The Process of Identity Adaptation (Oriai) in Community-Dwelling People with Schizophrenia
—Results from Content Analyses and Text Mining—

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Abstract—This study aimed to further elucidate the process of identity adaptation in people with schizophrenia by talking to them about their illness. Semi-structured interviews were conducted with nine community-dwelling people with schizophrenia. Analysis was performed using Krippendorf’s approach, and Text Mining. Eleven content categories were derived: “illness acceptance”, “self-control”, “help from family”, “help from friends”, “help from doctors or nurses”, “modifying thinking”, “social roles and activities”, “worthwhile work”, “enjoyment of life”, “being happy”, and “being free”. Participants with schizophrenia were found to attain “illness acceptance” based on “help from family”, “help from friends”, and “help from doctors and nurses”. Text mining results is 400 keywords were identified. The top 5 in order of importance and frequency were: “omou” (feel/think), “naru” (become), “iu” (say), “suru” (do), and “kusuri” (medication). As a result of an interactive process surrounding the concepts of “illness acceptance”, “self-control” and “modifying thinking” the participants sought out “social roles and activities” and “worthwhile work” to acquire a social identity. Thus, it was found that the participants felt they “enjoyed life and were happy” and “they were free”, because they were productive members of society.

Keywords: Schizophrenia, community-dwelling people with schizophrenia, illness, identity adaptation (Oriai), Text Mining

I. INTRODUCTION

Over time, schizophrenia has become a chronic illness. People living with a chronic illness need to adjust their daily lives to control their symptoms. Corbin and Strauss have described how people living with chronic illness need to go through a process of “identity adaptation” [1]. Expressed in Japanese as, “Yamai to ori ai o isuku ru”, which means “to come to terms with one’s illness.”

Previous studies on “identity adaptation” in people with schizophrenia include a study by Shinpou and Kunikata that assessed the process by which a sample of community-dwelling patients made themselves feel positive about their lives by coming to terms with living with their illness [2]. In another study, Kunikata et al. found that when patients with schizophrenia came to terms with their illness, they also enabled themselves to find a “sense of fulfillment” in their lives [3].

It has been suggested, that people with schizophrenia are not able to take their pathological experiences objectively because of the characteristics of the disorder [4]. As a result, they are excluded from society as they have been denied the opportunity to “tell their stories,” including talking about their illness, symptoms, and the problems in their lives [5]. However, some studies show us that people with schizophrenia have been able to describe the meaning of the illness for the themselves as well as understand their perceptions of the disorder by talking about their histories. As part of this discovery process, these studies describe the subjects’ experiences of the “suffering that comes from the illness itself,” “suffering due to having to reconstruct their own sense” and “suffering due to medication and hospital stays” [6,7,8]. Suffering due to having to “reconstruct their own sense” refers to the process of identity adaptation described by Corbin and Strauss [1]. Notably, few studies have assessed methods to help schizophrenic patients with the process of “identity adaptation”, as well as “reconstructing the self.” As stated by the subject of one study, “There was no one to give me a hand!” [6].

Several studies have been conducted outside of Japan on identity adaptation in people with a mental illness. Dinos et al. explored how mental illness is involved in people’s representations of their past, present and future selves and evaluated the meaning that these temporal comparisons produced for their sense of self [9]. Barham and Hayward reported on the dilemmas encountered by people with
schizophrenia in their efforts to sustain an identity. This involved acknowledging the fact that they were ill and accepting their illness as an essential part of themselves [10]. Taylor and Perkins studied people with chronic psychiatric illness who coped by viewing themselves as “typical psychiatric patients” or by denying they had psychiatric problems [11]. Finally, Estroff discussed questions regarding the relationship between illness and the identity, of schizophrenic patients such as whether the illness is something that happens to the self, or if the diagnosis robs a person of their identity [12]. Even in overseas literature, while we could obtain studies on the difficulty of accepting oneself as having a disability and on the reconstruction of identity, we found no studies on specific methods to help schizophrenic people with the process of identity adaptation.

Thus, this study aimed to find out more about the process of identity adaptation in people with schizophrenia. A sample of community-dwelling people with schizophrenia was interviewed about how they came to terms with their illness as they went about their daily lives.

II. METHODS

A. Participants

Participants were individuals diagnosed with schizophrenia in remission who recognized they were ill, felt positive about their present lives and had been living at home for more than a year.

B. Survey period

The survey took place during a 6-month period from September 2015 until March 2016.

C. Method of distribution and collection of questionnaires

Participants were recruited on a voluntary basis by providing a written explanation of the study’s purpose and ethical considerations to all the members of community activity support centers for people with disabilities. We scheduled one 30-minute semi-structured interview per person. In consideration of participant safety and maintaining the objectivity of the data, we asked two clinically experienced faculty members specializing in psychiatric nursing to attend the interviews. One faculty member was present at each interview. The interview was held in a private room at the support center to which the participant belonged. This provided a quiet environment in which we could have a relaxed conversation.

D. Question items

We asked each participant to freely talk about their gender, age, whether they had a family, when their symptoms first appeared, whether they had ever been hospitalized, and things such as how they found their way through life, what kinds of things had happened to them from the time they were born to the present, difficulties they had experienced because of their illness, things, and pleasures in their current life that were important to them, and activities they were currently involved in. Participants were also informed that they should not feel obligated to talk about anything they did not want to.

E. Analysis

1. Transcriptions of the semi-structured interviews provided the data for the analyses. Content analyses were performed via Krippendorf’s approach.

2. Interview data were also analyzed using text mining.

F. Ethical considerations

The study was conducted with the approval of the internal review board of the International University of Health and Welfare (approval number 15—Io—51). Participants were provided with verbal and written explanations stating the study’s purpose, its benefits, and risks, that participation was voluntary, that they were free to stop participating at any time, and that, whatever their decision, there would not be any unfavorable consequences.

RESULTS

III.

A. Participants

| Participant | Gender | Age group | Age at symptom onset (years) | Living alone or with family | Interview length (min.) |
|-------------|--------|-----------|-----------------------------|-----------------------------|------------------------|
| A           | Female | 40s       | 16-17                       | Alone                       | 50                     |
| B           | Male   | 50s       | 15                          | Family                      | 61                     |
| C           | Female | 20s       | 20                          | Family                      | 31                     |
| D           | Female | 40s       | 16                          | Family                      | 54                     |
| E           | Female | 40s       | 15                          | Alone                       | 46                     |
| F           | Male   | 40s       | 19                          | Alone                       | 54                     |
| G           | Male   | 60s       | 15                          | Alone                       | 56                     |
| H           | Male   | 40s       | 13-15                       | Family                      | 36                     |
| I           | Female | 50s       | 26                          | Alone                       | 36                     |

B. Identity adaptation

Analyses were performed on each case. Eleven content categories were derived from 120 subcategories found for all the participants: “illness acceptance”, “self-control”, “help from family”, “help from friends”, “help from doctors or
The participants gained “illness acceptance” based on “help from family”, “help from friends”, and “help from doctors and nurses”. “Illness acceptance” led to “self-control” and “modifying thinking”, which in turn affected “illness acceptance.” For example, one participant felt that he could make himself easy after he changed his way of thinking: “It was always a big deal for me that things didn’t go my way. It is so much easier now that I learned to let that go.” Another participant understood he could have a life in the community if he accepted his illness and exercised self-control: “I think we’re just like everybody else…as long as we take our meds. It’s hard for people like us to do things like rent an apartment, but I make sure I pay the rent on the day it’s due!”

By accepting their illness, participants could exercise self-control and modify their ways of thinking accordingly, because they wanted to have a social life in which they could play a social role or perform a social activity and do worthwhile work. As one of the female participants stated, “Even though I don’t get paid much, I get to chat with people all day long and listen to music I like while preparing lunch boxes.” One of the male participants stated, “Maybe it’s because life feels more worthwhile when you’re among people, so I’m involved in a club for people with schizophrenia called Circle of Friends.” Due to the work or activities, they were involved in, they made comments like “I think I’m lucky. I’m so happy!” which showed that they were able to “enjoy life”, “be happy”, and “be free”. These feelings are indicative of a person with schizophrenia who has successfully been able to come to term with their illness. However, the analysis also demonstrated that for them to experience those feelings, it was important that they have a social role to fulfill.

1) Text mining results

a) Keyword importance and frequency

In all, 400 keywords were identified. The top 5 in order of importance and frequency were: “omou” (feel/think), “naru” (become), “iu” (say), “suru” (do), and “kusuri” (medication).

b) The concept map

Concept mapping showed that “omou” (to think/feel), which had the highest level of importance, was related to the words “yoi” (good/better), “katte” (selfish/self-centered), “haha” (mother), “dekiru” (be able to/be capable), “kangaeru” (think/consider), “honto” (right/real), “nai” (not/none), “hataraku” (work/function), “tanoshii” (be fun/enjoyable), “kuru” (come), “yamai” (illness), “raku” (relaxed/easy) and “suru” (do). Of these, the strongest relationships were with dekiru and tanoshii.

“Naru” (become), the second highest in importance, was related to the third highest “iu” (say). The fourth highest “suru” (do) was related to “omou” (think/feel) and “suki” (like/love), “hanashi” (story/conversation), and “hito” (person), of which the strongest relationship was with “hito”.

The fifth-highest “kusuri” (medication) was shown to be related to “kiku” (be effective/work), “nomu” (take), “surai” (hard/painful) and “deru” (arise/result), the strongest relationship being with “nomu” (take).

3) Words participants used related to their thoughts or feelings (omou)

a) Yoi (good/better)

Participants used the word yoi when talking about their mental state being comparatively better and when explaining what fit with that mental state. They also used yoi when describing how their mental state had changed for the better.

b) Dekiru (be able to/be capable)

Participants used dekiru when talking about having gained self-confidence as the result of others drawing out their strengths which made them more capable. When dekiru was linked with “ukeireru” (to accept), it signified how “being capable” enabled them to accept their current situation better than “mae” (before).

c) Tanoshii (fun/enjoyable)

Tanoshii was used to indicate things they enjoyed in life, such as work and hobbies.

4) Kusuri – Words participants used related to medication

a) Nomu (take)

Nomu was used when participants talked about it being important to take their medication, as in, “I think one of the reasons I take my medication is that I’m the type that gets a sense of security after taking it. As a result, I practically never forget to take it.”
TABLE II  TOPS IMPORTANT KEYWORDS AND OCCURRENCE FREQUENCIES FOR THE OVERALL SAMPLE

| Rank | Keyword  | Importance | Relationships in the text | Frequency |
|------|----------|------------|---------------------------|-----------|
| 1    | Omou     | 7.279      | 141                       | 260       |
| 2    | Naru     | 6.665      | 121                       | 193       |
| 3    | Isu      | 6.289      | 113                       | 244       |
| 4    | Saru     | 5.619      | 112                       | 187       |
| 5    | Kasuri   | 5.531      | 32                        | 54        |

b) Kiku (be effective/work)
The word kiku was often used when participants talked about symptoms subsiding because of their medication, as in “Medication has been especially helpful when I feel panicy. I take it and, when I feel it start to work, the symptoms subside relatively quickly.”

IV. DISCUSSION

A. Characteristics of the identity adaptation process identified through content analysis

1) Help from others
The content analysis of the interview transcriptions showed that the identity adaptation process began with receiving “help from family”, “help from friends”, and “help from doctors and nurses”, which enabled “illness acceptance”. Regarding the importance of relationships with others, Yokoyama et al. described how acceptance by others gives this population the sense of security and confidence to self-disclose and leads to more interpersonal relationships and social participation [13]. Ushiroda has also reported that for people with schizophrenia “the presence of support from others” is needed for them to be able to accept their disability [14]. Other studies, such as one by Kanasaki and Miki, have found that people with schizophrenia hope that they will have family, friends and others who will help them in their long struggle with their illness [15]. Similar to the results of previous studies, this study found that in the process of identity adaptation, the help of others contributes to “illness acceptance”.

2) Factors affecting illness acceptance
a) Self-control
In 8 cases, “self-control” was found to have subcategories related to medication. The main subcategories were 1) “medication effectiveness” and “understanding the importance of medication” and 2) “coping with symptoms” and “symptom stability.” While there are previous studies that have pointed out the importance of medication, such as one by Tanaka [6], there are few that address this issue. On the other hand, we did find studies that reported participant problems with medication, such as one in which a subject commented, “I found out how frightening medication can be when it didn’t agree with me!” [16]. This study showed that most of the participants felt that taking medication was important. Also, the results indicated that illness stability is an important factor.

b) Modifying thinking
In the process of identity adaptation “self-control,” “modifying thinking” and “illness acceptance” mutually influenced each other. Analysis of the interview content showed that the effects of these concepts on each other were bidirectional, which appears to be a new finding.

c) The self as a social being
From the concepts of “social roles and activities,” and “worthwhile work”, it was clear that the participants were seeking self-identities as members of society. This study showed that the category “social roles and activities” included the subcategories of “responsibilities as a person with schizophrenia” and ‘repaying one’s debt to society.’ These points have not been mentioned in any previous studies, so it may also be a new finding.

B. Characteristics of the identity adaptation process identified through text mining

1) The significance of yoi, dekiru, and tanoshii
This study found that the word yoi (good/better) was strongly related to the word omou (feel/think) and was used by participants to describe how 1) their mental state was comparatively better 2) their current situation suited them better; and, 3) their symptoms had stabilized [26]. Kunikata et al. also found that symptom stabilization was a factor influencing patients’ feelings about their lives [27], suggesting that, for people with schizophrenia, it is an important element in their daily lives. The results of the present study support that finding. In the interviews, when talking about their symptoms, participants said things that indicated they made an effort to stabilize their symptoms, such as, “I feel better” and “I can be paranoid” indicating they made an effort to stabilize their symptoms, such as, “I feel better” and “I can be paranoid”. Looking at the words that indicated that the perception of being better made them “feel more relaxed”, it was clear that that perception was important to them. This suggested that it is important in nursing care to work to improve not only a patient’s mental state, their living situation and to stabilize their symptoms but to improve their perceptions of those things as well.

Dekiru (be able to/be capable) referred to improvement in competence resulting from the efforts of physicians and people around them to bring out their strengths. The analysis showed that support from others enabled them to do things in practice that increased their self-confidence. This suggested that dekiru was a word that was an important support to these people in their daily lives. Being stigmatized for having schizophrenia has been shown to significantly impact self-esteem [28]. In addition, the impact of social evaluation on self-assessment can result in poor self-confidence [29]. However, through experiences of “being capable”, participants in this study gained self-confidence. Further, results showed that “being capable” was related to “being able to” better “accept” their situation than before (“mae”). This suggested that for people with schizophrenia,
feeling they are also “capable” may be an important element that contributes to “oriai”, that is, to adapting their identity to their illness.

“Tanoshii” (be fun) was used to describe things they enjoyed in life, including jobs and hobbies. Setoguchi et al. defined the process of adapting one’s identity to include being schizophrenic as learning to “coexist with the illness”, “have a positive perception of the self”, “socialize with family and people in a way that fits one’s present self”, “develop different values” and “improve self-monitoring” in order to “live in a way they can be themselves” [23]. Although it was not clearly exactly what that meant, our results showed that it may mean “to enjoy” one’s life and work.

2) The significance of “kusuri”

“Kusuri” (medication) was shown to be strongly related to nomu (take) and kou (be effective/work). Tanaka studied individuals with schizophrenia and other mental disorders and found that the patients realized that taking medication was important [6]. On the other hand, a few other studies, including another by Tanaka, have found from subjects’ life stories or their interpretation that they “realized how frightening medication can be when the prescription isn’t right” [7], [29], [30]. This study found that most participants felt that it was important to “take” their “medication” and that their “medication” “worked”. These findings suggest that realizing the importance of taking one’s medication is an important part of the process of identity adaptation for people with schizophrenia.

V. CONCLUSION

1. The people with schizophrenia who participated in this study went through an identity adaptation process in which they gained “illness acceptance” based on “help from family”, “help from friends”, and “help from doctors and nurses”. Attaining “illness acceptance” enabled “self-control” and “modified thinking”. Making progress in self-control and modifying thinking also appeared to further illness acceptance, suggesting that there were mutual interactions among these three concepts.

2. Content analyses showed that “illness acceptance”, “self-control”, and “modifying thinking” enabled the study participants to hope for a self-identity as a member of society with “social roles and activities” and “worthwhile work”. It was clarified that living in society led them to feel that they could “enjoy life”, “be happy”, and “be free”.

3. Text mining found a strong relationship between the words “omou” (feel/think) and “yoi” (good/better), suggesting that it was important for participants to perceive that their mental state was “better”.

4. Text mining of the participants’ words found that the word “dekiru” (be capable) referred to the fact that they had become more capable as the result of others working to bring out their strengths. Becoming more capable was important to participants’ ability to “accept” their situation.

5. Text mining showed that participants believed that “taking” their “medication” was important and that they felt it “worked”.

6. As part of the identity adaptation process, people with schizophrenia evaluate whether they have sufficient support to assess their illness. If not, they need to determine the means by which support can be obtained and help themselves feel that they have a social identity.

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REFERENCES

[1] P. Woog, “The Chronic Illness Trajectory Framework: The Corbin and Strauss nursing model” [in Japanese], Y. Kuroe, K. Ichihashi, M. Takara (Trans.), Tokyo, Igaku-Shoin, pp. 16, 1995.

[2] T. Shimpou and H. Kunikata. “The process in which patients with schizophrenia coming to psychiatric day care or a small-scale workshops reach “oriai” with reality,” Journal of Japan Society of Nursing Research vol. 31, pp. 71-78, 2008.

[3] H. Kunikata, M. Kayahara, K. Ohmori, T. Shimpou, and Y. Okada, “Schizophrenic patients’ experiences in day care or small-scale workshops: A qualitative study,” Journal of Japan Society of Nursing Research, vol. 29, pp. 37-44, 2006.

[4] R. E. Hoffman, T. H. McGlashan, “Corticocortical connectivity, Autonomous Networks, and schizophrenia,” Schizophrenia Bull, vol 20, pp 257-226, 1994.

[5] K. Ishihara. “Research on people with schizophrenia” [in Japanese], Tokyo, Igaku-Shoin, pp. 19, 2013.

[6] M. Tanaka, “The meaning of illness for one mentally ill person with schizophrenia: The life history of community-dwelling Mr.” N. Nursing Research, vol. 33, pp. 37-58, 2000.

[7] M. Tanaka. “The life history of a survivor of mental illness in Japan and its interpretation (Part 1)—The factors having enabled him a community living and the relation between history and illness in an individual” [in Japanese], Bulletin of School of Nursing, Tokyo Women’s Medical University, vol. 5, pp. 1-15, 2002.

[8] M. Tanaka. “The life history of a survivor of mental illness in Japan and its interpretation (Part 2)—The meaning of illness: The fight of searching for the self-independency and the meaning of one’s own being” [in Japanese], Bulletin of School of Nursing, Tokyo Women’s Medical University, vol. 5, pp. 17-26, 2002.

[9] S1. Dinos, E. Lyons, W. M. Finlay. “Does chronic illness place constraints on positive constructions of identity? Temporal comparisons and self-evaluations in people with schizophrenia,” Soc. Sci. Med., vol. 60, pp. 2239-2248, 2005.

[10] Peter. Barham, Robert. Hayward. “In sickness and in health: dilemmas of the person with severe mental illness,” Psychiatry, vol. 6, pp. 1163-70, 1998.

[11] K. E. Taylor, R. E. Perkins. “Identity and coping with mental illness in long-stay psychiatric rehabilitation,” Br. J. Clin. Psychol., vol. 30, pp. 73-85, 1991.

[12] S.E1. Estoff. “Self, identity, and subjective experiences of schizophrenia: in search of the subject,” Schizophr. Bull., vol. 15, pp. 189-196, 1989.

[13] K. Yokoyama, T. Morimoto, S. Takeda, and N. Ikeda. “The process of self-disclosure and reduction of self-stigma in people with schizophrenia living in the community” [in Japanese], Japanese Journal of Psychiatric Rehabilitation, vol. 18, pp. 174-182, 2014.
[14] Y. Ushiroda. “The research of schizophrenia person’s obstacle acceptance process” [in Japanese], Niigata College of Nursing Gakuchô Tokubetsu Kenkyûhi Kenkyû hôkokusho, pp. 95-101, 2004.

[15] H. Kanasaki, and A. Miki. “The meaning of hope for schizophrenia patients receiving long-term medical treatment” [in Japanese], Journal of Japan Academy of Psychiatric and Mental Health Nursing, vol. 14, pp. 79-87, 2005.

[16] K. Watanabe and Y. Oishi. “The meaning of illness for one mentally ill person” [in Japanese], Journal of the Kanagawa University of Human Sciences, vol. 3, pp. 105-112G, 2006.
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