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Special Feature Article

Schizophrenia and Self-Stigma

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Abstract

In Emil Kraepelin's time, schizophrenia was called "premature dementia" and was regarded as a disease that was difficult to treat. Eventually, it became clear that schizophrenia could be treated with medication, mainly antipsychotic drugs, and psychosocial treatment; however, there were still many problems, such as the negative image of the disease that were barriers to treatment. Under such circumstances, the Japanese Society of Psychiatry and Neurology changed the name of the disease to "schizophrenia" in 2002, thanks to the efforts of family associations and other organizations, and with the help of the media, awareness of the disease gradually spread throughout Japan. The treatment and care of schizophrenia has progressed over the years, and nowadays, the aim is not only to alleviate clinical symptoms but also to achieve personal recovery. On the other hand, self-stigma is an obstacle to recovery, and it is deeply related to insight. In recent years, there have been many efforts to reduce the self-stigma that inevitably arises during the treatment process. It has become clear that knowledge of the disease is important, and that intervention with the patient and the patient's family is also effective. In Japan, the Speakers Bureau, which was held in Sendai in 2013, attracted attention as an anti-stigma activity by concerned parties. Currently, due to the spread of the COVID-19 and other factors, anti-stigma activities may only be held on a limited basis. However, relapses and re-hospitalizations for schizophrenia continue unabated. In such a situation, psychosocial interventions for

patients and caregivers can contribute to the reduction of self-stigma, and as a result, it is suggested that relapse and re-hospitalization may be prevented. In addition, treatment with long-acting injectable antipsychotics may also be appropriate from the perspective of medication adherence. The time has come when many patients with schizophrenia can overcome self-stigma, continue maintenance treatment without experiencing relapse or re-hospitalization, and pursue life as they see fit.

Keywords: schizophrenia, self-stigma, insight, recovery, maintenance therapy

Introduction

The word "stigma" has its origins in ancient Greece, where it referred to a mark or physical sign that was used to identify slaves, criminals, and traitors, and was considered to be something that would remain on the skin and never disappear. Our use of the word "stigma" was coined from this meaning, to distinguish between people by branding them as morally inferior and dirty. The American sociologist Goffman, E. defined stigma as "an attribute that is deeply discrediting" and "something that causes a particular individual to be stigmatized or despised by the whole or by ordinary individuals."⁴⁾ Stigma is not a term that is limited to the field of mental health and welfare, but is also used in other fields.

It can be broadly divided into public stigma and self-stigma. According to Koike et al.,¹⁴⁾ public stigma is what individuals have towards mental disorders or people with them, and can

be further divided into knowledge, attitude, and behavior. For example, this includes misconceptions such as "people with mental disorders are dangerous, scary, or pitiful," and a lack of knowledge, negative feelings, and non-accepting attitudes and behaviors that actually restrict the social participation, activities, and relationships of the target, such as not hiring people with mental disorders.

In contrast, self-stigma is something that people with mental disorders feel when they are subject to prejudice and discrimination. It includes: (i) perceived stigma, i.e., "feeling that many people discriminate against me because I am different"; (ii) experienced stigma, e.g., "being socially restricted because of a mental disorder"; and (iii) narrow-sense self-stigma, where the sufferer "thinks that society does not need them."¹⁴⁾ The biggest problem is that public stigma affects self-stigma, and the sufferer ends up accepting the rumours.¹⁴⁾

It is no exaggeration to say that knowledge of schizophrenia has progressed alongside the issue of self-stigma. Clinical interest in self-stigma related to schizophrenia is marked, as it is considered to be closely related to the quality of life, treatment outcomes, and recovery of patients. This paper reviews the history of "schizophrenia," with a focus on recent evidence, and then discusses the relationship between self-stigma and insight into disease, which is considered to be closely related to self-stigma. Finally, the impact of self-stigma on the maintenance treatment of patients with schizophrenia will be discussed.

I. The Birth of "Schizophrenia" and Subsequent Developments

This section reviews the trends in anti-stigma activities related to schizophrenia up to the present. The progress to date is summarized based on the discussion by Sato.¹⁹⁾ (Table) Schizophrenia originated from the concept of Kraepelin, E., who in 1893 described it as early-onset dementia of unknown cause, a genetic disease, and chronic progressive disease that eventually leads to personality deterioration. Based on this concept, the Japanese Society of Psychiatry and Neurology announced in 1937 that "dementia praecox" (early-onset dementia) was to be renamed

"schizophrenie" (schizophrenia). However, although this name became established, it continued to be a breeding ground for prejudice for many years, and in 1993, the National Federation of Families with Mentally Ill in Japan requested that the Japanese Society of Psychiatry and Neurology change the name of the disease again. Two years later, in 1995, the Japanese Society of Psychiatry and Neurology began to change the name of the disease, and this was reported in the book by Sartorius, N. et al.¹⁸⁾ as an anti-stigma activity unique to Japan. In the same report,¹⁸⁾ it was stated that the purpose of changing the name of the disease was to free the patients and their families from the shock of being diagnosed with "schizophrenie," to eliminate self-stigma, and it was hoped that there would be a long-term ripple effect in terms of eliminating public stigma. In 1996, the World Psychiatric Association (WPA) launched a program to tackle prejudice and stigma surrounding schizophrenia, and in 2001 the World Health Organization (WHO) stated in a report that a "paradigm shift from institutionalization to community care" was taking place, and mental health policies were announced in the UK. In 2002, the state of mental health in Japan was examined, and in August of the same year, the Japanese Society of Psychiatry and Neurology announced a

change in terminology from "schizophrenie" to "schizophrenia." This can be viewed as an epoch-making event in the history of psychiatric care in Japan. The following year, 2003, a mental health policy was announced in the United States, and in 2004, one of the visions of mental health and welfare reform was "the dissemination of correct knowledge of mental illness," and as part of this, the "Mental Barrier-Free Mindset (Kobe Declaration)" was issued. A report entitled: "Toward a Barrier-Free Mindset: For the Dissemination of Correct Knowledge on Mental Illness and Mental Disorders" was presented at the 2005 Science Council of Japan, calling for the elimination of stigma and promotion of activities for those involved. In 2013, Sartorius and Kiyohisa Takahashi pointed out that stigma hinders treatment and care, and called for long-term anti-stigma measures.

Next, we will introduce some of the evidence from Japan on stigma and its impact on schizophrenia (hereafter, until the end of this section, the review article is cited with permission from the original author, Koike, S. et al.).

Twelve years after the name change (2014) Koike et al.¹¹⁾¹³⁾ administered a survey to about 250 college students of a generation that grew up without knowing about the name change itself, i.e., a generation that was never

exposed to the media or school classes on the name change to schizophrenia. We prepared 10 diseases (depression, hypertension, hyperlipidemia, mental retardation, schizophrenie, bipolar disorder, dementia [chiho], schizophrenia, diabetes, and dementia [ninchi-sho]) and asked the students to name two pairs of diseases that indicated the same disease. The results showed that students were able to identify "dementia" in 88% of cases, but the agreement rate for "schizophrenia" was extremely low at 41%. In a study that looked at the intensity of stigma for four diseases: the former name schizophrenie, schizophrenia, depression, and diabetes, it was found that the order of intensity was schizophrenie > schizophrenia > depression > diabetes. Furthermore, when we divided the respondents into those giving correct or incorrect answers for the earlier "schizophrenie" and "schizophrenia" disease name agreement and investigated the extent to which they differed in their stigma, we found that the correct responders showed a smaller effect of stigma reduction than those giving incorrect answers. From this, it can be noted that even more than 10 years after the name change, there is still marked prejudice against schizophrenia, that more than half of participants in the study considered schizophrenie and

schizophrenia to be different diseases, and that the name change to schizophrenia contributed to reducing stigma. Eight more years have now passed since the study, and the term "schizophrenia" has become more widely used in the media. However, what kind of image do ordinary people have of "schizophrenia" as reported in the media?

Koike et al.¹²⁾ conducted a comprehensive survey over the past 30 years in Japan on the impact of the name change to "schizophrenia" in newspaper reports. We used a statistical method called text mining to analyze the words used in headlines of articles (including news) related to schizophrenia reported by the four major newspapers: Asahi, Sankei, Mainichi, and Yomiuri, as well as NHK, during the period from 1985 to 2013. From the annual changes in the number of articles that included the old name "schizophrenie" and new name "schizophrenia," "depression," and "diabetes," it was found that the number of articles mentioning "schizophrenia" had increased significantly from 2003 onwards, the year after the name change in 2002, compared with the number of articles mentioning "diabetes." In comparison with articles on "depression," the number of articles on both the old name and "schizophrenia" increased between 2000

and 2005. In addition, the term "crime" was found in over 20% of the text in articles on both the old name and "schizophrenia." Past research revealed that the public has low-level understanding that the old name "schizophrenie" now has the new name "schizophrenia." While the media has made some contribution to stigma reduction, this study highlights that "schizophrenia" is often associated with "crime" and remains misunderstood. According to the 2020 White Paper on Crime,⁸⁾ the crime rate among mentally disabled people is 1.0%, which is not high. One of the persistent causes of stigma is believed to be that "schizophrenia" is often reported along with crime-related events.^{2),5)}

By way of comparison, what was the impact on stigma in neighboring Asian countries that did/did not change the name of schizophrenia as in Japan? Yamaguchi, S. et al.²¹⁾ conducted a systematic review of the relationship between schizophrenia and stigma. Of the 10 studies conducted involving people aged 19 or over in countries that had changed the name, 9 showed that attitudes towards schizophrenia improved. However, it is interesting to note that in countries that had not changed the name, one out of five studies of persons 19 years of age or older found "worse attitudes toward schizophrenia."

II. Self-stigma and Recovery/Insight

What kind of impact does self-stigma have in actual clinical practice? The keywords that emerge in the process of answering this question are "recovery" and "insight" possessed by the patient.

What is the relationship between insight, which may emerge during the recovery process, and self-stigma? In the case of schizophrenia, if the illness is severe, insight is often lacking, but if the illness is mild from the beginning, or if it becomes mild through treatment, the patient may become aware that they may be ill, or notice that they are different from their original self. If this leads to treatment and care, it will result in a good clinical outcome, but if insight into the illness leads to self-stigma, it may result in a poor clinical outcome. Thus, the way in which the illness is perceived can lead to conflicting clinical outcomes (insight paradox).¹⁵⁾¹⁶⁾ For this reason, self-stigma is considered to be a regulator of insight and clinical outcomes. Self-stigma is also considered to be related to medication and treatment adherence, and there is some suggestion that it may be related to frequent relapses and readmissions to hospitals.⁶⁾¹⁵⁾ In particular, it is also considered to correlate with the pathological process of becoming intractable from the first episode of schizophrenia.¹⁹⁾

So, what methods can be used to reduce self-stigma in the first episode? In terms of reducing self-stigma in a larger number of subjects, as well as in terms of cost and use of minimal resources, the usefulness of interventions using video rather than face-to-face contact has recently been the subject of increased attention. According to a study conducted in New York, USA,¹⁾ a short video intervention was effective in reducing self-stigma in patients with first-episode schizophrenia. The protagonist of the video was a 22-year-old African American woman who had been diagnosed with schizophrenia. The intervention comprised a 90-second video in which she informed the participants, aged between 18 and 30, about her own first episode and how she successfully coped with difficulties in her daily life, the details of her medication, and its side effects.

Approximately 1,200 subjects were recruited on Amazon Mechanical Turk (MTurk), a leading crowdsourcing tool. A video intervention (randomized controlled trial) was conducted, and a web-based self-reported questionnaire was used to assess social distance (e.g., do you want your child to marry a person with schizophrenia?), the sense of being disconnected (e.g., are people with schizophrenia significantly different from people with other

illnesses?), stereotypes (e.g., people with schizophrenia cannot manage money, or they are violent), and social limitations (e.g., should people with schizophrenia marry and have children) in domains related to self-stigma. In all domains, the intervention group showed significantly less self-stigma than control group. In the secondary analysis, sex differences in stigma domains were found only in the video group, with stigma being reduced more in women. As for how stigma was reduced, Amsalem, D., et al. believe that the direct and honest manner in which the main character in the video describes the episode may have encouraged patients to be hopeful, thereby reducing public prejudice and encouraging first-time episode patients to seek help on a personal basis in the event of an emergency. Therefore, while further long-term, sustained effects need to be confirmed, video messages from people with first-episode schizophrenia in such a short period of time can contribute to reducing self-stigma in the early stages of the disease, and are considered to be an important tool that can lead to a good clinical outcome, namely recovery.

Recent evidence⁹⁾ reported that increased awareness of social support for caregivers of schizophrenia reduces the stigma of caregivers themselves. Karaçar, Y. et al. recommend providing information about schizophrenia,

promoting hope, training in social skills, and involving caregivers in the fight against stigma.

In Japan, peer activities for self-stigma reduction centered on patients, i.e., peer support and counseling, are also being promoted.¹⁹⁾ In particular, the fact that a patient who had disclosed the name of the disease gave a lecture on their own recovery experience at a Focused Group Meeting (FGM) became a hot topic. In addition, in the "class to learn about mental disorder," there were reports of self-stigma being improved through the experience of interacting with people with mental disorder,¹⁹⁾ and it is hoped that active peer support activities will continue to be developed in the future.

III. Impact of Self-stigma on Maintenance Therapy for Schizophrenia Patients

Schizophrenia is a chronic illness that has the potential to relapse. One of the causes is poor medication adherence.¹⁷⁾ In a study³⁾ that used the Medication Event Monitoring System (MEMS) to measure the medication adherence rate of schizophrenic patients who were discharged from hospital after taking oral antipsychotics during hospitalization, approximately 20% of patients were found to show poor medication adherence during the period from one week to one month immediately after discharge. This study

was conducted about 10 years ago, but even now, the rate of medication compliance in actual clinical practice may still not be satisfactory. Although this may simply be the result of forgetting to take medication, and some patients, especially first-time episode patients, when asked to continue taking their medication even though their positive symptoms, such as hallucinations and delusions, have reduced, may ask the simple question: "Why do I continue taking my medication when my illness has improved?" It is considered that some patients stop taking medication at a relatively early stage after discharge from the hospital, holding various thoughts related to their awareness of the disease, such as: "Why do I have to keep taking medication when I am not sick in the first place? Even if I take them during hospitalization, I want to stop taking them afterwards," "I'm afraid I won't be myself", and "I'll be ruined if I keep taking drugs."

It has been proven¹⁷⁾ that maintenance therapy with antipsychotic drugs is necessary for schizophrenia patients. However, the author believes that, due to the pathophysiology of schizophrenia itself, "lack of insight" may dominate the patient, especially in the early stages of the illness, and that, when this is combined with self-stigma, there are cases where it is not possible to receive

appropriate treatment or care. Therefore, psychosocial intervention for people with schizophrenia in the early stages, including relapse, is considered to contribute to reducing self-stigma.

Furthermore, interventions for family members who support the patient are also extremely important in reducing self-stigma. Hogarty, G.E. et al.⁷⁾ compared approximately 100 schizophrenic patients on maintenance treatment with long-acting injectable (LAI) antipsychotics in four groups: a combination group receiving social skills training (SST) for patients and family psychoeducation (FPE) for their families, an SST-alone group, an FPE-alone group, and a supportive psychotherapy group. The results showed that the relapse rate over a two-year period was the lowest in the group that received both SST and FPE. In addition, a Cochrane review²⁰⁾ also reported that psycho-education reduces relapse and re-hospitalization rates. In Japan, there is also evidence²²⁾ that psycho-education is effective in reducing self-stigma, and it is hoped that it will lead to a development where "no relapse is experienced," especially in the case of first-episode patients. However, it is not yet clear whether psycho-education for patients and their families contributes to reducing self-stigma. Therefore, we must exercise caution in this regard.

However, concerning LAI as a treatment tool, a large body of evidence indicates that it helps solve medication adherence problems and prevent relapse and re-hospitalization.¹⁰⁾ In addition, freedom from daily medication may also reduce self-stigma. Some patients may recognize that they themselves are ill due to taking oral medications every day, and this may cause them pain and make them ask themselves why they are the only one who has this disease. There are countless clinical cases of patients who suddenly have a question that triggers them to become desperate and stop taking their medication, or who pretend to take their medication but then throw it away or hide it in a drawer because they do not want to be scolded by their family members who live with them. Even in the era of atypical antipsychotics, this situation persists, and not only the LAI antipsychotics that are available in one-month preparations, but also the LAI antipsychotics that have recently appeared in three-month preparations may bring good news to people with schizophrenia from the perspective of reducing self-stigma.

Conclusion

In 2022, for the first time in several decades, mental disorders were mentioned in high school health and physical education textbooks, and

"schizophrenia" was included among them. It is very important to have a certain level of knowledge about schizophrenia, which is one of the mental disorders that commonly occur in young people, from an early age. We believe that the first step toward recovery is for patients to have a correct understanding of schizophrenia and be connected to medical care as soon as possible, and for them to be connected to necessary treatment and care when their own family members or acquaintances are affected by schizophrenia. If self-stigma arises in the process of recovery, various interventions, especially video tools and family intervention by the patients as described in this paper, can be extremely useful in reducing it. More careful psychoeducation and the use of treatment tools such as LAI would deepen patients' insight and enable them to live positively and successfully with schizophrenia as a chronic illness. By overcoming self-stigma, more people with schizophrenia will be able to live as themselves, and so achieve personal recovery. If more people with schizophrenia are able to live their lives as they wish, realizing personal recovery, their self-esteem will increase, and they will be able to give hope to others with schizophrenia, and self-stigma may even disappear. I sincerely hope that this kind of positive cycle will

lead to a society in which people with schizophrenia can live vibrantly.

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Table: Trends in Anti-stigma Activities

Year	Event
1893	The concept of dementia praecox with an unknown cause, as a hereditary disease, and chronic progressive illness leading to personality deterioration (Kraepelinian concept)
1937	JSPN (Japanese Society of Psychiatry and Neurology) announced "dementia praecox" = "schizophrenie"
1993	National Federation of Families with Mental Disorders requested JSPN to change the disease name
1995	JSPN initiated the name-change process, reported as Japan's unique anti-stigma activity
1996	The WPA (World Psychiatric Association) Programme Against Stigma and Discrimination Because of Schizophrenia launched
2001	WHO report "Paradigm shift from institutional care to community-based care" published; UK mental health policy announced
2002	Discussion on mental health approach in Japan; August: JSPN changed name from "Seishin Bunretsu Byo" (mind-splitting disease) to "Togo Shitcho Sho" (integration disorder syndrome)
2003	U.S. mental health policy announced
2004	"Proper knowledge dissemination about mental illness" promoted through "Kokoro no Barrier-Free Declaration" (Kobe Declaration)
2005	Academic conference on "Aiming for Barrier-Free Minds —For Proper Knowledge Dissemination about Mental Illness and Mental Disorders"
2013	Sartorius, N. and Takahashi, K. proposed that stigma hinders treatment and care; advocated for long-term anti-stigma measures

*JSPN: Japanese Society of Psychiatry and Neurology, WHO: World Health Organization, WPA: World Psychiatric Association

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