

Research Article

Qualitative Study of Resilience of Family Caregivers for Patients with Schizophrenia in Japan

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ABSTRACT

The goal of the study was to examine the resilience of family members who care for patients with schizophrenia in Japan. The average hospital stay of people with mental illness in Japan is the longest in the world. Support resources are lacking for community-dwelling people with mental illness. Therefore, after discharge, the role of a family caregiver is particularly significant in recovery of patients with schizophrenia to prevent recurrence and maintain stable life in the community. However, little is known about the resilience of family caregivers for people with schizophrenia in a Japanese cultural context.

The subjects of the study were 12 family members who cared for patients with schizophrenia. Answers in interviews of the subjects were analyzed using a phenomenological approach. Six themes were extracted with regard to resilience of family

caregivers for patients with schizophrenia who were adapting to community life. These were understanding the features of the disease, sense of mission as a family to protect the person with illness, learning of coping skills, understanding the gap between reality and the goal of social independence of the patient, finding positive meaning of their own experience, and formation of a social support network. The sense of mission of Japanese family members is likely to arise from the Oriental cultural background. Family resilience may be further enhanced by interventions early after discharge to assess the health status and potential for family care, to support acquisition of knowledge and skills by the family, and to improve social support.

Mesh Headings/ Keywords: Family caregiver; Mental health; Qualitative research; Resilience; Schizophrenia

Introduction

Patients with schizophrenia often have relapse of symptoms due to vulnerability to the stress of daily life [1]. Few such patients live independently in the community, and many depend on care and support for management of daily life from family caregivers. These caregivers play a major role in recovery of patients with schizophrenia by ensuring maintenance of life stability and prevention of relapse in the community. Caregivers require resilience to overcome the burden of care, and this requires health and life adaptation for themselves and their families. Definitions of the concept of resilience in the mental health area have changed over time. Basically, resilience is understood to indicate affirmative adaptation or the ability to maintain or regain mental health despite experiencing adverse circumstances [2]. Van Breda [3] defined resilience in caregivers as the characteristic of overcoming adversity to survive the day-to-day burden of caring for a family member who is mentally ill, and also to thrive; that is, to grow into a stronger, more flexible, and healthier person.

In studies of resilience of families of people with serious mental illness, such as schizophrenia, Enns [4] found that families with patients admitted to a psychiatric ward are looking for social support, and noted a tendency to consciously control emotional expression and communication. This suggests the importance of recognizing families of patients admitted to a psychiatric ward as a resource in care, and as beneficial to the outcome of the patient. Mannion [5] found that 83% of

spouses of patients with mental illness followed the adaptation and recovery process, with personal resilience of the family bringing positive changes. Subandi [6] stated the importance of increasing the empowerment of a family and family resilience as part of the treatment of patients with mental illness, and burnout and fatigue of families of patients with schizophrenia leads to reduced resilience [7]. In a literature review of resilience of families of patients with serious mental illness, Zauszniewski, et al. [8] concluded that the core concepts include risk and vulnerability, aggressiveness, and protective factors as indicators of resilience. In addition, such families are more likely to have excessive stress that may impair their own health, quality of life, and family function. However, resilience in the family allows this stress to be overcome and health to be maintained.

These previous studies suggest that resilience of family caregivers of patients with schizophrenia brings a positive change in recovery and adaptation of the family, reduces burnout and retains the physical and mental health of caregivers, improves quality of life, and optimizes family function. However, the resilience of family caregivers of patients with schizophrenia in a Japanese cultural context has not been investigated. Van Breda [3] stated that resilience in different cultures is unclear, and there is a need for research into cultural effects on resilience. The average hospital stay of people with mental illness in Japan is 291.9 days, and the longest worldwide [9]. But there have been no studies of resilience of family caregivers in promotion of social independence of patients with schizophrenia after discharge. Consequently, the aim of this study is to examine

resilience of Japanese families in the process of caring for a patient with schizophrenia.

Methods

Study design

The study was performed using qualitative descriptive research based on the phenomenological method. Resilience was defined as the ability to recover from adversity in daily life in the process of confronting problems and adaptation. A qualitative research method was used because this is most suitable for the aim of this study to create an understanding of the experiential meaning of resilience in family caregivers for patients with schizophrenia. To ensure the credibility of the study, we participated in a workshop on the phenomenological approach before the start of the analysis. In addition, this served as the final confirmation of whether descriptions were created as research results that reflected the perceived experiences of the participants. Ethical approval for the study was obtained from the National Center for Global Health and Medicine Ethics Committee. The participants were given a written explanation of the purpose of the study, content, procedures, anonymity, human rights, advantages and disadvantages associated with study participation, including that there was no disadvantage due to refusal of cooperation, and storage and disposal of data. After this explanation, the participants provided written informed consent.

Participants and recruitment

Potential study participants were identified through community support facilities that encourage self-reliance and social rehabilitation of people with serious mental disorders. The inclusion criteria were a primary family caregiver who had cared for a patient with schizophrenia for more than 1 year after initial discharge from a psychiatric ward. Caregivers of patients who were currently experiencing a relapse of schizophrenia were excluded.

Data collection and analysis

Data collection was carried out by a semi-structured interview of study participants that lasted about 60 minutes (an average of 51.9 minutes). The participants were asked "How did you face difficult events during the experience of caring

for the patient for more than one year so as to avoid relapse of schizophrenia?" and "How did you respond to these difficulties and continue with care?" Questions were non-directive and open-ended. Interviews were recorded on a digital voice recorder. Resilience of the family caregivers was interpreted using the phenomenological approach proposed by Giorgi [10]. Analysis included four stages: 1) read for a sense of the whole, 2) establish meaningful units, 3) describe meaningful units more explicitly in nursing-relevant language, and 4) obtain a structure for the responses.

Statistical descriptive analysis

All statistical analysis were performed in SPSS 24.0 J (SPSS Japan, Inc., 2016). The total number and percentages of the demographics was provided. The following demographics was also calculated : age.

Results

Descriptive statistics of the demographics characteristics are shown in Table 1 and 2, respectively. Twelve caregivers in urban areas of Japan were finally recruited in the study. The age of the participants (caregivers) was from the late 50 s to early 70s. The participants were all parents, and the majority were mothers (n=10, 83.3%). Five (41.7%) were in full-time or part-time employment. Over three-quarters caregivers were married or in a long term partnership. Nine participants had received regular treatment for diseases such as cardiovascular disease. The patients with schizophrenia (1 female and 11 males) had an average age of 28.8 years (range: early 20s to late 30s) at the time of interview of the caregivers. All had been diagnosed with schizophrenia and were taking psychotropic drugs.

Resilience of family caregivers for patients with schizophrenia

Six themes were abstracted from the family caregivers' experiences related to resilience in confronting difficulties in support for patients with schizophrenia to adapt to community life without relapse: (i) understanding the features of the disease, (ii) sense of mission as a family to protect a family member with illness, (iii) learning of coping skills, (iv) understanding the gap between reality and social independence for a patient with schizophrenia, (v) finding a positive meaning of their own experience and (vi) formation of a social support

Table 1: Demographic profile of the participants (Caregivers).
N = 12

Characteristics		n (%)	Mean ± SD (range)
Relationship of the patients with schizophrenia	Mother	10 (83.3)	
	Father	2 (16.7)	
Age (Years)			63.4±4.9 (55-74)
Employment at the time of interview	Employed	5 (41.7)	
	Unemployed	7 (58.3)	
Marital status	Married	9 (75.0)	
	Divorced	3 (25.0)	
Health status	Good	3 (25.0)	
	Bad	9 (75.0)	

Table 2 : Demographic profile of the patients with schizophrenia
N=12

Characteristics		n (%)	Mean ± SD (range)
Gender	Male	11 (83.3)	
	Female	1 (16.7)	
Age (Years)			28.8±4.4 (21-39)
Diagnosis	Schizophrenia	12 (100)	
Activities during the day	Part-time employed	3 (25.0)	
	Welfare factory*	6 (50.0)	
	Day hospital **	3 (25.0)	

*Welfare factories are small-scale halfway houses based on laws and subsidized by government. Clients gain work experiences and receive guidance for adjustment/return to socioeconomic activities. A welfare factory enters an employment agreement with its clients and pays at least minimum wage for their labor.

**Day hospital is a mental health service offered in hospital settings. Participants attend treatment/psychosocial programs.

network. The details of each item are described below.

Understanding the features of the disease

The resilience of a family member in caring for recuperation of a patient with schizophrenia after discharge depended on understanding the characteristics of schizophrenia. Families knew the name of the disease, but did not understand the nature of mental illness. It was difficult for them to understand why the medical condition of the patient quickly became unstable after improvement and this led to confusion in understanding the recovery barometer for schizophrenia. By obtaining knowledge and information about schizophrenia and understanding the characteristics of cognitive dysfunction and vulnerability to stress, the caregivers gradually accepted the truth without this being problematic:

“Even though I think he has become well, his condition can quickly deteriorate. After I was taught that this is due to a vulnerability to stress in people with schizophrenia, I could view the situation with patience.”

Sense of mission as a family to protect a family member with illness

The second factor in resilience of a family caregiver was a sense of mission as a family to protect a family member with illness. For caregivers, having a family member with a psychosis such as schizophrenia was initially unacceptable. They were jealous of healthy people of the same age and felt psychological distress regarding the difference in their circumstances. However, as the caregiver gradually came to understand that severe mental illness made self-management of daily life difficult, they came to recognize their mission to protect the family member with the disease. They began to feel that it was their own problem and to create an inner consciousness to confront the situation positively. This consciousness was a driving force to take autonomous care and confront difficulties:

“I was thinking that having a child with mental illness is unacceptable. Thinking about other children of the same age was painful and I think I envied their parents. However, this should not exacerbate schizophrenia because relapse is scary. Medical conditions are hard, but I want my child to heal quickly.

Families must work together because they are always involved. Parents have to care and we have tried hard as parents.”

Acquire coping skills

The third factor in resilience of a family caregiver was to acquire coping skills. This theme included three subthemes of flexibility, humor and hope. The family caregiver gave the necessary care for life rhythm establishment and drug management needed for recovery of the family member with schizophrenia. The caregiver learned coping skills depending on the recovery stage, such as changing care to facilitate independence of the patient. Caregivers acquired coping skills that allowed flexibility to respond to changing circumstances, to show humor to release pressure and to maintain hope, even if the family member failed several times in social skill training. By learning coping skills, the caregiver promoted adaptation and psychological stability of the family member with schizophrenia.

Flexibility: Family caregiver experiences were not straight forward with respect to recovery of the family member with schizophrenia. The caregiver has to support the stability and daily life of the patient by responding flexibly to changes in the state of schizophrenia and selecting the best action.

“It is difficult to understand because mental illness is not visible to the eye. Asking more of adult children because I think they are getting better may worsen the mental condition. Therefore, I did not go against the thoughts of my child; sometimes, for example, we acted together based on changes in the current situation. I continued to give support based on the needs of the family member with schizophrenia.”

Humor: When patients are feeling pressure about social participation and worrying too much about the views of others, a family caregiver can loosen this feeling by using humor purposefully. The caregiver can relieve the stress of the patient with such humor and this may make it possible for the patient to regain a clear mind and deal with the reality calmly.

“My son thinks others are looking at himself and tries to avoid the human eye. But, I said “You are a good guy, and this happens to everyone. Nobody is looking. You are self-conscious.” Through humor, the patient was able to go to the

barber's."

Hope: Even if the family member with illness fails many times in social skill training, other family members should not abandon hope that the patient will eventually get well. Maintenance of hope by the family caregiver allows the patient the opportunity to succeed without discouragement.

"My child could not get on a train because of his symptoms. I took him on a practice ride on the train with my husband. We tried to get him on the train, but he froze at the door. The train door closed and we did not ride. We postponed getting on to many trains while sitting on a bench, but I believed that he would eventually ride and we kept watching."

Understanding the gap between reality and social independence for a patient with schizophrenia

The fourth factor contributing to resilience of a family caregiver in supporting the independence of a family member with schizophrenia was understanding the gap between the current status of the patient and the abilities required to function in society. Caregiver tried to evaluate more objectively. These allowed the patient with schizophrenia to adapt to the rules and expectations of the society objectively and in line with social reality.

"When my adult child joins the society, he has to interact with people other than parents. It seems that my child's judgment is not good enough. So, I may sometimes interfere and warn my child if he does not observe the social rules of clothing and interpersonal relationships."

Finding positive meaning in their own experience

The fifth factor in resilience of a family caregiver was to view things positively. When a caregiver faces an unacceptable reality, they may have feelings of anger and self-criticism. In this situation, consideration of the implications and recapturing an affirmative position were important to change their world view. Through obtaining positive meaning from their own experience, the family caregiver was able to promote better control of emotions and adaptation for themselves and for the patient with schizophrenia.

"At first, I was troubled about my child from morning until night. I thought that parenting was related to the disease and I blamed myself that I may be the cause of the disease as a parent. Eventually, my health worsened. Then, I thought that I must change my attitude. I told myself that "there is no doubt that I had brought up my son well", and I began to become more settled in this regard."

Formation of a support network

The sixth factor in resilience of family caregivers was formation of a support network. The family faced a burden of care for the patient with schizophrenia, and formation of a support network for caregivers, through professional social rehabilitation facilities providing a variety of social experiences with others in similar situations was important. These activities relaxed the burden and eliminated the sense of isolation of the family caregiver.

"When the condition of the patient worsened, having

professionals to listen to the family empathically and say "It's all right" became important support for the family. The family cannot bear the burden of a child with illness. I have managed so far thanks to the surrounding support."

Comprehensive description

Resilience shown by a family in continuing with care of a patient with schizophrenia to permit adaptation to community life without relapse depended on understanding the characteristics of the illness, accepting the family member with schizophrenia, and having a sense of mission to protect the family as a driving force. Flexibility, humor, and maintenance of hope were all important, along with learning various skills and expanding coping ability. This involved understanding the capability of the family objectively and trying to fill the gap between the real world and the goal of independence of the family member with illness. When faced with reality and an unexpected predicament, the caregiver acted in an affirmative manner with control of their own emotions to maintain mental health. By forming a support network with medical staff and other caregivers for family members with the same disease, various challenges could be overcome. Such resilience of a family caregiver enhanced symptom management and daily life skills for patients with schizophrenia and promoted adaptation in society. The caregivers themselves had increased self-affirmation as a caregiver and this contributed to maintenance of their own health.

Discussion

Themes associated with resilience of family caregivers in care for patients with schizophrenia to adapt to community life without relapse were identified in this study. These are discussed below, with comments on the nursing assistance required to promote resilience in such family caregivers.

Resilience in caregiving for schizophrenia

The study identified three themes in resilience in caregiving for a family member with schizophrenia: understanding the features of the disease, learning coping skills, and understanding the gap between reality and social independence for the patient. Understanding the features of the disease includes recognizing that schizophrenia is not visible to the eye. The family caregiver initially could not understand the nature of mental illness and was confused, but gained a better understanding by obtaining knowledge and information about schizophrenia in books provided by medical staff. Understanding the characteristic cognitive dysfunction and vulnerability to stress in schizophrenia led caregivers to recognize the problems faced by the family member and accept the person as they are, Christensen & Jacobson [11] suggested that acceptance through such understanding helps the family to stand together, even with the unpleasant behavior of a patient with illness. When family caregivers can accept the diagnosis and evaluate a crisis situation passively, they can find different ways of adapting to their situation [12,13]. After a family understands the gap between reality and social independence of a patient with schizophrenia, care becomes more supportive. The caregiver has strengthened recognition of the real abilities of the patient, and the attitudes of the family towards the patient are then likely

to promote social adaptation.

Family caregivers expanded their own coping skills by having flexibility to respond to changing circumstances, using humor to allow patient to release pressure and maintaining hope without giving up. In a study of how families with mental illness, including schizophrenia, handle their emotions, Karp & Tanarugsachock [14] found that feelings of hope help the family. Tweedell, et al. [15] also found that hope is important in treatment, symptom management and QOL of families with chronic mental illness. The results of these studies support our finding that maintenance of hope is an important factor in resilience of family caregivers for patients with schizophrenia. Zauszniewski, et al. [8] found that integration of resourcefulness, tolerance, learning and consistency (coherence) was associated with improvement of family functioning and adaptation in a study of the resilience of families with a patient with a serious mental illness. These factors are similar to the factors of flexibility, humor, learning of coping skills and goals and evaluation that were found to be important in promoting resilience of caregivers in the current study.

Resilience due to the psychological characteristics of the family caregiver

Regarding the psychological characteristics of the family caregiver, two themes emerged: a sense of mission as a family to protect a family member with illness, and positive meaning of their own experience. Personal belief in a sense of mission as a family is a way of thinking in Asian culture. Especially in Japan, a culture that emphasizes the traditional Confucian idea has been handed down from generation to generation. That is not just an attitude of seeking personal happiness; the concept of symbiosis to try to live with the family and society is ingrained [16]. A tendency among modern Japanese people to emphasize relationships in families is increasing [17]. Under the influence of this cultural background, caregivers are faced with the unacceptable reality that their child has schizophrenia, and they feel that they must view this as if it were their own problem and confront the situation positively. This consciousness is a driving force to act autonomously to confront difficulty. In addition, the resilience of caregivers in trying to confront difficulties involved strength and awareness obtained from a positive understanding of their own experience. Bayat [18] suggested that to obtain meaning from adversity is an important factor in family resilience. Families with resilience often gained an affirmative (positive) sense from adversity, with lessons learned from many actions and events. In this way, families were able to change their world view and obtain a positive outlook on life, as reflected in the results of the current study.

Resilience due to a social support network

Finally, formation of a social support network contributes to resilience. Expanding the support network and obtaining reliable support from medical staff, caregivers for family members with the same disease, neighbors and other family members allowed caregivers to obtain the necessary support. Distributed care in nursing can overcome various issues. Takahashi, et al. [19] suggested that caring of the family

increases in the process of realizing a sense of security due to support from non-professionals, such as friends and people with children with the same disease, as well as from medical staff. The results of this study were similar for caregivers for patients with schizophrenia. Support and communication with other people in a network improved the resilience of the caregiver and influenced the caring ability of the family.

Implication for mental health nursing to promote the resilience of family caregiver

The results of this study suggest that the following nursing support is required to promote resilience of a family to care for a patient with schizophrenia. Direct support requires an explanation of the behavioral characteristics of a patient with schizophrenia and how to cope with this behavior, since these issues are difficult for a family to understand. Establishment of a system for psychological education and counseling will promote knowledge and understanding. A Japanese family caregiver will also have a background of Eastern culture and Confucianism and this includes a strong sense of the mission of a family. Therefore, it is important to evaluate the burden on the family and to consider the social support required for the family. Medical staff should understand the family's point of view and build a partnership with the family for support of the patient. As support for the period of transition to community life from discharge, each household situation and ability for disease management and care in the house should be evaluated in home-visit nursing care and outreach, with nurses joining the process to develop a care model suitable for each home situation and serving as an assistant. As indirect support for the family, emotional support by peer counseling is useful to facilitate family association and communication to alleviate psychological distress such as anger, sadness and embarrassment. These support approaches will promote resilience in a family caregiver, enhance family function, improve adaptation and recovery of the family member with schizophrenia and improve the health and quality of life of the family caregiver. Enhancement of care given by a family caregiver for a patient with schizophrenia may be possible using the results of this study to identify key roles of mental health nurses in support of such caregivers.

Conclusions

The participants in this study were twelve families who were able to assist in recovery of patients with schizophrenia for more than one year after their first discharge to community life. The results suggested that the resilience of the families prevented relapse and led to recovery from schizophrenia and successful adaptation to the local community. Therefore, the overall resilience of a family may have an important influence on recovery of a patient with schizophrenia.

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