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Special Feature Article

Roadmap to the Establishment of Psychiatric Patient's Advocacy System and Nationwide Expansion

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Abstract

The most important issues for psychiatric medicine face in Japan are guaranteeing the human rights of inpatients and ensuring the transition from hospitalization. An effective means for improving these issues is the introduction of "psychiatric patient's advocates" who visit hospitals from outside to protect the rights of patients. Patient's advocacy system can be a trigger to promote various reforms of psychiatric medicine. Now, there is an opportunity for the introduction of psychiatric patient's advocates. Herein, I propose the required role and character of such advocates, concrete project procedures, the legal basis, and a roadmap of activities necessary for realization at the national level.

Keywords: psychiatric hospital, human rights, patient's advocacy, advocate

Introduction

With revision of the "Act on Mental Health and Welfare for the Mentally Disabled" in June 2013, the guardian system for involuntary hospitalization

with the consent of a guardian was abolished, and discharge support was introduced. However, the systems for representation and human rights advocacy remained undeveloped. The

Health, Labour and Welfare Committees of both the House of Representatives and House of Councilors requested in their supplementary resolutions that this inadequacy be promptly addressed.

Subsequently, as part of a research project by the Ministry of Health, Labour and Welfare, the Japan Psychiatric Hospitals Association created the “Advocate guidelines” in fiscal year 2015.⁴⁾ However, the contents of these guidelines contained many problems.²⁾ In response, the certified NPO Osaka Center for Mental Health and Human Rights submitted “Draft Activity Guidelines and Project Model for Psychiatric Advocates”⁵⁾ to the Ministry of Health, Labour and Welfare on February 28, 2018, presenting the necessary forms of activities and feasible proposals.

Following this, the Ministry of Health, Labour and Welfare decided not to spend the 5 million yen allocated in the 2018 fiscal year budget for Training Persons Providing Decision-making Support.

As an alternative measure, from fiscal year 2019, a research team led by Ms. Chiyo Fujii of the National Center of Neurology and Psychiatry was established, and studies toward the realization of a human rights advocacy system have been underway. The main theme of the research is the design of a

system for advocates who visit from outside the hospital, and the project concept summarized by the research team¹⁾ closely resembles the individual consultation activities conducted by the Osaka Center for Mental Health and Human Rights.

This article discusses what kind of patient advocacy activities should be constructed and how they could be implemented.

I. Why patient advocacy is necessary

The purpose of an advocate is to protect the rights of patients. Then, why is it necessary to protect rights in the context of psychiatric care? First and foremost, it is crucial to clearly recognize the current situation.

In psychiatric hospitals, various human rights restrictions are routinely imposed. Involuntary hospitalization, seclusion, physical restraint, and restrictions on telephone use, visitation, or going out all constitute limitations of patient rights, even if the requirements and procedures are legally appropriate. Are these truly unavoidable measures, or are they being implemented too readily? In such situations, if there is no supporter on the side of the person subjected to rights restrictions, it is difficult to place limits on these actions.

Discharge or treatment improvement requests to the Psychiatric Review Board are triggered only upon the

submission of a request. Therefore, the system's passive nature is a weakness, and compared with the number of hospitalized patients, the number of petitions is extremely low, suggesting that the system is functioning inadequately.

Furthermore, incidents such as violence, abuse, and embezzlement by staff have continued to be revealed in hospitals across Japan in recent years. However, it is believed that only the tip of the iceberg is being reported. On-site inspections by administrative authorities are usually conducted after prior notice; thus, the real situation is not fully understood.

Issues also exist in areas of: daily life, such as meals, bathing, and management of personal belongings and money; the therapeutic environment, including bed surroundings, toileting, and lighting; and medical practices, such as explanation of medical conditions and prescription of medication. Many of these areas lack clear standards or rules and include problems that cannot be legally resolved. It is necessary to improve overall human rights conditions in psychiatric care and build a system of care that can be used with peace of mind.

In addition, excessively long hospitalizations, which may result in the loss of limited time in a person's life,

constitute a violation of the right to pursue happiness.

II. The role of the advocate's activities

1. As an ally of the patient

On psychiatric wards, staff have considerable authority. This is because they are in a position to determine matters such as discharge eligibility and behavioral restrictions. Nursing staff on psychiatric wards, unlike those on general wards, tend to place greater emphasis on group-based management. As a result, hospitalized patients are often compelled to follow ward instructions. To correct this imbalance of power, it is necessary for the patient to have "someone on their side."

As a method of human rights advocacy, there is also the ombudsman model, in which a neutral and impartial third party visits the facility. This model has been widely adopted in European countries, including by the European Committee for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment (CPT), and often carries supervisory and advisory authority. However, in Japan, the advocate model, where one stands on the side of the patient, is considered more appropriate. This model more readily earns the trust of patients, and the advocate's position is clearly defined. Furthermore, in relation to the hospital, being in a non-

authoritative role is more readily accepted.

Moreover, it is extremely important in the course of advocacy activities not to convey information heard from the patient during visits to the hospital, family, or any other third parties without the patient's consent (duty of confidentiality).

2. Empowerment

A vital role of the advocate is to engage with patients as fellow human beings. This is different from legal or regulatory forms of dispute. Simply meeting hospitalized patients and listening to their stories carries significant meaning.

Some hospitalized patients become apathetic or resigned due to prolonged institutionalized living, thinking "there's nothing I can do," or they have lost confidence, resulting in diminished awareness of their rights or motivation for discharge. It is an important role of the advocate to encourage such individuals, provide them with knowledge and information, and support them in expressing their own feelings so that they can regain and utilize their inherent strengths.

Although advocacy activities may lead to promoting discharge, tasks such as searching for community resources and co-ordinating with family members

or other related parties fall within the responsibilities of social workers.

3. The significance of entering the ward from outside

An important fact is that the advocate is an outsider to the hospital and physically enters the ward. To accurately understand the ward environment, including therapeutic setting and staff attitudes, it is preferable to go onto the ward rather than only meeting in a visiting room. Doing so also allows the presence of the advocate to become visible to other patients. They become familiar to the staff as well, and may even hear about the concerns of the personnel. When an external set of eyes and ears enters a closed facility, it improves transparency within the organization, enables early responses to minor human rights violations, and helps prevent small issues from escalating into serious ones.

4. Building trust without antagonizing the hospital

It is necessary to hold discussions with the hospital side as needed. While listening to the hospital's perspective, calm and composed exchanges of opinions should be conducted. A certain degree of tension is necessary, but the hospital should not be viewed as an adversary, nor should one adopt an aggressive or confrontational attitude.

Doing so makes it more difficult for the hospital to accept the advocate. Except for a minority of difficult administrators, there is likely a shared desire to provide safe medical care and improve the quality of treatment. Improving the human rights situation and therapeutic environment also benefits the hospital.

Advocates should not have authority over hospitals, and they must remain independent from administrative bodies. If they hold supervisory or advisory authority, the hospital is likely to become defensive and guarded.

To build trust with the hospital, those engaged in a patient's advocacy must devise ways and make efforts to create opportunities for the hospital to be able to perceive their humanity.

III. How to implement the program

1. Individual support and hospital visit activities

Should patients' advocacy by advocates be limited to involuntarily hospitalized patients, or should it also include voluntarily hospitalized patients? Should visits be limited to patients who individually request support, or should other hospitalized patients also be included?

Even in cases of voluntary hospitalization, many individuals are admitted not through their own voluntary decision but through passive consent. Some may be subject to

behavioral restrictions, including seclusion or physical restraint. Many patients are dissatisfied with their lives on the ward. Therefore, regardless of the legal classification of hospitalization, all patients should be eligible for support.

Moreover, providing support only to those who explicitly request it is insufficient. Some patients are unable to speak up. Others may have difficulties receiving support due to their mental condition or intellectual capacity. Some are in a psychologically powerless state. In the 2020 abuse case by nursing staff revealed at Kande Hospital in Kobe City, the victims were patients with dementia. The rights of such individuals must also be protected.

However, it is difficult to visit every involuntarily hospitalized patient. The number of new cases of compulsory and involuntary hospitalization with the consent of a guardian alone is approximately 190,000 per year, clearly highlighting a shortage of personnel.

Therefore, a realistic and effective approach is to combine both "individual support activities," in which advocates visit patients based on requests from the patient or family, and "hospital visit activities," in which advocates enter the ward and provide consultation without identifying specific patients in advance.

In fiscal year 2019, before the spread of COVID-19, the Osaka Center for

Mental Health and Human Rights conducted 179 visits as “individual consultation activities,” responding to contacts made via phone or letter (with 54 hospitalized patients), and also visited 11 hospitals as part of Osaka’s public program, “Therapeutic Environment Supporters,” responding to consultations on the ward.

Individual support activities should be conducted in pairs as a basic principle. The psychological and physical burdens are too marked for one person alone. Compatibility and sex-related considerations with the patient also exist. Regarding hospital visit activities, it is desirable to visit each hospital at least once a month, staying for about half a day. Initially, a team of five to six members is ideal, but once accustomed, two people can manage the visit. In the future, it would be desirable for advocates to be stationed at hospitals full-time.

2. Personnel, compensation, and insurance

There is no need to limit the attributes or qualifications of those who serve as advocates. Peer activities conducted by individuals with hospitalization experience can be highly encouraging for patients, but participation should not be limited to such people. The role may be filled not only by professionals in welfare,

healthcare, or law, but also by members of the general public. However, all participants, including professionals, should be required to complete a certain number of training days and be registered as qualified personnel.

Volunteer activities often face challenges regarding securing personnel and maintaining continuity. Therefore, appropriate wages or remuneration through service contracts, along with reimbursement for transportation and other expenses, are necessary. To prepare for possible accidents or disputes, it is essential to enroll in workers’ compensation insurance or personal accident insurance as well as liability insurance.

Regarding the employment of advocates, it depends on local circumstances whether the patient’s advocacy center (described below) directly employs or contracts them, or whether local welfare service providers employ them and receive service contract fees from the center, or a combination of both.

3. Establishment of a patient advocacy center in each prefecture

Even if advocates are trained, the program cannot operate on that basis alone. As a general rule, a “Patient Advocacy Center” (tentative name) should be established in each prefecture, with administrative staff in place. This

center would serve as the contact point for visit requests from hospitalized patients and their families, and be responsible for planning and coordinating activities, providing support, consolidating information, and conducting training.

To ensure independence and flexibility, the Patient Advocacy Center should be a private organization independent of administrative agencies or Mental Health and Welfare Centers, and the prefectural government should commission the project to such organizations. If there is a civic organization engaged in rights advocacy, that organization can be entrusted with the role. In areas without such organizations, a corporation can be established through co-operation among groups such as patient organizations, association of mental health social workers, bar associations, and family associations.

Separately from this, each prefecture should establish a regular forum for discussions involving relevant parties, including prefectural psychiatric hospitals association and administrative bodies, to facilitate information sharing and exchanges of opinions regarding advocate activities and the human rights situation in psychiatric hospitals.

IV. Requirements for realization

1. Implementation based on Act on Comprehensive Support for Daily and Social Life of Persons with Disabilities

Which legal framework is best suited for introducing advocates?

Incorporating the system into the “Mental Health and Welfare Act” would give legal authority to visits and ward entry. However, amending the law requires marked effort and time and would necessitate clarifying the division of roles with the Psychiatric Review Board. It is also highly likely to face opposition from the Japan Psychiatric Hospitals Association. Once implemented, such a system would be rigid and difficult to revise later.

Another method is to introduce the system as a community life support project under the “Act on Comprehensive Support for Daily and Social Life of Persons with Disabilities.” This approach aligns with the policy proposed in February 2017 by the Ministry of Health, Labour and Welfare (MHLW)’s “Study Group on the Future of Mental Health, Medical Care, and Welfare.”³⁾ Community life support projects are programs implemented by local governments, being separate from statutory disability welfare services, and are subsidized by MHLW. Since the definition of community life support projects includes human rights advocacy for persons with disabilities, the program can be introduced without

legal amendment. The administrative and political hurdles are lower, and the system offers greater flexibility in design and revision.

Because psychiatric rights advocacy requires specialized knowledge and psychiatric hospitals are unevenly distributed across geographic areas, this should be a mandatory initiative at the prefectural rather than municipal level. While concerns remain about disparities depending on local governmental interest, the ability to secure sufficient welfare budgets, and whether the program might be limited to simple welfare support, this remains the fastest route to implementation.

2. Legal enforcement not necessarily required

Regarding visits and meetings, legal enforcement is not strictly necessary. Meetings with individual patients who have made contact can, in principle, be carried out freely. Hospital visit activities that do not pre-identify subjects can also be conducted through discussions and trust-building with the hospital. In Osaka, both individual visits and ward-based activities have been carried out with the understanding and cooperation of the Osaka Psychiatric Hospitals Association.

The most effective approach is economic incentive through medical fee

reimbursement. Assigning reimbursement points for accepting individual visits by advocates or adding bonuses to hospitalization fees for hospitals that accept ward visit activities would encourage hospital participation. Additionally, the Ministry of Health, Labour and Welfare could issue a notice treating advocates on a par with attorneys or administrative officials.

3. Large budget not required

How much would the budget scale of the program be? Considering a scenario whereby two advocates (a pair) visit hospitals twice a week, they could visit eight hospitals once each per month. To cover the approximately 1,600 hospitals nationwide with psychiatric beds, 200 pairs, 400 individuals, would be required. If each advocate is paid an annual salary of 3 million yen, the total cost would be around 1.2 billion yen, and including insurance and transportation costs, it would total about 1.6 billion yen. If the personnel, office, and operating expenses of each Advocacy Center are estimated at 30 million yen annually, this would amount to approximately 1.5 billion yen nationwide. Even including training and public relations costs, it is estimated that full-scale national operations could be achieved with just over 3 billion yen annually.

Although the number of individual support activities is difficult to predict, if each pair of advocates conducts four individual meetings per week in addition to hospital visits, that amounts to 16 per month and 192 annually per pair. With 200 pairs nationwide, this would support 38,400 meetings annually. If staffing is insufficient, the number of advocates can simply be increased.

Psychiatric inpatient medical costs alone reached 1.3616 trillion yen in fiscal year 2018 (National Medical Care Expenditure), with each inpatient costing approximately 5 million yen annually. In contrast, the budget required for advocacy is minimal. Furthermore, if the activity results in a reduction of long-term hospitalization, it is likely to yield significant fiscal benefits.

4. Basic online courses and practical training in each region

Fujii et al., with the cooperation of the Osaka Center for Mental Health and Human Rights, are preparing a training course for advocates. The basic course will be conducted online, allowing participation from anywhere, and will cover fundamental attitudes, knowledge, and skills. Practical training will then be held in-person in each region where feasible. Furthermore, pilot projects will be

carried out in some areas, ultimately aiming for national institutionalization and budget allocation.

5. Developing core personnel and organizations in each region

The advocacy project cannot be realized by simply gathering participants for training and establishing a system through the Ministry of Health, Labour and Welfare. Personnel and organizations capable of fostering and operating the project in each region are essential. This requires securing core personnel, forming activity groups, collaborating with related organizations, and establishing a structure for Advocacy Centers.

Since fiscal year 2017, the Osaka Center for Mental Health and Human Rights has received support from the Nippon Foundation and worked to expand advocacy activities beyond Osaka. With this support, new mental health and human rights centers were established in Saitama and Kanagawa Prefectures, and ties with the center in Hyogo Prefecture were further strengthened. There has also been interaction with bar associations in Kyushu and Okinawa, where psychiatric legal support activities are strong. These efforts to sow and cultivate the seeds of advocacy across Japan are gradually bearing fruit. The Tokyo Center for Mental Health and

Human Rights has also re-established its organization.

Individuals interested in patient advocacy surely exist in every prefecture. Through advocacy activity exchanges and online training, if potential core personnel can be identified, advocates from Osaka and other areas can be dispatched to support local activity development and conduct practical training.

By collaborating with organizations such as patient associations, mental health social worker associations, bar associations, family groups, community welfare service providers association, disability organizations, the Japanese Society of Psychiatry and Neurology, and association of neuro-psychiatric clinics, and by establishing mutual forums with local psychiatric hospital associations, the nationwide roll-out of advocacy initiatives can be further accelerated.

Conclusion

The realization of a psychiatric advocacy system is achievable. At present, there is a prime opportunity to introduce this as a national system across Japan.

The advocacy system represents a practical mechanism for protecting the rights of hospitalized patients and is a critical turning point for the improvement and reform of psychiatric

care. We welcome diverse perspectives on the philosophy, system design, methods of operation, and training approaches. We also hope that committed individuals will actively participate in building patient advocacy activities in their respective regions and co-operate in advancing this initiative.

Editorial note

This special feature article is based on the symposium held at the 117th Annual Meeting of the Japanese Society of Psychiatry and Neurology, with Naoko Satake (Department of Psychiatry, Kohnodai Hospital, National Center for Global Health and Medicine) as the representative.

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