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The Role of Nurses in Parkinson's Disease

Michelle Hyczy de Siqueira Tosin and
Beatriz Guitton Renaud Baptista de Oliveira

Abstract

Background: The complexity of motor and nonmotor symptoms in patients with Parkinson's disease (PD) requires multidisciplinary health actions.

Objective: To describe the role of nurses as members of multidisciplinary teams tasked with treatment of motor and nonmotor symptoms and provide nursing protocols for the care of patients with Parkinson’s disease.

Methods: Analysis of the main diagnoses, outcomes, and ICNP® interventions identified by cross-mapping empirical evidence described in 2123 nursing documents and data from medical records of patients with Parkinson’s disease in the specialized rehabilitation program at the Sarah Network of Rehabilitation Hospitals in Brazil. The protocols were based on scientific evidence and international recommendations.

Results: Clinical nursing protocols were developed based on a standardized nursing language of diagnoses, outcomes, and interventions focused on motor and nonmotor symptoms and principles of rehabilitation.

Conclusion: These protocols are expected to guide the clinical reasoning of nurses for comprehensive care of patients with Parkinson’s disease and their families.

Keywords: Parkinson's disease, nursing role, specialist nurses, rehabilitation nurses, multidisciplinary teams

1. Introduction

Parkinson’s disease (PD) affects approximately 1% of women and men worldwide, especially those over the age of 60 [1]. It is a multisystem and neurodegenerative disease with genetic
and environmental factors that result in deficits in the production of neurotransmitters, including dopamine [2].

PD is diagnosed through a clinical evaluation of motor symptoms; the presence of nonmotor symptoms combined with the current lack of cure reflects the complexity of health care, which aims to control symptoms in order to maintain the quality of life of the patient and family [3–5].

Currently, health system remodelling is observed for the development of guidelines with multidisciplinary actions that address the complexity of care [6, 7].

Enabling health professionals with specific areas of knowledge allows standardization of behaviors that will minimize the challenges of interprofessional collaboration.

In this context, nursing care of patients with PD must focus on the biopsychosocial context and must be based on ethical, legal, operational, and theoretical assumptions of the profession for health promotion, prevention of complications, treatment, and rehabilitation [8].

Thus, the clinical reasoning of nurses should be based on the pathophysiology of the disease as well as the nursing process and should be structured in a standardized language for communication with other professionals on the team. Standardization of the nursing language enables communication and comparison of data between different contexts, countries, and languages, and maximizes dissemination of knowledge from clinical data [9, 10].

Among existing nursing terminologies is the International Classification for Nursing Practice (ICNP®), which was developed by the International Council of Nurses and is integrated into the family of international classifications of the World Health Organization [9]. This terminology allows development of terminological subsets of diagnoses, outcomes, and interventions targeted to specific areas of clinical nursing practice.

2. The role of nurses in Parkinson’s disease

Research has shown increasing specialization among nurses who care for patients with PD [11–13]; thus, knowledge of the pathophysiology of this disease is arguably an important starting point for vocational training [14]. Based on this, we sought to hierarchically organize the major motor and nonmotor symptoms of PD using evidence gathered from the literature (Figure 1).
The symptoms of PD are divided into motor and nonmotor; each of these classifications contains various other signs and symptoms related to both the neurodegenerative disease process itself as well as multifactorial causes. Thus, hierarchical organization of symptoms is not an easy task, and various descriptions have been proposed to facilitate understanding of the pathophysiology of the disease [15–18]; however, none of them have structured the symptoms into an organizational chart.

Our research on nursing diagnoses, outcomes, and interventions was based on this chart.

2.1. Nursing diagnoses/outcomes and interventions of ICNP® for patients with Parkinson’s disease in rehabilitation

We analyzed 2123 nursing documentations from 352 medical records of patients with PD who participated in a rehabilitation program at a specialized centre in Rio de Janeiro, Brazil, from May 2009 to March 2014. From these documents, empirical evidence regarding nursing diagnoses, outcomes, and interventions was extracted. These dates were cross-mapped with ICNP® 2013 and validated by judges (nurses) to build a terminological subset of ICNP® for patients with PD in rehabilitation [19].

The diagnoses, outcomes, and interventions were divided into categories including motor symptoms, nonmotor symptoms, and principles of rehabilitation, as shown in Figure 2.

Greater variability was observed in nursing diagnoses, outcomes, and interventions related to nonmotor symptoms of Parkinson’s disease; in general, it appears that nurses work in a comprehensive and communicative manner with other professionals on multidisciplinary teams.
### Diagnoses and Outcomes ICN® 2013 release

#### Motor Symptoms and Self Care and Safety

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Interventions ICN® 2013 release</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tremor</td>
<td>Teaching the Patient to Self Care</td>
</tr>
<tr>
<td>Hypoactivity</td>
<td>Teaching about Feeding Device</td>
</tr>
<tr>
<td>Impaired Ability To Communicate By Talking, Impaired Ability To Transfer, Impaired Bed Mobility, Impaired Mobility, Impaired Psychomotor Activity, Slurred Speech</td>
<td>Teaching Adaptation for Communication, Teaching the Patient to Applying Safety Device to Self Care, Teaching the Family to Obtaining a Caregiver, Teaching the Patient About House Safety, Teaching the Family About Fall Prevention, Teaching about Treadmill Technique, Referring To Physical Therapy, Teaching the Patient About Rehabilitation, Teaching the Group About Disease and About Rehabilitation, Teaching About Health Seeking Behaviour, Referring the Patient and Family to the Group to Teaching About Disease and Teaching About Rehabilitation</td>
</tr>
<tr>
<td>Self Care Deficit</td>
<td>Referring the Patient and Family to the Group to Teaching About Disease and Teaching About Rehabilitation</td>
</tr>
<tr>
<td>Impaired Ability To Bath, Impaired Ability To Dress, Impaired Ability to Feed Self, Impaired Ability To Groom, Impaired Ability To Perform Hygiene</td>
<td></td>
</tr>
<tr>
<td>Impaired House Safety</td>
<td>Referring the Patient and Family to the Group to Teaching About Disease and Teaching About Rehabilitation</td>
</tr>
<tr>
<td>Risk For Fall, Risk For Fall Injury</td>
<td></td>
</tr>
<tr>
<td>Impaired Walking</td>
<td></td>
</tr>
<tr>
<td>Wheelchair Mobility</td>
<td></td>
</tr>
<tr>
<td>Lack Of Knowledge Of Disease</td>
<td></td>
</tr>
</tbody>
</table>

#### Non-motor Symptoms - Disautonomic - Urigenous

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Interventions ICN® 2013 release</th>
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</thead>
<tbody>
<tr>
<td>Impaired Urinary System Process</td>
<td>Teaching the Patient about the Urinary System Process, Evaluating Genitourinary Status, Assessing Bowel Status, Measuring Fluid Intake, Measuring Fluid Output, Assessing Urinary Retention Using Ultrasound, Teaching for Urination Controlling, Teaching Self Catheterisation, Referring to Interprofessional Team, Catheterising Bladder to Collecting Specimen of Urine, Collecting Specimen of Urine</td>
</tr>
<tr>
<td>Urge Incontinence, Urinary Incontinence</td>
<td></td>
</tr>
<tr>
<td>Risk For Urine Infection, Urinary Tract Infection</td>
<td></td>
</tr>
<tr>
<td>Impotence</td>
<td></td>
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</tbody>
</table>

#### Non-motor Symptoms - Disautonomic - Gastrointestinal

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Interventions ICN® 2013 release</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impaired Gastrointestinal System Process</td>
<td>Teaching the Group About Eating Pattern, Teaching the Patient About Eating Pattern, Collecting Specimen of Faeces, Teaching the Group About Fluid Intake, Teaching the Patient About Fluid Intake, Teaching the Group about Gastrointestinal System Process, Teaching the Patient about Gastrointestinal System Process</td>
</tr>
<tr>
<td>Constipation, Impaired Swallowing, Nausea, Perceived Constipation, Bowel Incontinence, Abnormal Salivation</td>
<td></td>
</tr>
</tbody>
</table>

#### Non-motor Symptoms - Disautonomic - Cardiovascular

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Interventions ICN® 2013 release</th>
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<tbody>
<tr>
<td>Hypotension</td>
<td>Measuring Blood Pressure, Teaching Measuring Blood Pressure, Teaching About Disease, Referring to Interprofessional Team</td>
</tr>
<tr>
<td>Peripheral Oedema</td>
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</tbody>
</table>

#### Non-motor Symptoms - Sleep Disorders

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Interventions ICN® 2013 release</th>
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<tbody>
<tr>
<td>Impaired Sleep</td>
<td>Referring to Interprofessional Team</td>
</tr>
<tr>
<td>Nightmare, Somnolence</td>
<td>Teaching About Sleep, Teaching About Disease</td>
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</tbody>
</table>

#### Non-motor Symptoms - Neuro Behavioral

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<tr>
<th>Disorder</th>
<th>Interventions ICN® 2013 release</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impaired Mood Equilibrium</td>
<td>Facilitating the Family Ability to Participate in Care Planning</td>
</tr>
<tr>
<td>Anxiety, Depression, Chronic Sadness, Impaired Adaptation, Impaired Coping</td>
<td>Referring to Interprofessional Team, Teaching Family Support, Teaching About Disease</td>
</tr>
<tr>
<td>Impaired Cognition</td>
<td></td>
</tr>
<tr>
<td>Impaired Memory, Disorientation, Delirium, Hallucination, Agitation, Fear, Crying, Impaired Behaviour, Low Initiative</td>
<td></td>
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</tbody>
</table>

#### Non-motor Symptoms - Sensory

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Interventions ICN® 2013 release</th>
</tr>
</thead>
<tbody>
<tr>
<td>Altered Perception</td>
<td>Referring to Interprofessional Team, Teaching About Managing Withdrawal Symptoms, Teaching the Patient About Disease, Teaching the Patient About Eating Pattern</td>
</tr>
<tr>
<td>Dizziness, Fatigue, Pain, Weakness</td>
<td></td>
</tr>
<tr>
<td>Body Weight Problem</td>
<td></td>
</tr>
</tbody>
</table>

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2.1.1. Nursing diagnoses and outcomes related to motor symptoms, self-care, and safety

The motor symptoms of PD include resting tremor, muscle rigidity, bradykinesia, and postural instability. These symptoms were described in 1817 in a monograph by James Parkinson and are currently considered the cardinal signs for clinical diagnosis of the disease [20]. In the ICNP®, these symptoms are represented by the diagnoses and outcomes tremor, hypoactivity, and risk for fall.

2.1.1.1. Tremor

Resting tremor affects up to 75% of the patients with PD. It is characterized by involuntary tremors of the hands, lips, and jaw 4–6 Hz in intensity. They occur at rest but may worsen in stressful situations or while walking and stopping when actions are performed by the affected limb [21].

2.1.1.2. Hypoactivity

Muscle rigidity and bradykinesia are represented in the ICNP® by the term hypoactivity. This is a broad term that can be considered a syndrome that encompasses several specific terms corresponding to this diagnosis.

Muscle rigidity is characterized by disharmony of the flexor and extensor muscles, compromising joint mobility by making them rigid. Rigidity may lead to motor symptoms, among other problems, evidenced by reduced handwriting capacity, which is referred to as a micrograph in PD and is represented in the ICNP® by the term impaired psychomotor activity. Its prevalence in this population ranges from 10 to 63.2% [22].

Bradykinesia is defined as difficulty and slowness in initiating movement. It may affect the ability to perform simultaneous tasks and slow reaction times [14] and is associated with other disorders, such as decreased arm balance, hypomimia, and hypokinetic dysarthria, which are encompassed by the ICNP® terms slurred speech and impaired ability to communicate by talking.

Decreased arm balance occurs asymmetrically in the early stages of PD [3]. Hypomimia is defined as the reduction of voluntary orofacial movements that result in reduced facial
expression in patients with PD. These symptoms may be related to bradykinesia [3], as well as other cognitive disorders that impair emotional recognition of facial expression [23].

Lack of motor control speech, called hypokinetic dysarthria, affects about 90% of patients with PD. It is characterized by deficits in vocalization related to the variation in the height and intensity during speech [24–26]. Its pathophysiological mechanisms have been studied, and there is empirical evidence that in addition to motor mechanisms associated with bradykinesia, cognitive mechanisms of self-perception, and self-monitoring of speech are involved [24, 25].

2.1.1.3. Risk for fall

Postural instability is related to the loss of postural reflexes, which occurs in the later stages of PD. Instability is measured by retropulsion or propulsion tests. Postural instability is defined as more than two steps backward or forward, or when there is an absence of postural response. This symptom is the most common cause of falls and contributes significantly to the risk of fractures [17].

2.1.1.4. Lack of knowledge of disease or self-care deficit

Knowledge about the disease and its symptoms promotes better patient and family management of limitations. The role of the family, both to encourage maximum independence in the patient’s activities of daily living and to provide compensatory care for the deficits, is not an easy task. Thus, identification of these diagnoses is considered the starting point of the rehabilitation program.

2.1.2. Nursing diagnoses and outcomes related to nonmotor symptoms

The hierarchical organization of nonmotor symptoms includes disautonomic (urogenital, gastrointestinal, cardiovascular, and thermoregulation), sleep, neurobehavioral (mood, cognition, and psychiatric), sensory, and other subdivisions. In the ICNP®, these symptoms are represented by diagnoses and results, including impaired urinary system process, impotence, impaired gastrointestinal system process, hypotension, impaired sleep, impaired mood equilibrium, impaired cognition, and altered perception.

2.1.2.1. Impaired urinary system process

Bladder urogenital symptoms may be present in up to 96% of the patients with PD; they are characterized as storage symptoms (urgency, urge incontinence, increased daytime urinary frequency above eight micturitions, and two or more nocturnal micturitions) and emptying symptoms (hesitancy, decreased, or intermittent urine stream, sensation of incomplete emptying, and urinary retention) [27, 28].
2.1.2.2. Impotence

Sexual dysfunctions are the result of neurodegeneration and include difficulty with erection, loss of libido, and lack of orgasm. However, patients may also experience the opposite symptoms, mainly related to dopamine agonist therapy, which are characterized by obsessions or compulsions related to sex [15, 16].

2.1.2.3. Impaired gastrointestinal system process

In the ICNP® the diagnosis or outcome impaired gastrointestinal system process is also considered a broad term that may include specific diagnoses related to the same problem.

In PD, degenerative impairment of the vagus nerve, which is responsible for nervous control of the esophagus, stomach, and intestine via the parasympathetic and spinal cord system, causes dysfunction of the motility of the entire gastrointestinal tract, resulting in the following symptoms: oropharyngeal dysphagia (impaired swallowing), gastric stasis, constipation or slow motility (constipation), and sphincter dyssynergism and drooling (abnormal salivation) related to the decrease or absence of the swallowing reflex, which leads to the accumulation of saliva in the mouth [29, 30]. A review study also revealed that drooling may be related to both increased saliva production and slowed orofacial movements [31].

2.1.2.4. Hypotension

Orthostatic hypotension can result in dizziness during position changes (particularly to a standing position), fatigue, and even fainting and falls. This symptom may be subtle in early PD and does not necessarily worsen with disease progression [15, 16]. It affects about 40–60% of patients with PD, but only 20% may be symptomatic [32]. Supine hypertension, described in the organizational chart, is a sign recently debated among scientists who are in the early stages of studies on the pathophysiological mechanisms [33]. What we do know is that this symptom usually coexists with hypotension, both related to changes in the circadian rhythms of blood pressure [34].

2.1.2.5. Impaired sleep

Sleep disorders are very prevalent in patients with PD and have been studied extensively by scientists. Their pathophysiology is complex and results in overall impairment of the sleep–wake cycle [35, 36]. These disorders may negatively affect many biological functions and enhance associated symptoms such as cognitive, neuropsychiatric, and fatigue and affect quality of life of the patient/family [37].

2.1.2.6. Impaired mood equilibrium

Among neurobehavioral symptoms, mood disorders are present in 40–70% of patients with PD. The pathophysiological mechanisms of neurotransmitter regulation are demonstrably involved in the causes of depression (depression), apathy (low initiative), and social isolation.
(impaired socialisation) [16, 38, 39]. However, it is important to consider the impact of other symptoms, including motor symptoms, on the mood of patients with this disease [39].

2.1.2.7. Impaired cognition

The cognitive (minimum cognitive impairment and dementia) and neuropsychiatric (hallucination, delusion, illusion, and impulse control disorder) impairments associated with PD also have a complex pathophysiology; the manifestations vary in severity, tending to worsen with disease progression [39]. They deserve special attention from multidisciplinary health teams as they may endanger patient’s health and overwhelm patient’s families and caregivers [40].

2.1.2.8. Altered perception

Sensory symptoms directly related to the pathophysiology of PD include hyposmia and anosmia, ageusia, pain, and paresthesia [15, 16, 39, 41]. Fatigue has also been recently studied as an additional symptom. The prevalence of altered perception ranges from 33 to 58% and may be related to depression and apathy, sleep changes, cardiovascular dysfunction, motor symptoms, drug use, or insufficient blood flow in the frontal lobe [41].

2.1.2.9. Body weight problem

One review study described weight loss as a very common symptom in patients with PD, who have low body mass indexes compared with those of healthy controls matched by sex and age. The etiology has been described as multifactorial, related to motor symptoms, changes in eating habits, and medication use (especially levodopa) in addition to being potentially related to physiological changes in the neurodegenerative process [39].

2.1.3. Nursing diagnoses related to the principles of rehabilitation

Most of the symptoms of Parkinson’s disease can be controlled by drugs, which make it necessary to assess patient adherence to treatment.

Drug treatment regimens for PD are complex since the variability in symptoms denotes the necessity of drug combination subdivided into smaller doses over 24 hours [42]. While the indication and prescription of drugs are obviously performed by physicians, nurses play an important role in treatment adherence.

There are several reasons why patients may not adhere to drug treatment, which are classified as intentional and unintentional [43].

2.1.3.1. Lack of knowledge of medication regime and negative response to medication

One of the unintentional reasons for compromised treatment adherence is a lack of patient’s understanding on the importance of treatment. Patients often believe that drug therapy will cure their symptoms, not realizing that the therapy is aimed at reducing their severity in order to promote better quality of life. Moreover, the presence of motor fluctuations and complica-
tions of the therapy itself promotes disbelief regarding the effectiveness of treatment, which in turn contributes to nonadherence.

2.1.3.2. Medication supply deficit and impaired ability to manage medication regime

The factors associated with unintentional nonadherence are often a result of poor access to treatment because of the high cost of medications. Likewise, unintentional nonadherence may result from the patient’s inability to self-manage their medications. This inability may result from cognitive deficits, education level, and cultural, religious, and behavioral factors.

Thus, accurate assessment of the causes of nonadherence to drug therapy in patients with PD underscores the importance of the nursing care plan, which therefore will complement multiprofessional health actions focused on the patient, promoting improvement of their quality of life through better control of their symptoms.

2.1.3.3. Impaired quality of life and socialisation, inadequate routine, and caregiver stress

The impact of the disease on routine activities, socialization, and quality of life of patients who are affected by the symptoms of PD may compromise their independence in performing the activities of daily life as well as their professional lives. In a ripple effect, these problems will result in individual, family, and social losses [13, 44, 45].

2.1.4. Nursing interventions related to nonmotor and motor symptoms and principles of rehabilitation

2.1.4.1. “Teaching” interventions

Among the main nursing interventions mapped, those related to educational practice and used by nurses as the main tool for health promotion were of particular importance.

Health education is considered a change of strategy in care models and is an alternative used to improve the quality of health and life of the population through increased understanding of health and disease [46].

Health promotion actions in neurological rehabilitation facilitate recovery and adaptation to the limitations imposed by disabilities on individual and contextualized bases. These actions mainly focus on functional, motor, psychosocial, and spiritual aspects [46]. Therefore, it is imperative for nurses to establish bonds with patients and their families when providing orientations in order to promote facilitation and implementation of learning. In this coparticipatory relationship, the focus is on personal autonomy for affirmation of the principles of citizenship and democracy, with the aim to improve health status [46].

2.1.4.2. “Referring” interventions

We highlight the interventions that reveal the important role played by interprofessional nurses, which are based on the best evidence to identify symptoms and collaborate with the team through discussion and referral of patients for evaluation. These interventions show that
nurses are often the connection point with other members of the professional team in order to provide holistic care [47].

2.2. Nursing protocols for patients with Parkinson’s disease

Accurate identification of nursing diagnoses is essential for clinical practice since it enables proper planning of care, implementation of interventions, and efficient evaluation of the results. Therefore, it is necessary to use diagnostic support tools prepared in accordance with institutional settings and the complexity of patient’s conditions. These tools should still be based on the best clinical evidence and recommendations described in the scientific literature.

This subchapter presents several nursing assessment protocols in the context of the activities of daily living, gastrointestinal and genitourinary function, sleep disorders, hypotension, and medication adherence.

Nursing assessment for daily life activities in patients with Parkinson’s disease

Date: _____/_____/_______

Personal data

Name: _______________ Age: ___ Sex: ( ) Female ( ) Male Family/Caregiver: ________________

Date of onset of symptoms of Parkinson’s disease: _______________________________________

Concomitant diseases: ______________ Daily medications: __________________________________

Housing conditions and family support

( ) Own residence ( ) Rented residence ( ) Residence of relatives/friends ( ) Institutionalized

( ) House with a single level ( ) House with multiple levels ( ) Stairs with unilateral handrail ( ) Stairs with bilateral handrail ( ) Stairs without handrail ( ) No stairs ( ) Apartment with elevator ( ) Apartment with no elevator

Adaptation at residence? ( ) yes ( ) no Where?________________________________________

( ) Live alone ( ) Live with whom? _______________________ Family/caregiver support? ( ) Yes ( ) No

Routine

Describe your routine before the Parkinson’s disease diagnosis:_____________________________
________________________________________________________________________________

Describe your current routine:________________________________________________________
________________________________________________________________________________

Schwab and England activities of daily living [48]

100%-Completely independent. Able to do all chores without slowness, difficulty, or impairment. Essentially normal. Unaware of any difficulty.
90%-Completely independent. Able to do all chores with some degree of slowness, difficulty, and impairment. Might take twice as long. Beginning to be aware of difficulty.

80%-Completely independent in most chores. Takes twice as long. Conscious of difficulty and slowness.

70%-Not completely independent. More difficulty with some chores. Three to four times as long in some. Must spend a large part of the day with chores.

60%-Some dependency. Can do most chores but exceedingly slowly and with much effort. Errors; some impossible.


40%-Very dependent. Can assist with all chores, but few alone.

30%-With effort, now and then does a few chores alone or begins alone. Much help needed.

20%-Nothing alone. Can be a slight help with some chores. Severe invalid.

10%-Total dependent, helpless. Complete invalid.

0%-Vegetative functions such as swallowing, bladder, and bowel functions are not functioning. Bed-ridden.

MDS-UPDRS Part II scale can be applied

<table>
<thead>
<tr>
<th>Nursing diagnoses</th>
<th>Nursing interventions</th>
</tr>
</thead>
</table>

Evaluation of patient’s ability to perform activities of daily life is complex because it involves environmental aspects (usually related to the accessibility of the house), family support or caregivers, and commitment to the routine. The assessment should be based on standardized scales, such as the Unified Parkinson’s Disease Rating Scale (UPDRS) Part II and the Schwab and England activities of daily living scales widely used in research and clinical practice [48–50].

**Nursing assessment of bowel status in patients with Parkinson’s disease**

Date: _____/_____/_______

**Personal data**

Name: ______________ Age: ____ Sex: ( ) Female ( ) Male Family/Caregiver: ____________________________

Onset date of symptoms of PD: ____________________________________________________________

Concomitant diseases: ________________________________________________________________

Daily medications: ____________________________________________________________________

**Digestive system function**

Main complaint: _______________________________________________________________________

Onset of symptoms: _____ Presence of symptoms before PD: ( ) Yes ( ) No How many years? ______

Background surgical gastrointestinal tract: ( ) Yes ( ) No What: _______________________________

Regular monitoring by gastroenterologist: ( ) Yes ( ) No

Feel the urge for bowel movement? ( ) Several times/day ( ) Daily ( ) Every 1-2 days ( ) Every 1-__ days
Flatulence? ( ) Never ( ) Sometimes ( ) Often ( ) Always

Fecal Incontinence? ( ) Never ( ) Sometimes ( ) Often ( ) Always

When does fecal incontinence occur? (You can mark more than one answer)

( ) During a diarrheal episode ( ) Every time because of the urgency ( ) When coughing and rising ( ) Unexpectedly

**Rome III Criteria [51]**

Must include two or more of the following:

( ) Straining during at least 25% of defecations
( ) Lumpy or hard stools in at least 25% of defecations
( ) Sensation of incomplete evacuation for at least 25% of defecations
( ) Sensation of anorectal obstruction/blockage for at least 25% of defecations
( ) Manual maneuvers to facilitate at least 25% of defecations (e.g., digital evacuation)

( ) Fewer than three defecations per week

* Criteria fulfilled for the last three months with symptom onset at least six months prior to diagnosis

**Bristol scale**

In most evacuations, what is the characteristic of the feces? ___________________________

**Devices for evacuation**

<table>
<thead>
<tr>
<th>Complications</th>
</tr>
</thead>
<tbody>
<tr>
<td>( ) External device for evacuation ( ) Toilet</td>
</tr>
<tr>
<td>( ) Diapers</td>
</tr>
<tr>
<td>( ) Have you ever undergone intestinal cleansing</td>
</tr>
<tr>
<td>( ) Laxatives/or antigas medication Which? ( ) Other: ___________________________</td>
</tr>
</tbody>
</table>

How often do you use laxative or antigas medication? ( ) > 1×/month ( ) > 1×/week ( ) > 1×/day

**Complications**

( ) Diverticulitis
( ) Hernia
( ) Volvulus
( ) Other: ___________________________

**Mobility**

Are you dependent on others for evacuation: ( ) Yes ( ) No

Transfer to lavatory seat: ( ) Independent ( ) Dependent

Locomotion: ( ) Without assistance and without support ( ) Locomotion assistance

**Self-care**
Dependant on others to eat and/or drink ( ) Yes ( ) No Why? ________________ Daily water intake ______
Low tolerance for liquids? ( ) Yes ( ) No Do you have adipsia? ( ) Yes ( ) No
( ) Dysphagia for liquids ( ) Dysphagia for solids ( ) Need to change food consistency

Food routine:
Breakfast: _________________________________________________________________________
Snack: ___________________________________________________________________________
Lunch: ___________________________________________________________________________
Snack: ___________________________________________________________________________
Dinner: ___________________________________________________________________________
Supper: __________________________________________________________________________

Mental function
Dependant on others? ( ) Yes ( ) No Why? ________________
Cognitive disorders? ( ) Yes ( ) No What: ________________
Behavioral disorders? ( ) Yes ( ) No What: ________________

Housing conditions
Easy access to the bathroom: ( ) Yes ( ) No
Modifications made to bathroom/home: ( ) Yes ( ) No What: ________________
Modifications to the bathroom/home are required: ( ) Yes ( ) No What: ________________

Community, social, and civic life
Impact on labour activities related to constipation ( ) Yes ( ) No ( ) Not applicable
Impact on leisure activities related to constipation ( ) Yes ( ) No
Impact on quality of life related to constipation ( ) Yes ( ) No
Have financial resources for modifications, medicines, and intestinal devices? ( ) Yes ( ) No

Physical examination
Inspection:
- Skin: _________________________________________________________________________
- Contour: ( ) Plan ( ) Excavated ( ) Globular
- Symmetry: ______________________________________________________________________
Abdominal auscultation (Intestinal noises): ( ) 2 to 5/min ( ) < 2 to 5/min ( ) > than 2 to 5/min
Percussion: ( ) Tympanic ( ) Hypertympanic ( ) Massive Quadrant: ______________________
Abdominal palpation: __________________________

Nursing diagnoses    Nursing interventions
Evaluation of intestinal symptoms in patients with PD focuses on constipation, which is the main problem. However, it is important to assess other symptoms such as fecal incontinence and related factors that enhance intestinal symptoms such as changes in mobility/accessibility, swallowing, and cognitive function, among others. The Rome III criteria and the Bristol Stool Scale are recommended tools for evaluation of constipation [51, 52].

Genitourinary nursing assessment in patients with Parkinson’s disease

Date: ______/_____/_____

Personal data
Name: ______________ Age: ___ Sex: ( ) Female ( ) Male Family/Caregiver: _______________

Date of onset of symptoms of Parkinson’s disease: __________________________________________

Concomitant diseases: ________________________________________________________________

Daily medications: ___________________________________________________________________

Genitourinary, reproductive, and bowel functions

Number of pregnancies and births: _________ ( ) Vaginal birth ( ) Caesarean ( ) Abortions: _________

Main complaint: ___________________________________________________________________

Onset of symptoms: _________________ Presence of symptoms before PD: ( ) Yes ( ) No

History of uro/gynaecology surgery: ( ) Yes ( ) No Which: ___________________________________

Regular monitoring by urologist/gynaecologist: ( ) Yes ( ) No

Bladder control ( ) Yes ( ) No Urinary Urgency ( ) Yes ( ) No Urinary Loss ( ) Yes ( ) No

Intestinal function: ( ) Regular ( ) Irregular Frequency: _____________________________________

Do the bladder symptoms impact sexual capacity ( ) Yes ( ) No How? _________________________

Storage symptoms
( ) Urinary Urgency ( ) Urge Incontinence
( ) Stress incontinence ( ) Enuresis
( ) Increased frequency of diurnal urinary
( ) Nocturia. How many times?________

Voiding symptoms
( ) Decreased urinary stream ( ) Hesitation
( ) Urinary flow intermittent ( ) Voiding Effort
( ) Sensation of incomplete emptying ( ) Dysuria
( ) Dripping ( ) Initial Dripping ( ) Terminal Dripping

Complications of urinary tract
( ) Urethral fistula
( ) Cystocele
( ) Prostatic hyperplasia
( ) Urethral Stenosis
( ) Hydronephrosis D/E
( ) Urethral diverticulum

Urinary devices
( ) Toilet ( ) urinals bedpans
( ) Indwelling catheter
( ) Diapers
( ) Absorbent intimate feminine
( ) Catheterization intermittent bladder
( ) External condom collecting device
<table>
<thead>
<tr>
<th>Self-care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily water intake _________ Appropriate division of ingestion ( ) Yes ( ) No</td>
</tr>
<tr>
<td>Liquid dysphagia ( ) Yes ( ) No Low tolerance for liquids ( ) Yes ( ) No</td>
</tr>
<tr>
<td>Dependant on others for toileting ( ) Yes ( ) No</td>
</tr>
<tr>
<td>Do you require instruction on how to use the urinary device? ( ) Yes ( ) No</td>
</tr>
<tr>
<td>Mobility</td>
</tr>
<tr>
<td>Dependant on others ( ) Yes ( ) No Why? ________________________________</td>
</tr>
<tr>
<td>Impairment: ( ) Bradykinesia ( ) Tremor ( ) Postural instability ( ) Motor complications</td>
</tr>
<tr>
<td>Locomotion: ( ) Without Assistance and without support ( ) Locomotion with assistance Which? ______</td>
</tr>
<tr>
<td>Falls: ( ) Yes ( ) No ( ) Falls between bed- and bathroom: ( ) Yes ( ) No Risk of falls: ( ) Yes ( ) No Why?</td>
</tr>
<tr>
<td>Mental function</td>
</tr>
<tr>
<td>Cognitive/behavioral disorders: ( ) Yes ( ) No Which: __________________</td>
</tr>
<tr>
<td>Sleep</td>
</tr>
<tr>
<td>Dependent on medication: ( ) Yes ( ) No Wakes from sleep by urinary desire: ( ) Yes ( ) No</td>
</tr>
<tr>
<td>Sleep disorders: ( ) Yes ( ) No</td>
</tr>
<tr>
<td>Housing conditions</td>
</tr>
<tr>
<td>Live alone ( ) Yes ( ) No Accessible bathroom ( ) Yes ( ) No</td>
</tr>
<tr>
<td>It is able to maintain a safe environment without help? ( ) Yes ( ) No</td>
</tr>
<tr>
<td>Has made modification to the bathroom ( ) Yes ( ) No What?</td>
</tr>
<tr>
<td>Needs to modify the bathroom/home ( ) Yes ( ) No What?</td>
</tr>
<tr>
<td>Community, social, and civic life</td>
</tr>
<tr>
<td>Impact on labor activities related to genitourinary disorders ( ) Yes ( ) No Not applicable</td>
</tr>
<tr>
<td>Impact on leisure activities related to genitourinary disorders ( ) Yes ( ) No</td>
</tr>
<tr>
<td>Impact on quality of life related to genitourinary disorders ( ) Yes ( ) No</td>
</tr>
<tr>
<td>Have financial resources for modifications, medicines, and urinary devices? ( ) Yes ( ) No</td>
</tr>
</tbody>
</table>

**Nursing diagnoses**

**Nursing interventions**
Evaluation of bladder symptoms in patients with PD is complex because it involves investigation of urinary, gynecological/urological, cognitive/behavioral, and sleep symptoms, as well as mobility/accessibility and quality of life. Thus, nurse evaluations should focus on several aspects that may contribute to these changes in order to propose appropriate interventions. Some measurement scales may be used, including the Overactive Bladder questionnaire (OAB-q) [53], Questionnaire on Pelvic Organ Function [54], and the Scale for Outcomes in Parkinson's disease (SCOPA-AUT) [55].

Nursing assessment for sleep disorders in patients with Parkinson's disease

Date: _____/_____/_______

<table>
<thead>
<tr>
<th>Personal data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name: ___________ Age: ___ Sex: ( ) Female ( ) Male Family/Caregiver: ________________</td>
</tr>
<tr>
<td>Date of onset of symptoms of Parkinson's disease: ____________________________________</td>
</tr>
<tr>
<td>Concomitant diseases: ________________________________________________________________</td>
</tr>
<tr>
<td>Daily medications: __________________________________________________________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sleep assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complaint: __________________ Onset of symptoms of sleep disorder: ______________</td>
</tr>
<tr>
<td>Use medication to sleep? ( ) yes ( ) no Impact on quality of life of the patient: ( ) yes ( ) no</td>
</tr>
<tr>
<td>Has sleep routine? ( ) yes ( ) no Impact on quality of life of the family: ( ) yes ( ) no</td>
</tr>
</tbody>
</table>

Sleep disorders related to motor symptoms

| Difficulty with movement in bed: ( ) Yes ( ) No |
| Tremors that compromise the quality of sleep: ( ) Yes ( ) No |
| Morning dystonia: ( ) Yes ( ) No Restless leg syndrome: ( ) Yes ( ) No |

Sleep disorders related to nonmotor symptoms

| Hallucinations: ( ) Yes ( ) No |
| Sleep apnoea/difficulty breathing: ( ) Yes ( ) No |
| Pain: ( ) Yes ( ) No |
| Nocturia: ( ) Yes ( ) No |
| Mental confusion: ( ) Yes ( ) No |

Specific symptoms of sleep disorders

| Initial insomnia: ( ) Yes ( ) No |
| Terminal insomnia: ( ) Yes ( ) No |
| Nonrestorative sleep: ( ) Yes ( ) No |
| Sleep-talking: ( ) Yes ( ) No |
| Nightmares: ( ) Yes ( ) No |
| Vivid dreams: ( ) Yes ( ) No |

Specific symptoms of daytime sleep disorders

| Sleeping unexpectedly during the day: ( ) Yes ( ) No |
| Sleeping while talking: ( ) Yes ( ) No |
| Sleeping while watching TV: ( ) Yes ( ) No |
| Sleep while sitting: ( ) Yes ( ) No |
| Difficulty staying awake during the day: ( ) Yes ( ) No |
Evaluations of symptoms that cause sleep disorders should be approached with care and cover various related aspects, including motor/nonmotor function and night/day sleep disorders. Measurement scales can be used for this assessment and may include those recommended by the Movement Disorders Society Task Force: the PD sleep scale (PDSS), Pittsburgh sleep quality index (PSQI), SCOPA-sleep (SCOPA), and the Epworth sleepiness scale (ESS) [56]. We also emphasize that the PDSS scale has been revised and the PDSS-2 version has been validated [57].

**Nursing assessment for orthostatic hypotension in patients with Parkinson’s disease**

Date: _____/_____/_______

**Personal data**

Name: _________________ Age: ___ Sex: ( ) Female ( ) Male Family/Caregiver:________________

Date of onset of symptoms of Parkinson’s disease: _________________________________________

Concomitant diseases: _______________________________________________________________

Daily medications: ___________________________________________________________________

**Autonomic scale for outcomes in Parkinson’s disease (SCOPA-AUT): Hypotension section**

In the past month, when standing up, have you had the feeling of either becoming light-headed, not seeing properly, or not thinking clearly?

( ) Never ( ) Sometimes ( ) Regularly ( ) Often

In the past month, did you become light-headed after standing for sometime?

( ) Never ( ) Sometimes ( ) Regularly ( ) Often

Have you fainted in the past six months?

( ) Never ( ) Sometimes ( ) Regularly ( ) Often

**Composite Autonomic Symptom Scale (COMPASS 31): Hypotension section** [59]

1. In the past year, have you ever felt faint, dizzy, “goofy”, or had difficulty thinking soon after standing up from a sitting or lying position? (1) Yes (2) No

2. When standing up, how frequently do you get these feelings or symptoms?

(1) Rarely (2) Occasionally (3) Frequently (4) Almost Always

3. How would you rate the severity of these feelings or symptoms?

(1) Mild (2) Moderate (3) Severe

4. In the past year, have these feelings or symptoms that you have experienced:

(1) Gotten much worse (2) Gotten somewhat worse (3) Stayed about the same

(4) Gotten somewhat better (5) Gotten much better (6) Completely gone

**Physical Examination**

Blood pressure (BP) lying:_____X_____mmHg  Cardiac frequency (CF) lying:___hpm

BP in orthostasis:_____X_____mmHg (immediately)  CF in orthostasis:___hpm (immediately)
BP in orthostasis: ___X___ mmHg (after 3min) CF in orthostasis: ___ hpm (after 3min)

“Criteria for orthostatic hypotension: when a person moves from a supine to a sitting or a standing position occurs a decline of >20 mmHg in systolic blood pressure or a decline of >10 mmHg in diastolic blood pressure. The decrease must be present within 3 minutes after the postural change [60].

**Evaluation of orthostatic hypotension in patients with PD should be part of nursing protocol. Different measurement scales can be used, including those recommended by the Movement Disorders Society Task Force [58]: SCOPA-AUT and the Composite Autonomic Symptom Scale (COMPASS) [59]. Nursing care can be based on “Clinical Practice Guidelines: Patient Self-Management of BP Instability in Multiple System Atrophy, Parkinson’s Disease and Other Neurological Disorders” [60].**

### Nursing assessment for medication adherence in patients with Parkinson’s disease

**Date:** _____/_____/_______

#### Personal Data

Name: ________________ Age: ___ Sex: ( ) Female ( ) Male Family/Caregiver:_________________

Date of onset of symptoms of Parkinson’s disease: __________________________________________

#### Daily medication

<table>
<thead>
<tr>
<th>Number of pills/time of ingestion</th>
<th>Number of pills/time of ingestion</th>
<th>Medication action/Side effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Time-action:__________________</td>
</tr>
<tr>
<td></td>
<td></td>
<td>( ) dyskinesia ( ) wearing-off</td>
</tr>
<tr>
<td></td>
<td></td>
<td>( ) ON/OFF ( ) nausea/vomiting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>( ) No side effect ( ) Other:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>( ) take the pills with food/protein</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Morisky Medication Adherence Scale: High adherence (8 points), medium (6 to &lt; 8 points) and low adherence (&lt;6 points) [61]</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Do you sometimes forget to take your pills for PD? ( 0 ) Yes ( 1 ) No</td>
</tr>
<tr>
<td>2) People sometimes miss taking their medications for reasons other than forgetting. Thinking over the past two weeks, were there any days when you did not take your medicine? ( 0 ) Yes ( 1 ) No</td>
</tr>
<tr>
<td>3) Have you ever cut back or stopped taking your medicine without telling your doctor because you felt worse when you took it? ( 0 ) Yes ( 1 ) No</td>
</tr>
<tr>
<td>4) When you travel or leave home, do you sometimes forget to bring along your medicine? ( 0 ) Yes ( 1 ) No</td>
</tr>
<tr>
<td>5) Did you take all your medicine yesterday? ( 0 ) Yes ( 1 ) No</td>
</tr>
<tr>
<td>6) When you feel like your symptoms are under control, do you sometimes stop taking your medicine? ( 0 ) Yes ( 1 ) No</td>
</tr>
</tbody>
</table>
7) Taking medicine every day is a real inconvenience for some people. Do you ever feel hassled about sticking to your treatment plan?

8) How often do you have difficulty remembering to take all your medicine?

<table>
<thead>
<tr>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never/rarely</td>
</tr>
<tr>
<td>Once in a while</td>
</tr>
<tr>
<td>Sometimes</td>
</tr>
<tr>
<td>Usually</td>
</tr>
<tr>
<td>All the time</td>
</tr>
</tbody>
</table>

Self-care

Dependent on others for management of medications? ( ) yes ( ) no

( ) Dysphagia for liquids ( ) Dysphagia for solids: capsules/tablets ( ) Change the consistency of medications

Mental function

Cognitive disorders: ( ) Yes ( ) No What: ________________________________

Neuropsychiatric disorders: ( ) No ( ) Visual hallucinations ( ) Auditory hallucinations ( ) Impulsivity

( ) Hypersexuality ( ) Anxiety

Housing conditions

Live alone ( ) Yes ( ) No Easy access to where medications are stored ( ) Yes ( ) No

Community, social, and civic life

Impact on labor activities related to drug use? ( ) Yes ( ) No ( ) Not applicable

Impact on leisure activities related to drug use? ( ) Yes ( ) No

Impact on quality of life related to drug use? ( ) Yes ( ) No

Have financial resources to purchase medicines? ( ) Yes ( ) No

Support and relationships

Requires support of family/caregiver for management of medicines? ( ) Yes ( ) No

Resources to remember to take medication (box organizer, alarms, cellular)? ( ) Yes ( ) No

Have financial resources to purchase medicines? ( ) Yes ( ) No

Acquires the medications by the public health system? ( ) Yes ( ) No

Suffers consequences of insufficient supply of medicines? ( ) Yes ( ) No ( ) Public services ( ) Private service

Nursing diagnoses

Nursing interventions

Evaluation of medication adherence should consider aspects related to medication (expected, adverse, and side effects; action time; costs; etc.), other symptoms of PD (dysphagia, cognitive/neuropsychiatric disorders), impact on the quality of life, and family support/caregiver for management of treatment. The scale most commonly used in research and clinical practice is the Morisky Medical Adherence Scale (MMAS) [62–64].
3. Conclusion

The important role of nurses in the multidisciplinary care of patients with PD is obvious, and training of increasing numbers of professionals to meet the growing demand is an absolutely plausible goal.

Health actions based on comprehensive care centered on patients and their families, based on ethical, legal, operational, and theoretical premises of the profession and grounded in the concepts of prevention, promotion, treatment, and rehabilitation, provide quality and scientific rigor for patient care. These actions may help to improve the quality of life of individuals with neurodegenerative diseases that are multisystem, incurable, and often disabling.

Development of an organizational chart of the motor and nonmotor symptoms of PD and a survey of the main diagnoses/outcomes and nursing interventions based on a standardized language can direct clinical reasoning of professionals who care for these patients. Moreover, these tools may enable the development and/or improvement of clinical protocols that underlie the systematization of nursing care.

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References


