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Special Feature Article

"Shared Decision Making" from the Perspective of Patients and their Families: Wisdom and Ingenuity for Mutual Understanding

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Abstract

The intensity of decision making is multiplied for patients and their families when a disease that causes health problems, such as mental illnesses and life-threatening illnesses, are involved. Healthcare professionals are expected to participate in the decision-making process together with the patients and families to promote their interaction. Is "shared decision making" established currently in Japan? The practice of shared decision making is a fundamental problem in current medical care regardless of the disease that a patient has. "Patient-centered" has become a popular term; however, it may have been incorrectly interpreted, leaving decisions to be made entirely by the patients and their families. What is necessary to practice shared decision making in psychiatric care? I underwent psychiatric care when paternalism was the mainstream treatment approach. This study was conducted from the perspective of patients and their families based on my previous survey in which "clinical attitudes of psychiatrists" were evaluated by patients and families, together with my experience in hospices.

The tendency of having a pessimistic outlook because of professional experience should be corrected. To achieve this, an approach that I recommend is to learn about the patient's and family's lives, and acquire the habit of fact-based thinking. Other approaches include the following: shifting some tasks to other healthcare professionals,

learning from practice in private civic groups, and training specialists who can provide medical consultation about life events such as pregnancy and childbirth.

The basic spirit of "shared decision making" is to hear from patients and families about their daily lives, and to imagine specific difficulties that they are experiencing while maintaining respect toward them. In both psychiatric care and overall medical care, we need to think about "shared decision making" from the perspective that we will one day be in the same position (patients).

Keywords : shared decision making, supported decision making, recovery, paternalism, person-centered

Introduction

"Decision-making" is the process of selecting one of two or more alternatives, and it is not possible without multiple alternatives. The difficulty of decision-making lies in the fact that there are multiple options, which can lead to hesitation and conflict, but psychiatry has various problems that prevent shared decision-making at the stage of setting options in the first place. The following are examples: the pathophysiology of mental illness has not been elucidated, the priority of treatment approaches differs among physicians due to the assumption of various factors such as genetics and environment. Although there are guidelines, there is confusion in the disease classification itself, so in reality, it is close to a "you have to try to know which treatment is more effective for

which disease" situation. Clinical stage models such as at-risk mental state (ARMS) are also not widely evidenced enough to be used. There is a large variation in the quality of medical care, and nationwide "uniforming accessibility of medical care" has not progressed.

In order to provide multiple options under these circumstances, it is necessary for therapists to have a variety of values regarding the "goal of treatment".

In recent years, a paradigm shift is taking place regarding the goals of treatment for mental disorders.

The goal of treatment is not only to improve symptoms and functions (clinical recovery), but also to "lead a proactive and satisfying life" and "acquire a role in society" (personal recovery) despite symptoms 18).

In other words, it is not "recovery from mental disorder" but "recovery in mental disorder" 15). However, Klockmo et al. 8) points out that there is still a large gap between setting up recovery as a philosophy and individual professionals providing support that truly focuses on recovery.

The author received psychiatric treatment as a patient and family member at a time when paternalism was the mainstream 12)13). From the standpoint of those who experienced those times, the emergence of the concept of personal recovery is remarkable, but in reality, it is difficult to say that the patients and their families have been able to obtain treatment based on the idea of personal recovery.

In this paper, I would like to discuss the state of shared decision-making in psychiatry, referring to my experiences as a patient and family member, the "shared decision-making" situation at a hospice where I trained 30 years ago, and the results of a nationwide survey on "Clinical Attitudes of Psychiatrists" conducted by the author. The author then discusses the wisdom and ingenuity needed to make shared decision-making in Japan.

I. Shared Decision-Making that the Authors Could Not Experience and Shared Decision-Making as Seen in a

Hospice

There are two ethical principles in "shared decision-making": the first is that being able to make one's own decisions is a happy innate quality of human beings, and the second is that human beings are interdependent and therefore support for autonomy is essential for them to be able to make their own decisions 11). Autonomy means "to be able to regulate one's own actions independently, and to do so, to act in accordance with one's own established norms, free from external domination and control" 9). Regarding this "external domination and control", all medical professionals, not limited to those in psychiatry, need to humbly reflect on whether they are unconsciously "imposing their expertise" or "forcing conclusions".

When my mother and I were patients, paternalism was the mainstream and "domination and control from the outside" was taken for granted. On the other hand, there was a place where "shared decision-making" was established in the same period. This was the hospice ward where I trained and since my current attitude toward treatment is based on the experience in this hospice, I would like to share it with you.

1. Shared decision-making that I could not experience as a patient and a family member

The author's decision-making as a psychiatric user involved three major situations.

The first was decision-making as a "family member".

As an eighth grader, I was not included in any discussions about how to deal with the acute phase of my mother's schizophrenia. While I was away, my father tied my mother's hands behind her back and took her to the hospital, where she was admitted. When my father told me about this later, I understood his pain and his compassion for me, so I could not argue with him. After that, however, I began to feel as if I were an outsider, even though I was their only daughter, and thus a member of the family. I still wish that I had been allowed to participate in the decision-making process in my own way as a child.

The second is decision-making "as a patient", mainly with regard to medication.

I have been attending a psychiatry clinic and receiving drug therapy since I was a medical student. Due to side effects, I had difficulty studying for the national medical examination, so I threw away my newly prescribed medication in a trash can at the station, or "thinned out" my medication by taking only a portion of it. Eventually, I became so ill that I had to rush to the outpatient clinic on a day other than the

day on which I should be examined by my attending physician, the professor. The first thing the psychiatrist who examined me in the professor's place said to me was, "The professor gave you this medicine, so you have to take it....". He never asked me why I did what I did or the reason I did not want to drink. The professor never explained the effects and side effects of the drugs, and the patient's will be never taken into consideration in those days.

I refused to take the medication not because I was unaware of the disease, but because the side effects were too much for me. If I had been told why I should take the medication despite the side effects, how long I should endure the side effects, and what measures I should take to deal with the side effects, I would not have forcibly abstained from the medication. There was a tacit imposition of the idea that "patients should just be quiet and take their medicine". Even today, the author frequently hears similar concerns about drug therapy from patients and their families.

The medical staff's statement, "If you don't take the medicine, you will deteriorate and be hospitalized", in which the medicine takes the leading role, does not constitute "shared decision-making".

The third is decision-making in "pregnancy and childbirth".

When I found out that I was pregnant, I was really afraid of becoming a parent. I wondered whether my mother's disease would be inherited, What the odds of inheritance was, and whether I would be able to raise a child in a defective family. Even if I wanted to discuss these various concerns, there was no genetic counseling available at the hospital where I gave birth. Even before that, I could not tell anyone outside the hospital that I had a family member with schizophrenia. There was an inner prejudice, and I was afraid to ask for advice. We have raised our child with the belief that "our child has two psychiatrists, so even if he/she gets sick, we will be able to handle it". Since even the author, a professional, felt uneasy, it is not difficult to imagine the anxiety of the non-professionals involved.

2. Shared decision-making in a hospice

The author spent several years in a hospice ward, participating in rounds and ward meetings. It was 30 years ago, but there certainly seemed to be a spirit of shared decision-making.

The author remembers the case of a patient with head and neck cancer who communicated in writing. His consciousness was clear, his face was congested due to the pressure of the mass, his tongue was protruding out of his mouth, and pus had to be aspirated for 24 hours. The patient had no other metastases and was expected to survive

for six months as long as he was well cared for. The doctor in charge gave up all hope of saving the patient and said, "There is nothing more to do but suctioning", and did nothing to respond to the patient's wish to stay overnight or the family's reluctance to do so due to concerns about infection and treatment.

Under these circumstances, the patient was transferred to the hospice ward. At first, even in the hospice ward, it was extremely difficult to deal with patients and their families who could not communicate with each other and had nothing to do but suction. During the many conferences held, both the ward medical director and new staff exchanged opinions on an equal footing. One of the new nurses noticed that the patient was irritated by the writing itself, and everyone decided to observe the patient again. As a result, it was found that all staff members could almost read the patient's mood by his eye movements and raising and lowering of the hands, which led to stabilization of the patient. To resolve the patient's wishes and the family's concerns, the physician in charge expressed the opinion that the patient should be taught to manage suctioning by himself during the overnight stay, which was attempted despite some opposition among the staff. The family members were informed that they could read the patient's feelings from his

gestures and that the patient was practicing suctioning. We had the family members listen to the patient's wishes for the future in the presence of the doctor in charge. The caseworker consulted with the family about their burdens, and the patient was able to have regular overnight stays until the end of his life.

This hospice unit, not the university, taught the author the importance of listening to the patient's wishes first, watching the patient closely, and having discussions. This experience has remained the basis of the author's patient-physician relationship as a psychiatrist to this day.

This hospice was an extremely desirable place, greatly influenced by Kashiwagi 7), who established the founding period of hospice care in Japan. At that time, and even today, it seems that there are definitely not many hospices that can provide this kind of care at the end of life. Nonaka 16) reported the reality of cancer treatment in Japan, where shared decision-making is not often used, through his own experience as a cancer patient.

II. What prevents "shared decision-making" and how to deal with it

1. What can be seen from the distribution of the "Question Promotion Pamphlet"

The authors have developed a

"Question Promotion Pamphlet" for schizophrenic patients and their families as a tool for asking questions to doctors during consultations, and distributed it to patients, their families, and medical personnel 10). This is because asking questions to the doctor is the start of shared decision-making. When the author asked psychiatrists for their opinions, many of them expressed resistance to the use of the pamphlet, saying "It is good to use the pamphlet, but I am worried about the time required with so many questions lined up", or "I am not confident that I can answer such difficult questions".

This pamphlet includes questions such as "What is the cause of this disease?", "When will I be cured?", and other questions that are difficult to answer in current psychiatry. As such, some physicians may be reluctant to use the pamphlet. However, I believe that the patients and their families want to ask questions that are difficult for doctors to answer. I explain to physicians that the pamphlet is not intended to answer the right questions, but rather to help physicians and the parties/families discuss and think together.

In the age of paternalism, physicians may have maintained a pretense of "professional confidence". Today, the general public has access to specialized knowledge, and the "expert's monopoly on information" is disappearing. It

seems to me that the situation of "not having the confidence to answer the questions of the patients and their families based on the information" is what prevents shared decision-making. It is necessary for professionals not only to study information, but also to have an attitude of "try to answer questions based on the information that the other party has, little by little".

2. National Survey of Psychiatrists' Attitude Toward Medical Examinations

In a survey (14) conducted by the authors in 2015, which asked patients and their families to evaluate the "attitude of psychiatrists", the number one response of 6,000 people to the question, "If you could choose a doctor, what would be your number one criterion?" was "prescribing ability". "Personality and character" came in second, "communication skills" third, and "medical knowledge" fifth.

The 10 items listed as answer choices were items that were listed in a questionnaire given to the patients and their families in advance of the survey. The "prescribing ability" that the patients/families considered was "prescribing ability" that included an attitude of paying attention to side effects, respecting the feelings of the patients/families, and being proactive in reducing the amount of medication. The answers to this question indicate that it is impossible to have a situation where

"medical knowledge" is below a certain level and "prescribing ability" is high, but conversely, even if the prescription is correct based on high "medical knowledge", it may not be the prescription that the patient/family would want.

There are two possible reasons why prescribing ability was ranked first: one is the expectation that "if prescribing ability is high, symptoms may improve with better drug therapy", and the other is a reflection of the haste of not only physicians, but also the patients and their families, to "get rid of the symptoms as soon as possible with medication..." and the medical environment in which there is no time to spend on treatments other than drug therapy.

How can ingenuity be used in a time-poor environment?

The most common response to the question, "How would you like the doctor to exercise his ingenuity in the consultation?" was "Make it possible to consult with nurses and counselors about what cannot be done in the consultation". As important members of the treatment team, the patients and their families value the power of the co-medical staff, who are familiar with the actual conditions of their lives. Shifting tasks to the co-medical staff may be a realistic measure.

In addition, "Insufficient explanation"

by physicians was pointed out in almost all items in the survey. Even if the physician thinks he or she is explaining, if it is not understood by the patient, it is the same as not explaining at all. It is necessary for professionals to acquire the ability to provide explanations that can be understood by the patients and their families. Efforts should be made to explain the treatment in terms that the patient and family can understand, rather than in scientific terms, and to engage in dialogue with the patient and family members when they ask questions.

3. "Evidence" is needed as a basis for discussion

Most psychiatric disorders are long-term and chronic, so treatment is carried out while the patient is still living. In such cases, requirements other than medical treatment also become a major issue.

For example, driving a car, which is now subject to severe penalties under the revised Road Traffic Law and the Law on Punishment of Driving Causing Death or Injury in 2014, is a common cause of accidents caused by certain illnesses and drugs. However, these are not necessarily evidence-based laws, and Iwamoto 6) explains the need for continued scientific verification of driving and drug treatment, and for discussions that take into account the lives of the people involved and public

safety. The current situation is that there is an insufficient basis for shared decision-making on "whether to continue or stop operation".

The same can be said about pregnancy, childbirth, and childcare.

Many patients still desire to become mothers, but face great uncertainty. In order for shared decision-making in pregnancy and childbirth to be effective, the medical side needs accurate knowledge and accumulated data on genetics and child-rearing, but this knowledge is extremely limited.

Of the 1,334 clinical geneticists (as of October 21, 2019), only 10 psychiatrists nationwide have this certification 17). In addition, only a few cases of the effects of psychotropic drugs on infants during postpartum lactation have been investigated in Japan 3). Although genetic analysis has progressed dramatically, genetic counseling has not progressed much from decades ago, when the author gave birth.

Chiba et al. 4) pointed out that professionals acquiring skills in "evidence-based" support will lead to more realistic support for the challenges faced by the subjects of support.

Ishizuka et al. 5) cite a method in which medical professionals draw a family tree and explain it to the patient and family members who are concerned about heredity, which is another form of evidence-based shared decision-making.

Above all, preconception care must be provided for both the mother and the child, including mental illness, even before conception, so that "consultation leads to a healthy life". Otherwise, no matter how many support services are provided, there will be cases where mothers will hesitate to go to these services.

If we can accumulate evidence for providing support for driving, childbirth, and child-rearing, which are means of living, and train specialists who can explain the evidence and respond to the concerns of the patients and their families, we may be able to expand the flow of "shared decision-making" centered on them.

4. Learning from the Practice of Private Organizations and Other Departments

In the field of medical care, not only in psychiatry, but also in many other fields, misunderstandings between patient/family and those in charge of treatment sometimes lead to lawsuits. Consumer Organization for Medicine & Law (COML), a non-profit organization, was established in 1990 to "encourage cooperation between people in different positions toward the same goal", and to "encourage patients to make efforts as well".

Based on the idea that communication in the medical field is an extension of everyday communication, COML holds

"communication courses for patients", "how to discern information", and "patient care seminars for doctors". Representative Yamaguchi 19) says, "Patients' distrust is conveyed to the medical staff, and the medical staff becomes defensive. It is time for us patients to calm down a little and reconsider whether distrust is a good thing for our own treatment". I suggest that COML's ideas and methods be incorporated into psychiatry as part of the education of patients, family members, and medical care providers.

Overseas, decision aids (Decision-Making Guide) have been developed for important decisions. The "Ottawa Personal Decision-Making Guide" 2) is a method of listing the available options, and indicating the level of advantages and disadvantages, as well as importance, with a number, and arranging them in a list to compare them. The guide is designed so that the user can understand his/her own decision-making process by filling in the form in a step-by-step manner. The effects of these decision aids are that fewer people are unable to make decisions, that communication between doctors and patients improves, and that patients are more likely to be satisfied with decision-making and its process. We would like to consider the creation of such a guide as a way to address the problems of medical care as a whole,

including psychiatric care.

5. Correcting the pessimism of experts

The author believes that what is most necessary for "shared decision-making" to be effective is to correct the pessimism of experts. In severe cases with a chronic course, professionals may tend to be pessimistic because of their professional experience. Such preconceptions and pessimism on the part of those who provide support have a significant impact on shared decision-making. It is necessary to abandon the "common sense of professionals" acquired through experience.

Rather, a positive attitude based on "the unique experience of the profession" is what is needed. The author is reminded of a dialogue between three psychiatrists that appeared in a magazine nine years ago 1).

"I often hear the anger of bipolar patients and their families about the diagnosis and side effects of medications, and that is how troubled they are. I hope that this anger can be sublimated into positive energy to 'overcome bipolar disorder together' and lead to a better understanding of the pathology of the disease" (Tadafumi Kato).

"In my consultations, I sometimes discuss with patients how to answer questions they are anxious about, such as, "How would I answer if the company asked me about my medication?" It

would be good to learn such know-how practically through role-plays and the like" (Norio Ozaki).

"Everyone has some kind of disease, and if the disease cannot be controlled, he/she is called a 'patient'. On the other hand, if the disease is well controlled, the 'patient' is the same as a healthy person. We would like to help them fulfill their 'responsibility' to maintain their work and family life and complete their lives as a human being" (Tsuyoshi Akiyama).

As in the dialogue above, the author believes that shared decision-making is to think about support "concretely together" through role-playing and other activities based on skills learned through many years of experience.

In the process of people's lives, various "decisions" are necessary, and these decisions may be difficult even for those who are not ill. The people concerned and their families do not want medical professionals to decide how to live their lives. When they experience difficulties in their daily lives, they would like to "think together" about how to solve these difficulties by combining the expertise of professionals with the experiential knowledge of the patients/families involved. The specialists should first learn about the "difficulties in the lives of the patients and their families" and then have the attitude to think together about how to

exercise ingenuity in solutions to these difficulties. Unfortunately, such efforts are not found in medical books.

Even now, nine years after this dialogue, the words of the three experts sound fresh in the reality of psychiatric care in Japan. Even without special skills or tools, we hope that physicians will consider approaches and support that are unique to their patients by taking a close look at their individual lives and the problems they face.

Conclusion

What kind of lifestyle, hopes, and values the patient has, what kind of recovery means, and how it fits in with the wishes of the family. These are very fluid and abstract concepts, and therefore the only way is for the doctor in charge to listen and seek out the patient individually, no matter what department he or she is in.

What I appreciated most in my experience as a patient and family member was that our doctor also thought together with us in making decisions at each milestone of our lives. Rather than using abstract words such as "recovery", I believe that the wish of the patients and their families is to "think and worry together" about the problems in their actual lives. Other things will be managed in their own way by the parties concerned and their families, and they have no choice but to

do so.

In order to provide support that is useful in actual life, I would like to ask psychiatrists to know about the "actual conditions of the lives of the patients and their families". At present, it seems that there are too many specialists who do not know the actual situation. Before difficult discussions and tools are used, I would like you to humbly listen to the realities of the lives of the patients and their families, and then, with respect for them, use your imagination to think about the difficulties they are facing and think hard about them.

Finally, as a family member, the author's greatest wish was "one pill that would cure my mother, rather than 100 supporters and understanders". I hope that "co-creation" with basic researchers will also expand. The fact that a paradigm shift is taking place with the emergence of the concept of recovery is a great step forward, but I hope that the will of the patients and their families will be reflected in the research so that the light of hope for drug discovery will not be extinguished.

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