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Original Paper

Community-Based Medical-Welfare System for Severely Mentally and Physically Handicapped Persons in Japan

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Abstract

In 1967, Japan enacted a law and established a medical welfare agency which officially recognized the existence of "Jusyo-shinshin-syogai-ji." This literally means a child who has both a severe physical disability and profound mental retardation. Initially, institutionalization was the primary goal for all these children. However, the hospitals caring for "Jusyo-shinshin-shogai-ji" are now expected to play an important role as the community-based centers for the "normalization" of these children. Services such as a day care center, a rounds clinic in rural areas and short term home stays, among others, have already been instituted. Also, in progress is a volunteer program for supporting home based management for these children and their families. The purpose of this paper is to present a historical perspective of this system which is unique to Japan and to suggest ways for making a better tomorrow in the world.

I. Introduction

In 1955, "The Association for the Protection of People with Severe Mental and Physical Handicaps in Japan" was established through the great efforts of concerned people such as the families of the handicapped, and medical and social welfare workers. Even before 1955, this problem had been recognized by some people such as private social workers, religious men and educators, but there was no systematic, nation-wide effort

to help the handicapped.

"A child with the eternal incurable disease" or "a child with multiple deficiency" are terms that were used in reference to these people until 1958, when "Jusyo-shinshin-syogai-ji" came into general use. In 1967, for the first time ever, a statute called the "Revised Law for Child Welfare," provided that children who have both a profound mental handicap and a severe physical handicap would be called "Jusyo-shinshin-syogai-ji."

Since then, the number of hospital-homes for these people has increased. There are now 15,970 beds in 158 hospital-homes (80 national and 78 private) scattered all over Japan. When the law was enacted, institutionalization for all these persons was a primary goal. However, the hospital-homes for "Jusyo-shinshin-syogai-ji" are currently expected to play an important role as the community-based centers for the so-called "normalization" of these people. We are now providing comprehensive services such as a day-care center, a rounds clinic in rural areas, and short-term home stays.

II. Definition

The legally accepted concept of "Jusyo-shinshin-syogai-ji" is not a medical but a social welfere term. There is no internationally recognized term for "Jusyo-shinshin-syogai-ji." Therefore, at the 16th World Rehabilitation Conference in Kyoto (1988), Suemitsu proposed the Japanese term, "Jusyo-ji," which is an abbreviation of "Jusyo-shinshin-syogai-ji," as a standard term for these people. Subsequently, several Japanese associations concerned with the problems of "Jusyo-shinshin-syogai-ji" suggested "Severe Motor and Intellectual Disability (SMID)" by Dr. Hagberg of Sweden as a unified term. Because it has not yet achieved world-wide recognition, both "Jusyo-ji" and "SMID" are used in this report.

III. Current conditions and incidence of "Jusyo-ji"

Hamamoto et al. reported that in Japan, there were 0.99 "Jusyo-ji" per 1,000 children

Table 1 Children with multiple mental and physical disabilities, surveyed by a project team of the Ministry of Education, Culture and Science 1966

Intellectual disability / Degree of physical disabilities	85 or above A: normal	85-75 B: poor	75-50 C: educable debility	50-25 D: trainable imbecility	25 E: protection required idiocy
0: normal	1	2	3	4	5
I: inconvenient for everyday life	6	7	8	9	10
II: mild disabilities; able to make useful motion with some restriction	11	12	13	14	15
					behavior problems; blindness and deafness
III: moderate disabilities; useful motion is extremely restricted	16	17	18	19	20: serious mental disabilities
IV: severe disabilities; unable to make useful motion	21	22	23	24	25: severe physical disabilities

Table 2 Classification of "Jusyo-shinshin-syogai-ji"

IQ \ Ability	Able to Run	Able to Walk	Waking Disturbance	Able to Sit	Bedridden
70-80	21	22	23	24	25
50-70	20	13	14	15	16
35-50	19	12	7	8	9
20-35	18	11	6	3	4
0-20	17	10	5	2	1

*Classiaied (1) through (4) are called "Jusyo-shinshin-syogai-ji".

in the 3 to 7 years old range. Other studies done after the above 1967 survey showed similar results.

Because the life expectancy of "Jusyo-ji" is shorter than non-handicapped people, the number of "Jusyo-ji" in the total population has been estimated at around 0.3 per 1,000 people according to a survey done in Nagoya city. This means that there are approximately 35,000 "Jusyo-ji" in Japan (total population: 120,000,000). Of these, 10,000 "Jusyo-ji" are in hospital-homes. It is assumed that the remaining "Jusyo-ji" live at homes.

In the beginning, hospital-homes primarily played the role of saving lives and providing daily care. However, hospital-homes are currently expected to provide the various medical and educational services necessary for a better quality of life. This means that the number of professional staff members had to be increased. Hospital-homes also play an important role as community-based centers. Local medical centers are now sending them "the most extreme Jusyo-ji (SMID)," those requiring intensive respiratory care. Hospital-homes are also being asked to offer high quality therapy services.

IV. Home-based medical-welfare services for "Jusyo-ji"

Home based "Jusyo-ji" and their families receive financial support for their daily care from the national government and some local governments. In addition, the following medical-welfare services are trying to provide a better quality of life for them:

(A) Short-term stay service

In case of family emergencies, a short-term stay service for "Jusyo-ji" is available in the hospital-home. This service provides help to "Jusyo-ji" for as long as possible.

(B) Outpatient service

Outpatient clinics such as internal medicine, pediatrics, child neurology, psychiatry, orthopedic surgery and rehabilitation medicine function as a support network for the home-based medical-welfare system. For instance, Asahigawa Jidouin Hospital-Home now has 15,000 outpatients a year. In addition, many hospital-homes have recently initiated a dental care service for "Jusyo-ji."

(C) Day care center

In order to promote greater social participation for home-stay "Jusyo-ji," a day care center was established in 1990. The center

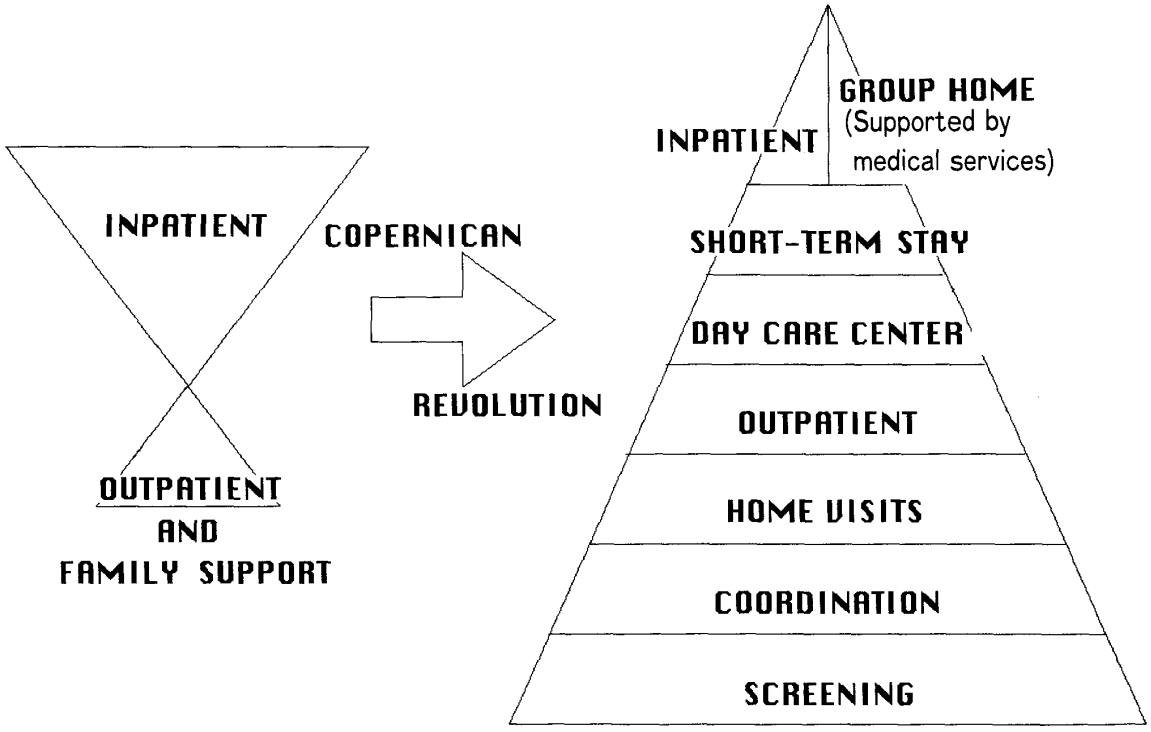

Fig. 1 Shifting roles of hospital-homes

offers various educational and therapeutic services which make their lives more healthy and meaningful after the compulsory education period has been completed. Transportation is provided between their homes and the center. Currently, there are 80 day care centers in Japan and the demand for this service is increasing.

(D) Home visiting service

Medical and educational staff members comprise a team which visits homes of "Jusyo-ji" and their families to assist in their home-based rehabilitation programs.

(E) Coordinator

The "Coordinator," one per 100 "Jusyo-ji," assures that the network of services provided by the hospital-home and home-based medical-welfare system are utilized properly.

V. Future tasks

From the previous discussion, it is clear that the legal acceptance of "Jusyo-ji" and their hospital-homes was very significant. We have been developing and improving our services for both inpatients and home-stay "Jusyo-ji" and their families. The following are the accomplishments:

(A) Promoted better understanding of their condition which incresed the number of volunteers

(B) Developed new medical and educational approaches

(C) Saved lives and/or lengthened life expectancy of "Jusyo-ji"

(D) Improved the quality of their lives

(E) Created the community- and home-based medical-welfare systems.

There are still some problems and tasks with which we have to cope in the future. For example, there are some differences in quality of service among all of the prefectures and even within a prefecture. Therefore, we must aim to have one day care center for each 500,000 to 600,000 population and make them as accessible as possible. We also need to change the relationships between hospital-

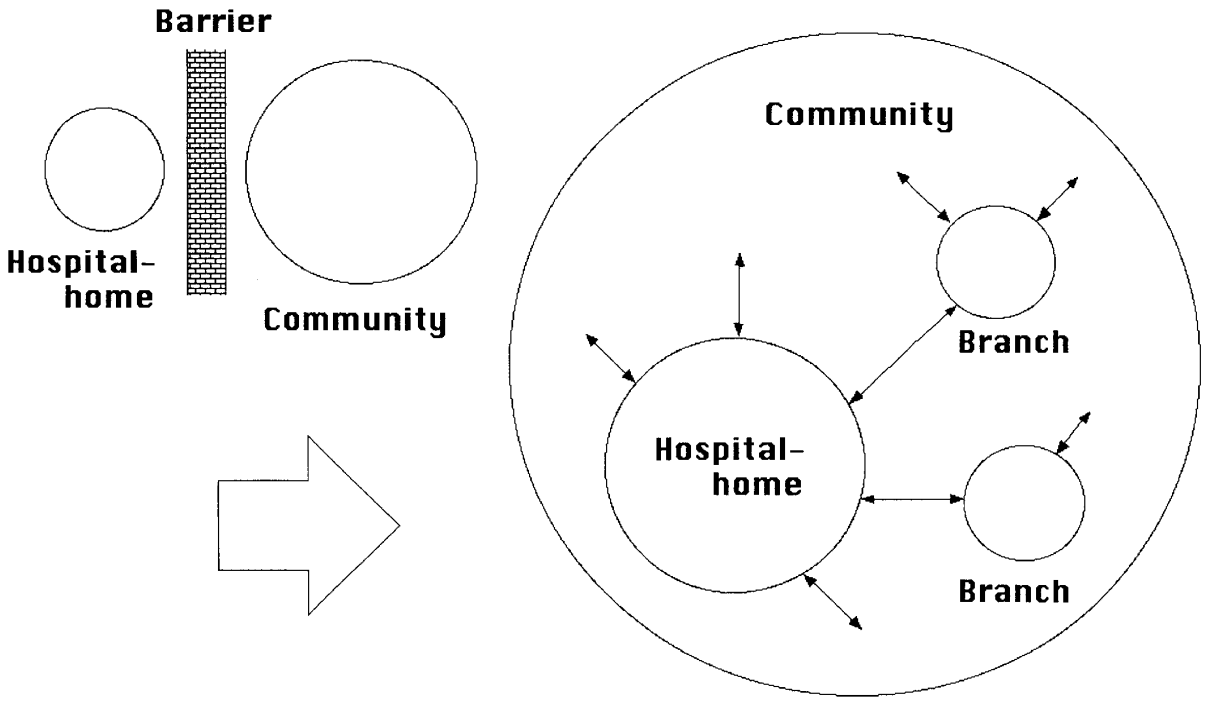

Fig. 2 Changing relationships between a hospital-home and community

homes and their communities. As mentioned before, institutionalization for all these children was a primary goal initially, but now there is a shift in the role of hospital-homes. A community-based medical-welfare system, integrating the home-based and the hospital-based medical-welfare systems, would break down some of the barriers that exist between a hospital-home and its community.

VI. Summary

The existence of "Jusyo-shinshin-syogai-ji," which literally means a child who has both a severe physical disability and profound mental retardation, has been legally recognized in Japan since 1967. A medical-welfare system was established to care for these children. Initially, institutionalization for all these children was a primary goal. However, the hospital-homes for "Jusyo-shinshin-syogai-ji" are currently expected to play an important role as the community-based centers for the process of "normalization." We are now providing comprehensive services such as day care centers, rounds clinics in rural areas and short-term stays. We are also developing a volunteer system for supporting home-based management of these children and their families. The purpose of this report was to discuss this unprecedented system from a historical perspective, to describe the progress that has been made and to identify the tasks that still remain for making a better tomorrow in the world.

This paper was presented at the World Congress of the World Federation for Mental Health in Dublin,Ireland in 1995.

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