Psychoeducation may Reduce Self-Stigma of People with Schizophrenia and Schizoaffective Disorder

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Summary: Previous studies suggest that self-stigma is related to social isolation and discrimination. Although it is known that stigma has cultural and social impacts, only a few studies in Japan have explored self-stigma in people with schizophrenia. The present study was conducted to investigate self-stigma in people with schizophrenia and schizoaffective disorder in Japan under a typical clinical setting, and to examine the effect of psychoeducation on self-stigma. Fifty-six participants (44 men and 12 women) who met the DSM-IV criteria for schizophrenia and schizoaffective disorder were recruited. All participants completed several questionnaires including social distance scale. Collected data were classified into an experiential or non-experiential group according to hospital records. The experiential group received psychoeducation which focused on reducing self-stigma by correcting inaccurate ideas about schizophrenia, and the relation between schizophrenia and criminal activity or violence, by watching videotapes and analyzing data from a report published by the National Police Agency. After the intervention, participants completed the Japanese version of the Social Distance Scale (SDS-J), the Knowledge of Illness and Drugs Inventory (KIDI) questionnaire, the Drug Attitude Inventory 10 (DAI-10), and the Birchwood’s Psychosis Insight Scale (BPIS). In addition Global Assessment of Functioning Scale (GAF) scores were calculated for each participant. Significant differences between the 2 groups were observed for the SDS-J, KIDI, and BPIS (P<0.01 for each). However, no significant differences were observed for the DAI-10, GAF, age, and duration of treatment. The results of a path analysis showed that increasing knowledge about schizophrenia and its treatment might play an important role in reducing the self-stigma associated with this disease. When performing psychoeducation for people with schizophrenia and schizoaffective disorder, we need to discuss the pervasive effects of stigma and discrimination.

Key words schizophrenia, self-stigma, psychoeducation, knowledge

INTRODUCTION

Recently, many studies have examined the stigma against people with mental illnesses. These studies were performed to determine the actual status and the effects of stigmatization, and to formulate methods to reduce stigma. Dinos et al. [1] found that 57% of people with a mental illness had experienced verbal abuse based on prejudice and 43% had experienced physical abuse. Dickerson et al. [2] examined 74 outpatients with schizophrenia in the United States and showed that not only had all subjects been stigmatized in some way, but that there was no relation between the intensity of such experiences and symptom severity or social function. Some researchers [3,4] have tried to explain that people with schizophrenia who experienced public stigma might have “stigma awareness”, and thus accept the “stereotype” associated with this disorder. Previous studies revealed that a label of mental illness causes discrimination and rejection for sufferers [5]. In particular, in Japan, the ideology of schizophrenia triggered a public stigmatizing attitude [6]. The earlier Japanese term for schizophrenia, “Seishin-Bunretsu-Byo (“mind-split-disease”), had

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Abbreviations: SDS-J, Social Distance Scale; KIDI, Knowledge of Illness and Drugs Inventory; DAI-10, Drug Attitude Inventory; BPIS, Birchwood’s Psychosis Insight Scale; GAF, Global Assessment of Functioning Scale.
the unwanted effect of misinforming people about the nature of the disease; to avoid this misinformation, the term was later changed to “Togo-Shicho-Sho (“integration disorder”). After this change, the public perception of schizophrenia was expected to change from an incurable and dangerous disease into a treatable and controllable disorder [6]. However, there is not enough evidence to show if this name change actually reduced public stigma against schizophrenia. Furthermore, it is necessary to examine whether people with schizophrenia experience “self-stigma,” which might have adverse effects. For example, self-stigma might damage self-efficacy and self-esteem of people with schizophrenia [7-9] and result in low adherence to psychiatric treatment [3,10]. We also found that patients with schizophrenia using a day treatment service in Japan regarded schizophrenia as a dangerous disease [11]; in other words, they experienced the self-stigma described by Corrigan [4].

Although previous studies suggest that self-stigma is related to social isolation [12-14] and discrimination [13], strategies for reducing self-stigma remain unclear. Although it is known that stigma has cultural and social impacts, only a few studies in Japan have explored self-stigma of people with schizophrenia.

The present study had two aims: (1) investigate self-stigma in people with schizophrenia in Japan under a typical clinical setting; and (2) elucidate the effect of psychoeducation on self-stigma.

METHODS

Participants

Fifty-six participants (44 men and 12 women) were recruited from Kurume University hospital (n=48) and a local private hospital (n=8). All participants met the DSM-IV criteria of schizophrenia and schizoaffective disorder (52 schizophrenia and 4 schizoaffective disorder) by their attending psychiatrist. All 56 participants underwent outpatient treatment; 30 participants received both outpatient treatment and day treatment at Kurume University Hospital. They were all at a stable phase of their disorder and had not been hospitalized in the past 6 months. All participants were Japanese and had at least a high school education. Participants with history of mental retardation were excluded. Twenty-nine participants attended a psychoeducational program and the other 27 participants received standard care without psychoeducation.

Intervention

Psychoeducation group meetings were held every week for 6 weeks. There were 4 groups with 8 to 10 participants each. These 4 psychoeducation groups were conducted using a standard manual and all took place during the same period. The psychoeducation program performed in the present study focused on reducing self-stigma. The actual program has the following aims: (1) To correct participants’ common and inaccurate ideas about schizophrenia by watching the videotape of a TV news story featuring a young woman with schizophrenia who described herself and her life, using her real name. Participants were encouraged to realize that she seemed to be quite happy and ‘cool’ and was not ashamed to have her condition broadcast on TV. (2) To correct the participants’ views on the relation between schizophrenia and criminal activity or violence by sharing data regarding the lack of correlation between crime and schizophrenia based on a National Police Agency report.

Measures

Stigma

The Social Distance Scale (SDS) was originally created by Whatley [15] in 1959 to assess prejudice against mental disorders. In 2006, Makita further translated and modified the original SDS into a Japanese version of the scale (SDS-J) [16] and statistically examined its reliability and validity. The scale consists of five items that participants rate on 4-point Likert scale (0-3 points); the sum of the ratings equals the social distance, with higher scores representing a greater desire to distance one-self from people with schizophrenia.

Knowledge

Participants’ knowledge about mental disorders and their treatment was assessed with the Knowledge of Illness and Drugs Inventory (KIDI), which was developed by Maeda et al. [17]. This questionnaire includes 20 items that participants were asked to agree or disagree with, with higher scores representing greater knowledge. The KIDI is frequently used to assess knowledge about mental disorders and treatments in Japan.

Attitude toward drug therapy

The participants’ attitudes toward drug therapy were assessed with the Drug Attitude Inventory 10 (DAI-10). DAI-10 consists of 10 items that participants can agree or disagree with, with higher scores representing greater willingness to receive medication.

Insight

Self-awareness of mental disorders among participants was assessed with Birchwood’s Psychosis Insight Scale (BPIS), which consists of eight items that
participants rate on a 3-point Likert scale (0-2 points), with higher scores representing greater awareness of mental disorders.

*Global functioning*

Global functioning of participants was measured by the Global Assessment of Functioning Scale (GAF). GAF scores were based on the periods when participants showed their best condition over the past 6 months.

*Procedures*

Institutional review board approval was received for this study, and all participants provided informed consent before participating in the research. The researcher gave a short briefing to the participants that stressed that they could choose not to participate or withdraw consent at any time during the study. Participants in the psychoeducation group then completed the SDS-J, KIDI, DAI-10, and BPIS after receiving psychoeducation. Participants in the non-psychoeducation group completed the same questionnaires during the same week as the psychoeducation group. Demographic data were collected in a prescribed method by the psychiatrists and social workers who were the main care providers.

*Data Analysis*

*Steps before path analysis*

Before path analysis, several steps were needed to minimize the number of variables so that the power could be maximized, and to clarify the relationship between SDS-J and other variables to elucidate the effect of psychoeducation on self-stigma. First, we examined which variables had an impact on SDS-J. We compared the mean total SDS scores of participants who received psychoeducation with the mean of those who did not receive psychoeducation using the Mann-Whitney U-Test. Differences in genders were compared using Fisher’s exact test. The Mann-Whitney U-Test was also used to analyze the results of age, duration of treatment, and GAF and three self-rating scales between the psychoeducation group and non-psychoeducation group. We then examined Pearson’s correlations between SDS-J and KIDI, DAI-10, BPIS, and GAF. Data were analyzed using SPSS (version 17.0 J).

*Path analysis*

Through the steps described above, we hypothesized some pathways to demonstrate the impact of psychoeducation on self-stigma. We examined these pathways with AMOS (version 6.0) to test the theoretical model.

**RESULTS**

The mean age of participants was 34.2 years (SD:10.4), and the mean duration of treatment was 155.4 (SD: 96.8) months. As shown in Table 1, there were significant differences between the 2 groups in SDS-J, KIDI, and BPIS (p<0.01 for each). On the other hand, the mean age of participants was 34.2 years (SD:10.4), and the mean duration of treatment was 155.4 (SD: 96.8) months. As shown in Table 1, there were significant differences between the 2 groups in SDS-J, KIDI, and BPIS (p<0.01 for each). On the other hand, there were no significant differences in GAF between the 2 groups.

| TABLE 1. Demographic data and comparisons of scores between participants who underwent psychoeducation (PE) and those who did not (Non-PE) |
|-----------------|-----------------|-----------------|
|                  | PE group (n=29) | Non-PE group (n=27) | p-value† |
| N                | 29              | 27               | n.s       |
| Age (yr)         | 35.6 (10.4)     | 32.8 (10.5)      | n.s       |
| Duration of treatment (months) | 168.3 (99.0)     | 141.7 (94.3)      | n.s       |
| Scores on assessments |                  |                  |           |
| SDS-J            | 5.02 (2.99)     | 9.40 (2.98)      | <.01      |
| KIDI             | 16.64 (2.42)    | 11.28 (2.70)     | <.01      |
| DAI-10           | 2.50 (4.81)     | 1.44 (3.30)      | n.s       |
| BPIS             | 11.74 (2.50)    | 9.56 (2.78)      | <.01      |
| GAF              | 45.84 (9.20)    | 49.66 (8.54)     | n.s       |

† Data were compared using the Mann-Whitney U-test.
SDS-J: The Japanese language version of Social Distance Scale
KIDI: Knowledge of Illness and Drugs Inventory
DAI-10: Drug Attitude Inventory 10
BPIS: Birchwood Psychosis Insight Scale
GAF: Global Assessment of Functioning Scale
hand, there were no significant differences in DAI-10, GAF, age, and duration of treatment.

Table 2 shows the mean scores of the five questions on the SDS-J. Mann-Whitney U-test indicated a significant difference between the results of the experimental vs. non-experiential group for all five questions (p<0.05 or p<0.01). Cronbach’s α coefficient for the SDS-J was 0.811, demonstrating a high reliability coefficient for the test.

**Correlation analysis**

The correlations between the SDS-J and KIDI, DAI-10, BPIS, and GAF are summarized in Table 3. The Pearson product-moment coefficient of correlation values were significant, so we selected SDS-J and KIDI, DAI-10, and BPIS as participants’ objective variables for path analysis. GAF was not significant, nevertheless we included GAF in the path analysis because GAF was the only variable that showed the participants’ pathological condition.

**Path analysis**

Results of the path for testing the hypothesized model are presented in Figure 1. This was the only pathway that showed goodness of fit ($\chi^2=9.69$, $p=.457$, $df=5$, root mean square error of association=.0042, goodness of fit index=.961). This present result indicates that psychoeducation reduces social distance in persons with mental disorder by increasing their knowledge about the disease.

**DISCUSSION**

Path analysis results in the present study show that
increasing knowledge about mental disorders and treatment, particularly schizophrenia, might play an important role in reducing the self-stigma associated with this disease. Regarding the specific relation between knowledge of illness and self-stigma, studies of people with HIV revealed an apparent relation between knowledge and self-stigma. Uys et al. [18] examined the level of self-stigma of 41 people with HIV/AIDS in five African countries who were receiving antiretroviral therapy and found that educational interventions, including providing information about HIV stigma and coping skills to reduce public prejudice, could reduce self-stigma. A similar outcome was observed in Zambia [19]; 322 people with HIV receiving antiretroviral therapy showed statistically significant reductions in stigma through community- and clinic-based educational interventions. The results of our study as well as past studies on patients with HIV suggest that interventions to increase knowledge level about an illness are important for the stigmatized people. In particular, people living in Japan are likely to lack knowledge about schizophrenia [6,20]; thus, early provision of correct information about schizophrenia for people with this disease is vital to prevent self-stigmatization.

Two essential questions remain unanswered: What kind of knowledge should we provide and how should we share the information? In our psychoeducation groups, we first emphasized the fact that there was a deeply rooted prejudice among the public based on inaccurate beliefs about schizophrenia (for instance, “Almost all people with schizophrenia are violent” or “People with schizophrenia should not be allowed to get married”). Second, we provided evidence to counter these beliefs and rumors (eg, the crime rate of people with schizophrenia in Japan was relatively low). Although participants indicated that they were slightly embarrassed and initially expressed complicated emotions, such as fear of being violent or unpredictable themselves, all participants in the psychoeducation group completed the sessions voluntarily and many of them regarded the psychoeducation as desirable. In particular, objective data regarding violence among people with schizophrenia seemed to relieve participants from ambiguous fears about their disease.

In Japan, providing accurate knowledge based on a biological model of schizophrenia has been considered the most important factor in psychoeducation for patients with schizophrenia. However, it is also important to share information about public prejudice based on inaccurate beliefs and irresponsible rumors, which may traumatize people with schizophrenia. Several studies suggest that causal attribution based on a biological disease model cannot reduce social distance for people with mental disorder [21-23]. When performing psychoeducation for people with schizophrenia, we need to not only provide a biological model of schizophrenia but also discuss the pervasive effects of stigma against them.

With regard to the use of a group approach, it is possible that the strong group identity helped participants develop a sense of resistance against stigma [24] because all participants who attended our psychoeducation had been receiving day treatment together. Lysaker & Lewis [25] also demonstrated the importance of performing psychoeducation in a group setting to reduce self-stigma by changing beliefs and responses to self-stigma. Regrettably, one limitation of our study design was that we could not investigate the influence of group identity.

We did not find any evidence that there was a positive relationship between self-stigma and GAF, attitude toward medication, and insight into the mental condition with path analysis. These results indicate that even participants who had high social functioning and good adherence could not reduce their self-stigma. Despite the lack of data regarding severity of psychotic symptoms in this study, neither good social adjustment nor a high level of insight appears to reduce self-stigma. Almost half a century ago, Doi, one of the most reputed psychiatrists in Japan, reported that people with schizophrenia experienced a greater sense of crisis when they were informed that they had schizophrenia than at the time they had developed schizophrenia, because of the impact of the extremely negative impression of the disease.

Lysaker et al. [26] examined 75 people with schizophrenia and demonstrated that even people with schizophrenia who were symptomatically stable and were well informed about their condition remained stigmatized.

Although there are few studies that considered the correlation between self-stigma and attitude toward medication, Tsang et al. [27] demonstrated that self-stigma did not correlate with attitude toward medication. In the present study, the level of attitude toward medication was already very high before participants underwent psychoeducation, so it is possible that there was no room for further improvement in our groups.

Limitations and future studies

Some limitations of this study should be noted. First, our study design was retrospective and thus there are methodological issues with regard to recruiting the participants. Second, the sample size of this study was
small and participants were recruited from a confined area so our results might not be generalizable to a larger population. Future studies should take these issues into account. Third, SDS-J was originally created for assessing prejudice against people with mental disorders and not for assessing self-stigma. In further studies, the scales which were created for assessing self-stigma such as ISMI (Internalized Stigma of Mental Illness [12]) or SSMIS (Self-stigma of Mental Illness Scale [28]) should be used.

The INDIGO (International Study of Discrimination and Stigma Outcomes) network of World Psychiatric Association showed the importance of increasing self-esteem for stigma reduction [29]. Thus, in further study we should seek effective ways to reduce self-stigma with assertive programs focused on self-esteem and psychoeducation.

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REFERENCES


