

Life Experiences of Informal Caregivers of Parkinson Disease Patients: A Qualitative Study

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Abstract

Parkinson's disease is a progressive neurodegenerative disorder that causes motor deficits (tremors, stiffness, bradykinesia, and postural instability). Everyone's experience with Parkinson's disease is unique however, many people living with this disease suffer different challenges and problems. Informal caregivers play a major role in the lives of patients suffering from Parkinson's disease. Caregiving is seen as the role and responsibility of the caregiver, which emphasizes the significant toll on their mental and physical health. This study investigates the experiences of informal caregivers of Parkinson's Disease patients through the Interpretative Phenomenological Approach. Using purposive sampling, the data was collected from five participants from different parts of Kerala through support groups. The data collection method adopted was a semi-structured interview conducted online where the responses were recorded and analyzed by thematic analysis. The findings of this study indicate that caregivers' experiences and challenges are critical to providing better quality care to Parkinson's disease patients and addressing caregiver needs. This research paper extensively discusses the identified themes during the process of research and elaborates on the experiences of the informal caregivers of Parkinson's patients. The paper also suggests future directions for further research in the area and its limitations and recommendations also have been discussed.

Keywords: Parkinson's disease, informal caregivers, bradykinesia, deep brain stimulation, perceived social support.

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“You have two hands. One to help yourself, and one to help others.” — Audrey Hepburn

Parkinson's disease (PD) is a neurodegenerative disorder that causes motor deficits (tremors, stiffness, bradykinesia, and postural instability) according to World Health Organization (2006). It was first described by physician James Parkinson in 1817 and it is the second most prevalent neurological disease after Alzheimer's disease. Tremors-trembling in the hands, arms, legs, jaw, or head; stiffness of the limbs and trunk; slowness of movement; and poor balance and coordination are the four basic symptoms of Parkinson's Disease This disease is caused by a combination of genetic and environmental factors leading to dysfunction in nerve cells or neurons in the basal ganglia releasing the neurotransmitter Dopamine. The symptoms of this disease usually begin from one side of the body and gradually worsen over time.

Parkinson's disease can affect both males and women. However, the condition is more prevalent in 50% of men than that in women. Age is a definite risk factor for Parkinson's disease. The majority of individuals with Parkinson's acquire the disease around the age of 60. PD patients are usually treated with drugs (such as Levodopa) to enhance the level of dopamine in the brain. Deep brain stimulation, or DBS, may be useful for patients who do not react well to medicines. (National Institute on Aging, 2017).

Parkinson's is a condition that entails significant strain on the caregiver of the patient. Caregiving is a process that offers physical, emotional, and economic support to the patient when it prevents early nursing home replacement. As the condition progresses. the patient faces increasing physical limitations, even in daily activities, and causes cognitive and psychological strains, resulting in high demands for caregivers. The role of the caregiver becomes inevitable as the disease progresses to a state where caring for the patient becomes the caregiver's primary role (Martin et al., 2007; Martin et al., 2012; Schrag et al., 2006). Caregiver spouses often spend less

time on their leisure time or vacations when compared to non-caregiver spouses and older spousal caregivers suffer age-related issues. Research evidence indicates that the caregivers of PD patients experience worse quality of life (QoL) since their social activities and job schedules are curtailed to focus on caregiving (O'Reilly et al., 1996).

To support caregivers in this situation, it is crucial to understand the extent of the caregiver- burden and the factors involved with increasing caregiver burden and suffering. Anxiety and depressive conditions, emotional turmoil, and concerns about financial strain are all examples of factors associated with caregiver burden. They are usually neglected since the emphasis is often on the patient and their illness. Medical professionals dealing with these patients sometimes underrate the significance of caregiver difficulties and their quality of life. Research done on caregivers of PD patients is limited. Families are the primary care providers, which significantly reduces the burden on social health resources. This has significant economic consequences because a large number of healthcare expenditures are covered by the families themselves (Cifu et al., 2006; Dowding et al., 2006). Hence, these factors underline the significance of conducting this study on caregivers.

The global population of patients affected by Parkinson's disease in 2020 is 9.4 M larger than 6M cases recorded in 2016. The surge in the prevalence rate draws attention to the increasing burden among individuals and society. It also points out the inevitable need for ways to address and manage this condition. According to a study that was conducted in Gujarat (Je et al., 2021), the rough prevalence of PD was 42.3 per 100,000 while the prevalence above the age of 60 was 308.9 per 100,000 indicating a rising prevalence with age.

Parkinson's disease sufferers require significant support from others due to impaired capacity, and physical and cognitive functions (Kwok et al., 2016). As a result of changes in the unpredictability of patients' signs and symptoms, the caregivers' emotional health worsens than their physical health often to the point of needing care themselves (Tan et al., 2010). Caregiving is time-consuming, and as a result, PD caregivers may be unable to spend as much time with friends and family, leading to social isolation (O'Reilly et al., 1996). If family caregivers do not have an adaptive coping strategy and do not get assistance from other family members or society, the condition may lead to a decline in health and quality of life (Lim & Zebrack, 2004). Instrumental support (e.g., assisting with dressing and bathing), emotional support, and informational support are all examples of PD caregiver tasks e.g., coordinating care and managing medications.

Numerous studies have found that negative psychological effects, such as anxiety and depression, are closely related to caregivers' perceived burden of Parkinson's disease. While continuing to fulfil caregiving responsibilities may have harmful impacts on PD caregivers, the stress associated with caregiving can be visible even in the early stages of the condition. (Mosley et al., 2017; Martinez-Martin et al., 2008; Bhimani, 2014; Caap-Ahlgren & Dehlin, 2002; Schrag, 2006; Zhong et al., 2015). Furthermore, PD caregivers may encounter stigma as a result of feelings of guilt and pity associated with the disease and its symptoms. As a result, it is crucial to identify caregiver strengths and variables impacting coping ability so that caregivers can continue to play a significant role.

Perceived social support deals with how people view friends, family members, and others as sources of material, psychological, and overall help when they are in need. A review indicated that having a high level of perceived social support is associated with improved physical and

mental health effects (Uchino et al., 2012). Mental health issues may be associated with low levels of perceived social support. Parkinson's disease patients and their families require social support from family, friends, and significant others through various forms like financial support, informational support, and psychological support. The caregivers require physical support to help the patients to get up from bed, or chair when they are facing physical challenges.

Coping is described as the thoughts and behaviors used to manage internal and external stressful events. When individuals are exposed to a stressor, the various methods in which they cope with it are referred to as coping styles. Persons suffering from Parkinson's disease as a result of the condition, both patients and family members may face stress (Miller et al., 1996). Over time, the progressive nature of the disease stage places a significant strain on family members or other caregivers. In such situations, caregivers have to use various coping strategies to overcome emotional difficulties and stress. A study has been conducted on the psychological impact of Parkinson's disease on the patient's support system. The results indicated that, as the severity of the symptom worsens, caregivers are required to take on additional and more difficult obligations, which often results in greater degrees of emotional, physical, and financial stress (Whetten-Goldstein et al., 1997).

Each family member has an integral role in the caregiving process and the patient's condition affects the entire family environment. Symptoms of Parkinson's are unpredictable and require a great deal of support. Caregivers often have many responsibilities to manage, leading to burnout and overlooking their own health. It is essential that caregivers take time for themselves and use coping skills to manage psychological stress. This study seeks to understand the unique experience of caregiving from the perspective of caregivers.

Need and Significance of the Study

This study deals with how the immediate caregivers of PD patients deal with the distinct experiences of caregiving the PD patients. The literature on this topic suggests that factors like how the family of the patient deals with challenges of caregiving and perceived social support are not explored in this population previously and it is not been extensively studied qualitatively studied area in India as well as in the population of Kerala. The researcher finds it as a relevant aspect that needs to be explored in this population considering its context. Parkinson's disease patients require a lot of support from others because of their limited movement, as well as their physical, cognitive and emotional deficits. Family members must adapt to the unpredictable nature of patients' indications and symptoms. As a result of caregiving PD patients, caregivers' mental health and their physical health may be challenged. Caregivers also need to take care of themselves to provide quality care to the patients.

Caregivers may get exhausted if their care responsibilities outweigh their resources. As a result, identifying caregiver strengths and factors influencing coping ability is critical so that caregivers can continue to fulfil the role. Patients suffering from Parkinson's disease, a disease affecting both physical and psychological challenges, may experience significant difficulties in their families. Each family member has a role to play in the caregiving process so which enables them to achieve healthy family functioning and have better control over the outcomes of stress. All of the information gathered can assist medical professionals and society understand the experiences of caregivers and providing appropriate support to them. This information can aid in developing psychoeducational programs for better management of PD patients.

When looking at the review of the literature, it was found that there were more quantitative studies conducted on the family caregivers of Parkinson's patients. They focused mainly on the caregiver burden, and the psychotic symptoms of Parkinson's disease, caregiver preparedness. Qualitative studies focus on the experiences of the caregiver, coping styles of the caregiver, palliative care for Parkinson's disease etc. It was observed that it would enrich the source of information if studies were conducted on both family caregivers and non-family caregivers.

Tan and his colleagues in 2012 investigated the experiences of Singaporean people taking care of Parkinson's patients. The findings of this study shed light on the coping and well-being of caregivers of patients with Parkinson's disease. The progressive nature of Parkinson's disease put a huge strain on caregivers' mental well-being. The findings of this study highlight the need for structured caregiver support and education to alleviate strain in caregivers at all stages of Parkinson's disease.

Houngard et al. (2011) found that the influence on everyday life and changes in the quality of life of living close to a spouse with Parkinson's disease were critical to the women's experiences. As the disease progressed and affected physical, cognitive, and emotional functioning, the need for care decisions for everyday activities and functions increased, and the women took on the role of informal caregivers.

Hodgson et al. (2004) conducted a phenomenological study that delves into the lives of ten couples who have Parkinson's disease. The research revealed five major themes: material regarding their relationship and disease history, their couple relationship, the impact of PD on the self and others, their link with resources, and survival methods. De Villiers et al., (2008) found that as a result of the condition and the financial strain it imposed on the family, caregivers faced

stress. Caregivers' primary requirements were emotional support, techniques to make caregiving responsibilities easier, time to socialize, and leisure time.

Chen et al. (2021) aimed to present an in-depth overview of existing information regarding the subjective experiences of family caregivers caring for Parkinson's disease patients, explain the factors that impact this experience, and provide evidence for healthcare services. The findings highlight the complicated and varied experiences of family caregivers for people with Parkinson's disease. It is vital to investigate how the influential elements might be changed to improve the lived experience of family caregivers. The following five themes emerged: (a) PD-related feelings; (b) family life problems; (c) external challenges; (d) adjustment and adaptation; and (e) external support.

Research Questions

1. What are the ways in which you deal with the difficulties of PD patients?
2. What are the coping skills of caregivers of PD patients?
3. What is the perceived social support of the immediate caregivers?
4. How do the caregivers spend their quality time?
5. What were the steps taken to inculcate hope in PD patients?
6. What are the emotional difficulties faced by the caregiver?

Method

This section discusses the underlying methods and process of conducting this research, and the details of this research study.

Aim

The aim of the study is to investigate the distinct experiences of informal caregivers of Parkinson's patients.

Research Design

The research method employed is the Interpretative Phenomenological approach. In this method, the research participants share their experience about caregiving provided to the Parkinson's patients. The approach to inquiry in this research study is the social constructivist approach where the research participants sought to reflect on the subjective meaning of their situation. This research provides an in-depth discussion of the distinct experiences of the informal caregivers of Parkinsons patients.

Participants

Data was collected from the informal caregivers of patients who were diagnosed with Parkinson's disease. The patients were diagnosed by a certified neurologist. The informal caregivers were selected from a support group for Parkinson's patients and caregivers. Using the purposive sampling method, the data was collected from five participants from different parts of the state of Kerala.

Procedure

Various clinics, hospitals and support groups were approached for data collection. Finally, a support group was identified. The permission for data collection was taken from the patients and caregivers. Purposive sampling method was employed for selecting the participants. Informed Consent forms were given to the caregivers and the patients before data collection and it was collected back from them after they had gone through them and fill them out. The study was initiated after taking approval from the President of the support group of the caregivers and

Parkinson’s patients. The group members gave their collective approval for the collection of the data. The data collection method adopted was a semi-structured interview and was conducted through the online mode. The online interview was conducted in Zoom or Google meet. The participants were asked open-ended questions. The online interview was recorded. The participants were debriefed about the study. The responses were transcribed and coded. The data were analyzed using thematic analysis. Then, the sub-themes and themes were extracted.

Results and Discussion

Table 4.1

Codes, Sub-themes and Themes Identified in Thematic Analysis

Codes	Sub-themes	Themes
I did not know about this disease We could deal with this Accept reality Shock, Sadness	Accepting the condition of the patient	Caregiver’s adaptation to patient’s condition
I cared for his father I was a nurse	Possessing professional knowledge, Lack of awareness, Experience in caring for a family member	Awareness of the condition
We tried Ayurveda Consulted different doctors Gathered information about various treatments	Change in treatment	Choosing the best treatment method
Hallucinations Stiffness, Slowness of movement, Dyskinesia	Motor Disturbances Sleep Disturbances, Post-surgery challenges	Challenging Situations as a result of difficult symptoms of PD

Increased anger, Depression, care for each other, less confidence	Change in the attitude of the patient	Nature of change of the relationship between caregiver and patient before and after diagnosis
Disappointment, care, love Fear, the constant need for the presence of a caregiver,	Caregiver's emotion expressed toward patient	Strongest emotions experienced in caregiving the patient
Prompt actions	Sincerity, Punctuality, Compassion, Patience	Behavioural skills of the caregiver
Controlling anger Cannot attend all occasions, Talk less on phone,	Adaptation	Change in the social life of the caregiver
Help to lift him Include in decision making, give support	Family support, love, respect, adjustment	Family attitude perceived by caregiver
Children support, encouragement, commitment, and faith in God	Co-operative attitude, Religiosity, Shared responsibility, Sincerity, family support	Family characteristics perceived by caregiver which enhances confidence
Huge friend circle Family help to manage home affairs, and neighbours Support through words, Faith in God	Family support, friends support, support, psychological support spiritual support	Sources of support perceived by caregiver
Divert my attention, Pray, cry, listen to music, and motivational talks, rethinking	Positive coping, emotional coping, Spiritual coping	Caregivers reflection on their coping styles
Don't keep time aside, Don't have time	prefer less quality time, guilty feelings upon spending quality time	Lack of Quality time for the caregiver
Don't visit doctor Did not think about my health	Self-neglect, Forgetting medicines,	Lack of self-care of caregiver

More importance to patient

The researcher performed five in-depth interviews. The verbatim of the interviews was transcribed. Codes were elicited and organized into meaningful units. Thematic analysis was done and finally, a list of themes was extracted from sub-themes to explain the results and validate the findings from them. Table 1 summarizes the study's codes, sub-themes and themes. The findings identified are as follows: Caregiver's adaptation to patient's condition, awareness of the condition, choosing the best treatment method, challenging situations as a result of difficult symptoms of PD, nature of change of the relationship between caregiver and patient before and after diagnosis, strongest emotions experienced in caregiving the patient, behavioural skills of the caregiver, change in the social life of the caregiver, family attitude perceived by the caregiver, family characteristics perceived by the caregiver that enhances confidence, sources of support perceived by the caregiver, caregivers reflection on their coping styles, lack of quality time for caregiver, lack of self-care of caregiver.

Discussion

The study aims to investigate the experiences of the informal caregivers of Parkinson's patients. As a researcher, I am also a caregiver of my family member who is suffering from Parkinson's Disease (PD), this has driven me with the inquisitiveness to investigate the distinct experiences of informal caregivers of the Parkinson's patients. Long-term caregiving is a continuous process in which the strain shifts over time. Stressors are managed by using various coping techniques. The unique interaction between patient and caregiver is crucial. The progressing condition of the Parkinson's patient causes physical and psychological strain on the

caregiver. Family plays a significant role in supporting the patient deal with the unpredictable nature of the disease.

Patients' spouses (women) were chosen as caregivers in this research. These women caregivers have increased responsibilities and perform multiple roles. They are currently homemakers, with two of them employed during the time the patient was diagnosed. Thyroid issues, arthritis, osteoporosis, migraines, and other health conditions affected the majority of the caregivers. The caregivers had a hard time embracing the health condition of the patient initially, but they eventually accepted it. When looking at caregivers' awareness of Parkinson's disease, they discovered that three of them had the experience of caring for PD patients in their families. One of the caregivers was a nurse by profession and was aware of the disease; however, there was another caregiver who had never heard of it. During the earliest stages of the diagnosis, this participant felt helpless as a result of this.

“I knew nothing about this disease, so I was blank when the doctor made the diagnosis; I did not know how to console my husband” (D.D., Personal Communication, April 12 2022).

However, it was a shocking event to the caregivers who already had taken care of a PD patient. It was an unexpected event for such participants.

“I never expected he would have this disease, he was a very active person and the youngest in his family. I was really sad. According to the doctor, when the disease gets genetically inherited, it should affect the eldest child.” (N.D., Personal Communication, 31 March 2022).

Parkinson's disease is a neurological disorder for which there is no cure. Medications, surgical procedures, and other treatments can only help alleviate the symptoms. The patient had an on-time and off-time, according to the caregivers. When patients are on-time, they are free of PD symptoms. Off-time refers to the time when individuals are experiencing PD symptoms. According to the caregivers, it is tough to manage the patients during this off-time. When they are unable to help the patient to their satisfaction, the majority of caregivers feel helpless. Patients remain frustrated and angry during this time since their mobility is limited and they are reliant on their caregivers. Caregivers report that tremors, slowness of movement, muscular stiffness, and loss of balance are among the most challenging symptoms to manage during the off-time.

“Whenever I try to lift him from bed and he is not able to get up, he thinks it is because I am not holding him properly. He becomes angry and shouts at me, I used to become helpless in such situations” (P.J., Personal Communication, 9 April 2022).

Caregivers indicated that patients preferred to change treatments to find the best one for them. They explored other allopathic treatments such as homoeopathy, naturopathy, and ayurveda. According to most of the caregivers, ayurvedic treatments provided temporary relief. Four of the five participants had undergone deep brain stimulation surgery (DBS). Caregivers of DBS patients encountered a variety of challenges, including dyskinesia, increased sleep, frequent falls, and trouble getting the patient out of bed. Another caregiver had trouble caring for the patient who had motor disturbances and lifting the patient during the ayurvedic treatment when allopathic medicines were stopped.

“He used to fall frequently after the DBS surgery, it was difficult to grab him” (S.H. Personal Communication, April 2 2022)

There was a difference in the patient's attitude toward caregivers, according to caregivers. Some of them stated that the patient's anger had increased, his confidence had reduced, and his decision-making abilities had degraded. Others stated that communication and care between the caregiver and the patient had improved. Disappointment, anger, love, and care were identified as the most powerful emotions experienced by caregivers when they think of being a caregiver. Previously, the patients had been self-reliant and productive. However, after the diagnosis, they became helpless and dependent on the caregivers, causing the caregivers to feel disappointed. They became angry when the patients expressed dissatisfaction with their care, despite their best efforts.

“He was a very active person; I did not have to go outside for anything. But, now he is totally dependent on me. He had developed an addiction to Syndopa- a prescription drug for PD. When his mobility became limited, he becomes angry.” (N.S., Personal Communication 5 April 2022)

Compassion, patience, sincerity, and adaptation were the skills perceived by the caregiver. Caregivers were compassionate to the patients when they experienced anger and frustrated since their movements become limited. Occasionally, the patients tend to be obstinate and insist on the immediate gratification of their needs. Such situations challenge the patience of the caregiver. Most of the caregivers reported to express their patience during such situations. The caregivers give priority to the patient and take utmost care to provide food and medicines on time to the patient. They take extra care to not to delay things.

The unpredictable nature of the disease creates two types of PD patients. One group prefers to limit their social interactions due to the PD. The other group tend to get disheartened and restricts their number of social events. As a result of this, caregivers are either unable to

spend much time on social occasions or do not attend them. The caregivers (women) get limited opportunities to go home. Although caring for patients was emotionally and physically draining, caregivers gave it their utmost to provide the best care possible. They put their personal preferences and well-being aside to satisfy the patient's needs. Tan et al. (2012) discovered that many caregivers had successfully adapted to caring and that their family relationships had strengthened following diagnosis. Benefit-Finding refers to an individual's attempt to get advantage from their difficulties as a consequence of caregiving. 'Benefit-finding' is prevalent in persons with chronic diseases and their caregivers (Pakenham, 2005) and is generally related to good adjustment and more adaptable methods of coping.

“I have the patience that I can say undoubtedly. Sometimes I ‘ll lose my control but still, I was able to tolerate it. God has given him to me, I should accept him; there is no one else to take care of him. He is beloved to me; I must look after him. My preference is not important; my responsibility is more important”

Caregivers confessed that their social life has changed drastically. Because the patient's condition is uncertain, they tend to spend less time outdoors. Patients have also reported feeling some level of discomfort and embarrassment when others express sympathy and observe their movements and mannerisms. The majority of them are reluctant to leave the house. On the other hand, there was a patient who had voice clarity problems, and his friends used to call him over the telephone less often. Though according to his caregiver, his friends used to call him less frequently, he takes the effort to contact them, and the patient spends most of his leisure time creatively; writing about religion and his illness.

“After the diagnosis, we were limited to our houses, we spend less time outdoors as we are unsure of when he would go to off-time and he felt uncomfortable when others show

overcare, sympathy or especially when they glare at his plight” (P.J., Personal Communication, 9 April 2022).

According to the caregivers' perceptions, the family's attitude toward the patient was supportive. The children usually maintained a friendly attitude toward the patient. They looked after the patient while the caretaker was away. Families expressed their love and respect for the patient. An informant admitted that they frequently consult the patient on all family matters and take decisions and that family members frequently prioritized the patient and adapted to the patient's routine. Their children or wives become annoyed occasionally when they are repeatedly called for something, and they do not attend to the patient. The family characteristics identified by the caregivers that enhanced their confidence were: cooperative attitude, perseverance, sincerity and support from other family members. According to the caregivers, family members were cooperative in managing household affairs as well as handling patients. They persevered when confronted with the challenges of caring for the patient. In their absence, the family members were sincere in their responsibilities and took good care of the patients. Other family members offered help to caregivers who were previously employed. They would take over the caregiver's role and manage household matters while they were at work. When the caregivers were dejected, family members provided emotional support.

Belongingness support, tangible support, informational support were different forms of support available, as reported by the caregiver. In addition to it, caregivers also found support and comfort from spiritual activities and resources Neighbours, friends, and extended family members occasionally come to see the patient, call, or inquire about the patient's status. The closely-knit social network provided psychological support.

Dekawaty et al. (2019) discovered that participants received family support in the form of attention from children, help from relatives, advice from parents, and the husband's acceptance of the role of caregiver. Wressle et al. (2007) highlighted how having psychological support from family members was crucial to family caregivers, potentially promoting positive well-being and reducing feelings of social isolation. Occasionally, extended family members and friends contribute to the expenses of treatment. In addition, they share information about the best doctors, hospitals and effective treatments for Parkinson's disease. It was noted specifically that all the informants mentioned the spiritual support they received. They believed that God gives them the strength to strive through the challenges and instill hope for patients' improved quality of life.

According to Dekawathy et al. (2019), caring for a family member with Parkinson's disease keeps the caregiver at home for an extended period. Coping with stress is a dynamic process that takes into account numerous factors, including the nature of the stressor or stimulus, personal traits, and external resources such as support from organizations, family, or health experts. All of these elements, as well as others, will have an impact on the chosen coping method (Stuart & Sundeen, 2006). Parkinson's disease is a progressive, chronic neurological disease that demands years of caregiving (Sullivan & Miller, 2015). Positive coping, emotional coping and spiritual coping was the perceived coping styles of the caregivers. Informants asserted that they usually divert their attention from negative thoughts. They listen to motivational and religious speeches. On most the days, they cope well, sometimes, they are overwhelmed by their emotions and they cry alone in the room to get relief. They also use strategies like listening to music, chanting prayers, and singing devotional songs to cope with emotional difficulties or stress.

“I used to cry alone in the bathroom or think a lot” (N.S., Personal Communication 5 April 2022)

Among all five caregivers, only two kept aside quality time for themselves. They felt they have no time to care for themselves and believed that the importance should be on the patient and family responsibilities. They felt guilty about spending quality time for themselves.

“I did not have time for myself, I was busy with home affairs and caring for the patient. I did not think about spending quality time for myself during that time. Our doctor also suggested me to keep aside some time for myself” (N.D., Personal Communication, 31 March 2022).

The need for respite care frequently arose due to poor caregiver health, as caregivers struggled to manage their patient's requirements all by themselves for a prolonged period (Hasson et al., 2010). It was recognized that respite care was often necessary for the well-being of the family caregiver, but they frequently disregarded the need for self-preservation since they did not want to leave the patient unattended (Hasson et al., 2010). When caregivers made time for themselves, feelings of guilt typically surfaced (Tan et al., 2012). Self-care, on the other hand, was conceptually (though not always practically) recognised as a means for people to recharge and enhance their physical and mental well-being (Abendroth et al., 2012).

The caregivers often neglect their health and self-care while caring for the patient. Caregivers reported giving less importance to their health, forgetting to take medicines or consulting a doctor. Despite the emotional strain, of feeling nervous, stressed out, and helpless, caregivers continued to provide care. Caring for the patient was stated to be more important than their own well-being. Caregivers disregarded their self-care and placed the patients' needs ahead

of their own (Abendroth et al., 2010). Furthermore, family caregivers were concerned about their ability to care for their relatives in the future as the condition advanced, as well as worried about them falling ill and unable to care for their patients (Abendroth et al., 2012; Tan et al., 2012; Wressle et al., 2007).

“I don’t handle my health well. I usually adjust it according to my circumstances. I visit Doctor only for checking Thyroid levels. I used to follow diet plan before now I have become a little fat. I drink less water also” (N.D., Personal Communication, 31 March 2022).

Conclusion

The findings of this study indicate that caregivers' experiences and challenges are critical to providing better quality care to Parkinson's disease patients and addressing caregiver needs

Investigator’s Experience

It was noted that all the caregivers were quite cooperative in sharing their experiences, and they supported and appreciated the researcher for choosing this topic. They were eager to share their experiences and had no hesitation about doing so. Despite physical and emotional challenges, the caregivers showed perseverance, dedication, and compassion for the patient. The spiritual support, friends and family support helped them remain committed to the caregiving despite the challenges.

Implications

These results will contribute to the formulation of policies that will allow the government and healthcare organizations to better support caregivers and individuals living with Parkinson's

disease. Improved caregiver support is expected to reduce the need for early institutionalization and inappropriate hospitalization of PD patients. Throughout the stages of PD, caregivers require emotional support that is suited to their unique needs. This helps us to assist them in adapting to changing caregiving responsibilities. Professionals can develop psychoeducational programs that will help people with Parkinson's disease and their caregivers have a better standard of living by understanding their experiences and attitudes as caregivers. More medical support for these patients and their caregivers is essential. Increased involvement of health professionals in assisting caregivers has to be prioritized. Further research is needed to develop and assess a caregiver education program. This might be based on the themes of the current study: how caregivers adapt to the patient's condition; challenging situations as a result of difficult symptoms of PD; strongest emotions experienced while caregiving the patient; sources of support perceived by the caregiver; family attitude perceived by the caregiver and family characteristics that increase the caregiver's confidence; caregiver's reflection on coping styles; behavioural skills of the caregiver and lack of quality time and self-care for the caregiver.

Limitations

The sample size of the research was small. The study lacked the experiences of male caregivers. The data was collected only from a few districts of Kerala. Network issues during the interviews were a technical problem during the course of the study.

Future Directions

Further research could be done including the male caregivers. The research sample size could be increased to obtain more rich data. The data collection could be extended to more districts of Kerala. Developing a psychoeducational module based on the findings of the study

could benefit the caregiving process and help the families with Parkinson's patients to cope and adjust better.

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