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Palliative Care for Parkinson Disease

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RELEVANCE OF PALLIATIVE CARE TO PARKINSON DISEASE

The World Health Organization defines palliative care (PC) as “an approach that improves the quality of life of patients and families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”¹ Advances in PC relevant to Parkinson disease (PD) include the following: (1) recognition that PC needs may emerge at any point of an illness, including at the time of initial diagnosis; (2) PC may be effectively delivered in diverse settings including outpatient clinics; (3) PC may be integrated into standard disease-focused therapies; and (4) PC may be delivered by clinicians not specializing in PC, so-called primary PC.^{2,3}

Despite significant morbidity and mortality (the Centers for Disease Control lists PD as the 14th leading cause of death⁴), there are many areas where persons living with PD have unmet PC needs under current models of care. Patients report that receiving the diagnosis of PD is traumatic and frequently given without acknowledging psychosocial consequences.⁵ Nonmotor symptoms such as pain and depression are under-treated, and other psychosocial issues such as caregiver support are rarely addressed.^{6,7} Most patients with PD do not receive hospice care and most of them die in hospitals or other institutions.^{8,9}

Growing evidence suggests that PC needs contribute to quality of life (QOL) in PD and that PC approaches may improve both QOL and symptom burden and reduce hospital deaths.^{10–13} There are a growing number of centers now offering PC for PD.¹⁴ In this article, the authors focus on primary PC skills relevant to PD, including providing a diagnosis and

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prognosis with compassion; discussing goals of care; complex symptom management; caregiver support; addressing social, emotional, and spiritual well-being; and discussing hospice (Box 1).

Providing Diagnosis and Prognosis with Compassion

There are few events as significant to patients as receiving their PD diagnosis.¹⁵ Although physicians may choose to focus on the relatively positive aspects of this diagnosis, namely that medical and other therapies can significantly improve many symptoms, they should not underestimate the potential impact of this diagnosis on patients and their families. Physicians can improve the experience by responding empathetically to emotional reactions, sharing information, and listening to the patient's hopes and expectations. Clinicians should provide adequate time for these conversations and anticipate a need for close follow-up to prevent feelings of confusion and abandonment. Consider these communication approaches:

- SPIKES mnemonic for important conversations: *Setting up the Interview*; *Assessing patient's Perception*; *Obtaining patient's Invitation*; *Giving Knowledge*; *Addressing Emotions*; *Strategy and Summary*.¹⁶
 - Within this mnemonic the authors highlight a few points. When getting an *Invitation*, be prepared for patients and their caregivers to have different desires for how much information they want. For *Knowledge*, it is important to let patients know how the diagnosis is made but not to overwhelm them. For the *Summary* step, the authors recommend having an opportunity for follow-up within a few weeks, as patients and families may need time to process this information and may not hear everything that is said at the first visit.
- NURSE mnemonic to address emotions: *Name the emotion*; *Understand and legitimize the emotion*; *Respect the challenges and courage of the patient*; *Support the patient and family*; *Explore approaches to working with this emotion*.¹⁷
- Prognosis discussions: consider questions of "How long?" and "How well?" when addressing prognosis, while tailoring the conversation to individual preferences.¹⁸

Discussing Goals of Care

In goals of care discussions, patients, families, and clinicians work together to develop guidelines for current and future care.¹⁹ Patients and family members share their values, hopes, and fears, and clinicians provide information regarding diagnosis, prognosis, and guidance on medical treatments and resources. Important issues to address include what activities are most important to maintain QOL and how the patient and family would like to navigate ongoing or increasing levels of patient dependence. The following questions are helpful in order to better understand patients' and families' values: How do you define QOL? What do you enjoy or look forward to? What is the toughest part of this? What are you most afraid of?

1. **Assessing Decision-Making Capacity:** goals of care conversations should be initiated early due to the possibility of progressive cognitive impairment. Clinicians should be careful not to overemphasize the primacy of patient desires when they lack capacity, nor to discount the desires of patients with the capacity to provide input despite mild to moderate dementia.²⁰ Capacity is best assessed in relation to specific decisions rather than globally and can be assessed by remembering 4 “C”s (a patient’s ability to understand their *Condition*, their *Choices*, the *Consequences* of choices, and *Consistency* of decisions over time).
2. **Advance Care Planning (ACP) and Advance Directives:** ACP is a process that includes identifying a legal health care surrogate decision maker, discussing personal values, documenting preferences in an advance directive, and translating preferences into medical care plans.²¹ Recognizing the importance of ACP as part of high-quality PD care, the American Academy of Neurology Parkinson Disease Quality Measurement Set recommends annual review of advance directives and designated health care surrogates.^{22,23} One approach to discussing ACP is to ask about advance directives and health care surrogates as part of your social history; this helps normalize the conversation and signals that it is a routine part of good care. It may also be prudent to not delve deeply into ACP when first giving the diagnosis to avoid overwhelming the patient. Evidence-based, state-specific advance directives designed to have low cognitive burden are available (<https://prepareforyourcare.org/advance-directive>).²⁴ The advance directives should be easily accessible and shared with the health care surrogate, other family members, and health care providers. A patient’s ability to engage in ACP in PD may be influenced by specific perceptions and misperceptions of ACP and symptoms (eg, apathy, cognitive dysfunction).²⁵ Optimal engagement of patients with PD and caregivers should proactively address misperceptions of ACP and use interdisciplinary team members (ie, social workers, nurses, others) to incorporate ACP into routine PD care.
3. **Anticipatory Guidance for Future Needs:** in addition to decision-making related to ACP, many individuals with PD will face difficult life transitions. A PC approach can incorporate open and ongoing conversations about decisions related to the medical impact on employment, living situation, financial, and safety concerns. One of the medical team’s primary responsibilities is to screen for safety concerns. The presence of safety issues may mandate the clinician to modify or even challenge previously stated goals of care and to play the “bad guy” in advocating for decisions that go against the patient’s wishes (eg, memory care placement) to avoid blame among family members.

Individuals with PD have increased risk of motor vehicle accidents.²⁶ Although state laws vary, the authors recommend patients with red flags (eg, family or patient brings up driving concerns, significant vision, motor or cognitive impairment) to either stop driving or get a specialty driving evaluation. Firearms and other potentially dangerous items should be secured, particularly from patients with psychotic symptoms. Verbal, physical, or sexual threats or abuse may be directed at either the caregiver or patient and may be more common in PD than previously believed.²⁷ Financial risk may arise through scams targeting persons

with impaired cognition or through spending by patients with poor judgment.²⁸ Falls and wandering may necessitate 24/7 supervision or placement in patients with advanced disease or dementia, and wearable identification, fall alert systems, and home safety evaluations are recommended to try to preclude placement.²⁹

Complex Symptom Management

Patient QOL in PD is heavily driven by nonmotor issues and these symptoms are underrecognized by clinicians.⁶ As a part of routine care, the authors recommend systematic assessment of pain, mood, psychotic and behavioral symptoms, sleep and energy, communication, autonomic symptoms, swallowing, and nutrition.³⁰

Pain is a common symptom in PD and a focused history and examination may reveal causes of pain that are related to PD and can respond to targeted treatments (eg, nocturnal leg cramps, off dystonia).³¹ Unfortunately, even with appropriate therapies, many sources of pain may not be eliminated and can become chronic sources of suffering. A PC approach to this chronic pain includes understanding the physical aspects of the pain, as well as its functional, psychological, and social impact. Clinicians should talk with patients about their goals for pain management, emphasizing that functional improvement may be more attainable than complete pain elimination and that side effects of medications must be weighed against function. A proactive approach should be taken to avoid preventable pain (eg, keeping joints mobilized, good skin care in bed- or chair-bound individuals) and treatment should be directed at specific causes when possible. Opioids may be used judiciously in PD, with a recommendation to start with short-acting opioids and keeping a focus on function if possible (eg, using an acetaminophen-hydrocodone tablet a few times a week before physical therapy or other life-affirming activities).³²

Sleep disorders and fatigue are common and may affect both patient and caregiver well-being. Management requires identifying and treating contributing factors such as depression, specific sleep disturbances, anemia, pain, and medications, particularly dopamine agonists that can contribute to excessive daytime sleepiness and even daytime sleep attacks.³³ Nonpharmacologic approaches include exercise, energy conservation strategies, mindfulness training, cognitive behavioral therapy, or acupuncture.^{33,34}

PD can lead to dysphagia, weight loss, and changes in appetite. These symptoms may be important prognostic indicators and can be used to support hospice referrals.³⁵ Modifications to diet should be made within the context of an individual's goals of care. For example, patients may forego pureed diets and choose to continue eating their favorite foods if they place a higher value on the pleasures of eating than minimizing risk of aspiration. Feeding tubes are rarely indicated in these conditions, and evidence does not support their use to prevent aspiration or prolong survival.³⁶ Enteral feeding may be considered when prolonged and difficult mealtimes reduce QOL, when dysphagia is advanced out of proportion to other signs of disease progression, or if maintaining artificial nutrition is consistent with goals of care.

Caregiver Support

Individuals with PD often develop long-term disabilities and rely on family members to meet daily care needs. Unfortunately, family caregivers frequently suffer from sleeplessness, fatigue, anxiety, depression, guilt, and impaired immunologic responses. Caregiver burden is defined by perceptions of adverse consequences of caregiving to emotional, social, financial, physical, and spiritual functioning.³⁷ Risk factors for caregiver burden include female sex, low education, residing with the care recipient, depression, social isolation, financial stress, higher number of caregiving hours, and lack of choice in caregiver role.³⁸ Distressed caregivers often develop negative attitudes toward the disease and relationship problems with the patient and other family and experience complex bereavement.³⁹

Attending to the health and well-being of family caregivers may be facilitated through interdisciplinary clinics including social work and counseling resources.⁴⁰ The National Consensus Development Conference for Caregiver Assessment recommends the following approach: (1) identify primary and additional caregivers; (2) incorporate needs and preferences of both the patient and caregiver in all care planning; (3) improve caregivers' understandings of their roles and teach them the skills necessary to carry out the tasks of caregiving; and (4) recognize the need for periodic reassessment of care outcomes for the patient and caregiver.³⁸

Clinicians can also perform a brief assessment of caregiver well-being or use a formal assessment tool.⁴¹ In addition to detecting caregiver issues early and making appropriate referrals, even brief inquiries directed to caregivers are deeply appreciated and let the caregiver know they are not alone.⁴²

Protective factors against caregiver burden include resilience, perceived competence, self-efficacy, social support, optimism, and emphasis on the positive aspects of care.³⁹ Some of these protective characteristics can be trained through targeted interventions. Available support for caregivers include educational materials, home health care or skilled nursing support, respite care, advocacy organizations, and local or online support groups.

Addressing Social, Emotional, and Spiritual Well-Being

PC goes beyond the medical model of psychiatric illness to embrace the many social, emotional, and spiritual issues that arise during serious illness. PD challenges person-hood in numerous ways including independence, social relationships, sense of identity, and appearance.⁴³ Social activity is critical for maintaining cognitive ability and social isolation adversely affects QOL and mortality in PD.⁴⁴ Social activity can be promoted through awareness, community organizations, and social work.

It is important to distinguish common but difficult emotional reactions to chronic illness from the psychiatric syndromes of anxiety and depression and to provide encouragement and support to patients and families who may already experience shame around these feelings. Common difficult emotions include grief, guilt, frustration, demoralization, anger, and fears about the future including financial issues, death, or dementia.^{5,7,42,43,45} These emotions are frequently driven by spiritual or existential issues including hopelessness, meaninglessness, loneliness, and death anxiety.⁴⁶ The search for meaning is one of the central coping

mechanisms when facing progressive illness and may buffer against depression, hopelessness, and desire for hastened death among terminally ill patients. Spirituality and religion also may provide meaning, and these factors may guide patient decision-making during illness. Chaplains or other spiritual guides may provide emotional and spiritual support, particularly for patients adverse to the idea of psychotherapy.⁴⁷ Other interventions that enhance meaning and build resilience include traditional psychotherapy, mindfulness-based approaches, gratitude journals, and narrative-based approaches.^{48,49}

Referring to Hospice

Hospice refers to PC at the end of life. In the United States, the Medicare hospice benefit is available to patients certified by 2 physicians to have a prognosis of 6 months or less. Hospice is fully covered for Medicare, Veterans Affairs beneficiaries, and most Medicaid and private insurances. The authors recommend 3 questions to facilitate hospice discussions and referrals. First, would the patient and family benefit from the services available from hospice? Hospice is commonly delivered in the home or current residence and includes education, caregiver support, and a team of visiting nurses, social workers, chaplains, volunteers, and bereavement support for the family. Second, are the patient's and family's goals of care aligned with hospice? A helpful question is, "If you were to develop a serious pneumonia, would you want to go to a hospital for intravenous fluids and antibiotics?" If the answer is no and the goals of care are comfort, hospice may be appropriate. If the answer is yes, one may consider home PC or other home services. Finally, does the patient qualify for hospice? Although there are limited empirical data³⁵ and no formal guidelines specific to PD, the authors advocate a proactive approach to referring appropriate patients to hospice by documenting the following: accelerating rate of progression, weight loss, dysphagia, falls, hospitalizations, and withdrawal from activities. One may also use Medicare Hospice Guidelines for "Dementia," "Adult Failure to Thrive," or "Neurologic Illness" if they apply, recognizing that these guidelines often lead to late referrals if strictly followed.

SUMMARY

PC issues are common in PD and a PC approach may improve the QOL of patients and family caregivers. Primary PC can be integrated into PD care and management through ongoing discussions about goals of care, assessment and management of a broad range of physical, emotional, social, and spiritual needs, attending to caregivers, and appropriate referrals to hospice.

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Box 1**Primary palliative care skills for neurodegenerative illnesses**

- Providing a diagnosis and prognosis with compassion
- Discussing goals of care
 - Assessing decision-making capacity
 - Advance care planning and advance directives
 - Anticipatory guidance for future needs
- Complex symptom management
- Caregiver support
- Addressing social, emotional, and spiritual well-being
- Referring to hospice care

KEY POINTS

- Palliative care (PC) aims to relieve suffering for persons affected by serious illness by addressing medical, psychosocial, and spiritual needs.
- Parkinson disease (PD) causes distress related to medical, emotional, social, and spiritual needs beginning at the time of diagnosis and throughout the entire course of the disease.
- PC approaches may improve quality of life for individuals with PD and their families throughout the course of the illness.
- A primary PC approach to PD includes providing the diagnosis and prognosis with compassion, discussing goals of care and advance care planning, systematic assessment of motor and nonmotor symptoms including psychosocial issues, and timely hospice referrals.