

Experiences of Family members of people with Parkinson's Disease

Kareemh Mutleg Alaswad Alanzy¹, Ibrahim naif mohana Alanzy¹, Nashami Mutleg Alaswad Alanzy², Fahad ayed abduallah alshammari³, Salma hamed fahad alshammari⁴, Amani faheid Ali Algarni⁵, Reem Saad Mohammed Al-Rashidi⁶, Munirah Saad ALazmi⁷, Aydah Habib Alshammry RN⁸, Abdullah Shaya Al Shammari RN⁹

¹*Nursing Technician, Primary health care center in Shamli*

²*Nursing Technician, Primary health care center In Labada-Hail*

³*Nursing specialist, Primary health care center in Labada-Hail*

⁴*Nursing technician, Primary health care center in aja-Hail*

⁵*Nursing Specialist, Maternity and Children Hospital*

⁶*Nursing assistant, Lubdah health Center*

⁷*Nursing technician, Maternity and Children Hospital*

⁸*Executive Administration of Nursing Hail Health Cluster, Nursing Technician*

⁹*Ophthalmology Center, Nursing Technician*

Abstract

Background: The people who are close to someone who has Parkinson's disease play a vital role in their everyday lives. It is crucial to support the patient's family members in providing care, adjust to their situation, and make psychosocial adjustments.

Objective: This study aimed to find and then compile family carers' accounts of caring for Parkinson's disease (PD) patients.

Aim: The purpose of this study is to describe the role that family members play in providing daily care for a family member who has Parkinson's disease and to investigate how family members perceive this role.

Conclusion: The themes represented many facets of the lives of family carers impacted by providing care for a member with Parkinson's disease (PD), and these pose questions for oversimplified notions of family caregiving and suitable support networks. The results also point to a number of suggestions for clinical practice.

Keywords: Parkinson, Disease, Family members, care givers.

Introduction

With a variety of etiologies and clinical manifestations, Parkinson's disease is an identifiable clinical illness. The fast rising global frequency of Parkinson's disease, aside from an infectious origin, has similarities to numerous characteristics frequently observed in pandemics. In most groups, 3–5% of Parkinson's disease is due to genetic factors

related to known Parkinson's disease genes, or monogenic Parkinson's disease. However, ninety genetic risk variants together account for 16–36% of the heritable risk of non-monogenic Parkinson's disease. Constipation, not smoking, and having a family with Parkinson's disease or tremor are additional risk factors that raise the risk of Parkinson's disease development by at least double. Ancillary testing is saved for

patients with unusual presentations; the diagnosis is dependent on clinical observations [1].

Parkinson's disease has a major effect on society. In terms of the number of people affected, this disease is quite common; in 2016, over 61 million cases were recorded worldwide. For unexplained reasons, the occurrence and frequency of this illness have significantly grown throughout the past 20 years. Parkinson's disease has a significant impact on a person. The distinctive quality of a degenerative illness is that it can persist for many years. When someone is impacted, the typical appearance is a slow onset that progresses to greater disability. Serious consequences of Parkinson's disease also affect caregivers; most report high levels of stress.⁴ The rising socioeconomic impact of Parkinson's disease on society [1].

Parkinson's disease (PD) is a chronic, multifaceted motor neurodegenerative condition (Dyck, 2009), typified by bradykinesia, stiffness, tremor, and aberrant posture. Apart from the somatic manifestations, patients may also have gradual decline in cognitive function and psychological challenges such as worry and sadness (Bhatia & Gupta, 2003). After receiving a diagnosis, most people with Parkinson's disease (PD) stay at home for many years, and when daily living activities become more challenging, family members frequently take on more unpaid caregiving duties. Family carers may need to make a number of adjustments as the disease worsens in order to manage the different physical, cognitive, and emotional challenges that persons with Parkinson's disease frequently face. The degree of care needed may vary as symptoms worsen, and providing care might involve emotionally, psychologically, physically, and socially taxing activities. [2].

The presence of a combination of cardinal motor features (tremor, rigidity, bradykinesia, and postural instability), other motor features (such as freezing of gait and abnormal postures), and numerous nonmotor features is still the basis for the clinical diagnosis of Parkinson's disease (PD). This is the case even

in the face of several attempts to find precise and sensitive biomarkers. Moreover, the presence of peculiar characteristics may indicate a distinct diagnosis. Levodopa medicine is still the recommended therapy for the motor features of Parkinson's disease (PD). Current clinical practice is evaluating and introducing novel delivery technologies and new levodopa formulations progressively in an effort to avoid or treat motor issues brought on by levodopa [3].

Dopamine agonists are also useful as monotherapy in mild cases of disease or as an adjuvant in cases of moderately advanced disease. When the condition worsens and patients experience side effects from levodopa therapy, such as dyskinesias and motor fluctuations, deep brain stimulation becomes a viable choice for treatment [3].

Informal care is typically provided by family members of the patient, and it is motivated by feelings of love, respect, caring, or thankfulness for the family member. On the other hand, routine adjustments might be necessary when care is provided by a single carer. Health practitioners who support the family should take these changes into consideration as they can lead to psychosomatic alterations in these individuals when combined with an overflow of care [4].

Because of this, the carer also requires assistance in order to adjust to their new routine. Nursing is a care science that can provide this carer with assistance in all areas, but occasionally it restricts its performance to attending to particular situations pertaining to the patient and does not extend its help to issues pertaining to the carer [4].

Literature review

After Alzheimer's disease, Parkinson's disease is the second most common and slowly progressing neurological illness. Parkinson's disease affects 41 per 100,000 people in the 40–49 age range, 107 in the 50–59 age range, and then increases progressively to 1087 in the 70–79 age range and 1903 per 100,000 in the

80+ age range. This means that the disease affects roughly 0.5–1% of people in the 65–69 age range and 1-3% of people in the 80+ age range. By 2030, there will likely be 8.7 million cases of Parkinson's disease worldwide, up from 4.1 million cases in 2005. Geographically, data also indicates an increasing tendency in patients from Australia, Europe, and North America; in Asia, data indicate around 646 cases per 100,000 patients and 1601 cases per 100,000 patients, respectively. Bradykinesia, tremor, stiffness, and postural instability are the four motor symptoms collectively referred to as parkinsonism that are indicative of Parkinson's disease. Parkinson's disease patients require a great deal of assistance from others due to their diminished capacity and physical and cognitive abilities [5].

Bradykinesia, tremor, stiffness, and postural instability are the four motor symptoms collectively referred to as parkinsonism that are indicative of Parkinson's disease. Parkinson's disease sufferers require a great deal of assistance from others due to their diminished ability and affected physical and cognitive skills. Alzheimer's disease, on the other hand, is a neurological condition marked by the irreversible loss of neurons in the cortex and hippocampus, which impairs memory, judgement, orientation to the environment, language, and decision-making [5].

Family members assist most Parkinson's disease sufferers. Those who supply direct care (to youngsters, the elderly, or those with chronic illnesses) are referred to as carers, and these family members fall into this category (Merriam Webster, 2018). Family members must adjust as carers to shifts in the erratic symptoms and indicators that patients present with. These conditions may result in the carers' mental health being worse than their physical health [5].

The motor symptoms of Parkinson's disease

Studies have revealed significant correlations between a range of motor symptoms linked to Parkinson's disease (PD), including speech output, handwriting and primary motor symptoms, gait and face motions, saccadic eye

movements, and finger and body movements [6].

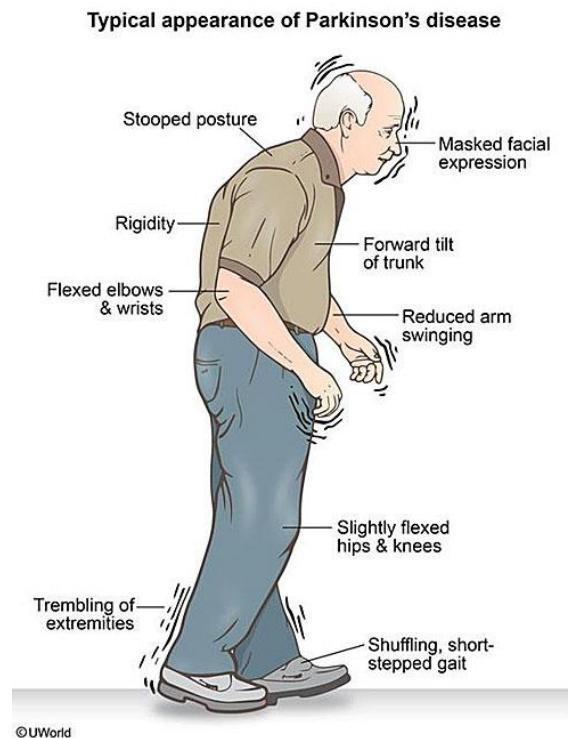


Figure 1. Typical appearance of Parkinson's disease [16].

Major motor complaints

Two of the main motor characteristics of Parkinson's disease (PD) are bradykinesia, or slow movements, and akinesia, or poverty of action, or trouble initiating motions. A patient's sensation of stiffness is linked to rigidity, which can be measured by a physician by looking at a muscle's resistance to passive stretching. It's interesting to note that the length and strength of the long-latency reaction were shown to correlate with the rigidity's clinically measured severity. Regarding tremor, it is possible to differentiate between the symptom's kinetic, postural, and resting forms. The most prevalent type of tremor in Parkinson's disease (PD) is resting tremor, which happens at rest. Essential tremor is more commonly associated with action/kinetic tremor, which occurs during purposeful movements, and postural tremor, which is the inability to keep a stable position against gravity [6].

One of the most typical issues for PD patients is alteration of gait. Patients with the condition

typically have a shuffling stride, which makes it difficult for them to raise their feet off the ground and impedes their ability to use their legs appropriately for propulsion and swing. PD sufferers frequently have micrographia, a small handwriting style [6].

The non-motor symptoms of Parkinson's disease

As Parkinson's disease progresses, non-motor symptoms (NMS) can become more prevalent, which can be a significant source of illness burden for both patients and carers. But the current understanding of NMS is lacking, especially because risk factors that are evaluated are heterogeneous and outcome definitions are not standardized. The best information on the risk factors for NMS in Parkinson's disease may be found in longitudinal research. These studies also give the most compelling evidence that risk factors for hallucinations, depression, apathy, excessive daytime drowsiness, insomnia, and problems in impulse control are present. Cognitive impairment, delusions, and depression all share shared risk factors. Numerous additional NMS also have similar risk factors, suggesting that NMS and deteriorating Parkinson's disease are interdependent [7].

Disturbances in autonomic function

Almost every facet of autonomic function may be impacted by autonomic dysfunction, which is prevalent in Parkinson's disease. Autonomic dysfunction can occur at any stage of Parkinson's disease (PD), and some of its symptoms, including constipation, may manifest years or even decades before motor collapse. Orthostatic hypotension is the most well-known kind of circulatory failure associated with Parkinson's disease (PD). Although not all of these people may have symptoms, about 60% of people may develop Parkinson's disease. When orthostatic hypotension is present in Parkinson's disease patients, diagnosis could be difficult [8].

Digestive dysfunction in Parkinson's disease (PD) manifests as dysphagia, gastroparesis, small intestine bacterial overgrowth, and bowel

dysfunction marked by reduced frequency and problems with the actual process of defecating [8].

Sleep disturbances

Sleep disturbances are one of the most prevalent NMS in Parkinson's disease (PD), accounting for between 60% and 90% of patients with insomnia, sleep disordered breathing disorders (SDB), excessive daytime sleepiness (EDS), rapid eye movement (REM) sleep behavior disorder (RBD), sleep-related movement disorders such as restless legs syndrome (RLS), and circadian rhythm disturbances. Sleep disturbances have a high degree of interindividual and nightly variability. Sleep disturbances reduce the effectiveness of patients' and caregivers' daily activities and quality of life (QoL), as well as the quality of their nightly sleep. In addition, they may adversely affect one's capacity for driving as well as mental, emotional, and cognitive processes. Particularly in the early stages of Parkinson's disease (PD), disintegration of sleep-regulatory pathways as a result of neurodegenerative processes impacting neurotransmitters and sleep regulation circuits appears to be important. Even though there are many variables at play in the complicated pathophysiology of sleep disorders in Parkinson's disease (PD), including unfavorable effects of treatment regimens and nighttime motor problems, it seems that these processes are important [9].

Neuropsychiatric symptoms and dementia

A qualified neuropsychologist conducted interviews with each patient and their primary carers in order to evaluate them using the 12-item Neuropsychiatric Inventory (NPI) based on their observations during the previous month. The NPI is a commonly used, validated, and standardized tool designed especially for assessing neuropsychiatric symptoms associated with dementia. Delusions, hallucinations, restlessness, depression, anxiety, euphoria, apathy, disinhibition, annoyance, abnormal motor behavior, nighttime behavior, and eating/appetite

behavior are all included in the 12-item NPI [10].

Sensory symptoms

Generally speaking, the side of the body that was first or more seriously impacted by the motor oscillations experiences sensory symptoms of Parkinson's disease. Furthermore, there is no correlation between certain sensory symptoms and the following factors: age at onset of Parkinson's disease (PD), levodopa dosage, years of treatment, levodopa use, levodopa use, depression, anxiety, sleep disturbances, motor fluctuations, or history of the disease in first-degree relatives [11].

The clinical course of PD

The way that symptoms progress varies greatly throughout persons. Early in the disease's course, symptoms are often modest and unilateral, and response to treatment is either fair or exceptional, with no daily variability in motor function. Even when the patient's symptoms worsen and contralateral side motor problems emerge, the medication normally works as intended, and the patient is generally in good health. This is commonly referred to as the honeymoon phase. As the condition progresses, the intensity of treatment increases, drug response becomes less predictable, and anti-parkinsonian medicines might trigger dyskinesias that could be fatal. If therapy doesn't improve, impairments related to speech, swallowing, balance, and gait may appear. After a long illness that has persisted for 10 years or longer, the majority of patients may also have certain non-motor symptoms, for which there are presently few viable therapies. These include disruption of the sleep-wake cycle, autonomic failure, depression, pain, cognitive impairment, dementia, psychosis, and sensory complaints [12].

Experiences of Family members

Because they bear the majority of the responsibility and burden of caring for a loved one who has Parkinson's disease, families with many members as well as larger social circles are impacted by the disease. According to earlier research, someone who gives a person in

need both physical and psychological care is referred to as an informal caretaker. The people who are most frequently impacted are the patient's close relatives, such as spouses or adult children. Expressions of concern, affection, gratitude, or respect for the sick family member are correlated with the family member's motivation to receive medical attention [13].

Researchers discover that the most common emotions reported by family members are melancholy and depression. These emotions become apparent when a family member with the condition faces the limits it imposes, causing their loved ones to feel fearful as well [13].

Family members are impacted by providing care for someone with a complicated chronic condition like Parkinson's because this can have an impact on one's bodily, social, and mental well-being in addition to one's financial stability. Family members must adjust psychosocially, support the individual in receiving care, and adjust to the person's condition. The illness may result in deteriorating health and a worse standard of living for family members in the absence of adaptable coping strategies, social support, and other family members [13].

Because Parkinson's disease (PD) causes reduced mobility, patients can rely on their careers. However, in order to meet the mental demands of their patients as well as the obstacles of providing everyday care, carers must also modify their mood during caring situations. Additionally, carers mentioned that if patients could find advice on how to deal with challenges in their day-to-day lives, they may make significant progress towards being able to walk normally once more as soon as feasible [14].

In previous research, a limited number of caregivers talked about their experiences caring for patients with Parkinson's disease (PD), revealing their sentiments of helplessness and depression brought on by the patients' negative emotions as the condition worsened. However, carers in those earlier studies primarily

discussed the day-to-day activities, psychological state, and level of assistance received by patients [14].

Care

Four themes emerge from carers' experiences caring for family members who have Parkinson's disease: adjusting to the family member's condition; the effects felt while providing care; the support obtained in doing so; and the carers' spiritual and cultural relevance. When family members were diagnosed with Parkinson's disease, carers had to undergo a period of adjustment or adaptation [15].

The carer may develop predispositions as a result of the perceived physical and psychological strains of providing care. If the carer does not have healthy coping strategies and the required assistance, the ongoing burden may cause issues for them [15].



Figure 2. Supporting Those with Parkinson's Disease and their Families [17].

For a customer in the first stage of PD, basic services like meal planning, cooking, and household organization might be ideal. However, when the illness worsens, more services can be required. Our clients who may have weakness or restricted movement benefit from personal care. We will consult with families and improve services as necessary to make sure every client is set up for success. It is more comfortable and familiar to carers, which benefits our clients and their families. The pain is usually alleviated by expertise, which facilitates everyone's adjustment to the circumstances [17].

Support

The majority of participants, especially those who were physically or visually impaired, had made modifications to their homes, such as installing walk-in showers, extra lighting, and railings. Numerous people received assistance in obtaining these from physiotherapists and occupational therapists, their local government, or Parkinson's UK. Together with medical experts, these provided participants with useful guidance and assistance when completing benefit applications and filing prescription claims [18].

In addition, family assisted elderly participants who lacked digital literacy in accessing webpages or emails. In comparison to carers who had greater family assistance for practical matters, those who had less family support felt more burdened and guilty about their negative emotions [18].

For the individuals in our research, psychological support came from a variety of sources, including fitness centers, social networks, family, friends, and occasionally prescription drugs like antidepressants. Our study was carried out at the height of the pandemic, a time when attention was focused on mental health. People from minority groups found it more difficult to obtain services, and loneliness and anxiety had a negative impact on the mental health of older people. Focusing on lifestyle choices at this period, according to the participants, enhanced their mental health has also been suggested by other research that looked at people with Parkinson's disease throughout the pandemic [18].

Conclusion

For family members, living with Parkinson's disease is a challenging existence. According to our research, most family members have comparable perspectives of their experiences. They are emotional beings who frequently experience mixed emotions, including fear, grief, and despair. But when people learn to live with the illness on a day-to-day basis, they become able to adjust and cope with it. They

also acknowledge the important lessons the illness has imparted upon them. They both concur that accepting the changes the illness brings about is essential. Their daily life and the persons adopt a slower pace. Family members' active participation in the general care and treatment of their loved ones is crucial. People affected by the disease can benefit immensely from a variety of educational possibilities, courses, social contacts, self-help groups, and platforms for experience sharing. Encouraging and enabling family members facilitates their ability to care for their loved ones, which improves everyone's quality of life.

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