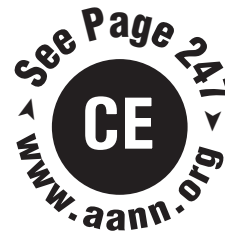


Characteristics and Symptom Management of Progressive Supranuclear Palsy: A Multidisciplinary Approach



Constance Ward

Abstract: Progressive supranuclear palsy (PSP), a neurodegenerative disorder that may be mistaken for Parkinson's disease early in its course, is the most common type of atypical parkinsonism. PSP is fatal; it transforms a normal person into an invalid within 5–7 years of the onset of symptoms. PSP requires a multidisciplinary approach to symptom management and treatment. The neuroscience nurse who is knowledgeable about PSP and the complex way in which it overlaps with numerous other devastating neurological diagnoses can help in achieving the correct diagnosis and treatment. The nurse must understand the disease pathophysiology and the plan of care required and is instrumental in recognizing the needs of the patient and the family.

Progressive supranuclear palsy (PSP), a rare and fatal neurodegenerative disorder, is underrecognized. It has an insidious onset, and symptoms progress rapidly during 5–7 years. Death usually results from aspiration or other infectious processes by the 10th year (Christensen, 1988). PSP is referred to as a Parkinson's-plus syndrome because of the associated clinical features, poor response to Parkinson's medications, distinctive pathological characteristics, and poor prognosis (Fig. 1).

Awareness of PSP was heightened when actor Dudley Moore was diagnosed with the degenerative illness in 1999. When Moore experienced the early symptoms of unsteadiness and slurred speech, it was rumored that he was an alcoholic. Because he could not remember his lines for a 1996 movie, Moore was fired. He created the Dudley Moore Research Fund for PSP a few years before he died in March 2002 of aspiration pneumonia, a complication of PSP (Karkabi, 2003).

The complex nature of PSP requires a multidisciplinary treatment approach to meet the needs of the patient, the caregiver, and the family. This article introduces each healthcare professional's role in the management of the PSP patient. Nurses play a major role in PSP patient care.

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They recognize the patient's needs, coordinate and involve other healthcare disciplines, and educate the patient and the family about the disease process.

Clinical Characteristics

Patients typically present with loss of balance and unexplained falls. Because the patient may report dizziness before loss of balance, the initial diagnosis may be an inner ear problem. An abnormality of extraocular eye movements, also known as supranuclear gaze palsy, is the classic symptom, but it may not be seen initially. Rigidity of the neck muscles and the extremities is often present. The patient may be diagnosed with atypical Parkinson's disease (PD). As the disease progresses, however, the eyes become affected, and the patient begins to experience double or blurred vision. The hallmark feature of PSP is seen when damage to the nuclei, pea-size structures in the brain, paralyzes the patient's upward and downward gaze (National Institute of Neurological Disorders and Stroke, 2004). A lack of supranuclear connections prevents the patient from voluntarily moving his or her eyes. The vestibular ocular reflex (the doll's eyes reflex) can be produced by passively moving the patient's head while his or her gaze is fixed on an object. This reflex is an indication of the functional integrity of the brainstem. Vertical eye movements are usually more

Parkinson's-Plus Syndromes

Corticobasal degeneration

Dementia syndromes

- Alzheimer's disease
- Dementia with Lewy bodies
- Pick's disease

Lytico-Bodig (Guamanian PD-D-ALS*)

Multiple system atrophy syndromes

- Striatonigral degeneration
- Shy-Drager syndrome
- Sporadic olivopontocerebellar atrophy
- Motor neuron disease—Parkinson's disease

Progressive pallidal atrophy

Progressive supranuclear palsy

*Parkinson's disease–dementia–amyotrophic lateral sclerosis (Waters, 2002).

Fig 1. Parkinson's-plus syndromes

affected than horizontal eye movements; the downward gaze is usually affected first, although in later stages of PSP the gaze may be affected in all directions.

The patient develops the classic appearance of sustained surprise, which is exhibited as either a startled facial expression or a stone face, due to contracted facial muscles. The patient may not be able to see food on a plate or an object in the path when walking. Later in the disease process, horizontal gaze paresis, eyelid apraxia (difficulty with voluntary eye opening), blepharospasms (involuntary spasmodic contractions of the orbicularis muscle), and severely reduced blinking occur. As the disease progresses, executive functions become impaired. Symptoms include mental slowness with slow informational and abstract processing, sleep disturbances, slurred speech, angry outbursts, dementia, impaired judgment, apathy, and depression (Sokol, 1999). There can be sudden spells of emotional instability, in which crying or laughing is exhibited without reason. Personality changes are common; family members report instances of irritability and social withdrawal (Hain, 2001). Further disease progression leads to swallowing difficulties, orthostatic hypotension, and urinary and fecal incontinence. Eventually, the patient becomes bedridden and requires constant care. Death usually occurs within the first decade after symptom onset, secondary to pneumonia, pulmonary embolus, infection, decubitus, cachexia, or immobility (Rajput & Rajput, 2001; Smith & Berry, 1990).

Diagnosis

Neuroimaging of the brain by computed tomography (CT) or magnetic resonance imaging (MRI) has shown atrophy of the midbrain, pons, cerebellum, and third ventricle and degeneration of the red nucleus in PSP patients (Rajput & Rajput, 2001). MRI is the preferred method of neuroimaging because other diseases that can mimic PSP (e.g., multi-infarct state, hydrocephalus, midbrain tumors) can be excluded (Rajput & Rajput); however, neither CT scan nor MRI can definitively diagnose PSP. Absolute confirmation can be achieved only by brain autopsy.

Incidence and Prevalence

PSP was first described as a distinct disorder in 1964, when three scientists published a paper that distinguished the condition from PD. PSP is sometimes referred to as dementia-nuchal dystonia or as Steele-Richardson-Olszewski syndrome, after the three scientists who defined it (Mark, 2001).

A report from a Rochester, MN, U.S.-population-based study (Bower, Maraganoke, McDonnell, & Rocca, 1997) found that PSP affects an average of 5.3 persons per 100,000 (0.0053%). Of all Americans ages 50–99 years, 20,000–80,000 are affected. The incidence increases with age, and men are more often affected than women. Although there is a rare instance of familial PSP, a positive family history is not considered a risk factor

(Rajput & Rajput, 2001). No reports in the literature show any specific risk by ethnicity, geographic location, or race. PSP is seen most often beginning in the fifth or sixth decade of life. Mean survival length is approximately 9 years from symptom onset (Rajput & Rajput, 2001).

Etiology

The symptoms of PSP are caused by a gradual deterioration of cells in the midbrain that are involved in eye movement and balance. The cause is unknown; however, recent genetic studies have suggested that some cases of PSP appear to result from an autosomal recessive condition in the tau gene (Hain, 2001). Tau is a protein that is abundant in six different forms in the normal human brain; it is important for maintaining the structure of brain cells. In PSP, pathological tau protein accumulates in the cells and glia of the brain, producing abnormal plaque and the support of a genetic factor or exposure to an environmental toxin, which causes the cells to die (Hain).

In PD, the substantia nigra neurons located in the basal ganglia are depleted by as much as 80% before symptoms of the disease (i.e., tremor, rigidity, akinesia, postural instability) become apparent (National Institute of Neurological Disorders and Stroke, 2004). Scientists do not know what causes these brain cells to die; however, there are theories related to aging and genetics, as well as exposure to manganese dust, carbon monoxide, herbicides, pesticides, and other exogenous agents (Waters, 2002). In PSP, the tau protein in the brain becomes pathological when it accumulates in abnormal clumps, causing cells to die. This causes an early loss of balance and falls, early cognitive problems, and gaze palsy (Hain, 2001). In PD, in contrast, the death of the neurotransmitter dopamine due to substantia nigra creates the characteristic symptoms of PD. In PSP, tremors are not always present, whereas tremors are a prominent sign of PD.

Case Study

Jeff was a 55-year-old successful businessperson who in 1996 began to exhibit some confusing symptoms, including loss of balance, unexplained falls, a peculiar gait, apathy, handwriting changes, and double vision. Jeff initially ignored his symptoms. When his career began to suffer, Jeff's family realized that something was amiss. Jeff sought medical attention and was diagnosed in 1998 with either PD or a gait difficulty. As his symptoms worsened, he developed a wide-eyed stare, a lack of facial expression, worsening double vision, speech and swallowing difficulties, problems processing information, and incontinence.

By 2000, Jeff was diagnosed with PSP, and his wife Heather stopped working to provide full-time care for Jeff at home. Jeff was unable to perform any activities of daily living, and he had to be bathed, dressed, and fed. Without total support to hold him up, walking became

nearly impossible. Communication was accomplished by the use of nods, thumbs up or down, and facial expressions that Heather learned to understand. Jeff heard and understood everything around him, but he was trapped inside a body that was failing him miserably. He opted for palliative care near the end. Jeff died of aspiration pneumonia in April 2005. A multidisciplinary approach was required to help care for Jeff during the 5 years between his diagnosis and his death.

Multidisciplinary Treatment Approaches

Successful management of a PSP patient involves the primary care physician, a neurologist, an ophthalmologist, a psychiatrist, a urologist, a nurse, a speech pathologist, occupational and physical therapists, a respiratory therapist, a nutritionist, a home health agency, clergy, support groups, a caregiver, social services, and hospice service (Bader & Littlejohns, 2004).

The neurologist assesses the patient and focuses on disease treatment. Dopamine and dopamine agonists may be prescribed; these may offer some short-term relief of the symptoms. According to Rajput & Rajput (2001), the four most commonly used medications in the treatment of PSP are carbidopa/levodopa, amantadine, imipramine, and selegiline; these result in the greatest improvement with the fewest side effects (Table 1). Carbidopa/levodopa inhibits the use of dopamine outside of the brain, which allows for more availability inside the brain. Dopamine is a neurotransmitter responsible for smooth motor movement, which is depleted in PD. Carbidopa/levodopa helps to replace missing dopamine in the brain, thereby reducing PD symptoms. Amantadine is an antiviral drug that may increase the release of dopamine in the brain; it is moderately effective for all PD symptoms. Imipramine is a tricyclic antidepressant whose action is to increase the performance of norepi-

nephrine and serotonin in nerve cells, thereby decreasing symptoms of depression and emotional incontinence. Selegiline is an antiparkinson agent that increases dopaminergic activity and decreases PD symptoms. Zolpidem (Ambien) has been reported to help parkinsonism and eye movements in PSP, but the benefit may be brief, and sedation is likely (Roth, 2001).

Occupational, physical, respiratory, and speech therapy consults may be considered. The goals of allied health involvement are to keep the patient mobile, sustain range of motion, incorporate breathing exercises to enhance lung capacity, and evaluate dysphagia that could place the patient at risk for aspiration.

A urologist may be helpful in ruling out any treatable causes of urinary incontinence. The nurse should inform the caregiver that incontinence may be disease related. Caregivers must be involved in decisions about bladder management, such as taking the patient to the toilet every 2 hours during waking hours, using adult diapers, and limiting fluid intake in the evening (Sjostrom, Holmberg, & Strang, 2002).

An ophthalmologist familiar with neurological diseases may notice quick eye movements, a slowing of visual pursuit (following a moving object), instability of fixation, a disturbance of convergence (which is needed for binocular focusing on close objects), blurred and double vision, and difficulty in reading; all of these compound gait difficulty (Liesegang, 1999). Fig. 2 depicts facial appearance and supranuclear gaze palsy in PSP.

PSP patients typically have a very low blinking rate (less than five per minute), so natural tears or lubricating ointments should be placed into dry eyes several times a day to avoid the risk of exposure keratitis. Some patients develop blepharospasms or eyelid apraxia. Botulinum toxin A (Botox) injections into the eyelid and the muscles surrounding the eye usually improve these conditions

Table 1. Medications Indicated for the Treatment of Progressive Supranuclear Palsy

| Drug | Indications | Dosage | Potential Adverse Effects |
|--|--|---|---|
| Carbidopa/levodopa (Sinemet) | Antidyskinetic; relieves Parkinson's symptoms | 25 mg–100 mg three times or more per day | Nausea, vomiting, confusion, orthostasis |
| Dopamine agonists Pramipexole (Mirapex) Pergolide (Permax) Bromocriptine (Parlodel) | Antidyskinetic; treats Parkinson's disease with or without levodopa therapy | 1.5 mg–4.5 mg per day 1 mg–4 mg per day 20 mg–80 mg per day | Nausea, vomiting, confusion, hallucinations |
| Amantadine (Symmetrel) | Antidyskinetic/antiviral; manages symptoms of Parkinson's disease and other extrapyramidal reactions | 100 mg twice per day | Lower extremity edema, livedo reticularis, confusion, dry mouth, hallucinations |
| Selegiline (Eldepryl) | Antidyskinetic; adjunct to carbidopa/levodopa | 5 mg–10 mg per day | Nausea, orthostasis, confusion, hallucinations |
| Tricyclic antidepressants Amitriptyline (Elavil) Imipramine (Tofranil) | Relieve depression and elevates mood | 25 mg–200 mg per day 25 mg–200 mg per day | Anticholinergic-type effects |
| Zolpidem (Ambien) | Antianxiety, sedative; hypnotic | 5 mg–10 mg per hour | Lethargy, drowsiness |

Note. From Mosby's Drug Guide for Nurses (4th ed.), by L. S. Roth, 2001, Englewood, CO: Skidmore-Roth.

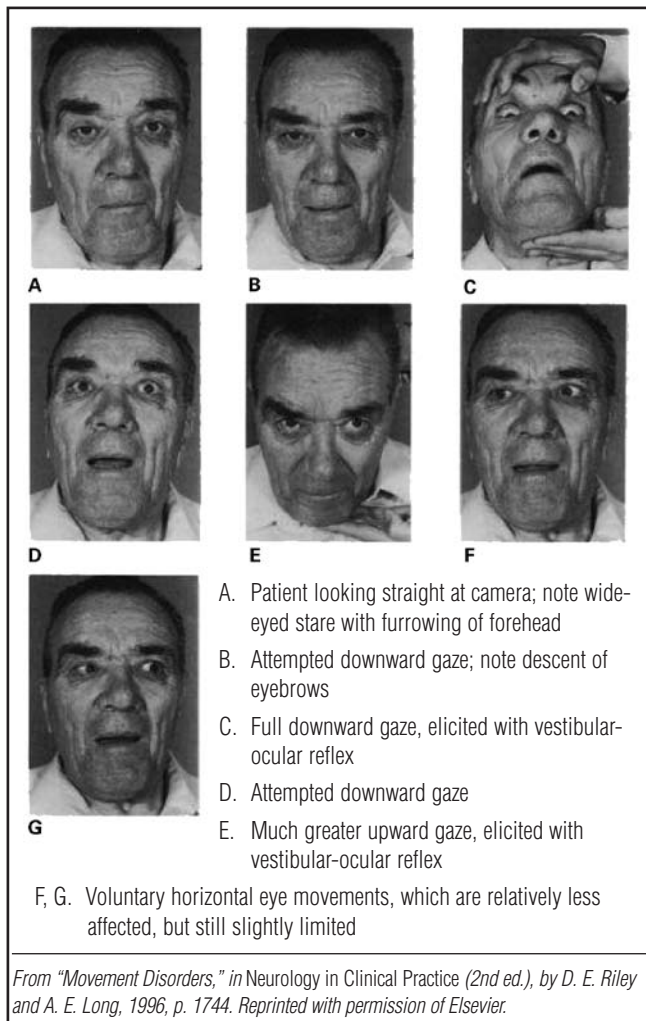


Fig 2. Facial appearance and supranuclear gaze palsy in progressive supranuclear palsy

(Hain, 2001). An ophthalmologist can provide visual aids such as prism lenses and tinted lenses (Solomon, 2000).

The PSP patient may exhibit personality and mood changes, ignore surroundings, and avoid social interactions. A psychiatrist can administer an antidepressant, provide counseling, and help the patient and the family cope with a reduction in the patient's self-concept related to loss of body functions, depression, and possible suicidal ideations. The PSP patient's behavior may become inappropriate; it may include sudden bouts of crying or laughing, often referred to as emotional incontinence (Mark, 2001). These behaviors may be disturbing to the caregiver because they seem to come out of nowhere. It is important that the caregiver understand that these behaviors are part of the underlying disease process (Barker, 2002). These changes are further complicated by the development of subcortical dementia, which occurs in both PD and PSP (Mark). The characteristics of this type of dementia are cognitive deficits (i.e., mental slowing, language difficulties, impaired memory) and alterations in personality (i.e., irritability, apathy, depression). This type

of dementia is less severe than is seen in Alzheimer's disease (Christensen, 1988).

The nurse can instruct caregivers to spend time with the patient to allow the patient to talk about his or her feelings. The nurse can refer both the patient and the caregiver for professional counseling if needed and can educate both the patient and the caregiver about the disease, its treatment, and its expected progression. If desired by the patient and the family, spiritual counseling with a minister, priest, or rabbi may need to be arranged. Intercessory prayers from others may be a form of comfort for the patient and the family.

Sleep disturbances can be associated with PSP due to cell damage in the area of the brain that regulates the sleep cycle. Symptoms include insomnia, frequent awakening, sleep apnea, and periodic limb movement during sleep. On the other hand, the patient may exhibit hypersomnia (i.e., excessive sleep). The PSP patient may need to undergo a comprehensive sleep study to characterize the sleep disturbance so the appropriate treatment can be given. The nurse should instruct the patient and the caregiver to provide a quiet area away from noise, eliminate caffeinated beverages before bedtime, increase outside time, and decrease daytime naps to promote better nighttime rest. For sleep apnea, a respiratory therapist can provide instruction on the use of continuous positive airway pressure, which can result in improved sleep. A variety of drugs is available to treat sleep apnea; the neurologist or primary care provider can prescribe them.

The nurse should instruct the caregiver to take the patient's temperature daily and should educate the caregiver about the signs and symptoms of aspiration pneumonia. The nurse and respiratory therapist should auscultate lung sounds on a regular basis. An elevated temperature could indicate that the patient has aspirated and may require evaluation by a primary care physician. The dysphagia that accompanies PSP creates a weakened cough, which is a significant factor in patients being unable to clear their lungs adequately.

Physical therapists familiar with neurological disorders should be consulted because of the frequency of falls, which can cause serious injury. The physical therapist can provide gait training; suggest preventive measures aimed at avoiding or buffering falls, such as the use of a transfer belt and the two-person assist as the patient becomes more physically impaired; suggest in-home safety measures, such as grab bars for the hallways and bathrooms; and determine the appropriate types of walking aids and a wheelchair, when the time comes. The caregiver and the patient may see the need for a wheelchair as a sign that the disease is progressing or that they are giving in to the disease. The caregiver and the patient should be assured that prevention of injury is most important and that use of a wheelchair may allow for a wider range of activity (Tetrud, 2000). The physical therapist can give instruction for range-of-motion exercises, both active and passive, to keep the limbs

flexible and help keep the patient mobile. The nurse should instruct the caregiver to provide a clear pathway for ambulation because the paralysis of the eye muscles may prevent the patient from seeing downward toward the floor. Instruction should be given for positioning and padding to prevent skin breakdown and for keeping the skin clean and dry. Eventually, the home may need modifications to accommodate the patient's declining state.

The PSP patient may develop severe dysarthria and swallowing problems. These problems are linked to neuronal damage within the brainstem and its connection to higher brain centers. Impaired muscles involved in speech and swallowing are a mixture of slowed reflexes and dystonia. Such impairment places the patient at risk for choking and aspiration (Verdun, 2000). To reduce the risk of aspiration and improve caloric intake, the caregiver should

- use a plate with a rim so that food will stay on the plate
- use a spoon with a modified grip
- place the chin in a downward or neutral position to close off the airway during swallowing
- place the plate on a book so the food is in the line of vision
- eliminate distractions during eating
- learn the Heimlich maneuver for use in the event of choking
- have suction equipment available for clearing the airway.

The speech therapist can also address communication difficulties. Slurred or garbled speech is not uncommon in the PSP patient. The speech therapist can provide a communication board and instruct the patient to speak slowly and teach those trying to communicate with the PSP patient to allow adequate time for responses.

If it is determined that the patient is at risk for aspiration, a comprehensive examination of swallowing should be performed; this involves fluoroscopy and video recording of the image as foods or liquids are being swallowed and delivered into the stomach. A nutritionist can offer advice on the food textures best tolerated to prevent aspiration. Adding thickeners to liquids may become necessary. If the patient cannot tolerate swallowing without risk of aspiration, a percutaneous endoscopic gastrostomy tube should be placed in the patient's stomach for direct nutrition. The nurse can educate the caregiver about tube feedings and positioning the patient to promote digestion and prevent aspiration. The need for tube feedings is another indication of disease progression; the patient and the caregiver must decide whether a tube should be placed. Stool softeners should be added to the daily regimen to permit an easier evacuation of the bowel (Verdun, 2000).

If the patient is hospitalized, consistent nurse assignment can provide valuable continuity of care. Consistent nurse assignment reduces the number of caregivers and the level of frustration for the patient and the family.

Home health care may be needed to assist with bathing, feeding, mobility, and other activities of daily living. The nurse who is knowledgeable and experienced in treating PSP can use these times to teach about medications, wound care, stress management, and activities of daily living. The home healthcare nurse is able to provide case management and care coordination by calling the primary care physician and discussing patient needs so physician orders can be written and acted upon. If the patient is spending too much time in bed, the nurse may believe that the patient should be seen by a physical therapist. Home health care, skilled nursing facility care, and hospice care should be discussed with the patient and the family early in the disease course.

A PSP support group can be a valuable resource the patient and the caregiver can tap into for support and other needs. Support groups can help families know they are not alone in their difficult struggle (Golbe, 2000). A list of PSP support groups is available on the Internet (at www.psp.org) or can be obtained by writing to the Society for Progressive Supranuclear Palsy, Woodholme Medical Building, 1838 Green Tree Road, Suite 515, Baltimore, MD 21208; SPSP@erols.com. The Society for Progressive Supranuclear Palsy is a nonprofit organization dedicated to promoting and funding research into PSP. Its mission is to "increase awareness of progressive supranuclear palsy, advance research toward a cure, educate health professionals, and provide support, education, and hope for persons with PSP and their families" (Society for PSP, n.d.).

The patient and the family should be educated about the progression and course of PSP early in its course. Advance directives and living wills are important issues that the patient and the family should address before cognitive function becomes impaired. PSP patients should be given the opportunity to decide what supportive treatment they desire when the end is near or when they are no longer capable of communicating their wishes. End-of-life care should be discussed early and should include whether the patient would want to be resuscitated or placed on a ventilator. The patient should complete an advance directive early in the disease course so that difficult, guilt-producing decisions do not pass to a family member.

End-of-life decisions may involve spiritual or professional support. Hospice services provide care for patients with terminal illnesses and usually are covered by Medicare. Depending on the patient's condition, hospice care may be offered in the home, in a nursing home, or in a hospice residential facility. Most of the time family members (e.g., a spouse) are able to stay with their loved one 24 hours a day, if desired. Hospice care is for the terminally ill who are believed to have less than 6 months to live. The care provided allows a caregiver time away from the tedious care the PSP patient requires. Hospice nurses comfort and support the family during the final journey their loved one must take.

Summary

The PSP journey is challenging and difficult, without any hope of cure. The informed nurse can provide valuable supportive resources to the family. Nurses can direct the patient and the caregiver to people who are also dealing with the daily struggles, uncertainties, and consequences PSP produces. Nurses can be instrumental in the care of the PSP patient through their knowledge about the disease and can communicate to the caregiver and the patient as needs present themselves. Nurses can help the patient and the family obtain the care and support needed during this painful journey.

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