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Special Feature Article

Housing First as a Human Right: Advocacy as the Basis for Shared Decision Making

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Abstract

In the field of psychiatric care, shared decision making has become important and specific devices are required in its practice. We created shared decision making tools called "Question Prompt Sheet" and "Medical Care Supplement". A perspective of advocacy is required as the basis for shared decision making. Housing First is one of the recent paradigm shifts in mental health services. It provides housing and medical treatment separately and independently. Housing is a basic human right and must not be lost, even without medical treatment. Even if the patient refuses to make a shared decision with the doctor, human rights, including housing, must not be violated.

Keywords: shared decision making, homelessness, Housing First, human rights, advocacy

Introduction

The purpose of this paper is to review methods of Shared Decision Making (SDM) and to critically examine what points should be considered when promoting SDM. First, I will give an

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overview of SDM by introducing a tool developed by the authors to support SDM, which has been increasingly recognized and practiced in the field of psychiatry. The importance of a rights protection perspective as a basis for implementing SDM is then discussed, and a new paradigm in mental health services called Housing First (HF) is illustrated as one specific methodology. Through this, the paper attempts to explore the method of psychiatric care based on human rights.

I. Shared Decision Making

1. In the field of psychiatric care, SDM, in which patients and medical staff discuss treatment goals and preferences, share necessary information, and decide on a treatment plan together according to the patient's thoughts and wishes, has been gaining importance. However, there are still many issues to be solved regarding how to implement SDM in practice.

In this context, the authors developed the "Question Prompt Sheet" and the "Medical Care Supplement" as tools to support SDM, which help people with psychiatric disorders to ask their attending physicians what they want to ask during psychiatric consultations and to communicate better with their physicians. The following is an overview of the elements and issues required to promote SDM through the introduction of tools developed by the authors. It should be noted that these tools were developed as a practical act to improve clinical psychiatry, and that no research has been conducted to verify their effectiveness.

2. Question Prompt Sheet

Question Prompt Sheet have been created and disseminated, mainly in the field of cancer treatment, to support patients in making independent decisions by asking doctors what they want to know in important interviews 6). In the midst of this trend, considering the needs in the field of mental health care welfare in Japan, one of the major issues was that there still exists a large authority gradient in the doctor-patient relationship. Therefore, the authors developed a Question Prompt Sheet for use in psychiatric outpatient clinics as a practical first step that can be taken immediately in clinical practice. This sheet is a tool for facilitating communication between patients with schizophrenia and their families, so that they can ask the questions they want to ask, obtain necessary information, and make treatment decisions independently at psychiatric outpatient clinics 2).

A working team of about 10 professionals in the fields of psychiatry and welfare, including this author, psychiatrists, mental health workers, and others, developed the Question

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Prompt Sheet while listening to the opinions of people with mental disorders, members of family associations, colleagues in each professional's workplace, non-professionals, and others. The sheet was made copyright-free and made available free of charge on a website 9). In addition, we requested cooperation from several organizations that operate information websites on psychiatric treatment and schizophrenia, and introduced them to the general public on their websites.

The content and format of a useful Question Prompt Sheet would vary depending on the characteristics of the facility being used and the needs of the users and professionals. It was also considered necessary to continue revising the questionnaire items in the future. Therefore, we prepared a Word document containing only the questions on our website and made it available together with the sheet as a copyright-free, reprintable, and repurposable document, in the hope that users would feel free to create revised versions for their own organizations and facilities, and that better Question Prompt Sheets and other SDM support tools would be created and disseminated throughout the country.

We received opinions from a wide range of people during the creation and publication process. After creating the Question Prompt Sheet, we made it available free of charge on the website and distributed more than 30,000 copies of the sheet at various occasions. We also accepted criticisms and comments for improvement by e-mail.

Many of the parties concerned and their family members expressed positive opinions about the existence of the sheet and the attitude of the supporters, "Please ask whatever you want to ask". On the other hand, there were also a number of complaints from the patients and their families about the attitude of the supporters, such as "I have been going to the hospital without receiving sufficient explanation, so I cannot easily ask what I want to ask" and "Whether I can talk and ask what I want to ask depends largely on the attitude and behavior of the doctors". This suggests that flexible provision of information and decision-making support are necessary according to the stage of treatment and recovery. We received many comments on how to improve the questionnaire items, such as "I would like you to add questions like these". and "Such perspectives are missing".

Many physicians and other professionals expressed their awareness of the structural problem of "not enough time for consultation in order to fully discuss important issues in the outpatient clinic". The impressions such as “I felt that the relationship changes

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when the sheet is not just left in the waiting room, but handed to the person while explaining it to them” and "I felt that the recovery was enhanced by the topic being discussed for the first time" pointed out that the attitude and behavior of the supporters had a greater effect than the content of the pamphlet itself. In addition, various criticisms, such as "the communication style assumed in the sheet, in which the patient asks questions and the doctor responds, is itself based on paternalism", "there are too many questions to understand all of them", and "the perspective of questions according to the treatment process and stages is missing", were raised mainly by psychiatrists and other professionals. There were also negative comments from psychiatrists, such as, "It is unnecessary for treatment", and “If this is approved, there is a concern that it will lead to complaints and criticisms against the doctors from the patients concerned, such as why the doctor did not explain that thing to the patient and why they are not fulfilling their accountability” 5).

3. Medical Care Supplement

Based on the opinions and criticisms of the Question Prompt Sheet, we started to create a new SDM support tool. In improving the sheet, we received many comments requesting the addition or modification of question items, and it seemed necessary to refresh the question items. On the other hand, since the topics to be discussed and the necessary SDM support tools may differ depending on the characteristics of the practice setting, the characteristics of the patient, and the stage of recovery, and the appropriate questions were also different for each individual, it seemed impossible to create a "complete and definitive Question Prompt Sheet". Therefore, we decided to create an application that allows users (patients and families) to add new questions by themselves, based on the questions in the sheet already created.

In creating the application as a SDM support tool, two main functions were defined: the first is to "ask what you want to hear", and the second is to "decide for yourself what values and goals you want to cherish".

For the first function, "Listen to what you want to hear", we created a content called "Concerned Chart". The "Concerned Chart" allows users to add their own questions to the Question Prompt Sheet in addition to the existing ones, and to take corresponding notes.

New questions added by users are shared with other users of the same app, who can "like" and install their favorite questions on their own devices. The questions with the most "Likes" can be viewed in order, allowing users to see what other users are asking. Each

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question also has a memo field where users can write down their own observations and discussions with their supporters.

For the second question, "Decide for yourself what values and goals you want to cherish", we created the "Me Today" content 1). In "Me Today," users can set up to five goals at maximum (the things they value most) by themselves, and then score them on a daily basis and evaluate them like a radar chart. The aim is to discover or rediscover one's own values, and to discuss them with surrounding supporters as a foothold for shared decision-making. This content was created with reference to the previously developed "SHARE" shared decision-making support tool 10).

The content thus created was made available as an application for free download from the application store for both Android and iOS 8). The name of the application is "Medical Care Supplement" with the meaning of an application as a supplement for communication that is lacking in psychiatric consultation situations.

From the standpoint of protecting personal information, the structure of the system does not allow the creators themselves to obtain any information about the users of the Medical Care Supplement. Therefore, we cannot know the exact information, but when we actually start the Medical Care Supplement and look at it, we can assume that there are a certain number of users who are using it. Of course, it is difficult to say that the number of users has expanded significantly, but it is possible to see that new questions are being shared from time to time, perhaps due to the fact that they are made available for free download.

II. Rights Advocacy

1. The need to combine the perspective of rights advocacy

It is important to note that the use of such a shared decision support tool does not necessarily mean that the patient is practicing shared decision making. For example, it has been suggested that patients may be reluctant to communicate with their physicians using a Question Prompt Sheet if their physicians are not willing to practice SDM. While recognizing that SDM is an ongoing process in which patients and physicians work together, it will be an issue for the future to build up clinical practice and research in an elaborate manner to determine what tools and approaches are effective in each specific situation.

Evidence of the clinical benefits of SDM is accumulating, but it is not conclusive 7). However, it should not be forgotten that SDM is not only recommended based on evidence of clinical efficacy, but is also strongly

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recommended due to the need for ethical practice based on the concept of human rights. In other words, even if we assume that there is no evidence of effectiveness for any clinical outcome, it is difficult to conclude that we should not aim for SDM on that basis alone. The Convention on the Rights of Persons with Disabilities, adopted with the slogan "Nothing about us without us", has been ratified in Japan. It is necessary to continue to verify the effectiveness of SDM, and to work toward its implementation and dissemination, while placing importance on the protection of rights.

On the other hand, we should be uncomfortable with the fact that SDM, which is a concept based on the premise that patients wish to use psychiatric treatment on their own initiative, is discussed in the context of forced hospitalization. Medical personnel should not talk about "SDM" in the context of behavioral restrictions such as forced hospitalization, isolation, or physical restraints. The "right to live without psychiatric treatment" must be guaranteed, and when talking about SDM, it is necessary to always have the perspective of rights protection outside of it. We must not forget that in order for interactive and companionate decision-making based on equal relationships to be possible, an equal support structure is necessary as a prerequisite. There is always a need for a foundation to protect human rights and to correct the authority gradient that exists so that patients are not "forced" to make shared decisions with their physicians.

In recent years, efforts to prevent and reduce coercion in psychiatry have become increasingly important. When talking about SDM, it is necessary to always include the perspectives of effective institutional design and rights protection against coercion as two sides of the coin. Only when the patient's right not to be coerced is protected, keeping in mind the authority gradient that exists between the patient and the health care provider, can a variety of choices be made by the patient himself/herself, and shared decision-making with the health care provider become possible. In order to achieve the goal of SDM, it is necessary not only to create and disseminate SDM support tools and programs, but also to design a mental health service system based on human rights, which is a prerequisite to the creation and dissemination of these tools and programs.

With this in mind, the following discussion will focus on the foundations on which SDM can take place. In other words, after asking what kind of support structure is necessary for SDM, the new paradigm of mental health services called Housing First (HF), which was developed to support those

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who are homeless, is positioned as the antithesis of compulsory psychiatric hospitalization and examines its philosophy from the perspective of human rights.

2. Housing First

In recent years, the paradigm of mental health services has changed drastically, and practices involving various ideas and philosophies, such as harm reduction, Housing First, open dialogue, party research, and co-creation, have been developed 4). Looking closely at these changes, we notice that the need to support human rights has been raised once again. Human rights are universal rights that people have simply by virtue of being human. Based on the awareness that mental health services may be violating basic human rights by excluding certain people and groups, especially overlapping minorities, due to their structure and culture, there is a growing movement to change the structure and culture of mental health services.

Housing First is a very simple concept: "First, secure a stable home, and then provide support according to the needs of the individual". Housing First began in the U.S. in the 1990s as an approach for chronically homeless people with mental illness or addiction. It has been adopted in Canada, France, Sweden, Spain, Portugal, the Netherlands, Australia, and other countries. Although it is still difficult to fully replicate this approach in Japan due to institutional restrictions, initiatives such as the "Housing First Tokyo Project" based in Ikebukuro and Nakano, Tokyo, have begun 3).

Housing First emphasizes the right of people to have a stable home. Having a home where privacy is maintained is a human right, and everyone has the right to live in a safe home. Having a key to a space that one can control is the very essence of one's dignity.

The cornerstone of Housing First is the "separation and independence of housing and support". Housing is never provided in exchange for psychiatric treatment or drug withdrawal. Receiving support services, including medical care, is based on the person's own will, and is not a condition for obtaining housing. They are also not involved in the evaluation of whether they can live in an apartment, manage their finances, or continue to go to the hospital (non-judgmental). We accept them as they are and provide them with stable housing first. All the person has to do is pay rent and receive regular visits, and the residence is not lost, regardless of whether or not the person receives support services. Even if the relationship with the caregiver breaks down once established, the person can continue to live in the apartment

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because having a stable place to live is a basic human right. Housing First is also distinct from "housing only". Support services are provided according to the needs of the individual, and having a home is not a condition for receiving such support. Support continues even if a person leaves housing for any reason and returns to living on the streets, is hospitalized, or imprisoned, and housing is provided as often as needed.

Housing First is designed to support community living for people with serious mental illness and addiction. The background of Housing First is the concept of harm reduction. Harm reduction is a public health practice or policy that aims to minimize the harm and risk associated with behaviors that are undesirable or dangerous to a person's health when that person is unable to stop the behaviors immediately. Housing First does not impose an "ideal state" of being able to receive treatment for mental or physical illness, get sober, and work. It is a highly pragmatic measure designed to reduce the physical and mental harm that can result from continued homelessness by providing a stable place to live. Even if it does not lead to support for mental illness or addiction and does not improve symptoms, the provision of stable housing reduces mental and physical burdens. Stable housing also leads to recovery and connection with others.

Housing First is positioned as an alternative to the "step-up model" of homeless assistance, which is to live in a group in a dormitory or shelter, receive employment support, obtain a job, and move to an apartment when the situation becomes stable. This model was born out of a serious problem in the field of assistance: people who are not good at living in groups or who have accumulated difficulties in relationships with others are more likely to stumble during the step-up model and end up living on the street again. This model may help to avoid the process whereby people tend to re-experience trauma due to interpersonal problems and disappear and return to the streets in the middle of the step-up model, by providing a safe and secure place to live without any conditions as a foundation for recovery at their own pace.

3. Starting with support for housing as a human right

Housing First is a concept that opposes institutionalization of all kinds, including long-term hospitalization in psychiatric hospitals. It is essential to start with housing support as an effective way to protect rights against coercion in psychiatric care as a basis for shared decision-making.

Housing is a basic human right, and at the same time, it is the foundation of

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various human rights. Having one's own private room with a key protects privacy and the right to freedom of the human spirit. Housing is also essential to shelter from the wind and rain and to protect oneself from the outside world (social and survival rights). An address is required to access various services, and it is also the foundation of the right to suffrage.

Human rights are universal rights that people have simply by virtue of being human, and no conditions are required other than being human. If we stand on the idea that housing is a human right, then no conditions should be required in order to obtain housing. This is the reason why Housing First seeks to thoroughly separate housing from receiving treatment and recovery, and to provide each separately and independently. Whether a person receives medical care or not, he or she must have a safe place to live, which is a human right and the basis of human rights.

SDM is an interactive and companionable decision-making process in a clinical setting, based on an equal relationship, and is an ongoing process conducted in cooperation between patient and physician. As a precondition for this equal relationship, it is necessary to guarantee a basis for life in which the patient's basic human rights are not violated even if the patient does not choose to make a joint decision with the physician. If the patient's human rights, including housing, are violated when he or she does not choose to make a shared decision with the physician, then the physician should not talk about SDM in such a situation.

In considering SDM, it is necessary to always have the viewpoint of rights protection as a prerequisite, and to provide concrete options and means. As the concept of SDM continues to expand, we need to deepen this discussion.

Conclusion

This paper has outlined Housing First, one of the recent paradigm shifts in mental health services, and discussed the need to keep a rights advocacy perspective in mind when using the concept of SDM, by learning from the philosophy behind the separation of housing and treatment. Although the concept of SDM has been recognized, the specific methods are still in the process of development, and further discussion, including critical perspectives such as those discussed in this paper, is needed to mature. It is difficult to implement Housing First perfectly within the current institutional design in Japan, and the reality on the ground is that various efforts and compromises are being made. In the context of rights advocacy, including perspectives other than

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housing, there are many issues to be addressed in the future, including the establishment of an institutional design for advocacy in inpatient psychiatric care. Of course, it is not always possible to put these issues into practice in an ideal way, but it is necessary to develop initiatives that lead to improvement of the quality of mental health services in a positive manner through repeated discussions and innovations in the field.

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