

Developing “Patients and Public Involvement” Nursing Support Program to Improve People with Schizophrenia’ s Family Resilience

メタデータ	言語: eng 出版者: 公開日: 2022-08-05 キーワード (Ja): キーワード (En): 作成者: 川口, めぐみ, 北岡, 和代, 片山, 美穂, 森岡, 広美, 川村, みどり, 中本, 明世, 看護学科コミュニティ看護学, Kawaguchi, Megumi, Kitaoka, Kazuyo, Katayama, Miho, Morioka, Hiromi, Kawamura, Midori, Nakamoto, Akiyo, Department of Community Nursing, Division of Nursing, Faculty of Medical Sciences, University of Fukui メールアドレス: 所属:
URL	http://hdl.handle.net/10098/00029198

Developing “Patients and Public Involvement” Nursing Support Program to Improve People with Schizophrenia’s Family Resilience

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統合失調症をもつ人々の家族レジリエンスを高めるための
患者・市民参画型看護支援プログラムの開発

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看護学領域コミュニティ看護学

Abstract:

The present study is designed to describe the process of developing the earlier nursing support program to enhance family resilience for people with schizophrenia as well as their parents. It is aimed at staging an intervention in the early stages of the onset of the disease. We especially focused on the process of modifying the previous nursing support program content by incorporating the concept of patients and public involvement into the program proposal created in our previous study. In the process of developing the previous nursing support program, we sought advice from the members of Japan Service Users Group Advising on Research (J-SUGAR) regarding the previous program. The advice clarified the importance of the following two items: (1) individualized intervention while taking into account the complex emotional state of parents dealing with their schizophrenic family members in the early stages of the onset; and (2) two-way communication through dialogue to solve problems through cooperation between nurses and parents who are aware of the actual problems, especially in people with schizophrenia in the early stages of the disease, when trust is difficult to establish.

Keywords: schizophrenia, family, resilience, nursing support programs, patient and public involvement (PPI)

要旨

本研究では、統合失調症をもつ人々および彼らの親を対象として、発症初期段階からの介入を目指した家族レジリエンスを高めるための看護支援プログラムの開発過程の報告を目的としている。特に、著者らの前研究で作成した看護支援プログラム（案）に、patients and public involvement（PPI）の概念を取り入れ、プログラム内容を修正していく過程に注目した。

プログラムの開発過程において、Japan Service Users Group Advising on Research（J-SUGAR）のメンバーからの助言により、(1) 統合失調症を発症した初期段階の人々に接する親の複雑な心情を考慮して個別での介入を実施すること、(2) 特に信頼関係が築けない初期段階の人々への対応として、実際の問題を認識している看護師と親が協力して問題を解決するために対話による双方向のコミュニケーションを行うことの重要性が明らかとなった。

キーワード: 統合失調症, 家族, レジリエンス, 看護支援プログラム, 患者・市民参画

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(Received 17 February, 2022 ; accepted 5 August, 2022)

Introduction

Expressed emotion study shows that family therapy is necessary to prevent relapse in people with schizophrenia. Leff et al. conducted a follow-up study of people with schizophrenia; the results showed that when family members make comments about people with schizophrenia, such as concerning their hostility and excessive emotional involvement, the relapse rate is higher¹⁻²⁾. This research has also been conducted in Japan and the empirical results have been confirmed³⁾. Therefore, in order to prevent relapse in people with schizophrenia, support to reduce the burden on family members, especially parents who come into contact with the schizophrenic person is being considered.

Alternatively, some studies have focused on the concept of resilience, which is the ability of humans to cope with adversity. Resilience research focuses on the individual's abilities or internal strength to be adaptive, despite a serious disability⁴⁾. Walsh proposed the theory of family resilience, which states that in addition to the resilience of the individual, the family group acquires coping skills by changing its functional system through its relationships with its surroundings and with assistance from others⁵⁾. Research that has incorporated the concept of family resilience includes those on immigrant families⁶⁾, military families⁷⁾, Poverty-stricken families⁸⁾, and the impact of family resilience and COVID-19 on children's well-being⁹⁾. Similarly, there are also studies that have been conducted with families of people with schizophrenia¹⁰⁾. However, there are still only a few studies that have taken into consideration nursing support to increase the family resilience of people with schizophrenia. No such studies have been conducted in Japan.

We thought it was important to focus on the family resilience of people with schizophrenia and the nursing support program. We found that according to previous studies, parents are unable to realize the presence of the disease among family members during the early stages of onset and have trouble coping with it. However, as parents gain knowledge and improve their way of

thinking, they are able to find new ways of dealing with the situation. Accordingly, people with schizophrenia and their parents reported that they could gain the power to enrich their own lives¹¹⁾. Based on these results, we developed the earlier nursing support program to enhance family resilience, focusing on intervention in the early stages of onset.

In Japan, the "Plan for Promotion of Research and Development in the Medical Field" demonstrated the need for promoting patient and public involvement (PPI) from the research planning stage¹²⁾. In this study, we attempted to develop a program by incorporating the concept of PPI into the previous nursing support program. We believe that the improved program will help people with schizophrenia find effective support for themselves and their parents to continue living in the community and will contribute to the construction of a regional comprehensive care system in the future.

Objective

The overall objective of the present research project was to develop a nursing support program for people with schizophrenia as well as their parents to enhance family resilience. It also aimed at staging an intervention in the early stages of the disease and evaluate its effectiveness. In the present study, we incorporated the concept of PPI into a nursing support program created in the previous study, and focused on the process of modification based on service users' advice. Such an attempt is yet to be made in Japan.

Methods

1. Developing a nursing support program

In our previous study¹¹⁾, 14 parents of people with schizophrenia were interviewed and asked the following question: How are the experiences of the parents associated with the schizophrenic person's experiences from the onset of the disease to the continuation of their daily lives in the community? The results of the interviews are presented in Figure 1. The following three

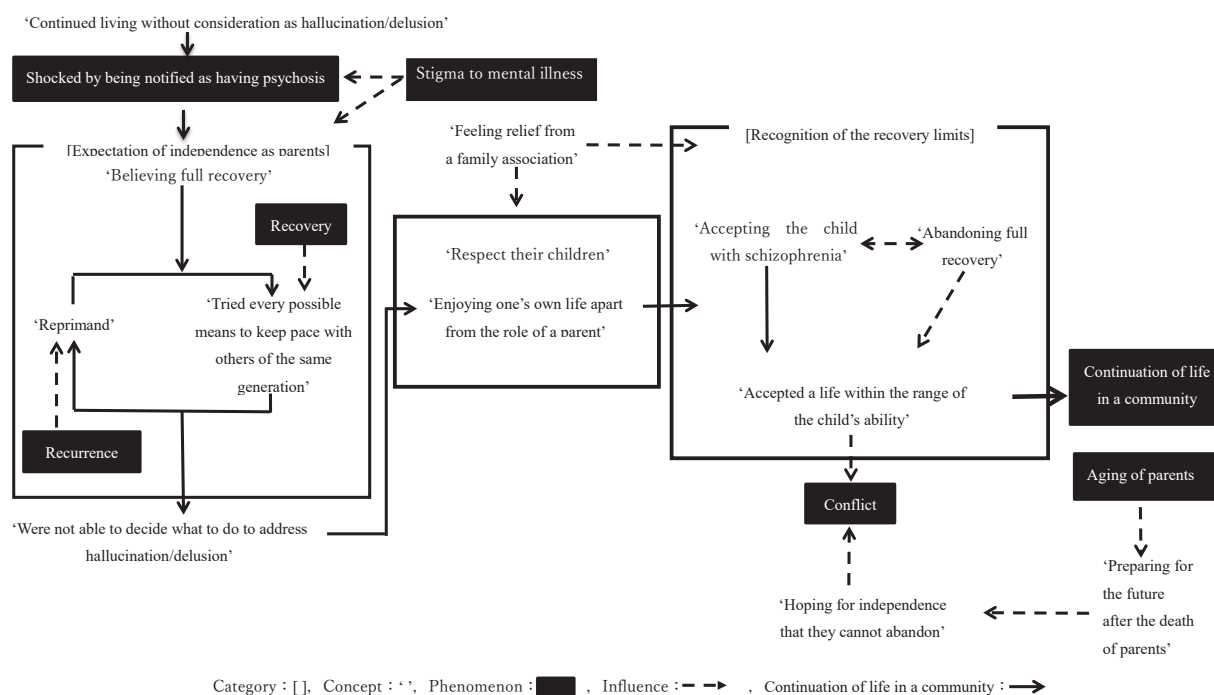


Figure 1. Process of associating with experiences by parents of schizophrenia patients from onset to the continuation of life in a community (Kawaguchi & Kitaoka, 2017)

points were crucial in increasing the family resilience of people with schizophrenia as well as their parents: (1) the need for psychoeducation about schizophrenia and the recovery process; (2) an evaluation of the parents' efforts to interact; and (3) the use of social skills training to develop techniques for prospectively capturing events with people with schizophrenia. Based on these findings, the previous nursing support program was developed.

2. Advice on the previous nursing support program from Japan Service Users Group Advising on Research Japan Service Users Group Advising on Research (J-SUGAR) is an initiative that allows people with mental illness to use their expertise as a concerned party and provide input on studies conducted by researchers¹³⁾. This initiative began in 2009, with the establishment of the service user group, which advised on research at the City University of London. Reportedly, in addition to researchers receiving advice from concerned parties, the initiatives of SUGAR help its advising members realize their growth and increase their confidence¹⁴⁾.

In 2019, Katsuragawa, Ohnishi, Miki, and, Kitaoka as collaborators launched J-SUGAR and conducted initiatives with 11 service users in Japan¹³⁾. Members understand the fundamentals of research, papers, and how to advise researchers on the initiatives of the research team. The content of the previous nursing support program for people with schizophrenia as well as their parents as a means of increasing family resilience was presented to 11 members of J-SUGAR using a Power Point presentation. The members provided feedback regarding the program and the program content was revised accordingly.

3. Period

The survey period for people with schizophrenia as well as their parents was from February 2020 to March 2021.

4. Ethical considerations

This study was approved by the Medical Ethics Committee of Kanazawa University (approval No. 655-

1). The outline of the study¹²⁾ was explained to the parents of people with schizophrenia at the time of the interview survey. It was also explained that a nursing support program would be developed based on the results of the interview survey. We have obtained written consent from all the subjects to publish the information in this study. Furthermore, the advice given by J-SUGAR members was anonymized.

Results

1. Outline of the previous nursing support program

1) Participant recruitment

Participants included both people with schizophrenia within one year of onset as well as their parents. The inclusion criteria were as follows:

- (1) Families with mutual relationships among members, as they are important for enhancing family resilience.
- (2) At the time of onset, parents were shocked by the onset and worried about coping with the situation; therefore, early intervention of support was considered important.

2) Location, time, and method

An outpatient clinic where the schizophrenic person was being consulted was chosen as the location to reduce the time required to conduct the research and the time to get them there.

The interview survey lasted less than one hour. Interviews and social skills training were allotted 40 minutes and psychoeducation centered on disease education was allotted 20 minutes.

The intervention varied for each family because the

content of each participant's troubles and symptoms were subjective. Furthermore, we intended to implement the same program for people with schizophrenia and their parents.

3) Implementation frequency and content

Psychoeducation was conducted six times (once every month) during the time of consultation. The contents of the psychoeducation were as follows:

- (1) Interviews elicited current problems in the living conditions of people with schizophrenia and their parents.
- (2) Social skills training encouraged cognitive reinterpretation and offered specific coping strategies.
- (3) Psychoeducation for disease education, information on social resources, and support for parents' lives (Table 1).

2. Modifications to the previous nursing support program

The previous nursing support program to enhance family resilience aimed at people with schizophrenia and their parents was presented to the members of J-SUGAR who provided advice. Subsequently, the following modifications were made (Table 2).

1) Participant recruitment

Participants in the program were limited to the parents of people with schizophrenia within three years of onset. The following issues were identified based on the advice of J-SUGAR members:

- (1) It is difficult to aim the study at individuals and their parents within one year of discharge, as

Table 1. Contents of psychoeducation

Contents	
First	Causes and symptoms of schizophrenia
Second	Course of schizophrenia and its state
Third	Treatment of schizophrenia (types of drugs, effects, side effects, and other treatments)
Fourth	Support for people with schizophrenia and their families (medical, health, and welfare)
Fifth	Recovery from schizophrenia
Sixth	Enhancing the lives of parents of people with schizophrenia

Table 2. Contradictory advice from J-SUGAR members with program modifications

Content of advice	Program modifications
<ul style="list-style-type: none"> · One year after the onset, some people may believe that they are not sick at all when going to the hospital · It may be difficult for people with mental illness to listen to other people, and even sitting still may be difficult · It may be difficult for us to go out just to participate in the program · It is absolutely impossible to be with family because fights erupt · The same content does not make sense because my family does not understand · We do not want my immediate family to see us struggling with the disease 	For parents of people with schizophrenia within 3 years of onset
<ul style="list-style-type: none"> · As a concerned party, we want to have a dialogue and not be lectured · We do not want others to know about their illness, so we think it's best to do it individually, not in a group 	The same nurse conducts the program each time and implements two-way communication through dialogue
<ul style="list-style-type: none"> · Family members are troubled by our response · My family wants to know how to respond properly · Parents are worried about not knowing who to ask about their illness or how to deal with the schizophrenic person in the family 	Time allocation and content will be based on the participant's response and understanding
<ul style="list-style-type: none"> · Some of them may not want to know their stress status 	Explanation of the results is based on the participant's wishes
<ul style="list-style-type: none"> · Participating in research makes us feel like we are being used as a guinea pig · Participants may cooperate if they are informed of the study's benefits 	Challenges in recruiting participants

they are often confused during the initial year of the onset of schizophrenia. Particularly, the individual's symptoms have not yet stabilized and they have difficulty receiving program intervention. Previous studies have also reported that people with mental illness in Japan take more than three years from discharge to follow the recovery process¹⁵⁾.

(2) Staging the intervention for the people with schizophrenia and their parents simultaneously may have a negative impact on the study's result.

2) Location, time, methods, implementation, and frequency

There was no modification in this section. However, the following precautions were added to the improved program in response to the advice from J-SUGAR:

(1) Assign the same nurse as the implementer of the improved program each time and work to build a relationship of trust. We set this up because the members expressed that they want to have a

dialogue and do not want others to know about their illness.

(2) Avoid one-sided, lecture-style interventions. Emphasis should be placed on allowing two-way communication between the nurse and the parent through dialogue on an equal footing.

(3) Time allocation and content examination should be conducted based on participants' response and understanding.

(4) The results of the study should be explained in accordance with participants' preferences, as some may not want to know their stress conditions.

Discussion

The present study developed the nursing support program to enhance family resilience in people with schizophrenia. We adopted the concept of PPI and modified the necessary support based on advice from J-SUGAR members. Recently, in Japan, there have been reports of PPI in practice by Yamaguchi et al.¹⁶⁾, a study

by people with mental illness, and a study conducted by a team of researchers and people with mental illness. However, there are still not many reports of such initiatives. In addition, the examination of the program content in the present study reaffirmed the importance of psychoeducation and social skills training for parents. Previously, there have been reports of decline in the rate of relapse and a reduction in the burden on families¹⁷⁾. However, it has been reported that the current situation in Japan is not widespread in psychiatric institutions¹⁸⁾. For the purpose of dissemination of psychoeducation and social skills training, whose effectiveness has been shown in the medical field, the content should take into consideration not only the effects that the medical staff emphasize but also the thoughts of the schizophrenic person receiving the program as well as their families. We discovered two points emphasized by the concerned parties in the content of the nursing support program developed in the present study.

1. Importance of individual interventions

The nursing support program developed in the present study was meant as an individual intervention. Implementation of psychoeducation and social skills training for families of people with schizophrenia includes individual interventions and group therapy, representing a group-based intervention. Álvarez et al. reported that self-help groups encourage members to gain an emotional connection with each other and teach them how to understand and cope with family illness¹⁹⁾. We believe that participation in the improved program with peers from the same position may have similar effects on psychoeducation and social skills training. Population interventions are, therefore, of great importance to people with schizophrenia as well as their parents.

However, members of J-SUGAR advised, “We do not want others to know about our illness.” According to results from the previous study, parents of people with schizophrenia had conflicts due to their own

prejudices and social prejudices at the onset of the disease in the schizophrenic person¹¹⁾. We deduced that parents might experience anxiety and resistance when receiving the program in a group setting. Therefore, we believe that our proposed individualized intervention through the previous nursing support program meets the requirements of J-SUGAR.

Our previous nursing support program targets people with schizophrenia as well as their parents. Family therapy, which emerged from family research on schizophrenia, approaches the family as a whole, particularly focusing on “relationships” among family members to understand family dynamics²⁰⁾. However, following J-SUGAR’s advice, the target of the improved nursing support program was limited to parents.

In the early stages of onset, participation in the program itself was a painful experience for those with schizophrenia. It was also considered that subjecting people with schizophrenia as well as their parents to the program at the same time as the onset of illness was likely to increase the parents’ emotional expression toward the schizophrenic person resulting in confusion. The age of onset of schizophrenia is from adolescence to young adulthood. This is a period when the individual is becoming psychologically independent from their parents but the social interaction skills have not yet fully developed. It is also a time when family members are likely to experience conflict²¹⁾. In addition, it can be assumed that further family conflicts may arise in the early stages of onset, when they have not fully accepted that there is a person with schizophrenia in the family, and do not understand how to deal with the situation. Therefore, it is assumed that J-SUGAR members were very resistant to the idea of targeting people with schizophrenia as well as their parents at the same time.

Furthermore, J-SUGAR members commented, “We do not want our immediate family to see us struggling with the disease.” It is possible that people with schizophrenia and their parents may be unable to talk frankly with each other. Therefore, in the early stages of the disease,

it is important to create an environment in which people with schizophrenia can concentrate on treatment to calm their symptoms. In turn, targeted interventions with the parent may help reduce parents' emotional expression, which may ultimately aid the recovery of the individual with schizophrenia. Therefore, our improved program begins with individual interventions with parents, in which we provide support while confirming their understanding of the disease, and offer social skills training to help them learn appropriate ways to cope with the schizophrenic person in their families. One merit of individual intervention is that it makes it possible to grasp the specific problems and needs of the individual. The various symptoms and family conditions of people with schizophrenia can lead to a variety of events that can be challenging. Therefore, even in terms of finding interventions that meet the needs of parents, it is critical to implement nursing support programs with tailored interventions for parents in the early stages of disease onset. Subsequently, the recovery process of individuals with schizophrenia as well as their parents can be clarified, and the learning effect may be fully realized by incorporating group interventions or interventions that bring individuals with schizophrenia and their parents together. The need for such individual interventions may be influenced by the cultural background of Japan, where prejudice against mental illness persists.

2. Dialogue that enables two-way communication on an equal footing

In the improved nursing support program, the same nurse was assigned each time as the implementer of the program, and we emphasized the importance of building trusting relationships. In addition, to check parents' responses, we incorporated interview time into the program, and implemented the program with two-way communication through dialogue on an equal footing. In Japan, social skills training can only be conducted when two or more experienced workers at an insurance-covered medical institution perform it for medical fees

and multiple professionals are expected to intervene. There are numerous benefits of having program experts with knowledge and experience in charge. However, in the nursing support program for parents dealing with people in the early stages of the onset, it is critical to build trust and create an environment in which the parent can express their feelings and listen to the other person's story.

In his research on doctor-patient communication, Teutsch cites the importance of compassionate and empathetic "two-way communication" ²²⁾. In addition, Katagiri et al. conducted a qualitative analysis of health guidance dialogue between nurses and patients, and reported that sharing knowledge about values and preferences through dialogue leads to building trusting relationships ²³⁾. Therefore, it is important to be aware of two-way communication through dialogue, especially in the early stages of the disease when it is impossible to build a trusting relationship, for nurses and parents who are aware of the actual problems, to work together and solve the problems.

Limitations and challenges of this study

One limitation of the present study is that the effect of the improved nursing support program developed for enhancing family resilience in people with schizophrenia has not been clarified, so it is important to validate this by conducting intervention research in the future. In addition, J-SUGAR members said, "Participating in research makes us feel like we are being used as a guinea pig." In other words, a major challenge pertains to explaining the benefits of research participation.

Conclusion

In the present study, the concept of PPI was incorporated into the nursing support program developed in the previous study, and modifications were made based on advice from J-SUGAR. As a result, the improved nursing support program limited to the target parents was created. The improved program content consisted of

three components: interviews, social skills training, and psychoeducation. The significance of the following was made clear. 1) Individualized intervention while taking into account the complex emotional state of parents dealing with their schizophrenic family members in the early stages of the onset. 2) By limiting participants, we aim to build trust with parents as we implement the improved program. Furthermore, it is also necessary to have two-way communication through dialogue to solve problems through cooperation between nurses and parents who are aware of the actual problems, especially in people in the early stages of the disease, when trust is difficult to establish.

Acknowledgment

We would like to thank the participants of this study and the members of J-SUGAR who gave advice on the content of the previous nursing support program. We would also like to express our deepest gratitude to Kayoko Ohnishi, Junko Katsuragawa, Sawako Miki, and the volunteer staff involved in J-SUGAR's operation for their support and understanding of our study's purpose. This study was part of the Grant-in-Aid for Young Scientists B from 2016 to 2020 (problem number: 16K20787) and the Grant-in-Aid for Scientific Research C from 2020 to 2023 (problem number: 20K10879). There are no conflicts of interest that need to be disclosed.

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