

A Literature Review on the Effects of Caring for a Family Member with Parkinson's Disease

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Abstract

Parkinson's disease affects many people worldwide, deteriorating their mental and physical condition. As this disease progresses patients become more reliant on their loved ones to care for them. The caregivers to these patients experience life changes as they become responsible for managing their own health as well as the condition of a loved one with Parkinson's disease. A literature review was conducted to review the research on how caregivers are affected mentally as they take on responsibility of caring for a loved one with a chronic illness as well as interventions that may benefit them.

Keywords: Parkinson's disease; Caring; Caregivers

What is Parkinson's disease?

Parkinson's disease (PD) is defined as a chronic disorder presenting with movement related problems including bradykinesia, tremor, stiffness, and gait freezing, as well as non-motor symptoms including neuropsychiatric changes such as dementia [1]. PD patients experience a life change when they are diagnosed with this disease. Although the disease may not affect them in every aspect of life at initial diagnosis, PD patients understand that their debilitation is imminent and they will eventually need help with almost all daily activities. As the condition progresses, patients rely more on other people to take care of them.

Although there has been a great deal of research conducted on how this disease affects PD patients, there is little knowledge on how their caregivers are affected. The findings of multiple studies were reviewed to answer the question: How are family members of PD disease patients affected as they take on the responsibility of caregiver?

Who are the Caregivers?

A qualitative study was conducted in Singapore on the experiences of caregivers of PD patients. There were twenty-one participants interviewed who had all been taking care of their loved one for over 6 months. Seventeen of the twenty-one caretakers were female, two-thirds were spouses and two-thirds of the care recipients were men [2]. Some of the other caregivers included daughters, sons, or friends. The most common situation was a wife caring for her husband with PD. It is important to recognize the extraordinary responsibilities of these caregivers and think about what they might also be going through in their own lives. A PD patient in his seventies will most likely have a wife who is about his age who may have her own health conditions to worry about. On the other hand, if a patient is diagnosed at a younger age their spouse may be taking care of them for a longer period of time.

The Effects of Time

The caregivers reported increased stress levels the longer they cared for their loved one and stress increased as the disease affected the patient psychologically [2]. The psychological stress of a caregiver builds as the patient loses independence as a result of disease progression. The results of a meta-analysis study conducted by Lau et al. in 2011 showed that the motor symptoms of PD had the greatest positive relationship with caregiver stress [3]. Patients become more reliant on their caretakers to perform activities of daily living (ADLs) the longer they live with the disease. Caretakers now need not only to take care of themselves, but their loved ones. They may have to help their loved one with simple tasks including feeding, bathing, and toileting.

Caretakers also have less time to themselves as more of their free time is utilized to help their loved one with ADLs. For example, now instead of just having to shower themselves, they have to take twice as much time out of their day (if not longer) to shower their loved one as well as themselves. Two thirds of the caregivers interviewed as a part of the Singapore study said that caregiving had restricted their lifestyle. One of the caregivers in this study who takes care of her husband said that "[my life] is quite hectic...he takes up all my day...it's tiring and I'm always busy" [2]. This situation shows how overwhelming the responsibility is to completely take care of yourself and someone else. It is comparable to having an infant child because the free time of the caregiver is so limited and the patient must always be within eyesight.

Financial Stress

As previously stated, the time spent caring for the PD patient increases as the disease progresses. A cross-sectional study was conducted in the United Kingdom on PD patients and their families to analyze various factors that add stress to the caregivers' lives. Over one quarter of the caregivers had reduced their working hours or had completely given up their jobs in order to care for their loved one. As a result, over 30% of caregivers were in a dire financial situation [4]. This financial stress affects the caregiver who may feel resentful towards the patient. Many patients eventually have to be placed in a long-term care facility, which can be very expensive.

A survey was conducted among 66 caregivers of PD patients. The study assessed specific needs of the caregivers and barriers to care of PD patients. Out of the 66 participants interviewed, 21.2% reported that a needed service to help with care was too expensive and 18.2% reported that their insurance did not cover services they needed to help care for their loved one [4]. These statistics show how a family's financial situation can affect the care that is provided to their family member with PD. If a family is struggling financially they will be less likely to put their loved one in a long-term care facility for fear of the cost. The family may continue to manage the disease at home as best they can for financial reasons, which could negatively impact the patient as well as the mental health of the caregiver.

Effects on Mental Health

A caregiver's overall health impacts the care they give to their loved one. The qualitative study conducted in Singapore revealed that spouses of PD patients accepted that it was their job to be the caregiver even though they feared for their own health as they took on this responsibility [2]. Many of these caregivers may not have realized what they were getting into when their loved one was first diagnosed, nor could predict the degree to which their own health would be impacted as they took on the role as caregiver. At a certain point, the stress of this responsibility will affect the quality of care that is provided to the patient [5]. If a caregiver is experiencing increased stress and burden, it is likely that they will not provide the best available care to their loved one because they will be so worn out themselves. The caregiver may begin to feel like their entire life revolves around making sure that their loved one is okay and they may even resent the patient.

On the contrary, a family member may feel guilty if they do not spend enough time with their loved one. They may think that if they were in this situation their loved one would do a better job taking care of them. If the patient is a parent, the caregiver may have feelings of inadequacy. This guilt can become overwhelming and cause the caregiver to have their life consumed by this new role. The caregiver does not realize how much they are missing out on and may feel a loss of their old life. It is common for caregivers to feel depressed. A reported 40-70% of caretakers of family members with chronic illnesses develop symptoms of depression and feel increased anxiety [6]. These feelings may be a result of isolation related to the amount of time it takes to be a caretaker, which can often outweigh the amount of time spent living their own life. Anxiety may be due to the constant fear of the illness worsening and something bad happening to their loved one. Due to the motor symptoms of PD, a big worry for caregivers is that the patient will fall. However, regardless of how much a patient is watched by their caregiver not all accidents can be prevented.

The uncertainty of this disease is also likely to weigh on the minds of family members as well. A qualitative study interviewing 18 caregivers asked participants about the multidimensional uncertainty of PD. Factors contributing to the stress of uncertainty were unknown cause and no known cure. Family members also had no way of knowing how quickly the disease would progress specifically in their loved one [5]. The progression of the disease would determine when the patient would need to be placed in a long-term care facility, tying into the financial impact of the disease on the family.

Impact on Physical Health

In addition to lifestyle and financial changes, taking on the role as caregiver can have a physical impact on family members. Results from the cross-sectional UK survey showed that 72.1% of caretakers felt emotional stress and fatigue and 51% of caretakers felt that their overall health was affected by living with someone with PD. "Although in most cases, care[givers] look after their first-degree relative with PD and consider it to be a family duty it causes stress, places a significant burden and has an impact on the care[givers] quality of life, including their physical and mental well-being" [4]. All of the mental stress that comes with caring for a PD patient can eventually translate into physical stress. For example, the increased amount of stress and worry can result in the caregiver not getting enough sleep. A lack of sleep can cause a weakened immune system, making the caregiver more vulnerable to illnesses [4]. When a caregiver gets sick it interferes with the quality of care patient receives, once again leading to poor outcomes for the patient as well as the caregiver. It is important that the caregiver finds relief from this stress and remembers that they need to manage their own health.

Methods of Stress Relief

Multiple studies have been conducted to determine which methods of stress relief work best for PD caregivers. One of the most popular ways to alleviate caregiver burden is through respite care [7]. Respite care is when a trained professional, such as a home health nurse, comes to the house and watches the patient to give the caregiver a break for a couple of hours. During this time the caregiver can be productive around the house, run errands, or simply relax. Respite care also gives the caregiver the opportunity to spend time with people other than the PD patient. It is common for the caregiver to feel as if they have lost the social aspect of their life because so much time has been consumed helping their loved one. Respite care gives caregivers the opportunity to escape their responsibility for a little while and enjoy themselves.

Caregiver support groups were also rated as one of the most helpful tools to alleviate stress [7]. For caregivers it is helpful to get advice on the subject and be able to talk with people they can relate to who are going through the same struggles. Support groups are also helpful in relieving anxiety for caregivers because some members' loved ones may be further along in the disease. Members of the support group can offer insight as to what to expect in the coming stages of the disease.

Attempting to alleviate the stress of the caregiver ultimately improves patient outcomes. If the caregiver becomes too overwhelmed, the care given to the patient will not be as efficient as it could be. That being said, it is important for the caregiver to know what they can and cannot handle. Nursing home placement may be necessary for the overall health of both the patient and their loved one responsible for them.

Conclusion

After reviewing several sources on the effects on caregivers of PD patients, a few conclusions can be made. A majority of the caregivers for these patients are spouses; more specifically they are women taking care of their husbands with PD. Most caretakers felt some degree of stress as they took on this responsibility. Emotional stress can lead to physical stress leading to exhaustion of the caregiver. The caregiver might feel increased symptoms of depression as they stray away from their former life and their time begins to revolve around the PD

patient. Anxiety is common among caregivers because of the unknown progression of the disease and constant fear that something will happen to their loved one. The literature revealed the importance of managing caregiver stress. The less stress on the caregiver, the better care the patient will receive, ultimately improving outcomes for both.

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