

# Female Families' Experiences of Caring for Persons With Schizophrenia

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The caring experiences of female families of persons with schizophrenia were described through exploring the families' descriptions of their experiences. Focus group interviews were conducted with 11 family caregivers. According to content analysis, the experiences revealed five major themes: early family experiences, family perceptions of illness and relatives with schizophrenia, family burden and suffering, family attitudes toward relatives with schizophrenia, and family thoughts about society and mental health resources. Also, the families had strength to overcome considerable adversity. It is needed for professionals to listen to family caregivers' narratives carefully and improve the support by focusing on accepting their experiences and histories with persons with schizophrenia.

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**I**N JAPAN, 1 out of 40, or 3,233,000 people consult a medical institution due to mental illness, of which 333,000 and 2,900,000 receive inpatient and outpatient treatment (Cabinet Office, 2012a). The mean duration of hospitalization in 2010 was 301 days (Ministry of Health, Labour and Welfare, 2011), and the number of psychiatric hospitals in 2010 was 1671 (Cabinet Office, 2012a).

According to the vision of reform of mental health and welfare proclaimed by the Ministry of Health, Labour and Welfare in 2004, the concept of "a transition from hospital-based treatment to community-based care" has been promoted. In this vision, "a change of nation awareness" was raised as an important issue. The Services and Supports for Persons with Disabilities Act was established in 2005 to provide support for community-based patients with mental illness. In 2011, mental disorders were added to so-called "national diseases" like cancer, stroke, acute myocardial infarction and diabetes. These diseases are a main target, and thus the circumstances surrounding people with mental illness and their families have markedly changed. Nowadays, the

discharge of both new and long-term inpatients has been promoted. Therefore, it is believed that the number of individuals with mental illness living in the community will increase, thus having

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a major impact on their families, especially female primary caregivers.

A 2007 study on community-based mental illness established that 76.8% of patients with mental disorders lived with their family, whereas 17.9% lived alone (Cabinet Office, 2012a). Historically, families have been regarded as caretakers for persons with mental illness and have been responsible for protecting them for long periods. Although long since abolished, the Mental Patient Custody Act of 1900 forced families to take custody of and protect persons with mental illness. The Mental Hygiene Act in 1950 claimed that a person with mental illness staying at home should be recognized as someone requiring medical treatment. The Mental Health and Welfare Act of 1995 intended to reduce the burden of families, and with revision of the act, the duties of caretakers were reduced, although the expectation of family caretakers has been maintained. The act defines a caretaker as a person who cooperates with the patient's medical care and protects the patient's assets and upon whose agreement is dependant for involuntary hospitalization.

Schizophrenia is one of the most serious diseases for the afflicted individual, the family of the patient and society at large, and this disorder affects 1% of the population worldwide (Minzenberg, Yoon, & Carter, 2011). As for psychiatric research on families, researchers have examined the difficulties and burdens of families of persons with schizophrenia (Awad & Voruganti, 2008; Gutiérrez-Maldonado, Caqueo-Urizar, & Kavanagh, 2005; Ramirez Garcia, Hernandez, & Dorian, 2009; Rose, Mallinson, & Gerson, 2006). Saunders (2003) reported in a literature review of families of persons with schizophrenia that severe mental illness brought sustained burden and psychological distress on caregivers, and patient's behavioral problems influenced accomplishments of family roles. In addition, there are studies on the experiences of caregivers of persons with schizophrenia, including aging parents' burden and unfulfilled needs for services (Smith, 2003), parents tend to blame themselves (Ferriter & Huband, 2003), the burden of the spouse as a result of the illness, and specific attitudes of the spouse (Jungbauer, Wittmund, Dietrich, & Angermeyer, 2004; Mizuno, Iwasaki, & Sakai, 2011), experiences and disadvantages of social discrimination (Angermeyer, Schulze, & Dietrich, 2003), and

experiences within the cultural context (Huang, Hung, Sun, Lin, & Chen, 2009). The studies describing experiences of families of persons with schizophrenia have been conducted in Japan (Fujino, Yamaguchi, & Okamura, 2009; Kagawa, Koshida, & Ohnishi, 2009; Kawazoe, 2007), but there lacks sufficient evidence of families' subjective views on their caregiving to identify effective family nursing intervention. The purpose of this study was to explore the caregiving experiences of female family caregivers of persons with schizophrenia through focus group interviews. The outcomes of this study may be a valuable reference for community mental health professionals seeking to develop a nursing approach for families.

## METHODS

### Subjects and Procedure

The participants of this study were recruited from two local family associations of persons with mental illness, and all participants had been members of the family associations for several years, and thus were acquainted with each other. Family association A consisted of 23 members (2 males, 21 females), whereas family association B consisted of 28 (4 males, 24 females). Within these associations, the members who agreed to take part in this study were seven (30.4%), and four (14.3%), respectively. Almost all the same members regularly attended meetings: association A had seven to eight members and association B had five to six members. First, the study protocol was explained to the families at the regular meeting of each family association, and then the date and time when the largest possible number of families could participate in the focus group interviews were decided.

The study used a descriptive exploratory design utilizing a focus group. Focus groups are considered a way to better understand how people from a homogeneous groups in a social interaction really feel or think about an issue (Krueger & Casey, 2000). Focus groups provide participants a safe environment to share experiences, ideas and beliefs, and express feelings. The familiar atmosphere facilitates narrating difficult or unpleasant topics. Compared with individual interviews, focus groups reduce the strain between the subjects and researcher, and the group dynamics stimulate thinking. The objective of this study was to explore families' experiences of persons with schizophrenia, towards

which the general public still has prejudice. Therefore, focus groups were chosen as the appropriate method to collect qualitative data. In the beginning of the focus group interview, written consent was obtained from the participants, and they were promised that their personal information would be strictly confidential. The focus group interviews were recorded using an IC device with the families' consent. The study was conducted with the approval of the University of Yamanashi faculty ethics committee.

### Data Collection and Analysis

A total of 11 families participated in one of the two focus groups, and these groups were conducted in the meeting room of each family association institution. Group A consisted of seven families, and group B consisted of four families, and the length of the group interviews was 165 and 126 minutes respectively. Focus group interviews were conducted using an interview guide (Table 1). Prior to the interviews, the authors reviewed the current literature related to the study theme, discussed the results, and created an interview guide. The interview guide included (a) symptoms and daily activities of the relatives with schizophrenia, (b) emotional responses to relatives with schizophrenia, relationship issues and coping ability, and (c) feelings toward schizophrenia and viewpoints from the public. The group moderator was an author who had expertise and experience in group intervention such as psychoeducation. Also, a co-author took on a supporting role. Around a table, we tried to create an atmosphere which facilitated conversation, and monitored the session so that the opinion of a particular family did not restrain the opinion of other families.

The focus group interviews were transcribed verbatim, and content analysis was carried out.

**Table 1. Focus Group Interview Guide.**

Please introduce yourself
1. Please tell us the symptoms and daily activities of your relatives with schizophrenia. How do you cope with issues/troubles in daily life?
2. How do you feel about your relatives with schizophrenia?
3. How do you feel about schizophrenia or mental illness in society?
4. What kind of influence do relatives with schizophrenia have on you and other family members?
5. What do you demand for professionals and/or psychiatric settings?

Each author repeatedly reviewed the interview transcripts, focusing on the feelings and thoughts of the families. Then, the authors independently summarized the descriptions of their experiences into brief expressions for each group, paying careful attention to the context, and grouped similar brief expressions into sub-themes. These sub-themes were then compounded into major themes, and repeated analyses of similarities and differences were conducted through the discussions by the authors. When no new themes emerged, we judged that data saturation had occurred. Moreover, the authors compared and contrasted themes to maintain coherence and reliability of the analysis.

Table 2 indicates the demographic characteristics of both the families and the persons with schizophrenia. All family caregivers were women, and were made up of eight mothers, one sister-in-law, one older sister, two younger sisters and two wives. Three of the 11 families had two relatives with schizophrenia. The mean age of the family caregivers was 65.1 years (SD=13.6), ranging from 37 to 76 years. Five of them were employed, and nine of them lived with the patients. The mean age of the persons with schizophrenia was 47.2 years (SD=14.3), ranging from 27 to 84 years, and the mean duration of illness was 23.6 years (SD=13.9), ranging from 10 to 61 years. All of them were receiving antipsychotic medication, seven of them were using day service centers and five belonged to work training institutions.

## RESULTS

Through analysis of the 11 families' transcripts, the families' experiences revealed five major themes. Italics indicate each sub-category within the theme.

### Theme 1—Early Family Experiences

#### *Courage to Consult a Professional and the Impact of Initial Admission*

Some families consulted a physician immediately upon noticing that their family members might have contracted a mental illness, while it took a long time for others to do so: "Although I had long felt that something was wrong with my son, I did not have enough courage to take him to a psychiatric clinic at once. We visited a hospital 6 months later." Families preferred a hospital located far from their

**Table 2. Demographic Characteristics of Families and Patients.**

Family caregiver's age	Relation to patient	Living with patient	Patient's age	Patient's gender	Duration of illness in years
68	Parent, Sister-in-law	With, With	27,62	Male, Female	10, 36
75	Parent	With	45	Female	26
71	Parent	With	47	Male	30
41	Sibling	With	39	Male	10
73	Parent	With	50	Male	29
71	Parent	With	43	Male	13
60	Parent, Spouse	Apart, With	37,62	Female, Male	17, 27
37	Sibling, Spouse	Apart, With	41,36	Female, Male	20, 10
76	Parent	With	49	Male	29
70	Parent	With	38	Male	13
74	Sibling	Apart	84	Male	61

home to one in the neighborhood because they did not want their neighbors to know about the patients.

At the time of hospital admission, families went through one of the most painful experiences in their lives: “When the heavy door to the ward was shut, my daughter cried out with all her might, ‘Mom’. The voice still remains in my head”; “After I left my son at the hospital, I suffered unbearable emotional pain. I imagined the picture of my son beyond the door, and felt like crying with a sense of guilt.”

#### *Reactions to Diagnosis of Schizophrenia*

All families were very surprised and shocked when the disease was diagnosed as schizophrenia. They could not understand the name of the illness or detailed explanations provided by psychiatrists: “At first, when the psychiatrist explained the illness to me, I could not make sense of it. However, I began to realize that my younger brother had schizophrenia because he had presented with many of the symptoms that the psychiatrist described.” Mothers could not accept the fact, thinking to themselves, “It is so unreasonable. Why my child?” For families, “the start was full of questions”, and “there was no information on what services were available to families.”

#### *Incomprehensible Symptoms and Abrupt Behavioral Changes*

Families did not know that their strange remarks and actions were attributed to psychiatric symptoms: “One evening, my son stared at the ceiling and said, ‘Let’s talk in a lower voice. Someone is eavesdropping on our conversation’. I said to him, ‘There is no one up there. You are just imaging things’” ; “I thought that he was just being lazy because he moved slowly and was unable to decide

anything by himself”; “My daughter was crawling around the floor like a fox. Just remembering it still frightens me.” A sibling could hardly rest or feel comfortable at home because her sister was very violent and hurled abusive remarks all the time: “My older sister was shy and quiet originally. But she changed completely. She often yelled, ‘I got fired from the company because of that woman’, hit her mother, and kicked the doors. I almost always felt restless in such a boisterous environment.”

#### *Confusion and Reticence With Discharged Relatives*

All families became confused and felt anxious when patients were discharged. A family was reluctant to accept patients in fear that their normal daily lives might be disturbed: “When my older sister was discharged to our home, our family became very confused, not knowing what to do. Our families’ mental states became increasingly unstable, and she was readmitted to hospital three months later.”

#### **Theme 2—Family Perceptions of Illness and Relatives With Schizophrenia**

##### *Inability to Comprehend Illness Over Time*

Families had gradually acquired knowledge and information on the illness. However, after more than 10 years from the onset, schizophrenia was still a strange disease to the families: “At first glance, my son did not look ill. The disease is very confusing and strange.” As for the cause of the illness, the following opinions were expressed: “Although it is controversial, I think that a lack of parental affection and child-rearing by mothers could be a cause”; “My son has been mentally

vulnerable since childhood.” Only siblings cited child-rearing by parents as a cause.

#### *Cling to Hope For Improvement*

Families felt sorry for the lives of the patients. However, families were hoping that patients' lives might improve over time: “I feel very sorry for my son because he will have to cope with the illness throughout his life. Although I do not expect him to be employed, I am still hoping that his life will take a turn for the better when he gets older.”

#### *Strong and Weak Points of Relatives With Schizophrenia*

As for the characteristics of patients, families commented as follows: “They cannot think flexibly, and are obsessed with or stick to something”; “This summer, my mother came down with an illness. I had to provide my younger brother with specific instructions. For example, ‘Prepare an ice pack because mother has a cold and fever’, and ‘Make a telephone call to the hospital and ask for a home visit by a physician’. He is insensitive to family problems.” On the other hand, there were comments on the strong points of patients: “When I was admitted to a hospital for treatment of the thyroid gland, my son said to me, ‘You should have consulted a physician earlier. You don’t want to die, do you?’ Although he was only able to express himself with rude language, he was worried about me in his heart.”

#### *Attitudes Toward Marriage of Relatives With Schizophrenia*

All families except one with an older brother with schizophrenia were against the idea of patients' marriage: “How can my son provide for his family when he cannot support himself” and “My younger brother who has no job is too optimistic and dreams of getting married.” However, families knew that they should not oppose patients' marriage just because they have a mental illness, and felt conflicted: “They have the right to marry someone regardless of whether they have a mental illness or not. I feel sorry that they are not allowed to get married because of the illness. However, in reality, I have no choice but to discourage them.”

### Theme 3—Family Burden and Suffering

#### *Hidden Physical and Psychological Effects*

Families experienced physical problems and psychological stress: “I feel pain in the joints of my feet”; “I have been taking medicine for hypertension for the past 10 years”; “I become frustrated living with the patient because he cannot think or act flexibly. Just seeing his behavior makes me irritated.” However, they did not know that they were under intense stress, and could not view their own lives in an objective manner: “I am not really sure that I have hypertension just because I feel stressed out in daily life”; “Strangely, I do not feel tired in recent years. Maybe I have got used to it after many long years of hard work, or I just cannot feel fatigue.”

#### *Worry About the Future and Anxieties From Misinformation About Schizophrenia*

Families worried about the future of patients: “Will the patient be able to live alone after his parents die?”; “Who knows how many more years my parents can take care of my older sister? If my parents came down with an illness or die suddenly, her condition might worsen. We sometimes hold family meetings to discuss how she should live on her own.” Mothers were worried that siblings hesitated to marry or give birth: “My son (sibling of patient) does not seem to think about marrying. He said, ‘I will take care of my younger sister (patient).’ My husband also has a mental illness, and I am worried that my son is very determined to take care of both his sister and father. I want my son to get married. It is my only dream”; “Recently, I discovered that my daughter (sibling of patient) will not have children. She said, ‘It is not because of you, mother.’ However, I am sure that she hesitates to have children because both her younger brother and aunt have schizophrenia.” A sibling who participated in this study had to give up on marriage because of a person with mental illness in her family: “Once I had to give up marrying a man. When I talked to his parents about my sister’s illness, they immediately opposed our marriage, saying ‘You will sully the purity of our blood.’ Generally, people believe that a psychiatric illness is inherited and transmitted and brings disgrace to a family.”

*Grudges Against Relatives With Schizophrenia*

Families had been conflicted for a long period of time: “I do not know how many times I have wished to die. Like other families, I thought that I would have been better off if I had died” and “My older brother almost died of pneumonia, but he survived. I angrily said to the physician, ‘Why did you save his life? You should have let him die.’ I feel sorry for my brother about his illness. Nevertheless, I had wished for a long time that someone would kill my brother or he would disappear.”

**Theme 4—Family Attitudes Toward Relatives With Schizophrenia***Educational Approach for Relatives With Schizophrenia*

Mothers wanted patients to learn a minimal level of interpersonal communication skills and social norms: “I encourage my daughter to do household chores, respond to visitors, and answer the phone as much as possible so that she will take interest in people and things surrounding her and become more considerate. That is my responsibility as a parent.” Basically, they were careful to be patient and generous: “Once the patient has learned something, I then expect him to learn more, go further, and do things better and faster. However, this makes patients with schizophrenia feel stressed out. It is important to be patient and observe their progress little by little, as if raising a baby”; “When teaching the patient what is right and wrong, there is a need to interact with him in the same manner as with healthy persons. Families should be determined to do everything they can to persuade him to stop breaking rules.”

*Evolution of Attitudes Toward the Illness and Relatives With Schizophrenia*

As families gradually understood the illness, the way they interacted with patients changed over time: “It took me 20 years to start asking for support and help in the family instead of struggling with problems alone”; “Participation in this family association by talking with other families helped me organize my thoughts and feel refreshed; I could restart”; “There is no end to this issue. We have to continue to learn about the illness and mental health care.” A mother said half-jokingly, “I was destined

to take care of my son with schizophrenia. Thinking that way makes me feel better.”

There were changes in the psychological and physical distance between patients and their families: “I used to feel as if I were being whirled in a washing machine. I was swayed by the condition of his illness and could not maintain emotional balance because I did not keep an appropriate distance from the patient. Now I feel much better”; “We were required to carefully observe my brother all day, and our lives revolved around him. Eventually, all of us became exhausted, and realized that we should have maintained a certain distance from him. This approach worked, and our family, including my brother, started to feel at ease.” Families maintained an appropriate distance, both physically and psychologically, from patients.

**Theme 5—Family Thoughts About Society and Mental Health Resources***Influences of Prejudice in the Public Sphere*

A strong prejudice against psychiatric illness still exists, and all families, including those who had disclosed that their family member had a schizophrenia, worried about the public eye: “If people in the community encounter something they cannot make sense of, they keep away from it or pretend they don’t see it.” A family with two persons with schizophrenia moved to another place because they caused trouble to people surrounding them: “My husband verbally abused and frightened neighbors. When my daughter was also diagnosed with schizophrenia, I decided to leave here and move to a quiet place along with my family.” Families did not completely disclose that there was a person with schizophrenia in the family. A mother hesitantly said, “I hate to say this, but I do not want people to see me visit an organization for the families of psychiatric patients.”

*Difficulty in Connecting With Other Family Caregivers*

There were families who narrated the feelings of other families: “We cannot easily invite other families to join our family association. Even if I think that this family has a person with schizophrenia, I do not know how to invite the family or what to say”; “It is difficult to enroll new members

in the association because people do not want others to know that their family member has a mental illness.”

#### *Attitudes Toward Psychiatrists and the Public System*

Families wanted the attending psychiatrist to be clear and unambiguous about the patient's illness while taking into consideration their feelings: “I understand that the psychiatrist said that with good intentions, trying not to make us worry. However, being informed of the fact that it is a severe illness would help me organize my feelings. I want to know how difficult it is to cope with the illness and prepare myself accordingly.” Families assumed that psychiatrists anticipated family's reactions, and thus did not clearly explain the illness: “The psychiatrist did not provide me with a detailed explanation, probably because he thought that I would become confused and not be able to accept the fact.”

With recent changes in mental health welfare policies, there have become fewer opportunities and places for consultation, and life has become harder for patients and their families: “Prior to the municipal merger, I often consulted a health center in the neighborhood, and so did the patient. Now, there is no one to look to”; “From the hospital to the community, it is easier said than done. Once a patient is discharged, the family is obliged to take care of him. Patients and their families are isolated in the community.” Moreover, they expected the family associations to play more versatile roles apart from its primary purpose of supporting families: “An open-air café for families to gather together casually” and “A place where families who had cared for patients at an acute phase advise other families who are caring for the patients at a similar phase.”

#### DISCUSSION

It took a long time for families to consult a clinic; even when something was wrong with the patients or there were changes in their conditions, it was not easy to determine whether an illness had caused it. A delay in getting appropriate help is due to the general lack of information about severe mental illness and the lack of visibility of psychiatric professionals (Kawanishi, 2006). The sense of resistance on the part of families to psychiatric

hospitals delays the onset of treatment (Franz et al., 2010), and families' intention to hide their patient by consulting a hospital far away in order to avoid the public eye prevents them from having the courage to consult professionals. To reduce delaying psychiatric treatment and promote early intervention, programs such as pre-counseling are necessary for families to participate in prior to consulting psychiatric hospitals or medical institutions. For example, as in the first consultation, when the patient is first discharged, ward nursing staffs should help confused families with psychological education including offering information, and cooperating with other professionals.

When family members were diagnosed with schizophrenia, their families became confused about the diagnosis. They could not make sense of it or believe it. Despite their confusion and emotional distress, they wanted to receive a detailed explanation on the severity of schizophrenia as early as possible so that they could prepare themselves. If families realize the severity of the illness later, it will be more difficult for them to organize their feelings and change the way they cope with the illness. In Japan, the term “schizophrenia” has long been translated as “seishin-bunretsu-byo” meaning mind-split disease; it is given an image as an incurable disease. However, it was replaced by the term “togo-shiccho-sho” meaning integration disorder with a possibility to recover (Sato, 2006). According to the results of a survey, psychiatrists do not inform patients and their families of the diagnosis because families cannot understand (Ucok, Polat, Sartorius, Erkoc, & Atakli, 2004). This is consistent with the families in this study who assumed that the reason doctors withheld telling the truth was that the doctor feared the families would deny the diagnosis, and fall into a state of confusion were they informed honestly about the disease.

For the families, schizophrenia was still a mysterious illness, they gradually accepted relatives with schizophrenia as they were, acknowledged their strong points, and distanced themselves appropriately from the patients. Families attempted to view their children, brothers and sisters, or husbands with schizophrenia as persons belonging to families and society, rather than recognize the pathological states of the illness. In terms of social involvement, they advised the patients to properly behave and acquire

interpersonal skills so that society would accept them, while being careful not to indulge them or use the illness as an excuse. In particular, mothers provided the patients with education as if they were re-raising babies or infants.

Families still remember the first day of admission to the hospital when they felt as if they were abandoning the patient. Those are painful memories, and they still suffer from them. It is important for nursing professionals to understand the family caregivers' past conflicts and emotions that continue to the present day. Such empathy can help in alleviating suffering that often overwhelms the caregivers. On the other hand, families expressed hope for improvement. Hope is an important factor in recovering from schizophrenia (Turner-Crowson & Wallcraft, 2002). Similarly, hope is a necessary step in the process of reestablishing a healthy family dynamic. Maintaining even a modicum of hope within the family becomes one stage in dealing with suffering.

During long-term caregiving, the families tend to unknowingly build up physical and psychological stress. There were two main anxieties: the future, and the influence on siblings. Families conducted meetings towards achieving an independent future for the patients (as one sibling did). In addition, it is important to prepare a network of social resources for supporting future life. Magliano et al. (2004) indicated that a strong supportive network could effectively reduce families' worries about the future. Professionals assess not only present necessary resources but also resources which may be necessary in the future. Regarding the influence on siblings, three siblings from this study are married and have given birth. However, mothers were sad when siblings expressed hesitation to marry and have children. Siblings hesitated to marry or give birth due to the fear of passing on the illness (Stålberg, Ekerwald, & Hultman, 2004). The vague fears associated with misconceptions about and prejudice against persons with mental illness that the siblings experienced or acquired throughout their lives. It is necessary to establish appropriate facilities for families to consult with and provide opportunities to learn about genetic diseases and heredity so that they will not harbor prejudice.

A deep-rooted prejudice against persons with mental illness still remains in the community and this encourages many family caregivers to keep themselves out of public view. As previously

mentioned, the prejudice led to delayed treatment and incorrect public awareness. The negative image of schizophrenia causes families to have a sense of guilt. It is assumed that families hesitate to invite other families to join the family association because they understand how other families feel; they used to hide their patients from the public eye. The more families deepen their understanding of mental illness through experience and education, the wider the gap they feel between their perception of the illness and the rest of society (Kawanishi, 2006). Therefore, families in this study are even more aware of the rejection that psychiatric patients experience at the hands of local communities. Moreover, families have conflict about a patient's marriage. Family caregivers of male patients opposed marriage, probably because of the traditional Japanese concept of men's role in society: a man is supposed to be the breadwinner. However, the idea that persons with schizophrenia should not be allowed to marry could risk promoting prejudice of people with mental illness. There is a conventional idea in Japan that a marriage is a relationship between two families. Families who oppose marriage are assumed to fear that the patient could cause trouble to the spouse's family, or that the couple's children might inherit the disease. As for single males with schizophrenia, the level of housing conditions, employment, daily functioning, and psycho-social state were lower, and the number of friends was smaller, compared to married males with schizophrenia (Salokangas, Honkonen, Sten-gård & Koivisto, 2001). It is important for families to understand that marriage may lead to positive effects on the social skills and quality of life of patients, and enrich their lives.

There was a wide gap between the administrative policies to promote community care services and the recognition of families. No families believed that the policies improved their present condition. Projects for discharge promotion must be designed according to the needs of families, and extracting these families' needs is also one of the nurse's roles. Each family in this study was actively learning about the illness, patients, mental health services, and coping mechanisms while simultaneously overcoming a variety of problems. To develop effective measures for community mental health care, families with extensive experience and capability should be actively involved as peer supporters. Of course, to take full advantage of their



ability, it is essential to develop and improve professionals' back-up systems.

Finally, family caregivers in this study were all female and members in the family association were predominantly female. The [World Federation of Mental Health \(2010\)](#) estimated that globally, about 80% of caregivers are female. The caregiver role has traditionally been entrusted to females; the percentage of female caregivers caring for the elderly is 69.4% ([Cabinet office, 2012b](#)). There are numerous female family caregivers handling plural roles because females are mainly responsible for the housework, child-rearing and caregiving. It must be emphasized that these caregivers not live a life exclusively bounded by caregiving.

The experiences of family caregivers became clear in this study. Nursing professionals fundamentally need to listen to families' narratives diligently and collaborate with families in creating meaning from their experiences. [Rose, Mallinson, and Walton-Moss \(2004\)](#) reported that building rapport is an essential element of any intervention. Listening to family caregivers' experiences is a practical way to understand them and build rapport for developing an effective nursing approach. At that time, it is necessary to acknowledge caregivers' experiences, especially those in which they cannot help but think, "How nice it would be if patients would just die or disappear," or, "I would be free from sufferings if I die."

The limitations of this study included the following: First, as only about 20 to 30% of the families who had enrolled in the family association participated in the meeting or activity, examining recruiting methods is a future subject. Second, the participants all belonged to community family associations, and they had some awareness as caregivers and knowledge of the illness. Therefore, they may not be representative of families of persons with schizophrenia who do not use such a resource. Finally, clarifying the specific caregiving experiences of those with two relatives suffering from schizophrenia is required.

#### CONCLUSION

Female family caregivers of persons with schizophrenia had complicated feelings which lasted from onset of the illness to the present time. Although their attitude toward schizophrenia changed, they experienced prolonged hardships

and emotional conflict, lived with haunting prejudice, and were dissatisfied with the community care system. On the other hand, families had strength to overcome considerable adversity. Community mental health nursing for family caregivers needs to be improved by focusing on accepting families' unique experiences along with their histories with persons with schizophrenia.

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