Compassion Fatigue Among Family Caregivers of Schizophrenic Patients

Ratchaneekorn Upasen[1] and Weeraphol Saengpanya[2*]

[1] Faculty of Nursing, Chulalongkorn University, Thailand
[2] Faculty of Education, Chulalongkorn University, Thailand
* Weeraphol Saengpanya, corresponding author. Email: weeraphol.s@chula.ac.th
Submitted: 26 March 2021, Accepted: 6 August 2021, Published: 29 August 2021
Volume 30, 2022. pp. 1-17. http://doi.org/10.25133/JPSSv302022.001

Abstract

Caring for schizophrenic patients can cause long-term family caregivers to experience suffering and compassion fatigue (CF). However, the manifestations of CF among family caregivers of schizophrenic patients are unclear. The purpose of this study was to explore manifestations of CF among family caregivers of schizophrenic patients. In this study, grounded theory was used, and purposive and theoretical sampling was employed to recruit participants. Data were collected from 29 family caregivers through in-depth interviews and field notes. Constant and comparative methods were used to analyze data. The study revealed that participants had experienced several manifestations of CF, including stress, physical and mental exhaustion, disheartenment, anxiety and uncertainty, difficulty sleeping, a feeling of endless hard work, and a strong bonding with the patient. Compassion fatigue among family caregivers is a major concern impacting their ability to care for and aid schizophrenic patients. These findings can alert mental health professionals, including mental health nurses, to improve awareness and understanding of CF experienced by family caregivers. Mental health professionals can use these findings to develop plans to assist family caregivers of schizophrenic patients in alleviating manifestations of CF among these caregivers.

Keywords

Caregiver; compassion; family; fatigue; schizophrenia

Introduction

Schizophrenia is a severe mental illness. There are 21 million schizophrenic patients worldwide, with a global incidence of 0.24 cases of schizophrenia per 1000 (Sadock et al., 2017). A survey conducted by the Department of Mental Health (2019) in Thailand found that 57,096 patients were diagnosed with schizophrenia, making it one of the leading psychiatric disorders in Thailand (379,755 patients). Schizophrenia is a form of mental illness exhibited by disorderly thinking, emotions, perception, and behaviors (Rueangtrakul, 2014). The illness shows chronic progression, with periodic relapses common among patients, and cannot be completely treated (Harvey et al., 2019; Sadock et al., 2017). In terms of pathology, the illness causes a deficit of self-care, a lack of vocational skills, loss of perception, lowered social skills, and a decline in personality (Lortrakul & Sukhanit, 2012). Although patients can remain functional within their communities, they tend to periodically exhibit positive, negative, and other symptoms of the illness. In addition, research shows that schizophrenia is a debilitating disease seeing as schizophrenic patients are often cognitively, functionally, and socially impaired (Harvey et al., 2019), which influences their lifestyles (Kalinowska et al., 2021).

From a report by the Department of Mental Health in 2016, it was found that around 30% of schizophrenic patients in communities in Thailand exhibited a variety of negative symptoms; examples of these include possessing a ‘poker face’ (appearing unaffected by stressful situations), being laconic, showing an absence of eagerness, and lacking the basic living skills required to perform daily activities and live with other people (Department of Mental Health, 2016). Then, caring for the patients in the community may influence the family caregivers. In the Thai context, when a family has a member diagnosed with an illness, it is the responsibility and a traditional belief in the Thai society which family members must take care of the unwell family members at home rather than sending them to stay at hospice care (Petcharatachart, 2006). For instance, a family with two members, a mother, and a son suffering from a disease or high dependence on care, leaves the mother providing care alone. The son’s illness may impact the mother who cares for the son. The mother must encounter difficult things such as leaving work that results in problems with the family's financial, physical, mental health, and social interaction (Sawatphol, 2017).

Several studies explicitly stated that family members who were the primary caregivers of schizophrenic patients at home encountered severe difficulties, affecting their ability to care for the patient. For example, when patients experience relapses or display violent behavior, caregivers were required to find ways to control the patients, obtain help from the police, ensure patients attended hospital appointments and managed the patient’s medication (Conn, 2003; Kung, 2003; Sawatzky & Fowler-Kerry, 2003; Young et al., 2019). In addition, family members were forced to deal with the constantly changing mental symptoms of schizophrenic patients, such as delusions, hallucinations, and weird and violent behaviors, as well as other symptoms such as anxiety and stress (O’Brien et al., 2008; Young et al., 2019). However, the family caregivers, particularly the primary caregivers, still lack in understanding of the illness and medication, resulting in poor guidance for medication compliance, a gap when communicating with health professionals, and inadequate assessment follow-up (Alasmee & Hasan, 2020). These symptoms and limitations can cause primary caregivers to feel overburdened, and that proper caregiving is beyond their ability, causing health problems and a deteriorating quality of life (Wan & Wong, 2019; Young et al., 2019). This is in accordance with a previous study that showed that family caregivers experienced a poor quality of life due to the additional responsibilities of caring for a patient (Ndikuno et al., 2016). Additionally, other studies found that family caregivers experienced CF while caring for patients (Blair & Perry, 2016; Lynch & Lobo, 2012;

Perry & Edwards, 2015), especially family caregivers who had been caring for patients either over a long period or caring for patients with severe acute diseases (Lynch & Lobo, 2012). However, it is unclear how prevalent CF is among family caregivers of people with schizophrenia.

Compassion fatigue (CF) is defined as an expression of emotions, feelings, and behaviors of helplessness, disappointment, stress, a feeling of endless hard work, guilt, uncertainty, social isolation, dissatisfaction, and a lowered level of ability among family caregivers (Blair & Perry, 2016). These stressful effects of CF were directly caused by caring for patients in order to relieve the patients' suffering. From reviewing international literature on CF, it was found that most studies focused on caregivers who were members of healthcare teams, primarily nurses in long-term care situations such as dealing with cancer patients or patients with acute and severe mental disorders (Centrano et al., 2017; Denigris et al., 2016; Dikmen et al., 2016; Lynch & Lobo, 2012; Sinclair et al., 2017). These studies illustrated that the suffering caused by a patient's illness could affect caregivers even though these caregivers had a professional healthcare background and possessed the requisite ability to provide care to patients with compassion, generosity, and helpfulness.

However, only a few studies on CF among family caregiver groups exist. For example, Perry and Edwards (2015) conducted qualitative research on CF among caregivers at long-term care centers. Their results revealed that most family caregivers experienced CF when they had to look after patients with chronic diseases over a long period due to having to provide constant monitoring and protection regarding the demands and response to treatment of the patients (relentless vigilance). Simultaneously, family caregivers were required to deal with continuous changes and role confusion (Perry & Edwards, 2015). This was consistent with a literature review on CF of family caregivers by Blair & Perry (2016), which showed that most family caregivers felt responsible for adequately looking after patients due to their emotional attachment to, and satisfaction gained from, taking care of the patient. However, caregivers may at times feel guilty, helpless, disappointed, uncertain, indifferent, and dissatisfied when constantly forced to give care to patients. These findings were consistent with a study conducted by Day and Anderson (2011), who reviewed the literature on CF of caregivers of patients with dementia. Their results revealed that most caregivers experienced CF through feeling disappointment, helplessness, and a lack of interest and intention towards patients, ultimately resulting in the avoidance of providing care to the patient. Other studies showed that CF occurred among family caregivers who looked after patients with an understanding and realization of the suffering caused by patients' illness (Blair & Perry, 2017; Day & Anderson, 2011; Lynch & Lobo, 2012; Perry & Edwards, 2015). Consequently, if family caregivers do not receive help in relieving CF, it may cause family caregivers to encounter multiple problems such as depression, stress, a feeling of being overburdened, the impairment of relationship with other persons, and other health problems, leading to caregivers being ignorant toward patients or the termination of caregiving (Blair & Perry, 2017; Day & Anderson, 2011). These effects reflected the necessity of nurses and health professionals to emphasize and understand the problems and effects occurring with family caregivers, especially CF, due to the direct experiences of family caregivers.

However, although current studies focusing on CF in nurses and family caregivers of patients with problems other than schizophrenia exist, there are currently no studies on CF among family caregivers of people with schizophrenia in Thailand. Consequently, this lack of information may cause mental health professionals to lack a correct understanding of the problems experienced by caregivers looking after schizophrenic patients during each phase of mental illness. Therefore, this study aims to understand the CF experienced by family caregivers caring for schizophrenic patients to enable nurses and health professionals to reduce or prevent CF among family caregivers. These results could potentially improve and expand mental health services for family caregivers and schizophrenic patients to enable them to satisfactorily spend their lives together. To accomplish this, this study explored the manifestations of care among family caregivers of schizophrenic patients.

Method

Study design

This study is part of a larger grounded theory study that aimed to explore manifestations of CF among family caregivers of schizophrenic patients. Just as with the larger study, utilizing grounded theory, this study seeks to create fundamental theories or principles based on facts obtained from real situations and the perception of persons in those situations (Glaser & Strauss, 2017).

Participants and sampling

The settings for this research consisted of a psychiatric hospital and a general hospital with a Department of Psychiatry overseen by the Department of Mental Health and the Office of the Permanent Secretary for the Ministry of Public Health. The participants were selected using purposive and theoretical sampling in order to gain more complete and reliable data. Purposive sampling selects participants with qualifications as defined by the researchers. The inclusion criteria were as follows: 1) The participants must be primary caregivers over 20 years of age and who provide care for schizophrenic patients who are family members diagnosed with schizophrenia; 2) the participants must be family members who were relatives and who were not hired for caregiving, with their primary duties of directly looking after schizophrenic patients without receiving any compensation for at least two or more years; 3) the participants could expound upon their suffering due from caring for schizophrenic patients; and 4) they were able to communicate their willingness to participate in this research by using the Thai language. Moreover, this study also applied theoretical sampling to obtain informants with qualifications consistent with its concepts and theories. The research also found that data saturation occurred after interviewing the twenty-ninth family of caregivers.

Ethical consideration and approval

In order to protect the participant's anonymity, informed consent and the right to decline participation at any time during the research were presented. In addition, this study received ethical approval from the Office of the Research Ethics Review Committee for Research Involving Human Subjects: The First Allied Academic Group in Health Sciences, Chulalongkorn University (Project No. 106.1/63).

Data collection

Data collection was conducted over five months, from August to December 2020, after receiving permission from a psychiatric hospital and a general hospital. After gaining consent forms from the 29 family caregivers of schizophrenic patients, researchers made appointments with the informants by giving them opportunities to choose the date, time, and venue of the interview with consideration for the privacy, satisfaction, and convenience of transportation.

Data were collected using in-depth interviews with family caregivers who accompany the patients to the hospital for outpatient services.

During interviews, researchers used open-ended questions to encourage the informants to speak about their experiences with compassion fatigue caused by their willingness to give care to patients with compassion and sincerity. The central question used for gaining data with the family caregivers was, "Could you tell me about your experiences about caregiving at home with a schizophrenic patient?" The question would make the informants feel free to answer the questions and provide as many details as possible. During the interview, the informants' behaviors, facial expressions, and gestures were observed. The duration of each interview was 45-60 minutes and was recorded for subsequent data analysis. For checking the rigor of the data, the transcripts were returned to three participants to validate the data. No participants add more any data.

Data analysis

Data from this research were analyzed using the constant comparative method (Glaser & Strauss, 2017). The data analysis of this study occurred alongside the data collection process. The researchers used the following guidelines to find and mutually discuss what data occurred and how to gain such data again. Open coding was the first stage of data analysis, in which researchers read the conversation with each informant several times thoroughly and repeatedly line by line, word by word, or phrase by phrase. Subsequently, the researchers provided substantive theory code that would be provided in each conversation and used this coding repeatedly. If a message had a phrase or sentence similar to the defined code, such code would be given as well. To provide codes, the researchers defined the codes based on the types of situations, activities, and behaviors currently experienced by the informant. Simultaneously, the researchers compared information from each situation, activity, and behavior extensively in order to consider whether it was a similar or different situation, activity, or behavior with similar meanings. Selective coding was the process used to reduce defined codes to obtain variables or occurring issues. After providing codes, the researchers searched for major categories by classifying information with coding. If they had the same or similar meaning, they would be classified in the same group. Subsequently, the researchers defined or named such categories. Theoretical coding consisted of the researchers considering the involvement and connection of each category, sub-category, and property after obtaining these. Emerging categories and properties were then linked with theoretical codes. Examples of major categories, sub-categories, and coding are presented in Table 1.

Table 1. Examples of Major Categories, Sub-Categories, and Coding

Major categories	Sub-categories	Coding
Experiencing compassion fatigue	Living with stress for an extended period	- So much stress each day - I was stressed - It was stressful in my life
	Physical or mental exhaustion or both	- I was very tried - I feel mental exhaustion - I had physical or mental exhaustion or both
	Being disheartened	- Being disheartened - I was disheartened - It is disheartening sometimes
	Anxiety and uncertainty	- It is worrying about the patient

Major categories	Sub-categories	Coding
		- I was worried and concerned about the patient's symptoms - I was not sure when the patient would be better and normal
	Difficulty sleeping	- I could not sleep well - I kept watching the patient at nighttime - I could not sleep early
	Endless hard work	- It was hard for me to do everything - It is hard work all the time - I felt that I must work hard all the time
	Strongly bonding with the patients	- There is still bonding between me and my son (the patient). - I still love the patient - There is bonding between me and the patient

Findings

Demographic characteristics

Twenty-four interviewed participants were female. The mean age of the participants was 51.5 years. Twenty-one participants were married. Most of the participants had a primary school education level. The length of caring for the schizophrenic patients of most participants was 2-5 years. For the relationship with the schizophrenic patients, most of the participants were the mothers of the schizophrenic patients. Details of the personal characteristics of the participants are presented in Table 2.

Table 2: Demographic Characteristics of the Twenty-Nine Participants (n = 29)

Personal characteristics	Total of participants
Gender	
Male	5
Female	24
Ages (years)	
25-35	5
36-46	5
47-57	10
58-66	6
67 and above	3
(mean = 51.55, min = 28, max = 76)	
Marital Status	
Single	6
Married	21
Divorced/Separated	2
Education level	
No study	2
Primary school	16

Personal characteristics	Total of participants
Secondary school	8
Bachelor's degree and above	3
Length of caring for patients (years)	
2-5	12
6-10	8
11-15	2
More than 16	7
(mean = 9.87, min = 2, max = 30)	
Relationship with the patient	
Mother	13
Father	2
Husband	2
Wife	2
Others (daughter/son/brother/sister/niece)	10

Experiencing compassion fatigue in caring for persons with schizophrenia

In caring for people with schizophrenia, 29 participants were primary caregivers experiencing compassion fatigue (CF) while caring for schizophrenic patients. The participants shared their experiences about CF in various feelings and forms of suffering comprising seven themes: living with stress over a long period, physical or mental exhaustion or both, disheartenment, anxiety, difficulty sleeping, endless hard work, and living with uncertainty. Details for each theme are described as follows:

Living with stress for long periods

Caring for schizophrenic patients impacted the family caregivers, including primary caregivers, to experience stress. Even though the participants had experienced stress over extended periods, the participants still felt compassion for and sympathized with the schizophrenic patients. Most of the participants shared their experiences about stress while providing care for the patients. The participants understood and accepted that they were stressed, but they tried to engage in the positive self–talk that they must fight through this because they loved and were compassionate toward their patients. One participant stated:

> *I was stressed, but I had to be conscious. I kept looking after the patient. I think that he suffered from abnormal symptoms each day. I understood him. Sometimes, I think that I seem to be like the patient. I went out from home for a while. I told myself I would be back. Then, I must keep taking care of my patient because I loved and sympathized with him.* (Case 12)

Additionally, the participants shared the negative consequences of being stressed, including headaches, physical and mental weakness, and difficulty making decisions. The participants also shared that they recognized the patient's illness, and one patient understood that it was due to the patient's advanced age. As one participant stated:

> *I provided care for the patient for a long time. I was stressed. I accepted that I was very stressed. I also could not sleep sometimes. I also felt that losing energy, headache, and dizziness. I could not want to decide about anything. However, I told myself that I must be conscious and tried to think that the patient was ill and very old.* (Case 29)

Caring for schizophrenic patients caused the participants to feel stressed due to living with the stress for an extended period. As a result, the participants suffered from physical or mental exhaustion or both.

Physical or mental exhaustion or both

Physical or mental exhaustion is the second theme that was described by the participants. Most of the participants shared feelings of exhaustion while caring for schizophrenic patients. The participants' described their exhaustion as being very tired, feeling weakness, or being drained of energy, both physically and mentally. The participants also shared that they were constantly exhausted and that it was never-ending, particularly in terms of mental exhaustion. Aside from this, the participants were much more mentally exhausted when the patients expressed more psychotic symptoms of schizophrenia, including both positive and negative symptoms. Physical exhaustion experienced by the informants included muscle weakness, sleepiness, and dizziness. The participants defined mental exhaustion as a feeling of dread, a lack of motivation, a feeling of not caring for or detachment from the patient, headaches, perceived problems with caring for the schizophrenic patients, and other responsibilities that seemed impossible to overcome. Mental exhaustion may be caused by physical exhaustion. As one participant stated:

> *I felt that I was exhausted both physically and mentally, in particular mental exhaustion. I must be patient for the family. I felt that due to the patient being disabled and unable to do anything. The patient did not listen to me. I tried to talk about something, but the patient did not listen to me. I told myself that I must be patient and keep going.* (Case 14)

One participant also shared an experience of both physical and mental exhaustion while caring for the schizophrenic patient. The participant, however, mentioned that physical exhaustion could occur and disappear within a few days; the mental fatigue, however, was more challenging to deal with. The participant stated:

> *My opinion, caring for this schizophrenic patient made me have a feeling of both physical and mental exhaustion. I think that I was physically exhausted. I could overcome the exhaustion. I was able to be patient. However, I was unable to control or release the mental exhaustion for few days. Sometimes, when I was mentally exhausted, I would often quarrel with my family members, such as my husband. I wanted to go away from my home.* (Case 15)

Being disheartened

Most participants shared that caring for schizophrenic patients also gave them a sense of disheartenment or despair. The participants talked about the demoralization, declining motivation, and frustration experienced while caring for a schizophrenic patient. When describing these feelings, the participants stated that they occurred in a near-constant state. In addition, these feelings occurred at a higher level either when the patient was exhibiting active psychotic symptoms or when the family caregiver was forced to be the sole long-term care provider. As a result, they occasionally did not want to provide care for their patients. This is demonstrated in the following comments from participants:

> *Often, I felt that it was disheartening. I want the patient to be better. I think. But sometimes, I was okay about caring for the schizophrenic patient at their home. I never thought that the patient might not be better. Let it go. What would happen? That would be it.* (Case 30)
>
> *I was disheartened, but I had to fight. If I did not fight, then no one would. In addition, I worked so hard because I needed to take care of my son. I wanted my son to have money and food. I must work to gain money and to get food for my son. I prepared food before he woke up in the morning.* (Case 24)

Anxiety and uncertainty

Sometimes, the participants also had felt anxiety about caring for their schizophrenic patients. This anxiety caused them to experience physical and emotional health problems. The participants stated that they felt anxious and uncertain about the schizophrenic patient. They always thought of the patients' illness even when they left the household to go to work. They also worried that the psychotic symptoms of the patient might present at any time, especially in the form of aggressive behaviors, shouting, and running away from the home to a neighbor's house. The participants' anxiety and a sense of uncertainty impacted both their physical and emotional states, inducing fear, headaches, and grouchiness. As the participants said:

> *I was worried about the patient's symptoms. I had a fear that the patient would self-harm and others- harm, as with my neighbor. Around my house, I had rental houses. So, I did not want to have problems with the neighbors. I was not sure about that.* (Case 7)
>
> *I had a big concern that the patient might return to using drugs and alcohol with his peers. I was very anxious when the patient went out to party with peers at night. I followed him to the party but kept looking after him carefully from a distance. I did not want him to be angry.* (Case 19)

One participant, especially, had shared that she almost constantly felt anxiety because the patient could not take care of himself, exhibited by the patient ignoring or forgetting to take his medicine, displaying poor hygiene, or sleeping for the entire day. The patient's disturbance influenced the participant's state of anxiety, as the participant stated:

> *It's very worrying. I had extreme anxiety each day. I pitied him when he had more active psychotic symptoms. The patient was single. His mother was very old. Sometimes, the patient helped me to take care of my kid. I must take care of him. If I did not care him, no one took care of him.* (Case 9)

Additionally, the participants expressed that they were required to live with a constant sense of uncertainty about the future from the schizophrenic patients' mental illness while caring for them. Most of the participants shared experiences that caring for schizophrenic patients gave them a feeling of unpredictability. They also described those schizophrenic patients often expressed psychotic symptoms in various ways, including paranoia, shouting, and displaying aggressive behaviors. They also did not know when these symptoms would occur, so the participants carefully monitored the patients all the time. At the same time, they were concerned about the patient's future. As one participant stated:

> *I felt that it was uncertainty about our future. The patient, sometimes, had more paranoid and walked outside to other places. At night, the patient did not sleep; he walked all the time. I did not know that he would be better. I watched the patient every night. I also was concerned with him because there was uncertainty about the patient's symptoms. It has happened many years. It might have occurred.* (Case 2)

One participant also described that caring for the schizophrenic patient affected her emotions and gave her a sense of uncertainty. The participant sometimes felt negative emotions such as anger, irritability, and disappointment. As the participant said:

> *I felt that it's uncertain, but I had to care for him further. I accepted that he was ill. He also accepted his illness. Sometimes, I could not stand. I was angry and edgy. I was fierce with him. I was irritable with his behavior disturbances. I did not know when it was going to be better.* (Case 27)

As illustrated above, the participants experienced anxiety and uncertainty while providing care for schizophrenic patients. The participants' anxiety and uncertainty caused them to have difficulty sleeping.

Difficulty sleeping

The participants suffered from difficulty sleeping, which they felt was due to providing care for the schizophrenic patients. They also reported that this difficulty could have been caused by anxiety and stress. Sometimes the participants experienced sleepless nights, including short sleep duration and frequent awakenings during the night because of disturbing behaviors by the patients, including them walking around and talking to themselves. Because of this, the participants experienced physical weakness, headaches, and dizziness. One consequence of this was that the participants were forced to take sleep medication. The participants stated the following:

> *Often time that I could not sleep at all at night. Some nights, I was sleepless. When I would wake up in the morning, I felt that I lost all my energy. Now, I still am tired, but it's not much.* (Case 11)
>
> *I could not sleep. I took medicine for sleeping. I thought that I was very stressed. I did not sleep until 1 AM. I saw a doctor. He told me to go to the hospital to get medication. I was very old, so it was difficult to go anywhere. I wanted to be home with my son.* (Case 17)

Endless hard work

When caring for schizophrenic patients, most participants perceived that their caring duties involved endless hard work. The participants understood that schizophrenia is a disease where the patient must be medicated or treated for many years. They, however, did not know exactly what were the causes of the illness. The informants took a major role in caring for the patient, as the participants had to care for the patients without a break every day. Some participants were required to care for the patient alone. In addition to this, they also had to leave home to work every day. The feelings of endless hard work they described might be caused by perceived physical and mental exhaustion, disheartenment, anxiety, stress, and the difficulty sleeping experienced by the participants. Even though the participants had ongoing hard work, they still sympathized and were compassionate toward the patients. As one participant said:

> *I lived with the patient. His father died. I had to work to gain money every day. However, I had to care for the patient. It was hard work. I did not have a cousin in this province. My cousins lived in another province.* (Case 26)

One participant stated that even though she lived with her son, who was ill, and her husband, the participant, and her husband both had to go to work outside. The participant felt that caring for the patient felt like endless hard work. The participant felt this way because she and her husband were both very old and had to work hard to care for the patient and earn money for the family. As the participant stated:

> *Sometimes, I cried. My husband and I were very old. I felt that I had to bear everything. It is such hard work that was not ended. I tried to talk with the patient about the burden. My husband and I could not stop caring for the patient. It was a responsibility. I told the patient. However, I tried to hearten to the patent.* (Case 12)

Even though the participants experienced living with stress for an extended period, physical or mental exhaustion or both, disheartenment, anxiety and uncertainty, difficulty sleeping, and endless hard work, they still felt a strong bond with their patients.

Strongly bonding with the patient

Strongly bonding with the patient is the last characteristic of CF found among the participants. Even though the schizophrenic patients could experience disturbances, including positive and negative symptoms, the participants still felt strongly bonded with their patients. Most of the participants expressed a willingness to care for the schizophrenic patients because the patients were loved, family members. In addition, the participants shared that they had a positive relationship in the family and were willing to spend time talking with the patients. As one participant said:

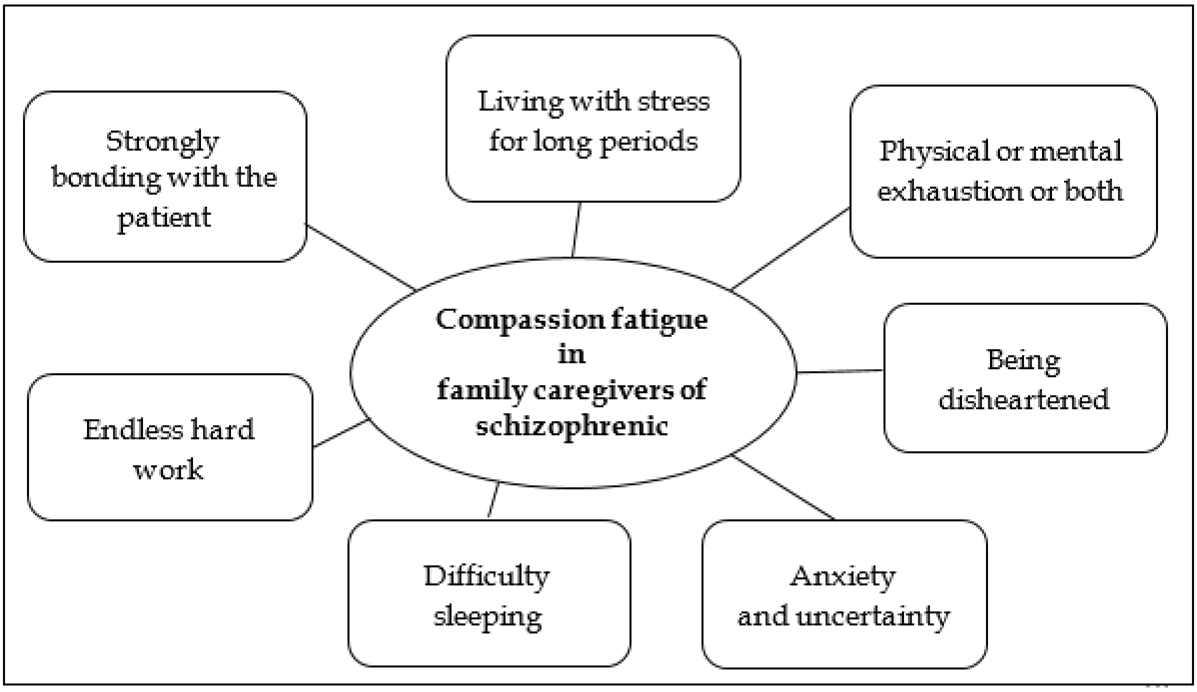
> *I lived with only the patient. The patient was my son. Sometimes, the patient always talked to me that there was someone who liked to tease him. So, I tried to give him mental support. I asked him who did it. He said that it was in his ears. So that it was an auditory hallucination, it is bonding between me and the patient. However, I still love him as usual.* (Case 19)

Some participants expressed that the patient was a good person and could perform tasks for the family. Additionally, some participants stated that patients could take care of themselves and show love toward their family members, particularly participants who were mothers. Sometimes, when the participants were stressed, the patients provided mental support and reassurance to the participants. This reflects a strong bond between the mother and the patient. As one participant said:

> *I think that it's still bonding between me and my son (the patient). The patient always talked to me and gave suggestions to me on how to do or solve the problems. The patient taught me to think before speaking out. I had more power and encouragement to live further. Live as like this in every day.* (Case 12)

When caring for people with schizophrenia, the participants who were family caregivers, particularly primary caregivers, experienced compassion fatigue characterized by living with stress for long periods, physical or mental exhaustion or both, being disheartened, anxiety and uncertainty, difficulty sleeping, endless hard work, and strong bonding with the patient. Most of the participants manifested CF in most aspects. Some participants began with only feeling disheartened, but after a few days, the participants faced other elements such as living with stress, physical or mental exhaustion or, anxiety and uncertainty, difficulty sleeping, or the feeling of endless hard work. Even with these feelings, the participants still felt a strong bond with the patients. They were also still providing care for their patients even though they were suffering from CF. The CF in family caregivers of a schizophrenic patient is presented in Figure 1.

Figure 1: CF in Family Caregivers of Schizophrenic Patients



Discussion

The study revealed that the interviewed family caregivers were experiencing compassion fatigue (CF) from providing care for schizophrenic patients. These findings are consistent with previous studies that found that the family caregivers who provide care for ill family members experienced CF, including stress, uncertainty, and feelings of endless hard work (Blair & Perry, 2017; Lynch et al., 2018; Perry & Edwards, 2015). From our findings, it is also possible that providing care for schizophrenic patients caused family caregivers to experience CF due to prolonged and intense care, on account of the suffering of the patient combined with continuous contact with them as length or years spent providing care can induce stress among the family caregivers (Lynch et al., 2018). Family caregivers are also forced to live in high-stress environments (Bush, 2009; Lee et al., 2019), which is consistent with previous studies stating that the causes of CF in family caregivers, such as hard work in caring for others and caring without rewards and results, come from the surrounding environment and workplace

(Perry & Edwards, 2015; Tunajek, 2006). This means that living in high-stress environments over a long period may negatively influence an individual's mental health in terms of stress.

Living with stress for long periods is the first theme that was described by the participants. The participants who live within tense environments for a long time might face continuous stress (Perry & Edwards, 2015). A fundamental cause of the participants' stress may be caused by providing care for schizophrenic patients' worsening problems. Even though the schizophrenic patients eventually returned to the community and live with their families, they still have disturbances regarding thoughts, emotions, perceptions, and behaviors. At the same time, these disturbances can present at any time due to various factors (Rueangtrakul, 2014). It is also possible that these disturbances can invoke the participants' perceived stress in their lives (Franza et al., 2015; Gloria et al., 2018). In addition, our findings are congruent with a previous study that found the increased duration of illness and care due to severe or persistent schizophrenic symptoms invited the informal caregivers to perceive an increased level of stress (Kamil & Velligan, 2019). According to the Stress Process Model (SPM) for family caregiving adapted by Whitlatch et al. (2001), a stressor of a family caregiver is the existence of long-term care at home. The family caregiver may be stressed and physically and mentally exhausted. Sometimes, the participants perceived less stress when the patients' psychotic symptoms were decreased.

Physical or mental exhaustion or both is the second category in which the family caregivers in this study shared their various experiences of CF due to caring for schizophrenic patients. The participants experienced varied feelings of exhaustion that matched a previous study, which found that the caregivers of individuals with persistent schizophrenia often felt overwhelmed (Kamil & Velligan, 2019). Most of the participants experienced both physical and mental exhaustion; however, some only experienced mental fatigue. It is possible that causes of the exhaustion might come from prolonged care, the existence of persistent negative symptoms, and the unpredictability of the schizophrenic patients' symptoms and behaviors. Because of these impairments and disabilities, the participants were required to perform various caregiving tasks for the patients. At night, the caregivers were required to monitor the patients to protect them from self-harm, prevent them from harming others, and prevent them from leaving the house. Moreover, the participants were required to work each day to earn money and perform household chores. Due to the added responsibilities and their daily work routines, the participants perceived both physical and mental exhaustion. However, in this study, even though the participants experienced physical or psychological exhaustion or both, they tried to encourage themselves to fight through their fatigue.

Also, family caregivers were disheartened from providing care for schizophrenic patients. These findings reflect that physical and mental exhaustion may be related to disheartening among the participants. The participants described that they sometimes felt they had lost motivation and confidence and felt helpless trying to properly care for the patients because they were the sole care providers and did not know how to deal with the exacerbation of psychotic symptoms. Furthermore, the participants perceived that they faced anxiety and uncertainty. The themes of having anxiety and uncertainty also emerged in this study. It was revealed that caring for schizophrenic patients caused the participants to feel anxious and uncertain about the future. The participants were disheartened, anxious, and uncertain because they felt they needed more competence. They required more knowledge and skills about caring for schizophrenic patients, especially when the patients experienced a relapse of psychotic symptoms. Sometimes, the schizophrenic patients had decreased psychotic symptoms. However, sometimes the schizophrenic patients expressed active psychotic symptoms. Therefore, the participants felt that they could not deal with this situation effectively. Participants also wanted to know how to encourage the patients to be able to self-monitor their medications. This finding is consistent with a previous qualitative study which found the primary caregivers had poor guidance for medication compliance (Alasmee & Hasan, 2020).

In this study, the participants retained autonomy in caring for the patients; however, they could not control or provide care to the patients all the time because they needed to do other work. They also experienced anxiety and uncertainty, causing both objective and subjective caregiving burdens. Additional negative consequences found among the participants were difficulty sleeping and a feeling of endless hard work. The sub-categories of difficulty sleeping and endless hard work emerged from the study, supporting a systematic study that found that family caregivers experienced poor sleep quality, including short sleep duration and frequent night awakenings (Byun et al., 2016). Another previous study found that nearly 45% of caregivers reported suffering from sleep maintenance insomnia and role overload (Liang et al., 2020). The participants in this study also perceived caring for the patient that is endless hard work. This might be caused by caring for the patients for years and not knowing when it would end.

Our findings also revealed that the participants experienced a strong bonding with the patient. Even though the participants lived with stress, physical or mental exhaustion or both, disheartenment, anxiety, and uncertainty over long periods and had difficulty sleeping and a sense of endless hard work, they still expressed a strong feeling of bonding with the patients. They explained that they always felt love, sympathy, kindness, and responsibility toward the patients. Besides, the participants mentioned that they must engage in giving care to the patients because of being a good person of the patients. This finding conforms with findings in previous studies that found that family members possess an emphatic response, inability to detach, lack of feeling successful, emotional attachment as the primary motivator, and a sense of responsibility (Blair & Perry, 2017; Perry et al., 2010).

Conclusion and recommendations

Our findings revealed that the interviewed family caregivers of schizophrenic patients experienced compassion fatigue. The manifestations of CF included living with stress for long periods, physical or mental exhaustion or both, disheartenment, anxiety and uncertainty, difficulty sleeping, endless hard work, and strong bonding with the patient. As such, there is a growing need to support these family caregivers so that they can live without CF while providing quality care for the patients. The family caregivers' CF should be mentioned in mental health policy so that mental health centers can provide counseling and helping centers to help these family caregivers in caring for schizophrenic patients. In addition, mental health professionals, including psychiatrists, nurses, psychologists, educators, and others, should develop effective interventions to alleviate the physical and psychological CF of family caregivers using respite care and various relaxation techniques. The schizophrenic patients' psychotic symptoms may be influenced by the caregiving abilities of the family caregivers. Improving the caregivers' competence in caring for the schizophrenic patients and empowering enhancement should be provided for the family caregivers so that the schizophrenic patients can live with their families and receive an acceptable quality of care to live happily in the community. For further research, factors influencing CF and strategies to cope with CF should be studied.

Acknowledgments

The authors are incredibly grateful to the family caregivers who participated in this study. This research is funded by the Ratchadaphiseksomphot Endowment Fund of Chulalongkorn University: CU_GR_62_86_36_01. The authors also want to thank the Faculty of Nursing and Faculty of Education, Chulalongkorn University, for giving their time and facilities to conduct this research.

References

Alasmee, N., & Hasan, A. A. (2020). Primary caregivers experience of anti-psychotic medication: A qualitative study. *Archives of Psychiatric Nursing, 34*(6), 520-528. https://doi.org/10.1016/j.apnu.2020.09.002

Blair, M., & Perry, B. (2017). Family caregiving and compassion fatigue: A literature review. *Perspective, 39*(2), 14-19.

Bush, N. J. (2009). Compassion fatigue: Are you at risk? *Oncology Nursing Forum, 36*(1), 24-28. https://doi.org/10.1188/09.onf.24-28

Byun, E., Lerdal, A., Gay, C. L., & Lee, K. A. (2016). How adult caregiving impacts sleep: A systematic review. *Current Sleep Medicine Report, 2*(4), 191-205. https://dx.doi.org/10.1007%2Fs40675-016-0058-8

Centrano, G., Tedeschi, F., Rabbi, L., Gosetti, G., Lora, A., Lamonaca, D., Manthorpe, J., & Amaddeo, F. (2017). How are compassion fatigue, burnout, and compassion satisfaction affected by quality of working life? Findings from a survey of mental health staff in Italy. *BMC Health Services Research, 17*(1), 755. https://doi.org/10.1186/s12913-017-2726-x

Conn, V. (2003). Working with families. In W. K. Mohr & B. S. Johnson (Eds.), *Johnson's psychiatric-mental health nursing* (5th ed., pp. 53–75). Lippincott Williams & Wilkins.

Day, J. R., & Anderson, R. A. (2011). Compassion fatigue: An application of the concept to informal caregivers of family members with dementia. *Nursing Research and Practice*, 408024. https://doi.org/10.1155/2011/408024

Denigris, J., Fisher, K., Maley, M., & Nolan, E. (2016). Perceived quality of work life and risk for compassion fatigue among oncology nurses: A mixed-methods study. *Oncology Nursing Forum, 43*(3), E121-E131. https://doi.org/10.1188/16.onf.e121-e131

Department of Mental Health. (2016). *รายงานประจำปีกรมสุขภาพจิต ปีงบประมาณ 2559 [Annual Report 2016].* Ministry of Public Health. https://www.dmh-elibrary.org/items/show/333

Department of Mental Health. (2019). *รายงานประจำปีกรมสุขภาพจิต ปีงบประมาณ 2562 [Annual Report 2019].* Ministry of Public Health. https://www.dmh-elibrary.org/items/show/189

Dikmen, Y., Aydin, Y., Basaran, H., Filiz, Y. N., Denat, Y., & Arslan, G. G. (2016). Prevalence of compassion fatigue in emergency and intensive care nurses in Turkey. *Oxidation Communications, 39* (4-I), 3190-3198. https://scibulcom.net/en/article/iF0uFg4apE1t0s4rtGoq

Franza, F., Del Buono, G., & Pellegrino, F. (2015). Psychiatric caregiver stress: Clinical implications of compassion fatigue. *Psychiatric Danubina, 27*(Suppl. 1), S321-S327. https://pubmed.ncbi.nlm.nih.gov/26417788/

Glaser, B. G., & Strauss, A. L. (2017). *The discovery of grounded theory: Strategies for qualitative research.* Sociology Press.

Gloria, O., Osofo, J., Goldmann, E., Parikh, N. S., Nonvignon, J., & Kretchy, I. M. A. (2018). The experiences of providing caregiving for patients with schizophrenia in the Ghanaian context. *Archives of Psychiatric Nursing, 32*(6), 815-822. https://doi.org/10.1016/j.apnu.2018.06.005

Harvey, P. D., Strassnig, M. T., & Silberstein, J. (2019). Prediction of disability in schizophrenia: Symptoms, cognition, and self-assessment. *Journal of Experimental Psychopathology, 10*(3), 1-20. https://doi.org/10.1177%2F2043808719865693

Kalinowska, S., Trześniowska-Drukała, B., Kłoda, K., Safranow, K., Misiak, B., Cyran, A., & Samochowiec, J. (2021). The association between lifestyle choices and schizophrenia symptoms. *Journal of Clinical Medicine*, *10*(1), 165. https://doi.org/10.3390/jcm10010165

Kamil, S. H., & Velligan, D. I. (2019). Caregivers of individuals with schizophrenia: Who are they and what are their challenges? *Current Opinion in Psychiatry, 32*(3), 157-163. https://doi.org/10.1097/yco.0000000000000492

Kung, W. W. (2003). The illness, stigma, culture, or immigration? Burdens on Chinese American caregivers of patients with schizophrenia. *Families in Society: The Journal of Contemporary Social Services*, *84*(4), 547-557. https://doi.org/10.1606%2F1044-3894.140

Lee, E., Daugherty, J., Eskierka, K., & Hamelin, K. (2019). Compassion fatigue and burnout, one institute's intervention. *Journal of PeriAnesthesia Nursing, 34*(4), 767-773. https://doi.org/10.1016/j.jopan.2018.11.003

Liang, J., Aranda, M. P., & Lloyd, D. A. (2020). Association between role overload and sleep disturbance among dementia caregivers: The impact of social support and social engagement. *Journal of Aging and Health*, *32*(10), 1345–1354. https://doi.org/10.1177%2F0898264320926062

Lortrakul, M., & Sukhanit, P. (2012). *จิตเวชศาสตร์ รามาธิบดี* [Ramathibodi Psychiatry] (3rd ed.). Beyond Enterprise.

Lynch, S. H., & Lobo, M. L. (2012). Compassion fatigue in family caregivers: A Wilsonian concept analysis. *Journal of Advanced Nursing*, *68*(9), 2125-2134. https://doi.org/10.1111/j.1365-2648.2012.05985.x

Lynch, S. H., Shuster, G., & Lobo, M. L. (2018). The family caregiver experience – examining the positive and negative aspects of compassion satisfaction and compassion fatigue as caregiving outcomes. *Aging & Mental Health*, *22*(11), 1424-1431. https://doi.org/10.1080/13607863.2017.1364344

Ndikuno, C., Namutebi, M., Kuteesa, J., Mukunya, D., & Olwit, C. (2016). Quality of life of caregivers of patients diagnosed with severe mental illness at the national referral hospitals in Uganda. *BMC Psychiatry, 16*, 400. https://doi.org/10.1186/s12888-016-1084-2

O'Brien, P. G., Kennedy, W. Z., & Ballard, K. A. (2008). *Psychiatric mental health nursing: An introduction to theory and practice.* Jones and Bartlett Publishers.

Petcharatachart, A. (2006). *การสร้างเสริมสุขภาพครอบครัวไทย [Thai Family Health Promotion]*. Prince of Songkla University.

Perry, B., Dalton, J. E., & Edwards, M. (2010). Family caregivers' compassion fatigue in long-term facilities. *Nursing Older People, 22*(4), 26-31. https://doi.org/10.7748/nop2010.05.22.4.26.c7734

Perry, B., & Edwards, M. (2015). A qualitative study of compassion fatigue among family caregivers in long term care homes. *Perspective*, *38* (3), 14-22.

Rueangtrakul, S. (2014). *ตำราจิตเวชศาสตร์ [Psychiatry]*. Rueankaew Publisher

Sadock, B. J., Sadock, A. V., & Ruiz, P. (2017). *Kaplan and Sadock's Comprehensive Textbook of Psychiatry*. Wolters Kluwer.

Sawatphol, C., Pengpinit, T., Senanikorn, A., & Srisuraphol, W. (2017). การดูแลผู้สูงอายุที่อยู่ในภาวะพึ่งพิง ในพื้นที่ภาคตะวันออกเฉียงเหนือของไทย [Caring for dependent older adults in the Northeast of Thailand]. *Journal of MCU Peace Studies,* *5*(Sp1), 387-405. https://so03.tci-thaijo.org/index.php/journal-peace/article/view/85915

Sawatzky, J. E., & Fowler-Kerry, S. (2003). Impact of caregiving: Listening to the voice of informal caregiver. *Journal of Psychiatric and Mental Health Nursing, 10*(3), 277-286. https://doi.org/10.1046/j.1365-2850.2003.00601.x

Sinclair, S., Raffin-Bouchal, S., Venturato, L., Mijovic-Kondejewski, J., & Smith-MacDonald, L. (2017). Compassion fatigue: A meta-narrative review of the healthcare literature. *International Journal of Nursing Studies, 69*, 9-24. https://doi.org/10.1016/j.ijnurstu.2017.01.003

Tunajek, S. (2006, September). *Compassion fatigue: Dealing with an occupational hazard*. AANA NewsBulletin. https://www.aana.com/docs/default-source/wellness-aana.com-web-documents-(all)/compassion-fatigue-dealing-with-an-occupational-hazard.pdf?sfvrsn=982c4bb1_2

Wan, K. F., & Wong, M. M. C. (2019). Stress and burden faced by family caregivers of people with schizophrenia and early psychosis in Hong Kong. *Internal Medicine Journal*, *49*(S1), 9-15. https://doi.org/10.1111/imj.14166

Whitlatch, C. J., Schur, D., Noelker, L. S., Ejaz, F. K., & Looman, W. J. (2001). The stress process of family caregiving in institutional settings. *The Gerontologist, 41*(4), 462-473. https://doi.org/10.1093/geront/41.4.462

Young, L., Murata, L., McPherson, C., Jacob, J. D., & Vandyk. A. D. (2019). Exploring the experiences of parent caregivers of adult children with schizophrenia: A systematic review. *Archives of Psychiatric Nursing*, *33*(1), 93-103. https://doi.org/10.1016/j.apnu.2018.08.005