

Research on the process by which parents of children with schizophrenia associate with their experience: From onset to continuing life in community

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Research on the process by which parents of children with schizophrenia associate with their experience: From onset to continuing life in community

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Abstract

This study presents the process of associating with experiences by parents of children with schizophrenia from onset to continuation of life in the community. Semi-structured interviews were conducted among 14 parents of children with schizophrenia. The results were analyzed using Kinoshita's modified grounded theory approach. Based on the results, two categories and 13 concepts were extracted.

When children with schizophrenia experienced onset, their parents 'continued living without consideration as hallucination/delusion.' When the children were diagnosed as having schizophrenia, the parents were shocked by psychosis, and started the process of the [expectation of independence as parents.] This shock was influenced by the parents' prejudice. The parents associated with their experience by 'believing full recovery' of children, and 'tried every possible means to keep pace with others of the same generation' when children showed recovery. They also associated with their experience by 'reprimand' children when children experienced recurrence. The parents repeatedly experienced these two associations and 'were not able to decide what to do to address hallucination/delusion.' However, they were gradually able to 'respect their children' and 'enjoying one's own life apart from the role of a parent' based on the central concept of 'feeling relief from a family association,' and entered the process of the [recognition of the recovery limits.] The parents were able to 'accept a life within the range of the child's ability' by 'accepting the child with schizophrenia,' which led to continuation of the child's life in the community. Associates of 'accepting the child with schizophrenia' and 'accepted a life within the range of the child's ability' were influenced by 'abandoning full recovery.'

However, parents became devoted to 'preparing for the future after the death of parents' for the child as they grew older, and the feeling of 'hoping for independence that they cannot abandon' for the child arose in the parents' mind, causing conflict with 'accepting a life within the range of the child's ability' in the parents' mind.

KEY WORDS

parents of children with schizophrenia , associating process , continuation of life in a community

Introduction

In Japan, social resources for persons with mental disorders were improved by enforcement of the Services and Support for Persons with Disabilities Act in 2006. In 2017, the government of Japan strove to build an integrated community care system for persons with mental disorder, and promoted activities such as strengthening cooperation of healthcare and welfare specialists who are involved in the life transition

in community, providing houses, and training peer supporters. In the treatment of schizophrenia, the number of persons who are remitting is increasing due to advances in medicine and enhancement of psychiatric rehabilitation. For these reasons, it is important for persons with disease to continue their lives in communities. Activities toward deinstitutionalization have progressed. Reportedly, 76.8% of persons with mental disorders who live in communities live with their families. Most of them live with their

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parents¹⁾. Persons with schizophrenia occupy the first place of hospitalized persons by disease classification among mental disorders²⁾. For that reason, most persons with schizophrenia presumably live life in communities with their parents. However, families feel burdens associated with the onset of schizophrenia in family members³⁾. Moreover, hostile, critical, or too emotionally involved associates to persons with schizophrenia arise in family members as the contact time with person increases⁴⁾. These expressed emotions become stressors to persons with schizophrenia and increase the recurrence rate⁵⁾. Based on these observations, nursing care support to families in addition to support of the person is important for persons with schizophrenia to continue life in a community while preventing the recurrence of symptoms.

Many studies of burdens on families and the associates of families to burdens have been reported among studies of families with persons with schizophrenia. It has been reported from studies of family burdens that families are adversely affected by self-accusation, helplessness, economic burdens, troubles in human relationships, deterioration in their own health conditions, loss of their own free time, and so on^{3), 6-8)}. Moreover, reported factors associated with family burdens include factors attributable to family members themselves (age, educational level, and sex) as well as factors attributable to persons with schizophrenia themselves (disease duration, number of times hospitalized, severity of symptoms, presence or absence of suicidal ideation, and the level of need for care.)⁹⁻¹²⁾. Studies of the associates by families of persons with schizophrenia have demonstrated that families associate in four patterns: an integration type, where family members specifically emphasize the life of the persons with schizophrenia and rate their own life as secondary; a self-preservation type, where priority is assigned to the family members' own life; a mutual prosperity type, where they try to protect both the lives of the persons with schizophrenia and of family members; and a helpless type, where no life of any family member is protected¹³⁾. According to those types, families associated positively and actively with intent not to avoid difficulties but to solve problems that arise during life with persons with schizophrenia¹⁴⁾. Families address changes in the family system associated with having a person with schizophrenia in the family through building a relationship with society and the roles and associates of their own¹⁵⁾.

The following have also been reported in studies of the psychology of families with persons with schizophrenia: The acceptance process by families with persons with schizophrenia follows the five stages of shock, denial, confusion, effort for resolution, and acceptance¹⁶⁾. Parents tend to be emotionally involved in the child's state in their early stage of onset, but learn to observe their symptoms and abnormal behaviors by understanding what they feel during these¹⁷⁾. Some differences exist in the acceptance of hospital discharge of persons with schizophrenia by their family members between those who live with them and those who do not¹⁸⁾.

Few studies have specifically examined the continuation of life of people with mental disorders in a community. A study of persons with mental disorders at least three years after hospital discharge demonstrated that they followed the recovery process by which they accepted their current life by assigning importance to their experiences caused by the disease¹⁹⁾. However, there is no report focusing on the continuation of life in the community of persons with schizophrenia with the subjects as their families. It has been an important task in recent years for persons with schizophrenia to continue life in a community. It is important to prevent recurrence in persons with schizophrenia, clarify family associates to continue life in a community, and to consider nursing care support. For that purpose, this study was conducted to clarify the process of associating with experiences by parents of children with schizophrenia from the onset of the condition to the continuation of their life in a community. Those persons with schizophrenia have reached adulthood in the continuation of their life. But this study is examined in the context of the relationship with parents and their children. Therefore, we use the expression of child, or children with schizophrenia.

Methods

1. Study design

Parents associate with their experience with their children having schizophrenia from its onset to the continuation of their life in the community, which is the phenomenon to be clarified in this study, involves direct social interactions between a parents with a child with schizophrenia and another family member, healthcare and welfare experts, fellow members of associations of families confronting similar circumstances, and residents

of local communities. Psychiatric care must also consider nursing care support for children with schizophrenia to continue life in a community. Results of this study are intended for application to practical nursing care support. Results suggest that Kinoshita's modified grounded theory approach²⁰⁾ to emphasize the researcher perspective and to facilitate practical utilization in similar social situations was suitable for this study.

2. Subjects

Subjects were 14 parents of the family association belonging to the 'A' Prefectural Federation of Mental Health and Welfare Party. Subjects participated in actual activities of the association, and they lived together with children with schizophrenia. The children with schizophrenia had been visiting a psychiatry outpatient clinic, continued their life in a community for at least three years since the last discharge from the hospital, and had been attending activities such as employment support facilities, day care, or part-time jobs during the daytime.

3. Survey period

From February 2016 to April 2017.

4. Survey method

Semi-structured interviews lasting about an hour per subject were performed twice in accordance with the interview guidelines prepared by the researcher. The interview contents were recorded using an IC recorder with the consent of the cooperator. In the first interview, a survey was performed in accordance with the interview guidelines. A verbatim transcription was prepared by the second interview. The researcher checked in the second interview if there had been any mistakes in the understanding of the researcher. In addition, the researcher posed additional questions related to matters that were not fully understood in the first interview.

5. Survey details

Questions in the interview included "What have your family members experienced since the onset of schizophrenia in your family? What changes, if any, occurred in your life? Was there any event or person that affected the change?" on condition that the answers be presented in the subject's own words. The researcher did not excessively interrupt the subject and emphasized listening. Additional questions were posed as appropriate for obscure expressions of feelings or experiences in the subject's associates.

6. Analytical method

Verbatim transcriptions were read thoroughly. The analysis emphasis was set as "parents who belong to a family association and participate in activities there, and who live together with children having schizophrenia." The analytical theme was set as "the process of associating with experience by parents of children with schizophrenia from onset to the continuation of life in a community."

Verbatim transcriptions were read repeatedly along with the analysis theme from the viewpoint of the analytical emphasis. Parts related to the analytical theme were extracted. Concepts were formed through interpreting the phenomena. Similar cases and opposite cases were investigated for each concept formed. Relations between concepts and the formation of categories were considered at the point when more than one concept was formed. This procedure was repeated to prepare a resulting diagram showing the relation between concepts and categories.

To ensure the analytical reliability and validity, it was supervised by experts in the Japanese Society of Modified Grounded Theory Approach in the process of analysis. It was also supervised by the organizer of the society and by collaborators. Details of the analysis were modified based on their advice. Theoretical saturation was reached at the point when there was no more new concept or category extracted. At that point, the author inferred that the study phenomena were explained adequately. In addition, we explained our research purpose to president of the family association, and we got introduction of parents who could talk their experiences in detail.

7. Ethical considerations

The study was approved by the Medical Ethics Committee of Kanazawa University before the start of the study (Approval number 655-1, January 21, 2016). The selection of subject candidates was asked to the president of the family association who had communicated well with them.

In advance, subject candidates were given oral and written explanations presenting the study overview, survey methods, benefits and shortcomings, the option of withdrawing consent, that a participant might recall experiences in the interview which might cause mental burdens and measures for that, and methods for personal information protection. Persons who were willing to cooperate in the study were again provided with written

and oral explanations of the overview of the study at a later date. They gave written consent. A place such as a meeting room was secured to conduct the interview according to the request of the subject. The interview was conducted in a private room to ensure privacy protection. Also, at the second interview, we confirmed the mental burden and confirmed the intention of participating in the research again.

Results

1. Summary of subjects (Table 1)

Subjects of the study were 7 fathers and 7 mothers aged 67.9 ± 7.2 years (mean \pm standard deviation). Children with schizophrenia were 11 men and 3 women aged 39.6 ± 6.3 years on average. The duration from onset was 20.3 ± 5.6 years. The mean duration of the continuation of life in a community was 13.6 ± 6.2 years.

The mean time of two interviews was 1 hour and 47 min \pm 25.7 min.

2. Process of associating with experiences by parents of children with schizophrenia from onset to the continuation of life in a community

As a result of analysis, two categories and 13 concepts were extracted as associates processes to parents of children with schizophrenia from onset to the continuation of life in a community. Hereinafter, categories are shown in [], concepts in ' ', and the talk of a subject in italic in " ". Details were supplemented in () where the meaning of the talk of a subject was obscure. Relations between concepts and categories are shown in the result diagram (Fig. 1).

The process of associating by parents consisted of two categories of [expectations of independence as parents]

and the [recognition of the recovery limits].

When children with schizophrenia experienced onset, their parents 'continued living without consideration as hallucination/delusion.' When the children were diagnosed as having schizophrenia, the parents were shocked by psychosis, and started the process of the [expectation of independence as parents.] This shock was influenced by the parents' prejudice. The parents associated with their experience by 'believing full recovery' of children, and 'tried every possible means to keep pace with others of the same generation' when children showed recovery. They also associated with their experience by 'reprimand' children when children experienced recurrence. The parents repeatedly experienced these two associations and 'were not able to decide what to do to address hallucination/delusion.' However, they were gradually able to 'respect their children' and 'enjoying one's own life apart from the role of a parent' based on the central concept of 'feeling relief from a family association,' and entered the process of the [recognition of the recovery limits.] The parents were able to 'accept a life within the range of the child's ability' by 'accepting the child with schizophrenia,' which led to continuation of the child's life in the community. Associates of 'accepting the child with schizophrenia' and 'accepted a life within the range of the child's ability' were influenced by 'abandoning full recovery.'

However, although parents 'accepted a life within the range of the child's ability,' they were devoted to 'preparing for the future after the death of parents' for the child as they grew older. During this association, the feeling of 'hoping for independence that they cannot abandon' for the child arose in the parents' mind. Consequently,

Table 1. Summary of subjects

Subject	Age (decade)	Relationship	Child's sex Male/Famale	Child's age (decade)	Duration from onset	Duration of stay at home (year)	Total time of interviews
A	60	Mother	Male	30	15years	15	1hrs45min
B	70	Father	Male	40	25years	13	1hrs42min
C	70	Mother	Famale	30	18years	18	2hrs19min
D	70	Father	Male	30	21years and 3months	5	1hrs48min
E	50	Father	Male	30	20years	5	1hrs22min
F	60	Father	Male	30	17years and 6months	16	2hrs24min
G	70	Father	Male	50	30years	29	1hrs28min
H	60	Mother	Male	40	16years	16	1hrs08min
I	60	Father	Famale	30	17years and 6months	10	1hrs43min
J	70	Father	Male	40	24years	18	2hrs43min
K	70	Mother	Famale	50	30years	15	1hrs40min
L	60	Mother	Male	30	10years	9	1hrs34min
M	60	Mother	Male	40	21years and 8months	8	1hrs51min
N	60	Mother	Male	40	18years	14	1hrs29min
Mean \pm SD	67.9 \pm 7.2			39.6 \pm 6.3	20.3 \pm 5.6	13.6 \pm 6.2	1hrs 47min \pm 25.7min

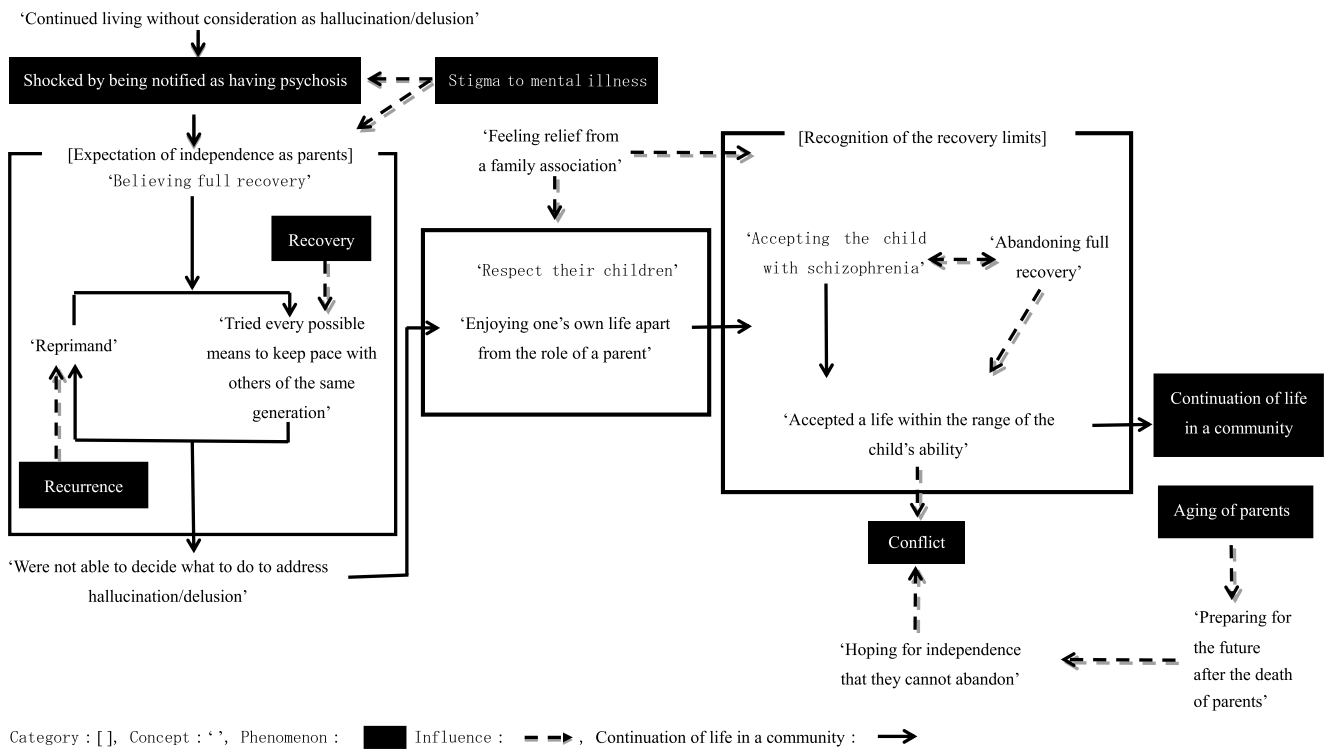


Figure 1. Process of associating with experiences by parents of children with schizophrenia from onset to the continuation of life in a community

'hoping for independence that they cannot abandon' and 'accepted a life within the range of the child's ability' exist simultaneously in the parents' mind, leading to conflict in the parents' mind.

3. Component concepts in the [expectation of independence as parents]

In the process of the [expectation of independence as parents], parents were deeply shocked by the reality that their children had psychosis when the children were diagnosed as having schizophrenia. As an associate to the impact, the parents believed that the disease would be cured, and 'believing full recovery' to stabilize their own mind.

"Right when we first came here, the doctor told us the name of the disease. Then he told us it's a disease and my child will get better all right. But it's not a disease that would not heal. There are medicines sure enough. And he said that there are kinds of medicines, and it might not sound proper but we can try and see which medicine fits my child and therefore, you know, my feelings too. That is how I understood it." (C.)

"Because there was this leaflet that said many people get better after 10 years without taking medicines, and

seventy to eighty percent can live independently if they are treated properly. Well, I thought this would be about 10 years. I thought my child ought to get well again." (J.)

Then, parents who believed in full recovery 'tried every possible means to keep pace with others of the same generation' so that children could somehow return to their life before the onset of schizophrenia when recovery was visible in them by receiving medical care.

"First, I thought it would be for about a few months; and I wanted my child to graduate from high school (from which my child had been absent because of the onset.) When I talked a little with my friends, and when I asked if they could do something so that my child could graduate, well no, they could not. So my child managed to go to a part-time high school. So well. I'm worried. I compare other children and (my child) , and (other children) go to university, or work. I had my child go to a vocational school in front of the station, but my child can't keep up." (D.)

Parents also were deeply disappointed when they experienced their child's bad conditions or readmission to hospital, although they believed in the full recovery of their children and had tried everything to achieve it.

Nevertheless, parents encouraged themselves somehow and had no doubt about full recovery. They continued to hope for full recovery by 'reprimand' their children.

"My husband, as if he rejects it, well, he loses his temper when (my child) has an episode, and says, "You have to do this!" When (my husband) comes home from work, he tries every day to have (my child) exercise, telling him to go walk for 30 min, do gymnastics, and you know, making lists of many things." (H.)

"I have high expectations after all. I have them for myself. My expectations are too high, and I have forced them on my children. Naturally, I have expectations as a parent, and I feel that they should too. I do not let them do things I don't approve of, and I cannot help but force those values on my children." (L.)

4. Component concepts in the [recognition of the recovery limits]

1) Accepting the reality of having to give up full recovery

Parents 'were not able to decide what to do to address hallucinations and delusions' about how their children could achieve recovery they had hoped for through experiencing deterioration and recurrence in their children many times.

"It was with great caution. I was beside myself every day. I was watching over my child, and wondering, what can I do if anything should happen? How can I go on?" (L.)

"My child was in a state like she had become well but not yet well. Somehow she was suddenly all violent or selfish, and I thought she became like some person did not know herself. She became violent when she felt desperate. Things like that happened all the time." (N.)

Then, parents understood unwillingly that there was no other course than to 'abandon full recovery' because their children showed no recovery in a way that parents had hoped, no matter how much time passed.

"Well, it's because, to put in extreme terms, parents understand what state our children are in now. So it is completely different from the image I had about my child before the onset. My perspective is reasonable, I think." (B.)

"How many years have passed? I do not say that it cannot be helped anymore, but, I guess I've made him my dependent and I've arranged services and support for persons with disabilities for him. I suppose I have to accept his disease. The words 'persons with disabilities' do

not sound good. I am not trying to say I don't like it, but I feel he is becoming like that." (H.)

2) Acquisition of new associates through connection to the family association

Parents were able to 'feel relief from a family association' by joining a family association and knowing more about the difficult experiences of others and those whose child's recovery did not progress as much as they had hoped.

"Well, when I heard them say, well everyone (in the family association) and other parents (and children with schizophrenia) only think of their own experience with the disease, it was as if something that I had been stuck in was suddenly gone. It was like I could speak more all of a sudden. They understood my feelings, and I came to understand theirs." (N.)

Then, because parents could 'feel relief from a family association,' they found knowledge related to the disease affecting their children and associates practiced by other parents in the place of the family association, and 'accepting the child with schizophrenia.'

"My family, you see, although the burden is heavy, well the disease is no more or no less than that. You feel you give up after all, or you feel you have to carry it. You have to go on living from that point on." (L.)

"I do not have my child hospitalized any more. I used to have her hospitalized when she was worse. I'm getting familiar with associates by the family, and I can watch over her quietly by her side. I used to interfere in everything before because I did not know, and it might not be good for her sometimes. I can watch her until it is over." (K.)

Parents also understood the need to direct their attention to the thinking of their children themselves. They associated with their experience by 'respect their children.'

"My father would not listen to me after all. I think he had a feeling like that. But, maybe it would be better if I just listen. It's just I listen to the mind (of my child.) I say nothing. From me." (F.)

"It's like a consultation counter, maybe my wife was taught that she had to be kind to our son because he was like this because of the disease, after she went there with our son, she talks to him very much, and consults with him. She does not neglect him. She builds a parent-child relationship anyway. Then she puts things right." (G.)

Moreover, parents became conscious that they needed

to have a satisfying life themselves while carrying out the parent role as a family member simultaneously. They acquired the associate of 'enjoying one's own life apart from the role of a parent.'

"Because, hey, I have my own life, and my life will become chaotic if I keep on feeling depressed about my son forever. In that sense, now I can think reasonably, you know, that my child is one thing, and my own self is another." (B.)

Then parents 'accepted a life within the range of the child's ability' by acquiring new associates. This led to continuation of the life of children in the community.

"I set the scale one year ago. Now my child is so much better than at the point of hospital discharge. All the staff here (employment support facility) say so too. You can't see (recovery) on a scale of half a year or one month." (K.)

"I'm glad that my child is becoming better little by little. The doctor said she would not recover anymore, really. And that's right, but I do not think she is completely cured because there were times when she was being absent-minded or something, though she was working. Even so, I think it's sufficient if the present conditions hold." (M.)

3) Feelings that arise from preparing for the future life of children

After the continuation of the life of children in community, parents came to understand that there would be a limit in the present life of children that was supported by parents, and began 'preparing for the future after the death of parents' for the child' by building relationships with healthcare, welfare experts and children's neighbors.

"I think it would be better for my child if he could go on home with the support of, say, various services such as home nursing; you know, home helpers. He must also be stronger while we parents are well." (D.)

"People have their own patterns of social relations, but it's not something you should fuss over. I believe everyone in the neighborhood cares. No one in the city is like that. When (my child) just passes by, she only has (to) greet them. Then, when she greets them and passes by without realizing it, they will think, who's that girl? Then, they will help her in case of emergency. I hope she can feel that." (I.)

During that time, parents were anxious about the life of children at some later date when they can no longer support their life, 'hoping for independence that they cannot abandon.' However, they also understood properly

that 'accepted a life within the range of the child's ability' which was the associate they were taking now, was important, remembering their experiences since onset in children. Because of this, parents suffered a conflict between the 'hoping for independence that they cannot abandon' associate and the 'accepted a life within the range of the child's ability' associate.

"It's no help to be always angry about my child that he is far from supporting his parents but is still supported by his parents. We have built our house on our own, and things like that. You know, my child is now older than my age that time, but he does nothing of that kind. It's a little annoying sometimes." (E.)

Discussion

1. Promotion of understanding of schizophrenia

Parents noticed that the change in their children had been different from before on the occasion of their violent language and incomprehensible complaints at the time of onset. However, they did not recognize the changes as symptoms caused by disease, and continued living. Kawazoe²¹⁾ reported that the mothers of children with schizophrenia were optimistic about the situation during the stage with no insight immediately after onset that their children would recover to normal as before. The present study produced results similar to those obtained by Kawazoe.

The susceptible age for schizophrenia is puberty to adolescence. All children of the subjects of the present study had onset of schizophrenia from their late teens to early twenties. In general, puberty is in the second period of rebelliousness when children are beginning to be independent from their parents, although they also have immaturity, resulting in the appearance of unbalanced behaviors²²⁾. Adolescence is the period during which children suffer conflicts because they have to become physically and mentally independent from their parents and live as a member of society²²⁾. For that reason, it is considered that the parents who were examined in this study considered the changes in their children as a growing process specific to these periods. Then they watched over their children and continued living. Also, in schizophrenia, there is a characteristic that it is normal development until onset and difficult to see a change in appearance due to onset. From this also, parents did not grasp the change of the child as a disease, and watched

over their children. Parents were shocked when notified of the psychosis when physician gave the diagnosis of schizophrenia. This impact was affected by stigma to mental illness. However, they also understood that their children were ill and had earnest hopes for a full recovery. They therefore experienced disappointment themselves when their children exhibited repeated recovery and recurrence but showed not as much recovery as they had hoped.

From the points described above, the parents' understanding that the child was ill and was expected to show a full recovery is regarded as an associate of their own way to mitigate the shock by being notified about the disease of their children as psychosis. Iwasaki⁷⁾ reported that the families of children with schizophrenia suffer self-accusation: "Why didn't we notice unusual changes in our son or daughter?" and "Our son or daughter could have been better if they had visited a hospital earlier." Parents who suffer such self-accusation association to self-accusation felt as parents by hoping for the full recovery of their children because of the belief that children would fully recover and because they responsibility as parents that they would have to make their children fully recover.

Based on these points described above, it is necessary for nurses to provide support to mitigate parents' self-accusation, along with support to promote the understanding of schizophrenia while supporting hopes for a full recovery, which is the associate in the parents' own way. For that purpose, it is important for nurses to build relationships with the children with schizophrenia and their parents at the point when medical care is provided to children. It is important for nurses to check the acceptance of the disease by parents that is associated with onset in children continuously, as well as the parents' associate. Above all, nurses must listen to parents' hardships and accept the associate in the parents' own way. Moreover, it is important to promote understanding using individual interviews, psychoeducation in groups, and programs such as SST while keeping pace with acceptance of the disease by parents: schizophrenia is a chronic disease for which the persons must continue their life while repeatedly experiencing recovery and recurrence.

2. Parents' contradictory associates: expectations of independence and acceptance of children with schizophrenia

Parents abandoned hopes for full recovery of their

children and accepted their schizophrenia, which led to continuation of the life of children in a community. However, when parents grew older and began to understand that there were limits for parents to support their child's life, hope for their child's independence that they could not abandon arose in their mind. Parents were affected by conflict between these two feelings.

Fujino et al.³⁾ reported that the core of the anguish felt by families with children with schizophrenia is anxiety about the child's future after the death of the parents. That result mirrors those of the present study, which showed that parents grew anxious about the child's future as parents themselves grew older. Parents wish their children to lead an independent life. They cannot abandon hope for their independence when they think of their end, leaving their children behind. However, as a result of trial and error in associating for a long time, it is considered that parents understand that it will engender the deterioration of symptoms in children if they have expectations for children and take a reprimand associate. A conflict occurs for that reason between the two feelings of the hope that they cannot abandon and the acceptance of their children.

Based on these results, nursing care support is important to help parents accept appropriate expectations for their children and to support the feelings of parents who must continue living while accepting their children with schizophrenia. Recently, family resilience²³⁾ has been attracting attention, where families as groups repeat changes and growth constantly as a functional system through relations with and help from surroundings. One study by Nakahira et al.¹⁵⁾ demonstrated details of the power of families among studies of families with persons with mental disorders in Japan.

Nurses must provide support during hospitalization and outpatient visits of children such that they sympathize with their parents' expectations while they help parents to be aware of their and their children's abilities that enable them to overcome hardship in continuing life in a community to date. For that purpose, it will be effective as support to report those changes in children and to teach them techniques that make them capable of cognitive reinterpretation so that they can positively interpret events with their children. It is also necessary to recognize the efforts of the associates taken by parents to date, and to accept their feelings so that parents themselves can be

aware of their own abilities.

3. Nursing care support to support the continuation of the child's life in the community

As revealed by this study, parents gave up on the recovery of children and accepted life within the range of the child's ability, which led to the continuation of the life of children in the community. Peer support at the family association also strongly affected the process of accepting the life of children. However, parents felt anxious about times when they would no longer be able to support the child's life because they would grow older even though they had once accepted the child's life. This anxiety suggests the necessity of organizing a system to provide social support for children with schizophrenia and their parents. Such a system would introduce parents to peer support such as family associations and would introduce children to necessary social resources at the point when medical care is provided to children, to support the continuation of the life of children in a community.

Research limitations and future tasks

This study is a survey of parents belonging to family associations in 'A' prefecture. It is also necessary to

consider the possibility that the analysis results are biased because it cannot be denied that the subjects are parents who are highly conscious of the child's recovery in the first place. After all, all parent subjects belong to family associations.

In addition to consideration of nursing care support, future studies must apply the survey continuously with parents other than those belonging to family associations and with family members other than parents.

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統合失調症の子をもつ親の経験：発症から地域生活継続に至るまで 親はその経験といかに付き合っていたのか

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要 旨

子が統合失調症の発症から地域での生活を継続していくまでに、その親はそれらの経験とどう付き合っていたかのプロセスを明らかにした。統合失調症の子をもつ親14名を対象として、半構造化面接を実施し、木下の修正版グランデッド・セオリー・アプローチを用いて分析した。結果、2つのカテゴリー、13の概念を抽出した。

子の発症当時の親は、子の症状を「幻覚・妄想と捉えず生活を継続」していた。子が診断を受けることで親は精神疾患への衝撃を受け、【親としての自立への期待】のプロセスに入っていた。この衝撃には、親自身の偏見が影響していた。親は、子の「完治を信じる」ことを行い、子の回復が見られると「同世代と足並みを揃えるために手を尽くす」ことを行っていた。また、子が再発を経験すると「叱咤激励する」ことを行っていた。この二つを幾度も経験することで親は「幻覚・妄想への対応に迷走」していた。しかし、「家族会から安心を得る」ことをコアの概念として、「子を尊重する」ことや「自分の人生を楽しむ」ことができるようになり、【回復の限界の認識】のプロセスに入っていた。親は、「統合失調症の子を受容する」ことで「子のできる範囲の生活を受け入れる」ことができ、子の地域での生活継続に至っていた。「統合失調症の子を受容する」と「子のできる範囲の生活を受け入れる」ことには、「完治を諦める」ことが影響していた。その一方で、年齢を重ねるにつれ、子の「親亡き将来の準備をする」ことに力を注ぐようになり、子の「自立への捨てきれない望みを抱く」思いが沸き上がり、「子のできる範囲の生活を受け入れる」こととの間で、心の葛藤を生んでいた。

別刷請求先

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