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Challenge of psychiatric rehabilitation for patients with long-term hospitalizations using the Nirje's normalization principles as a valuation standard: two case studies

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Abstract : This research investigates the current care of hospitalized, chronically mentally ill persons to determine to what extent current hospitalization supports Nirje's principles of normalization. We propose that care-providers try to incorporate rehabilitation programs that help the patients acquire the pattern and rhythm of living necessary for them to live in the community in their daily hospital life rather than to fit the patients into hospital rules or schedule. Therefore, care-providers must look back on their own views of the humanity, disabled people, and support and may have to change them if necessary. It is important that care-providers do not give up having psychiatric patients not give up restoration of normal social living. To develop such individual attempts into rewarding activities, it is necessary to set goals in the hospital and to let an interdisciplinary team work to achieve them. Moreover, the situation is expected to change if efficient care management is implemented to support psychiatric patients in the community. High-quality care to realize independent living of patients in the community including collection and distribution of information, management of symptoms, assistance for self-care, and psychological education is provided at hospitals that maintain the idea of, and strong belief in, providing high-quality care for returning patients to the community. The findings of this study will provide insights into how to design better hospitalization and/or community care for the mentally ill. J. Med. Invest. 53: 209-217, August, 2006

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INTRODUCTION

Regarding people with mental disorders, inpatients account for 0.34 million and those who live at home account for 1.82 million in Japan. The average length of stay for hospitalized patients is 331 days and much longer compared with America and European nations. Since the amendment of

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the Mental Health Law in 1987, the protection of human rights of people with mental disorders has been one of the most important issues of the health and welfare measures for people with mental disorders. According to the Patient Survey in 1996, patients who are hospitalized for five years and more account for 46.5% (45.7% in the same survey in 1993), which shows that their social rehabilitation has not progressed (1).

According to the New Plan for the Disabled (2003-2007) announced by the Japanese government in December, 2002, to embody the normalization principle of socially hospitalized psychiatric patients, socialization facilities and group homes will be prepared, and about 72,000 patients be discharged and returned to the society within 10 years (2). Additionally, Hospital Reports in the year 2000 shows that the mean duration of hospitalization at prefectural psychiatric hospitals was 200-300 days in 5 prefectures, 300-400 days in 21 prefectures, 400-500 days in 16 prefectures, 500-600 days in 2 prefectures, and 600 days or longer in 2 prefectures. The mean duration of hospitalization was shortest at 262.2 days in Yamagata Prefecture and Tokyo and longest at 642.9 days in Tokushima Prefecture (3).

The Japanese government's 1995 Plan for the Disabled: 7-year Strategy for Normalization set specific numerical goals for construction of facilities for the disabled by the year 2002. This Government Action Plan for Persons with Disabilities was formulated by the Headquarters for Promoting the Welfare of Disabled Persons in December, 1995, as an implementation plan of priority measures to further promote the "New Long-Term Program for Government Measures for Disabled Persons" formulated in March, 1993. The Action Plan is a seven-year strategy from fiscal 1996 to fiscal 2002 and includes not only health and welfare measures, but also the measures for people with disabilities as a whole, such as housing, education, employment, communication and broadcasting.

As basic concepts, the Government Action Plan for Persons with Disabilities is based on a concept of rehabilitation that aims for the restoration of rights as a full citizen in all stages of their lifetime, as well as a concept of "normalization" that aims for a society in which people with disabilities live their lives and are active the same as people without disabilities. The Action Plan strives to promote measures on a priority basis from the following seven viewpoints: 1) to live together in the community; 2) to promote social self-sufficiency; 3) to promote barrier-free access; 4) to aim to improve quality of life; 5) to ensure safe livelihood; 6) to eliminate mental barriers; and 7) to promote international cooperation and exchange suited to Japan(4).

As of 2001, however, none of the goals has been attained. Specifically, the welfare homes and factories were less than 50% of goal. The core facilities necessary to support patients' resuming a normal social life were identified as commuters' work center, residents' work center, welfare factory, life training facility (residential dormitory), and welfare home. By 2000, at least one core facility had been developed in only 315 communities (cities, towns, or villages) or 9% of all local governments (5). Facilities remained underdeveloped and implementation of the 7-year plan has fallen far behind.

Deinstitutionalization has led to a rapid shift from reliance on state hospitals to use of communitybased inpatient psychiatric services. While these inpatient units were initially envisioned as an integral part of the community mental health system, a number of sociopolitical and clinical pressures have caused general hospitals to respond to their new responsibilities in different ways (6, 7). Psychiatric care has changed considerably in most western countries. Large institutional mental hospitals have been replaced by community-based services that focus efforts on preventing severe episodes of disorders and the necessity for longterm hospital treatment. In Japan, health professionals and policy makers have recognized the importance of such movements as already stated, but changes have been slower than expected. Japanese psychiatry services remain predominantly hospital-based. A decline in hospital beds was observed from 1994, but the total number of inpatients is still 2.9 per 1,000 people, compared to 0.9 in the United Kingdom and 0.5 beds in the United States. Such reliance on hospital-based psychiatry is a barrier to the development of communitybased psychiatry (8). Consequently on the basis of findings, there will be conclusions about what the strategic factors are, how to think about them, and how to implement normalization so that chronic patients might re-enter society.

We need to analyze the generating process of institutionalism, the process of deinstitutionalization, the quality of a care of psychiatry, the motivation of care-provider, and other factors in order to expedite the social rehabilitation of mentally ill people who are hospitalized for long periods. The purposes of these researches examined current institutional care for chronic, psychiatric patients with long-term hospitalizations with focusing using Nirje's (9) principles of normalization as a valuation standard.

METHODS

Conceptual Framework

The items to be studied were created using Nirje's normalization principle, i.e.," All people with intellectual disorders or any other disorder can exercise their rights to obtain a lifestyle and a state of daily living that are as close as possible or identical to those in an environment or conditions of living in the local community or culture in which they live ".

Nirje mentioned eight conditions for normalization of lifestyle: 1) A normal daily rhythm, 2) a normal weekly rhythm, 3) a normal annual rhythm, 4) normal experiences of development in the lifecycle, 5) respect of individuals and self-determination, 6) normal sexual relationships in the culture, 7) a normal economic status in society and the right to acquire it, and 8) normal environmental setting and standards in the local community.

However, Nirje developed his theory for persons with intellectual handicapped. Ohgimi, *et al*. (10) modified the concepts for adult patients suffering from mental illness and excluded those portions pertaining to disordered children. Items in a Scale for Understanding Normalization (SUN) were developed for use by health professionals involved in the care of daily living for psychiatric patients. The question relating to " normal sexual relationships in the culture "was excluded since verification would be problematic.

Analytical Methods

The Kawakita's KJ (AB type diagram) method was used for analyses (11, 12). It draws the commonalities among the various phenomenons, and generalizes/abstracts significant findings. Each observation was recorded as a clear and concise text on a card, and then the sentences were qualitatively classified and categorized. Next, each category was given a name that represented its characteristics. The procedure up to this point was the KJ method. In the next step, the named categories were re-arranged to best represent their relations (type A diagram method) followed by their inter-relations and cause-effect relations (type B description of interpretations). This analytical procedure was the AB type diagram method. Procedurally, 1) each category obtained by the KJ method, 2) the name of each category was defined, 3) similar categories and interrelations of categories were analyzed, and 4) the results of analyses were evaluated by four specialists: 1 psychiatrist; 1 psychiatric social worker instructor; and 2 community nursing and public health nursing instructors to increase validity and reliability.

Sites and Periods of Observation

Psychiatric hospital A (Conventional hospital) and B (This hospital has always been concentrating on community rehabilitation) were chosen for comparative review of major issues in psychiatric patients' social rehabilitation.

Hospital "A" had 308 beds, with a nursing standing order ratio of 3.5 : 1. Eighty percent of inpatients are schizophrenic patients. The staff compositions of this hospital were 5 psychiatrists, 99 nurses (49 registered nurses and 50 practical nurses) and 1 occupational therapist (OT).

In hospital " A ", the closed and open wards for males and females were observed for three days from July 31 to August 2, 2002. The candidate for observation was the staffs (6 nurses, 2 psychiatrists, and 1 OT in general every day) who were working in the wards mentioned above.

Hospital "B" had 600 beds, with a nursing standing order ratio of 3.5 : 1. Seventy nine percent of an inpatient was schizophrenic patients. The staff compositions of this hospital was 17 psychiatrists ; 209 nurses (156 registered nurses and 53 practical nurses), 19 OTs, 13 public health nurses (PHNs) and 15 psychiatric social workers (PSWs).

In hospital "B", the mixed gender closed wards and the social rehabilitation open wards for males were observed for three days from August 5 to 7, 2002. The candidate for observation was the staffs (12 nurses, 4 psychiatrists, 2 OTs, 2 PHNs and 2 PSWs in general every day) who were working in the wards mentioned above.

Observation Methods and Ethical Considerations

Seven observers' composition were third year five nursing students (one person has the bache-

lor's degree of law), one psychiatric nursing researcher who takes charge of instruction of their investigation and one nurse who belongs in the graduate school of the social welfare.

First, five observers were instructed in observing using the SUN mentioned above. An interview was also conducted in order to clarify the unclear points of observation results. Next, to ensure the inter-rater reliability on scale items, the degree of agreement between two raters (scorer and referee) was evaluated. In addition, two nurses evaluated the objectivity of observed results. Care services and amenities in daily living for patients were studied at each ward. The team of seven observed the work of care-provider and/or patients-careprovider interactions in the hospital, in order to evaluate the method of offering care service to a patient

Moreover, the focuses of collected data were careprovider's attitudes, and the correlation of patient and care-provider's conversation. The amenities in these hospitals (comfortable habitation environment) were also observed. It was reviewed by each hospital's Research Ethics Committee whether this study's participants' dignity and rights and safety and well-being were guaranteed or not throughout the conducted research project.

RESULTS

Findings revealed 13 categories of constraints to implementing the normalization principle, which were further grouped according to patient or careprovider: (category 1, C-1) patient gives-up, (C-2) care-provider gives-up, (C-3) patient acceptance of status quo (unfounded belief), (C-4) care-provider acceptance of status quo (unfounded belief), (C-5) care-provider's convenience, (C-6) management by care-provider (protective), (C-7) patient isolation, (C-8) patient's lack of information, (C-9) lack of institutional care policies for care-provider, (C-10) patient's low self-esteem, (C-11) care-providers' attitude toward the disabled (prejudice), (C-12) hospital self-sufficient (total institution) and (C-13) care-provider's motivation & accomplishment. The meanings of each category are described in the following table.

Gives-up was a category common to both patients and care-providers. During data analysis,

Category	Definition
1: patient gives-up	Patients often say, "Care-providers would not listen to me. "(1) Patients get little information concerning social living due to long hospitalization and do not know what situation they are in. (2) They do not bother to take the trouble of changing the present state. Due to combinations of factors (1),(2) and others, patients begin to think that they must accept the present situation as they have nowhere else to go.
2 : care-provider gives-up	Care-providers often say, "I have practiced medicine or nursing like this, and it is difficult to do new things from now." (1) They think that " new things are not worth doing, "because policies of medical care and nursing differ according to the opinions of the superiors (hospital management). (2) They feel the dilemma that they cannot return patients to normal social life no matter how hard they may work because of the deficiency of social resources. (3) With regard to the behavior, they resist changes in policies to maintain the present system or adapt themselves to the present system.
3: patient acceptance of <i>status quo</i> (unfounded belief)	Patients hospitalized over a long period become used to changing clothes without shutting the certain or to using the toilet without closing the door. Some patients stop feeling embarrassed even when they are naked. Patients consider following the conventional rules of the hospital to be good behavior as a patient. They do not notice or avoid noticing differences between daily living in hospital wards and that outside the hospital.
4: care-provider acceptance of <i>status quo</i> (unfounded belief)	Care-providers often say," Calling patients by their nicknames makes the relationship between patients and care-providers closer. "They consider performing routine work according to the conventional hospital policies to be a good thing. Care-providers control the living of patients, and patients conform to this control. Care-providers consider it to be good for patients.

Table Results of Categorization and Definitions of Categories

5 : convenience of care-providers	Care-providers often say, " It's all right, because there has been no note of claim dropped in the opinion box placed in the ward. "The schedule and rules of daily living of patients including the days and time of taking a bath and the number of patients who take a bath at once are prepared according to the convenience of care-providers depending on the nature of work and the available number of care-providers, and they differ from the common rhythm of daily living in the society. They also do not match the patients' needs. In addition, the initiative and self-determination of patients' are not considered.
6 : management by care-provider (protective)	Care-providers often say, " Dosing management can be made more reliably when handled by care-providers so that it is not left to individual patients. "Some patients say," I have not helped myself to rice for several tens of years. "In the correct sense of the word, support of daily living should be provided according to the self-care ability of each patient, but care-providers do even what patients can do by themselves in the discretion of care-providers.
7 : patient isolation	Some patients say," The elevators stop after a certain hour, so we cannot go out of the ward. We cannot see stars at night outside the ward. "There are grating and tempered glasses in windows, which would not open. Patients are allowed to go outdoors only on the hospital premises. Psychiatric patients are isolated in a restricted place for the defense of the society against them or due to the care-providers' views of them.
8: patient's lack of information	No sufficient information is given concerning social living or its restoration by patients.
9: lack of institutional care policies for care-provider	Whether the clear concept of the hospital about community care is announced or not and whether the concept is understood by each member of the hospital staff or not are expressed here as "whether there is an idea for care or not ".
10 : patient's low self-esteem	Patients may say, "I can't do anything about it, because I am insane." They must change, or sometimes abandon, the objectives of their lives that strongly support their self-images. Moreover, as they also experience words and behavior of care-providers that damage their self-respect and prejudice of the society, they consider themselves worthless.
11 : care-providers' attitude toward the disabled (prejudice)	There are improper speeches or behavior of care-providers directed to patients or indecent dressing of care-providers that does not match their role model. For example, care-providers may address patients with words such as "Hey "and" You, there ". This may degrade the patients' self-respect. There are also other words that suggest that care-providers do not regard patients as recipients of services. In addition, care-providers may carelessly expose the chain with a key of the ward on to the patients' site, which promotes the formation of a superior-subordinate relationship between care-providers and patients.
12 : hospital self-sufficient (total institution)	Most of the facilities run by hospitals for helping patients restore social activities are concentrated in the same region. For patients to use facilities of rehabilitation such as group homes, they must be transferred to hospitals that have group homes. National resources of support provided in local communities are inadequate, professionals that provide care in local communities are deficient, and they are not sufficiently rewarded. In addition, understanding of local people is poor so that despite maximum efforts by the hospital, welfare develops no farther than acceptance of patients at the social resources arranged around the hospital.
13 : care-provider's motivation & accom- plishment	A factor that promotes an action is a motive and motivations for accomplishment is a desire to carrying out something difficult to the end and succeeds. Medical and nursing actions may be inspired by the desire' care-provider's motivation & accomplishment "despite the presence of a heap of difficult problems today. Community care is possible only with high motivation.

the factor was studied from the viewpoints of patients and of care-providers and evaluated as to what occurs if a person gives-up and what care behavior manifests if he/she does not give up. A

diagram was prepared showing the relationships on gives-up

The category observed in the patients and careproviders in common was "gives-up". In analyzing the associations among categories and preparing the diagram of interrelations among factors that affect the care, we noted the common factor of " gives-up " from the viewpoints of patients and care providers and evaluated what happens if they give up and what care behavior is produced. We, then, prepared a diagram of relationships among factors that affect the care (Figure).

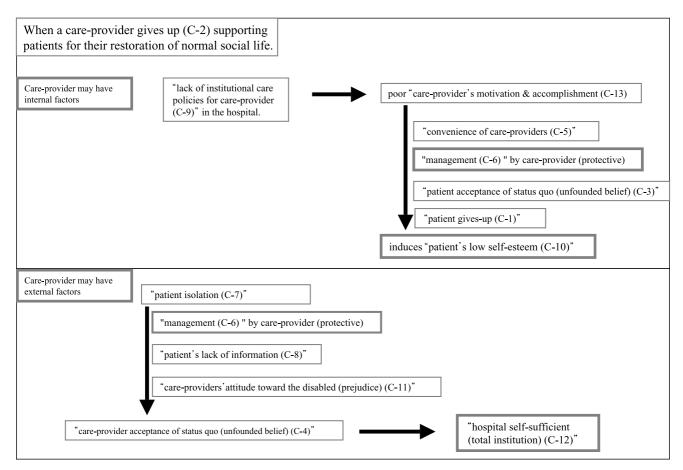


Figure . Analysis of factors that affect care services for achieving the normalization principle of principle of patients with mental dis orders who have been hospitalized a long period.

The care-provider may have internal (psychological) and/or external factors if the care-provider gives up (C-2) supporting patients for their restoration of normal social life. Internal factors are considered to be affected by " lack of institutional care policies for care-provider (C-9) "in the hospital. A low concept of care is reflected in a poor identity of the care-provider as a professional. This is considered to result in poor self-respect, poor self-efficacy, poor self-confidence based on lack of knowledge, and a poor sense of occupational ethics in the care-provider. On further evaluation, a low concept of care is considered to prohibit care-providers to feel satisfaction with their work and to lead to a poor" care-provider's motivation & accomplishment (C-13) ".

Conventional care was collective and supervisory care from objective viewpoints according to the " convenience of care-providers (C-5) " rather than care catering to subjective needs of patients and their self-care capacity. By" convenience of careproviders (C-5) ", the phenomenon of " management(C-6) "by care-provider (protective), convenient for care-providers occurs. As care-providers provided, and patients accepted, such care as a matter of course" patient acceptance of status quo (C-3) ", self-management and initiative are subdued, and patients become dependent "patient gives-up (C-1) ", leading to institutionalism. The above factors also contribute to " patient gives-up (C-1) ". In hospitals where the policy of isolation and management of psychiatric patients persists, a

superior-subordinate relationship is formed between care-providers and patients, and it appears in the authoritative and oppressive attitude of careproviders. This induces " patient's low self-esteem (C-10) ".

Concerning external problems with" care-provider gives-up (C 2) ", there are effects of the past policies of Japan to patients with psychiatric disorders. A " care-providers' attitude toward the disabled (prejudice) (C-11) " states that patients with psychiatric disorders are worthless and dangerous persons has led to care based on the principle of social defense, which has confined patients continuously in psychiatric hospitals and " patient isolation (C-7) " from society.

Additionally, mistaken perceptions such as that " psychiatric disorders never cure ", " patients feel more comfortable when they are in the hospital ", and " the patients' families feel secure when the patients are in the hospital "have been transmitted to part of the care-providers even to date, and the old (protective) view that psychiatric patients should be isolated and "management by careprovider (C-6) "still lingers on " care-provider acceptance of status quo (C-4) ". These complex factors, there is also the problem that information needed for developing the patients' abilities for their living in the community is not provided " patient's lack of information (C-8)". These bring about the situation of" hospital self-sufficient (total institution) (C-12) ".

DISCUSSION

There were multiple interactions among the 13 categories influencing the implementation of Nirje's normalization principle. A major identified problem was, a care-provider gives up on patient's ability to learn or resume normal social life. A careprovider's disinterest might be due to internal (psychological) and/or external factors. Another major variable was lack of institutional care policies for care-provider. The absence of a hospital's vision of health care including its purpose in the community and lack of policies to implement that vision prevented ward staff from intervening collectively and knowledgeably in patient care. A traditional, custodial concept of care was common among staff rather than ideas and procedures for social normalization. A care-provider's low concept of care as well as a confused or poor professional identity led to feelings of dissatisfaction with care and lack care-provider's motivation and accomplishment.

The caring that is nursing must be a lived experience of caring, communicated intentionally, and in authentic presence through a person-with person interconnectedness, a sense of oneness with self and other (13). Such high concept upheld by the hospital is considered to promote improvement in the quality of care. However, a splendid concept makes no sense unless it permeates through the entire hospital and is put into practice. Even in a situation where each care-provider does not give up high-quality care, a low concept of the hospital may affect the behavior of care-providers. It may further be reflected as poor confidence in the potential of patients as human beings and treatment contrary to " care that I would want to received if I were a patient ".

The exceptional allocation of a smaller medical staff to psychiatric hospitals (1/6 of the physicians and 1/3 of the nurses compared with non-psychiatric hospitals) is causing the lack of human resources for care (14). We considered that these factors were to be reflected in the qualification of individual careproviders including the personality and view of care and the function and quality of interdisciplinary care provided by the hospital and to promote " gives-up " of care-providers. This leads to their poor identity as a professional and reduced motivation to new activities. Also, reduced motivation may appear as care behavior at a low ethical standard, i.e. treating patients in a manner contrary to " care that I would want to receive if I were a patient "based on the normalization principle. A hospital with a low concept of care cannot provide support or rehabilitation for community care, and this negligence erodes the sense of unity in the hospital staff. Studies (15, 16) have shown that caring behaviors of nurses and nursing staff attitudes are directly related to patient satisfaction. As Osanai (17) expressed this situation as "Institutions in Japan remain the same as jails in sprit", care based on poor motivation goes no farther than care to maintain the status quo (compliance to the establishment).

In conventional psychiatric nursing, the nurse's diagnosis of the self-care level was limited to clarification of problems with the patients, and patients were regarded as "individuals incapable of selfcare ". This is another problem that resulted in failure of developing the latent self-care abilities of patients. Also, because of the lack of social resources, action plans of the psychiatric care team focused on community care have not been worked out. These problems together caused prolonged hospitalization, reduced initiative and self-care abilities, and institutionalism. Chronic social disablement is caused by three types of factor: impairment, e.g. slowness in schizophrenia; social disadvantage, e.g. lack of opportunity to develop social or vocational skills; and an under confidence or unduly low self-esteem which is reactive to impairment and disadvantage. The last of these factors is particularly evident in 'institutionalism', a condition in which the individual comes to acquire contentment with institutional life and wishes to lead no other. Many long-stay patients in large mental hospitals used to be 'well-institutionalized' but it became recognized that retraining and rehabilitation could lead to successful resettlement outside hospital (18).

According to Bandura (19), the central premise of social learning theory is that behavior is determined by a continuous, reciprocal interaction cognitive, behavioral, and environmental factors. Bandura asserts that through various interventions, individuals can improve their ability to perform certain cognitive and social activities. In this context, self-efficacy is a person's belief in his or her capacity to organize cognitive, social, and behavioral skills into integrated courses of action. When an intervention enhances clients' beliefs about their ability to perform particular tasks, their selfefficacy is increased. The assumption is that a belief that certain actions can be accomplished will improve the likelihood of achieving the desired outcome.

High-quality care fulfills the 4 aspects of the quality of life (QOL), i.e. 1) Activities: Voluntary and enthusiastic participation in activities of various fields and freedom of self-realization and choice; 2) Human relationships: Relationships with familiar and unfamiliar people; 3) Self-respect : Selfconfidence and self-acceptance; 4) Basic sense of happiness in life: Rich experience, sense of security, and high-quality living (20). For example, according to Borge and others, they reported that the variables of loneliness, satisfaction with neighborhood, and leisure time activities explained 63 percent of the variance in patients' subjective wellbeing. Most long-term patients who had moved out of psychiatric institutions were satisfied with their living situation and reported a relatively high quality of life (21). The limitation of this research is small study population. However, if care-providers do not "gives up ", the concept and ethics of the hospitals remain high. This" not giving up "is supported by the motivation and enthusiasm of careproviders to realize the normalization principle. It is provided to ensure a state in which the normalization principle that people with and without disabilities can live together in the community is realized.

CONCLUSION

We propose that care-providers try to incorporate rehabilitation programs that help the patients acquire the pattern and rhythm of living necessary for them to live in the community in their daily hospital life rather than to fit the patients into hospital rules or schedule. Therefore, care-providers must look back on their own views of the humanity, disabled people, and support and may have to change them if necessary. It is important that careproviders do not give up having psychiatric patients not give up restoration of normal social living. To develop such individual attempts into rewarding activities, it is necessary to set goals in the hospital and to let an interdisciplinary team work to achieve them.

Moreover, the situation is expected to change if efficient care management is implemented to support psychiatric patients in the community. Highquality care to realize independent living of patients in the community including collection and distribution of information, management of symptoms, assistance for self-care, and psychological education is provided at hospitals that maintain the idea of, and strong belief in, providing highquality care for returning patients to the community. By receiving such high-quality care, patients are encouraged " not to gives up " and to pursue hope and possibility, develop self-respect through experiencing self-acceptance and self-efficacy, and keep hoping for returning to normal living. Strong determination " not to give up " hope for normalized living in both patients and care-providers is considered to produce synergism and make living of patients in the community possible. The findings of this study will provide insights into how better to design hospitalization and/or community care for the mentally ill.

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