

ORIGINAL ARTICLE

The Sasagawa Project: A model for deinstitutionalisation in Japan

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(Received for publication on November 8, 2004)

(Revised for publication on January 13, 2005)

(Accepted for publication on January 20, 2005)

Abstract. Japanese psychiatric services are still typically hospital-based. The Sasagawa Project is the first systematized deinstitutionalization project in Japan that aims to make the transition from hospital to residential living while ensuring both the quality and continuity of care for the patients. Seventy-eight (51 males) patients (mean age 54.6) with chronic schizophrenia, who were considered appropriate for discharge received continuous cognitive behavioural therapies based on the Optimal Treatment Project manualised protocol, both before and after the hospital closure. During the first 12 months after the deinstitutionalisation was initiated on April 1st, 2002, ten people had incidents that interrupted their stay in the residential Sasagawa Village. A common criticism of many treatment outcome trials is that evaluation is focused on changes in clinical severity. In the Sasagawa project the transition appeared to have been smooth and relatively few incidents occurred could be related to the transition to a less intensive residential care. This project might be a useful model for effecting and monitoring transition from hospital to community care in Japan and other countries where such changes have been proposed. (Keio J Med 54 (2): 95–101, June 2005)

Key words: deinstitutionalisation, schizophrenia, outcome, psychiatric rehabilitation, psychiatric hospitals

Introduction

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 Large institutional mental hospitals have been replaced by community-based services that focus efforts on preventing severe episodes of disorders and the necessity for long-term hospital treatment.^{1,2}

In Japan, health professionals and policy makers have recognized the importance of such movements, but changes have been slower than expected.^{3,4} Consequently 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,⁵ compared to 0.9 in the United Kingdom and 0.5 beds in the United States.⁶

Such reliance on hospital-based psychiatry is a barrier to the development of community-based psychiatry.

The Sasagawa Project aims to make the transition from a hospital to a residential facility while ensuring both the quality and continuity of care for the patients.

The aim of this paper is to describe the rationale, methods, and recruitment of the Sasagawa project and the community “survival” twelve months after the hospital closure. This is an ongoing, prospective, pragmatic, observational study that has been developed to provide clinical and economic information about Japanese inpatients with schizophrenia, their families, mental health professionals and policy makers in our attempts to develop community-based psychiatry. The study will provide data to test additional hypotheses.

In particular, the interactions between environmental change and the course of mental disorders, patterns of treatment, and the association of treatment with outcomes.

Although there have been many follow-up studies of patients discharged from mental hospitals,⁷ there have been few long-term prospective studies with systemic assessments. Furthermore, description of the process of closure has often been unclear and the results focused on community tenure, homelessness and associated social incidents such as criminal events.⁸ Crucial issues about retraining of hospital-based staff and the application of manualised evidence-based treatment strategies had seldom been addressed. The most comprehensive study, the Friern Hospital Project, was carried out in London in the 1980s.⁹ The extensive documentation provided enables clear comparisons to be made between patient relocation programmes of this kind on a wide range of clinical and social variables. The change from a passive lifestyle where staff made everyday decisions for patients to one where patients were required to solve problems, make decisions and plans for their daily lives might be expected to re-activate neurocognitive functions that had been dormant for many years of institutional care of the kind usually provided in Japan.

This report will focus on the process of closure of a long-stay hospital and the community tenure of patients in the first year after transition to residential care.

Method

A summary of the Sasagawa Project study is shown in Table 1. The study was designed to evaluate a group of people with chronic schizophrenia over 5 years of continued optimal treatment and to use a range of measures that reflected the broad impact of this disorder on many aspects of peoples' lives.

Data is being collected prospectively throughout the 5 year period by the participating psychiatrists during treatment visits that are part of normal care. The Institutional Review Board approved the protocol. The study was explained to the patients by the principal investigators. Written informed consent was obtained from all patients.

Setting

Sasagawa Hospital was a private long-term inpatient unit with 107 patients in the suburbs of Koriyama city; population around 300,000. It was affiliated with Asaka Hospital, a nearby acute neuropsychiatric unit. The Sasagawa hospital was founded for the psychiatric rehabilitation for the people with chronic mental illness by Dr. Yuju Sakuma in 1978. Most of these patients had

no relatives willing or able to provide them with a place to live in the community. Most suffered from severe persistent psychotic and residual symptoms and had frequent admissions to the acute unit. Thus, a range of intensive specific services were needed to help them adjust to living in the community.

Subject selection

Patients were selected who were considered appropriate for discharge from inpatient care. Eighty-eight percent of the inpatients at Sasagawa Hospital were discharged when the hospital closed on 31st March 2002. The remaining 13 were transferred to another mental hospital for continued inpatient care. Of the 94 discharged people, 78 (51 males) were diagnosed as chronic schizophrenia by two psychiatrists independently. For this study, these 78 people with chronic schizophrenia are being evaluated prospectively throughout a 5-year period.

Design

The project started ten months prior to closure of the Sasagawa Hospital. A project team of twenty multi-disciplinary members was recruited and a Non-Profit Organization (NPO) was founded. The following plan was made:

1. Sasagawa Hospital would close at the end of March 2002;
2. The building would be restructured to provide (i)a residential facility, the "Sasagawa Village," and (ii)a community support centre called "I CAN." The refurbished buildings would provide living facilities similar to Japanese homes, e.g. tatami flooring, spa baths, etc.
3. These two facilities would be managed by the NPO.
4. A range of acute services, such as day-night hospital and community nurse visits, would be provided as necessary by Asaka Hospital.
5. Continuous cognitive behavioural therapies based on the Optimal Treatment Project manualised protocols²² would be provided to patients before and after the hospital closure.
6. An information system would be developed to document the process and outcome of the project by all members of the multi-disciplinary team.
7. The Sasagawa Project plan would be discussed repeatedly with patients, their families and people who were residents in the neighbourhood of the hospital/residence.

This plan was implemented in its entirety without notable problems.

Table 1 A Summary of the Design of the Sasagawa Project Study

Type of study	Observational, non-interventional	
Primary objectives		1 To understand the outcomes of the people with chronic schizophrenia who had been discharged from the mental hospital after long years of inpatient cure 2 To evaluate the effects of various factors on the outcomes including premorbid factors, psychiatric symptoms, cognitive functions, insight, drug attitude, and so on.
Patients	Schizophrenia diagnosed with ICD-10 ¹⁰ criteria	1 Ex-patients with chronic schizophrenia discharged from the Sasagawa Hospital 2 Patient consent
Selection criteria		
Study investigators	Psychiatrists in charge of in the project	All patient care is at the discretion of the participating psychiatrists and co-professionals
Methods		Data collection to be conducted for a minimum of 60 months
		Data collection points to be baseline assessment (before discharge), 1 month, 3 months, 6 months, 9 months, 12 months, 18 months, 24 months, 36 months, 48 months, 60 months.
Measures	Demographics	Age, gender, diagnosis, diagnostic history, premorbid functions (PAS ¹¹), alcohol and substance dependency/abuse
	Functioning	Living conditions, work, social functioning (REHAB ¹² , SFS ¹³)
	Clinical status	GAF ¹⁴ , PANSS ¹⁵ , CPS-50 ¹⁶ , David's Insight Scale ¹⁷ , REHAB ¹²
	Tolerability	Suicide attempts, extrapyramidal symptoms, tardive dyskinesia, hyperprolactinemia
	Medication neuroleptics	Antipsychotic medication: name, CP equivalent dosage, reason for change
	Medication others	Other medications: Anticholinergics, antidepressants, anxiolytics/hypnotics, mood stabilizers
	Compliance	Compliance: Patient and Nurse report
	QOL	Community Health Record: Criminality, violence, victimization
	Neurology	WHO-QOL ¹⁸ , schizophrenia QOL ¹⁹
	Neurocognition	Neuroimaging (MRI), Neuropsychological study (EEG)
	Medical resource	Neuropsychological tests: Mini-mental status (MMS) ²⁰ , Rey's figure test ²¹ , digit span, fluency tests, letter cancellation tests, Trail making test A, B ²¹
		Medical resource use: Days/admissions for in-patient facilities, out-patient visits, day night care visits
Funding of Research	Costs	Direct costs
	None	

ICD: International Classification for Diagnosis, QOL: Quality of Life, PAS: Premorbid Adjustment Scale, SFS: Social Functioning Scale, GAF: Global Assessment of Functioning, PANSS: Positive and Negative Syndrome Scale, CPS: Current Psychiatric Status, CP: Chlorpromazine, REHAB: Rehabilitation Evaluation Hall and Baker.

Staff training

All the professional staff of the ex-Sasagawa hospital was relocated to Asaka Hospital or the affiliated community nursing center that applied the same treatment without notable trouble. They were trained to implement the Optimal Treatment Project strategies for mentally disordered people living in the community. This included the full range of empirically-based treatment strategies that have been associated with improved clinical, social and family outcomes for psychotic disorders (optimal pharmacotherapy, assertive community treatment, psychoeducation, carer-based stress management, social skills training, supported employment, and specific cognitive behavioural strategies for persistent residual psychotic and non-psychotic symptoms and behavioural problems).²² In addition, ten staff received three days training at the Village ISA in Long Beach (California, USA) to study multiple community support systems. This helped NPO staff adjust their attitudes from those of hospital workers to those of case managers or “life coaches” in the community.

Patient/Resident training

A copy of the Japanese translation of the OTP treatment manual for consumers and their carers^{23,24} was given to each patient, and at least 10 sessions were completed prior to their discharge. These initial sessions focused on education about their disorders, medication, adherence and the recognition of the early signs of a major exacerbation. After discharge the training programme continued, with a focus on problem solving day to day stresses and life changes associated with patients' efforts to achieve their personal life goals, as well as biomedical and psychosocial strategies to cope with residual psychotic, negative and anxiety symptoms, or antisocial behaviours. Early recognition of exacerbations resulted in assertive intensive care being provided in the residence with support from additional staff from Asaka Hospital.

Evaluation

A wide range of standardized scales were used to assess clinical symptoms, social support, social activity, family function, quality of life, and neuropsychological functions (see Table 1). The assessment of clinical severity in the Sasagawa project includes not only overall severity, measured with the Global Assessment of Functioning (GAF) scale,¹⁴ but also specific ratings for positive, negative, depressive and cognitive symptoms. Tolerability assessments include mass index, extrapyramidal symptoms, hyperprolactinemia and sexual dysfunction.

Results

Sasagawa Hospital closed as planned on the 31 March, 2002. The day after the closure, the residential facility “Sasagawa Village” was opened and 94 patients, including the 78 diagnosed with chronic schizophrenia, took up residence in the refurbished building. Four were diagnosed as having epilepsy, 4 as mental retardation, 1 as a major mood disorder, 1 as schizoaffective disorder, 1 as a behavioural disorder due to alcohol, 1 as a Klinefelter syndrome. The remaining 4 people had schizophrenia, but had moved from the acute unit of Asaka hospital to Sasagawa Hospital at the end of March without participating in the training before discharge. Therefore, the total number of the subjects with schizophrenia for this study was 78 (51 males), with a mean age of 54.6 years. Table 2 shows descriptive details of the patients included in the study.

During the first 12 months after the deinstitutionalization, ten people had incidents that made their continuous stay in Sasagawa Village impossible. The incidents were classified in three categories: 1) physical conditions, 2) psychotic exacerbations, and 3) accidents. Six people were admitted to hospital with serious physical illnesses. Two did not return to Sasagawa Village; one with complications of heart disease and the other after surgery for ossification of posterior longitudinal ligament (OPLL). The other four were admitted with acute MI, adynamic ileus, glaucoma, and pneumonia, and returned to the Sasagawa village after a few months. Three residents had major psychotic or affective exacerbations. Two were admitted to the acute unit and returned to the Sasagawa Village after a few days of intensive care. The third committed suicide at Sasagawa Village during a major depressive episode. The last of the 10 residents who did not stay at the Village

Table 2 Details of the Patients

age (range)	54.6 ± 7.2 (34–67)
mean age of onset	23.1 ± 5.9
total length of stay in life (months)	312.0 ± 122.7
Diagnosis by ICD-10	
Paranoid Schizophrenia	34 (43.6%)
Residual Schizophrenia	42 (53.8%)
Simple Schizophrenia	2 (2.6%)
PANSS score	
positive	9 (7–25)
negative	19 (7–29)
general	26.5 (16–41)
GAF score	57.5 (25–82)
CP equivalent dosage (mg)	587.5 (66.7–3433.5)

ICD: International Classification for Diagnosis, PANSS: Positive and Negative Syndrome Scale, GAF: Global Assessment of Functioning, CP: Chlorpromazine.

throughout the 12-month follow-up drowned in the shallow garden pool. The circumstances of his death appeared accidental.

In summary, the outcome 12 months after hospital closure were: successful community tenure 68 (87.2%), physical illness 6 (7.7%), major exacerbations 2 (2.6%), death-suicide 1, accident 1 (1.3%).

The activity of the patients appeared to have increased. In addition, the morale of the staff and their attitudes towards residents appear to have changed in a positive way. Before discharge, patients' everyday lives were managed totally by hospital staff. With the move to the Village, their life style had changed dramatically. For example: Case K.I. a 56-year old man who had been in hospital for the past 23 years re-started his career as a house cleaner. He participated in the day-night care programme three days a week and the job coach training on the remaining two days. The day-night care programme involves sports, karaoke, playing musical instruments, and group meetings. He was able to take medicine by himself regularly and enjoyed cooking with his friends living in the Sasagawa Village. His psychopathology remained stable with some persistent negative symptoms such as slightly diminished emotional responsiveness and restricted affect. Specific communication skills such as expressing pleasant feelings were repeatedly trained and practised and his interpersonal communication skills improved markedly since his discharge.

Case M.N. is a 53-year old woman who had spent the past 24 years admission in Sasagawa Hospital. She now participates in the day-night care three days a week and enjoys playing Japanese harp together with her friends living in the Sasagawa Village. She often had some quarrels soon after the closure, but training in problem solving skills helped her cooperate with others and remedied her diminished social drive.

All the residents utilize various living supports in the community, for example, meal delivery services, visiting nursing services, community recreation centres, etc. On the other hand, most manage their own possessions, daily schedules, and medication.

Discussion

This preliminary report of the Sasagawa project suggests that transition from hospital to community-based care of patients with severe and persistent chronic schizophrenia is feasible in Japan. Almost all patients who had been resident in a long-stay unit were able to be managed in a residential programme with extensive clinical and social supports and ongoing treatment aimed at clinical and social recovery. In the first year after hospital transfer only 5% suffered a major exacerbation of their mental disorders, and a similar pro-

portion experienced severe physical illness. There were no reported incidents of criminal or violence, or cases of homelessness. Careful planning that minimized social and clinical dislocation may have contributed to this successful transition. Education for neighbours of Sasagawa Hospital was repeated on several occasions so that people understood the needs for accepting the changing methods for the community care of mentally challenged people. The agreement of the local mayor was considered a very important step towards gaining the cooperation of neighbourhood as a whole.

The most comprehensive study for assessing the effects of a closure of a mental hospital, the Friern Hospital Project,⁹ carried out in London in the 1980s reported the one-year outcome in the community.²⁵ A total of 278 patients were discharged in phases over the first three years. At the time of reassessment one year after discharge, 7 (2.5%) had died, 6 (2.2%) were lost to follow-up, and 5 (1.8%) were in hospital at the follow-up point. In total, 260 (94%) were living outside the hospital one-year after discharge. However, many had had their stay in the community interrupted during that first year by brief admissions. The process of treatment before and after discharge did not appear to change in any remarkable way, with pharmacotherapy and supportive case management appearing most prominent. An earlier study in the United States contrasted three approaches to rehabilitation in a hospital closure programme.²⁶ The more goal oriented behavioural intervention focusing on training patients in skills needed to live in the community appeared to be superior to case management and milieu type strategies in maintaining community tenure after discharge. More recent studies of deinstitutionalization for long-term mental illness in Australia and Italy have shown that high levels of community tenure can be achieved where a well-organised programme of hospital closure is undertaken.^{27,28}

The current project is ongoing and subsequent reports will attempt to answer questions about which types and severity levels of clinical impairments, social disabilities, and subjective well-being factors are most responsive to community-based treatment strategies and how deinstitutionalization influences long-term outcomes in terms of health status, work, and social functioning, quality of life and costs. The findings from the Sasagawa project may contribute to the current debate about transition from hospital to community-based services in Japan.

One matter worthy of special mention is that all the patients and staff were trained and prepared for the integrated community-based psychiatry service following the Optimal Treatment Project protocols. These include treatment manuals that provide a full range of pharmacological and psychosocial strategies that have

been proven efficacious in random-controlled trials. The rehabilitation was not based on the clinical experience and ad hoc ideas of the staff, but on well-organized goal and problem-oriented behavioral and cognitive methods that address clinical issues, such as adherence to medication and early warning signs of impending exacerbations and early crisis intervention, coping with residual positive, negative, anxiety and affective symptoms, as well as social and interpersonal issues, such as friendships, intimate relationships, work, hobbies and leisure, and problems of aggressive behaviour and substance use. Earlier versions of these cognitive-behavioural strategies for cases of chronic schizophrenia were employed with very similar results in the pioneering study of Paul and Lentz.²⁶ Thus, the Sasagawa project has sought to update the treatment programme with the latest evidence-based strategies, not merely provide alternative living arrangements and social structures for patients as has been the usual practice in other countries. The staffs were trained in the psychosocial treatment methods in a series of structured role played practice sessions. In order to maintain their level of technical skills for managing people with mental illness in the community, 5-hours supervision sessions with continued role-played practice were held every month by psychiatrists, who had received extensive training in the cognitive-behavioural methods.

Before the closure of the hospital, considerable attention was paid to ethical issues such as the patients' agreement for the transition, as well as relatives' agreement for discharge of patients from the hospital. Moreover, extensive and repeated consultation meetings were held with the neighbours of the Hospital. Some did not totally agree with the new living facilities for mentally ill patients and had high levels of stigma, but with education on mental disorders and their modern treatment, most finally adopted somewhat positive attitudes towards the project. However, such changes in attitudes are often fragile so that in order to sustain and develop further support from the local community, it is essential to demonstrate positive results. The entrance hall of the ex-hospital ward on the ground floor of the Village is used now as the communication salon opened to all people in the community. Many events are held there and people with and without mental illness are invited as guests. School pupils often stay in the salon and enjoy accessing the Internet using the computer there. School teachers who had heard about this also come to the salon and the local communication between people in the community and ex-patients is expanding naturally. Because this project has been conducted at only one institution in one area where the local community has been highly supportive, these findings might not be generalized to other hospital relocation projects and further research is needed.

The part of this study had presented in the meeting of the 14th International Symposium for the Psychological Treatment of Schizophrenia and other Psychoses. Melbourne 22–25, September, 2003.

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