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Psychosocial Support in Parkinsonism Care Dyads: Caregivers and Care Recipients

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Abstract

Parkinson's disease is a progressive neurodegenerative disorder characterized by movement-related symptoms, cognitive decline, and psychological complications. Social support and networks play a crucial role in managing the disease, with patients often relying on close relationships for care and assistance. The effectiveness of support depends on the availability of informal caregivers and the quality of family relationships, highlighting the importance of both informal and formal caregiving in managing Parkinson's disease.

Caring for individuals with Parkinson's disease is demanding, especially for informal caregivers who face increasing physical, emotional, and psychological strain as the disease progresses. This burden can lead to caregiver burnout, impacting their well-being and the quality of care provided. Comprehensive support services, including education, respite care, and counseling, are crucial to promote caregiver well-being and ensure effective care for individuals with Parkinson's.

Multidisciplinary interventions involving neurologists, psychologists, and other specialists are essential for managing Parkinsonism symptoms, supporting caregivers, and improving quality of life.

Keywords

Parkinson's disease, neurodegenerative disorder, James Parkinson, Shaking Palsy, dopamine deficiency, levodopa, carbidopa, dopamine agonists, deep brain stimulation, tremors, muscle stiffness, slowed movements, balance problems, freezing of gait, sleep disturbances, fatigue, gastrointestinal problems, cognitive complications, neuropsychiatric complications, anxiety, hallucinations, delusions, depression, apathy, psychosis, emotional distress, counseling, psychological support, social network theory, social support, social identity, social control, loneliness.

Main Paper

Parkinson's disease is a progressive neurodegenerative disorder named after James Parkinson, who first referred to it as "Shaking Palsy." The disease develops gradually, and many people may not notice its symptoms in the early stages. As the condition progresses through several stages, symptoms become more severe, and from around the third stage onward, individuals often begin to depend on others for assistance. In advanced stages, mobility may become severely limited, sometimes requiring a wheelchair or bed rest. The disease is caused mainly by a dopamine deficiency in the brain. Medications such as levodopa combined with carbidopa are commonly used to increase dopamine activity and manage symptoms. If these medications become ineffective, dopamine agonists or surgical treatments such as deep brain stimulation may be recommended. Healthcare professionals carefully adjust medications to maximize a patient's functioning and quality of life.

Early symptoms typically include tremors, muscle stiffness, slowed movements, and difficulty performing physical tasks. Problems with balance, walking, and freezing of gait can increase the risk of falls and reduce participation in social activities. Many patients also experience pain.

In addition to movement-related problems, many patients may have sleep disturbances, persistent fatigue, and gastrointestinal problems. experience cognitive and neuropsychiatric complications. These may include slowed thinking, difficulties with planning and decision-making, memory decline, and, in advanced stages, dementia. Psychological symptoms such as anxiety, hallucinations, and delusions are also common and may result from disease progression or medication effects. These symptoms can significantly reduce quality of life and make daily activities more challenging. Around 40% of patients experience conditions such as anxiety, depression, or phobias. Depression can worsen physical functioning, accelerate disease progression, and contribute to cognitive decline. Other common non-motor symptoms include apathy and psychosis. Younger individuals diagnosed with Parkinson's disease may experience greater emotional distress because the illness can disrupt employment, relationships, and family life. Counseling and psychological support can help patients and their families cope with these challenges and maintain emotional well-being.

In the context of Parkinson's disease, social network and social support theories have gained increasing recognition because patients often require continuous care and assistance throughout the progression of the disease. Social relationship and social support theories emphasize the roles of social identity, social control, and loneliness in influencing health outcomes and well-being. According to Uchino (2004), "Social support promotes healthy behaviour". Social identity boosts social esteem and helps provide meaning to an individual's life (Thoits, 1983). The social control model improves a healthier lifestyle (Lewis & Rook, 1999). Loneliness and stress-related theories predict that social support plays the role of a 'safeguard tool' against the damaging impacts of loneliness on health (Cohen & Herbert, 1996).

Social network theory highlights the importance of social contacts and interpersonal relationships. A larger social network increases opportunities for social interaction and support, thereby enhancing an individual's access to resources and assistance (Worcester, 1990; Pierce & Sarason, 1991).

The hierarchical-compensatory theory further emphasizes care recipients' expectations regarding sources of support. According to this theory, individuals prefer to receive assistance from those who are closest to them, such as spouses and family members, before seeking help from friends, neighbors, or formal care providers. Typically, the elderly prefer their spouse as a caregiver; if unavailable, their firstborn child is usually the next choice. Caregivers among friends or neighbors are considered a last resort (Cantor, 1991).

Care provided by a preferred individual leaves patients' self-esteem preserved and emotional distress mitigated. However, close relationships, particularly those within the primary and informal support network, are crucial sources of long-term care as they are familiar with the individual's lifestyle, preferences, and behavioral patterns. This can positively influence the caregiving process for older adults with parkinsonism. That is why family members such as spouses and children typically provide sustained and comprehensive support, while neighbors and other community members generally offer more limited or short-term assistance (Messeri & Silverstein, 1993).

The effectiveness of such support depends on the availability of informal caregivers and the quality of family relationships. In many cases there is a need to have formal care givers. As stated above, the neurodegenerative nature of Parkinson's disease demands the need for caregivers who can be professional like home health visiting nurses, rehabilitation therapists, and healthcare social workers.

Providing care for individuals with Parkinson's disease is highly demanding for both formal and informal caregivers, as the progressive nature of the disease can have a significant psychological and emotional impact on those providing care. Caregivers offer extensive support that ranges from assisting with basic activities of daily living, such as bathing, dressing, and feeding, to managing more complex responsibilities, including arranging transportation to medical appointments, coordinating healthcare services, monitoring treatment plans, and addressing the evolving physical, cognitive, and emotional needs of the individual. As the disease progresses, these caregiving responsibilities often become increasingly challenging, placing considerable demands on caregivers' time, energy, and overall well-being. As the disease progresses and the patient's level of dependence increases, caregiving demands often become more intensive and time-consuming. Prolonged involvement in these responsibilities can place significant physical, emotional, and psychological strain on caregivers, increasing their risk of stress, anxiety, exhaustion, and burnout. Common signs of caregiver distress may include persistent sadness, sleep disturbances, emotional outbursts, irritability, and feelings of being overwhelmed.

Research indicates that informal caregivers, particularly family members, often experience a greater caregiving burden than formal caregivers due to their close emotional relationship with the care recipient and the lack of financial compensation for their caregiving responsibilities. Providing care for older adults with Parkinson's disease can be especially demanding, as the progressive nature of the condition leads to a gradual decline in both motor and non-motor functions. As symptoms worsen over time, caregivers must adapt to increasing physical, emotional, and practical demands, making long-term care both challenging and stressful (Lai & Tsui, 2001). Symptoms such as tremors, rigidity, postural instability, cognitive changes, and reduced functional capacity can significantly limit independence and increase the need for continuous supervision and assistance. Consequently, caregivers frequently face substantial emotional, social, and physical demands, underscoring the importance of caregiver support services, education, and respite care programs. One of the most common challenges faced by caregivers is caregiver burnout. Providing continuous assistance with daily activities, mobility, medication management, personal care, and emotional support can be physically demanding and emotionally exhausting. Over time, these responsibilities may lead to chronic stress, fatigue, social isolation, anxiety, and depression.

Another major challenge involves changes in family roles and relationships. Spouses, children, or other family members may gradually transition from their traditional roles to becoming primary caregivers. This shift can place considerable emotional strain on relationships and may result in feelings of grief, sadness, frustration, guilt, or resentment as caregivers adjust to new responsibilities and changing family dynamics.

Many people with Parkinson's experience sleep disturbances, including insomnia, frequent nighttime awakenings, vivid dreams, REM sleep behavior disorder, and nocturnal restlessness, often requiring caregiver assistance during the night. As a result, caregivers frequently experience interrupted and inadequate sleep, leading to chronic fatigue, emotional distress, reduced coping capacity, impaired concentration and decision-making, and a decline in overall physical and mental health. Over time, these sleep-related challenges can increase caregiver burden and negatively affect the quality of care provided. These concerns underscore the need for comprehensive caregiver support, including education, respite care services, counseling, and access to psychosocial resources, to promote caregiver well-being and enhance their ability to provide effective and sustainable care. With advancements in healthcare and technology, increasing attention has been given to preparing formal caregivers to provide comprehensive and person-centered care. Key areas of training include the management of medication side effects, development of effective communication skills, and implementation of cognitive and brain-stimulating exercises that support mental functioning and overall well-being (Wittenberg, Ferrell, Koczywas, & Ruel, 2017). Such training equips caregivers with the knowledge and skills needed to respond effectively to the fluctuating nature of Parkinson's disease symptoms and to provide high-quality care that promotes patient comfort, safety, and dignity.

Effective management of Parkinsonism requires a comprehensive multidisciplinary approach, as the disease affects not only physical functioning but also emotional and social well-being. Optimal care is achieved through the coordinated efforts of healthcare professionals, caregivers, and community support services, working together to address the complex and evolving needs of the individual.

Physical and occupational therapists play a vital role in helping patients maintain mobility, improve balance, and perform activities of daily living more safely and independently. These interventions can reduce the risk of falls, preserve functional abilities, and enhance overall quality of life. Speech therapists contribute by addressing communication difficulties and swallowing disorders, enabling individuals to express themselves more effectively while reducing the risk of aspiration and other complications associated with impaired swallowing.

Equally important are support groups and community organizations, which provide emotional support, practical guidance, and opportunities for social connection for both patients and caregivers. Sharing experiences with others facing similar challenges can lessen feelings of isolation, strengthen coping skills, and foster resilience. Organizations such as the Parkinson's Foundation and the Family Caregiver Alliance offer educational resources, counseling, support programs, and other valuable services that help care partners navigate the ongoing demands of Parkinsonism.

In addition, the involvement of neurologists, psychologists, and other specialists is essential for addressing the medical, cognitive, and emotional aspects of the condition. Together, these multidisciplinary interventions can significantly improve symptom management, support caregiver well-being, and enhance the overall quality of life for individuals living with Parkinsonism.

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