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NEUROLOGY AND PRECLINICAL NEUROLOGICAL STUDIES - REVIEW ARTICLE

Far from being the end of the road: taking a closer look at neuropalliative care in Parkinson's disease

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Abstract

Parkinson's disease (PD) is now recognized as a multisystem, heterogeneous neurodegenerative disease with fluctuating trajectories and complex symptom profiles. Despite therapeutic advances, many patients (particularly women and those in late stages) and their caregivers face substantial unmet needs across physical, psychological, social, and spiritual domains, which highlight the need for a more integrative care model. Palliative care, defined as holistic, person-centered care for individuals with life-limiting illnesses, is increasingly recognized as particularly relevant in PD, from early to terminal stages. However, its implementation in neurology remains limited, notably due to persistent misconceptions, and delayed or absent referrals. This narrative review therefore aims to equip PD care teams with a clearer understanding of palliative care principles and their applicability to PD, by synthesizing emerging evidence in neuropalliative care, and providing practical recommendations for integration into routine neurological practice. Building on the specificities of quality of care for chronic conditions, optimal neuropalliative care in PD involves regular (re)assessment of symptoms and priorities, effective management of the chronic-palliative interface, good communication, continuity of care (including neurological care until the end of life), and a multidisciplinary network of professionals working both in the community and in specialized clinics, while leaving room for the involvement of caregivers. Far from being "the end of the road", neuropalliative care is a strategic and compassionate response to the evolving complexity of PD, which ultimately enhances quality of life, supports families, and reinforces the neurologist's pivotal role in longitudinal, person-centered care.

Keywords Parkinson's disease · Palliative care · Neuropalliative care · End-of-life · Uncertainty · Disease trajectories

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Introduction

"In medicine, this is known as the WICOS problem: Who Is the Captain Of the Ship?
The nephrologists disagreed with the ICU doctors,
who disagreed with the endocrinologists,
who disagreed with the oncologists,
who disagreed with the gastroenterologists."
"When Breath Becomes Air" - Paul Kalanithi, MD (1977–2015)[1]

Over the last few decades, disorders affecting the nervous system have accounted for a significant and steadily increasing share of the overall burden of disease worldwide, as assessed by the Global Burden of Disease Study (Feigin et al. 2020; Deuschl et al. 2020; Steinmetz et al. 2024). Among these, an estimated 11.77 million people were living with Parkinson's disease (PD) in 2021 (Luo et al. 2025) - the number of people affected being even higher when considering the heavy burden PD places on caregivers and families (Rosqvist et al. 2022; Aamodt et al. 2024). PD is a complex neurodegenerative condition that is not limited to disorders of the dopaminergic system (Weiner 2008; Csoti et al. 2016; Ahlskog 2020; Antonini et al. 2023; Morris et al. 2024). It is rather characterized as a systemic condition affecting multiple organs and neurotransmitters pathways, with clinical manifestations at the crossroads of almost all medical subspecialties, underpinned by a high degree of interindividual heterogeneity in terms of symptom burden and severity, clinical subtype, trajectory of decline and disease progression rate (Weiner 2008; Klotsche et al. 2011; Csoti et al. 2016; Titova et al. 2017; Poonja et al. 2021; Antonini et al. 2023; Morris et al. 2024). The increase in PD prevalence, which now exceeds predictions based solely on aging and population growth (Ben-Shlomo et al. 2024; Luo et al. 2025), and the concerning projections for 2050 (Su et al. 2025) call for the implementation of multifactorial preventive measures and high-quality care for those already affected (Schiess et al. 2022; Luo et al. 2025). Regarding the latter, specificities of quality of care for chronic conditions have been recently defined (Ku et al. 2024). They combine *effectiveness* (providing science-based services to all those who could benefit from them and refraining from providing them to those who are unlikely to benefit), *efficiency* (using appropriate resources while avoiding waste), *safety* (avoiding harm to patients and staff), *equity* (ensuring that all eligible patients can access good-quality healthcare, regardless of personal characteristics), *accessibility, timeliness and affordability* (reducing delays, access barriers and financial risk), *continuity of care* (relational, informational and management continuity) and *person-centeredness* (Ku et al. 2024). Being a progressive, fluctuating, and currently incurable neurological condition, with several progression milestones (Akbar et al. 2021; Gonzalez et al. 2022; Brumm et al. 2023) and acute complications (e.g. pneumonia, urinary tract infections, falls) that can precipitate death (Zheng et al. 2012; Goy et al. 2015; Prasad and Pal 2019; Simonet et al. 2020; Williams et al. 2022), PD fits in the multimorbidity illness trajectory (Murray et al. 2024). Its evolving layers of complexity ultimately lead to a high level of physical and psychological needs, and a loss of autonomy throughout time (Santos García et al. 2017; McLean et al. 2017; Tenison and Henderson 2020; Fabbri et al. 2020). Despite notable advances in medical and surgical approaches (Foltynie et al. 2024) as well as models of care (Bloem et al. 2020b; Pirtošek 2024) in the last decades, unmet needs are still significant in PD, both for people living with the condition -and especially women (Subramanian et al. 2022) and late-stage PD (LSPD) patients (Saleem et al. 2013; Read et al. 2019; Rukavina et al. 2021)- and for their caregivers (Hatano et al. 2009; Lee et al. 2019a; LeWitt and Chaudhuri 2020). Physical, social, psychological & spiritual dimensions are all affected, significantly impairing quality of life, regardless of the disease stage - and even of the age at diagnosis (Saleem et al. 2013; Demeulemeester et al. 2015; Mehanna and Jankovic 2019; Zhao et al. 2021; Santos García et al. 2021; McDaniels et al. 2023; Bublitz et al. 2024). Considering that these burdens align with the concept of "*total pain*" developed by Dame Cicely Saunders (1918–2005), founder of the modern hospice movement (Ong and Forbes 2005), application of the palliative care principles and strategies therefore appear to be particularly relevant in PD (Ghoche 2012; Kluger et al. 2017). Palliative care can be defined as holistic care that prioritizes quality of life for people of all ages with life limiting conditions (Peeler et al. 2024), including neurological disorders (Robinson and Holloway 2017; Kluger et al. 2023). Palliative care has gained attention over the last two decades in the field of PD, most notably in North America (Borasio et al. 2003; Thomas and MacMahon 2004a, b; Hudson et al. 2006; Bunting-Perry 2006; Chen et al. 2008; Miyasaki et al. 2012; Ghoche 2012; Kluger et al. 2020). However, the persistent myth and widespread belief of dying "*with*" PD and not *from* PD (despite numerous studies showing higher risk of mortality and an increased risk of dying from complications directly related to PD (Goy et al. 2007; Posada et al. 2011; Allyson Jones et al. 2012; Choi et al. 2019; Ryu et al. 2023; Sipilä et al. 2024; Benito-Rodríguez et al. 2025) on the one hand, and the stigma and misconceptions surrounding palliative care, notably the frequent confusion between hospice/end of life care and palliative care (also seen among neurologists (Álvarez Saúco et al. 2024; Wan et al. 2024) on the other, mean that PD patients are often not referred to specialist

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[1] https://med.stanford.edu/news/all-news/2015/03/stanford-neurosurgeon-writer-paul-kalanithi-dies-at-37.html.

Table 1 Palliative care: concepts and definitions (Ong and Forbes 2005; Hui et al. 2014; Sudore et al. 2017; Rietjens et al. 2017; Creutzfeldt et al. 2019; Macchi and Lum 2022)

Concept	Definition
Palliative care	Specialized medical care that aims to recognize, prevent, and alleviate physical, psychological, social, and spiritual suffering and improve communication about end of life and quality of life for patients with serious illness and their families Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope
Palliative care approach	An approach that improves the quality of life of patients and their families facing serious illness Encompasses both primary and palliative care
Primary palliative care	Palliative care provided by the patient's primary medical team (e.g. neurologist, general practitioner…)
Specialized palliative care	Palliative care provided by a specialized consulting palliative care team (which may serve as part of inpatient, outpatient or home palliative care teams, or work in hospice)
Neuropalliative care	Disease-specific palliative care for people with serious neurologic illnesses Emerging field of medicine dedicated to meeting the unique needs of people living with neurologic illness through palliative care approaches
Neuropalliative care approach	Holistic approach to people suffering from neurological illness
Advance care planning (ACP)	Ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate Process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illnesses.
Advance directives (AD)	Legal documents that outline an individual's preferences regarding major medical decisions (written document) A document to record values, goals, and preferences to be considered when the patient is unable to express their preferences, saved in such a way that they can be found when they are needed and regularly reviewed and updated over time
Total pain	Suffering that encompasses physical, psychological, social, spiritual, and practical dimensions
Transition of care	Changes in the place of care, level of care, and/or goals of care
End-of-life care	Comprehensive care for dying patients in the last few hours, days or weeks of life
Hospice	A formal system of interdisciplinary care that provides palliative care services to the dying in the last months of life (6 months)

palliative care (Fox et al. 2015; Miyasaki 2019), or referred too late -which incidentally reinforces its association with terminal care and death (Flieger et al. 2020). This is sadly in line with other medical conditions, as only a small fraction of people around the world who would benefit from palliative care receive it (14%), making it an overlooked global health priority (Peeler et al. 2024), while palliative care needs are expected to further increase in the future (Etkind et al. 2017). Although each country and healthcare system is subject to specific constraints, this narrative review aims to educate clinicians on the significance and benefits of palliative care (concepts and definitions are summarized in Table 1), and to provide practical and pragmatic recommendations for the care and support of people with PD and their caregivers, by summarizing the growing literature on neuropalliative care and PD. Far from being "the end of the road", palliative care is actually all about paving the way for a better future.

Beyond stigma and misconceptions: the true meaning of palliative care

> *"O, be some other name!*
>
> *What's in a name? That which we call a rose,*
>
> *By any other word would smell as sweet."*
>
> William Shakespeare, Romeo & Juliet - Act 2, Scene 2 (1597).

Neurological disorders have been recently identified as the leading cause of disability worldwide (Harris 2024), while being associated with a significant burden on patients, their families and societies as a whole (Olesen et al. 2012; Chaudhuri et al. 2024; Steinmetz et al. 2024; Li and Jönsson 2025). Despite intensive research into neuroprotection and disease-modifying therapies, with major advances in multiple sclerosis, most neurodegenerative diseases (including PD) remain incurable, with significant unmet needs in care provision (Cummings 2017; McFarthing et al. 2024; Kalia et al. 2024). A holistic approach combining the framework of palliative care and the expertise of neurological care therefore appears to be particularly relevant and justified in the treatment of such diseases. If most of the published evidence regarding the benefits of palliative care (including early integration) is currently found in the oncology literature (Creutzfeldt et al. 2019; Pitzer et al. 2024), the recently structured field of neuropalliative care has begun to provide high-quality research, notably in PD, where (non) randomized controlled trials exploring palliative care initiatives have already been conducted (van der Marck et al. 2013; Veronese et al. 2017; Kluger et al. 2020; Fleisher et al. 2022). Nonetheless, the need for more rigorous empirical evidence persists, which led the newly created International Neuropalliative Care Society (INPCS) to issue a white paper delineating the most salient research priorities in this domain (Lau et al. 2025).

Setting the scene: core concepts of palliative care

Rooted into the 1960's hospice movement and oncology field (Mount 1976; Saunders 2000), palliative care has evolved over the decades and expanded into the earlier stages of disease, as well as into the world of chronic illness, enhancing the quality of care and medical decision-making alongside disease-specific treatments (Quill and Abernethy 2013). Reflecting this evolution, a multitude of definitions now exist, with varying emphasis on early intervention and remaining life span (Doyle 2003; Chen et al. 2008; Ryan et al. 2020; Radbruch et al. 2020). Unfortunately, this variety can be a source of confusion and ambiguity regarding the meaning and delivery of palliative care (Doyle 2003; Chen et al. 2008; Monterosso et al. 2016; Ryan et al. 2020). The World Health Organization (WHO) defines modern palliative care as "*an approach that improves the quality of life of patients and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification*, *correct assessment and treatment of pain and other problems*, *whether physical*, *psychosocial or spiritual*."[2]. According to Dame Cicely Saunders, it is *"a philosophy based not on physical facilities but on attitudes and skills*" (Saunders 2001). Palliative care is therefore a model of health care delivery, a "*wide-reaching concept for high quality of care for all patients with serious illness*", provided by an interdisciplinary team of professionals (Chen et al. 2008; Creutzfeldt et al. 2019). Irrespective of length of life remaining, palliative care should be available as needs develop and before problems become unmanageable (Chen et al. 2008), as it addresses the multifaceted aspect of care for patients facing a serious illness, including total pain (which encompasses physical, psychological, social, emotional, and spiritual components (Ong and Forbes 2005) and complex communication interactions (Strand et al. 2013). Palliative care can be delivered at different levels and through different services. Regarding levels of palliative care, a distinction is made between a palliative care *approach*, *primary* palliative care (for non-specialized settings) and *specialized* palliative care (Jünger et al. 2012; Payne et al. 2022). As in any medical specialty, certain skills and approaches need to be known and used by all clinicians, including neurologists, as part of "basic", generalist or primary palliative care (Quill and Abernethy 2013; Creutzfeldt et al. 2019; Miyasaki et al. 2022; Hauser 2022). Skill sets required for primary palliative care include basic management of pain and symptoms (including depression and anxiety) and basic discussions about prognosis, goals of treatment, suffering and code status (Quill and Abernethy 2013). Thus, core palliative care skills for neurologists include providing symptom management (including common palliative care needs), basic psychosocial and spiritual support, compassionate communication skills to sensitively share diagnosis, prognosis and elicit serious illness conversations (using the Ask-Tell-Ask, NURSE, SPIKES or REMAP frameworks), engaging in shared decision-making and recognizing caregiver distress and needs (Creutzfeldt et al. 2018a; Brizzi and Creutzfeldt 2018; McFarlin and Barclay 2019; Schwartz et al. 2019; Armstrong et al. 2021; Ng et al. 2023; Kluger et al. 2023; Jackson and Emanuel 2024). Specialized palliative care, which requires a team approach whose main focus of work is to care for palliative patients, deals on the other hand with complex physical and/or psychological symptoms (e.g. refractory pain, existential distress), conflict resolution regarding goals or methods of treatment (within families, between staff and families, and among healthcare professionals) and cases of near futility (Quill and Abernethy 2013; Payne et al. 2022). Thus, specialized palliative care provided over 16 weeks by an expert team (physician, nurse, psychologist, physiotherapist and volunteer) in a randomized controlled trial significantly improved quality of life, pain, breathlessness, sleep disturbances and bowel symptoms in patients suffering from advanced neurodegenerative disorders, including PD (Hoehn and Yahr stage$\geq$4) and atypical parkinsonism (Veronese et al. 2017). Palliative care services include the palliative care unit, inpatient hospice, day care centers as well as "mobile" teams such as hospital palliative care support team and home palliative care team (Jünger et al. 2012). If access to palliative care services is now recognized as a human right (Kluger et al. 2023; Lau et al. 2025), several barriers have been identified for adult inpatients, notably having a noncancer condition, poor coordination, insufficient expertise, clinicians' emotional discomfort and difficult prognostication, negative perceptions of palliative care and misleading communication (Pitzer et al. 2024).

Dispelling Myths about palliative care

Owing to its historical development from the hospice movement, palliative care has long been considered to be equivalent to end-of-life care for patients with terminal cancer, both by the general public, patients, caregivers

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[2] https://www.who.int/news-room/fact-sheets/detail/palliative-care [Accessed March 27th, 2025].

and healthcare professionals (McLaughlin et al. 2011; Fox et al. 2015; Kelley and Morrison 2015; Monterosso et al. 2016; Creutzfeldt et al. 2018b; Zwicker and Lutz 2018; Ryan et al. 2020; Hudson et al. 2021; Batzler et al. 2024). The subsequent stigma (i.e., association with medical failure or abandonment, diminished care, reduced medical options, lack of hope, dependency, imminent death and dying) remains a reality, still propagated by misinformation, late referral to specialized palliative care services and the continued practice of palliative care mainly as end-of-life care, despite evidence of the benefits of its early integration into patient care (Flieger et al. 2020; Lalani and Cai 2022; Alcalde and Zimmermann 2022; Batzler et al. 2024). Such negative stereotypes, propagated by individual and general beliefs and attitudes, may prevent willingness to utilize palliative care, depriving patients from the benefits of the palliative approach (Shen and Wellman 2019; Pitzer et al. 2024). From the clinician point of view, referral reluctance may be driven by the fear of upsetting patients (Kelley and Morrison 2015; Hawley 2017; Gove et al. 2017). Similarly, patients may be reluctant to accept a referral or to request access to palliative care services for fear of upsetting their doctor, see him withdraw from their care, and/or being seen as giving up or being "weak", as suggested by the reversed mirror image of the too often used war metaphors (Hauser and Schwarz 2015, 2020; Hawley 2017; Solano 2019; Shen and Wellman 2019). Hence, socio-cultural, socio-economic and ethnic factors all play a role within the processes of stigmatization of palliative care, while cultural (family and religion) and knowledge issues (lack of information, lack of nuanced knowledge, low literacy, poor physician communication) are of central importance in the misconception-driven underutilization of palliative care (Drisdom 2013; Fox et al. 2015; Kelley and Morrison 2015; Collins et al. 2020; Lalani and Cai 2022; Batzler et al. 2024). Palliative care, however, is neither "just hospice" nor only deals with pain management: it is provided concurrently with disease-directed therapy, throughout the disease course, by a multidisciplinary team (Hawley 2017; Hauser 2022). Its delivery is also not limited to specialized palliative care teams, as previously highlighted (Hauser 2022). Existing misconceptions over the concept of palliative care have led many to suggest changing its name to "*supportive care*" (Cherny 2009; Hui et al. 2013; Hudson et al. 2021). However, more than a mere "rebranding" (which would likely only affect referral rates for a short term, while increased confusion in terminology), what is crucially needed is better education and reframing to change the attitudes and preconceptions of professionals (starting with neurologists) and the public (Kelley and Morrison 2015; Boyd et al. 2019; Liney 2019; Murray et al. 2019; Zimmermann 2019; Hudson et al. 2021). This is particularly illustrated by the fact that the longer palliative care structures have been established in a country, the better the population knows and understands them (Batzler et al. 2024). Additionally, a survey of the Canadian public highlighted that only a small percentage of respondents (15%) believed that renaming palliative care would make them more willing to engage with it if they were diagnosed with a serious illness (Zimmermann 2019).

Neuropalliative care: a blooming field at the intersection of palliative care and neurology

Conversely, palliative care specialists, typically trained in internal or general medicine, may be less comfortable with managing people with neurological disorders (Kluger et al. 2021). The needs of people with neurological disease and their caregivers (symptom profiles, existential distress due to loss of autonomy, psychological suffering, prognostic uncertainty) and specific issues associated with the care of neurological diseases (illness trajectories, communication barriers, threats to personhood due to functional and cognitive change, chronic disability with or without fluctuations in clinical status) call for a palliative approach combined with the unique expertise and specificities of neurology (McLaughlin et al. 2011; Ghoche 2012; Borasio 2013; Creutzfeldt et al. 2019; Oliver et al. 2020). Therefore, while all neurologists are required to provide primary palliative care, neurologists with expertise in palliative medicine, i.e. *neuropalliative care specialists*, are uniquely positioned to provide disease-specific palliative care for people with serious neurologic illnesses, regarding disease trajectory, prognosis, symptom management, and specialized end-of-life care (Bernat et al. 1996; Ng et al. 2023). Among neurological diseases, amyotrophic lateral sclerosis (ALS) has historically been universally recognized as a terminal illness requiring palliative care (Norris et al. 1985; O'Brien et al. 1992; Borasio 2013). However, the progression and challenges associated with ALS are far from unique among diseases treated by neurologists: many neurological illnesses are either life-threatening or life-limiting, and can cause physical, psychosocial, spiritual or existential suffering from the moment of diagnosis (Foley and Carver 2001; Goy et al. 2008a; Borasio 2013; Kluger et al. 2023). Consequently, the American Academy of Neurology (AAN) Ethics and Humanities Subcommittee issued in 1996 a series of papers highlighting that neurologists (i) had a duty to provide adequate palliative care, (ii) did not have a duty to provide assisted suicide or active euthanasia, (iii) should encourage improved physician education on palliative care, and that patients had the right to refuse life-sustaining treatment, the latter being on the basis of ethical concepts of respect for personal autonomy and legal concepts of self-determination

(Bernat et al. 1996). It was, however, not until 2007 that the first neurologist-led, team-based, palliative care program for movement disorders (or "*Palliative Parkinson's Clinic*", involving neurological, nursing, spiritual, and palliative expertise) was established in Toronto (Canada) by movement disorders specialist and 2025 AAN President Awardee Janis M. Miyasaki[https://journals.lww.com/neurotodayonline/fulltext/2025/04170/it_takes_determination_and_discipline__getting_to.7.aspx? context=latestarticles] (Ghoche 2012; Miyasaki and Kluger 2022). In the early 2010's, a retrospective study showed that patients with neurological disorders (mainly driven by ischemic stroke) were the second most common patient population to receive inpatient palliative care services in a US center (Chahine et al. 2008), while advanced PD patients were shown to suffer from a similar degree of symptoms as metastatic cancer patients (Miyasaki et al. 2012). Neuropalliative care would finally emerge as a new medical subspecialty in the mid-2010s (Robinson and Barrett 2014) - not falling into the trap of overspecialization (Oren et al. 2020) but rather providing a tailored approach to complex needs by effective delivery of care. Most of the main neurology professional organizations, such as the AAN[3], the European Academy of Neurology (EAN)[4] and the Movement Disorders Society (MDS)[5] now include special interest groups and scientific panels dedicated to palliative care for people with neurological disorders (Miyasaki and Kluger 2022). Likewise, palliative care societies, such as the European Association of Palliative Care (EAPC)[6] or the American Academy of Hospice and Palliative Medicine (AAHPM)[7] have created groups focusing on the care and needs of neurological populations. But the main development in recent years has been the creation of the International Neuropalliative Care Society (INPCS)[8], a global interdisciplinary organization founded in 2020, with the mission of "*raising standards of care for all people affected by neurologic illness*", and promoting neuropalliative care around the world (The Lancet Neurology 2021; Miyasaki and Kluger 2022; Kluger et al. 2023). Guidelines, white papers, practice surveys, educational programs (including e-learning) and international collaborations have steadily emerged from these diverse groups (Oliver et al. 2016, 2020; Pace et al. 2017; Solari et al. 2020; Miyasaki et al. 2022; Taylor et al. 2022; Kluger et al. 2022; Ng et al. 2023; Bu et al. 2024; Lau et al. 2025).

Caring for the chronically and critically ill individuals, managing incurable diseases from their diagnosis onwards, and often viewed by patients as their primary (rather than consulting) physicians, neurologists are optimally positioned as primary palliative care providers, in both the outpatient and inpatient care settings (Foley and Carver 2001; Robinson and Barrett 2014; Wan et al. 2024). However, communication challenges and barriers, misconceptions about palliative care, and gaps in knowledge have been frequently reported by neurologists and residents alike (Vishnevetsky et al. 2019; Zehm et al. 2020; McConvey et al. 2022; Bombaci et al. 2024; Sharma et al. 2025), which calls for further education and training (Creutzfeldt et al. 2018a; Miyasaki et al. 2022; Álvarez Saúco et al. 2024; Bombaci et al. 2024; Wan et al. 2024). While many neurologists and movement disorders specialists do incorporate certain elements of the palliative care approach into their practice (Miyasaki et al. 2022), few do so in a systematic and/or comprehensive manner (Liu et al. 2017; Kluger and Quill 2021). Notably, advance directives are not routinely addressed in patients with chronic neurological diagnoses, and early palliative care consultation has yet to be routinely established for PD patients (Liu et al. 2017; Taylor et al. 2022; Álvarez Saúco et al. 2024). Engagement in advance care planning and goals of care setting, while anticipating functional declines (physical and cognitive), should nevertheless be systematically considered to maximize symptom management (Taylor et al. 2022; Álvarez Saúco et al. 2024). Failure or delay to initiate care planning and palliative care by neurologists may result from a complex interplay between patient, physician, and resource accessibility factors (Wan et al. 2024). When provided, the extent and timing of involvement of palliative care services in the care of patients with neurological disease has been shown to vary regionally, nationally, and internationally (Creutzfeldt et al. 2019; Oliver et al. 2023), and across neurological diseases (Oliver et al. 2020). Although there is good collaboration between neurology and palliative care (i.e. joint meetings, clinics and telephone contacts) in the care of people with ALS and brain tumors, this is much less the case for other progressive neurological diseases, such as PD (Borasio 2013; Oliver et al. 2020; Álvarez Saúco et al. 2024). This may reflect differences in understanding of the likely prognosis and/or palliative care needs, referral appropriateness, and/or staff concerns about the potentially large numbers of patients and the resulting subsequent pressure on resources if patients with neurodegenerative diseases were referred to palliative care services (Hepgul et al. 2018; Oliver et al. 2020; Miyasaki et al. 2022). There are therefore a number of areas of improvement mutual education and increased collaboration between

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[3] https://www.aan.com/membership/join-an-aan-section-or-community.

[4] https://www.ean.org/home/organisation/scientific-panels/palliative-care.

[5] https://www.movementdisorders.org/MDS/About/Committees--Other-Groups/MDS-Study-Groups/Palliative-Study-Group.htm.

[6] https://eapcnet.eu/eapc-groups/reference/neurology/.

[7] https://aahpm.org/membership/communities/.

[8] https://www.inpcs.org/.

neurology and palliative care (Oliver et al. 2020), notably through new integrated models of care (Hepgul et al. 2018). Breaking medical silos, ensuring continuity of care and addressing the complex needs of patients with neurological disorders and their families requires a coordinated approach and a multidisciplinary team, whose members vary depending on the needs and values of the patient and their caregivers (Zwicker and Lutz 2018; Brennan et al. 2022; Araújo et al. 2024; Bakewell 2025; Lau et al. 2025). Documenting key elements such as illness understanding, patients' hope and worries, goals and values and recommendations made to the patient and their families in the medical record is essential to ensure coordination of care between members of the team (Jackson and Emanuel 2024). The many physical (pain, dry mouth/increased saliva, constipation, loss of appetite, fatigue, insomnia) and psychosocial symptoms (grief, depression, anxiety, spiritual suffering, loss of dignity, depersonalization) associated with neuropalliative care should be considered with the same degree of importance as disease-specific symptoms (Brizzi and Creutzfeldt 2018). Providing an appropriate response to these numerous and complex needs requires a multidisciplinary team, whose members may include (but are not limited to), depending on available resources, neurologists/movement disorders specialists, neurosurgeons (in case of deep rain stimulation -DBS), neuropalliative care specialists, palliative care physicians, primary care physicians, geriatricians, PD nurses, nurses, dietitians, pharmacists, (neuro)psychologists, occupational and physical therapists, speech and swallowing therapists, respiratory therapists, spiritual counselors (e.g. chaplains), health aids, community advocates, patient support and advocacy groups, hospice workers and social workers (Borasio 2013; Zwicker and Lutz 2018; Oliver et al. 2020, 2023; Brennan et al. 2022; Lau et al. 2025). Much like in PD (van Munster et al. 2022; Thomas et al. 2024; Fujita et al. 2024), nurses have been shown to play a pivotal role in providing palliative care (Rosa et al. 2021). Most importantly, the multidisciplinary team must include patients and their families as core members (Giles and Miyasaki 2009; McLaughlin et al. 2011; White and Palmieri 2024).

Neuropalliative care in PD: an evidence-based manifesto

In addition to the fact that PD is not generally conceptualized as a terminal illness (Bloem et al. 2020a; Hvisdak et al. 2022), the frequent assimilation of palliative care with end-of-life care may be linked to the classic four stages description of PD course (diagnosis, maintenance, complex and palliative), where the term "palliative" is associated with the final stages (MacMahon and Thomas 1998). This terminology and classification are therefore to be abandoned. In PD, palliative care needs are apparent throughout the disease, whether at diagnosis (a life changing moment (Shaw and Vivekananda-Schmidt 2017; Subramanian et al. 2024) during transitional phases to a more advanced stage of the disease, or at the end of life, both for patients and their caregivers (Goy et al. 2008a; Borasio 2013; Bouça-Machado et al. 2017; Kluger et al. 2023), even though they fluctuate over the PD course and vary across individuals (Kluger et al. 2023). While neurologists are optimally positioned for providing primary palliative care to most patients over the PD course, specialized palliative care interventions are needed to address complex situations (Liu et al. 2017; Kluger and Quill 2021). The involvement of palliative care principles and specialists have notably been shown to help patients better face the unpredictability of PD (Ghoche 2012), and a burden similar to patients with cancer (Miyasaki et al. 2012; Kluger et al. 2019). A five pillars framework has since been developed by the Parkinson Foundation: it includes care partner support, management of nonmotor symptoms, spiritual and emotional support, advance care planning and timely referral to specialized palliative care or hospice (Hvisdak et al. 2022; Seshadri et al. 2024). While several assessments tools are available to guide clinicians in identifying individual unmet needs for both patients and caregivers(Table 2), trigger criteria for referral to specialized palliative care services, particularly hospice (Table 2), have been identified for progressive neurodegenerative conditions, including PD (Hussain et al. 2018; Miyasaki 2019; Tarolli and Holloway 2020; Akbar et al. 2021; McConvey et al. 2022). They generally include (i) deterioration in physical function, dysphagia, significant complex symptoms and pain; (ii) weight loss and respiratory symptoms; (iii) recurrent infections and cognitive decline; and/or (4) aspiration pneumonia, with a high burden in the last 2 years of life and a rapid increase in the last 6 months (Hussain et al. 2018). They can therefore be broadly categorized into PD-related symptoms/complications, and indicators of burdensome disease progression and increasing needs for both patients and caregivers (Garon et al. 2025).

Estimating prognosis, mortality and causes of death in PD

The WHO Mortality Database (1994–2019) shows a global rising trend in PD mortality (Lampropoulos et al. 2022). Age, gender, racial, and geographic disparities are noted (Lampropoulos et al. 2022; Sokhal et al. 2024; Akhtar et al. 2025). The reliability of death certificates is limited by the frequent underreporting of PD as either the primary or underlying cause of death (Benito-León et al. 2014; Hobson and Meara 2018; Shi and Counsell 2021). This not

Table 2 Trigger criteria and assessment tools for referral to specialist palliative care services in parkinson's disease (Saleem et al. 2013; Gao et al. 2016; Brizzi and Creutzfeldt 2018; Miyasaki 2019; Sannes and Kluger 2019; Holden et al. 2019; Lennaerts-Kats et al. 2020b; richfield and Johnson 2020; Akbar et al. 2021; Macchi and Lum 2022; Margolius and Samala 2022; McConvey et al. 2022; Hvisdak et al. 2022; richfield et al. 2022; Garon et al. 2025)

Triggers and assessment tools	Patient with PD	Caregiver / care partner
Triggers for specialized palliative care, i.e. extra layer of support for complex symptom management, by palliative care and/ or neuropalliative care specialists	Diminished quality of life due to refractory/intractable symptoms (e.g. pain unresponsive to PD medication) Complex symptom management (e.g. severe chronic pain) Behavioral complications /cognitive changes Psychological, emotional, spiritual, or existential distress Hospitalization(s) Falls Weight loss (unintentional) Loss of autonomy (ability to drive, daily living activities) / Acceleration in changes in functional status Caregiver distress	Psychological distress = burnout, anxiety, depression, feeling overwhelmed Social isolation Frailty, health issue, change in functional status Financial issues/ concerns
Triggers for hospice referral (end-of-life care), i.e. when prognosis seems to be closer to months than years	Increasing emergency room visits / recurrent hospitalizations (falls, pneumonia) Secondary conditions = dysphagia / silent aspiration / aspiration pneumonia, pressure ulcers, weight loss (unintentional) and/or diminished appetite High burden of non-dopaminergic symptoms (diminished efficacy or need for dopaminergic medication) Accelerated functional decline/ significant decline following single hospital stay Presence of comorbid conditions likely to contribute to a life expectancy ≤ 6 months (e.g. organ failure, terminal cancer)	Safety concerns (including physical or sexual abuse) Patient with accelerated functional decline/ significant decline Patient nearing end-of-life phase
Evaluation Tools/ scales	Palliative care / non-PD specific: Edmonton Symptom Assessment Scale (ESAS), Palliative Care Assessment (PACA) tool, Integrated Palliative Care Outcomes Scale (IPOS), Suprise Question (SQ), Palliative Outcome Scale (POS), 8-item palliative care outcome scale of symptom burden (IPOS Neuro-S8) IPOS neuro/IPOS NEURO-8/IPOS Neuro-S8, /IPOS Neuro-s24n Palliative care / PD specific: ESAS-PD, NAT-PDC disease, POS-S PD Symptom burden & quality of life / non-PD specific: Patient-Reported Outcomes Measurement Information System (PROMIS-29), Quality of Life-Alzheimer Disease (QOL-AD), McGill Quality of Life Questionnaire (McGill QOL) Symptom burden & quality of life / PD specific: Parkinson's Disease Questionnaire (PDQ-39, PDQ-8)	Non-PD specific: Zarit burden interview (ZBI), Marwit & Meuser Caregiver Grief Inventory-Short Form (MM-CGI-SF) PD specific: Parkinson's disease caregiver burden (PDCB) questionnaire

only undermines their use as the sole tool for identifying cases or analyzing mortality in epidemiological studies, but also points to a potential lack of awareness among clinicians regarding the significance of PD as a cause of death (Benito-León et al. 2014; Hobson and Meara 2018; Shi and Counsell 2021). Pneumonia has been consistently identified as the leading cause of death in PD (Marttila et al. 1977; Beyer et al. 2001; Fall et al. 2003; Pennington et al. 2010; Hobson and Meara 2018; Shi and Counsell 2021; Fonseca et al. 2024), including in patients treated with deep brain stimulation (DBS) (Rocha et al. 2021; Kim et al. 2022). This may partly explain why seasonality (winter) appears as a risk factor for death in PD (Fonseca et al. 2024). More importantly, it suggests the need to focus on the modifiable risk factors of pneumonia (i.e. dysphagia, aspiration management, oral health) notably in hospitals and nursing homes (Nóbrega et al. 2008; Chang et al. 2016; Hollaar et al. 2016; Won et al. 2020; Brooks 2023), as PD patients have >3 times higher risk of aspiration pneumonia compared to controls (Chua et al. 2024). PD-related complications such as aspiration pneumonia, and injuries related to falls, may account for the increased risk of mortality associated with PD (Goy et al. 2007; Posada et al. 2011; Allyson Jones et al. 2012; Miyasaki 2019; Choi et al. 2019; Ryu et al. 2023; Sipilä et al. 2024; Benito-Rodríguez et al. 2025). PD-related excess mortality has been shown to be significant even early during the disease (related to motor severity and phenotype), and to more than double the risk of dying over the 10-year follow-up period, correlated with the development of clinical milestones (Gonzalez et al. 2022). Falls, hallucinations, the development of PD dementia and admission to a nursing facility more than double the risk of death, with a cumulative effect (HR of 10.83 in those experiencing all four milestones) (Gonzalez et al. 2022). Despite identified mortality predictors (Fernandez and Lapane 2002; Akbar et al. 2021; Gonzalez et al. 2022), cohorts studies and new methods identifying different trajectories in PD (Sato et al. 2006; Formica et al. 2025), prognostic uncertainty remains at the individual level, which significantly adds to the psychological burden of the disease, for both patients and caregivers (Hurt et al. 2017; Aboelzahab et al. 2025).

Symptom burden and unmet needs of patients with PD

Starting from prodromal symptoms leading to the diagnosis onwards, patients with PD face a number of transitions, life disruptions (e.g. workforce exit, loss of driving ability), prognosis uncertainty and growing symptom burden, challenges and safety concerns (Wressle et al. 2007; Saleem et al. 2013; Boersma et al. 2016; Bloem et al. 2021; Read et al. 2022; Timpka et al. 2023; Pedrosa et al. 2023; Subramanian et al. 2024; García et al. 2024; Aboelzahab et al. 2025). The subjective experience of PD and its impact on quality of life are shaped not only by the motor and nonmotor symptoms (Morimoto et al. 2024), but also by how they disrupt the person's interaction with their environment and sense of self (Rutten et al. 2020; González et al. 2025). Some individuals struggle to cope and adapt, leading to psychological distress (Rutten et al. 2020; Lou et al. 2024). Fears and uncertainties of people with PD have been shown to encompass *current* and *anticipatory* concerns across multiple dimensions, covering both health and social issues: motor and nonmotor symptoms, disease progression, treatments and access to healthcare (especially access to specialists), quality of life, employment, social networks and stigma (Trahair et al. 2025). Research on patients' perspectives regarding palliative care needs in PD has identified several core themes associated with major challenges: living with (non)motor symptoms, feelings of loss, changes in roles, relationships, and concept of self, concerns about the future, and gaps in their care (i.e. diagnosis, education about the disease, and advance care planning) (Boersma et al. 2016). Therapeutic needs and priorities in symptom management evolve and shift throughout the disease course (Lee et al. 2019b; Port et al. 2021), which underscore the need for regular reassessment. Unmet needs may be more frequent in patients with more severe nonmotor symptoms (Saleem et al. 2013; Lee et al. 2019b). Geriatric PD patients face additional complexity, owing to the frequent multimorbidity and resulting polypharmacotherapy (and therefore potential drug-related safety issues) related to age (Klietz et al. 2019a; Bamford and Henderson 2021), but also because they are often undertreated (especially in nursing homes), resulting in more frequent OFF periods and higher symptom burden (Weerkamp et al. 2012, 2013; Hoegh et al. 2013; Hommel et al. 2020; Schrag et al. 2020). Because caregivers are an important part of the treatment team, special attention may be given to potential unmet needs of female patients, as women with PD have fewer informal caregiving resources (Dahodwala et al. 2018). Many symptoms, as well as medication side effects (Perez-Lloret et al. 2012), tend to be under-reported by patients, under-recognized by clinicians (especially in case of dementia or communication issues) and are therefore undertreated (Kluger et al. 2023). Optimal communication about OFF periods (hence symptom burden) can be hindered by factors related to patients, caregivers and/or physicians (Armstrong et al. 2019; Chahine et al. 2021). Systematic recognition and triage of patients' needs related to quality of life and (non)motor symptom burden should therefore be a key component of every visit, using PD-specific or general assessment scales if needed, to facilitate referral to specialist palliative care of individuals with more complex and demanding care needs (Miyasaki 2019; Richfield and Johnson 2020; Richfield et al. 2022; Morimoto et al. 2024). Disease stage, available time and the presence of cognitive impairment influence tools choice (Richfield and Johnson 2020). PD burden and palliative care needs can be assessed using the Edmonton Symptom Assessment System revised for Parkinson's Disease (ESAS-PD), which was one of the first scale developed to assess of palliative care needs in advanced PD, the Palliative outcome score-symptoms-PD (POS-S PD) or the Needs Assessment Tool-PD (NAT: PD-C), the suitability of the latter for everyday clinical use having been recently demonstrated (Miyasaki et al. 2012; Miyasaki 2019; Richfield and Johnson 2020; Richfield et al. 2022). Other assessment tools include the IPOS neuro/IPOS NEURO-8, IPOS Neuro-s24, Palliative care assessment (PACA) tool (Richfield and Johnson 2020). Due to variations in the covered domains, more than one tool may be needed to achieve a comprehensive and holistic assessment of the patient's needs. (Richfield and Johnson 2020). Of note, the recently published RADboud indicators for PAlliative Care Needs in Parkinson's Disease (RADPAC-PD) tool has been proposed to facilitate identification of the palliative care needs of PD patients on an annual basis in daily practice (Lennaerts-Kats et al. 2020b). Unmet informational needs should be properly addressed by PD care teams, while emotional needs may require the intervention of specialized palliative care services (Lou et al. 2024; Kinger et al. 2024).

"It's a disease of families"[9]: caregiver burden in PD

Caregiver burden, associated with providing care to an individual with a chronic illness or disability, is well recognized in PD, as in other neurologic illness (Sannes and Kluger 2019; Aamodt et al. 2024). Although it poses an increased risk of physical and mental issues (including burnout) and

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[9] https://journals.sagepub.com/doi/abs/https://doi.org/10.1177/1742395318799852.

it has been identified as one of the six WHO priorities to address global disparities in PD (Schiess et al. 2022), it is often overlooked in practice (Sullivan and Miller 2015; Seshadri et al. 2024), especially at the end of life (Goy et al. 2008b). Additionally, the emotional impact of the diagnosis on caregivers and families is still seldomly addressed (McLaughlin et al. 2011; Schiess et al. 2022). Predictors and contributors to caregiver burden in PD have been recently reviewed (Aamodt et al. 2024). While societal and cultural factors contribute to caregiver burden, several patient-related factors are to be considered. They include age of onset (greater burden with late-onset PD), PD duration, motor symptoms (motor symptom severity and disability, higher mean levodopa equivalent daily dose, levodopa-related motor complications), and nonmotor symptoms (with a greater impact on caregiver strain than motor symptoms) - particularly neuropsychiatric symptoms (depression, apathy, cognitive impairment, hallucinations, delusions, psychosis, agitation, and aggression) and sleep disturbances (Macchi et al. 2020; Aamodt et al. 2024). Others factors are related to the caregiver and include gender (greater burden in female caregivers), relationship to the patient, medical and psychiatric comorbidities (Dahodwala et al. 2018; Aamodt et al. 2024). Shift in roles (e.g. from spouse to caregiver), decreased socialization, disruption in relationships, prognosis uncertainty, assuming decision-making responsibilities for the patient, anticipatory bereavement (pre-death grief), financial preoccupations and relentless caregiving tasks (especially tasks involving physical effort) negatively impact emotional health (stress, spiritual well-being) and health-related quality of life, decrease self-care, and increase stigma and social isolation for caregivers (Wressle et al. 2007; Goy et al. 2008b; McLaughlin et al. 2011; Carter et al. 2012; Hurt et al. 2017; Lennaerts-Kats et al. 2020a; Macchi et al. 2020; Kluger et al. 2023; Aamodt et al. 2024; White and Palmieri 2024). The occurrence of physical or sexual aggression of caregivers by patients in the advanced stages of the disease is rarely investigated during consultations, but may be significant, adding to the overall burden (Bruno et al. 2016). Finally, the potential negative impact of medical teams should not be overlooked, such as lack of information (e.g. about prognosis or homecare services), lack of continued and coordinated care plans, or (unwillingly) making the caregiver feeling alone / as an outsider to the care team (Giles and Miyasaki 2009; McLaughlin et al. 2011; Seshadri et al. 2024; White and Palmieri 2024). Of note, studies conducted among bereaved caregivers revealed a feeling of "being behind the times" (due to lack of proactive palliative care planning), a poor access to palliative care services and negative experiences with healthcare professionals due to lack of communication, coordination and/or knowledge of PD or palliative care (Hasson et al. 2010; Lennaerts-Kats et al. 2020a). These findings underlines the needs of better education on both PD and palliative care among clinicians providing psychosocial support, respite care and/or support for unequal gender dynamics in the face of unique caregiving and interpersonal challenges remain an important unmet need in PD (Goy et al. 2007, 2008b; Schwartz et al. 2020; Seshadri et al. 2024). Neuropalliative care aims to meet the unique needs of both patients and caregivers affected by neurologic illness. Assessing caregiver health (physical and mental), values, knowledge, skills (knowledge on PD), resources (social support, coping strategies) and addressing unmet needs are therefore integral to the neuropalliative care approach (Sannes and Kluger 2019; Hvisdak et al. 2022). As such, the Zarit Caregiver Burden Interview (ZCBI), often used to measure caregiver burden in palliative care or neurodegenerative diseases, including PD (Lithin et al. 2020; Kühnel et al. 2020; Zhao et al. 2024), and/or the Parkinson's disease caregiver burden (PDCB) questionnaire should therefore be routinely used (Richfield and Johnson 2020). Furthermore, specific situations (Table 2) should be recognized by neurologists as triggers for increased caregiver support and/or referral to social worker, psychological support, or other appropriate members of the multidisciplinary team (Sannes and Kluger 2019).

Neuropalliative care delivery in PD: when, how, with whom?

Adopting a neuropalliative care mindset throughout the disease continuum, while integrating PD specificities and individual wishes, are therefore unique challenges to navigate as PD care teams (Table 3). Moreover, access to specialized palliative care remains highly variable across geographic regions and healthcare systems. In many settings, especially in rural or resource-limited areas, dedicated neuropalliative specialists are scarce or entirely absent. This disparity can contribute to significant health inequities, with some patients and families lacking essential support. Although the previously mentioned limits and barriers exist, there are several ways of delivering palliative care for people with PD: neurologist- or primary care-based palliative care (primary palliative care) or specialized palliative care (extra layer of support for complex symptom management) through consultative specialty palliative care, or neuropalliative care specialists (Tarolli and Holloway 2020; Margolius and Samala 2022; Hvisdak et al. 2022). All of these models have specific strengths and weaknesses, the main ones being related to expert knowledge (in PD and/or palliative care), relationship with the patient, provider availability and comfort with proactive identification and treatment of PD symptoms as well as advance care planning (Tarolli and Holloway 2020). Perhaps one of the most telling examples of the

Table 3 The parkinson's disease journey: a neuropalliative care roadmap, from diagnosis to end-of-life (Carter et al. 2012; walker 2013; tuck et al. 2015; Navarta-Sánchez et al. 2017; Klietz et al. 2018; Vaughan and Bruno 2022; Kundrick et al. 2023; Mantri et al. 2024; Subramanian et al. 2024)

Parkinson's disease (PD) stage	Goals	Potential needs	Recommended measures
Diagnosis	Timely diagnosis	Patients: psychological distress (shock, anxiety), information needs about prognosis, treatments	Empathic, sensitive disclosure of diagnosis
	High quality communication	Caregivers: emotional impact, information needs about prognosis, treatments	Early patient and caregiver education: treatment goals and options, symptoms, prognosis, treatment side effects, available resources (time to ask questions, quality & quantity of provided information)
			Establishing a trusted therapeutic relationship (family involvement in disease discussion)
	Facilitation of disease acceptance (including addressing stigma and misconceptions)		Addressing emotional concerns and providing emotional support
	Treatment initiation (symptom burden)		Counseling for employment-related concerns (++early onset PD)
	Provision of psychological & emotional support		Multidisciplinary management (i.e. neurologist, PD nurse, allied health professionals)
Early to moderate PD (Hoehn & Yahr 1–2)	Empowering patients	Patients:	Regular motor and nonmotor symptom assessments (including treatment side effects)
	Counseling patients through progression of illness and prognostication	Coping with motor complications and non-motor symptoms (pain, sleep disorders, fatigue, impulse control disorders)	Multidisciplinary management (i.e. neurologist, PD nurse, allied health professionals)
		Work-related, social and family disruptions	Information, discussion and planning of device-aided therapies (if appropriate)
		Difficulties managing advanced therapies (DBS, subcutaneous pumps)	Addressing emotional concerns/fears and providing emotional support
		Fears = progression uncertainty, future cognitive impairment and/or becoming a burden on others	Early integration of Advance Care Planning (ACP) = goals of care discussions, advance directives (assessing mental capacity)
	Decreasing morbidity and preventing potential complications through a multidisciplinary approach	Caregivers: shifts in relationship, increasing responsibilities	Supportive ongoing care and specialist input as needed (e.g. dietitian, physiotherapist…)
	Counseling patients through progression of illness and prognostication		Patient and caregiver education
			Counseling for employment-related issues (++early onset PD)
			Caregiver support: psychosocial, financial assistance counseling

Table 3 (continued)

Parkinson’s disease (PD) stage	Goals	Potential needs	Recommended measures
Advanced PD (Hoehn & Yahr 2–4)	Counseling patients through progression of illness and prognostication	Patients:	Specialists palliative care consultation for complex symptom management
		Severe motor and non-motor fluctuations (pain, dysphagia, cognitive decline, hallucinations)	
		Difficulties managing advanced therapies (intrajejunal pumps)	
		Dealing with the challenges of restricted activities and social isolation	
		Fears = progression uncertainty, future cognitive impairment and/or becoming a burden on others	
	Coping with disease progression and loss of autonomy	Caregivers: high caregiver burden (physical, psychological, financial strain)	Multidisciplinary teams including neuropalliative care specialists
	Addressing growing caregiver burden		Addressing emotional concerns/fears and providing emotional support
	Symptom management including psychological stress of the patient and family		Advance directives documentation and regular review
			Multidisciplinary management
			Regular caregiver assessment and structured support
			Caregiver: psychosocial support, financial/social assistance, respite care
Late-stage PD (Hoehn & Yahr stages 4–5)	Referral to hospice when appropriate	Patients:	Proactive monitoring of symptoms and clinical triggers
	Addressing growing caregiver burden	Severe disability, loss of autonomy	Triggered referral to specialist palliative care (hospice, mobile palliative teams)
		Progressive cognitive impairment	Symptom-oriented care planning (pain, nausea, agitation)
		High physical symptom burden (pain, aspiration risk, infections, falls)	Pneumonia risk factor mitigation
	Relief of symptoms and distress	Dealing with the challenges of restricted activities and social isolation	Structured end-of-life (EOL) discussions and planning: treatment goals/options, device-aided therapy adjustments, Do Not Resuscitate -DNR- orders, life expectancy/prognosis, request for hastened death
		Caregivers: severe caregiver strain and risk of burnout, coping with prognosis uncertainty	Multidisciplinary management
			Regular caregiver assessment and structured support
			Caregiver: supportive counseling for pre-death grief, financial/social assistance, respite care
			Family communication about EOL care
End-of-life phase	Relief of symptoms and distress	Patients:	(Outpatient) hospice service
	Addressing caregiver strain and grief	Terminal complications (aspiration pneumonia, infection, delirium, pain, agitation)	Active management of comfort care = adequate analgesia, sedation, careful continuation of dopaminergic treatments with use of alternative medication routes (transdermal, subcutaneous)
		Ethical and practical questions (withdrawal of treatments/devices)	Multidisciplinary management
		Emotional and existential distress	Clear communication regarding prognosis, goals of care, and withdrawal of interventions
		Caregivers: emotional and existential distress, grief, bereavement	Structured EOL care communication and delivery (patient, family, medical teams): treatment goals/options, device-aided therapy adjustments, Do Not Resuscitate -DNR- orders, life expectancy/prognosis, request for hastened death
			Intensive psychosocial and spiritual support (chaplaincy, counseling services)

necessary combination of (i) these two areas of expertise and (ii) palliative care delivery models is the end of life of PD patients. If end-of-life care is frequently managed by palliative care specialists, the continued involvement of PD specialists is equally crucial, as their expertise is needed for (i) the management of PD-related (non)motor symptoms (i.e. rigidity, pain, dysphagia), (ii) the management of dopaminergic and device-aided therapies (including whether and how these medications/devices should be tapered as patients near the end of life) and (iii) guidance in the management of other symptoms (e.g. nausea, vomiting, agitation, pain, insomnia) which may lead to the "classic" palliative/hospice use of antidopaminergic agents, the latter being of course likely to exacerbate parkinsonian symptoms and decrease patient's comfort (Sankary et al. 2020; Hvisdak et al. 2022; Azoia et al. 2023; Béreau et al. 2024). Pain evaluation and management in PD are not adequately controlled by "classic" palliative care protocols, as facial/body expression of pain differs from the general population (Priebe et al. 2015) and pain may be driven by dopaminergic deprivation and/or OFF periods (Quinn et al. 1986; Brefel-Courbon et al. 2005; Gerdelat-Mas et al. 2007; Storch et al. 2013; Sung et al. 2018; Florin et al. 2020). Careful pain assessment using appropriate scales (such as the King's PD Pain Scale (Hasson et al. 2010; Chaudhuri et al. 2015) and optimizing dopaminergic therapy are therefore required before other therapy is started (Wasner and Deuschl 2012; Buhmann et al. 2020). Continuation of dopaminergic medications until death is thus advisable to ensure patient's comfort (Miyasaki 2019; Nair et al. 2022), but also to minimize the risk of delirium associated with increased pain in older patients (White et al. 2024). Maintaining adequate dopaminergic stimulation is also particularly important in relation to swallowing function (Schindler et al. 2021) and psychoemotional management, notably for "anxious fluctuators", who experience significant worsening in anxiety in the off state (Pontone et al. 2022). The classic "*last in*, *first out*" principle and stepwise approach to withdrawals of PD drugs (Bamford and Henderson 2021) must therefore be carefully reconsidered. In case of swallowing difficulties, several alternative routes of administration for antiparkinsonian medication are to be considered (Alty et al. 2016; Teranaka et al. 2025). The initiation of rotigotine transdermal patch (Ibrahim et al. 2021; Hindmarsh et al. 2021; Hewer et al. 2024), subcutaneous apomorphine injections (Dewhurst et al. 2009), and continuous subcutaneous apomorphine infusion (Béreau et al. 2024) in the setting of impaired oral intake has been documented as part of PD terminal care management. To date, the possible benefits and safety of continuous subcutaneous infusion of foslevodopa/foscarbidopa (fLD/fCD) have not yet been studied in this indication. In the specific context of terminal management, administration of oral PD medications (mainly levodopa formulations) through nasogastric tube feeding is not recommended, owing to the invasiveness of the procedure (Yardley and Donaldson 2010), drug compatibility and/or stability issues (Tan et al. 2023; Sommerfeldt et al. 2024), interactions between levodopa and enteral nutrition (Cooper et al. 2008; Bonnici et al. 2010; Whitman et al. 2016) and availability of the previously mentioned suitable alternatives (Gilbar 1999; Sommerfeldt et al. 2024). Levodopa/carbidopa intestinal gel infusion (LCIG), and now levodopa/carbidopa/entacapone intestinal gel infusion (LECIG), are also recommended - provided that it is sufficiently anticipated, given the need for surgery (Galli et al. 2025). Of note, aspiration pneumonia does not appear to be prevented by gastrostomy tube insertion in Parkinsonian syndromes (Marois et al. 2017). Having regular contact with PD-specialized health care is seen by patients and caregivers as important even in late-stage PD (Rosqvist et al. 2021), and has been associated with improved selected clinical outcomes and greater survival (Willis et al. 2011). These findings, and the numerous evidence of fragmentation of care (O'Neal et al. 2022) and/or suboptimal access to PD-specialized care (or neurological care) for women, minorities (Willis et al. 2011), late-stage PD patients and long-term care facilities residents (Safarpour et al. 2015; Worthington and Ney 2015; Eggers et al. 2018), underline the need for continuity of care through new, integrated models, bringing neuropalliative care and expertise closer to the patients' home: telemedicine/telehealth support, home care mobile teams, nurses-driven remote management (Kluger et al. 2020; Fleisher et al. 2022; Afshari et al. 2025). An integral part of the palliative approach, advance care planning is defined as the process of discussing (between patients, families, and healthcare providers) and recording patient preferences regarding goals of care, ultimately enabling individuals to make plans about their future health care -especially patients who may lose capacity or communication ability in the future (Brinkman-Stoppelenburg et al. 2014; Rietjens et al. 2017; Sokol et al. 2019; Hvisdak et al. 2022). As PD progression is associated with increased disease burden, increased caregiver burden, and impaired health-related quality of life, advance care planning provides a valuable opportunity to map out future care by clarifying patients' core values and preferences as they face potential physical and/or cognitive decline (Jordan et al. 2020; Hvisdak et al. 2022). To date, there are many untapped opportunities for advance care planning in PD (Churm et al. 2022), even though its clinical and therapeutic management poses several ethical conundrums (e.g. prodromal PD, personality, decision making, impulse control disorders, long-term dementia risk) (Appel-Cresswell and Stoessl 2011; Shaw and Vivekananda-Schmidt 2017; Sokol et al. 2019;

Hug 2021; Hoy and Chiong 2024; Gallagher et al. 2024). For instance, the expanded use of device-aided therapies (DAT), such as deep brain stimulation (DBS), CSAI, LCIG, LECIG, and fLD/fCD subcutaneous infusion, has yet to benefit from a neuropalliative care approach, even though a number of gaps and unmet needs are already emerging, such as continuity of care, long-term safety (i.e. neuropsychiatric symptoms, personality changes, surgical complications), individual trajectories or end-of-life management (Sokol et al. 2019; Sankary et al. 2020; Auffret et al. 2023; Goldin et al. 2024). Advance care planning discussions should be initiated by neurologists and/or PD care teams, taking into consideration both (i) PD specificities and typical complications (Klietz et al. 2019b) and (ii) patients and caregivers perspectives, desires and potential misconceptions or reluctance (Tuck et al. 2015; Sokol et al. 2019; Kluger et al. 2019; Lum et al. 2019; Klietz et al. 2020; Macchi and Lum 2022; Nair et al. 2022; Seshadri et al. 2024). These discussions need to be initiated early in the PD course (Macchi and Lum 2022; Garon et al. 2025), owing to the impact of cognitive concerns and/or neuropsychiatric adverse effects on patients' decisional capacities (Abu Snineh et al. 2017; Taylor et al. 2022; Gallagher et al. 2024), and carried out continuously, with particular attention to specific triggers (Macchi and Lum 2022) -notably those highlighted in Table 2. An increasing number of web-based resources on neuropalliative and end-of-life care are now available (Nair et al. 2022) and should be shared with patients and their families, as well as non-specialist healthcare professionals (e.g. INPCS [https://www.apdaparkinson.org/article/death-parkinsons-disease-3/], American PD Association[https://www.apdaparkinson.org/article/death-parkinsons-disease-3/], Parkinson's UK[https://www.parkinsons.org.uk/about-us/end-life-and-assisted-dying]). Request for hastened death are not uncommon in PD (Nuebling et al. 2021; Trejo-Gabriel-Galán 2024), notably due to (fear of) loss of independence, sense of identity and dignity (Weisbrod and Quill 2019). While the available legal options (i.e. withdrawing/withholding life-sustaining treatment, physician assisted death, voluntary stopping eating and drinking, voluntary active euthanasia) vary both regionally and internationally, the initial response to such inquiry should be exploration (not denial or affirmation) (Weisbrod and Quill 2019), psychological support (Nuebling et al. 2021) and involvement of specialized palliative care services (Nair et al. 2022).

Conclusion

In the last two decades, there has been a growing interest in palliative care and PD. Building on the specificities of quality of care for chronic conditions (effectiveness, efficiency, safety, equity, accessibility, timeliness and affordability, continuity of care - (Ku et al. 2024), optimal neuropalliative care in PD involves regular (re)assessment of (subjective) symptoms and priorities, effective management of the chronic-palliative interface, good communication, continuity of care (including neurological care until the end of life), and a multidisciplinary network of professionals working both in the community and in specialized clinics, while leaving room for the active (and voluntary) involvement of caregivers (Giles and Miyasaki 2009; Bouça-Machado et al. 2017; Schwartz et al. 2019, 2020; Subramanian et al. 2024; Morimoto et al. 2024). Neurologists are well aware of the potentially disastrous consequences for patients and their families of common myths and misconceptions about PD and its treatment (Ahlskog 2020). Misconceptions about palliative care, that are sometimes present within (and even shared by) PD care teams, are to be added to this extensive list. Change must therefore begin with neurology, where palliative care must be considered and advocated for what it is: not end-of-life care nor the withdrawal or replacement of medication, but optimal medical care throughout the disease course with quality of life as treatment goal, for both patients and their caregivers (Cherny 2009; Borasio 2013; Shurer et al. 2023). In short, "*it is about how to live well*" (Kluger et al. 2020). The most pressing research priorities in neuropalliative care have been defined as "(1) *patient- and care partner–centered symptoms and outcomes specific to neurologic illness and tools for their assessment*, *(2) development of effective neuropalliative care interventions and delivery models*, *and (3) methods to support the ability to foster*, *deliver*, *and measure goal-concordant care over time*" (Lau et al. 2025). Several studies and cohorts are currently ongoing, with the notable examples of the PD-PAL project[10] and the CLASP consortium[11], which mainly focus on late-stage PD. The development of PD-specific neuropalliative care needs checklist (Zacharias et al. 2024) and set of standards (Rogers et al. 2023), consensus-based recommendations for advance directives (Klietz et al. 2020) and international guidelines for palliative care in PD (Miyasaki et al. 2022) should therefore be a priority on a joint agenda for neurology and palliative care clinical organizations. In light of the ever growing evidence of its significance for quality of care, promoting the acceptance of palliative care and fostering its integration into standard neurological practice has now become "*a clinical*, *ethical*, *and humanistic imperative*" (Cherny 2009).

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[10] https://www.pdpal.eu/.

[11] https://www.ucl.ac.uk/ion/research/research-departments/clinical-and-movement-neurosciences/centres-and-projects/care-late.

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Declarations

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