Developing guideline-based quality indicators for Parkinson's disease in primary care, extractable from the electronic medical record.

Maxime Foidart, KU Leuven

Promotor: Dr. Steve Van den Bulck, KU Leuven

Co-promotor: Dr. David Spitaels, KU Leuven

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Abstract

Background: Parkinson's disease (PD) is the second most common neurodegenerative condition and a considerable cause of disability and its prevalence has been rising since 1990. Studies have shown a lack of knowledge and confidence, as well as a lack of guideline adherence for PD in primary care. Quality indicators (QI's) are increasingly applied by many healthcare settings in order to assess and enhance quality of care. Our aim in this study is to develop a set of evidence based QI's for primary care, extractable from the EMR, in order to enable automated quality assessment for PD care.

Methods: In this study, we used the RAND-modified Delphi method. Recommendations and existing QI's were selected out of national and international guidelines. After being filtered by the SMART principle and EMR extractability, the recommendations were presented to a multidisciplinary panel through a written questionnaire. They were individually rated on a 9-point Likert score by each panelist and thereafter analyzed based on the median Likert score, prioritization and agreement. Afterwards the recommendations were discussed during an online meeting, for in- or exclusion to the final list. After final appraisal of the core list of recommendations, they were transformed into QI's.

Results: After applying the SMART principle and accounting for EMR-extractability, a set of 43 recommendations was presented to the panel. After the consensus meeting, a core set of 14 recommendations was translated into QI's. Subsequently, another 18 recommendations were added to a list of potential future QI's. This core set consists of QI's concerning diagnosis, pharmacological treatment of motor symptoms, non-pharmacological treatment of non-motor symptoms, non-pharmacological treatment of motor and non-motor symptoms, and prevention.

Conclusion: We developed a list of 14 evidence based QI's for PD in primary care, extractable from the EMR and available for automated quality assessment.

1. Introduction

Parkinson's disease (PD) is the second most common neurodegenerative condition and a considerable cause of disability. In 2016, roughly 6 million people were affected by this disease worldwide. [1, 2]. According to a systemic analysis for the Global Burden of Disease study in 2016, the prevalence of PD has been rising since 1990. [1] Despite advancements in the comprehension of the pathogenesis and epidemiology of PD, its etiology still remains unclear, and treatment is focused on managing its symptoms. [2,3] PD is typically presented with a set of motor and non-motor symptoms, which have a significant impact on quality of life.[2,4,5] The motoric symptoms of PD include bradykinesia, rigidity, resting tremor and postural instability. The non-motor symptoms can consist of olfactory dysfunction, cognitive impairment, psychiatric symptoms, sleep disorders, autonomic dysfunction, pain and fatigue [2,4]. Along with the advancement of the disease, patients with PD will be progressively more dependent on caregivers and the health-care system. [6-9] Especially non-motor symptoms like cognitive impairment or hallucinations are recurrent causes for hospital admissions in late stage PD.[2] Patients with PD are mostly managed by specialized healthcare, namely neurologists and specialized nurses. [4]

As well as specialist healthcare, patients also benefit from involvement from their general practitioner (GP), providing added value in the quality of care. GP's have an important role in providing care to patients with chronic conditions, keeping in mind personal context and socio-

economic factors. Primary healthcare professionals, who are well aware of the patients and relatives preference for care, could play an important part in the wellbeing of the patient with PD, especially during the advancement of the disease. [10] A study in the Netherlands has shown that individuals with PD could gain advantages from collaborative care, where both generalist and specialist care are appreciated for their specific qualities of patient-centeredness and disease-specific knowledge. [11]

GP's in general may not feel confident enough providing PD-related care, given the low prevalence and diversity of presentations of PD as not all patients present with the classic symptoms (tremor and rigidity) [11-13]. A study by Khan et al [2] also concludes that primary care providers more often than not lack sufficient knowledge to recognize the condition early on and manage it, leading to a lowering of quality of care in patients suffering from PD. Other studies have also shown a lack of confidence and knowledge, as well as a lack of adherence to evidence-based guidelines for PD in primary care settings. [12,14,15]

The electronic medical record (EMR) is seen as an optimal instrument for quality informatics, monitoring health providers' performance and evaluating quality of care, since it can be used to store computerized data. [16,17] Quality indicators (QI's) are increasingly applied by many healthcare settings in order to assess and enhance quality of care [16, 30-32], they are explicitly defined measurable items referring to the outcomes, processes, or structure of care. By developing QIs which are extractable from the EMR, we can assess and improve the adherence to guidelines for treatment and follow up and thereby quality of care for PD by performing internal audits and automated feedback reports. [18] These QIs can also contribute to curbing the socio-economic burden of PD, which is major and increasing, according to a study performed by L Feigin et al. [1].

QI's for PD have been developed in the past (Eric M. Cheng et al. [19]), however they are not proposed for use in primary care nor are they adjusted for extractability from the EMR. Since the prevalence of PD is rising, and primary care having a central role in managing chronic diseases like PD [12], a tool for assessing and improving guideline adherence could prove valuable for primary care providers.

Therefore, the aim of this study is to develop a new set of evidence based EMR-extractable QIs, which are relevant in general practice and can be used as a tool to improve the quality of care for PD.

2. Methods

2.1. Study design

In this study, we used the RAND-modified Delphi method to develop a set of quality indicators. We included the following steps: (1) A selection of evidence based recommendations, guidelines and existing quality indicators to include in to a written questionnaire; (2) The individual rating of the included recommendations on specific criteria by a panel of experts, including an analysis of the results and a feedback report; (3) A face-to-face consensus round with all the panel members based on the feedback report; (4) A final appraisal of the set of recommendations; (5) Transformation into a final set of quality indicators.

2.2. Study population

A selection of healthcare workers, experienced in giving care to patients with PD contacted by email. Patients with PD were contacted through their general practitioners. The panel consists of a multidisciplinary team, which include 3 neurologists, 3 GP's, 2 patients with PD, a physiotherapist, an

occupational therapist and a PD specialized nurse. The participants were informed about the aim and methods of the study through information letters and were asked to sign an informed consent.

2.3. Data collection

2.3.1. Selection of recommendations

First, we conducted a broad search for national and international guidelines for PD on the world wide web. Secondly, an extensive literature review of guidelines was performed to collect recommendations and existing quality indicators about PD. Using the PUBMED database, we searched by MeSH-terms "Parkinson's disease" AND "recommendations" OR "guidelines" OR "quality indicator" OR "quality of care". The inclusion of guidelines and recommendations was based on relevancy in primary care and publication date (not older than 20 years). We exhaustively collected all recommendations and existing QI's from these guidelines, categorizing them regarding their content (definition, diagnosis, therapy, follow-up and end-of-life care). Following this, all recommendations were selected for inclusion using the SMART-principle . Meaning statements which were not Specific, Measurable, Assignable, Realistic or Time-specific for primary care were excluded. Recommendations not eligible for EMR-extraction were excluded as well. The exhaustive list was filtered by the investigator and by a second independent investigator, ensuring quality control. The differences between the filtered results were reviewed in a second phase, in order to decide which ones to include or exclude. The final list recommendations was formulated into a written questionnaire.

2.3.2. Written questionnaire round

2.3.2.1. Formulation. The written questionnaire was presented to the multidisciplinary panel. Each panel member was asked to individually rate the recommendations on a 9-point Likert scale, with 1 being the lowest score (poor recommendation) and 9 being the highest score (good recommendation). The panelists were able to classify any recommendation as 'non assessable' in case they were unable to score the recommendation. (For instance the pharmacological therapy recommendations could not be assessed by practitioners without a medical background). For each recommendation the panelist could declare the decisive factor in their judgment of the score, either by importance or by EMR extractability. Subsequently the panel members were asked to prioritize each of the recommendations per category in a top 3 or top 5 (depending on the number of statements per category). Finally each panelist could suggest an additional recommendation or make remarks about the included ones. The patients included in the panel were assisted by the investigator in filling out the questionnaire.

2.3.2.2 *Analysis.* The results from the written questionnaires were listed on an excel file to formulate a feedback report.

The recommendations and QIs were assigned as having a high, uncertain or low potential to measure the quality based on these three criteria; on the median Likert scale score, prioritization and degree of agreement among the panel members (Table 1).

1. Likert scale score

   Each panel member individually rated the recommendations on a scale from 1-9, whereas 1 is the lowest and 9 is the highest score. The Likert scale score was the median score for each recommendation.

2. Prioritization

For each category, the panel ranked a top 5 or top 3 of recommendations. If a recommendation gets ranked first, it will receive 5 points. If it gets ranked second, it will receive 4 points. If it gets ranked third, it will receive 3 points, and so on. Recommendations which are not mentioned will receive 0 points. The prioritization score will be expressed as a percentage, calculated by dividing 'the amount of points a recommendation scored' by 'the maximum number of points a recommendation could have scored'.

3. Agreement

Agreement was defined as ≥70% of the panel members giving a median Likert score of ≥7, and disagreement was defined as ≥30% of the panel members giving a median Likert score ≥7 AND ≥ 30% giving ≤3. The recommendations which score differently were defined as having no agreement (Table 1).

Recommendations which received a median Likert score ≥ 7, a prioritization score ≥ 20% and agreement from the panel members will be classified as a high potential recommendation. Recommendations which received a median ≥ 7, a prioritization score 1-20% and agreement, OR received a median < 7 , a prioritization score ≥ 20%, regardless of receiving agreement, will be classified as an uncertain potential recommendation. Every other recommendation will be classified as a low potential recommendation (Table 2). These results will be presented to the panel during the consensus meeting, in which the recommendations will be either in- or excluded to the final list.

Table 1: Preselection and agreement

Median Likert score	Top percentage	
≥ 7	≥ 20%	Selection
≥ 7	1 – 20%	Discussion
< 7	≥ 20%	Discussion
Other		No selection

Agreement	
≥ 70% in highest tertile	Agreement
≥ 30% in highest tertile and ≥30% in lowest tertile	Discussion
Other	No selection

Table 2: Classification of recommendations

	Preselection	Agreement	Conclusion
Recommendation 1	Selection	Agreement	High potential
Recommendation 2	Discussion	Agreement	Uncertain potential
Recommendation 3	Discussion	Discussion	Uncertain potential
Recommendation 4	Selection	Discussion	Uncertain potential
Recommendation 5	Selection	No agreement	Uncertain potential
Recommendation 6	No selection	No agreement	Low potential

2.3.3. Consensus meeting round

The results of the analysis were formulated into an individual feedback report for each panel member. The report included all recommendations with their respective median Likert score, along with the degree of agreement score (green for high potential, orange for uncertain and red for low potential agreement). Newly added recommendations and remarks by the panelists were included as well. The feedback reports were sent back by email to the respective panelist prior to the online consensus meeting. During the meeting, the high potential recommendations were reviewed firstly and were included unless a panelist judged otherwise. Likewise, the low potential recommendations were excluded, unless deemed otherwise by any participant. The uncertain recommendations were openly reviewed and discussed in group, applying the SMART-principle and accounting for EMR-accountability, until reaching agreement. If consensus could not be reached, the recommendation was excluded.

2.3.4. Final appraisal

The results of the consensus meeting were listed into a final set of recommendations and sent to the all panelist for final appraisal.

2.3.5. Translation of recommendations into QI's

Finally, the definitive list of recommendations were translated into QIs. For example, 'If Parkinson's disease is suspected, refer people quickly and untreated to a specialist with expertise in the differential diagnosis of this condition.' was translated to 'the percentage of patients in which Parkinson's disease is suspected, which were referred quickly and untreated to a specialist with expertise in the differential diagnosis of this condition'.

2.4. Ethical approval

This study was presented to the ethical committee of KU Leuven with number MP023473 and approved by the Onderwijs-begeleidingscommissie (OBC) on 03/01/2023.

3. Results

3.1. Selection of recommendations

Our extensive search in the World Wide Web and the PubMed database yielded 8 national and international guidelines which were relevant for our study, containing 380 recommendations, as well as a list of 82 already existing quality indicators [19-27]. Applying the SMART principle and accounting for EMR-extractability on the exhaustive list, as well as merging similar recommendations, resulted in a set of 43 recommendations (Figure 1).

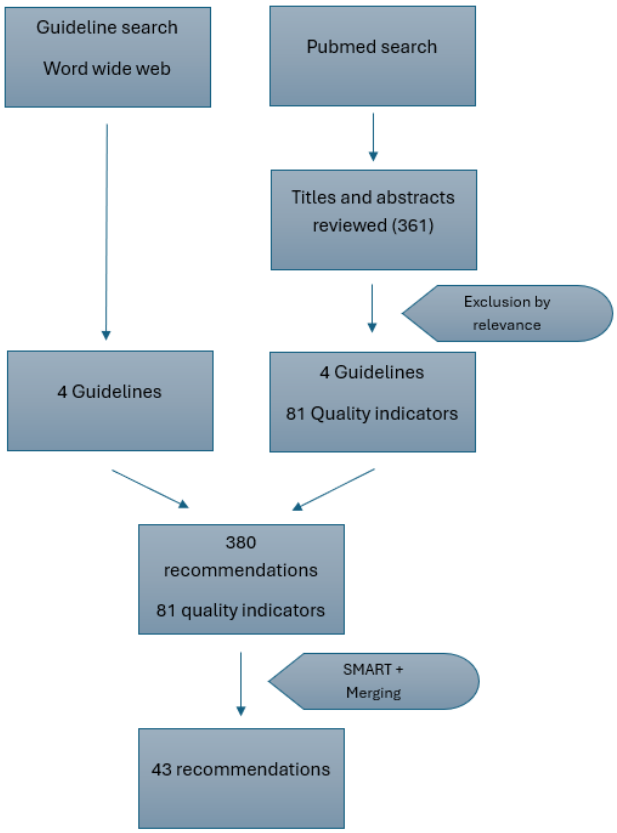


Figure 1: Selection of recommendations

3.2. Written questionnaire round

The list of selected recommendations were poured into a written questionnaire, these were filled out by all participants (11/11) separately. Due to the complexity of the recommendations for non-professional healthcare, the PD patients filled out their questionnaires under supervision of the main investigator. 22 Recommendations were rated as high potential (green), 11 as potential (green) and 10 were uncertain(orange).

3.3. Consensus meeting

The consensus meeting could be attended by 6 out of the 11 panel members (3 GP's, 1 neurologist, 1 patient with PD, 1 physiotherapist specialized in neurological disorders). Out of the 43 recommendations, 1 high potential, 2 uncertain and 7 low potential were excluded. Resulting in a list of 33 recommendations. 3 Recommendations were adjusted due to EHR-extractability by the expert panel. No extra recommendations were added.

3.4. Extra round for screening on EMR extractability

During the review of the selected recommendations by the expert panel and after examination of the ICPC and ICD-10 codes we noticed a lack of codes to extract every selected recommendation in the list. Subsequently we performed another screening by manually using the EMR to check the recommendations for EMR extractability. After reviewing the list, 18 recommendations were

excluded from the primary list, and assembled into a secondary list of 'future potential recommendations'. The final primary list consists of 14 recommendations, since another 2 were merged.

3.5. Final appraisal

Both lists were presented to all panel members by email. 1 recommendation got reformulated. No other changes were proposed.

3.6. Translation into quality indicators

All 14 recommendations were translated into QI's, listed below. The list consists of 2 QI's concerning diagnosis, 2 concerning pharmacological treatment of motor symptoms, 3 concerning non-pharmacological treatment of non-motor symptoms, 5 concerning non-pharmacological treatment of motor and non-motor symptoms, 2 concerning prevention.

3.7. Final list of QI's

Table 3. Final list of QI's

Diagnosis
a. % of patients presenting with tremor, stiffness, slowness, balance problems and/or walking difficulties, who are referred to a neurologist.
b. % of patients who have been diagnosed with PD by a neurologist, who have visited a neurologist within 6-12 months to evaluate the initial management.
Pharmacological treatment of motor symptoms
a. % of patients with PD who have not been administered/prescribed anticholinergics.
b. % of patients with PD who have not been abruptly discontinued anti-parkinsonian medication
Pharmacological treatment of non-motor symptoms
a. % of patients with PD who have not been administered/prescribed typical antipsychotic medication
b. % of patients with PD who have not been administered/prescribed metoclopramide.
c. % of patients with PD treated with levodopa and dopamine agonists, who have gastro-intestinal motility problems (anorexia, nausea, vomiting) who are offered domperidone.
Non-pharmacological treatment of motor and non-motor symptoms
a. % of patients with PD who experience balance of motor issues, who have been offered physical therapy.
b. % of patients with PD who have communication, swallowing or saliva problems, who have been offered speech therapy
c. % of patients with PD with decreased functional capacity for activities of daily living, who have been offered occupational therapy
d. % of patients with PD who have been weighed at each visit.
e. % of patients with PD with 10% loss in body weight in the last year, who have been documented as 'weight loss'.
Prevention
a. % of patients with PD who have received a pneumococcal vaccination.
b. % of patients with PD who have received an annual influenza vaccination.

4. Discussion

In this study, we developed a set of 14 evidence based QI's for PD in primary care, using a RAND-modified Delphi method, suitable for extraction from the EMR. The set includes different aspects of care for PD patients, specifically diagnosis, pharmacological treatment of motor symptoms, pharmacological treatment of non-motor symptoms, non-pharmacological treatment of motor and non-motor symptoms and prevention. By implementing this set of extractable QI's into the EMR, internal audits and feedback intervention can be organized to assess and ultimately improve the quality of care for PD in primary care.

Since PD comprises a broad array of symptoms, motoric as well as non-motoric, it is a complex disorder with a great diversity of symptoms. The initial list presented to the panel and discussed during the consensus meeting, included recommendations covering orthostatic hypotension, psychosis, cognitive impairment, urinary dysfunction etc. Many of these recommendations, although deemed fit for measuring quality of care for PD by the multidisciplinary panel, are too complex for extraction from primary care EMR. Therefore, after the consensus meeting we performed another screening by using SMART and for EMR-extractability, since it's essential the set of QI's are eligible for internal audit, excluding another 18 recommendations. We excluded QI's who were, with the current set of ICPC codes, not yet extractable from the EMR in primary care. For example; '*If someone with Parkinson's disease develops dyskinesia and/or motor fluctuations, including 'wearing off' of medications, seek advice from a healthcare professional specializing in Parkinson's disease before adjusting therapy.'* , was excluded from the final list, since it is currently not possible to code for 'wearing off' or 'motor fluctuations' specifically.
By future updates or expansion of the set of ICPC codes, more QI's could be eligible for internal audit in the EMR, allowing to better assess and improve the quality of care for PD in primary care, motivating us to create the second list of future potential QI's (see Addendum 1), rather than disregarding them.

Our multidisciplinary panel consisted of 3 GP's, 3 neurologists, 2 patients, 1 PD-specialized nurse, 1 physiotherapist specialized in neurological disorders and 1 occupational therapist. Neurologists have a primary role in managing pharmacological therapy, as the role of the general practitioner is primarily fulfilled by prompt referral upon suspicion of PD, managing non-Parkinson specific medication, and referring to the appropriate paramedical institution when necessary, as is reflected through the final list of QI's. Although a study in the Netherlands concluded that patients with PD see a limited role for GP's in the management of early staged PD and were more likely to seek advice through specialty healthcare or by self-management. [11, 28] The final list emphasizes the supportive and coordinating role a GP could play in managing PD.

The questionnaire presented to the panel only included one recommendation concerning Parkinson specific medication, namely *'Offer levodopa to individuals in early stages of Parkinson's disease whose motor symptoms affect their quality of life.'*, although pharmacological treatment of motor symptoms with Parkinson specific medication is generally managed by a neurologist. During the consensus meeting, one neurologist stated that a trial with levodopa started by the primary care physician could prove valuable for the differential diagnosis of PD in anticipation of the consultation with the neurologist. Although GP's are usually not familiar with initiating levodopa treatment, and it is unclear whether there is global consensus regarding the initiation of levodopa in primary care. Since the panel supported its approval during the questionnaire and the consensus meeting, we decided to add this QI to the secondary list, possibly proving its value in the future. Most pharmacological QI's included in the final list concern contraindicated medication, for example '*anticholinergics*'. During the consensus meeting these recommendations were primarily backed by the GP's, since the mentioned pharmacologicals are commonly prescribed in primary care and can easily be overseen in PD patients with multiple comorbidities. A study performed on a large Scottish

primary care database concluded that polypharmacy poses a significant issue in patients with PD, since patients treated for motor symptoms are often treated for associated comorbidities, such as depression, psychosis or other mental health disorders [17,29]. GP's play a central role in managing medication usage and should be wary of polypharmacy in patients with PD.
All of the recommendations about referral to occupational, speech and physical were included. Their importance was nuanced by all paramedic panelists. The physiotherapist attending the consensus meeting underlined the role paramedicals can have in providing additional mental support during therapy. GP's should be attentive to speech or communication problems, a decrease in functional capacities in activities of daily living (ADL) and balance/motor problems in PD patients. Due to their closer proximity to their patient population, GP's can identify symptoms at an early stage and should proactively make quick referrals.

The recommendations regarding early care planning, appointing a surrogate decision maker and informing patients and family members about the progression of the disease and the side effects of medication sparked discussion during the consensus meeting. Although being important recommendations, everybody agreed that providing all this information at once can be very overwhelming for the patient, and that it is more appropriate to do so gradually as the disease progresses and considering the patient's personal context. The occupational therapist, who could not attend the meeting, also emphasized the importance of delivering this information gradually and multidisciplinary through a motivation letter on her questionnaire. Therefore the panel rejected these recommendations, as we cannot objectify at which point in the disease progression and they should be applied.

Although not represented in the list of QI's, primary care providers can also be integral in managing patients who are evolving into a late stage PD. As patients will be more reliant on close proximity care and house visits, especially if palliative care becomes necessary. [11] A longitudinal study by A. Plouvier at al. [10] is currently examining the transition of patients into late stage PD and how exactly PD patients' expectations of their GP compare to the GP s view on their role. Aiming to provide insight to when primary care should interfere in the PD patient's care into the development of the disease.

A strength of our study is the diversity of the multidisciplinary panel, including medical as well as paramedical professionals involved in care for patients with PD, as well as patients being involved in the development of our QI's. All panelists completed the written questionnaire. Although only 6 panelists were able to attend the consensus meeting, all participants were able to review and approve the final list. One of the limitations of our study was the lack of knowledge about EMR-extractability in primary care by most participants. Another limitation was the inclusion of the patients, since patients with early stage PD were not aware of all associated conditions from which they did not suffer, and patients with late stage PD, frequently suffering multiple comorbidities, would struggle contributing to the study.

In this study, we developed a set of QI's for PD, to offer primary care physicians a tool to assess and improve the quality of care for their PD patients and enhance confidence in offering PD related care.

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Addendum 1: List of recommendations for potential future QI's

a. Offer levodopa to individuals in early stages of Parkinson's disease whose motor symptoms affect their quality of life.
b. Treatment of excessive daytime sleepiness should focus on identifying a reversible cause such as depression, poor sleep hygiene, and medications associated with altering sleep patterns.
c. Individuals with Parkinson's disease experiencing sleep attacks should be advised against driving, exposing themselves to occupational hazards, or performing safety-sensitive duties.
d. If someone with Parkinson's disease develops orthostatic hypotension, check the person's current medications to address potential pharmacological causes, including: antihypertensives (including diuretics), dopaminergics, anticholinergics, and antidepressants.
e. In patients with Parkinson's disease and cognitive impairments, investigate treatable causes of dementia and, if present, exclude them.
f. All individuals with PD and psychosis should undergo a comprehensive evaluation to exclude other treatable causes.
g. If a patient with Parkinson's disease (PD) has persistent medication-induced hallucinations or delirium that do not improve with adjustments to PD medication (including discontinuation or reduction of anticholinergics, amantadine, dopamine agonists, and/or levodopa), then a trial of quetiapine or clozapine should be considered.
h. If a patient with PD is prescribed clozapine for hallucinations or another psychosis, blood should be monitored weekly for the first six months of treatment and then every other week to monitor for agranulocytosis.
i. Evaluation of potential causes of urinary dysfunction in patients with PD, such as prostate hypertrophy or cancer, is recommended.
j. Consider referring people in early stages of Parkinson's disease to a physiotherapist experienced in Parkinson's disease for assessment, education, and advice, including information on exercise.
k. All patients with PD and their caregivers (if applicable) are recommended to consult one or more Parkinson's disease advocacy and support organizations for information, education, and support.
l. Provide oral and written information about the side effects of therapy to individuals and their family members and caregivers (if applicable) when starting treatment for Parkinson's disease.
m. Patients should be warned about the potential of dopamine agonists to cause impulse control disorders and excessive daytime sleepiness and should be informed about the effects on driving and operating machinery.
n. If someone with Parkinson's disease develops dyskinesia and/or motor fluctuations, including 'wearing off' of medications, seek advice from a healthcare professional specializing in Parkinson's disease before adjusting therapy.
o. Good sleep hygiene is recommended for people with PD and any sleep disorder.
p. Advise patients with PD to avoid factors that may cause orthostatic hypotension, such as sudden changes in posture, large meals, hot baths, and vasodilator medications.
q. In all PD patients, the development of urinary incontinence should be queried annually.
r. All patients with Parkinson's disease should be asked about recent fall incidents at least once a year.