

# Palliative care for Parkinson's disease

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**Abstract:** Parkinson's disease (PD) is a slowly progressive multi-system neurodegenerative disorder, with no available disease-modifying treatment. The disease is associated with motor and non-motor symptoms leading to impaired quality of life, disability and significant caregiver distress. Patients with PD benefit from palliative care which provides a holistic approach to meet their multi-faceted needs, including symptom control, communication needs and caregiver support. This article would review on recent articles addressing palliative care for PD.

**Keywords:** Parkinson's disease (PD); palliative care; prognostication; motor symptoms

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## Background

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with all life-threatening illnesses. Palliative care is important in neurology as the trajectory of many neurological conditions is progressive and incurable (1). Patients with Parkinson's disease (PD) are known to have motor and non-motor symptoms which become refractory to treatment with time, associated caregiver distress and increased mortality. Palliative care seeks to reduce suffering in PD patients and their families through physical, psychosocial and spiritual support. Applying palliative care in PD has been specifically addressed in international symposium (2), by professional society (3) and in national guidelines (4,5).

## Disease burden and mortality in PD

PD is a slowly progressive multi-system neurodegenerative disorder, mainly affecting patients in later years of life (6). It is the second most common neurodegenerative disease worldwide, with its incidence and prevalence on the rise along with aging of the population (7).

The characteristic classical motor features (the parkinsonian symptoms) of PD include bradykinesia, rigidity, resting tremor and postural instability. Patients

with PD also suffered from multiple non-motor features including olfactory dysfunction, cognitive impairment, psychiatric symptoms, sleep disorders, autonomic dysfunction, pain and fatigue (6). As the disease progresses, both motor and non-motor symptoms become prominent and treatment-resistant. Advanced PD is identified by disability requiring help for the activities of daily living, presence of motor fluctuations with limitations to perform basic activities of daily living without help, severe dysphagia, recurrent falls, and dementia (8). Up to now there are no disease-modifying treatments that can stop or delay the disease process or mortality.

Patients with PD were found to have more physician consultations and more emergency department visits per year than did reference subjects of similar age and sex in a population-based study (9). They also have greater and earlier need for institutional care (9). A cross-sectional analysis of a hospital admission data involving more than 180,000 patients with PD found that they had more hospital admissions compared with patients without PD (10). The main reasons for admission were pneumonia (13.5%), motor decline (9.4%), urinary tract infection (9.2%) and hip fractures (4.3%), and they occurred 1.5 to 2.6 times more frequently in patients than controls. They were almost twice as likely to be hospitalized for more than 3 months (ratio 1.90, 95% CI: 1.83–1.97) and more likely have in-hospital death (ratio 2.46, 95% CI: 2.42–2.49).

The mortality risk among PD patients is shown to be increased by 1.5–2.2-fold in two meta-analyses (11,12). Increasing age and presence of dementia were most commonly associated with increased mortality (11,12). In post-mortem studies, mean duration of disease until death ranged from 6.9 to 14.3 years (11). Data on cause of death from retrospective review on death certification suggested that patients with PD are more commonly died from dementia, pneumonia and other infections, as compared with general population in which death from cancer and ischaemic heart disease is more prevalent (13,14).

### Starting palliative care in patients with PD

Patients with PD benefit early from palliative care in view of the impact of the disease impairing autonomy and quality of life. The provision of palliative care in patients with PD focuses on unmet needs and should be aligned with patient priorities. It is recommended that a palliative care approach should be applied from the early phase, throughout the course of the disease, complementing but not replacing other treatments (5). However, like other patients with chronic neurological condition, the individual needs may vary over time, therefore it is suggested that a model of dynamic involvement of palliative care services should be adopted (15). The services can be triggered at times of particular symptoms or psychosocial issues—such as the start of new interventions (e.g., artificial nutrition) or at the very end of life.

For patients with complex physical, social, psychological and/or spiritual needs that do not respond to simple or established protocols of palliative care, there should be access to the support from specialist palliative care service (16,17).

However, rate of use of hospice in PD patients has been low (18,19). Caregivers often considered palliative care services to be synonymous with hospice care, and hence they did not consider this service option (20). Health care workers also have uncertainty about timing of palliative care, such that it was often not introduced until a crisis point (21).

### Prognostication in PD

A way of identifying patients with palliative care needs is by prognostication. Pulling together a range of clinical, social and other factors that give a whole picture of deterioration, prognostication by a health care profession can be done

intuitively by a surprise question “would you be surprised if the patient were to die in the next year, months, weeks, days?” (22) A negative answer should prompt palliative measures that might be taken to improve the patient’s quality of life and in preparation for possible further decline (22). On the other hand, some general markers of advanced disease may also prompt clinician the need of palliative care for a PD patient, including weight loss, declining functional status, frequent infections and hospitalizations, skin breakdown and evidence of malnutrition (23). Another simple estimation is by using the palliative performance scale (PPS) which measures the functional status of a patient. PPS has been shown to guide prognostication (24) and it is used to determine the eligibility for enrolment in palliative care benefits program (25).

Currently there are no specific tools to predict prognosis in PD. A study aiming at recognition of hospice eligibility for PD tried to identify variables which have a higher probability of occurring uniquely in 6 to 12 months before death when compared to 18 to 24 months before death (26). The results suggested that body mass index less than 18 kg/m<sup>2</sup>, accelerated weight loss and a reduction in prescribing of dopaminergic medications as side effects outweigh benefit are the specific predictors.

On the other hand, there are specific guidelines to prompt earlier identification of patients with advanced PD and likely limited survival (*Table 1*).

### Symptom burden in advanced PD

There are established guidelines in management of motor (4,28-31) and non-motor (4,28,31-34) symptoms in PD. However, symptom burden in advanced PD is still high, and it has been reported to be of similar degree as in metastatic cancer (35).

The motor symptoms of PD progress over years and the Hoehn and Yahr scale is a commonly used system for describing this (*Table 2*) (36). After the honeymoon period in early years of PD when antiparkinsonian drugs usually provide excellent control over the motor symptoms of bradykinesia and rigidity, majority of patients begin to experience less reliable drug response upon disease progression. Patient would experience complications from the long-term drug treatment, including motor fluctuations (wearing-off and on-off symptoms) and dyskinesia. In advanced PD, prominent motor symptoms, as reported in a cohort of 50 patients with stage 4 or 5 of Hoehn and Yahr,

**Table 1** Guidance to identify advanced PD patients with palliative care needs

## Gold Standard Framework (GSF) Proactive Identification Guidance (22)

Indicators of a limited life expectancy in advanced PD

- (I) Drug treatment less effective or increasingly complex regime of drug treatments
- (II) Reduced independence, needs ADL help
- (III) The condition is less well controlled with increasing “off” periods
- (IV) Dyskinesias, mobility problems and falls
- (V) Psychiatric signs (depression, anxiety, hallucinations, psychosis)
- (VI) Similar pattern to frailty listed in GSF

## Hospice guidelines for neurologic disease in US (27)

- (I) Critically impaired breathing including dyspnea at rest, vital capacity ,30%, O<sub>2</sub> need at rest, and refusal of artificial ventilation, or
- (II) Rapid disease progression (to bed-bound status, unintelligible speech, need for pureed diet, and/or major assistance needed for ADLs) with either
  - (i) Critical nutrition impairment in the prior year (inability to maintain sufficient fluid/caloric intake, continuing weight loss, dehydration, and refusal of artificial feeding methods) or
  - (ii) Life-threatening complications in the prior year (recurrent aspiration pneumonia, pyelonephritis, sepsis, recurrent fever, or stage 3 or 4 pressure ulcers)

PD, Parkinson’s disease; ADL, activities of daily living.

**Table 2** Hoehn and Yahr scale

Stage	Description
1	Unilateral involvement only usually with minimal or no functional disability
2	Bilateral or midline involvement without impairment of balance
3	Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent
4	Severely disabling disease; still able to walk or stand unassisted
5	Confinement to bed or wheelchair unless aided

include severe akinesia, postural instability, freezing of gait, dysarthria and dysphagia (37).

Both motor and non-motor symptoms are prevalent in advanced PD. Using a checklist with 20 symptoms relevant in palliative care, a cross-sectional community study on 85 patients with PD stages 3–5 Hoehn and Yahr reported a mean of 10.7 physical symptoms (38,39). Pain, fatigue, daytime somnolence and problems with mobility were found in more than 80% of PD patients. More than half of patients also had constipation, loss of bladder control, swallowing difficulties, drooling, breathlessness

and sleep problems. Among these symptoms, pain, fatigue, constipation and drooling were rated as causing severe problems. Anxiety and depression were also reported in 70% and 60% of patients (39).

From the patient’s perspective, there is a recent questionnaire survey (40) which included 814 PD patients (70% were of stages 3–5 Hoehn and Yahr) who felt subjectively severely affected by their illness. The commonest reasons for feeling severely affected were mobility impairment (34.9%), coordination problems (17.0%), speech problems (12.2%), and limited day-to-day activities (7.8%), e.g., getting dressed and personal hygiene. Significant associations were observed between subjectively felt severe affectedness and Hoehn and Yahr, poorer health, higher nursing care level, and having no children (40).

There are symptom assessment tools that could help better delineation of the palliative care needs in PD. Palliative care outcome scale (POS) (41) is a 10-item reliable and validated core outcome measure that was designed to cover those domains considered important for palliative care, including pain control, symptom control, patient anxiety, family anxiety, information, sharing feelings, depression, self-worth, practical needs and time wasted (41). POS with additional Parkinsonism Plus symptoms (POS-PP) is a 20-item validated extension of the core POS

assessing symptoms (POS-S), with additional Parkinsonism Plus symptoms added (38). Edmonton Symptom Assessment System (ESAS) (42) is commonly used for symptom screening and longitudinal monitoring in patients seen by palliative care in both inpatient and outpatient settings. It has been psychometrically validated and translated into over 20 languages (43). It assesses nine common symptoms including pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, wellbeing and shortness of breath. To address PD specific symptoms, there is a modified version of ESAS (ESAS-PD) with coverage of clinically relevant symptoms, including constipation, difficulty swallowing, stiffness and confusion (35). This tool was found to be responsive to treatment, and patients with advanced PD were able to complete ESAS-PD independently or with caregiver assistance (35).

### **Advance care planning (ACP)**

In the definition recently endorsed by the European Association for Palliative Care, ACP is a process enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate (44). ACP is known to be associated with the end of life wishes more likely to be known and respected, the bereaved family members with less stress, anxiety and depression, and a higher satisfaction in patient and family (45). In view of the impact of PD on cognitive function and communication in its progression, patients should have an opportunity to address on ACP early in the disease. The content of ACP can be more targeted later upon progression of disease.

However, it is recommended that ACP should be adapted to the individual's readiness to engage in the ACP process (44), as some patients with early stage PD felt that ACP may be too depressing, hoping that a cure would come in time for them (46). In a survey of 267 patients with PD on preferences about prognostic and end of life discussions (47), although 94% of patients preferred early information on prognosis and treatment and 68.5% actually reported having some kind of ACP document, only about half of the patients wanted to discuss advance care document early. A smaller proportion wanted early discussions about end-of-life care planning (27%) or end-of-life care options such as hospice (21%), and a very small number felt end-of-life issues should never be discussed (47). More commonly patients would like to discuss these issues

when their disease worsened, therefore it is recommended that potential triggers for initiation of ACP should be identified and developed (44). In the case of PD, these could be progression of disease in terms of their motor and non-motor features (4), deterioration in functioning and transitions in care.

ACP usually involves patient and their important ones, usually their family/caregivers, and the health care team. Though patients would agree on their own responsibility to bring up discussions on issues of life expectancy, end-of-life care planning, and end-of-life care options such as hospice (47), they might not know to whom they should turn for ACP (48). Some thought that their neurologist should raise these topics (47), while some with advance directives did not include their physician in the process and believed it should be done by the family or a lawyer (48). Caregivers of PD patients may wish the health care professional to have greater input to inform the ACP. In a study of 64 spouses of patients with PD (49), while most (92%) believed that they would be involved in the decision making, 70% also thought that physicians should be involved.

### **Caregiver needs and support**

A caregiver refers an individual who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental health conditions (50). Family caregivers are the greatest support of patients in advanced diseases especially when they wish to be cared for at home. On top of the caregiving role, the multiple roles played by the caregiver of palliative care patients include well-being enhancer, "handyman" in daily tasks, minimizer/manager of suffering, palliative care facilitator and responsible for the continuity of care, learner in care provision and decision-maker at the end-of-life (51).

While many PD patients felt their families were anxious or worried about them (39), most PD caregivers themselves indeed felt unprepared for their role (52). Particular challenges to PD caregiver are the cognitive, personality and behavioral changes that may occur, especially in advanced stages of disease (5).

A meta-analysis on factors associated with PD caregiver distress integrated findings from ten studies on the correlates of caregiver distress in terms of depressive symptoms, burden, as well as stress induced by the caregiving role (53). Motor symptoms of patients with PD were found to have the strongest relationship with

caregiver distress. Increased motor symptoms and higher dependency in activities of daily living showed the highest effect sizes on caregiver distress ( $|r| = 0.42-0.43$ ) than did patients' higher level of depression ( $r = 0.37$ ), more advanced disease stage ( $r = 0.33$ ), longer duration of disease ( $r = 0.31$ ), as well as poorer cognitive functioning level ( $|r| = 0.28$ ). On the contrary, a systematic review on predictive factors of psychosocial outcomes in caregivers of PD patients found that psychological and non-motor symptoms appear to be more important than physical symptoms and levels of disability (54).

So far research on effective interventions for caregiver of patients with PD is limited and inconclusive (2). A systematic review by Hempel *et al.* (55) evaluated 30 studies (24 full studies and 6 studies published as abstracts) to identify and examine the evidence on psychosocial interventions for caregivers. Day care, night-sitting services, community care assessment, web-based instructional videos on caregiving tips/strategies, formal education classes, and support groups are identified intervention. However, the clinical or cost effectiveness could not be assessed in most of the intervention because of weak research designs, small numbers of participants and inconsistent results. On the other hand, a psychosocial intervention of eight weekly sessions of 90-minute duration, the Patient Education Program Parkinson (PEPP) (56), was shown to benefit PD caregivers in a randomized controlled trial. A significant effect for the caregivers on psychosocial problems and need for help was found. Patients' and caregivers' mood also improved significantly after each session.

Though at the mean time research on effective caregiver interventions in PD is pending, caregivers can benefit from information in internet resource (e.g., Parkinson's UK <https://www.parkinsons.org.uk/>, National Parkinson Foundation <http://www.parkinson.org/>) and local social agents which provide generic support to caregiver. Referral to a clinical psychology may help caregiver in emotional distress. Bereavement care is also an integral part of the support to caregiver in end-of-life care.

### Multidisciplinary approach

Teamwork is the most effective way to accomplish complex tasks. Because of the multifaceted needs of patients with PD, a multidisciplinary team (MDT) approach should be adopted and delivered in a coordinated manner.

An MDT in PD has combination of different members which might include neurologist, general practitioner,

palliative care specialist, gerontologist, rehabilitative specialist, PD nursing specialist, physiotherapist, occupational therapist, speech therapist, dietitian, psychologist, pharmacist, social workers, spiritual care workers and voluntary organizations, as well as support from various specialists including gastroenterologist, neurosurgeon, sleep specialist and urologist (5,57,58). Despite the diverse disciplines, an ideal model would be an "interdisciplinary" approach which is based on synergistic and interdependent interaction of team members, like a hand able to achieve more than total of each individual finger can alone (59). Also it is important to have a clear, defined pathway to follow when an individual needs help or advice and to have a single point of contact, i.e., a "key worker(s)" (5). This key worker can be a PD nursing specialist in all stages of PD (58). For PD patients in end-of-life phase who preferred to die at home, the key worker may be a community hospice nurse (60). Caregivers should also be included in the teamwork. Engaging caregivers in understanding of disease and deciding of treatment could contribute to greater satisfaction of care and improve adherence to therapy (57).

A recent review of evidence of MDT interventions in people with PD (57) has covered 13 studies including 6 RCTs. The studies involved patients with both early and late stage by Hoehn and Yahr staging of disability in PD. In general, MDT approach was shown to improve the health-related quality of life and motor function for patients with PD and quality of life of their caregivers. The limitations of the review include the lack of a systematic literature search and the limited number of controlled studies.

### Conclusions

A palliative care approach should be introduced early in the course of PD. Palliative care for PD should be need-based, focusing on improving of QOL and autonomy, ACP and support to caregiver. An ideal model of care would be interdisciplinary team providing clear care pathway and a single point of contact. Future directions should include development of tools to guide prognostication and referral to specialist palliative care, assessment of specific palliative care intervention for patients with PD and model to guide caregiver assessment and support.

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## Footnote

*Conflicts of Interest:* The author has no conflicts of interest to declare.

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