



Family experiences in communicating with family members experiencing social isolation after hospitalization

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KEYWORDS

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Abstract

Objective: Social isolation is one of the negative symptoms of schizophrenia that is likely to persist after hospitalization. This study aimed to describe family experiences in communicating with post-hospitalized family members experiencing social isolation.

Method: This study used a descriptive phenomenology qualitative approach. The research sample consisted of seven participants selected by a purposive sampling method. Data were obtained through in-depth interviews with family members of people with schizophrenia who experienced social isolation after hospitalization. Data were analyzed using Colaizzi's method.

Results: Five themes emerged in this study: a) emotional reactions towards communication changes after hospitalization; b) family coping strategies in communicating with post-hospitalized clients; c) stigma and emotional expression as factors aggravating limited social interaction; d) types of family communication used to fulfill the psychological needs of patients, and e) family involvement in communicating with socially-isolated clients after hospitalization.

Conclusions: Family communication becomes part of the adaptation of the family to caring for a family member with a chronic illness. It is recommended that nurses provide mental health education and psychological education on communication skills to family caregivers.

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Introduction

Psychiatric disorders are becoming a public health problem worldwide. Schizophrenia is a serious and persistent neurobiological brain disease¹. According to the National Institute of Mental Health, schizophrenia is a serious psychotic disorder that occurs in approximately 1.1% of the population at the age of 18 years²⁻⁴. Data from the National Health Research of The Health Ministry of Indonesia in 2013 show that

the prevalence of severe mental disorders has reached 1.7 per mile⁵. Despite the low incidence of schizophrenia, the prevalence of this disease is quite high because the disease is categorized as a chronic illness, with higher rates of relapse and re-hospitalization^{6,7}. Moreover, the symptom and prognosis severity⁸ of schizophrenia tends to lead to higher rates of disability, mortality^{1,9}, and suicide⁴.

Schizophrenia is a major psychotic illness causing a series of symptoms, including both positive and negative symp-

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toms that impair cognitive thought, socialization skills, and ultimately personality^{1,2,7}. Although medication can control the positive symptoms, even after these symptoms have abated, the negative symptoms persist frequently^{7,10}. Negative symptoms in schizophrenia include flat affect, decreased willingness to engage in social activity⁷, apparent loss of normal functions or a deviation from social norms, including withdrawal, lack of speech, and general uncommunicativeness¹¹. Those suffering from schizophrenia may also be socially isolated¹² and exhibit self-neglect¹³. Schizophrenia also impacts cognitive and communicative processes, inducing problems with interpersonal relationships⁴ and complications of everyday interactions¹³.

Schizophrenia is linked to social isolation, which may develop before the onset of illness or continue in the absence of more dramatic positive symptoms. Schizophrenia is also linked to the subsequent onset of psychosis^{7,13,14}. Social isolation occurs in the prodromal and residual phases of schizophrenia^{2,12}. Over time, it presents a major barrier to recovery and improved functioning in daily life^{7,15}. Although patients may be safely discharged after hospitalization¹, recovery is considered a lifelong process, in which relapses and re-hospitalizations may occur. Some individuals who experience relapse are not hospitalized because their relapse is successfully managed by community services¹⁶, but despite much effort in community treatment, patients still experience stigma and discrimination^{15,17-19}.

Studies indicate that people with long-term mental disorders live marginal lives characterized by severe disability, stigma, discrimination, social isolation, unemployment, homelessness, and poverty^{13,15}. They need support systems, such as those found in extended family members, friends, and co-workers²⁰. The family environment is known to be a contributing factor to a patient's likelihood of relapse or rehabilitation²¹. A high-functioning family helps maintain communicative, emotional, and behavioral control and also helps the patient develop problem-solving and coping behaviors²¹. Despite their prevalence and effects, little to no research has examined the role of family communications in socializing and shaping family members' understanding of and experiences with mental illness.

Method

This study used a qualitative research method with a phenomenological approach. This study aims to dig deeper into family experiences in communicating with post-hospitalized family members experiencing social isolation. Family communication processes lasting for years were explored through an in-depth interview process. The selection of participants was achieved via a *purposive sampling* technique with the following criteria: a) family of clients with social isolation after hospitalization which have been allowed to return home for 6 months to 3.5 years; b) families of patients experiencing social isolation who act as caregivers and stay in one home; c) family members aged 18 years and older; d) family members able to communicate in Bahasa well, and e) family members willing to consent to participation by signing an approval sheet.

Before collecting data, this study gained approval from the ethics committees of the Faculty of Nursing, Universitas

Indonesia. This study was conducted in an ethical manner by upholding the principles of beneficence, respect for human dignity, justice, non-maleficence, confidentiality, and anonymity. The main instruments of this study were interview guidelines, field notes, and voice recorders. The data collection method in this study used in-depth interviews and field notes. The results of interviews were stored in recorded interviews and verbatim transcripts, then analyzed by using Colaizzi's method²². The legality and validity of the study was determined according to four criteria: credibility, confirmability, dependability, and transferability. This study took place in participants' houses after their family members were released from hospitalization.

Results

Participants were family members of people with schizophrenia who were hospitalized during the period of March 2013 (3 years 2 months ago) until August 2015 (10 months ago). All of the participants had a history of hospitalization or admission to mental hospitals. All had current nursing diagnoses at discharge in the form of medical diagnoses of schizophrenia and social isolation. Six of these patients were receiving psychiatric follow-up treatment and were currently on psychiatric medication. One of them never attended an outpatient department after hospital discharge. In general, participants were parents of children suffering from schizophrenia. There were 7 participants, 4 females and 3 males, with the age range of 52-72 years old. Participants had varying levels of education, starting from not graduating elementary school up to graduation from an undergraduate program. All participants were living with their loved ones and had been providing care for longer than 3 years, in spite of most of the patients being between 15-25 years old.

This research revealed five themes related to family experiences in communicating with family members who experienced social isolation after hospitalization: the emotional reaction to changes in the communication of their suffering loved ones post-hospitalization, coping strategies of families in communicating with patients post-hospitalization, stigma and emotional expression as factors that aggravate social interaction in the family and society, forms of family communication in meeting the patients' psychological needs, and the family as a support system through interaction. An explanation of each theme will be provided below.

Theme 1: emotional reactions to changes in patient communications post-hospitalization

Data on emotional reactions to changes in patient communications post-hospitalization was obtained from 2 sub-themes: changes in the post-hospitalization communication and emotional reactions of the family. The first sub-theme was obtained from 2 categories: positive changes and negative changes. This is illustrated in the following participant statements:

"[...] in a certain moment, he asks me something, 'Mom, what are you cooking? What is the menu?' And So on..." (Mrs. S).

"[...] now it's already been better, sometimes he can answer a phone call" (Mrs. Ai).

The second category was negative changes perceived by participants, as described below:

"[Speaking unclearly] I cannot get the point... I ask a question, he replies to others; he is still confused; he often forgets what I asked" (Mrs. Ai).

"[...] He says nothing, umm, he can't start a conversation" (Mrs. S).

The second sub-theme was the emotional responses, and these were divided into positive and negative emotional responses. The first category was a positive emotional reaction involving responds to positive changes in communication from the patient, i.e., "love" and "happy".

"[...] I love you, when parents love their children, it's normal; it's an obligation..." (Mr. S).

"[...] I love my children, so much, uhm there are no parents like Mr. I and Mrs. J, I love my children so much, whatever it takes..." (Mrs. J).

The second category covered negative emotional reactions in response to changes in patient communications, i.e., "sadness", "fatigue", "fear" and "shame":

"[...] I'm sad, I've taken care of him for 30 years, Now, he seems like a kid again, even a real kid is easier, that's become my destiny..." (Mrs. Ai).

"I speak many times, I'm tired..." (Mr. A).

Positive changes in client communication are met with positive emotional responses from family members, whereas negative changes provoke negative emotions. Negative changes post-hospitalization were revealed more by families, so negative emotional reactions were found to be more common than positive ones.

Theme 2: family coping strategies in communicating with clients post-hospitalization

This theme described constructive and destructive coping from the family. The first category involves constructive coping by seeking spiritual support and providing a sense of comfort.

"[...] Ya Allah Subhanalloh, I still can take care of him, I always pray to Allah, Ya Allah, my Lord, lengthen my life, my son can easily answer if somebody speaks to him...." (Mrs. M).

"[...] No violence, because it is hurt..." (Mrs. J).

The second category involves coping with destructive marked with the ignorance keywords such as "I don't care" and relented, and not dare to speak.

"[...] Just slow down, if I think hard, I get confused, I will be sick as well, so, I never think about it, sometimes I think it, just a bit, no more..." (Mrs. Ai).

"[...] Yeah, she is succumbing; her mother is not brave enough to talk; she never asks for food and just looks after her..." (Mr. Sw).

Theme 3: stigma and emotional expression as factors that aggravate social interaction

This theme had 2 categories presented by 2 participants: i.e., labeling and response to stigma.

"[...] no one has pity for my son; many people hate him, some neighbors are afraid of him [...]" (Mr. Sw).

"[...] in the end, our name will be famous ... Take a look at Mr. Sw's children; they are not taken care of properly [...]" (Mr. Sw).

"[...] no one to wants to hear nor tell my story; if I tell or share my feelings, I will be laughed at [...]" (Mrs. M).

The second category was a response to stigma stated by the four participants who responded to the stigma experience by the family and family members who experienced social isolation post-hospitalization:

"[...] Yes, we do not know the feelings of others, we don't tell anyone [...]" (Mr. S).

"[...] Unexplainable, shameful, for example, when he says the words 'dog' or 'pig,' we had better seclude before the surrounding environment knows it [...]" (Mr. Sw).

Theme 4: forms of family communication in meeting psychological needs

Communication is a way for a person to convey emotion. This theme was derived from the experiences of parents in communicating with family members who experienced social isolation resulting from a lack of communicative capabilities. These family communication skills are divided into three categories: persuasive, informative, and instructive.

"[...] to commend the child: please bring that glass and put it in order..." (Mrs. M).

"[...] it means nice if it is done each day, essentially, just to make them happy..." (Mr. S).

Theme 5: family involvement in communicating with clients

There were 2 sub-themes obtained within this category: the family itself and other sources of social support.

Five participants expressed the active involvement of parents.

"knowing the mistake after checking the medicine, running out of medicine before follow-up appointment" (Mrs. Ai).

"[...] Dad, try to control it, (check the letter), it is checked by his father [...]" (Mrs. J).

The category of passive family involvement was expressed with the keyword "I don't care", "speaks only when necessary," "brother is busy," and "no chat invitation." The state-

ment is contained in the transcript of the participants as the following:

"[...] my mother rarely speaks, my husband speaks rarely as well, only when they need something [...]" (Mrs. S).

"[...] my brother is busy with the band; I will call him sometimes 3 or 4 times, and text him without a response [...]" (Mrs. J).

The social support from the community was presented by the participants in the following statement:

"[...] all the neighbors here already know; if she comes out, they (neighbors) ask, 'How are you?' 'Feel healthy?'" (Mrs. M).

"Ms. S, please don't smoke, it's not good for a woman like you, hei Sr, wash your clothes, sweep your floor, let's get to work, said the neighbors" (Mrs. Ai).

Discussion

This study highlighted 5 main themes surrounding family frustrations when providing support and care for relatives suffering from schizophrenia: *a*) emotional reactions towards communication changes after hospitalization; *b*) family coping strategies in communicating with post-hospitalized patients; *c*) stigma and emotional expression as factors aggravating social isolation; *d*) types of family communication that fulfill the psychological needs of patients, and *e*) family involvement in communicating with socially-isolated patients after hospitalization.

Communicative changes perceived by the family show the existence of the caring processes that take place during post-hospitalization. However, most patients with schizophrenia have difficulty functioning in the community, and few lead fully-independent lives. This is primarily due to persistent negative symptoms, impaired cognition, and treatment-refractory positive symptoms⁷. Relapse refers to a breakdown or failure in a person's attempt to maintain a change in any set of behaviors²³. This view of relapse facilitates the understanding that relapse is part of a natural process and not a failure¹³. The caring process of family members efforts to establish and maintain good relationships with patients is an important aspect of the treatment and the healing process²⁴. Effective communication skills are vital to patient rehabilitation. Communication may affect the results of patient care. All participants have either positive or negative perceptions of changes in patient communication after hospitalization²⁵.

Schizophrenics have difficulty in family functioning; the patient's perception of family functioning could reflect the characteristics of their disorder. Studies have noted a discrepancy in the perception of family functioning between patients and family members depending on the patients' diagnosis of schizophrenia, depression, or bipolar disorder²¹.

Other factors affecting patient recovery include medication adherence and empowerment within the family. The model of evidence-based psychosocial rehabilitation proposes that individuals must be empowered to achieve personal goals, develop expectations, respect those who support them, take responsibility to become informed and

reliable in organizing themselves when sick, and achieve personal goals²⁶. Unfortunately, antipsychotics can also worsen cognitive function, which harms prefrontal networks, motivation, and learning processes²⁷. In general, negative and cognitive symptoms are resistant to treatment with antipsychotics²⁸. Therefore, it is necessary to explore alternative therapies.

Negative symptoms are not only resistant to antipsychotic treatment but also to conventional psychotherapy interventions. Moreover, 24% of patients experience at least one period of negative symptom exacerbation after antipsychotic medication stabilization²⁹. Furthermore, negative symptoms are significantly associated with poor social functioning. This has significant impact on quality of life and social functioning, especially for post-hospitalized patients.

Both patients and caregivers need a great deal of support in different forms, be it practical or emotional support. Unfortunately, most of the caregivers in the present study reported that they did not receive sufficient support. Social support was also found to be strongly correlated with the functioning of the families caring for schizophrenics. Social support provided by relatives strongly correlates to all dimensions of family functioning²⁰. Social support can be provided both informally (e.g., by family, friends, friends, neighbors, and social groups) and formally (e.g., by professionals and agencies)¹³. Thus, strengthening family functioning may involve the development of informal supportive networks for families and the expansion of natural social networks. A study in India has shown that families with schizophrenic members are more vulnerable to stress due to a lack of social support²¹.

The patient's age and education correlate with psychiatric symptoms: the older the age and the lower the level of education, the more severe the symptoms⁶. Lower levels of education could be related to severity of symptoms for several reasons. Stigma may take the form of being silent, only talking when necessary, and not wanting to start a conversation. This hampers the communication process in families and may also interfere with the recovery process post-hospitalization. Stigma also affects quality of life.

Ineffective forms of communication, including anger, pushing, and threatening, become communication barriers for people experiencing social isolation. People with mental illness and their parents often fail to convey a sense of intimacy in their communication patterns³⁰. The failure of parents to communicate effectively leads to the possibility of confusion, distress, and dysfunctional communication patterns in children. People who have difficulty communicating experiences experience and cause anger, frustration, and depression³¹.

A characteristic family environment, called high expressed emotion (EE), has been identified that defines a relapse-prone family environment in which one individual has schizophrenia³². People with schizophrenia often experience aspects of family life as stressful; they relapse more often and more severely when there is an intense atmosphere of criticism, hostility, or emotional over-involvement³³. With the advent of deinstitutionalization, caregivers have increasingly assumed greater responsibility for the care of their mentally-ill relatives, and the consequent negative caregiving experience is a likely cause of stress manifested in heightened EE³⁴. EE is depicted as a toxic element or a

potentiator of relapse in patients with schizophrenia⁸. In addition, EE is a robust and valuable predictor of symptom relapse in schizophrenics^{6,33,35}.

Family stigma is low in the early stages of a psychotic disorder, with families endorsing many supportive statements. For example, patients are often encouraged to vote, patients want to work, and family members express a belief that mental illness should be protected legally as a disability and parity should exist in insurance coverage³⁶. One characteristic of family stigma is social isolation. Members of these families keep to themselves and usually do not invite others into the home or tell them what is happening⁷.

The implementation of family duties requires the skill and ability of all members of the family to achieve the highest degree of health. Establishing and maintaining good relationships with patients is an important aspect of the treatment and healing process²⁴. Effective communication skills are key to achieving this goal. All the participants of this study claimed to have sufficient ability in caring for patients, but it still needs to be improved. The family must help patients meet needs that cannot be met independently.

Families must continue to maintain the physiological needs of mentally-ill family members in order to improve their quality of life³⁷. This provokes concerns associated with the need to continue being a caregiver for the child who is now an adult, worrying about who will care for the patient when the parents are gone, dealing with the social stigma of mental illness, and possibly facing financial problems, marital discord, and social isolation. In addition, family members can benefit from a supportive environment that helps them cope with the many difficulties presented when a loved one has schizophrenia. The communication of positive attitudes toward schizophrenia can promote an interpersonal climate of respect, neutrality, and trust³⁸. Every decision should involve the family, especially if that is what the patients demand²⁰. Parents should encourage other family members, including extended family, to talk openly and freely in an understanding environment, learn from others who are in similar situations, learn how to ask for assistance and to access services, develop friendships to overcome any sense of isolation, and receive emotional support¹³.

The results of this study pinpoint some ways to care for patients, such as providing comfort to family members, modifying the environment, providing a variety of activities, and remaining in communication with family members with mental disorders. Families must maintain a home atmosphere that is favorable to the health and development of family members by facilitating the needs of each family member and still supporting each other in various situations.

Those suffering from schizophrenia have a decreased ability to perform behaviors that satisfy the instrumental and affective needs of the other family members. Moreover, they also experience lack of transmitting clear and directive verbal messages. The family member show interest and care to one another (affective involvement) and maintain the standard of discipline maintained by their caretakers²¹. The goal of supporting this continuum of behaviors is to assist the patient in accessing support systems for physical or mental problems and to in the development of new interests, hobbies, and friendships to decrease social isolation and increase self-esteem¹¹.

This study revealed five sustainable themes that explain the process of communication between patients' post-hospitalization and family members at home. Based on the research findings of this study, it is clear that communication is a means of information exchange in the process of family care. The results also indicate that communication is dynamic and can change at any time to adjust to situations and conditions in the family. Communication skills are essential because effective communication is a cornerstone of the recovery process³⁹. Communication between patients' post-hospitalization and family members relates to the patient socialization process.

There were several limitations of this study. All participants of family members with social isolation were parents and may have similar experiences in communicating. Relationships between siblings or couples may result in different communications and perspectives. This study focuses on family communication; other relationships still need to be examined further. Additionally, in-depth interviews do not fully describe family communications. Observation techniques may expose intimate family relationships via both verbal and non-verbal communication. Regardless, successful communication is an essential component in empowering patients to take control of their recovery.

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Conflicts of interests

The authors declare no conflicts of interest.

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