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# Family experiences as a caregiver for patients with Parkinson's disease: a qualitative study

*Journal of Research in Nursing*

2019, Vol. 24(5) 317–327

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DOI: 10.1177/1744987118816361

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### Abstract

**Background:** Parkinson's disease is a chronic progressive neurodegenerative disorder with unpredictable symptoms, which leads to stress for individuals caring for their family members. Most patients with Parkinson's disease in Indonesia are cared for by family members. Their treatment requires continuous supervision and a great deal of attention.

**Aims:** Accordingly, this research explores caregivers' experiences in caring for family members with Parkinson's disease.

**Methods:** This study is qualitative with a phenomenological design. Participants, selected via a purposive sampling technique, were individuals caring for and living with family members suffering from Parkinson's disease. The data were analysed using the Colaizzi approach.

**Results:** This research identified four themes: the ways in which members of the family adapt; the impact of the patient's condition on the caregiver; support received in providing care; and the cultural and spiritual meanings the caregiver obtained when providing care.

**Conclusion:** This study uncovered several aspects that contribute to the understanding of the life of family members as caregivers for Parkinson's disease patients. This research also found there is still limited psychosocial support from health workers, so it is necessary for them to be more proactive in providing support for family members who care for patients with Parkinson's disease.

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**Keywords**

adaptive coping, care burden, neurodegenerative disorders, social support

**Introduction**

After Alzheimer's disease, Parkinson's disease is the most chronic progressive neurodegenerative disorder and the second most common (Williams et al., 2014). The prevalence of Parkinson's disease rises from 41 per 100,000 people at 40–49 years, 107 at 50–59 years, steadily increasing to 1087 at 70–79 years and 1903 per 100,000 over age 80 (Cacabelos, 2017) – approximately 0.5–1% among persons 65–69 years of age, rising to 1–3% among persons 80 years of age and over. It is estimated that the prevalence of Parkinson's disease will have increased from 4.1 million people in 2005 to 8.7 million by 2030 (Pringsheim et al., 2014). By geographic location, it also shows a rising trend in patients from North America, Europe and Australia; in Asia it is found in around 646 per 100,000 patients with 1601 per 100,000. Parkinson's disease is characterised by four motor symptoms named parkinsonism: bradykinesia, tremor, rigidity and postural instability (Mauk, 2014). As a result of impaired capacity and physical and cognitive functions, Parkinson's disease patients need significant help from others (Kwok et al., 2016). In contrast, Alzheimer's disease is a neurological disorder characterised by an irreversible loss of neurons in the cortex and hippocampus, resulting in impairment of memory, judgement, orientation to surroundings, and language and decision making (Nussbaum and Ellis, 2003).

Most patients with Parkinson's disease are helped by family members. These family members are considered the caregivers, which can be defined as a person who provides direct care (for children, elderly people, or the chronically ill) (Merriam Webster, 2018). As caregivers, family members need to adapt to changes in the uncertain signs and symptoms that arise in patients. These circumstances can cause the caregivers' mental health quality to be lower than their physical health quality (Tan et al., 2010).

Caring for individuals with complex chronic conditions such as Parkinson's has an impact on the caregiver (usually a family member) because the caring responsibility can affect financial stability as well as physical, social and emotional health (Reinhard et al., 2015). Caregivers can also become in need of care, especially if they neglect themselves (Stuart, 2016). If the family caregivers do not have an adaptive coping mechanism and lack support from other family members and society, the condition may cause a decrease in health and quality of life status (Lim and Zebrack, 2004). Accordingly, the objective of this research is to explore family members' experiences in caring for relatives with Parkinson's disease.

**Methodology**

This qualitative research uses a descriptive phenomenology approach. The participants were family members who were also caregivers. They were selected using a purposive sampling technique with the following inclusion criteria: individuals who take care of family members with a doctor's diagnosis of Parkinson's disease, or who live with family members who have Parkinson's disease, and were willing to take part and be interviewed and recorded.

There were five participants in this study. Three interviewees were children of Parkinson's patients and two were patients' spouses. The participants' ages varied, the youngest being 31

years old and the oldest 67. Most participants worked, although one was a full-time housewife. Three participants had elementary-level education and two were high school graduates. The shortest length of diagnosis was 2 years and the longest was 7 years. The participants had never attended any family therapy prior to being involved in this study.

Before data collection, this study was approved by an ethical committee. All procedures were carried out with adequate understanding and written consent. Briefly, the researchers explained the study to all potential participants. Those who agreed to participate were asked to provide consent by signing or thumbprinting on a consent form. Data collection was conducted with in-depth interviews using voice recorders and taking notes. The researcher interviewed five participants in an agreed place, such as their home or workplace. At the time of the interview, the researchers looked for data on the characteristics and participants' experiences during the treatment of family members with Parkinson's disease. In addition, the researchers made observations on the environmental surroundings to note the cleanliness of their surroundings and the appearance of participants, which could indicate any issues in maintaining personal standards.

The Colaizzi data analysis method was used (Streubert and Carpenter, 2011) whereby the researchers 1) describe life experiences by compiling studies on the literature, theories and empirical research related to the caregiver experience in caring for family members with Parkinson's disease, 2) collect descriptions of the five participants' life experiences through in-depth interviews and taking notes, 3) create and read the interview transcripts to give the whole picture of the caregivers' experiences in caring for family members with Parkinson's disease, 4) choose significant and meaningful statements from the transcript and relate them to research objectives, 5) articulate the meaning of each significant statement by choosing keywords and compiling the statements into categories, 6) classify meanings into themed groups by arranging the theme grille tables containing category themes and sub-themes, 7) write about the in-depth picture, 8) validate the description with the five participants and 9) incorporate the data from the validation into a final description.

## Results

After the data gathered from the unstructured in-depth interviews were transcribed verbatim, the researchers conducted a read and re-read process to obtain a general sense of the whole content. Each transcript was then scrutinised to obtain significant clues or keywords and the meaning formulated into categories, sub-themes and themes. Finally, all the themes were generated to develop a general description for the results and validation of the findings sought from the research participants in order to compare the researcher's descriptive results with their experiences (Streubert and Carpenter, 2011).

Table 1 shows the keywords and themes generated from the study. The result identified four themes: 1) adaptation to the family member's condition, 2) perceived stressors, 3) family and social support and 4) perceived spiritual and cultural meaning.

### *Theme 1: Caregivers' adaptation to their family member's condition*

The caregivers' adaptation to the condition of their family member with Parkinson's disease is expressed through the acceptance of the condition and an effort to live with the situation.

**Table 1.** Keywords and themes.

Categories	Sub-theme	Theme
It's all-natural event in our life I am happy living with my parents Be patient in going through the life events What will be, will be Accept the condition due to age Everything happening is normal, due to the age	Accepting the situation  It is part of God's willing	Caregivers' adaptation to family members' condition
Irritated Sad Afraid Tired	Psychological burden  Physical burden	Perceived stressors
Health complaints Children's support Sibling support Parents' support Spouse support Attention support Financial support	Family support  Social support	Family and social support perceived by caregivers
It is a life test Training your patience Be grateful, you still have a chance to take care of parents	Spiritual meaning  Cultural meaning	Spiritual and cultural meaning
Willing to take care of the parents Being grateful to still have parents Payback to the parents		

The situations faced are represented in the participant's statement below:

It's been years facing this sadness so it's been long enough living with it. Crying is only in the heart. I can no longer do it out loud because it will add to my parents' sadness. (P2)

Some participants also said there was nothing they could do except pray and face the issue. For example:

How can I say it, I live just like that. I pray the most, pray. (P5)

What else can I do? It is a hell of a disease. So, we used to face it. Yes, I just surrender, I resign to such fate. (P1)

Meanwhile, some of the participants tried to accept the events as part of life. The participants expressed that acceptance would make the situation better. For example:

Yes, what else can we do? Just accept it . . . submit to a fate like this. (P1)

That's why I feel sorry for my father but I promised [to look after] my father [when he] is old. So, yes . . . I have surrendered just like that . . . we also have to accept what has been given by God. We just simply follow it. (P3)

Some participants also related the situation to their creator's will, through spiritual aspects such as:

Yes, we think just we let it go with God. All of us will be old and die in the end. (P4)

### *Theme 2: Perceived stressors by caregivers*

There were two types of effect perceived by the participants: psychological and physical. Psychologically, participants felt stressed and sometimes expressed their irritation at the patient's attitude during treatment, as in the following:

Well, I was just annoyed he did not want to follow the rules. He was prohibited to eat this and to do that, but he still ignored it. (P1)

Yes, sometimes we are irritated with father. He is often fussy, sometimes he repeats my name all the time. (P3)

Other participants expressed psychological responses where patients often complained and said they wanted to die alone. Participants cried when expressing their irritation:

My mother likes to complain, 'Yeah God let me die . . . I feel sorry for my children . . . Dear God'; it annoyed me if mother said things like that. (P5)

Other psychological responses were expressed by participants due to their sadness towards other people's negative responses to them, such as when a patient often forgot where he lived:

Father likes to walk far. Every time, he was escorted by people back home. I do not know. He said he was confused about the way home. Well, there I feel sad because later there are people saying my husband was not guarded, not taken care of, sometimes I cry when I think about it. (P4)

Most participants in this study felt an impact on their physical condition during their family member's treatment. Tiredness, for example, was expressed by participants during patient care, as in the following phrase:

Yes, there is tiredness, right. Washing, cooking. . . (P2)

For example, if he wants to urinate, he has to be lifted. If he wants to drink, he wants to tilt here, he will be tilted. I feel so tired. (P3)

Physical responses felt by participants can also affect their sleep and health conditions, as illustrated by the following expression:

Yes, sometimes it feels sad. Oh my God, I work. I want to take care of my children. I take care of the husband. I feel like I drop when my mother is sick. Sometimes, mother cannot wake up, the griping pain continues. She asks for a massage every night. I get less sleep. (P5)

### *Theme 3: Family and social support for caregivers*

There are two forms of perceived support: that from the family and that from the community. The type of family support that caregivers received was related to finances,

which helped the caregivers in buying medication and meeting personal expenses for both patients and carers. For example:

Yes, I have a child who also likes to send me money to buy medication and to pay for my expenses. (P4)

Aside from the nuclear family, support was also gained from the extended family, such as cousins, as illustrated by the following quote:

My mother is happy if we are happy. Like yesterday, I told her, 'Mom, your brother's son gives us money.' Well, she will be happy. (P2)

The caregivers also gained support from their husbands:

I was afraid my husband would not accept this. Thank God my husband accepts it. It means my husband is married not only to me but my family as well. (P5)

In addition to support from their family, participants also received moral and material support from neighbours:

Sometimes, there are neighbours who ask about the condition. They provide us with food or money. (P1)

God also does not want to help us if we do not fight right. It is impossible for God to give us money immediately . . . let's sell things, many neighbours buy them here. (P2)

Whether it is enough or not, there is help from the people who rent a stall in front of the house. Thanks to God. (P4)

Because doctors say she should eat a lot of fruit for digestion, sometimes neighbours also give us fruit. (P5)

In terms of social support, the researchers could not obtain any information related to the role of health professionals from the interview. All participants stated that they went to the hospital regularly (once a week or once a month). There is no type of service provided by a health worker other than checking the general situation and giving medicines to the patient. Annoyance was expressed by the third participant, who stated that she was upset due to always having to wait a long time for medication, and sometimes she felt hesitant to visit the hospital unless the patient had relapsed.

#### *Theme 4: Spiritual and cultural meaning*

The participants also perceived spiritual and cultural experiences. Such spiritual experience in this study is expressed in the following extracts:

Yes, maybe that's a test . . . Yes, it feels like our test. Look at people who are now healthy, we don't know how they will become later. (P1)

If we patiently care for the elderly, maybe it's the way we atone for our sins. (P2)

Sometimes I think this is probably the result of my patience so far to take care of mother. (P5)

I think if it is a stroke, it would be so hard. Compared to others who have a stroke, it is difficult. I'm grateful my father can still walk and carry out his activities, he still can do a little and not trouble the children. He is still strong. (P3)

Yes, I'm just thankful that it's not like a stroke. Not too tired of taking care of him. If God wants to take him, he will still be taken. I'm just thankful that he can still bathe himself. (P4)

Both spiritual and cultural meanings emerged in this study. Based on their cultural background, Indonesian people are used to taking care of their own parents and regard it as a repayment for their parents' sacrifice so far:

My parents have taken care of us all the time . . . now, we care for our parents sincerely. (P2)

We are grateful to still have parents, even if only my father is left. We can still take care of him . . . so we can take care of him until death. (P3)

Yes, it is time for us to repay the services of our parents. Any way to make her happy. If you can make them happy, try to make them happy until they die. (P5)

## Discussion

Caregivers' experiences in caring for family members with Parkinson's disease fall into four themes: adaptation to the condition of family members; impacts felt during caring; support received in providing care; and the spiritual and cultural significance for the caregivers. In accepting family members with Parkinson's disease, caregivers went through a process of adaptation or adjustment. The adjustment process is further described in adaptation theory. There are several things to be observed in the adaptation stress model: predisposing factors, precipitation factors, assessment of stressors, coping resources and coping mechanisms.

The perceived psychological and physical stressors of caring can become predispositions for the caregiver. The continuous burden can cause problems for the caregiver if they do not have positive coping mechanisms and the necessary support. In this study, the results showed that most participants have reliable coping mechanisms such as accepting their parents' conditions and relating the event to spiritual aspects. This was shown by the participants' expressions of acceptance in dealing with the condition of family members who had Parkinson's disease. This acceptance was expressed through statements of accepting fate and regarding it as destiny. Such acceptance is considered to be the final stage of grief when an individual has accepted the reality of the situation and has ideas about the cause of a problem. Individuals gradually adjust to their circumstances (Ross, 2009). Acceptance is a condition where an individual accepts the reality of life and all experiences, good or bad. It is characterised by a positive attitude, a recognition or appreciation of individual values, and the recognition of their own behaviour (Ross, 2009). At the time of the visit, the researchers observed the third participant who was assisting his father to urinate and the fourth participant who was helping to select clothes for her husband and dressing him. In their research Kartika et al. (2015) confirm that acceptance is an individual's final stage of adjustment. When viewed from the perspective of care provision, 2–7 years is a long time for adjustment. This acceptance arises when the disease suffered by a patient has lasted for so long that the caregiver has begun to get used to it.

In contrast, the participants received some financial support from their families and social support from friends and neighbours, but the role of health professionals has not yet been well examined. Similar to Alzheimer's disease, Parkinson's disease is progressive and characterised by uncertainty in causes and symptoms, as well as unstable progress (Basjirudin, 2012). This form of support is in line with Friedman's (2010) theory, which



classifies family support into emotional support awards, materials and information. Adaptation processes are necessary for caregivers in the face of such uncertainty. Stuart and Sundeen (2016) explain that sudden, unnatural and unexpected events are situational crises that can undermine the individual's coping ability, resulting in anxiety. Anxiety is one sign of low-quality mental health.

Coping with stress is dynamic and involves many aspects, such as the nature of the stressor or stimulus itself, personal characteristics, and external resources such as support from groups, family or health professionals. All these aspects alongside various other factors will affect the selected coping mechanism (Stuart and Sundeen, 2005). Parkinson's disease is a progressive, chronic neurodegenerative disorder that requires caregivers to spend years in the caring process (Sullivan and Miller, 2015). As part of this, caregivers will go through different stages of coping mechanisms that will affect the treatment.

During their role as caregivers, participants felt an impact on their lives. This is reflected in their psychological and physical responses. Psychological responses were felt by most participants and can be seen in the participants' expressions of irritation, annoyance and sadness. Sullivan and Miller in their (2015) study explained the psychological effects of negative emotional responses experienced by caregivers while caring for family members that arise as a result of anger (at their unwell family members, the illness, or God). These psychological conditions can ultimately result in the emergence of negative or suicidal behaviour. Meanwhile, the participants in this study expressed some stress and experienced unpleasant situations or emotions from caring for patients. It had not yet come to hopelessness or destructive behaviour. Health workers should be concerned with building collaborations to provide maximum support for Parkinson's disease caregivers.

Many participants experienced physical changes during treatment. They described responses such as fatigue and health problems. Fatigue is a physical effect of caring for family members with Parkinson's disease. This illustrates that caring for family members with Parkinson's disease requires considerable energy. The expenditure of energy was not just physical but also physiological.

Other physical responses experienced by the participants may affect sleep and health. The fifth participant confessed she experienced health problems when the patient relapsed. She was unable to sleep because the patient always complained of pain and asked for massages. This was in accordance with Lai and Thomson's (2011) study explaining that treating family members who are sick can affect a caregiver's health in the form of sleeplessness, headaches and weight loss.

Caring for a family member with Parkinson's disease keeps the caregiver at home for a long time. This situation changes the caregiver's course of action, including performing health self-examinations. Sullivan and Miller (2015) explained that impacts on physical health are felt by caregivers because they generally spend their timing giving treatment and neglect to check their own health.

This diversity of responses is also explained by Kartika et al. (2015) in their study of families caring for chronically ill patients. The response experienced by different families depends on the onset, duration and prognosis of the disease, as well as the stress experienced. In addition, Widyastuti et al. (2011) explain that families provide positive and negative responses during the treatment of elderly people with dementia. The responses are influenced by the perspective of the family on providing care. Families who view the providing of care for the elderly as an obligation experienced pride and increased satisfaction, and expressed a positive response. This is similar to the second participant, who expressed pleasure in living with his mother. He showed



a positive response to the situation. In this study, no negative financial impact was found as participants received economic support from their families and neighbours. Families and communities also gave moral support.

Tan et al. (2010), in their study, explained that caregivers' mental health is of a lower quality than their physical health. This was a result of the increased load and pressures felt by the caregiver. To overcome this, Parkinson's disease caregivers need internal and external support in carrying out their responsibilities. Support has financial, physical and psychological forms. Such support can reduce the negative effects felt by the participants. In this respect, this study found two forms of support: family and community.

The participants obtained family support in the form of attention from children, assistance from relatives, advice from parents, and acceptance of the role as caregiver expressed by the husband. In research on terminal disease caregivers, Wakhidah (2015) explains that the family has an important role for the caregiver, especially if there are financial problems. This may be why economic impacts do not appear in the current study.

Community support is obtained from the surrounding environment, including from neighbours. This support is received in moral and material forms. Wakhidah (2015) states that relationships and attachment (social support) are needed to achieve psychological wellbeing as a caregiver. In addition, Sujatmiko (2016) states that the benefits of social support obtained by a caregiver from the people around them can help in overcoming emerging stress. The social support received is influenced by educational background, sex, duration of care, age, and occupation.

A limitation of this study is that it did not look in depth for support from health workers. All participants said they went to the hospital regularly (once a week or once a month). There was no form of service provided by a health worker other than checking the general situation and giving medicine to patients. Annoyance was expressed by the third participant, who claimed to be upset by having to wait a long time for treatment. Consequently, they did not often go to the hospital and only visited if the patient relapsed.

This research also found that participants felt spiritual and cultural wisdom in providing care to family members with Parkinson's disease. They expressed a spiritual meaning of resignation, patience and gratitude, and regarded the situation as a test. This condition supported the findings of another study (Fajriyati, 2016) on stroke patients' caregivers, which found that in dealing with these problems, caregivers chose religion as the main coping mechanism. Some participants' coping strategies included a resigned attitude of leaving everything to God's will and believing that what happens is best for them.

In addition to coping mechanisms, this study found that most caregivers of Parkinson's disease patients are their children. In Asian cultures, alongside the religious influence, taking care of parents when they are old is part of an obligation children need to fulfil. It is part of a devotion to elders who have taken care of their children, as mentioned in some of the participants' responses. Participants believed that taking care of patients is not a burden but a devotion. This is contrary to Sullivan and Miller's (2015) study, which claimed that the demography of more than half of caregivers for those with Parkinson's disease are spouses. A slight difference from the results of the present study was that most of the Parkinson's patients were widowers or widows, so the role of caregiver was taken by their children. This difference is also consistent with the characteristics of families in Indonesia who respect their elders and live with and take care of their parents until the end of their lives. In addition, the obligation to take care of parents is considered a form of moral

responsibility and is embedded in deeply rooted cultural norms in Indonesia (Widyastuti et al., 2011; Effendy, 2010).

## **Conclusion**

Our results showed that family members who acted as caregivers adapted to the patient's condition. The adaptation process sometimes produces both positive and negative ways of coping. This will affect caregivers' physical and emotional conditions, and therefore they will need social support. In this case, caregivers received support from their families and society. Moral or psychological support from health workers was unavailable. Caregivers should be taught techniques and strategies for building positive coping methods in order to achieve positive outcomes from their situation. Some participants have been able to culturally and spiritually interpret situations. In a spiritual way, participants show gratitude, practice patience and regard the situation as a test. In addition, participants who are the children of patients interpret it as a form of repayment. This study has implications for practice in providing information on the adaptation process experienced by participants. This would be beneficial for mental health nurses in improving nursing care for patients and their families.

### **Key points for policy, practice and/or research**

- Understanding the perceived experiences and perceptions of family members as caregivers can help nurses to develop care educational programme that can support a better quality of life for people with Parkinson's disease and their carers.
- Health professionals were rarely involved in supporting these patients and their family carers. Attention needs to be given to increasing health professional involvement in providing support to lay carers.
- Further research to develop and evaluate an educational programme for caregivers is needed. This could be based on the four themes generated from this study - how members of the family adapt; the impact of the patient's condition on the caregiver; support received in providing care; and the cultural and spiritual meanings the caregiver obtained when providing care.

### **Declaration of conflicting interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

### **Ethical considerations**

This research obtained ethics approval from Ethical Commission, Faculty of Medicine, Universitas Andalas.

### **Funding**

The author(s) received no financial support for the research, authorship and/or publication of this article.

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