Community care and management of long-term condition

An Information Booklet on Epidemiology, Impact, Evidence-Based Management and Person-Centred Care

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Introduction

In the United Kingdom, Parkinson's places a substantial demand on the health care services, social care system, and family carers (Parkinson's UK, 2024). Effective management requires collaboration of working across primary, secondary, and specialist services with personalized care planning (NHS England, 2023). This booklet will evaluate epidemiology, impacts, models of care, UK policies, and management related to Parkinson's disease.

Parkinson's disease is one of the fastest-growing neurological disorders, and represents a significant public health challenge due to the aging population and also increasing life expectancy (World Health Organization (WHO), 2023; Feigin et al., 2021; Dorsey and Bloem, 2020). It is a progressive long-term condition caused by degeneration of dopamine-producing neurons within the substantia nigra of the brain (National Institute for Health and Care Excellence (NICE), 2022). It results in motor and non-motor symptoms, which can gradually impair the individual's physical, social, and physiological function. It doesn't have a cure currently, so the management is focused on the control of the symptoms, maintaining independence, and also improving the quality of life (NICE, 2022; Bloem, Henderson et al., 2020).

Understanding Parkinson's Disease

What is Parkinson's Disease?

Parkinson's disease is a chronic progressive neurodegenerative disorder that can primarily affect movement, but it also causes a spectrum of non-motor symptoms (Bloem et al., 2021; Schapira et al., 2022). This condition starts to develop as the dopamine-producing neurons in the substantia nigra pars compacta gradually degenerate, which leads to a reduction in levels of dopamine in the basal ganglia (NICE, 2022).

Loss of dopamine disrupts motor control, which can lead to progressive movement difficulties and also non-motor symptoms. As a consequence, the individual experiences increasing difficulty initiating and controlling movement, which is combined with numerous cognitive, emotional, and autonomic symptoms (Schapira et al., 2022). Although Parkinson's disease is associated with older adults, it is not considered a normal consequence of ageing (WHO, 2023).

Many of the individuals received a diagnosis after the age of 60, but approximately 5-10% developed young onset of the disease before the age of 50 (Parkinson's UK, 2024). This type of variation highlights that there is a need for personalized assessment and review regarding the trajectory of the disease.

Clinical Features

The cardinal motor symptoms include resting tremor, slowness of movement (Bradykinesia), muscular rigidity, postural instability, and impaired balance. Bradykinesia is considered essential for the clinical diagnosis, and it is also accompanied by a reduction in facial expressions, diminished arm swing while walking, micrographia, and difficulty performing everyday activities such as eating independently and dressing. In addition to motor impairment, various non-motor symptoms can frequently develop before movement abnormalities become clinically apparent (Bloem et al., 2021).

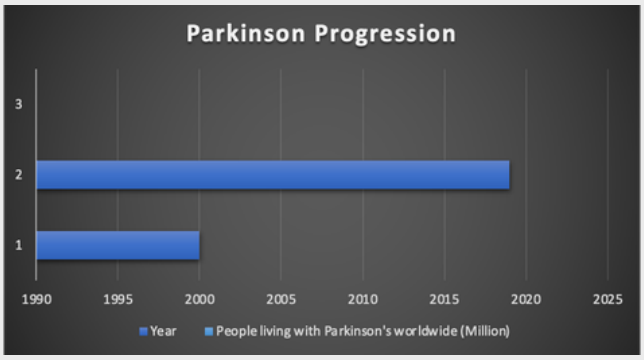
These symptoms include depression and anxiety, cognitive impairment, sleep disturbances, loss of smell, dementia in later stages, fatigue, Constipation, urinary dysfunction, pain, and orthostatic hypotension. Growing evidence suggests that the non-motor symptoms also contribute equally. Sometimes they are more significant, which reduces the quality of life rather than the motor functions, as they can remain under-recognized and also inadequately treated (Schapira et al., 2022).

Disease Progression

This disease progresses through several stages, which range from mild unilateral symptoms to disability that will require full-time assistance (Postuma and Berg, 2024). As the complication disease advances, there are complications such as dysphagia, recurrent falls, cognitive decline, aspiration pneumonia, which become increasingly common (Aarsland et al., 2021; Schapira et al., 2022). In consequence, the management extends beyond pharmacological treatment. Recognizing Parkinson's disease as a lifelong condition can help support person-centered care.

Burden and Prevalence of Parkinson's Disease

The understanding of the epidemiology of Parkinson's disease is important to appreciate the growing impact on the healthcare system and society. Parkinson's disease is recognized as the fastest-growing neurological disorder worldwide, while its prevalence is increasing due to an ageing population, improved life expectancy, environmental influences, as well as improved diagnostic practices (WHO, 2023; Feigin et al., 2021).



Global prevalence

According to the World Health Organization, more than 8.5 million people worldwide were living with Parkinson's disease in 2019, which was double the number since 2000 (WHO, 2023). The global deaths attributable to Parkinson's disease have increased by over 80% during this period, with disability-adjusted life years associated with that condition also rising sustainably (WHO, 2023). Unlike other neurological disorders, the increasing burden of Parkinson's disease cannot be explained only by the aging population (Bloem et al., 2021; Feigin et al., 2021). The Global Burden of Disease study identifies that Parkinson's disease is one of the fastest-growing causes of neurological disability, which increases the demand for health care, long-term social care, and rehabilitation (Feigin et al., 2021).

Burden in the United Kingdom

In the UK, Parkinson's disease affects more than 153,000 people, around 18,000 new diagnoses each year, which equates to one diagnosis every hour (Parkinson's UK, 2024). The current demographic projection estimates that the number of people who are living with Parkinson's disease in the UK will substantially increase by 2030, as there is an increase in longevity and also in the ageing population (Parkinson's UK, 2024). Beyond the prevalence, Parkinson's disease will require long-term, multidisciplinary social care and health care, which includes rehabilitation, medication, and palliative care (NICE, 2022). Disease increases the pressure on the NHS as well as the social care services. The disease also creates a substantial economic cost through reduction in employment, informal caregiving, and early retirement, while many family members also reduce working hours.

Burden of Disease

The burden of disease cannot be measured through mortality, as there are individuals who live with the conditions for decades. Instead, the Disability-Adjusted Life Year (DALYS) provides a much more comprehensive measure as it combines the years of life lost because of premature mortality with the years lived with the disability (WHO, 2020).

Parkinson's produces relatively fewer deaths than other chronic illnesses, but it contributes disproportionately to disability, as there is progressive motor impairment, cognitive decline, and a reduction in healthy life expectancy. The early diagnosis and multidisciplinary action can help reduce disability. DALYS can provide a comprehensive measure of the burden of disease than mortality alone.

Causes and Risk Factors

Parkinson's disease develops through interaction between genetic, environmental, and age-related factors, and most of the cases remain idiopathic (Bloem et al., 2021; Tolosa et al., 2021).

Age

Age is considered to be the strongest recognized risk factor, as the prevalence of the disease increases after 60 years, as there is neuronal degeneration, which accelerates with advancing age (WHO, 2023).

Genetics

Approximately 10-15% of individuals report that there is a family history of Parkinson's disease. The advancements in molecular genetics have identified that mutations in genes including LRRK2, SNCA, PARK7, PINK1, and PRKN can influence neuronal survival, protein degradation, and mitochondrial function (Schapira et al., 2022; Kalia and Lang, 2015). However, these mutations only account for a minority of cases, which reinforces that Parkinson's disease is multifactorial rather than being purely hereditary.

Environmental factors

Increasing evidence has also linked long-term exposure to pesticides, herbicides, and industrial solvents with the elevated risk of the disease. Agricultural workers and individuals who are constantly exposed to certain environmental toxins demonstrate that there is a higher risk than the general population. The air population has also emerged as one of the possible contributors, as the chronic exposure to particulate matter can promote neuroinflammation and also the oxidative stress.

At the same time, several studies have also reported that regular physical activity appears protective through the mechanism that involves improved mitochondrial function, reduction in inflammation, and enhanced neuroplasticity (Bloem, Henderson et al., 2020).

Sex

Men are 1.5 times more likely to develop Parkinson's than women (WHO, 2023). The reason for this remains uncertain, but it might involve the hormonal influence, genetic susceptibility, and the occupational exposure. Oestrogen has also been proposed to exert neuroprotective effects, but the evidence is still inconclusive.

Previous Injuries

Previous traumatic head injuries have also been associated with a modest increase in the risk of the disease, particularly after repeated injuries. Researchers suggest that chronic neuroinflammation, which is initiated by trauma, can accelerate the degeneration of dopaminergic neurons (Schapira et al., 2022). The other lifestyle factors, which include smoking and consumption of caffeine, have also demonstrated that there is a complex association in the epidemiological studies. However, these findings cannot be interpreted as a recommendation, as their overall health risk outweighs any potential neurological benefit.

Overall, the contemporary evidence suggests that Parkinson's disease starts from multiple interacting environmental and biological pathways. The multifactorial understanding supports that there is a need for ongoing research into preventive strategy while it is also important to highlight that the earlier identification of an at-risk individual and timely implementation of evidence-based intervention can help.

Impact of Parkinson's Disease

Physical Impact

Parkinson's disease progressively impairs physical functioning while also reducing independence and quality of life. Even though the motor symptoms are the most recognizable features, their effects go beyond the moment as they can influence communication, mobility, nutrition, and the ability to perform daily life activities. Bradykinesia is known to be a hallmark symptom as it affects daily functioning. Individuals often experience difficulty initiating movement, writing, dressing, or even performing self-care activities, which leads to greater dependence on family members and carers. Although dopaminergic medication can improve symptoms during the early stage, its effectiveness often declines as the disease progresses, which results in unpredictable on-off periods and motor fluctuations (NICE, 2022).

In later stages, postural instability increases the risk of falls, fractures, and hospital admission, which makes physiotherapy an essential part to maintain balance and mobility. Non-motor physical functions, including dysphagia, constipation, chronic pain, and fatigue, reduce the functional ability and quality of life (Schapira et al., 2022; Aarsland et al., 2021). Recent evidence also suggests that these motor functions can have a greater impact on well-being than the motor environment, which highlights the importance of multidisciplinary care and holistic assessment (Bloem, Henderson et al., 2020).

Psychological Impact

The psychological impact of Parkinson's disease is often profound, and it can develop before even motor symptoms become apparent. Depression, anxiety, dementia, and cognitive impairment contribute substantially to the reduction of quality of life, but these symptoms are frequently underdiagnosed because they are attributed to aging and physical disability (Aarsland et al., 2021). Depression results from neurobiological changes and the emotional impact of progressive disability, which reduces independence, and there is also uncertainty regarding the future. The anxiety starts from concern regarding the progression of the disease, fall and the effectiveness of medication, while it also reduces confidence and limits participation in work and social activities.

The cognitive decline can impair memory, attention, and decision-making, which increases the dependence on carers. Sleep disorders, hallucinations, and psychosis can also occur during the advanced stages or after long-term dopaminergic therapy.

Social Impact

Parkinson's disease also contributes to social life as it affects employment, community participation, and relationships. Progressive motor impairment, fatigue, and cognitive difficulties can reduce work capacity, which leads to a reduction in hours, early retirement, or even loss of the job. Therefore, many individuals experience financial insecurity and a loss of personal identity (Parkinson's UK, 2024; Copeland et al., 2024). Communication difficulties and a reduction in facial expressions also make social interaction increasingly challenging. Many of the individuals are likely to withdraw from hobbies, social events, and community activities due to embarrassment and fear of falling. This social isolation contributes to loneliness, depression, and anxiety. The financial burden also extends beyond the health care costs to home adaptation, assistive equipment, and a reduction in household income.

Impact on Families and Informal Carers

Parkinson's disease also has a considerable impact on family members who become informal carers responsible for managing medication, mobility assistance, and emotional support. As the disease progresses, caregiving responsibility increases, which results in anxiety, chronic stress, financial hardship, and sleep disturbances (Parkinson's UK, 2024).

The family members might reduce working hours or leave employment to provide care, while changing family rules can affect the emotional well-being and relationships (Copeland et al., 2024). The current policy of the NHS recognizes carers as partners in care planning and recommends providing education, access to community support, and respite services (NHS England, 2023).

Evidence-Based Management of Parkinson's Disease in the NHS

The effective management of Parkinson's requires a multidisciplinary approach that can address motor as well as non-motor symptoms while also promoting quality of life, self-management, and independence (Parkinson's UK, 2023). As the disease is incurable and progressive, the treatment focuses on control of symptoms, reducing complications, and maintaining daily functioning. NHS care emphasizes person-centered management, which recognizes that disease progression and symptoms are different among different individuals (NICE, 2022; NHS England, 2023).

Pharmacological management

Medication is a primary way of treatment where NICE recommends levodopa as a first-line therapy when there are motor symptoms affecting the quality of life. Dopamine agonists and monoamine oxidase-B inhibitors might also be used as the early stage or even alongside levodopa, while catechol-O-methyltransferase inhibitors can reduce wearing-off symptoms (NICE, 2022). The long-term treatment can lead to complications such as hallucinations and dyskinesia, which makes regular medical review essential.

Non-pharmacological management

The medicine alone is not sufficient, so NICE recommends multidisciplinary case care which involves specialist nurses, neurologists, occupational therapists, physiotherapists, dieticians, and psychologists. Physiotherapy can help in improving balance and mobility, promotes independence, while speech therapy can support communication and swallowing. Regular exercise can improve functional ability and mobility.

Advanced Therapies and Person-Centered Care

Advanced interventions such as deep brain stimulation or infusion therapies can benefit selected patients who have severe motor fluctuations. The contemporary NHS practices also promote supported self-management, personalized care planning, and shared decision-making, which helps individuals participate in their treatment decision-making process and also improves long-term outcomes (NHS England, 2023).

Models of Care

UK Model: NHS House of Care Model

The House of Care model is a key fundamental framework for managing long-term conditions with the help of a collaborative partnership between patients and healthcare professionals. Then, only focusing on medical treatment, it promotes personalized care planning, coordinated multidisciplinary services, and self-management (NHS England, 2023). For the people who have the disease, this model will support regular care planning, medication review, and also the collaboration between primary care, community organization, and specialist neurological services.

The strength of this model is in recognizing physiological, social, and physical needs in the management of medicine. However, the implementation is different across the UK as there are workforce shortages and regional differences in the availability of service, which limit the consistent delivery of person-centred care

International Model: Wagner's Chronic Care Model

This model is widely used internationally to improve the outcome for chronic diseases. It has self-management support, community resources, a clinical information system, multidisciplinary care, as well as the evidence based decision making (Wagner et al., 2001). In the disease, the CCM encourages a coordinated follow-up, proactive monitoring, and the education of the patients through integrated healthcare systems.

Compared to the House of Care model, it puts a greater focus on the healthcare system redesign and the management of information. Although the implementation of this model requires considerable investment, both of the models demonstrate that effective long-term condition management is dependent upon proactive and patient-centered care rather than episodic treatment.

Health and Social Care Policies

UK policy plays an important role in improving the management of Parkinson's. NHS long-term plan promotes personalized care, integrated services, supported self-management, and prevention, which enables people who have died to remain independent (NHS England, 2019). NICE guideline NG71 also provides evidence-based recommendations for medication rehabilitation diagnosis and ongoing review, which helps in reducing the variation in the care across the NHS (NICE, 2022). The Health and Care Act 2022 also established integrated care systems so that there can be improvement in collaboration between NHS organizations, voluntary services, and local authorities (UK Government, 2022).

For Parkinson's, ICSC supports coordinated care pathways while improving the communication between healthcare workers. Finally, the Comprehensive Model of Personalized Care also promotes shared decision-making and supports self-management. Policies help in encouraging holistic management, which recognizes the needs of the individuals who are living with the disease. However, there are shortages of workers and increasing demand, which continue to limit the overall implementation across the country and highlights that there is need for investment in community-based services.

Recommendations

The following recommendations can help improve the long-term outcomes for people who are living with Parkinson's disease. Firstly, increase public awareness and professional education so that there can be earlier recognition and diagnosis. Second will be to expand the access to Parkinson's disease specialist nurses across all of the integrated care systems so that continuity of care can be improved. Improve access to multi-disciplinary rehabilitation services, which include occupational therapy, speech and language therapy, physiotherapy, psychology, and dietetics. Next will be to strengthen the personalized care planning through regular shared goal setting and decision-making process. Increase the availability of structured self-management education programs and also provide peer support groups. Enhance the support for the family carers through psychological support, caregiver education, and the services.

Improve the integration between NHS, social care, and voluntary organisations so that there can be a reduction in fragmented care. Finally, encourage earlier advanced care planning and discussion regarding end-of-life care and palliative care so that treatment will align with the patient's preference. The implementation of these recommendations can help in improving quality of life while also reducing avoidable hospital admissions and supporting the delivery of person-centered care throughout the trajectory of the disease.

Conclusion

Parkinson's disease is a complex progressive neurological disorder that can affect physical health, social participation, psychological well-being, and family life. Although there is currently no cure, the advancement in pharmacological therapy, personalized care, and multidisciplinary rehabilitation can significantly improve the long-term outcome. Contemporary research demonstrates that successful management can extend beyond the control of symptoms, while it will require coordinated services that recognize the preferences and goals of the individual and understand the social circumstances. The House of Care model, the Chronic Care model, and current NHS policies can provide a valuable framework to deliver integrated and person-centred care. The continuous investment in specialized services, multidisciplinary collaboration, family support, and supported self-management is important so that the growing needs of Parkinson's disease can be met and people who live with this disease can live well despite the challenges.

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