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Self-stigma of Schizophrenia Patients with Work Experiences and Reasons Not to Disclose Their Illness

Hatsumi Yoshii^{1*}

¹Tohoku University Graduate, School of Medicine, Japan.

Author's contribution

The sole author designed, analyzed and interpreted and prepared the manuscript.

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ABSTRACT

Questionnaires were distributed to 49 stable schizophrenia patients with work experience who were either hospitalized in an open ward of a psychiatric hospital or were outpatients of the hospital to gain understanding of schizophrenia patients' experiences at work, reasons for not disclosing their illness, and self-stigma. The questionnaire used in the present study consisted of 3 sections. Section 1 collected demographic information. Section 2 assessed the social distance of schizophrenia. Section 3 examined the reasons for not disclosing mental illness. The Kruskal–Wallis test and Mann–Whitney U test were used to examine associations between Social Distance Scale Japanese version (SDSJ) score and demographic characteristics. I categorized the qualitative data on reasons for non-disclosure and analyzed these categories. Work experience as a full-time employee was associated with total SDSJ score ($p < 0.05$). The four reasons not to disclose illness to the employer at the time of employment were: avoiding non-employment, avoiding worse treatment, feeling no need to disclose, and feeling unable confess. The three reasons for not disclosing illness to the employer once employed the job were: anxiety about stigma, anxiety about dismissal, and feeling no need to disclose. Measures for reducing self-stigma should focus on people with schizophrenia who currently work full-time. At the same time, it is necessary to establish measures based on evidence. Such measures should also include support for illness disclosure.

*Corresponding author: E-mail: hatsumi@med.tohoku.ac.jp;

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1. INTRODUCTION

Schizophrenia is a chronic illness that may last a lifetime. The onset of schizophrenia is typically between ages 15 and 25 in males and between ages 25 and 35 in females [1]. Many schizophrenia patients not only suffer from the illness but are also faced with stigma [2,3]. Stigma takes two forms: the stigma that the patients confront from society and the self-stigma that results when schizophrenia patients are forced to recognize themselves as a group that should accept stigma [4,5]. Stigma deprives psychiatric patients of employment opportunities, alienating them from society [6,7]. Similar to the abuses of being stigmatized by others, self-stigma may become an obstacle to work. Some studies have pointed out that many people with severe mental illness (including schizophrenia) have high levels of self-stigma and that this is positively related to self-esteem [8-10]. Other studies have shown that older schizophrenia participants report lower levels of self-stigma [10,11]. In addition, self-stigma has been shown to affect meaning in life [12]. Work is one of the most significant aspects of life. Therefore, it is important to clarify what influences self-stigma at work, especially when we try to encourage schizophrenia patients to work.

This study aimed to clarify the reasons why schizophrenia patients with work experience choose not to disclose their illness. Patients are likely to be worried about whether or not to disclose their illness, and identifying the influences of these choices may be helpful for their employment support. In this research, I targeted schizophrenia patients with work experience who were currently undergoing treatment at a psychiatric hospital in Japan. Participants were asked about their experiences at work, their choices not to disclose their illness, and their self-stigma. The scope of measures of coping with stigma should be adjusted for particular groups of people. Studies on coping with stigma are being carried out in various countries worldwide, but it is important that they limit their target groups and make use of methods calibrated for each group under study [13,14]. Here, the investigation is focused on Japanese people.

2. METHODS

2.1 Participants and Ethical Considerations

The survey was conducted at a psychiatric hospital in Niigata, Japan. Questionnaires were distributed to 49 stable schizophrenia patients who were either hospitalized in an open ward of a psychiatric hospital or were outpatients of the hospital. All respondents completed a questionnaire that was prepared for this study as well as another survey on self-stigma of schizophrenia and work experiences. The participants were told that the content of the investigation would be used for research only, that they could withdraw from the study at any time, that their participation would be kept confidential, and that all data would be handled anonymously. Approval to conduct this research was obtained from the Graduate School of Medicine, Tohoku University, and from the hospital where the study was conducted.

2.2 Questionnaire

The questionnaire used in the present study consisted of three sections. Section 1 collected demographic information on respondents, including age and educational background (Table 1). Section 2 comprised eight items on the social distance of schizophrenia. Social distance has the same meaning as stigma. I used the Social Distance Scale Japanese version (SDSJ) to research self-stigma [15]. The SDSJ is an 8-item inventory [15] adapted from the Whatley Social Distance Scale [16] and modified by rephrasing portions for schizophrenia patients. Items on the scale include "I would not ride in a taxi driven by someone with schizophrenia who had been in a mental hospital" and "I would rather not hire a person with schizophrenia who had been in a hospital." (Appendix 1). Respondents are asked to report how often each statement is true on a scale ranging from 1 (strongly disagree, 0 points) to 4 (strongly agree, 3 points). Totalled responses result in a score ranging from 0 to 24, with higher scores indicating higher levels of social distance. Section 3 examined the reasons not to disclose their mental illness. First, I asked all participants whether they had disclosed their mental illness when becoming employed and starting work. Second, I asked participants who had not

disclosed their mental illness about the reason for not doing so. For these questions, participants were encouraged to write their answers freely.

2.3 Analysis

Statistical analysis was performed using SPSS Version 18 software. The Kruskal–Wallis test and Mann–Whitney *U* test were used to examine the associations between SDSJ score and the demographic characteristics of participants. A *p* value of less than 0.05 was considered to indicate statistical significance, and all statistical tests were two-tailed.

The content of participant responses on reasons for non-disclosure of mental illness was transcribed verbatim, after which the raw data were coded according to context, and each code was categorized according to their common characteristics. These subcategories were then classified into more abstract ideas, which were analyzed using Atlas. ti 7.0.

3. RESULTS

3.1 Participants

The participants were Japanese schizophrenia patients. I obtained 43 valid responses, including 32 men (74.4%) and 11 women (25.6%). The modal age was 40 years, with 15 participants of that age (34.9%). High school education was the most frequent category (18 people, 41.9%). Disability pension was the main resource to support themselves for 21 (48.8%) of the patients in the study. The majority of participants (93.0%) had been hospitalized in a psychiatric hospital. In terms of the number of different locations where they had worked after the onset of the illness, the largest category was 3–5 locations (19, 44.2%; Table 1).

3.2 Factors Associated with SDSJ Score

Experience working as a full-time employee ($p < 0.05$) was associated with total SDSJ score (Table 1). Those with experiences working as

full-time employees scored higher on social distance (median score = 12.00, interquartile range = 11.00–16.00) than did those without such experiences (median score = 9, interquartile range = 3.25–2.00). The results of the Kruskal–Wallis test showed no significant difference in the scores on the questionnaire between participants with different educational backgrounds, ages, sources of living expenses, ages of the onset of illness, or numbers of previous workplaces after the onset ($p > 0.05$; Table 1). Likewise, the results of the Mann–Whitney *U* test showed no significant difference between male and female participants categorized or between those who had and had not been hospitalized at a psychiatric hospital ($p > 0.05$; Table 1).

3.3 Reasons Schizophrenia Patients Do Not Disclose Illness Reasons for Non-disclosure at Time of Employment

Of the 43 participants, 25 did not disclose their illness to their employer at the time of employment (Table 1). Ten participants provided an explanation of their reasons. From these responses, I was able to extract 10 different content categories (codes), such as “I didn’t think I would be hired if I disclosed” and “I couldn’t confess” (Table 2). After extracting these categories, they were summarized into four items: “to avoid non-employment,” “to avoid worse treatment,” “feeling no need to disclose,” and “feeling unable to confess.”

3.4 Reasons for Non-disclosure while Working

Of the 43 participants, 24 did not disclose their illness to their employer while they were working (Table 1). Six of them explained their reasons. I was able to extract six different codes from these six responses, such as “I thought I would be viewed as weird” and “I might be fired” (Table 3). After categorizing the responses into these codes, they were summarized into three items: “anxiety about stigma,” “anxiety about dismissal,” and “feeling no need to disclose.”

Table 1. Relationships between SDSJ and demographic profiles

		SDSJ total score		
		n	Maximum score: 24 Median (25%, 75%)	P
Age				0.176
20s		1	-	
30s		9	5.00(2.00, 10.00)	
40s		15	12.00(9.00, 12.00)	
50s		9	11.00(3.50, 15.00)	
60s		8	12.00(8.50, 16.75)	
70s		1	-	
Sex				0.315
Male		32	11.00(8.00, 14.75)	
Female		11	10.00(4.00, 12.00)	
Educational background				0.500
Junior high school		3	16.00(11.00, -)	
High school		18	10.50(6.75, 14.25)	
Vocational school		8	11.50(5.25, 12.00)	
Junior college		2	7.50(4.00, -)	
University		12	10.00(3.50, 13.50)	
Sources of income				0.436
Earned income and savings		4	10.00(8.25, 11.75)	
Disability pension and public assistance		10	7.00(1.00, 13.00)	
Disability pension		21	11.00(7.00, 14.50)	
Supported by family		4	8.50(5.00, 13.50)	
Other		4	12.00(12.00, 13.50)	
Age of onset				0.414
Younger than 10		1	10.00(2.00, 15.00)	
10s		8	12.00(9.00, 14.00)	
20s		23	9.00(1.50, 10.50)	
30s		5	8.00(1.00, 14.25)	
40s		4	7.00(3.00, -)	
50s or older		2	-	
Hospitalized in psychiatric hospital or not				0.571
Yes		40	11.00(5.75, 12.75)	
No		3	12.00(3.00, -)	
Number of workplaces worked after the onset				0.310
1		7	8.00(3.00, 12.00)	
2		10	9.00(7.50, 12.00)	
3 to 5		19	12.00(4.00, 14.00)	
6 to 10		6	11.00(10.75, 16.25)	
more than 11		1	-	
Work experiences as a full-time employee after the onset				0.022*
Yes		15	12.00(11.00, 16.00)	
No		28	9.00(3.25, 12.00)	
Disclosed the illness to the boss when hired or not				0.585
Yes		8	11.50(5.25, 14.25)	
No		25	11.00(5.50, 15.00)	
Yes or no according to workplaces		10	9.00(4.75, 12.00)	
Disclosed the illness to the boss while on the job or not				0.799
Yes		10	11.00(7.75, 12.75)	
No		24	11.50(3.50, 15.50)	
No answer		9	9.00(6.00, 12.00)	

Kruskal–Wallis test, Mann–Whitney U test; * $p < 0.05$

Table 2. Reasons for not disclosing illness to the employer at time of employment (free descriptive answers)

Category	Code
To avoid non-employment	I thought I wouldn't be hired I don't want to be rejected I'm embarrassed if I'm rejected I didn't think I would be hired if I disclosed
To avoid worse treatment	Thought I wouldn't be hired, or I would get worse working condition and treatment Then I wouldn't get high salary Thought it will be a disadvantage
Feeling no need to disclose	There was no need to tell of the illness No need to say
Feeling unable to confess	I couldn't confess

Table 3. Reasons for not disclosing the illness to the employer while on the job (free descriptive answers)

Category	Code
Anxiety about stigma	I thought I would be viewed as weird Seen with prejudices
Anxiety about dismissal	I might be fired I may be fired
Feeling no need to disclose	I know about myself best I didn't think it was necessary

4. DISCUSSION AND CONCLUSION

This study assessed associations between demographic and social factors and levels of self-stigma in schizophrenia patients, as measured by Social Distance Scale Japanese version. The results demonstrated that only employment status was a factor in determining social distance scale scores. Experience with psychiatric hospitalization, educational background, and the number of previous workplaces after the onset of the illness were not determining factors. The difference in employment patterns could be interpreted as a level of self-stigma and a degree of reduction difficulty in different sectors. Among patients, SDSJ scores were associated with work experience as a full-time employee after the onset of illness (Mann–Whitney *U* test, *p* value = 0.022). This result is different from common analytical studies that have used stigma level. Munoz et al. [17] reported that, when group differences in high and low self-stigma, most socio-demographic variables (age, educational

level, etc.) seem to have no relation with the level of self-stigma. This result for employment patterns found in this study could be interpreted as meaning that people with wider social contacts had higher self-stigma. A key question for future study involves potential differences in self-stigma by working time. People with work experience as a full-time employee will have plenty of opportunities to be in contact with others who are not aware of their illness. In contrast, part-time employees' opportunities to be in contact with such people last only for a short time. Alternatively, the findings might be explained by full-time employees tending to take up jobs with a great deal of responsibility. I will explore these possibilities in future research. Considering that schizophrenia patients with work experience as full-time employees have higher self-stigma, unless measures to cope with self-stigma are taken, it would be difficult to promote regular employment among this group. This finding has immense significance to those involved in psychiatry in Japan and the rest of the world who strive to raise the employment rates of schizophrenia patients.

Taking a long-term view, as social stigma decreases, self-stigma may also decrease. A previous study on social contact and stigma indicated that people may become broader-minded and more accepting of difference through intergroup contact, with differences going beyond age and affinity orientation [18]. Therefore, it seems desirable to increase opportunities to join with others at workplaces. However, according to statistics of the Japanese Ministry of Health, Labour and Welfare [19], the employment rate of mentally-disabled people is significantly lower than that of physically-disabled people (0.7% vs. 19.3%). Therefore, opportunities for contact with mentally-disabled people in the workplace are

likely to be very limited. To cope with self-stigma, trials such as psychoeducation [20], cognitive-behavioral therapy [21,22], sharing of personal narratives about hopes and aspirations in a group [23,24], and peer support [25,26] have been conducted. However, there is no evidence that these trials were effective in decreasing self-stigma. In future research, I will explore this area. In particular, intervention studies are needed that are targeted at schizophrenia patients with full-time employee experiences or those who are currently in full-time employment.

I have explored the reasons why schizophrenia patients did not disclose their illness when they are begin employment, concluding that this decision was made to avoid possible rejection or worse treatment based on the illness. Practical and moral pressures contributed to tensions between disclosure and non-disclosure of mental illness in the workplace [27]. In addition, I have explored the reasons why these patients did not disclose their illness while on the job. They cited anxieties about stigma and dismissal. This indicated that users of mental health services face difficulties in deciding whether to disclose a mental health problem to an employer [28]. Because of their self-prejudices, schizophrenia patients may leave their jobs, miss out on opportunities for an independent life, and be less apt to seek treatment [29-32]. Additionally, people with mental disorders commonly suffer from stigma after disclosure [33]. These findings emphasize the necessity of gathering evidence using long-term measures of coping with self-stigma.

A previous study reported that requiring greater interpersonal disclosure may help to reduce stigma [18]. However, little support for illness disclosure is available, and there is a tendency to avoid this area because of the very delicate nature of the issue. In the future, it will be necessary to establish measures of coping with self-stigma, including illness disclosure. In particular, it is essential that future research give more deliberate consideration to strategies for anti-self-stigma education for patients with a variety of characteristics. At the same time, together with measures to decrease social stigma, measures directed specifically toward those schizophrenia patients who work full-time should be taken to care for self-stigma.

Only four out of the 43 participants in this study were living on their own income and savings (9.3%). For various reasons, most of the subjects did not work. Additional results might have been

possible if I had been able to sample more schizophrenia patients on the job.

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COMPETING INTERESTS

Author has declared that no competing interests exist.

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APPENDIX 1

SDSJ Item

- | | |
|---|--|
| Q1. It is best not to associate with a person with schizophrenia who had been in a mental hospital | Q5. I would rather not hire a person with schizophrenia who had been in a hospital |
| Q2. It is wrong to shy away from a person with schizophrenia | Q6. School teachers with schizophrenia who have been in a mental hospital should not be allowed to teach |
| Q3. It would bother me to live near a person with schizophrenia who had been in a mental hospital | Q7. If I needed a baby sitter, I would be willing to hire a woman with schizophrenia |
| Q4. I would not ride in a taxi driven by someone with schizophrenia who had been in a mental hospital | Q8. I would be against any daughter of mine marrying a man with schizophrenia who had been in a hospital |

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