

# Palliative Care in Parkinson's Disease: Implications for Neuroscience Nursing

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**A**bstract: Parkinson's disease (PD) is a chronic, progressive neurological disease affecting 1.5 million Americans. The modern success of pharmacology and deep-brain stimulation surgery to treat the motor symptoms of tremor, rigidity, and bradykinesia provide PD patients with longer lives and increased motor functioning. However, in the moderate and advanced stages of disease, the therapeutic benefits of pharmacology diminish and motor symptoms are more complicated to treat. The nonmotor symptoms of PD receive little attention in clinical settings, although they can lead to disability and caregiver burden. The Center to Advance Palliative Care advocates applying the principles of palliative care to chronic disease. Likewise, the World Health Organization has redefined palliative care to include life-threatening illness. The Parkinson's Disease Model of Care (PDMC) takes the precepts of palliative care and presents a model for the neuroscience nurse to use in individual care planning across the trajectory of disease. The PDMC guides the nurse in providing relief from suffering for PD patients and their families, from diagnosis through bereavement, with an emphasis on advance care planning.

Parkinson's disease (PD) is a common, chronic, progressive, neurodegenerative disease with an annual incidence of 25.6 cases per 100,000 individuals. Approximately 1.5 million Americans are currently diagnosed with PD, and 60,000 new cases are diagnosed each year. Prevalence in the United States and Canada is estimated to be 369 per 100,000 individuals, and prevalence increases with age (Rajput & Rajput, 2002; Siderowf, Cianci, & Rorke, 2001). There is no cure for PD and the cause of the disease continues to elude medical science (Siderowf, 2001).

Motor symptoms of resting tremor, rigidity, and bradykinesia characterize PD. As the disease progresses, balance and gait become more affected and disability increases. Nonmotor features of PD (Table 1) can occur at any stage of disease and can contribute to significant disability. The neuropathology of PD is related to the depletion of dopamine-producing cells in the substantia nigra.

PD can be divided into three stages: early, moderate, and advanced. Each stage of PD demonstrates a

progression of disability, with increasing complexity of care required to manage motor and nonmotor symptoms. Physicians who specialize in movement disorders report that no two cases of PD are alike. Thus, each case presents with a unique set of symptoms and disease trajectory. Often physicians will be guided by the historical course of disease to provide a future estimate of disease progression (Duda & Stern, 2005), leaving the patient and caregiver with a sense of uncertainty about future disability and dependence on others. Factors related to the rate of PD progression are presented in Table 2.

PD is a chronic, progressive disease with limited therapeutic options in its advanced stages. The precepts of palliative care provide a framework to guide the treatment and care of patients with PD and their families. The World Health Organization (2005) defines *palliative care* as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with 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.

The American Academy of Neurology Ethics and Humanities Subcommittee (1996) published a series of papers on palliative care and ethical considerations in patient management that states

Many neurologic diseases are progressive and incurable. The optimal care of such patients requires that neurologists understand and apply the principles of palliative medicine. Indeed, the principles of palliative care are relevant to the management of many patients because minimizing distress and controlling pain and other symptoms are important even for patients with curable disease (p. 870).

This article applies the principles of palliative care to PD treatment and provides neuroscience nurses with a model of care. This model guides nurses through the three stages of PD and incorporates the concept of palliation from diagnosis through bereavement. Significant works from geriatric nursing, palliative care, hospice care, gerontology, and medical neurology are cited.

## Palliative Care

The concept of palliative care in PD has received little attention in nursing literature and research. In 2004 a two-part series of articles was published that provided a paradigm of disease management for PD, in which

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**Table 1. Nonmotor Features of Parkinson's Disease**

Category	Symptom
Neuropsychiatric	Depression
	Anxiety
	Psychosis
	Dementia
	Personality changes Hypersexuality
Sleep disturbance	Vivid dreams
	Insomnia
	Daytime sleepiness
	REM sleep disorder
Autonomic dysfunction	Constipation
	Impotence
	Urinary symptoms
	Decreased olfaction
	Orthostatic hypotension
	Diaphoresis
	Sialorrhea Weight loss
Pain	Musculoskeletal
	Radicular-neuropathic
	Dystonic
	Central
	Akathisia
Visual	Blurred vision
	Diplopia
Other	Dysphagia
	Dysarthria

palliative care was presented as end-of-life care (Thomas & MacMahon, 2004a, 2004b). Historically palliative care in the United States has been viewed as end-of-life care and has often been synonymous with hospice care. This old model is giving way to a new philosophy to support the patient and family throughout the entire spectrum of chronic disease. Palliative care is currently conceptualized with a longitudinal model that encompasses the entire course of chronic illness from diagnosis to hospice care. To meet the challenge of the shifting healthcare landscape, the Center to Advance Palliative Care (2004) presented a model of care for chronic disease (Fig 1).

Palliative care has been studied extensively in the cancer population and is beginning to be adapted for other chronically ill populations. Palliative care is now viewed as both a philosophy and a model of care. Hospitals are investing in palliative-care programs to improve quality of life for patients and to reduce costs through advance care planning (Center to Advance Palliative Care, 2004). By assisting patients and their family members plan for

**Table 2. Features Related to Rate of Parkinson's Disease Progression**

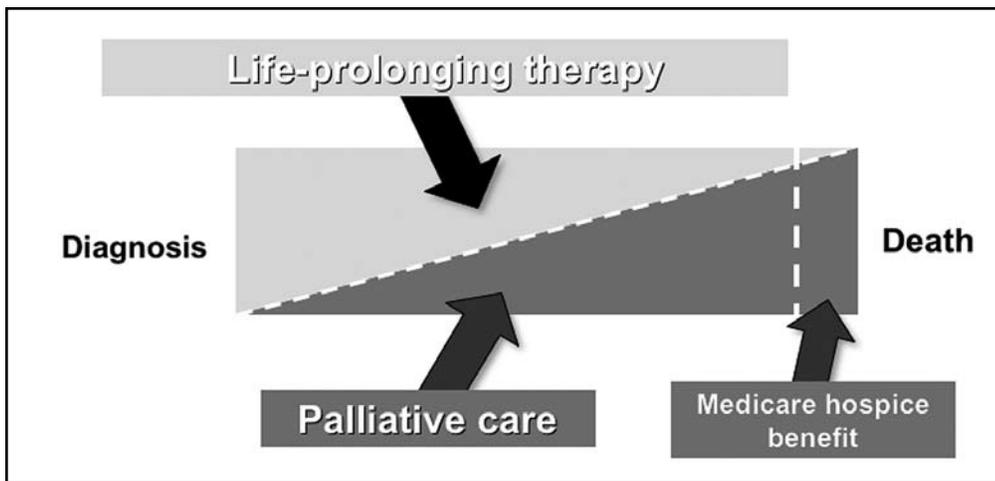
Rate of Progression	Related Feature
Rapid	Rigid-predominant motor symptoms
	Onset at older age
	Presence of cognitive impairment
	Depression
Delayed	Tremor-predominant motor symptoms
	Onset early in life

future care, hospitals can reduce the use of emergency medical resources and acute hospitalizations at the end of life. Likewise, patients with PD and their families who receive clinical services can actively engage in advance care planning driven by the principles of palliative care. Gradually incorporating palliative care throughout the three stages of PD will help the patient and family make a successful transition through increasing levels of disability while maintaining autonomy and dignity.

### The Palliative Care Imperative

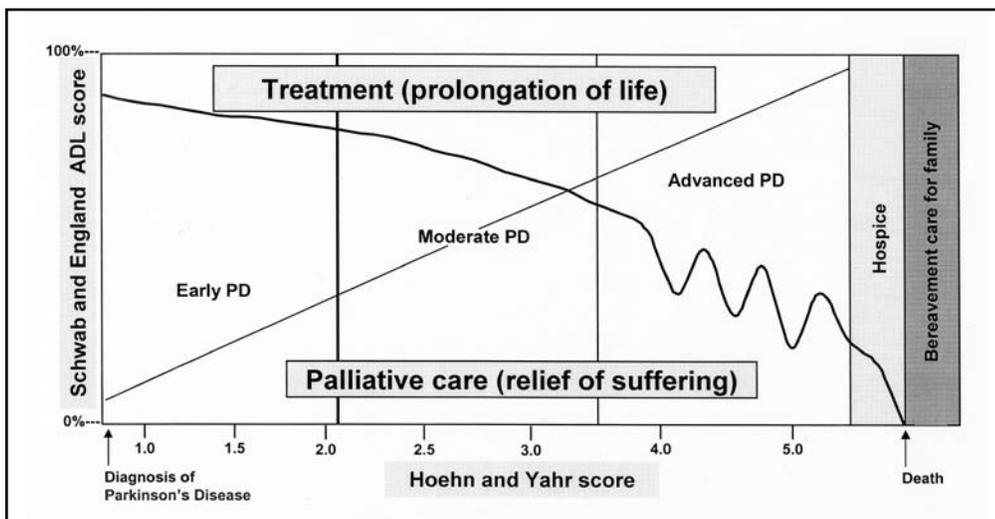
The need for neuroscience nursing to change the current model of care delivery for patients with PD is influenced by the growth of the elderly population. In the United States, the number of individuals age 65 years of age or older is projected to increase from 35 million in 2000 to 71.5 million by 2030. Thus, individuals 65 years or older will make up 20% of the total U.S. population by 2030 (Federal Interagency Forum on Aging-Related Statistics, 2004). This staggering increase in the aging population will strain healthcare resources and change traditional models of healthcare delivery. Neuroscience nurses will care for increasing numbers of patients with PD and their family members across the healthcare continuum.

Building on the Center to Advance Palliative Care model, the Parkinson's Disease Model of Care (PDMC) was developed to help the neuroscience nurse use the principles of palliative care, from the time a patient is diagnosed with PD through bereavement care (Fig 2). The PDMC uses the Hoehn and Yahr score along the vertical axis to demonstrate stage of disease and the Schwab and England Activity of Daily Living (ADL) score along the horizontal axis to reflect activities of daily living (Fahn, Elton, & Members of the UPDRS Development Committee, 1987; Hoehn & Yahr, 1967; Schwab, England, & Peterson, 1959). The Schwab and England ADL score is represented by a line moving through the three stages of PD, illustrating the slow decline in functioning over the course of disease. In the advanced stage, the dark line representing the Schwab and England ADL score fluctuates to illustrate acute episodes of disability followed by partial recovery. From the advanced stage of disease, the model moves to traditional hospice care at the end of life and incorporates bereavement care for families.



**Fig 1.** The role of palliative care during the course of illness

Note. From *The Case for Hospital-Based Palliative Care*, by Center to Advance Palliative Care, 2004. © 2004 Center to Advance Palliative Care. Reprinted with permission.



**Fig 2.** Parkinson's disease model of care

The PDMC is designed to provide neuroscience nurses with a clinical model to individualize care for patients and families throughout the course of disease. The model incorporates traditional life-prolonging treatment, palliative care, hospice care, and bereavement services.

### Advance Care Planning

Advance care planning (ACP) is the cornerstone of palliative care. The patient's ability to achieve autonomy in the context of a chronic, progressive neurologic disease is paramount in developing a longitudinal care plan. ACP is a collaborative, continuous process that starts at the time of diagnosis and continues throughout the course of chronic disease. Healthcare providers frequently struggle to determine when to initiate discussions about ACP out of concern for implying that the patient is at the end of life. By including the ACP process in the standard of care for patients at diagnosis, conversations about ACP can

begin and treatment goals can be evaluated over the course of disease.

The two overarching goals of ACP are (a) establishing a communication process that incorporates the patient's care desires and (b) creating contingency plans to achieve those care goals (Teno, 2003). In establishing the contingency plan, patients need to identify a proxy to act as their surrogate in case they become unable to communicate their own treatment needs and desires. The neuroscience nurse can help the patient identify a proxy. The proxy is typically a spouse, adult child, or other family member. Palliative care is often referred to as family care, and *family* can be defined as "anyone who shows up when illness strikes...and stays on to help" (Levine, 2003). Key steps to ACP include actively listening to patients regarding the quality of their life, working with patients to develop health-care goals, and formulating contingency plans to meet the objectives of palliative care throughout the course of disease (Teno).

The ACP process spans the continuum of care for the patient with early, moderate, and advanced PD. Traditional legal documents, such as the advance directive and durable power of attorney for health care, can be the outcome of the ACP process. The durable power of attorney for health care is a document in which an individual identifies a proxy to make healthcare decisions in case the individual becomes unable to communicate healthcare preferences. The advance directive provides specific instructions on care and treatment and can serve as a guide to the proxy in making healthcare decisions. Instructions related to resuscitation, pain management, hydration, and artificial nutrition are contained in the advance directive. Each of the 50 states defines the legal elements of the durable power of attorney for health care and advance directive. Thus, such documents should be relevant in the state in which the patient resides. However, the essential aspect of ACP is the naming of a proxy (Ramsey & Mitty, 2003).

## Early Disease

Patients in the early stage of PD typically have good motor and cognitive function. They are usually fully engaged in social life, working, and contributing to society. The early stage of PD is the ideal time to start the ACP process, because patients have full capacity to engage in healthcare decisions.

The first step of ACP is to ask the patient to describe understanding of PD in the context of the quality of life. Patients' perceptions of quality of life will differ based on their level of disability, emotional life, and relationships with others. A baseline assessment of cognitive function, depression, and support system is important in assessing patients' ability to comprehend and collaborate in the ACP process.

When communicating with the patient in the early stage of PD, the neuroscience nurse needs to understand what type of information the patient is ready to receive. Is the patient a person who likes to plan for the future? If so, she may be interested in detailed information to assist in planning for life with PD. Is the patient seeking reassurance? If reassurance is the objective of the conversation, she should receive less detailed information. A good place to start the conversation is to ask the patient what she anticipates will be the effect of PD on her life. A follow-up question could ask about the type of information the patient wants to receive. Another approach is to open a discussion with the patient about experience with other people with PD and investigate perceptions through life experience (Education in Palliative and End-of-Life Care Project, 2003).

In the early stage of PD, the palliative-care plan encourages patients to complete a durable power of attorney for health care and begin to discuss the possibility of medical emergencies. Identifying a proxy increases the probability that patients' wishes will be carried out in the event an unexpected medical incident leaves them unable to express their healthcare directives.

## Palliation of Early PD Symptoms

In the early stage of PD, nonmotor symptoms can emerge and present as debilitating complications. Depression, sleep disturbances, and pain can lead to disability and negatively affect quality of life for patients and their families. Several studies have documented the occurrence of pain, depression, and sleep disorders before the presence of motor symptoms and diagnosis of PD (Morgan & Sethi, 2005).

Forty percent of patients with PD experience pain as a nonmotor feature of disease. Pain in PD has been categorized as musculoskeletal, radicular-neuropathic, dystonic, central, or akathisia. Patients with PD may present with complaints of aches, shoulder pain, cramping, and arthritis. Others may complain of pain distributed along a nerve root in a neuropathic distribution. Early-morning dystonia is common and can present as acute cramping pain. Pain

associated with PD typically fluctuates throughout the day and is mediated by the administration of antiparkinson medications (Ford, 1998).

Pain management in PD can be achieved through careful adjustments of antiparkinson agents such as levodopa and carbidopa, entacapone, pramipexole, ropinirole, pergolide, and apomorphine. Other medications, such as clozapine and gabapentin, have been documented to be beneficial in managing pain in patients with PD. Careful evaluation for other origins of pain should be part of the care plan. Referral to a pain specialist is beneficial if pain is not mediated with medication adjustments (Sage, 2004).

Depression is prevalent in 40%–60% of patients with PD and contributes to significant morbidity. The depletion of serotonin in the brains of depressed PD patients is well established and provides a neurochemical model for depression in PD. Depression in patients with PD is underrecognized and undertreated. Slowness of movement, stooped posture, and slowed thought processes are common, making the recognition of depression difficult. Asking the patient if she believes life is worth living is a useful way to assess for depression. Depressed patients often reply that they feel life is not worth living and that they are a burden to their family. Vegetative symptoms, such as early-morning awakening, decreased appetite, and decreased energy can also assist in evaluating for depressive symptoms in PD. Early recognition and treatment of depression are essential to achieve optimum management of both motor and nonmotor symptoms (Weintraub & Stern, 2005).

Medications commonly prescribed for the treatment of depression in PD include fluoxetine, bupropion, fluvoxamine, paroxetine, sertraline, venlafaxine, mirtazapine, and citalopram. Electroconvulsive therapy is also an option for treatment of depression for patients who do not respond to pharmacological therapy or who are acutely suicidal (Chow, Masterman, & Cummings, 2002; Weintraub, & Stern, 2005).

Sleep disorders are prevalent and multifactorial in patients with PD. Sleep disturbance in patients with PD can be related to motor symptoms, medications, comorbid conditions, or associated sleep syndromes. The motor symptoms of PD often diminish the ability of the patient to turn over in bed, producing sleep fragmentation. The presence of nighttime dystonia can produce painful leg cramping that wakes the patient. Restless leg syndrome can produce dysesthesias of the lower extremities, which are relieved by moving the legs, further disturbing the quality of sleep.

Dopaminergic medications, such as the agonist class of medications prescribed for PD, can produce excessive daytime sleepiness, which may interfere with driving, working, and social activities. Vivid dreams can also be a side effect of dopaminergic therapy and diminish the quality of sleep. Sleep apnea is also associated with

PD and can contribute to daytime sleepiness. Patients experiencing sleep difficulties should be assessed for their current PD therapy and referred to a sleep specialist for evaluation (Morgan & Sethi, 2005).

In the early stage of disease, it is important to evaluate the psychosocial aspects of the patient's life. The diagnosis and subsequent management of PD can affect self-esteem and change long-term relationships. Newly diagnosed patients need to evaluate professional obligations that can affect employment and financial security. Concern about disability and its impact on the family can weigh heavily on the newly diagnosed patient. Thus, asking patients about their support systems can be helpful in managing their long-term care.

### **Moderate Disease**

In the moderate stage of PD, patients begin to experience diminished benefit from antiparkinson medications. This phenomenon is often called narrowing of the therapeutic window. Motor fluctuations and dyskinesias emerge, and nonmotor complications become more evident (Duda & Stern, 2005). Comorbid medical problems can complicate care, and activities of daily living (ADLs) become burdensome. In the moderate stage of disease, PD patients begin to depend on assistance from others, and caregiver burden may surface as a problem.

The moderate phase of PD is marked by diminished benefit from antiparkinson medications and progression to bilateral symptoms, with decreased balance. The PDMC offers a view of the moderately impaired PD patient with a Hoehn and Yahr Staging score of 2.5–3 (mild bilateral disease, with recovery on pull test; and mild to moderate bilateral disease, some postural instability, and physical independence, respectively). The PDMC describes a slow decline in ADL scores across time.

In the moderate stage of disease, the ACP process must become more active. The location of the documents for durable power of attorney for health care should be reviewed with the patient. Writing an advance directive may allow the patient to maintain autonomy in documenting her preferences for care. The proxy should be fully engaged in these discussions and kept informed of the patient's wishes.

### **Palliation of Moderate PD Symptoms**

Symptoms in the moderate stage of disease vary greatly from one patient to the next. This section is a reference for palliative management, not an exhaustive list of symptoms amenable to palliation.

The diminished efficacy of antiparkinson medications and subsequent narrowing of the therapeutic window produce a phenomenon called on-off fluctuations. Fluctuating regulation of dopamine in the brain results in alternating periods of normal mobility with periods of immobility. On-off periods can be unpredictable and can last minutes or hours. Patients experience pain, mood

fluctuations, and anxiety in the off state. Often, patients will describe their feet as being glued to the floor; this is called freezing of gait. Freezing of gait contributes to falls, urinary incontinence, and disability (Giladi, Kao, & Fahn, 1997; Giladi et al., 2001).

Falling and associated fall-risk factors have received little attention in PD research. Approximately 70% of PD patients fall, 13% weekly. Falls result in hip fractures, injuries, hospitalizations, and disability. Longer duration of disease, dyskinesias, freezing of gait, postural instability, increased disability, depression, and weaker proximal lower extremity strength have been identified as fall-risk factors for patients with PD. Randomized clinical trial results are not available to guide fall prevention in PD. A referral to rehabilitation medicine and a structured plan of care with an experienced physical therapist can help with strengthening and gait training. The patient may also benefit from using assistive devices and modifying the home environment to prevent falls (Robinson et al., 2005).

More than 40% of patients with PD experience lower urinary tract symptoms. Urinary frequency, urgency, nocturia, dribbling, and incontinence are common complaints (Campos-Sousa et al., 2003). To date, no research exists to guide the treatment of these symptoms. However, standard nursing care of toileting schedules, dietary modification, bowel management, and pelvic floor exercises may be beneficial. The use of absorbent products and catheters is also an option. Medications for the treatment of neurogenic bladder, such as oxybutynin, tolterodine, and trospium, can be efficacious (Bennett et al., 2004; Rovner, 2004). However, PD patients on medications for the treatment of neurogenic bladder symptoms should be monitored for confusion and other mental status changes.

On-off fluctuations are best managed through careful titration of antiparkinson medication. Adding concomitant medications and adjusting dosages for optimum motor control can diminish on-off fluctuations. Referral to a movement disorder specialist is recommended to optimize PD medications. A psychiatrist can address the presence of a mood or anxiety disorder and help select the best treatment.

Patients can experience on-state dyskinesias, which result from having to overmedicate with antiparkinson medications to achieve mobility. Dyskinesias are described as abnormal movements of the head, neck, trunk, and limbs. Patients describe dyskinetic movements as wiggly, jumpy, or dancelike. Dyskinesias can be exhausting and socially embarrassing. Some patients report that they have been accused of being under the influence of alcohol or other substances when they experience dyskinesias in public. However, most patients with on-off fluctuations report that dyskinesias are acceptable if they are able to achieve good mobility. Because dyskinesias result in increased physical activity, patients need to monitor their weight and caloric intake to maintain normal body mass. A consultation with a dietitian is often beneficial.

Patients who have 3 or more hours a day of off time or have troublesome dyskinesias and whose medications have been optimized should be evaluated for deep brain stimulation surgery. Parkinson patients considering deep brain stimulation surgery should have good mobility in the on state, because the best possible outcome of the surgery only equals the quality of the patient's most effective antiparkinson medication regimen (Jaggi et al., 2004; Simuni et al., 2002).

In the moderate stage of PD, the psychosocial impact becomes more evident. The need to adjust medication, increased disability, and diminished independence can lead to role changes within the family. The nurse can assess for and identify resources for the patient and family to maintain independence in the community. Support groups are a source of support and information. Local community, civic, and religious organizations can provide respite care, companionship, and transportation.

### **Advanced Disease**

In the advanced stage of PD, life-prolonging therapy gradually is replaced by palliative measures in the care plan. The patient may experience multiple acute episodes of physical disability and cognitive decline related to PD or comorbid diseases (Tetrud, 2005).

In the advanced stage of disease, ACP takes on an active role. The patient, family or proxy, and healthcare provider should intermittently review the advance directives as to the patient's wishes about pain management, fatigue, nausea, vomiting, bowel management, urinary tract disorders, artificial hydration, artificial nutrition, dementia, agitation, and restlessness. Once the patient has identified her desires for symptom management, a discussion should occur on withholding or withdrawing treatment at the end of life. The patient and family may benefit from consultation with a palliative-care specialist. The patient and family should be educated on the benefits of hospice care and encouraged to select a hospice program for future services.

### **Palliation of Advanced PD Symptoms**

Cognitive problems have been reported to affect as many as 78% of the PD population; they are prevalent in advanced PD. Cognitive difficulty can present as a mild impairment early in the disease, primarily affecting executive functioning, which governs planning and memory. With advancing age, dementia becomes more prevalent among PD patients. (Weintraub & Stern, 2005). Research into the treatment of dementia in this population is limited. Several recent studies have examined the effects of cholinesterase inhibitors. The common drugs prescribed for dementia are galantamine, rivastigmine, and donepezil. However, no randomized clinical trial has been conducted to prove the benefit of one drug over another in treating dementia associated with PD (Aarsland, Hutchinson, & Larsen, 2003).

Wandering, sundowning, agitation, and combativeness can be behavioral symptoms exhibited by PD patients who

have dementia. Behavioral symptoms can be difficult for families to manage in the community and can precipitate nursing home placement. The neuroscience nurse is in a unique position to educate caregivers on behavioral management of the PD patient who has dementia.

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*Once the patient has identified her desires for symptom management, a discussion should occur on withholding or withdrawing treatment at the end of life.*

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Wandering patients' safety is often challenging to maintain. Obtaining a MedicAlert® tag and informing the local police and fire department of the risk of wandering can help in locating the patient quickly, if necessary. Neighbors are often willing to keep a watchful eye for a wandering patient. Alarms on doors can alert the family when a door is opened. However, special door locks are undesirable because difficulty of use in the event of a house fire.

Sundowning (i.e., evening agitation with dementia) can be mediated by enhancing environmental stimuli. Turning on lights and reducing shadows reduces misinterpretation of visual stimuli and assists in safe ambulation. Playing soft music and providing a calm environment can help minimize agitation in the evening. Medications can be prescribed to decrease agitation and promote sleep.

Psychosis can affect patients whether or not they have impairment. Hallucinations and delusions are the most common psychotic symptoms of PD and are often related to the side effects of antiparkinson therapy. In advanced disease, the best approach to managing medication side effects is to reevaluate the current pharmacologic therapy. Medications such as amantadine typically do not provide symptom management in late-stage disease and can contribute to the development of hallucinations. It is beneficial to evaluate the use of a dopamine agonist, such as pergolide, pramipexole, and ropinirole, in advanced PD and to move toward levodopa and carbidopa as monotherapy to reduce psychotic symptoms (Tetrud, 2005).

As PD advances, patients often experience an impaired ability to swallow. Swallowing difficulty is most apparent as choking on liquids, which can lead to aspiration pneumonia. Assessing for choking and swallowing difficulty is important in advanced PD. Many patients will benefit from a swallowing assessment to provide risk estimates for aspiration and therapeutic techniques to improve swallowing. Frequently, fluids can be thickened to a honey consistency to make swallowing more efficient and reduce the risk of aspiration (Ramig, Countryman, Fox, & Sapir, 2002). The use of a feeding tube should be discussed with the patient and proxy, with consideration of its risks and benefits.

In the advanced stage of PD, the psychosocial aspects of disease can be severe. Caregiver burden and the

increased physical needs of the PD patient can precipitate nursing home placement. Maintaining the patient in the community is the objective of care. To achieve this, the nurse must work with the multidisciplinary team to facilitate home care services and organize volunteers to assist with care. Home-safety evaluations by a physical therapist can indicate home modifications to increase independence. Consultation with a social worker can link the patient and family with community resources.

## Hospice

Seventy percent of Americans die in the acute care hospital setting, undergoing life-prolonging procedures at the end of life. Only 15% of Americans have the benefit of hospice services, and 50% of those are cancer patients. The multidisciplinary skills of the hospice team support the patient and family through end-of-life care and include bereavement services for families (Foley & Carver, 2001).

Toward the end of the advanced stage of PD, the neuroscience nurse should collaborate with the treatment team to make a referral to hospice care. Hospice provides noncurative care to patients. The ACP is used to transfer care of the patient to the hospice team. The patient, family, and proxy should have addressed issues such as artificial nutrition, do-not-resuscitate orders, comfort-care-only orders, do-not-hospitalize orders, and pain management throughout the ACP process.

Hospice is paid for by Medicare Part A and is available as home care or inpatient care. Medicare has three eligibility criteria for entering hospice care. The first asks the physician to determine, to the best of her knowledge, that the patient has 6 months or less to live. This requirement is often a roadblock in managing patients with chronic neurologic disease. Most hospice program directors will work with referring healthcare providers to determine hospice eligibility and overcome barriers to care. The second eligibility criterion requires the patient to accept palliative care and not curative care. Finally, the patient must be treated in a Medicare-approved hospice program (Egan & Labyak, 2001).

## Bereavement Care

The end of a PD patient's life is often arduous. The caregiver may be exhausted from providing years of physical and emotional care. Many caregivers have invested so much of themselves in the caregiving role that they are socially isolated and have few support systems to assist them through bereavement.

A patient's death is the time when caregivers need support in redefining their roles and reorganizing their lives. Losing a family member brings with it a change in social expectations for the caregiver. The lifting of care burden opens a window for formal grieving. Family and friends comfort the bereaved person for a short period of time after the death, but the need for emotional support lasts for years. This is the time when a referral to bereavement counseling is essential to help the family

and caregiver make a successful transition to a noncaregiving role (Levine, 2003).

Most hospice programs provide a year of bereavement services. For families who do not have hospice care at end of life, bereavement services are available through religious and not-for-profit organizations. Grief support groups can be located through an Internet search; frequently they are available through senior service and other community organizations (Levine, 2003).

## Summary

Changing demographics in the United States and the increase in chronic disease provide challenges for neuroscience nurses. The PDMC has been developed to help the neuroscience nurse provide longitudinal care plans for patients and families across the healthcare continuum, using the principles of palliative care.

Neuroscience nurses can facilitate palliative care for PD patients by using the ACP process. Identifying key treatable symptoms and providing comfort measures can promote quality of life in the context of a chronic disease. Helping provide a patient and family with a good experience at the end of life is within the neuroscience nurse's scope of practice through advocacy for the principles and philosophy of palliative care.

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