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

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#### **KEYWORDS**

Family communication; Social isolation; Stigma; Post-hospitalization

#### **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 disease<sup>1</sup>. 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 years<sup>2-4</sup>. 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 mile<sup>5</sup>. 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<sup>6,7</sup>. Moreover, the symptom and prognosis severity<sup>8</sup> of schizophrenia tends to lead to higher rates of disability, mortality<sup>1,9</sup>, and suicide<sup>4</sup>.

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<sup>1,2,7</sup>. Although medication can control the positive symptoms, even after these symptoms have abated, the negative symptoms persist frequently<sup>7,10</sup>. Negative symptoms in schizophrenia include flat affect, decreased willingness to engage in social activity<sup>7</sup>, apparent loss of normal functions or a deviation from social norms, including withdrawal, lack of speech, and general uncommunicativeness<sup>11</sup>. Those suffering from schizophrenia may also be socially isolated<sup>12</sup> and exhibit self-neglect<sup>13</sup>. Schizophrenia also impacts cognitive and communicative processes, inducing problems with interpersonal relationships<sup>4</sup> and complications of everyday interactions<sup>13</sup>.

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<sup>7,13,14</sup>. Social isolation occurs in the prodromal and residual phases of schizophrenia<sup>2,12</sup>. Over time, it presents a major barrier to recovery and improved functioning in daily life<sup>7,15</sup>. Although patients may be safely discharged after hospitalization<sup>1</sup>, 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 services<sup>16</sup>, but despite much effort in community treatment, patients still experience stigma and discrimination<sup>15,17-19</sup>.

Studies indicate that people with long-term mental disorders live marginal lives characterized by severe disability, stigma, discrimination, social isolation, unemployment, homelessness, and poverty<sup>13,15</sup>. They need support systems, such as those found in extended family members, friends, and co-workers<sup>20</sup>. The family environment is known to be a contributing factor to a patient's likelihood of relapse or rehabilitation<sup>21</sup>. A high-functioning family helps maintain communicative, emotional, and behavioral control and also helps the patient develop problem-solving and coping behaviors<sup>21</sup>. 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 method<sup>22</sup>. 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 subthemes: 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).

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