

Stigma Experienced by Caregivers of Patients with Schizophrenia: A Qualitative Study

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Abstract

Background: Stigmatization of patients with mental illness has been investigated in numerous studies. Little research has explored how caregivers of schizophrenia patients perceive and experience stigmatization.

Aim: This study designed to explore the subjective experience of stigma from the perspectives of caregivers of patients with schizophrenia, during the process of caring schizophrenic patients.

Methods: A qualitative study with in-depth interviews was used. Narrative data was obtained by 15 caregivers of schizophrenia patients. A thematic analysis method was used to analyze data.

Results: Four themes, including 10 sub-themes linked to the stigma experience of care givers. The four themes were: (a)symptom disturbance is the fundament to the root of calamity;(b)negative perception is a shackle strapped to you for all life; (c) illness in a family leads to a lifelong labor; (d)not knowing the path of the future.

Conclusions/Implications to clinical practices: The findings from this study could help psychiatric nurses to recognize the stigma experience caregivers had faced during the process of caring schizophrenia patients. The findings also call for the development of anti-stigma programs, which are needed to help reduce discrimination towards individuals with schizophrenia in Taiwan.

Introduction

Schizophrenia is a type of mental health disability characterized by such symptoms as hallucinations, delusions, or lack of insight. Due to a lack of public understanding, a patient with schizophrenia is often stigmatized and referred to in negative terms such as “violent” or “frightening” [1]. In clinical practice, when nurses discuss discharge plans with families of mentally ill patients, these families often demonstrate feelings of helplessness and inferiority because they fear the patient might be rejected by the general public when he/she returns home. The negative impression of the general public toward patients with mental illnesses creates difficulty for the patients’ family members.

Stigma refers to feelings of shame rather than a mark engraved on a person’s body [2]. Lee [3] analyzed the concept of “stigma,” indicating that stigma is a diverse concept and a symbol of being disreputable that arouses hatred and annoyance in others. Stigma symbolizes a meaning of shame that far exceeds the meaning on the surface. Stigma comprises two components: specific factors that cause people of the outside world to discriminate against patients, and the awareness of patients themselves. Struening et al. [4] also indicated that stigma includes rejection by others in addition to individual shame. Stigma comprises negative internal emotions triggered by external factors, therefore patients with mental illness often feel ashamed because of their disease condition or their perceptions of inferiority to others. This feeling of shame may originate from interacting with family members, spouses, friends, or colleagues [5]. Many mentally ill patients internalize their past experiences of stigma into long-term negative perception, resulting in low self-esteem and self-efficacy [6].

Family members are crucial as caregivers for mentally ill patients [4]. This role induces the perceptions of care overload, fear, and distress among family members [7]. Approximately 75% of patients with schizophrenia are primarily cared for by their parents. Female family members living with these patients are typically the ones

who provide the patients with complete information [8]. According to Lee, et al. [9] family members feel that caring for patients with schizophrenia is a type of never-ending labor and suffering in which they have no choice but to adequately fulfill the role and responsibility entailed within. The primary caregivers of mentally ill patients realize that the impact of stigma stems mainly from the characteristics of mental illness [10]. After an unexpected onset of schizophrenic symptoms, the social distress triggered creates social stigma, which extends its influence from the patient to his/her family members.

According to the literature review, caring for patients with mental illness is a responsibility primary caregivers assume, but not by choice. In addition, the negative perception of stigma generates an intangible burden. Link et al. [10] reviewed 109 empirical articles (that have assessed mental illness stigma) published between January 1995 and June 2003, the results showed that the qualitative research in this review of journals was relatively rare (13.8%). Of the 109 empirical studies, family members was the most rare type of study populations, only 10.1% (n=11) studies assessed stigma in sample of caregivers of patients with mental illness. As the same condition, few qualitative studies have extensively investigated the social stigma experienced during the care process among family members who care for mentally ill patients in Taiwan. Therefore, the present study aimed to clarify the experiences of primary caregivers when caring for patients with schizophrenia to examine these caregivers’ perceptions of being

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Citation: Huang HM, Jen YC, Lien YF (2016) Stigma Experienced by Caregivers of Patients with Schizophrenia: A Qualitative Study. Int J Nurs Clin Pract 3: 182. doi: <http://dx.doi.org/10.15344/2394-4978/2016/182>

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stigmatized, in Taiwan. The results of this study can help nurses who specialize in mental health understand the experiences of stigma among the family members of patients with schizophrenia, thereby strengthening cooperation between the two parties.

Materials & Method

This paper is a portion of a larger research area whose aim was to develop an understanding of stigma perceptions and coping behaviors of schizophrenic patients' families [11]. The study used a qualitative approach with in-depth interviews to explore the stigma experience from the perspectives of caregivers of patients with schizophrenia during the process of caring schizophrenia patients.

Participants

In this study, a purposive sampling was used because it would provide rich information data [12]. Through referrals from hospital nurses, 15 primary caregivers (i.e., family members) of patients with schizophrenia were interviewed in this study. Except for family members who themselves are mentally ill, the participants of this study had to meet the following four inclusion criteria: (1) They were primary caregivers of patients who had been diagnosed with schizophrenia by a physician in accordance with the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition; (2) they had cared for these patients for at least 2 years; (3) they were able to communicate in Mandarin Chinese or Taiwanese; and (4) they signed the research consent forms.

The 15 primary caregivers of patients with schizophrenia in this study comprised eight men and seven women. Their ages between 29 and 83 years; average age was 57 years, and five were older than 60. Eight of them were unemployed, and nine were the parents of their patients. In addition to the parents of the patients, the participants also included the patients' sons, sisters-in-law, husbands, and older sisters. The participants had cared for the patients for a period between 4 and 33 years, and seven had cared for the patients for at least 20 years.

Data collection

The research site was the psychiatric ward of a teaching hospital in Southern Taiwan, where the acute, chronic, and day-care wards offered a total of 120 beds provided specifically for schizophrenia care. After the consent of the participants was received, 50- to 60-minute in-depth interviews were conducted in the ward meeting room. Audio recordings were used to collect data. Data were collected for analysis until data saturation was reached [13]. After a pilot study, the interview guidelines were revised and contained the following three questions: (1) Please describe your experience in caring for the mentally ill patients; (2) what is your opinion regarding the general public's thoughts and perceptions of mentally ill patients?; and (3) what situations have you encountered due to the fact that one of your family members has schizophrenia?

Ethical considerations

Institutional Review Board (IRB) approval was obtained from the study hospital (No: 96-01-05). Four steps were taken to protect participants from harm. They were: (1) The consent letter had to be signed by the participants before the interview; (2) The participants could decide to continue or withdraw from the study at any time. (3) Each participant's personal information was collected by code to ensure confidentiality. (4) The researcher would follow-up with the participants and contact them within one week after the interview

and referral would be made to a mental health professional if deemed necessary.

Rigors

The rigor of this study was established by using four methods of Lincoln and Guba [14]. They were: (1) Credibility: three participants were invited to member check hence helping review the meaning, sub-themes and themes that emerged from data analysis; (2) Transferability: Verbatim text of the interview has been transcribed accurately for presentation in this study. The findings were provided to one clinical nurse. (3) Dependability: two researchers who have experienced in qualitative research scrutinized the total process of the data analysis; (4) Conformability: All of the original material, including verbatim draft, reflective journal and data analysis records were locked in a personal filing cabinet.

Data analysis

Thematic analysis method was used to analyze the interview data [13]. The analysis was performed according to a continuous "whole-part-whole" framework. To summarize the interview data, common themes, meanings behind the experiences, and nature of these experiences were extracted on the basis of the participant experiences.

Results

Nearly all participants in the study reported perception of stigma across a variety of social settings that they encounter on a daily basis. Although it is not surprising that participants report stigma across these varied social relations and identity domains, our purpose here is: (a) to point to the quality of stigma as lived experience in each of the contexts, and (b) to indicate how the set of contexts constitutes a comprehensive framework of the struggle to caring patients recover from psychotic illness. After data were organized and analyzed, four themes and 10 subthemes were derived to reveal the nature of care involved in the stigma experiences of the primary caregivers. Subsequently, the themes of these stigma experiences were listed in Table1 to show the associations among the themes.

Themes	Subthemes
Symptom disturbance is the fundament to the root of calamity	1. Multivariable symptoms that are disturbing to the self
	2. I also suffer when you suffer
Negative perception is a shackle strapped to you for all life	1. Stigma from others is a bitterness that is difficult to express
	2. A shackle of inheritance that is strapped to you for life
	3. A self-imposed stigma that is triggered occasionally
Illness in a family leads to a lifelong labor	1. I must assume the responsibility alone of being an irreplaceable caretaker
	2. Financial burden has added to the family's woe
	3. A care process filled with multitude of conflicts
Not knowing the path of the future	1. A small wish that is difficult to come true
	2. Multiple obstacles ahead in the future

Table 1: Themes of stigma experiences.

Theme 1: Symptom disturbance is the fundament to the root of calamity

During the care process, the participants felt heavily burdened when perceiving the patients' positive and negative mental symptoms. The participants believed that the patients' mental symptoms affected the patients and themselves. The two subthemes, "multivariable symptoms that are disturbing to the self" and "I also suffer when you suffer," reflect the disturbing effects that the patients' mental symptoms have on the participants.

Multivariable symptoms that is disturbing to the self

To the caregivers of people with schizophrenia, the multiple symptoms of the patients with schizophrenia often resulted in a behavior and thought process that differed from those presented before the onset of the disease. Consequently, the patients could not meet social norms and departed from social expectations. In facing all sorts of symptoms/ signs, there were emotional consequences to having such a highly stigmatized illness, causing their primary caregivers to experience negative evaluations and feelings of shame.

Ms. C: The first time he showed symptoms, I had not had any children yet. At that time, he would hit people, and his condition was not stable. Everyone believed that he was violent. He went in and out of the hospital frequently. As a result, after that incident, he went into the hospital again... Yes! I hid in a corner with my children. My children were older then, one was four and the other was five. When he had outbursts then, he would still hit people.

I also suffer when you suffer

The primary caregivers suffered when witnessing their family members struggle with mental illness. The recurrence of mental illness also disturbed the lifestyles of these family members. A participant shared his experiences when being disturbed by his patient's symptoms as follows:

Mr. J: ... When it is most severe, she strips herself naked. This worries me until I cannot sleep. Hey! So I watch her. If she strips herself naked at night, then I cannot sleep. I watch her all night to make sure she does not run out. If she runs out, it would be humiliating.

Theme2: Negative perception is a shackle strapped to you for all life

The participants expressed feelings confined by stigma during the care process through the subthemes of "stigma from others is a bitterness that is difficult to express," "a shackle of inheritance that is strapped to you for life," and "a self-imposed stigma that is triggered occasionally." They were visibly upset as they recounted the process of caring for the patients. They also used words and phrases such as "lunatic" and "ticking time bomb" to describe their experiences. Two of the participants narrated their experiences of stigma as follows:

Stigma from others is a bitterness that is difficult to express

After the patients were discharged and returned home, they were avoided in the participants' communities. The isolation and community ridicule inflicted incessant pain upon the participants, deeply ingrained inside them.

Mr. L: Our society cannot accept this kind of disease. Nobody can accept it. You say you would feel sympathetic. To put it bluntly, if my

family did not have such a patient, if you took the children outside and saw someone like that, then you would say, "Ah, that lunatic" and pull the children away quickly.

A shackle of inheritance that is strapped to you for life

For the participants, some stigma emanated from the misconception regarding genetic disorders. The participants were concerned that the mental illness is an intergenerational disorder, and worried that they would become mentally ill in the near future. A participant disclosed her perception of genetics as follows:

Ms. H: Because my mother-in-law is also like this, I wonder whether she has these genes... I do not know whether it is hereditary or not, but when Ah-Wu (patient pseudonym) was young, he was not like this. He began to be like this after he joined the military. Is it genetic or not?

A self-imposed stigma that is triggered occasionally

The participants experienced stigma related to schizophrenia diagnosis when caring for the patients. They believed that patients with schizophrenia are hospitalized in a "lunatic asylum" or a "cuckoo's nest," where they are subject to unexpected treatments, which trigger self-stigma in the participants.

Mr. L: That was just the first time! I was worried after my mother was sent over. At that time, I had never had any contact with this kind of patient. I just said to myself, "It is all over. Mother must be sent to a lunatic asylum to a cuckoo's nest. She will receive some kind of electrotherapy or electrical shock or whatever." I felt very panicky at that time.

Theme3: Illness in a family leads to a lifelong labor

Because their family members had mental illnesses, the participants experienced the following care-related situations: "I must assume the responsibility alone of being an irreplaceable caretaker," "Financial burden has added to the family's woe," and "a care process filled with multitude of conflicts." Caring for mentally ill family members is an irrevocable responsibility carried on their shoulders and a burden encumbered with lifelong labor. The participants delineated their life experiences as follows:

I must assume the responsibility alone of being an irreplaceable caretaker

The participants felt obligated to care for the patients because of their love for their children, filial piety, obligation to siblings, loyalty between husband and wife, and sense of responsibility. However, the participants often felt lonely and helpless when caring for the patients because they perceived that nobody was willing to assist them. Some of the participants felt that they could break free from their roles as primary caregivers only when they died. A participant recalled her experience as follows:

Ms. D: Would people be like this if they had nothing wrong with them? When people are okay, they do not break and smash objects. They do not throw objects like this. I almost collapsed from wrestling with him (to stop him). Seeing how upset he was also made me feel upset! I was the only one trying to stop him. No one paid attention to me.

Financial burden has added to the family's woe

The participants believed that because of various stigma-related situations, such as being "physically incapable," "unable to concentrate," or "their medical records showed schizophrenia," the patients could not find stable work. They were also required to help the patients cope with the aftermath of their outbursts. Consequently, this job instability and the aftermath inflicted incurred additional financial burdens that added to the family's woe.

Ms. K: It is frustrating! I am concerned with him and have to watch him every day by myself. I am afraid that he will pound against the wall and hurt himself, that he will hurt someone else, everything! It is like we elders have to take responsibility for his cost of living. Our financial situation is not good. It is frustrating!

A care process filled with multitude of conflicts

The patients' conditions were inconsistent. Moreover, the care belief held among the participants and the family members differed. Questions ranging from where to settle the patient, to whether the patient should be discharged from the hospital are all stigma-related situations perceived by the primary caregivers during the care process. It can be said that the care process involved constant conflicts between patients and their families. A participant gave an account of her experience as follows:

Mr. N: The night before the day I took my mom here (hospital), it was my sick wife's turn to argue with me. It wasn't purely an argument, it was more like she was insanely mad screaming at me (Mr. N reveals feeling of helplessness yet with an indignant expression on his face).

Theme 4: Not knowing the path of the future

The participants were well aware that their hope for the disease to be cured and for patients to become self-reliant so that family members no longer have to care for them cannot be realized. In addition, institutions cannot provide care to patients for long period. When faced with the dilemma in patient care after the patient is discharged, the participants felt a sense of uncertainty for the future ahead of them. This theme, "not knowing the path of the future" comprised two subthemes: "a small wish that is difficult to come true" and "multiple obstacles ahead in the future." The participants had the following views:

A small wish that is difficult to come true

The participants hoped that the conditions of their family members would improve and that the patients could be settled in hospitals. However, as they experienced mental illness stigma during the care process, they realized that these hopes were unrealistic and that they could only yearn for such hope. One participant shared her experience as follows:

Ms. K: I think it does not matter if he does not work; if he is well, then that is fine with me. It is okay if he does not work just so long as he is well. As long as he does not have outbursts and worry me so much, that will be good enough.

Multiple obstacles ahead in the future

During the care process, the participants held no hope for the future,

feeling "hopeless" and "worrisome." They had no idea how to proceed further and thus could only wait and see what lies ahead. A participant described the future resettling of her patient as follows:

Ms. F: Ah! There is no hope. What can I hope for at this point? There is absolutely no hope. I do not dare think of it [eyes tearing up]. Anyway, I will just go with the flow. That is how it is when you reach this point!

Discussion

In this study, stigma toward the participants originated from participants' interaction with others in their daily life. The participants experienced stigma more deeply than others did. The participants personally experienced how society perceives and treats mentally ill patients. According to the findings of this study, the participants experienced helplessness derived from the uncertainty for the future (i.e., the theme, not knowing the path of the future). As indicated by Phelan, et al. [15], stigma is a problem that must be overcome to care for mentally ill patients. In this study, as the patients' mental symptoms grew more severe, the participants' burden to provide care became heavier, and the shackle of the mental illness stigma became more tightly bound to the participants. Additionally, media reports of violence committed by mentally ill patients increased the stigmatization of participants [16]. Yeh [17] reported that the burden imposed on the primary caregivers of patients with schizophrenia in the community stems from the caregivers' sense of stigma and guilt. In the present study, the participants also stated that, when their family member was diagnosed with mental illness, their only option was to exhaust their own physical strength and endure the mental suffering.

The participants in this study felt heavily burdened because of the duty of care that falls upon them. In actuality, the head of a household typically experiences a heavy burden [18,19]. Having a mentally ill patient at home is a never-ending labor and burden they had to carry, though not by choice [9].

Conclusion

This study presents experiences of stigma encountered in the process of caring for mentally ill patients. During this process, primary caregivers encounter many problems. Because their family members had mental illnesses, the caregivers experienced stigma in four forms when providing care: "symptom disturbance is the fundament to the root of calamity," "negative perception is a shackle strapped to you for all life," "illness in a family leads to a lifelong labor," and "not knowing the path of the future." The caregivers felt that they were unable to escape the stigma that accompanied caring for their mentally ill family members. They were disturbed by their family members' symptoms. They were forced to exert their utmost effort, both mentally and physically, in caring for their family members because "they are my family." As observed from their care experiences, family members were worried that when they are old or dead, what would happen to the patient. Nevertheless, by continually monitoring patients' conditions to predict the future, these family members transformed the terror palpating within them into courage for facing their future predicaments. Therefore, it is crucial that mental health nurses can help family members adapt to patient mental illness while understanding the difficulties these families face.

Limitations

This study adopted convenience sampling because of human

resource limitations. Participants were recruited only from one hospital in Southern Taiwan. Additionally, the research topic centered on the experiences of stigma among the primary caregivers of schizophrenia patients during the care process. However, because in-depth interviews were conducted for a small sample in this study, the results cannot be generalized to the primary caregivers of patients with schizophrenia in hospitals across Taiwan.

Suggestions

The primary caregivers of mentally ill patients experience stronger stigma than community people do. To mitigate such suffering, nurses could understand the stigma faced by primary caregivers. Thus, this study provides the following recommendations for nurses: (a) The results of this study clarify the suffering primary caregivers experience when caring for mentally ill patients because of the stigma surrounding mental illness. Fighting stigma for caregivers of schizophrenia patients is the other big challenge, since it requires changes in societal imagination. Health education approached should be promoted for community people. Nurses could hold community events (similar to those held for smoking and betel nut cessation) in which they can educate people on the concept of mental health, to enhance people's understanding of patients with mental illnesses. Consequently, the stigma that community people have toward mentally ill patients can be eliminated. (b) The development of means to increase access to information and knowledge about the illness may be the most viable way to obtain improvement. Nurses can provide the caregivers of schizophrenic patients with improved care experiences through family support groups. (c) Nurses should understand that the primary caregivers of mentally ill patients typically gain distinct lived experiences during the care process. This study investigated only 15 primary caregivers of patients with chronic schizophrenia. Future researchers are recommended to expand the research sample to enhance the transferability of the research results.

Competing Interests

The authors declare that they have no competing interests.

Author contributions

HMH is responsible for the idea behind this study and its structure. YCJ collected all the data and the data analysis. HMH & YFL are responsible for the introduction and discussion part. All authors developed the preparation of the manuscript.

Acknowledgements

The authors thank the 15 caregivers of schizophrenia patients who participated to the study, and thank the reviewers for their comments for improving the manuscript.

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