Special Feature Article

What Does It Mean to Respect the Rights and Intentions of Patients in Psychiatric Practice?: Findings from the Development Study of the Computer System "SHARE"

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Abstract

Psychiatric clinical practices are usually based on the patient's self-reported symptoms and worries. Whether this "self-reporting" can be carried out in a safe and secure environment affects the quality of the clinical practice.

Shared decision making (SDM) is an interactive process between at least two parties (patient and provider) in which the sharing of information and opinions occurs, patient preferences and provider responsibilities are discussed, and both parties agree on a course of action (Matthias, 2012). This means that treatment, including prescriptions, should be decided in the process of dialogue between the patient and provider, especially to reflect the voices of the patient.

We developed an Internet-based software program for SDM called SHARE (Support for Hope and Recovery) and introduced it into comprehensive care for medication consultations. SHARE is a tool used to prepare clinical examinations with the help of peer staff, and by clearly stating "my intentions," "the key to my well-being," and "my goals for today's examination," the patient's desired life and desired treatment are clearly communicated to the attending psychiatrist during the daily examination process. It prevents the mid-to long-term treatment flow from becoming something the patient does not understand.

From a worldwide perspective, SDM in clinical psychiatry aims to achieve equality between patients and psychiatric health care providers, protect the human rights of patients who are often placed in a vulnerable position, and decide the content of treatment while holding both patients and psychiatric health care providers responsible. Therefore, SDM cannot be established in an environment where the treatment of patients is predominantly determined through non-consensual decision making; the development of SDM is accompanied by the maturation of a community-centered mental health system, which is the basic mental health and welfare measures in Japan.

Introduction

In recent years, "shared decision-making (SDM)" has been attracting attention in various fields of medicine. SDM is simply defined as "the process by which physicians and patients make decisions together regarding treatment." 2) In SDM, the "process" of deciding on treatment is important, as patients and physicians discuss treatment goals, each other's roles, treatment preferences, and scientific evidence 19). In this paper, we discuss whether SDM is feasible in psychiatric care in Japan, and describe the role of our computer system, SHARE (Support for Hope And Recovery), in enhancing its feasibility.

I. SDM in the context of psychiatric care in Japan

Is SDM feasible in psychiatric care in Japan?

It is difficult for people to continue to

express their thoughts and feelings, in other words, their will, in an unfamiliar place where there is a strict hierarchy, such as on a psychiatric ward where one is involuntarily hospitalized? In such an environment, when symptoms are difficult to control, when "the possibility of danger to the patient or others is extremely high in view of the symptoms," or when it is deemed unavoidable to "protect the patient's life and prevent serious physical injury," medical staff may use isolation or restraint as "therapeutically necessary actions" 6). In this environment, patients are constantly exposed to the risk of being denied their "will" regarding treatment and care and being deprived of their words even if they express their "will". In this context, is "shared" "decision-making" between doctors and patients really possible? Although it largely depends on the quality of communication between the staff of the medical institution and patients, there are patients who have been silenced in an environment where non-consensual means of treatment are employed and their declaration of intent is treated only as a "symptom", and people have despaired at the experience of "not being treated as a person." Rebuilding trusting relationships with these people is extremely difficult. Narrative research on involuntarily hospitalized participants identified a

central theme of "not being respected as a person," and three sub-themes of: "not receiving care for myself," "receiving meaningless/poor care," and "feeling inferior as a person" 11). The experience of involuntary hospitalization is an experience of being housed in a place different from one's usual life and of not being respected as a person, and because it is perceived that one is prohibited from expressing judgments and actions that are natural for a citizen, it makes one aware of a clear hierarchy in human values; that is, those who prohibit other parties from expressing their intention and those who are prohibited from expressing their intentions, and it leads to a perception of oneself as inferior 5).

The risk of falling into a similar hierarchy may exist in the psychiatric examination room, where the doctor-patient relationship tends to be bilateral. The major difference between a psychiatric examination and a physical examination is that the content of the former is largely based on the patient's self-report, rather than on the doctor's objective observations and examination results 9). The quality of the consultation depends on whether this "self-report" can be done in a safe and secure environment. However, it is up to the physician to decide who chooses the topic, what information to share, and what kind of discussion to

have during the short consultation time, and there is no guarantee that patients will always be able to make acceptable decisions regarding treatment. Furthermore, in an environment where hospitalization is the mainstay of psychiatric care in Japan, these doctors receive much of their training on psychiatric wards where 46% 8) of admissions are involuntary, and 54% of voluntary admissions spend all day on closed wards 12) .

The author's impression is that the current situation is extremely pessimistic for a "process in which doctors and patients make decisions together regarding treatment" to occur as a matter of course without any special training.

II. What SDM asks: The possibility of change in the consultation scene

Under these circumstances, however, I would like to stick to SDM. The following discussion will be based on the examination scene during psychiatric home-visit treatment, outpatient treatment, and day care.

Yamaguchi et al. 18) argue that the backgrounds of the development of SDM are as follows: (1) clarification of contracts such as the content of treatment developed from informed consent and informed choice (responsibility lies with both the medical personnel and patient), (2)

development of the concept of the person-centered view, and (3) development of evidence-based practice. In Japan, where involuntary hospitalization is still the mainstay of treatment, as described above, it is difficult to say that the process described by Yamaguchi has become common practice. At this point, the foundation for SDM dissemination is weak in Japan.

However, in 2004, the Japanese government announced the basic policy concept of reforming mental health care and welfare, "from a focus on inpatient care to a focus on community life,"7) and this has not changed as a trend. Here, "focus on community life" does not only mean that the site of treatment should be in the community. It may also mean the development and implementation of treatment and support programs that help patients continue to lead a comfortable community life.

In this context, the goal of treatment and support is to continue to promote the process of individual "recovery" in the recent concept of mental health welfare. Recovery is, for example, "the process by which people are able to live, work, learn, and participate in their communities, and for some individuals, recovery is the ability to lead full and productive lives despite a disability, and for others, it is the reduction or alleviation of symptoms." 13) In the

context of recovery, the goals of treatment and support are not confined to "convalesce of symptoms or cure," but include various aspects such as being inhibited by having a disease, reinstatement from discrimination and prejudice suffered, or being able to enjoy life as a citizen. In this context, the doctor's job is not to isolate a patient's symptoms in the simple form of a physical or mental disorder and work to cure it. The doctor's "reaching out" attitude is required to consider with the patient how to cope with "problems" that are intertwined with symptoms, such as difficulties in daily life and interpersonal relationships, and flashbacks to trauma. In pharmacotherapy, physiological and mental statuses alone are not enough to determine prescriptions. It is also necessary to take into account the question of what dosage form the patient can easily continue to use, and what prescriptions can be devised to minimize side effects and interference with daily life.

Matthias, M.S. et al. summarize some of the literature, and in a simpler and more specific way, they define SDM as "an interactive process where at least two people (service provider and user) share information, discuss (support) options, user preferences, and service provider responsibilities, and together agree on future actions (content of support)." 10) Based on this definition, the table attempts to sort out what kind of information the two parties will be exposed to, dividing it into the context created by the patient and that created by the attending physician.

In the process of the conventional form of psychiatric treatment, that is, "the doctor asks, the patient answers, and the doctor decides on a treatment plan," the main context is to identify symptoms, determine a diagnosis, and provide a treatment plan, and medical conversations tend to concentrate only on the right half of the table. However, the context of this area alone does not tell us whether the patient will accept the treatment plan proposed in this way. If the patient finds it difficult to accept the policy, it is not because of selfishness on the part of the patient, but because of the patient's life history. Therefore, from SDM's point of view, we try to listen to the left side of the table, so that the patient can talk about, for example, his/her preferences regarding treatment, his/her important values in life, or traumatic experiences that have affected his/her life. The physician should consider treatment as a collaborative process with the patient, and seek to learn about the patient's past coping mechanisms, his/her strengths, and environment. Then, while expressing what he/she can do and the limitations, the physician

examines the appropriateness of the proposal of what he/she wants to ask the patient to do. The ability to make a satisfactory choice about the course of treatment via such a dialogue leads to the patient's active participation in the treatment.

In order to make "focus on community life"-mental health care welfare policies a reality, it is necessary to realize medical care that accompanies the process of recovery, and for this purpose, it is necessary to respect the context created by the patient, and to realize medical examinations in which the problems of daily life are considered together. SDM is an interactive process that can touch on these issues, and that is why we should pay attention to it.

III. Computer system for SDM, SHARE

In the above-mentioned context, we have developed a computer system for SDM, SHARE 15), and have tried to position it in a comprehensive care system, including psychiatric consultation. The goal is to create a feasible SDM system for psychiatric care to "focus on community life" in the current clinical practice of psychiatry in Japan.

SDM tools used as references in the development of SHARE were Common Ground, 3) a leading example of a recovery-oriented SDM tool in the United States, and the SDM tool 14)

developed by the U.S. Department of Health and Human Services, Office of Substance Abuse and Mental Health Services.

SHARE has the following characteristics. First, it is a pre-visit preparation tool which is patient-friendly, and allows doctors to provide medical care attuned to the patient's recovery process. 4) SHARE can be input from a touch-screen PC. With the help of peer staff, as described below, patients input information about themselves in advance. The content of this information is intended to convey the patient's own problems in daily life.

The first entry is the "Hope and Recovery Notebook." This is to be filled out in advance of the SHARE consultation. It includes a "My intention" section in which the patient expresses what he/she wants to tell the attending physician, what is important in his/her life, and what he/she wants the attending physician to know, and a "Key to My Vitality" section in which the patient writes what he/she does on a daily basis (other than taking medications) to keep well. In addition, the user writes down "triggers when I feel unwell" and "signs that occur in me when I feel unwell". The writing is shown during each visit, but it can also be changed and updated.

The next entry is a "SHARE Sheet" to be filled in at each visit. The SHARE

sheet includes items such as a review of the contents of SDM discussed during the previous visit, a review of whether the patient has used the "Key to My Vitality" since that time, and whether there have been any triggers that have made him/her feel unwell or signs of a change in the physical condition. In addition, the patient enters information that he/she wishes to report in the "My physical and mental condition" section, such as "how well I feel today," how troubled I am about my symptoms, and how troubled I am about "my life," such as my financial situation and housing environment. The patient also fills out a check sheet to report side effects of medications, to state whether there are any medications that he/she is not taking, and whether there are any medications that he/she would like to have changed.

In this way, the patient can summarize "my goals for today's visit" by entering information about himself/herself on the touch screen, such as "I want to discuss this," "I need the doctor to listen to me," "I want to ask questions," and "I want to get information."

This information is then inputted into a sheet, which is used during the consultation with the attending physician.

The consultation over this sheet becomes the central topic of the interaction, and the patient's values and preferences for treatment are also discussed. At the end of the consultation, what is mutually agreed upon by the patient and attending physician is summarized in the "SHARE of the Day" (the contents of SDM). In a pilot study conducted when we were developing SHARE, we found that the majority of users of SHARE were satisfied with their consultation and felt that their relationship with their doctor had improved, even though there was no significant difference in the length of the consultation 17). SHARE is considered to have contributed to the realization of the medical treatment desired by the patients themselves.

The second characteristic of SHARE is that, in principle, patients receive support from peer staff when they enter SHARE before their consultation. Peer staff members are employees who contribute to patients' recovery by interacting with them in various situations, drawing on their own life experiences, such as their own experiences with mental illness, their own experiences using services, or their own experiences on the road to recovery 1). Peer staff utilize knowledge and sensitivity developed through their own experiences, as well as empathic messages emanating from similar experiences. With helping to input the content in the use of SHARE, peer staff play a significant role in supporting the

patient's own active participation in the consultation by stating what he/she wants to say in his/her own words during the preparation for the consultation 16).

The third feature of SHARE is that it can be shared with other paramedical staff, and there is a possibility to use it to provide support depending on the patient's perspective. The ability to share the patient's problems, "my intention," and "the key to my vitality," and to share with the supporting medical staff what kind of SDM "today's SHARE" the attending physician will create with the patient based on these contexts, will be useful in providing lifestyle support from the patient's perspective, and will also ensure the quality of SDM in terms of not viewing the consultation room as a closed-off place.

In other words, the second and third features will make the hierarchical relationship between the attending physician and patient more moderate and clarify the attending physician's position as a "member of the support team." This is because third parties, such as peer and paramedical staff, also become members of the team who think together about the patient by sharing the details of the medical consultation through SHARE. That is to say, it plays a role in promoting a supportive environment, including medical examinations, the concept of a person-centered view, which places the focus of support on respecting the patient's wishes and values, attending to the patient's distress, and making continuous efforts together for improvements.

IV. SDM and person-centered view

When we consider again what kind of place a clinic is, we can say that it is a place where the nature of a disease is determined and the act of "treatment" is applied to the patient, and at the same time, it exists to alleviate the anxiety and fear of the patient and increase hope and the joy of living. However, any treatment always entails risks. After considering the risks and benefits, a choice must be made among various options: is it better to "remove the disease" as in surgery and radiotherapy, "treat the disease so as to minimize its impact on life" as in drug therapy, "minimize the impact of the disease on life by extending the strength of the healthy parts" as in psychotherapy and rehabilitation, or "do nothing in order to live a full life"? There are always unknowns in choosing among various options; therefore, it is necessary to choose "a satisfactory option". SDM aims to make this process a joint patient-medical provider effort.

In the case of psychiatry, as mentioned earlier, the patient's behavior, facial

expressions, and self-reports constitute the bulk of the information handled during the examination, and the psychiatrist's perception of these factors has a marked influence on the diagnosis and treatment plan. On the other hand, it is not only the scientifically based treatment that eases the patient's anxiety and fear and increases his/her hope and joy of life, but, based on the SDM principle, it is also important to ensure that the treatment fits the patient's preferences and values and does not interfere with the patient's ability to enjoy his/her daily life. If we look at SDM as a process, it is extremely important that the patient feels comfortable in dialogue with his/her doctor at each visit, and that his/her words are accepted and approved, for example, as a prerequisite for deciding on what to prescribe as treatment.

Not every visit is a new decision-making process. In reality, it is often agreed upon during the consultation that "the same prescription should be given again". However, in the dialogue leading up to that point, topics that the patient wants to talk about are discussed, and depending on the content, they may be "problems and joys of life" that are beyond the scope of psychiatry, for which the attending physician does not have answers, but by sharing these stories, the patient's troubled yet joyful life is acknowledged, and this gives hope and a sense of living. Such a process of trust between people may be included in the SDM process 20). SHARE as a computer system, as described above, prevents the mid- to long-term course of treatment from becoming something that is beyond the control of the patient by clearly indicating "my intention," "the key to my vitality," "my goals for today's examination," etc., thereby making the daily examination process a person-centered approach, and clearly communicating to the attending physician what the patient desires in his/her daily life.

As shown in the table, SDM in psychiatry aims at an interactive process in which the context created by the patient and that created by the attending physician are combined, and the patient's way of life is respected and satisfactory choices are made. In this context, it would be fair to say that SDM aims to realize the equality of healthcare providers and patients as its view of the world. The human rights of patients, who are often placed in a vulnerable position, are protected, and treatment decisions are made in a process of dialogue between the patient and health care provider, with both parties taking responsibility. Therefore, to return to the point made at the beginning of this paper, SDM cannot be established in an environment where

non-consensual decisions on patient treatment are predominant.

Conclusion

In order to incorporate the SDM process into clinical psychiatry, it is necessary for a supportive attitude toward patient recovery to take root as part of the treatment culture. This is synonymous with the further promotion of the policy of "from a focus on inpatient care to that on community life." The elimination of institutionalization does not necessarily mean the closure of psychiatric wards alone. It also means abolition of the relationships that have been the norm in the psychiatric ward system, the one-sided treatment and management of patients' lives by medical personnel, the focus on alleviating symptoms without examining the lives of individual patients, and the use of medical care to deter violence and disruptive behavior toward others. Instead, it means listening to the patient's values, what he/she has learned from the trauma and suffering in his/her life, and how he/she wants to live. It is no longer about seeing patients only within the confines of a medical-patient or family relationship, but rather about encouraging and working together to create new interpersonal relationships, roles, and rewards within the open network of the local community. SDM is part of the maturation of such a community life-centered mental health care system.

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Table Information that is communicated during the consultation - According to the definitions of Matthias et al. (2012)		
An interactive process in which the patient is treated as a person and can make choices that make sense to him/her	Context created by the patient "I want to talk to you regarding what to do about this difficult life I'm leading."	Context created by the attending physician "Let's take the 'symptoms' as the problem and figure out what to do about them."
Physician and patient share information	What are the problems in my life right now? How is it painful? What kind of condition do I want in my daily life? What measures have I already taken to achieve this? My strengths, preferences, and values (what values do I emphasize now, and what are the ideas that bind me?) What past traumas have affected me?	When do your symptoms intensify? When are the symptoms not bothering you? How do they relate to sleep and autonomic symptoms? What other psychiatric symptoms do you have? What is your medical history?
Discuss support and treatment options, user preferences, and physician's responsibilities	What kind of treatment do I want? What treatments do I not want? What do I want from my doctor? What do I not want? What has been good and bad about the treatment so far?	My (the attending physician's) view on the treatment My (the attending physician's) ideas about useful drug therapy options My (the attending physician's) suggestions for psychotherapy other than medication, life support, etc. Presentation of social resources that I (the attending physician) am aware of
Both parties agree on future actions (details of support)	What can I do from now on for my treatment? What do I want in my life? I want to know what my doctor thinks about my way of life, including my problems. I want to know about the side effects of my treatment. What can I expect from my doctor? Who else can I talk to besides my doctor?	My (the attending physician's) recommendation for you to deal with the situation Suggestions about what I can do as the attending physician

12