bit? How much? Tell me, I don't know.

-- Well, one ounce costs about 3000 yen.

And how many times will that last?
-- Probably four or five times.
Isn't that expensive -- almost 1000 yen each time.
-- Well, yes.
Have you done any other drugs?
-- Yes. LSD.
How did you take it? By injection or did you eat it?
-- I ate it.
How many times?
-- One time
Which did you like better?
-- The LSD.

The physician turns to the resident and asks him, "Have you seen anything like this before?" --Only in text books. The physician turns back to the patient, who says that he did drugs mostly when he was playing with a band. The physician asks, "Why -- is it because you can make great music when you are high?" -- Yes.

The physician then moves on to the problem of seizures and asks the patient and the family to describe his seizures. He then asks the patient if he always takes his medication, to which the patient answers, "Yes, most of the time."

The patient's mother looks up at this point and says, "Well, in the afternoons, it is hard to get him to take the medication, but in the mornings it is easier."

The resident discreetly passes the blood level tests to the physician, who looks at the patient and asks, "Really? You aren't taking your medication. I can tell. Did you take your medication this morning?" -- Yes.

Yesterday morning? -- No.

The physician then asks questions about whether the patient drops things often or has jerking feelings in his legs or arms (these are signs of myoclonic seizures and absences[42]), to which the patient answers positively. The patient then adds that sometimes he listens to people and does not understand what they are saying.

The physician tells the patient that he is probably having a number of seizures he does not know about, and goes on to ask when he first started noticing this sort of strange behavior.

His mother breaks in and says, "Well, when he was in elementary school, he talked about the clock looking weird to him, and he would come home from school and talk a lot, which I thought was very strange. So from that time on, he visited a psychiatrist. I thought, something is strange about this boy."

The physician acknowledges this comment and goes on to look at the EEG again, particularly at the pages whose corners he has turned over. He then asks the patient what kinds of friends he has, to which the patient laughs and answers, "Dangerous ones."

The physician then turns and says to the resident (who has been recording the details of this clinical visit in the out-patient chart), "Out spoken. doesn't sleep well. Idiopathic epilepsy. Extroversion." He goes on to describe the various types of seizures that he believes the patient is having using technical terms in a mixture of English and Japanese.

The physician turns to the residents and says "underestimation" and "epileptic optimism" in English loudly. He then reverts to Japanese and says to the patient "You have a sickness that is easily cured, but you aren't taking your medication." He looks at the patient and says, "Your face color *(kao iro)* is very bad," then looks at the mother and asks "Has he always been like that?" The mother answers, "Yes. He says that his work is very difficult and is tired as a result."

The physician begins writing the clinical diagnosis in the chart.

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[42] Myoclonic seizures are simply jerking motions which usually occur in one of the limbs. Absences are very brief periods, as short as one second long, during which a person may lose consciousness temporarily. Both are classified as epileptic seizures.

The patient looks up at this point and says politely, "What is the name of my sickness?" The physician says "Idiopathic generalized epilepsy."

The patient looks confused and says, "That is a very complicated name. What does it mean? "

The physician looks up from his writing for a second and says, "Yes. It is very complicated, isn't it." He does not explain and goes on writing the diagnosis up. Arrangements were made for the patient to be admitted to the hospital, and the patient and family left the clinic.

* * *

In the case above, the young man described his problem in terms of seizure control. The reason he was admitted to the hospital was ostensibly given simply as seizure control through 'pharmaceutical therapy'. However, staff described another problem -- bad personal habits -- as significant and in need of treatment. Because of the social processes in place at the institute, the staff was able to make the final decision about which signs the patient presented should be considered symptoms of disorder.

* * *

According to institutional objectives, behavioral change is one significant objective of hospitalization. While this objective shapes patient selection, patients at the JEC give very different reasons for being in the hospital. In casual conversations and clinical encounters, the reason most patients give for coming to the hospital is 'to have their epilepsy cured'. When they describe the reasons that they have chosen the JEC, many patients note that they were referred to the hospital by their local physicians or that advertisements or articles about the center prompted them to visit the center. In addition, many people who visit the out-patient clinic and who are admitted into the Center as in-patients note that they have chosen the center because it is a 'specialized center' for the treatment of epilepsy.

The Center's patients do not speak of their difficulties related to epilepsy simply in terms of seizure control. They also speak about their dislike of the side effects of the medication they take or the embarrassment or trouble of taking medication every day. Many patients, both men and women, describe the problems they have finding stable work and articulate concerns about the future, getting married, having a driver's license (often a perceived ticket to autonomy) and about being completely dependent on their parents or other people.

Approximately half of the patients in the adult wards are men and half are women. Most of the patients are young, unemployed and unmarried. The mean age of the residents of the ward in July 1991 was 26. At this time, only 6 of the residents were over the age of 35. Most of the residents were unmarried, and over half were unemployed. Many of the remaining half were either students or worked in part-time jobs. Most did not have university degrees, although some had or were in the process of receiving junior college degrees or vocational training certificates. (Ironically, many of those who had stable jobs or prospects for stable work were selected to receive the most efficacious form of therapy in the ward, surgery, while those judged to be best prepared for reintegration into society were enrolled in the more 'intensive' occupational therapy program.)

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In summary, staff select patients for treatment at the JEC using standards which include the evaluation of both personal habits and also physiological problems. They describe both to patients as important factors which will affect seizure control. They say that this will, in turn, affect patients' *quality of life*. Patients, on the other hand, do not point to shortcomings in their own behavior or lifestyles, but to problems in society which result from having epilepsy and being discriminated against. These include problems getting married, being able to find employment, and being able to lead independent lives. In their accounts of admission to the hospital, they are primarily concerned with having their epilepsy <u>cured</u>.

On learning to become a moral person: comprehensive care and social rehabilitation

The therapies for in-patients which are practiced at the JEC can be divided into two categories. Different staff members in the hospital are responsible for each type of therapy. The therapies include: (1) pharmaceutical or surgical therapies, which the Center's physicians are in charge of, and (2) rehabilitation therapies, for which social workers, nurses, and recreational therapy (paramedical) staff members are held responsible.[43] Enforcement of the authority of the institute's knowledge and practices by staff occurs in a setting in which patients cooperate to make the hospital run smoothly *and* in which little obvious (i.e. direct and verbal) pressure is placed on the patients to conform to institutional imperatives. Techniques of manipulation which the staff employ bring about compliance *despite* the emphasis on cooperative practices (cf. Rohlen 1983, 1989; Peak 1989).

The following is a description of each of these therapies and the ways in which their goals were presented to and discussed with patients and among staff in 1991.

Living with the group, independence, a regular life and good sleeping habits

While the name 'comprehensive care' may suggest a formalized set of techniques and *therapies* with defined beginnings and ends which are conducted in therapeutic classrooms, the most fundamental moral precepts which staff of the JEC attempt to teach patients -- 'independence', 'living with the group', 'maintaining regular living and sleeping habits' --- cannot be found in neat, defined packages of written rules and ethical codes taught to patients in the classrooms of the institute's therapy building. Instead, as in many other Japanese social institutions with similar goals (cf. Kondo 1987, 1990; Reynolds 1980, 1983; Lebra 1976), these basic living values, fundamental elements of the JEC's treatment methods, are encouraged through regular, habitual daily practices in each of the wards at the JEC.

According to the staff, the need for the behavioral reform therapies practiced at the JEC stems from an extreme lack of independence and problematic behavior in many of its patients. Nurses at the JEC say that these problems arise because many of the people who are admitted into the hospital have been spoiled by their parents and have not learned to care for themselves in the most basic ways. They have not learned to 'live in a group' or to work cooperatively with other people. Some of the patients, they say, have always been given their favorite foods, are allowed to watch television all day long, and do not wash their own

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[43] Although these might equally be called medical and non-medical therapies, the Center's director explicitly notes that the distinction is not drawn by hospital personnel (for funding reasons among others).

clothes or know how to dress themselves. According to staff, these problems often result because families have spoiled the patients unintentionally and therefore have made them grow dependent.

Furthermore, they say that the people surrounding the person with epilepsy (i.e. well-intentioned family and friends) often worry about possible accidents far more than the person having seizures. As a result, they place undue restrictions on the patient. Examples of these restrictions include: not being able to participate in sports, not being allowed to participate in school activities, and not being allowed to go places alone.

Finally, many of the JEC's patients have had a very difficult time becoming financially independent. According to staff, this may have occurred because they have quit school at an early age (because of seizures) and therefore are not technically skilled. Staff add that because many of the JEC's in-patients spend most days at home, they have not had the opportunity to develop proper social skills. Many patients therefore have interpersonal problems on the job when they *do* get jobs and either quit or are fired from their jobs. Finally, some staff members stress that one very important factor shaping financial and emotional dependence are the societal restrictions on people with epilepsy, particularly restrictions on the types of jobs they can hold.[44]

With respect to therapies, staff say that they attempt to break patients' bad habits and to foster independence by routinizing patients' days and giving them the responsibility to care for their own living space and clothing. They emphasize the necessity of these daily routines in an introductory document which is discussed with and given to all patients. The document's authors do not simply describe the necessity of 'regular living habits' to everyday life. They also discuss a postulated causal relation between lowered seizure frequency and the living habits encouraged at the JEC.[45] According to staff at the JEC, emphasis on this

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[44] This was one of the primary reasons that the hospital was established. It is discussed in greater detail in the section entitled "The establishment of a comprehensive care center in Japan" (Chapter 2).

[45] The nurses who run each of the hospital's wards prepare the information sheets containing rules and schedules. The information sheets differ from ward to ward.

causal relationship represents their attempt to reinforce the necessity, after discharge, of maintaining the practices and habits which permeate daily life at the JEC.

Habituation to daily routines begins on the first day of admission to the JEC. Days for in-patients begin with a 6 am wake up call, 6:30 am morning stretching exercises, and breakfast at 7 am. Preparation for bed begins at 8:30 pm, and lights out is at 9 pm every evening.

As part of the process of (moral) education at the JEC, staff teach patients who cannot wash clothing how to wash it. They give patients who have trouble getting along with other patients sets of rules to read, think over and post. Patients who do not know how to pick out clothing and dress themselves are given basic rules to follow. Staff have designed these rules to habituate patients to these everyday tasks. When staff members describe these activities, they stress the importance of cultivating independence (lack of dependence on others) and the ability to 'live with a group'.

Staff supplement these daily practices with subtle and not so subtle reminders of their relationship to overall health, well-being and seizure control. For example, once a month, one of the attending physicians gives a lecture to patients. In the lecture, the physician reinforces the important effects that the changes in life-style which staff recommend have on the patients' health (i.e. on their epilepsy).

In this hour-long lecture, the physician generally describes one aspect of epilepsy from a medical perspective. He gives the lecture in simple, straightforward terms so that the patients will understand. He then broadens the explanation to the ways in which other aspects of the hospital's treatment program will effect the patients' lives. The descriptions are often used largely to encourage medical compliance. The talk is always followed by a question and answer period.

Topics which have been covered in these talks include: descriptions of seizures, descriptions of which patients can receive surgery and why, and general descriptions of what can lead to increases in seizure frequency.

All patients are required to attend these lectures, and some bring along notebooks and listen attentively while others joke about headaches before the talks and pay little attention during the talks. A chalk board is brought out to the day room for these and other meetings. During the meeting, the physician in charge sits in front of the long, cafeteria-type tables. The ward's patients sit at the tables.

The following is a detailed description of a talk which was organized and given by one of the ward's neuro-psychiatrists. The talk exemplifies one way in which particular daily habits reflecting ideas of group interdependence, humility, and routine are cultivated in the JEC's patients. It highlights the ways that their necessity is reinforced and naturalized in the arena of the hospital ward.

* * *

The physician's talk was about living with epilepsy and was divided into three areas of concern: (1) seizures, and what makes them occur more frequently; (2) psychiatric problems and living with a sickness *(seishinteki na mondai; byooki o mochi nagara kurasukoto)*; and (3) participating in society. The physician listed 5 topics under the first category which were concerned primarily with daily practices which would lead to an increase in the frequency of seizures. His first point under this category concerned the importance of regular, daily intake of medication. He pointed out that one half to two thirds of all patients with chronic conditions sometimes forget to take their medication and described this forgetfulness as understandable. He stressed at the same time, however, that patients should be careful to take their medication because the medication does not work unless the full dosage prescribed is taken.

His second point concerned lack of sleep and its possible relationship to increases in seizure frequency. He noted that because of this possible relationship, people with epilepsy should sleep each night for 8 hours and set regular hours if possible and added that drinking alcohol, because it made one sleep less, was something that should be limited. He went on to stress that if anyone in the ward was having trouble sleeping, they should take sleeping pills. Although he said that he knew many of the Center's patients were against taking sleeping pills, he stressed that they would be better off taking medication so that they could sleep well and seizures would not then occur.

He went on to continue his discussion on the regulation of liquor intake. He told the patients that in some people with epilepsy, alcohol triggers the occurrence of seizures or has some sort of negative effect. He then went on to note that although alcohol intake was not strictly forbidden (by physicians) for people with epilepsy, they must limit the amount of liquor they drink. His fourth point under the first category concerned what he said were the impacts of nerves, being nervous/worried and stress *(sutoresu)* on the occurrence of seizures. He recommended to the patients that they lead as calm a life as possible, without stress.

The fourth point the physician made concerned exercise. He noted that exercising was not a problem, but over-exertion from exercise would possibly bring about the occurrence of seizures. The physician drew a simple diagram of the body and lungs to explain that while normally, the body takes in oxygen and releases carbon dioxide, during exercise the opposite happens. This, he said, produces a greater tendency to have seizures. In the final point in this category, the physician noted that one of the greatest problems people with seizures had was in the water -- asserting that more people with epilepsy die from drowning in the bathtub than for any other reason. He recommended not going to the ocean because of its waves, but assured his audience that swimming in a swimming pool was allowable. In his opinion, he said, he would discourage overeating and drinking too much.

In his talk, the physician covered problems which he said commonly existed among patients with epilepsy under the second category: 'psychiatric problems and living with a sickness'. He noted that many people with epilepsy had problems with their interpersonal relations *(taijin kankei)*. He stressed the importance of practicing conducting proper interpersonal relations in the hospital as well of learning how to do things on one's own and being independent. He stressed during this talk that as adults, people must go out into society after leaving the hospital and leave the house and do things on their own initiative.[46]

The third and final category the physician covered in his lecture was entitled 'participating in society'. The physician emphasized during this that the goal which the patients in the hospital should strive for is to participate in society. During this part of the talk, he emphasized that the people with epilepsy should look at their abilities realistically, noting that things that one considers oneself as being able to do 100% should be reconsidered, one's expectations lowered and be considered 80% rather than 100%. His main emphasis was on urging people to match their abilities with problems that might come up because of seizures in order to find a suitable job.

Four questions came up after the session, each one asked by patients wanting clarification on the rules described. To a question about going to the ocean when accompanied by one's parents, the physician answered that as long as the person's parents didn't lose sight of her it would be fine. To a question concerning whether or not day time naps could be taken to make up for a lack of sleep, the physician answered no. To the mother of one of the hospital's in-patients' question about a variation in the side effects and sleepiness depending on the drug given, the physician answered that there should be no difference. And finally, to a question from a shy patient about whether it was important to choose spending time with people over spending time alone, the physician answered that it was.

* * *

In addition to the required monthly talks and habituation into the daily practices described above, staff have put other rehabilitation practices and therapies in place to encourage responsibility and interdependence in-patients. These practices resemble those found in other Japanese social institutions (Rohlen 1974, 1983, 1989; Peak 1989). For example, all patients are responsible for the management of the ward, including the management of minor conflicts in the ward, tidiness and other problems which might surface. Each month the patients hold a patient meeting which all patients must attend. Those patients with complaints or issues which they would like to air submit notes with these comments on them before the meeting. The issues are brought up, defended and voted upon at the monthly meetings. There are no officers, elected or not. Rather, power is shared between all patients. Each month a new room of patients (approximately four to six people reside in each room) is

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[46] *"jibun no chikara de ie kara dete; jibun no ishiki de. . ."*

put in charge of the treasury (dues are collected from each patient on the ward) and of management of problems in the ward.

During the monthly patient meetings, after patients make suggestions or comments, the floor is opened up for discussion, comments or criticism. A vote is usually taken and resolutions are passed if there is total agreement on the floor. Those who abstain or vote against a particular proposal are given the opportunity to voice their opinions. Only after total agreement is reached is a proposal passed.

Areas of discussion during these meetings often revolve around problems with television time, keeping the day-room clean, and around objects which are commonly used. Not all patients find this particularly interesting or helpful, nor do all patients participate fully. Many patients, however, raise their hands and voice opinions.

Though staff nurses attend the meetings, comments from them rarely surface and, if they do surface, they come only <u>after</u> the meeting has effectively ended. Physicians and other staff members do not attend the meetings.

Day Care and occupational and exercise therapy: improving interpersonal relations

The mandate to habituate patients to the outside world, to life in a group (*shuudanseikatsu*) (cf. Lock 1991; Rohlen 1989; Peak 1989) is also carried over to daily rehabilitation therapies at the JEC. While ward-oriented therapies are decidedly directed at cultivating the habits fitting of 'life in a group', Day Care and occupational/recreational therapy activities have been instituted to encourage other personality and behavioral characteristics which have been deemed necessary in the mature adult, the *shakaijin*. These characteristics include the improvement of *work skills*, and the encouragement of self-confidence, perseverance, humility, habituated and regular activity, good 'interpersonal skills' and independence (self-reliance).

Two weeks after checking into the hospital, all patients, with only special exceptions, must begin attending the JEC's occupational and exercise therapies. The activities are held in a gym-like building which houses a volleyball/ basketball court, a clay firing kiln, a *kara oke* singing room, a wood working room, a kitchen, a traditional tea room, a special Day Care activity room and several other craft rooms. Eight occupational therapists staff the Day Care center.

Personality changes which the staff encourage with the therapy activities are not only emphasized in the daily activities required of the JEC's patients. Staff also circulate descriptions of the purposes of Day Care and occupational therapy in at least three separate documents: (1) the introduction to the ward that they give to all patients and (2) two separate advertisements of the center (produced for families and physicians who might refer patients to the JEC). The authors of the documents describe vague, causal connections between the JEC's occupational and recreational therapies and the reduction in seizure frequency or other bodily (health) issues.

The introductory document all patients receive upon their arrival at the JEC reads as follows: "One of the purposes of occupational therapy is to provide an in-hospital experience most nearly resembling life in society. . . Seizures and medication may influence performance of vocational/occupational activities. These activities are planned to treat (provide therapy for) problematic areas other than epileptic seizures." In the same document, the authors describe the necessity of daily exercise. They assert that "a fitting amount of exercise reduces the frequency of seizures while also having a positive effect on psychological well being. Of course, it has positive effects on the strength of the body. For those patients without handicaps -- let's exercise with enthusiasm!"

The authors of both of these statements make vague references to the importance of the JEC's therapeutic activities. They do not specify the particulars of problems 'outside of seizures' or the benefits of daily exercise. Nonetheless, the precepts, rules, and therapies of the ward are laid out and legitimated on this document through their vague causal relation to the maintenance of bodily health and their implied positive effects on seizure control.

With respect to these therapies, patients in the adult wards are divided into two distinct groups: those who participate in 'Day Care' activities and those who participate in both recreational and occupational therapy. According to the hospital's plan, Day Care is differentiated from regular occupational therapy in that its activities are meant to simulate the regularity of a working schedule. Staff divide the groups by 'level' or 'ability'. Patients in the Day Care group are seen as the more 'able' patients.

'Comprehensive care', as it is interpreted by the institute's staff, shapes the process by which patients are selected to participate in these therapies. The number of patients who can participate in 'Day Care' is limited to ten per ward. Therapists, physicians, and nurses say that patients who they select for this therapy should ideally be those who will benefit from the training. In other words, these patients will, upon discharge, take full advantage of the skills they are taught during the therapy activities.

The policy of selective elimination of Day Care participants does not result in *overt* discrimination against certain people. When asked who was eligible to participate in Day Care, physicians, social workers, therapists, and nurses said that women *and* men, educated *and* uneducated patients, and previously employed *and* unemployed patients were eligible. Yet, in July 1991 though the patients in one adult ward were half men and half women, all of the patients from that ward whom staff had assigned to Day Care were male (representatives from other wards, however, included both men and women).

Patients who participate in Day Care activities meet for therapy in the morning and afternoon five days a week, with the exception of some Fridays. They engage in daily activities which staff describe as simulating a <u>real</u> work environment. The hospital's occupational therapists supervise them.

The remaining forty or so patients in the ward attend therapy activities in the same building. Their schedule is as regular as that of the 'Day Care' group but not as 'intensive'. These patients go to occupational therapy three mornings a week. The remaining time in their daily schedules is filled with recreational therapy and other activities. They attend 'occupational therapy' on Monday, Wednesday and Friday in the morning and 'recreational therapy' on Tuesday, Wednesday, Thursday and, occasionally, Friday afternoons. On Fridays, some patients must attend talks or discussion groups.

Although in theory, staff describe contrasts between Day Care and occupational therapy, in practice, the two types of therapy are nearly identical. Day care activities are simply occupational therapy activities conducted twice daily instead of three times a week.

When a patient is assigned to one of these groups, the physician in charge of her case must fill out a form which includes the person's address, educational history, disease name, seizure history and types, and an evaluation of the person's present abilities, problems and future goals. She then gives Day Care therapists copies of this document. The therapists attend the daily staff meetings during which nurses introduce new patients and staff discuss the daily activities and problems of patients.

As with ward activities which encourage 'life in a group', staff never mention the object of behavioral reform directly to patients *during* rehabilitation therapies, nor do they present patients with rules and precepts which will lead to 'correct' behavior *during* the therapies. Instead, they encourage desired personality characteristics and behaviors through habituation to particular practices.[47] Though therapists evaluate patients according to the categories mentioned above (perseverance, independence, work ability, etc.), they do not tell patients that they will be evaluated. Staff members do not discuss the evaluations with patients at any point before, during, or after admission and discharge.

When patients first begin attending occupational therapy, staff tell them to choose projects they are interested in completing independently. Occupational therapists supervise Day Care participants, while nurses supervise the remaining patients. Low staff intervention characterizes the therapy activities. While a number of staff members 'supervise' patient activities, they spend very little time involved in individual projects. Instead, they spend their time emulating the behavior expected of patients. They produce their own crafts, work independently, and refer to manuals when needed.

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[47] Indeed, when asked to make sense of the JEC's therapy activities, patients generally refer to them as time fillers or as 'fun' and as different from daily life in a normal hospital. They also describe them as tiresome or boring at first, but as activities to which one can become accustomed.

Staff discourage patients from relying on assistance from them. The therapists often tell those patients who *do* ask for assistance to refer back to the manual from which they were working. They usually encourage patients to work in silence and tell them that they must complete all projects they begin. They scold patients who progress on their projects too slowly.

On most afternoons, non-Day Care patients go to the gym or outdoors to play team sports, games in which all (non-Day Care) patients must participate. Only those who have been medically excused (usually about 2 people) are permitted to watch. Usually, nurses assign patients to volleyball teams. After the games, the hospital's patients must take the volley ball net down and collect the sports equipment that was used.

Hospital officials categorize the above forms of treatment (occupational and other therapies) as strictly medical (Seino, personal communication). The descriptions in the sections above suggest that these practices resemble those at other institutions in Japan (cf. Reynolds 1980, 1983; Lebra 1976; Kondo 1987, 1990). Moreover, they demonstrate that vague references to causal connections between health, well being, and the JEC's therapy activities have leaked into the rhetoric surrounding the justification for conducting the therapies. This has allowed for the legitimation and naturalization of the authoritative knowledge about disability and disorder related to epilepsy which permeates daily life of the JEC.

Pharmacological and surgical therapy: comprehensive care and biological intervention

Pharmacological and surgical intervention comprise the other essential component of the comprehensive care plan of the JEC. While these forms of intervention may seem to exist in a separate realm from the occupational and recreational therapies, staff members of the JEC insist that they are used only in reciprocal interdependence with the therapies described above. Boundaries between (conventionally understood) biomedical treatments and other treatments offered at the center are, at best, unclear. For, as many of the JEC's physicians insist, seizure control without social rehabilitation does not meet the goals of comprehensive therapy endorsed by the JEC. Physicians therefore integrate these therapies fully into the 'comprehensive care' framework.

The biological therapies can be divided roughly into two categories: surgical therapy and pharmaceutical therapy (adjustment of medication). Specialist trained in different areas of medicine treat people who fall into the two categories: neurosurgeons are responsible for the medical treatment of and selection of surgical patients, while the ward's neuro-psychiatrists are responsible for those who are admitted for 'adjustment of medication'.

Adjustment of medication

While specific reasons that patients are admitted vary widely, most patients have the problem of intractable epilepsy -- seizures which have not been *adequately* controlled through pharmaceutical intervention -- in common. At the JEC, staff routinize, regulate and homogenize the lives of in-patients under the reasoning that this routinization will facilitate the process of discerning whether the patients' seizure intractability has resulted from 'irregular living habits' or from the inefficacy of prescribed medication.

All of the Center's patients who are diagnosed with epilepsy must take some sort of anti-epileptic medication (AED) daily. As most of the patients who are admitted to the JEC are having trouble with seizure control or with side effects of their medication, 'pharmaceutical therapy' largely consists of changing patients' levels from medication until seizure control is attained with minimal side effects. This is very difficult in many cases. Staff may change prescribed levels or types of medication as often as once a week.

Intake of medication is turned into a daily mealtime ritual at the JEC. Staff have inscribed reasons for its necessity in the patients' introductory document. Its necessity is reinforced by the appearance after each meal of a medicine cart manned by a nurse. The cart contains a separate drawer for each patient. In discussions and clinical encounters, nurses and physicians describe causal connections between regular life habits, adequate amounts of sleep and low seizure frequency to patients. All patients with trouble sleeping are given sleeping pills regularly in addition to their regular medication.

Daily physician rounds usually involve short reports from patients concerning seizures from the previous day and their problems with their medication. The rounds are supplemented by once-weekly grand rounds with the hospital's Deputy-Director. During grand rounds, the Deputy-Director sometimes makes recommendations about pharmaceutical or treatment changes which might be suitable for particular cases.

Although staff usually tell patients that they will be admitted to the hospital for approximately three months, many of the people who are in the hospital for 'adjustment of medication' stay in the hospital for six months, a year, or more. Physicians note that this often results from difficulties in controlling seizures in cases in which the physician, the family or the patient want the patient's seizures to be completely controlled before discharge from the hospital.

Surgery

The translation, naturalization and wedding of practices and goals of the comprehensive care plan to the seemingly neutral and universal language of rehabilitation, *quality of life*, disability and social well being is particularly apparent in the area of surgical treatment. Unlike 'adjustment of medication', which is offered to all patients at the institute, surgery has only been offered at the JEC to extremely limited numbers of people (by 1991, between 20-30 patients/year) since 1983.[48]

Physicians at the JEC usually account for the low number of surgeries historically. They point to the lack of Japanese neurosurgeons who are trained to perform surgery for epilepsy, and say that this resulted from an agreement in 1975 by all Japanese neurosurgeons trained to perform surgery for epilepsy to quit performing surgery (Seino and Mihara 1991). Since that time, only a few patients have been given surgery.[49]

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[48] This statistic is drawn from hospital records compiled by the institute's neurosurgeon.

[49] Since surgery has been shown to be highly efficacious in controlling seizures originating in the temporal lobes of the brain, the patients who receive surgery comprise a highly privileged group who stand a good chance of achieving complete or nearly complete remission of their seizures (cf. Rasmussen 1983; Mihara et al. 1990).

The JEC's physicians select surgical candidates with great care. They emphasize in discussions and case conferences that the reasons for performing surgery are related to the institute's larger goals to improve social rehabilitation *(shakaifukushu).* As such, they note that those patients who are chosen by the Center's physicians to receive surgery are *only those whom the staff identify as most likely to benefit from surgery* (i.e. those patients who will be able to rehabilitate fully and re-enter society after surgery).

The Center's physicians divide the patients on whom they perform surgery into two major groups. The first group of patients consists of people in whom the surgeons have found circumscribed 'organic' or 'tumoral' lesions in the temporal lobes of the brain with imaging studies. If the location of the lesion corresponds with the location of epileptogenic areas in the brain (located through video/EEG monitoring) *and* neuro-psychological tests suggest that significant neuro-psychological deficits will not result, they will perform surgery.[50]

Surgeons select the second group of surgical candidates, those in whom circumscribed 'organic' or 'tumoral' lesions cannot be found, using a strict set of criteria. The institute's surgeons have constructed these criteria to match the goals of the 'comprehensive care center' (Mihara et al. 1990). Initial selection of patients from the second group is based on these five criteria: (1) The epileptogenic focus must be localized in the temporal lobes; (2) The patients must have received appropriate medical treatment for five years; (3) Complex partial seizures must occur at least weekly; (4) The patients must be older than 15 years of age and have no persistent psychiatric symptoms; and (5) Good social adjustment must be possible when control or improvement of seizures is achieved.

Those patients who the institute's staff deem as satisfying the five criteria listed above move on to the first of a three-step evaluation procedure. The staff use these criteria to further eliminate patients from consideration for surgery. Step I of this process consists of further testing, including: (1) a reappraisal of intractability; (2) a neuro-psychological

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[50] These patients made up almost half of the surgical patients -- in a 1990 paper, Mihara et al. note that of 60 patients who had received surgery, 33 were non-tumoral cases and 27 were tumoral cases (Mihara et al. 1990:277).

evaluation (including an Amytal test for memory, IQ, Rorschach, Baum, and other personality tests); (3) imaging studies (CT, MRI, Tomo-PET and SPECT); and (4) recording and observation of spontaneous seizures (Mihara et al. 1989a: 109; 1989b: 276; 1989c: 537; 1990: 286). Step II consists of depth-electrode implantation, and Step III is the neurosurgery (excision of part of one of the temporal lobes of the brain).

What are the expected goals of surgery for epilepsy at the JEC, given the strict criteria for the careful selection of surgical candidates? In papers, staff physicians, social workers and nurses emphasize changes in seizure frequency and social rehabilitation among patients who have received surgery. The authors of one such paper argue that "the indications for surgery and post-operative care are of practical importance" (Mihara et al. 1990:276) because surgery can control seizures. This in turn, the authors argue, can bring about full-time employment (and therefore an increased *quality of life)* in the people in whom seizures are controlled.

The authors of the article review both seizure frequency and 'job placement status' after surgery as essential elements of the surgery's 'practical importance'. In these papers, the authors relate the criteria used to select candidates for Step I to two issues: (1) proof of medical intractability (the first three criteria) and (2) fairly definitive proof that the surgery will serve a 'social' function (the last three criteria). Judging from the text of the article, then, the ultimate goals of surgery at the JEC are both seizure control and social rehabilitation. Staff describe both probable reduction in seizure frequency *and* changes in the occupational status as essential factors to consider when they select patients for surgery.

How do the social priorities that the authors describe translate into the selection of patients who will receive surgery? In the articles, the authors do not describe the patients who were eliminated before Step I studies. Nonetheless, the priorities and standards of 'comprehensive care' are also reflected in the distribution of patients staff eliminated from consideration for surgery during and after Step I. Mihara et al. report that of 142 people chosen using the initial 5 criteria listed above, 66 were dropped from consideration for surgery following Step I studies (Mihara et al 1990).

The authors grouped the people they eliminated from consideration after Step I into six categories: (1) 25 (38%) had either multiple, extra-temporal, extensive, or undetermined epileptogenic foci; (2) 18 (27%) were classed has having 'psychological problems', including those who were considered psychotic, having character/behavior abnormalities, and those who were not compliant with their drugs or with the Step I examinations; (3) 7 (11%) were seen as in danger of functional deficits post-surgically; (4) 3 (4%) had structural or functional abnormalities in the brain; (5) 6 (9%) were seen as capable of working even with recurrent seizures; (6) 7 (11%) were seen as needing reappraisal of drug treatment (1990: 277).[51]

Thus, people were not simply eliminated from consideration for surgery for physiological reasons. The breakdown above indicates that the hospital staff also eliminated a number of people who had either 'psychological problems' or could work in spite of their seizures. In the process of eliminating patients from consideration for surgery, staff effectively have ultimate power in defining 'disability', 'awareness' and 'social necessity'.

As with other patients at the institute, the daily life of surgical patients is dictated by therapies devised under the comprehensive care plan. In other words, all possible surgical candidates are integrated in to the daily life at the institute. They are required to attend occupational and recreational therapy (or school) daily and participate in the management of the ward. The patients differ from other patients, however, in two ways (1) staff keep them on a fairly regular admission/discharge schedule and discharged them upon completion of their tests and/or surgery; and (2) staff have selected them carefully via the process described above. The patients who are selected for surgery are therefore usually the most highly educated and best prepared for 'reintegration' into society in the ward.

The following narrative describes one young patient who was removed from the list of possible surgical candidates, but was, nonetheless, kept in the hospital for rehabilitation therapies. I hope to demonstrate with this narrative (1) the inseparability of evaluation for

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[51] At the MNI, surgical patients are not selected using criteria like those used at the JEC, but rather simply by whether or not their seizures will be easily controlled through surgery. For example, in a 1991 paper by Andermann, most references to selection of patients to receive surgery were to their physiological eligibility for surgery. Direct references were *not* made to their 'job placement status' (Andermann 1991).

surgical therapy and the goals of 'comprehensive care' and (2) the differences between surgical patients and non-surgical patients in the amount of time they spend hospitalized and in their 'social' prognosis.

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Aoyama kun's story[52]

At the nurses' report one August morning, the night nurse in charge reported that Aoyama Hideo kun, who had left the afternoon before on a week-long holiday pass, had written a note to staff members. In the note, he wrote that he believed that he had caused problems in the ward and was seen by the ward's staff as being 'bad'. He wrote that he promised to be better-behaved when he returned to the hospital the following week. "Please watch me and see how good I will be," he wrote in his note. Staff members attending this meeting smiled after the nurse described his note.

Aoyama kun, 15, had been admitted to the adult ward (though he was not considered an adult yet) for possible evaluation for surgery.[53] At the time he wrote the note, he had been an in-patient at the hospital for 6 months. This was his third admission to the hospital, his first admission being approximately three years before and the second time, approximately one year before he wrote this note. He was admitted to the children's ward and stayed hospitalized for nearly 5 months the first time (rare for children in this hospital), while the second time, he stayed in the adult ward for one month simply as a trial to see if he would have any problems staying in the adult ward. This time, it was estimated before admission that he would remain in the hospital for 2 months.

The contents of the note did not come as a complete surprise to the staff, for during the weeks immediately preceding this visit home, they said that Aoyama kun had caused a number of problems with other patients and the ward's staff members. Though he got along well with his physician and was eager to show him new pictures of cars, rock stars, and comic books, they said that he had not gotten along well with other staff members and patients recently.

A. Hospital records

According to hospital records, Aoyama kun had his first seizure when he was nearly two years old and has been having them since. He has two types of seizures, the first of which are simple partial seizures (absences) and the others which are complex partial seizures. The simple partial seizures are accompanied by a feeling of fear and occur approximately one to two times a week, while the complex partial seizures occur once a week.

Records show that he has been treated with medication for temporal lobe epilepsy by out-patient physicians, but the medication has been, for the most part, unsuccessful at bringing his seizures adequately under control. His physicians have also noted the possibility that his seizures might originate in the frontal lobes. When he was admitted to the hospital this time, he was taking 4 different kinds of anti-epileptic medication (AEDs), and the last time he was admitted to the hospital, he was taking 5 different kinds of AEDs.

When he was discharged from the children's ward in 1988, staff nurses who filled out his discharge summary noted that although his appetite was good, and he had no trouble completing tasks independently, he had problems falling asleep (and sleeping) because of night-time seizures. They also noted in his records that he had problems with interpersonal relations *(taijin kankei)*. The Center's social worker noted that his mother had said that

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[52] 'Kun' is a diminutive usually used when addressing young boys in Japan.

[53] All patients who were under consideration for surgery were admitted into this adult ward for their pre-surgical evaluations. A few of the patients in this adult ward were considered children (15 years of age or under) by the physicians in the hospital.

seizures had not interfered much with his 'everyday life' *(nichijoo seikatsu)*, though he had many problems keeping up in school. His parents were considering putting him in a 'special education' *(tokushuu)* school because of his problems in keeping up.

After his second time in the hospital, this time in the adult ward, nurses and day-care workers made some of the same observations. They noted that although he was friendly with others in the hospital, he would converse with his fellow patients well past lights out every night. Under the heading of 'living habits', they noted that his problems falling asleep and would often come out into the day room and to the nurses' station well past lights out.

'MR+' (mental retardation, positive) was marked on his first admission chart and his current attending physician had written 'possible mental retardation' on his current chart. He had been given an IQ test by the institute's psychologist three years before, who had found his IQ to be 59, or 'mental retardation level'.

B. Aoyama kun

One May afternoon, Aoyama kun was sitting with another of the ward's patients in the hospital lobby, angry with another patient. He had gone for a walk with a fellow patient and was staring at the floor, fiddling with his shoes. He said that the children's ward was different from the adult ward -- people got along in the children's ward and the nurses and physicians were not so strict in the children's ward.

He had always, as long as he could remember, had this seizure problem, and he had checked into the hospital in order to have it treated immediately after graduating from junior high school. He was now taking correspondence courses and was interested in finding an office job after finishing the course. He received packages every few weeks from his correspondence school and sometimes had trouble completing the assignments (he often elicited the help of other patients and staff members).

He spent much of his time socializing with other patients, and had made some good friends in the hospital. In addition, he said that he was interested in learning about gardening, and was particularly interested in flowers and other plants. When he was in the ward, he often browsed through a book about plants and gardening.

C. Nurses and other staff members

In a casual discussion about the lives of people with epilepsy and their employment opportunities, one of the ward's nurses said that many of the patients had problems finding employment. He conjectured that the problems in finding employment were based not on a lack of employment opportunities, but rather on disparities between what types of work the patients wanted to do and what they could feasibly do, given their abilities. He said that their pride was too 'high' and they needed to lower it.

Aoyama kun was a good example of this problem, he said. He opened Aoyama kun's chart to the results of the IQ test and, stressing the score, said that Aoyama wanted to do something that would require the skills of a person with average abilities. He said that he was simply not capable of doing that sort of job.

In other conversations, staff members noted that arrogance like Aoyama kun's was common in the people that were admitted to the hospital. They said that often, because the patients had a chronic sickness, their families treated them in special ways -- they spoiled them. They also told these people that they could do things that they just did not have the ability to do.

With respect to Aoyama kun, they noted that not only was he arrogant *(poraido ga takai)*, but he also had poor living habits and had trouble getting along with others (i.e., he had problems with his interpersonal relations). The staff said that his poor living habits resulted from his environment at home and being spoiled by his parents.

In addition, some staff members described his problems in relation to his age, saying that he had not had any problems when he had been admitted previously because he had been in the children's ward. In the children's ward, they said, he did not have problems because he was spending time with children. He was not expected to understand how to cooperate with the group the way that the adults were. They said that the adults were probably less tolerant of Hideo kun than the children had been -- there, they said, he was the oldest of the children, and in the adult wards, he no longer the oldest and is a child once again. They said that Aoyama kun, like many other patients in the hospital, had problems with interpersonal relations, perhaps a result of having been spoiled by parents.

D. The physician

Aoyama kun had been admitted in February for consideration for surgery, and his chart showed that he had undergone the preliminary tests for surgical candidates. His chart even showed a sketch of his brain, showing the part of the temporal lobe which was to be excised. By June, however, none of the staff members spoke in terms of Aoyama being a surgical candidate.

During a clinical session with Aoyama kun , the physician discussed Aoyama kun's case. He said that although Aoyama kun had been considered for surgery, the staff had decided against it because they were not convinced his problems with seizure control would be resolved through surgery. He then using the English adjective, said *'immature seikaku'* (immature personality). Aoyama kun did not understand what the physician said, nor did he question him about the meaning of the adjective. The session continued, and the physician told him that regular sleeping habits were important, and that the sleeping pills which had been prescribed were to help him sleep at night. Aoyama kun left the consultation room shortly afterwards.

When the morning consultations were over, the physician expanded on his interpretation of Aoyama kun's problems. He said that Aoyama kun was not leading a regular life, that he was staying up at night, which made him sleepy during the day. Because of these irregularities, the physician said that he could not know how bad his seizures *really* were or how difficult they were to control. The physician went on to say that he had character problems, and was a bit immature and, what he really needed was to mature and to act more like an adult.

In a discussion later on, the physician continued. He stressed that Aoyama kun's greatest problem was that he had been spoiled by his parents, and that this time in the hospital, the staff decided not to perform surgery on him. They decided instead to make his days and nights more regular. He said that Aoyama kun's problem was that when he was a child, his auras were very scary at night and his parents would let him stay up at night. He couldn't sleep because he was scared by his auras. And as a result, he got into the habit of staying up all night. He was then very tired during the day. One result of this irregular sleeping pattern, the physician said, was that during the day, he would have seizures.

The physician then said that he didn't think he could help him with what was already wrong -- his habits. He added that he didn't think he could eliminate the seizures which were the scariest and most troublesome for Aoyama kun. The best he could do, he said, was try to teach him to get along with people and have regular sleeping patterns (to sleep at night and to stay awake during the day). After all, his greatest problem was with his *life attitude (seikatsu taido).*

With respect to age, the physician added that he thought that Aoyama kun's age was not quite right for surgery. He said that patients at this age who had received surgery had the greatest problems with going out into society (to work), adding that he thought that after patients had a little more time out in society and were a little more mature they stood a better chance of doing well after surgery. He reinforced his argument using the example of a young man, 18, who had received surgery a year before and had recently returned to the hospital ward for 'psychiatric therapy' (i.e. He had returned because he was depressed after having received surgery and had not begun working because he was so depressed).

E. Action taken and therapies used

Although Aoyama kun had been scheduled to stay in for only a short period of time (two months), the staff had decided recently that he should be kept in the hospital for about three more months. As a comprehensive care center, therapies were aimed explicitly at the social rehabilitation of people with epilepsy, and, as such, involved seizure control therapy as well as therapies which would treat the problems which staff had pointed out in discussions about Aoyama kun (e.g. problems with interpersonal relations, arrogance, immaturity, life-habits etc.).

What staff had described as Aoyama kun's problems with interpersonal relations and with arrogance did not go untreated. However, the staff did not *discipline* Aoyama kun directly for the problems they described. When staff noticed problems he caused, the head nurse spoke with him gently but authoritatively. She had stressed in other discussions that the most important aspect of ward life for the patients was for them to learn to work together in a group and to think about others when living in the group.

Aoyama kun's fight with a fellow patient who also attended Day Care was the cause of great concern for staff members. After he had the fight, he decided that he no longer wanted to go to Day Care and would spend all of his Day Care hours (every morning and afternoon) gardening. This was accepted by staff, and he spent every morning for a few weeks gardening by himself while the other patients in the ward attended their therapy activities.

Staff members described this problem as simply one example of the many problems Aoyama kun had caused. Staff members noted that he had many problems getting along with other patients, staying up late at night (past lights-out every night) and in other life habits. The staff did not respond directly with discipline, punishment or threats to what they described as problems. Rather, they said that they would teach him how to live as a mature adult (in a group).

His physician, whom Aoyama kun liked better than other staff members, called him aside one day, talked to him, and gave him a piece of paper with a set of rules on it. The physician told him to read the rules every night before bed, upon waking in the morning, and if he became angry at another one of the patients. He told him that the rules were to be hung on the inside of his locker. He also reminded Aoyama kun of the importance of regular living habits and stressed that he should sleep at night and stay awake during the day. He told him that if he had trouble sleeping, he should tell the night nurse and he would be given a sleeping pill immediately, since keeping regular habits were important in the prevention of seizures.

The staff did not intervene in any other way, and, for the most part, were not openly disparaging of Aoyama kun even if they disapproved of his actions. After a few weeks of working alone in the garden and receiving advice from one of his fellow patients, he returned to Day Care, where he began immediately to work on a project that he wanted to send home. In Day Care, staff publicly ignored what they described as misbehavior behind his back. His peers, however, did intervene. One fellow patient, for example, took him aside many times and discussed his conflicts with other patients with him. Other patients also intervened, but to a lesser degree.

After a while, Aoyama kun did begin to change the way he treated his fellow patients and the staff members. He worked more cooperatively with other patients in the hospital and attempted to make up with those with whom he had disagreements. By the time he returned home for the week-long visit and wrote the note to the staff, the staff was fairly sure that the therapies and environment had begun to teach him how, effectively, to become an adult and to live cooperatively in a group with others.

Meanwhile other patients who had been admitted for evaluation for surgery completed their required tests and were discharged. Others whose evaluations for surgery began after Aoyama kun's received surgery were preparing to return home or had already gone home.

* * *

This is only one of many examples of the ways in which surgery for epilepsy is integrated into the 'comprehensive care' program. In this case and many others, those who do not satisfy the institute's ideals stand a decreased chance of receiving surgery. Ideal, cooperative people who are humble, well behaved and prepared for work will most likely receive surgery. In the example above, staff members eliminated Aoyama kun from consideration for surgery and maintained the ideals embodied in the JEC's institutional plan through a social process of knowledge production. They carried this out in an atmosphere of friendly help during which they did not display direct opposition to his actions (cf. Peak 1989).

* * *

In summary, the JEC was established only after lobbying by lay organizations and physicians. Both groups pointed to social problems which people with epilepsy endured -- problems with discrimination, employment, and prejudice. The result of this lobbying was the creation of the JEC, an organization which was to address these problems through 'comprehensive care' therapies. At the JEC, in the process of medicalization, social issues have been recast as problems of individual behavior. The JEC's therapies are designed to address the moral (i.e. behavioral) inadequacies of individuals with epilepsy.

As many anthropologists of Japan have noted about other therapies and workshops in Japan, the therapies at the JEC have not concentrated on the 'psychological' (i.e. talk therapies) but have focused primarily on behavioral reform with an express goal of social reintegration and entrance into the work force (Lock 1991; Kondo 1990, 1989; Reynolds 1980; Caudill and Doi 1963; Lebra 1976: 200-214). This stance has resulted not only in the use of behavioral modification techniques, but also in the selective distribution of efficacious therapies to people who meet ideal qualifications.

Thus in effect, rather than addressing the social issues which were central to the efforts to establish the JEC, the JEC's institutional goals have been shaped by ideas which are found more generally in Japanese institutions (esp. schools and businesses) (cf. Lebra 1976; Rohlen 1974, 1983; Lock 1986, 1988, 1991). Rather than aiming at social transformation, staff at the JEC encourage changes in individual behavior. Their aim is to prepare non-aggressive, non-haughty, patient, disciplined, confident people for entrance into the work force. Although the JEC's staff endorse a policy in which decisions are made <u>cooperatively</u> and emphasis is placed on patient autonomy in decision-making, the social process of knowledge production in place at the institute usually ensures that institutional goals maintain their dominance (Young 1980, 1988).

3. Resistance to the moral order

I stress that the institutional structure of the JEC was not imposed on the Japanese people in a one-sided initiative from the Japanese government, but was created in response to a joint lobbying effort by people with epilepsy and professionals. These groups argued that the government had not adequately addressed the social problems that people with epilepsy faced. Their efforts therefore shaped changes in Japanese health care policies for people with epilepsy.

Similarly, the existing policies and authoritative knowledge at the JEC are not static, unchanging entities, simply imposed from above, but are under constant revision due to challenge and contestation. It will be my contention in this section that the medical practices and institutional policies at the JEC are constantly under criticism from dissenting staff members and patients. This *resistance* and these struggles against authoritative knowledge about epilepsy and disability related to epilepsy occur daily. Through the processes in place at this institute, processes which resemble those in Japanese schools and businesses (cf. Rohlen 1983, 1989; Peak 1989), the resistance is sometimes subverted and overcome and at other times may be the precursor to change.

Resistance to the knowledge production process at the JEC can take on at least two forms. It might take the form of unorganized 'everyday resistance' (cf. Scott 1985, 1990) in which the process of production of knowledge is momentarily interrupted by staff or patients at the JEC. Or it might take on a more organized, overt form which is more difficult to assimilate back into the knowledge production process at the JEC.

Some examples of the first form of resistance are: opposition by individual staff members to a decision by a physician not to allow a particular patient to have surgery or to place restrictions on a patient; a patient's disagreement with a physician's interpretation of her seizures as 'pseudoseizures'; or a patient's refusal to participate in rehabilitation activities or refusal to be discharged. This type of resistance is easily re-integrated into the knowledge production process (Young 1988: 14).

The events surrounding the following case serve as an apt example of the first type of resistance. A woman who had received surgery had trouble adjusting afterwards. She was 53 years of age at the time she received surgery. Soon afterwards, another woman who was approximately the same age, Inoue san, was admitted for observation under the impression that she would receive surgery. The hospital's nurses were also under this impression.

During one staff meeting in which both nurses and physicians participated, one nurse mentioned that she thought that Inoue san had been admitted for surgery. The JEC's neurosurgeon replied quickly that Inoue san would not be considered for surgery because the elimination of seizures would not be necessary for a woman of her age. She was a housewife, he reasoned, and spent most of her time at home. He also used the example of the problems with the other 53-year-old woman to support his claim that Inoue san would not adjust well. Although one nurse mumbled at this point that Inoue san might appreciate the surgery more than some other patient might, the possibility of surgery for her was not mentioned again.

While the nurse's comment was meant to question the criteria used to select patients for surgery, thus momentarily halting the knowledge production process, it was easily subverted and re integrated into the process by the neurosurgeon. The fundamental principles of the comprehensive care program (social rehabilitation) were used to (re) assert the primacy of benefits to *society* over *individual* benefits from the treatment program.

In addition, in many cases at the JEC, staff members are sympathetic with the problems which the hospital's patients have and do not want to force (psychological) pain on the institution's patients. The actions of these staff members also act as a form of resistance in the process of knowledge production.

For example, one woman, Sachiko, had been admitted to the hospital several times, the most recent of which was an emergency admission. She had overdosed on her anti-epileptic medication and had been in the hospital for 18 months since her emergency admission. She had gone home to visit only one time. The visit had ended with disastrous results, and she was not interested in going home again.

In daily conversations, she revealed that she did not want to go home because she did not get along with her brother's new wife, who, she felt, treated her poorly. Her parents had died, and she was left in the custodial care of her brother and this sister-in-law. Her other siblings had married and were now living in separate households in the same small village. She lived on a farm and said that when she had lived at home, she usually did not leave and occupied her days largely with helping around the farm.

Though her prefecture sponsored workshops for disabled people, she had never attended any because joining workshops would mean indicating to the prefectural government that she had epilepsy. She and her family were afraid that this would lead her brother to lose his job as a bus driver, as his company might suspect that he, too, might have epilepsy. She said that because her brother was the main bread winner in the family, ensuring that his income was not severed was far more important than allowing her to attend an occupational workshop.

She had recently developed a condition during which she could function and write but could not speak. These events occurred every morning after breakfast and lasted for several hours. Her physicians took EEGs (during which they could not detect epileptic activity) while she was experiencing one of the events. They attempted unsuccessfully to control her condition through medication. Her stay in the hospital lengthened and she did not go home to visit her family.

The institute's therapists and staff, when asked about why she had been in the hospital for such a long time and when she might go home, said that her case was quite complex and that she had many problems at home. One therapist said that it didn't look like the in-hospital therapies would help Sachiko much, but that because she had so many problems at home, they would not force her to leave yet. He elaborated on her story in much the same way that Sachiko had. He described her problems with her family and how she would not be able to participate in therapy programs available in her area. He also said that the institute's social worker had discussed her problem many times with her family but was not able to find any solutions.

While staff had sympathy for Sachiko, they could not allow her to stay in the hospital indefinitely, particularly once her stay had surpassed 1 1/2 years. Their sympathy for her dilemma was overridden by the institutional imperative that the JEC was not to function as a custodial facility. According to these imperatives, emphasis was to be placed on social rehabilitation and the expedient discharge of patients (as expedient as physicians deemed necessary). Staff members encouraged Sachiko to visit home, and though she had not returned home for good by the time I completed my field research, she had agreed to go home for a visit. The staff expected to discharge her soon afterwards.

In many other cases, the JEC's patients express overt resistance to the institute's policies and refuse to accept staff decisions. In the two cases described below, staff subvert resistance fairly easily through 'indirect' rule. The patients' decisions result from staff manipulation although they are *ostensibly* made independently (cf. Peak 1989; Rohlen 1989).

* * *

1. Yamada san's struggle

Yamada san looked worn and her eyes had bags underneath them. When the deputy-director reached her bed on grand rounds one Monday, she looked at him, began to cry and said that she had not been able to sleep since her seizure frequency had gone down, that she was worried about having to go home. She did not, she asserted, want to go home.

The Deputy-Director appeared to be somewhat uneasy and paused for a moment. He then told Yamada san gently but firmly that because her seizures had been brought under control, she would soon have to go home. He and the medical residents, attending physicians and nurses accompanying him on grand rounds proceeded to the next bed. Yamada san appealed to the audience for sympathy, and the anthropologist who had accompanied the staff on grand rounds stayed behind to comfort her.

After the staff had moved on to the next patient, Yamada san continued to cry and explained why she did not want to go home. Here in the hospital, she said, she was kept on a very regular schedule and could study and learn to read. She could lead a life where she would not be dependent on her mother. She said that none of this would be possible after leaving the hospital and that when she returned home she wanted to find a job or something to get her out of the house ; anything. When asked if she thought that she might be able to find classes or some other activity after returning home, she said -- no, that things wouldn't be the same because after she went home, she knew things would change back to the way they always had been -- that she would be treated like a child. She said that she would get her favorite foods every day and that she would spend her days watching television and being taken care of by her brother and her mother rather than studying and doing things independently as she did in the hospital.

When Yamada san's seizure frequency went down to almost zero per day, some of her fellow patients and others who were in the hospital commented on how lucky she would be if her seizures were controlled. During these occasions, she looked down and mumbled "perhaps it is not such a good thing." She made it clear on these occasions that seizures or no seizures, she saw many advantages of being in the hospital over not being in the hospital.

This was not the first or last time that Yamada san discussed her problems with others at the hospital. At other times, she spoke about her mother, her previous problems in school, and her living situation at home. She spoke about how she had wanted to be a school teacher when she was young but had only finished school up to the end of elementary school. She said she had been taken out of school by her parents because of her epilepsy. She spoke also of how although her family cared deeply for her, she was only a burden and had brought only pain to them. She spoke about wanting to get a job and wanting to learn to read or to return to school in one breath while moving on in the next breath to a description of how that could never happen outside of the hospital. She blamed this not only on her mother, but also on of herself. She stressed that she would only revert to the same old habits of waking late in the morning and watching television all day and of being accompanied everywhere she went by her mother and brother.

Many times, she described her greatest problem as being over- dependent. She was dependent on her mother, on her brother, and on the nurses at the hospital. In the next sentence, she would describe how she had been much worse before her first admission to the hospital, how she had been spoiled *(wagamama)* and overly dependent after her first admission to the hospital but she had gotten better (this was her third admission into the hospital). She said she hated the hospital at first and wanted to go home every day during her first admission, but since then, at the hospital, she had learned to wash her own clothes, live with a group and get along with others, eat foods that she did not necessarily want, work at something and finish it. The list went on and on. But, she would continue, things always changed when she went home, changed back to the way that they were where everything she wanted was always given to her. She wanted, she said, to live in her own apartment and have a part time job -- any job.

Soon after the confrontation described above, Yamada san began reporting more seizures to the medical staff. She went from reporting zero or only a few seizures a day to ten, twenty and more.

A. Background

Yamada san, 39 years of age, is an in-patient at the JEC. This is her third time in the hospital, and at the time she made the statement she had been in the hospital for approximately 6 months. Her first two times in the hospital took place approximately 10 and 8 years before this visit. The first time, she stayed in hospital for over a year and the second time for only a few months. After the two episodes of hospitalization, a new epilepsy clinic was built near her home and she started going to it for her monthly check-ups. However, almost one year before the confrontation described above, she decided on her own accord that she wanted to check into this hospital again. Previous to admission to the hospital this time it was found that the level of anti-epileptic medication in her blood was lower than it should have been, given the amount of medication she should have been taking.

B. The patient charts and hospital records

Hospital records show that Yamada san's present diagnosis is secondary generalized epilepsy. Although the general diagnosis of epilepsy has not changed since her first visit to the hospital, the specific category of epilepsy under which her problem has been categorized has changed over the years, due to technological changes and subsequent changes in the international classification system of epilepsy and epileptic seizures. Her seizures are described in her chart as consisting of two general types: (1) generalized tonic-clonic seizures and (2) light falls or blackouts. She had her first seizure when she was ten years of age and, since then, has had virtually no seizure free periods lasting longer than a week or two.

Yamada san's medical charts contain other descriptions of her. They say that she is emotionally labile (perhaps as a result of epilepsy, the chart says) and that she is overly dependent and selfish. There are comments on her chart about her sudden drop in academic performance after her first seizure and other descriptions of a decrease in intelligence between when she took her first IQ test (as a young girl) and her most recent one.

This is Yamada san's sixth month in the hospital, and her charts show that the staff has had various problems with her. Listed in a special red nurses' notebook are problems in the ward with specific patients and actions taken to resolve the problems. On each page are three columns: 'problem', 'counter-measure' and 'evaluation'. Since Yamada san's arrival, staff nurses have devoted three pages in the notebook to her case (most patients are not even listed in the book). They describe problems with walking, with her appetite, with dizziness/unsteadiness *(furatsuki)*, and with her spending too much time in her room alone.

As with the first two times that she was admitted into the hospital, the charts say that Yamada san was admitted this time ostensibly for seizure control. In this context, this means that physicians change the levels and types of anti-epileptic medication that an in-patient is taking regularly and watch to see whether or not the drug (relatively) successfully controls the patient's seizures. During this stay in the hospital, days during which Yamada san had as many as 60-80 small seizures were recorded. At the time that she made the statement to the hospital's vice-director, she had not had a seizure for three days.

C. Escalation

The staff: management and interpretations of the problem

Members of the nursing staff and staff physicians describe Yamada san's problem as a common one. They say that, like Yamada san, many people who are admitted to the hospital first dislike it intensely because of the rules and expectations placed on them to be independent. Like Yamada san, many of the patients at the hospital, they say, have been over protected and spoiled by their families and therefore do not have skills fitting of 'living in a group' *(shuudanseikatsu)*. Nurses and physicians report that low comprehension *(rikairitsu ga hikui)*, problems with interpersonal relations *(taijin kankei)* and over-dependence *(amae ga ooi)* are among the most common problems of the hospital's patients. For example, some patients, some nurses say, have been so sheltered that they cannot even pick out their own clothes much less wash them when they are admitted into the hospital. They add that one of the purposes of the staff and the activities planned for the in-patients is to encourage independence and maturity by means of group living and occupational and recreational therapies. Because many of the patients who are admitted to the hospital have seizures which are difficult to control, perhaps the best that the hospital can do for them is to provide them with some sort of preparation to live in society, they say.

However, staff members note that the effects of the therapies are often limited to the time period when the patients are in the hospital, for they return to the same families and the same situations at home. They say that many of the patients who come to the hospital do not have friends or work and often find that staying in the hospital is preferable to living at home. The adult ward differs from the children's ward, they say, because children have a place to go -- school -- after they are out of the hospital. As a result, only in very extreme cases are children kept as in-patients in the hospital for more than three months.

When Yamada san began reporting an increase in seizure frequency, she was treated as if the seizures were 'real'. However, there was gossip among the staff members that Yamada san was only having her 'blackout' seizures while she was around people in the day room. The staff members said that it was not clear whether her seizures were 'real' epileptic seizures or 'pseudoseizures', i.e. seizures which, when they occur are probably induced consciously by the patient rather than being unconscious manifestations -- non-epileptic seizures. One staff member noted that during a meeting of the ward's patients, for example, Yamada san had three seizures and one in the middle of when she was making a comment. Others said that the new seizures didn't look like her other ones because she was falling to the right rather than to the left as she had always done before. Each of these comments indicates that it was unclear to staff members whether her seizures were epileptic or faked pseudoseizures.

The ward's staff members scheduled weekly meetings to discuss 'problem' patients at this 'comprehensive care' center. Additional meetings were held if deemed necessary. With respect to Yamada san, the floor staff first consulted the physician in charge of her case about what to do about the sudden rise in seizure frequency and her behavioral problems. A staff meeting was held to decide what measures to take to deal with the sudden problematic behavior. During this meeting, a new set of rules for Yamada san were drawn up and inscribed in the nurses' red book which listed eight specific limitations -- for example, after having three seizures in the day room, she would be told to return to her room because it was 'unsafe' for her to be out (i.e. she might hurt herself falling down). In addition, her participation in hospital activities (occupational therapy) was restricted for the same reason. She would be told to brush her teeth sitting down at the nurses' station (the other patients brushed their teeth in the day room) and that the nurses' aide would do her laundry for her.

D. Yamada san's physician

Yamada san's physician, when asked by the anthropologist about her case, said that Yamada san's latest seizures were probably pseudoseizures. He said that because her increase in seizure frequency had occurred at almost the same time that she began talking about not wanting to return home, he was fairly sure that the seizures she was having were pseudoseizures. He said that physicians had many ways of dealing with cases similar to this one, but that he thought that the best thing to do in this particular case was to be strict with the patient by (1) telling her that the seizures were not real and (2) putting limitations on her actions when she did report a great number of seizures.

Her physician had met with the Center's social worker, who had tried to find places near Yamada san's home where she might be able to do crafts or attend workshops. He noted that few centers for unskilled workers or workshops existed in her home town, but that epilepsy support groups met there once a month. He added that he had been in contact with Yamada san's mother, who wanted her daughter to return home. In one communication, Yamada san's mother said that Yamada san had previously tried taking classes and attending workshops near home, but had not continued them once started.

The physician then said that he and the staff planned to urge Yamada san to go home on passes for days or a week at a time, which might (1) get her used to being at home again and (2) show her that home is actually preferable to the hospital. He went on to say that one reason that she was probably reluctant to return home was that she was afraid of the unknown, that she was comfortable at the hospital and did not want to change for fear that returning home would not be nearly as fun, comfortable or as active as being in the hospital. At the hospital, he said, life was regular, there were always young people around, and if there were ever any problems, there were nurses to solve them. He added that he hoped the prospect of having something to do upon her return home might make returning home a more attractive option to Yamada san. He emphasized also that because her seizures were controlled (for the time being), it was important for her to return home. He said that Yamada san would be encouraged to return home by her mother and brother while out on her passes.

He later said that in many cases, pseudoseizures were mixed with 'real' seizures and that in cases in which a mixture was suspected, all physicians could do was try to treat the real seizures with the available medication and hope that the frequency of pseudoseizures would go down after the epileptic ones were controlled. Other physicians, when asked about pseudoseizures, made similar observations. They described the differences between pseudoseizures and epileptic seizures as twofold: (1) pseudoseizures did not produce characteristic epileptiform patterns in the EEG while epileptic seizures did and (2) there were medications which could be used to control epileptic seizures while there were none for pseudoseizures. They said that the defining line between epileptic and 'pseudo' seizures was not at all clear, and that sometimes the occurrence of one type triggered the other.

During daily visits with her physician, Yamada san, like all of the other patients in the ward, reported her seizure frequency. In one such clinical visit, after she reported the frequency, the physician asked her to describe the seizures. During these discussions, she sometimes strayed from the description of seizures to the events surrounding them. The physician urged her, during these descriptions, not to stray from the point and to simply describe the seizures. After her descriptions, he told her whether the seizures she described could be considered seizures or not based on whether she remembered them or not. During subsequent meetings, Yamada san was careful to describe only the 'seizures' which the physician had acknowledged as 'seizures'. She would note the others, but only in passing.

After these measures (isolation, 'toughening', etc.), Yamada san's self reported seizure frequency went down. She continued to speak with people in the ward, this time talking about how she had been far too dependent on the staff but how she now was better. Approximately six weeks after Yamada san told the deputy-director for the first time on grand rounds that she did not want to go home, she returned home on a week-long pass. The staff was fairly confident that Yamada san would return home for good after a few more week-long passes home.

* * *

The events surrounding Yamada san's struggle were not the most typical of those I witnessed while doing my field research. She caused more problems and was more overtly expressive of her worries than many of the JEC's in-patients. A number of other patients at the JEC, however, described problems and fears similar to hers. Staff also noted that her problems were quite common among patients at the JEC.

In discussions, staff members at the JEC expressed an awareness of the *social* and *political* origins of the problems which people with epilepsy face and a desire to ameliorate these problems. However, the institutional context did not allow the staff to act on this awareness when they dealt with Yamada san's case. The staff followed institutional imperatives and emphasized control of the biological signs of epilepsy in terms prescribed by the physicians. In addition, staff members described what institutional goals identified as positive changes in Yamada san's personality/behavior. They attributed changes to her many stays in the institute: she was far less dependent and complained much less than when she was admitted the first time. The staff was therefore successful in meeting institutional goals. Not only were Yamada san's seizures controlled, but she had become much more accustomed to the requirements of 'life in a group' *(shuudanseikatsu).*

Yamada san, on the other hand, did not appear to be convinced that the changes produced in the institute were positive. She expressed a desire to stay in the hospital despite seizure control. Moreover, behavioral and personality changes which the moral education at the institute had brought about only appeared to have resulted in frustration on her part. During and after her hospital admissions, she became aware not only of changes in her personality, behavior, and physical condition, but also of the futility of the changes and how short-lived they were, given her surroundings at home.

Despite differences between institutional goals and what Yamada san interpreted as the benefits of the changes produced by the institute, institutional goals prevailed. When Yamada san began her struggle to stay in the hospital, staff members (physicians and nurses) did not change the ways in which they acted around her, nor did they oppose or discipline Yamada san directly for what appeared to be non-compliance. Yamada san's resistance was overcome by staff members, not through force or direct coercion, but rather through indirect maneuvering. Yamada san was not sent home, nor was she told directly that what she was doing was *wrong*. The staff, in fact, said that they would never forcibly discharge a patient from the hospital and that they *always allowed patients to make decisions on their own.*

Yamada san was treated *in public* as if her seizures were real and as if the staff sympathized with her problems. Furthermore, the disciplinary action which the staff took was *not* described to Yamada san as being action taken in order to restrict and frustrate her, but rather as being the imposition of cautionary rules which would keep her from hurting herself when she had seizures. By the end of the long struggle, Yamada san had no opponent against which to resist. Her frustrations appeared to have been produced by her own shortcomings and she became apologetic about her behavior.

Thus, though Yamada san's decision to go home for her first week-long pass *appeared* to have been made on her own accord, it was the product of the staff's indirect manipulation of her opposition to institutional imperatives.

* * *

In the following example, a young man is convinced to choose surgery despite his initial decision not to have surgery.

2. Tsuchida san

A young man, Tsuchida san, 26 years of age, was admitted to the JEC by a physician who suggested that he receive surgery. The surgeon said that this patient was chosen because he had what appeared to be a defined calcification in the area in his brain from which his epileptic seizures were said to originate. He therefore did not fall into the group of patients who had been selected for their potential to socially rehabilitate to receive surgery, but was identified as a tumor patient. Nurses and physicians noted that his IQ was rather low and that he was overweight, something which might cause complications in the surgery. The physician, nonetheless felt strongly that he should receive surgery.

This was his third time in the hospital, and he had wavered between wanting the surgery and not wanting it, for, he said, he was frightened about what might happen as a result of surgery. He decided at one point that he did not want to have surgery.

Although he had stated fairly definitively that he did not want surgery, his physicians (and his parents) wanted him to have surgery. When he said that he did not want to have surgery, the nurses and surgeons did not say that he should have it, nor did they try to convince him to have surgery by discussing it with him. Instead, he was housed with all of the other male patients who were about to receive surgery. He was required to attend group discussion meetings slotted *only* for those patients who were definitely proceeding to surgery (most patients included in the meetings were about to receive Step II tests or had already received them). And during the meetings, he was urged to watch the other patients, see how their surgery came out, and make his decision.

He remained unsure about (or unwilling to have) surgery for approximately 6-8 weeks. All the while, the staff treated him like any other patient and did not try to convince him to receive surgery. But they did not discharge him during this time period. After this period of waiting, he changed his mind, and, following the example of his fellow patients, decided to have surgery. The staff *never* appeared to direct his resistance to their decision about surgery nor did it appear that they tried to convince him (verbally). The result of this almost invisible struggle was that the patient decided to act according to the wishes of the staff and have surgery.

* * *

As in Yamada san's struggle at the JEC, the staff did not force Tsuchida san to make the decision that they wanted him to make. The staff, however, was able to manipulate his surroundings in such a way that he was finally convinced that the decision which the staff had encouraged was the correct one. The final decision appeared to have been made by Tsuchida san *on his own.* While Yamada san's case was more extreme, the same methods were used by the staff to gain compliance in both cases. Both patients appeared to have made the decision that the staff wanted them to make on their own. Most importantly, institutional objectives ultimately gained dominance in the acts of resistance described above.

For the most part, as in the examples above, resistance at the JEC consists of isolated incidents whose effects on the process of knowledge production and on the content of authoritative knowledge are not significant. The resistance is easily overcome and subverted. Dissenting staff members are usually reminded of institutional goals. Similarly, staff members usually convince patients who refuse to return home or comply with therapy activities to return home or participate in therapy activities.

* * *

Some resistance, however, takes on a more organized or overt form which is not so easily re-integrated into the knowledge production process. First, the practices at the JEC may not be accepted by professionals at other epilepsy treatment centers. Scientists may direct overt criticism of the Center's practices and policies to staff who attend international congresses or scientific meetings. For example, the criteria used to select patients for surgery at the JEC appear to have undergone enough international criticism to have caused the JEC's surgeons to qualify their criteria for patient selection. In a 1990 English language publication, the JEC's surgeons make the comment, "We are aware that patients with character disorders and/or behavioral abnormalities may be able to live self-supporting lives if surgical intervention would lessen the severity of their seizures. These exclusion criteria are obviously open to discussion" (1990:279). In Japanese language papers, the same authors do not note the possibility of using different criteria to select surgical candidates (cf. Mihara 1991; Matsuda et al. 1989).

Second, other actions and behaviors of patients at the JEC, if they emerge in a pattern noticed by staff members, may signal to the staff that there are problems with the Center's policies and practices. This may produce overt *resistance* to the knowledge production process. Some examples of this are: (1) the pattern of repeat hospitalizations and refusals to be discharged from the hospital among non-surgical patients and (2) the significant number of post-surgical patients who have readmitted themselves to the Center despite seizure control.

With respect to the first category, during my field research in 1991, some patients refused to return home because they felt that they were too dependent on their families or because they did not have anything to do once they had returned home. Others were reluctant to return home because they felt that the institute's therapies did not satisfy their expectations of full seizure control. They and their families pressured the institute's physicians to continue treatment until full seizure control had been attained.

Regarding the second group, a number of patients returned to the hospital after surgery because their expectations about what would happen after surgery were not fulfilled. Though their seizures may have been controlled, they were unable to find employment with which they were satisfied. Other patients did not want to continue taking medication when their seizures were brought under control. They subsequently quit taking their medication. Some patients said that they would not tell their employers that they had epilepsy afterwards and considered it cured after surgery.

Patients in both of these groups alerted the staff to the contradictions between what the patients expected would happen after they were hospitalized at the institute (cure of their problems related to epilepsy), and what happened when they returned to society, i.e. they experienced virtually no improvements in their lives. Many nurses, therapists and physicians were aware of and sympathetic with the dilemmas of the patients. They did not dismiss the patients' opposition to institutionally sanctioned goals and interpretations of epilepsy and disability.

* * *

Based on my observations in 1991, I believe that changes in hospital practices which resulted from these acts of resistance did not address the contradictions in the therapeutic system which dissenting patients and staff had pointed out. First, regarding the international criticism about exclusion criteria for surgery in the 1990 paper, by 1991, the Center's selection criteria had not undergone any significant changes, despite international criticism *and* the existence of 'comprehensive care team' meetings which all staff members were allowed to voice their opinions about treatment policies. Furthermore, in later papers, the measurement of the program's efficacy by means of 'rate of employment' is used to support the continuation of institutional policies. More women and children now receive surgery, but *those who receive it were chosen by physicians at the JEC* *as exceptions.* Physicians and staff at the JEC still hold the ultimate power to decide who will receive surgery.

One case which occurred in 1991 demonstrates the continuing dominance of using 'social utility' as a major criteria for the selective elimination of patients from consideration for surgery. A young woman, 22 years of age and a high school graduate, was under consideration to receive surgery. She was eliminated from consideration for surgery because she was "the type who would simply work as an office lady for a few years and then get married."

The implied assumption in this interpretation is that surgery would not produce the same social benefits in her that it might in another patient. Though there may have been protests about the decision by staff members in staff meetings, the woman was not given surgery because she did not qualify for surgery under the basic criteria of the comprehensive care program. She was not told why she was not given surgery and was shifted to simply receiving pharmaceutical treatment. In a number of similar cases, staff have quietly and definitively eliminated 'unsuitable' patients from consideration for surgery.

Second, despite sympathy from many staff members about the social problems that many of their patients face, refusals to leave the hospital and repeat hospitalizations by non-surgical patients and self re-admissions by post-surgical patients have not brought about an internal examination of problems with the comprehensive therapy program. Instead, new practices which simply maintain the status quo have been added to the Center's comprehensive care program.

For example, in 1991, the Center's social workers instituted a night hospital program to ease people back into the community. Under this plan, a few hospitalized patients can work part-time in the community by day and return to the hospital at night. The purpose of this program is to facilitate adjustment to society in a select group of patients by habituating them to part-time work.

Social workers make arrangements for those patients who refuse to leave the hospital to participate in community self-help organizations and occupational therapy programs. In addition, staff members are now careful to concentrate explicitly on the goal of 'lowering' the patients' pride and expectations about life outside of the hospital.

Finally, problems with post-surgical patients who are readmitted to the hospital despite seizure control have resulted in (1) the addition of required group therapy meetings and (2) explicit cautions from physicians and staff members to patients about the limits of the surgical therapy.

Staff describe the group therapy meetings as discussion sessions. They say that their primarily purpose is to ease post-surgical rehabilitation by lowering patient expectations about possible improvements in their lives after surgery. The meetings are held on Friday afternoons, a time during which other patients are playing sports, singing in the *kara oke* room, or watching video-taped movies in the day room. Approximately ten people attend each meeting, including the organizer of the meetings (one the Center's social workers), two nurses, one surgeon or physician from the ward, one of the clinical psychologists and the patients in the institute who are surgical candidates or have already undergone surgery. Those patients who have been readmitted to the hospital post-surgically for psychiatric reasons <u>do not</u> usually participate in the meetings.

In person and in academic papers, staff associate the reason they hold the meetings with the Center's mandate to provide 'comprehensive care'-- social rehabilitation -- for the institute's patients. They say that they are obliged to provide care for problems patients have with *social adjustment* rather than simply aiming to facilitate seizure control in-patients. For example, in one paper, a social worker and several nurses of the ward write:

> Meetings are not only held so that [patients] can listen to the experiences and opinions of others, but are also sessions during which all patients must give their personal opinions [about surgery]. With respect to this, this is a time when patients are able to judge the possibilities for social adjustment objectively . . . Although these meetings are group-type therapies, they help the psychiatric dimensions *(seishin men)* of the problems of individual patients (my translation) (Asano et al. ms.: 76).

Asano et al. argue that the elimination of seizures only eliminates *one part* of a patient's problem. The remaining parts of a patient's problem, they state, are related to the individual's personal history, for which social psychological care is necessary. Though the authors discuss *psychiatric dimensions* of the patients' difficulties, these dimensions are ultimately connected in the papers and in hospital discussions to the goals of the comprehensive care program -- *social adjustment*.

This interpretation of the problems anticipated in people after surgery has been shaped by and now shapes the content of the discussions and the practices of the center's surgeons, staff members and social workers. At each group meeting, either one of the physicians or the social worker asks a question directly to one of the patients. The staff member's question usually centers on worries or fears related to surgery. Periodically, during group discussions, the physicians or social worker emphasize to patients that the only change that surgery will bring about will be a reduction in seizure frequency. They suggest that neither the patient's abilities or the ways in which relatives and acquaintances treat the patient will change.

The following is a description of one of the meetings which I witnessed during the summer of 1991.

* * *

The meeting is held on a hot Friday afternoon at 1:30, and the patients who are not required to participate in the surgical meeting are playing softball outdoors or singing in the *kara oke* room.

The room used for the group meeting is one reserved for occupational therapy (crafts) during the week. 2/3 of the room is carpeted, and there are two large windows on one side of the room. A number of low folding tables are piled by the windows.

The patients and staff members who are required to attend the meeting drift in slowly, one by one or in pairs. Though tea is provided during the meeting, most patients have brought cans of coffee-drink (bought at the hospital's vending machine) to the meeting. In all, 9 patients -- three women and six men -- attend the meeting. They range in age from 16 (a young woman) to 28.

Two nurses arrive carrying tea cups and thermos of tea. The social worker, carrying her notebook, then arrives. A student nurse arrives a few minutes later, and then one of the JEC's psychologists arrives. All staff members (except the social worker) are wearing standard white, starched hospital uniforms.

There is some laughter and chatter when people enter the room, and, after arriving in the room, the patients and staff members pull the low tables out and arrange them in a circle. Some people then sit down on the floor at the low tables, while others look out the windows.

The patients wait for the physician, who is late for the meeting, and the chatter and jokes continue. The patients are now sitting at the table, and most of the men begin to smoke. One of the patients has hidden the vending-machine coffee can belonging to another patient (a patient who is considered a little 'slow' by people on the ward). Some teasing ensues, laughter, and he then gets the coffee back. Ten minutes later, the physician arrives, a silence falls over the room.

The meeting begins with a question from the social worker, directed at a patient, Suzuki san who has already had surgery and will soon return home. One nurse and the student-nurse begin taking notes on the session.

The social worker asks Suzuki san gently what he plans to do once he returns home. He answers that he is not sure what he will do when he gets home, but he might be able to work at the grocery store where he was employed before being admitted to the hospital. He lights up a cigarette, his second since arriving in the room, and looks at the floor after giving his answer.

The social worker looks around the room and asks how many of the people in the room have lost jobs to epilepsy. Almost all patients in attendance raise their hands.

Silence. A question about work is directed at Tatara kun, who is described by nurses as 'cheerful' *(akarui)*. He makes a few jokes and there is laughter in the room.

The social worker then turns to Ikegami san, who has recently been admitted to the hospital.[54] The social worker and asks her what her worries are *(shimpai)* and waits patiently for a reply.

She smiles, looks directly at the social worker, and says brightly, "Nothing. I'm not really worried about anything. Everything is fine." The social worker then asks if having her hair cut off for surgery worries her, and she says, no, that at first she was worried about it, but she now isn't.

At this point, the physician says, "When you were in the hospital before, you were opposed to having surgery. . . "

Ikegami san answers, ". . . My parents wanted me to have the surgery, but I didn't want to have my hair cut and didn't want to have the surgery. At the time, I didn't think that there was any problem with having my disorder (epilepsy). I was a student and the seizures didn't seem to make any difference, but now that I have finished school, I find that it makes a difference."

The physician asks "Have you had any problems with people at work?"

"None. They all tell me to 'go for it' *(gambatte)*. Everyone at work supports my decision," answers Ikegami san.

The physician goes on to say, "we talked about your case at the physician's conference the other day. . . you didn't want to have surgery before. . ."

She responds by saying, "I've decided that things have changed. I went home and talked to my friends and discussed this and it makes more sense now to have the surgery. I am sure that I want to have it."

The social worker then turns to another young woman, Kazuko chan,[55] who will soon have depth electrode studies and asks her about her worries.

She replies that her parents were the ones that were worried before, and they were the ones opposed to her surgery. However, they are not worried now. She goes on to say, "the biggest thing that we [she and her parents] are worried about is if I will be able to have the surgery. I am worried that if, after the surgical insertion of depth electrodes, the seizures will turn out to be from both sides [therefore making localization of seizure onset difficult and surgery almost impossible]."

The physician picks up on what Kazuko chan says and stresses to everyone in the room that seizure control is not guaranteed after having surgery. He directs this particularly at a young man, Tatara kun, who has had as many as 60-80 auras and absence seizures a day. What will you do if the seizures are not controlled, the physician asks?

Tatara kun replies with a smile that he would be happy if he only had seizures in the evening. He talks about the ways his seizures have changed (and how his life subsequently changed), that when he was in elementary school, his seizures only happened during the evening and didn't interfere with his life, but after he started junior high school, his 'falling' seizures *(taoreru)* began. He jokes and says that this is probably because this is when he began to have to use his head and school got more difficult. He then goes on to say that he does not have the 'falling' kind of seizure any more, and someone else in the room replies that this is probably because he no longer has to use his head.

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[54] Ikegami san's case was presented during the Thursday evening physician's conference about surgical patients, and it was pointed out that when she came two years ago she was completely against having surgery. She had recently decided to have it. Her physician could not explain why she has changed her mind at the meeting.

[55] 'Chan' is a diminutive used to address young women in Japan.

The questioning moves to Itoo san, the largish man whose can of coffee was taken at the beginning of the session. The physician ribs him about his weight. (He has been opposed to having surgery since he entered the hospital. His parents and the physician, however, want him to have surgery and have kept him in the hospital to help him get used to the idea of having surgery. He is considered overweight and has been put on a strict diet by the nurses.)

The physician then asks him a question about his worries. He does not understand, and the physician asks him one more time. He still does not understand, so the physician rephrases the question, and he responds by saying that he would like to have his seizure frequency reduced. The physician then turns to Tatara kun and says gently, well, you should watch and see how Tatara kun's case comes out and then decide whether or not you want to have surgery. Tatara kun chimes in and urges him to watch and see how his case turns out, and makes another joke.

Attention turns back to Suzuki san, who is asked by the social worker and physician what his biggest worry is -- work, they ask? He says that he is worried primarily about two things. First, he says that his seizures are the type that only appear after being tired out. Otherwise, they don't usually occur. He then goes on to say that he has not had any seizures since surgery, but he does not know if that means anything because he has not exerted himself at all since surgery. He then says that he will work at a grocery store part time and then look for a full time job later on. But his main worry is whether or not he will have seizures, he says.

Attention moves on to Mori kun, who had surgery one month before the meeting. He says that the first thing that *he* is going to do is find a cute girl -- a girl friend. He then laughs.

The physician then looks around the room and tells the patients (once again) that their seizures may not be controlled by the surgery they are about to receive, and that some people might still have some seizures after surgery. He and the social worker both go on to say that having seizures or not will not change their lives, that they will still be the same people and that they will have the same relationships with the people surrounding them (i.e. their families and employers). They stress that seizure control will only change one part of their lives.

Kazuko chan pipes in and says that she is worried about having her Amytal test[56] the day after she is implanted with depth-electrodes. The physician and social worker reassure her that there is no relationship between the two, and there is nothing to worry about.

The talk moves back to Itoo san, and a question about his worries is aimed at him again. He does not say anything. There is an uncomfortable silence for a few seconds.

Attention then moves to Kuroda kun, who has just had his depth electrodes removed and is awaiting surgery. He is asked about his family and reminded about how they will not change after he has had surgery, how they will probably treat him the same as they always had before he had surgery.

One of the patients, a man who had surgery and has returned for his two-year tests breaks in and adds his support for what the physician and social worker have said. He says that he has been disappointed and depressed since surgery ended, and goes on to say that he thought that he would be able to do everything better once he had gotten rid of his seizures and it turns out that not much changed in his life since he had surgery. He says that he still has to take his daily medication, and that things are just the same.

The social worker stresses this point and reminds the patients attending the meeting that people's lives will not change after surgery. The meeting ends. As we are cleaning up the room and putting the tables away, the social worker notices that Keiko chan, one of the younger members of the group, was not asked any questions. She looks at Keiko chan and

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[56] The Amytal test is an invasive psychological test which is given to all surgical candidates. Sodium amobarbitol is injected into a carotid artery, thus blocking brain function on one side of the brain momentarily. It is used to predict where speech and memory are localized in the brain. The results are used to ensure that the surgery will not damage the main speech and memory areas of the brain.

makes a comment to this effect. Keiko chan grins and heaves a sigh of relief at not having been called upon.

* * *

Thus, a number of patients who are extremely depressed and have had problems adjusting to society have returned to the hospital. They have described differences between their expectations and what they were actually able to accomplish. In an effort to address these problems, the JEC's staff have established biweekly group therapy meetings. While these group meetings were instituted by staff ostensibly to *help* patients adjust psychologically, this narrative suggests that the therapies do not actually provide an arena for patients to discuss their fears comfortably. They *do,* however, provide an arena for staff to attempt to lower patient expectations of the treatment program and the effects it will have on their lives.

During these meetings and clinical encounters, as in the example above, staff members deliberately emphasize the limits of the therapy. They say that the therapy will neither change society nor the individual's abilities but will simply control seizures. They ask patients to describe their fears and attempt to elicit 'realistic' goals from them. In the cases described above, resistance to the knowledge production process has only resulted in the reshaping of the treatment program by the staff according to the fundamental principles of comprehensive care.

* * *

The details of the struggles described above suggest that interpretations of disorder and disability which are dominant at the JEC do not arise from nature, nor are they accepted without resistance. At the JEC, daily acts of resistance against the moral order are subverted and overcome quietly. The methods by which the struggles I discussed in this chapter were overcome are similar to those described in ethnographies of other Japanese institutions (Rohlen 1989; Peak 1989).

In some cases the staff has responded to *resistance* by reformulating policy and by attempting to change patient expectations. In the cases described above, obvious shortcomings produced changes in the JEC's policies. Yet, the result has simply been the absorption, reinterpretation, and re-assimilation of these criticisms into the existing comprehensive care framework.

As in examples cited by Rohlen (1989) and Peak (1989), the JEC's institutional imperatives gained authority in indirect ways in these struggles. This occurred *despite* subjective awareness on the parts of both staff and patients of the contradictions inherent in of the JEC's therapeutic goals (i.e. that the therapies were not achieving the purposes of preparing people for the work force as their intentions stated they were).

4. Conclusion

Medical knowledge and practices are not unchanging entities, located outside of society or history. Rather, they are products of specific histories, societies and local settings. I began this thesis with an observation about a puzzling difference between treatment methods and alternatives used in a Japanese and a Canadian institute in Montréal. This difference existed despite interests in both institutes in the treatment of epilepsy through *comprehensive care* which was meant to improve the *quality of life* of people with epilepsy.

Through an examination of the establishment of the Japanese institute (the JEC), the objectives of other social institutions in Japan, and the development of the JEC's comprehensive care treatment program, I have suggested that the treatment program at the JEC represents a unique program whose content and structure has been influenced by international debates about epilepsy, disability and the treatment of epilepsy. It has also been shaped by an existing morality which pervades other social institutions in Japan (cf. Lock 1988, 1991; Rohlen 1974, 1989). As such, it has developed objectives that differ radically from those of the institute in Montréal.

The treatment framework at the JEC, 'comprehensive care', is one whose overriding concern is social normalization/rehabilitation through the treatment of the biological, psychological, and social problems of people with epilepsy. It was set up in response to groups who noted the social inequities and problems with discrimination that people with epilepsy face in every day life. Staff at the JEC place emphasis on (1) behavioral reform through in-hospital occupational and recreational therapy activities *and* (2) biomedical treatment.

While the social issues which inspired the establishment of the JEC pervade the talk of staff of the JEC and the Japanese lay organization, the JEC has been transformed into an arena in which the status quo is conserved through practices subsumed under the rubric of 'comprehensive care'. The institute's therapies serve to mold behavior in individuals who do not conform to societal ideals.

I have emphasized in this thesis that knowledge about epilepsy and disability related to epilepsy at the JEC is the product of both conventional knowledge, as described above, and of challenges to it. For example, the fight to establish the JEC was initiated by lay and professional groups who stressed the government's responsibility to address the needs of people with epilepsy, and decidedly not the government. In addition, at the JEC, everyday acts of resistance are an essential part of the production of authoritative knowledge about epilepsy. They have sometimes inspired the revision of particular institutional policies. Unfortunately, though the examples cited above have led to changes in institutional or governmental policy, the changed policies have simply served to maintain the status quo.

The institutional goals and framework of the JEC usually maintain their dominance via social processes, namely a process of knowledge production with a strictly maintained social division of labor. In the processes in place at the JEC, dominant accounts of epilepsy and disability subvert and overcome alternative accounts through the staff's indirect manipulation of resistance.

I have suggested that authoritative knowledge about epilepsy and disability related to epilepsy at the JEC is ideological in that it naturalizes an historically contingent interpretation of the individual in relation to society (Lock 1988, 1986). In doing so, it justifies a particular distribution of medical services. It legitimates the particular ways that signs are interpreted as symptoms of disorder at the JEC. Finally, it forces people to act in ways that they may not have chosen to in other circumstances.

The physicians at the JEC are not villains and practices at the JEC are not isolated form the larger social context of Japan. Rather, the JEC's therapies and practices reproduce many of the ideals which dominate practices in Japanese institutions, including businesses, schools and medical institutes (cf. Rohlen 1974, 1983, 1989; Kondo 1990 1987; Lock 1991; Smith 1983; Lebra 1976; Reynolds 1980, 1983). In these contexts, management of struggles and contestation of authority are sent in an environment of hierarchical control combined with decentralized authority (Peak 1989; Rohlen 1989).

In an example which resembles the case at the JEC, Lock has described narratives surrounding 'school refusal syndrome' in Japan. She suggests that the problem of 'school refusal syndrome' must be seen in the larger context of debates in Japan about problems related to modernization. Despite what she found to be awareness of the complexity of the problem of school refusal, she found that the treatment programs for it, like those at the JEC ultimately focused on the molding of 'moral' individuals according to standards very similar to those at the JEC (Lock 1991:525-528).

Lock goes on in her paper to argue that an interpretation of school refusal syndrome which describes it as an individually based, moral problem in school refusers and their families carries within it a certain danger. It is, she argues, "dangerous because it helps to deflect attention away from larger social issues. . ." (1991: 528).

Extrapolating from Lock's point, I close with these questions: Does the treatment program in place at the JEC now deflect attention from the larger social issues which first fueled the lobbying efforts *for* the JEC? And does the description of disability related to epilepsy as tied to problems of individual character legitimate the rigid maintenance of present (perhaps ineffective) therapeutic methods and prevent a more flexible, less moralistic stance in therapy? It remains to be seem how deeply the voices of lay groups, individuals with epilepsy, or dissenting staff members will influence (or be allowed to influence) the composition and goals of therapeutic practices related to epilepsy in Japan in the future.

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