SPECIAL ARTICLE

Quality improvement in neurology: Parkinson disease update quality measurement set

Executive summary

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Supplemental data at Neurology.org

Approximately 630,000 people in the United States carried a diagnosis of Parkinson disease (PD) in 2010, and worldwide estimates indicate that up to 10 million individuals may be diagnosed currently.[1,2] The national economic burden of PD was estimated to exceed $14.4 billion in 2010.[1] PD is a heterogeneous disorder with motor and nonmotor features that are often underdiagnosed and, in turn, provided limited treatment options. The American Academy of Neurology (AAN) created a quality measurement set in 2010 to provide a framework for measuring progress on addressing these treatment gaps in care.[3]

In 2014, the AAN formed a multidisciplinary PD update quality measurement set work group to review the previously developed measures and identify opportunities to improve and define new quality measures aimed at improving the delivery of care and outcomes for patients with PD. In this executive summary, we report on the updated quality measurement set developed by the work group and shown in table 1. The full measurement set document, including specifications, is available in appendix e-1 on the *Neurology*® Web site at Neurology.org and at aan.com/practice/quality-measures/.

The AAN has designed and coordinated several other quality measurement sets, including headache, multiple sclerosis, and multiple dystrophy, and led this measure development project.[4–6] The details of the full AAN measurement development process are available online.[7] The AAN Parkinson's Disease Update Quality Measurement Set is intended to support quality improvement initiatives allowing physicians to select areas to assess and potentially track trends and changes over time. In addition, these measures have been and may continue to be utilized in public reporting, payment, and potentially inform maintenance of certification performance in practice programs.

OPPORTUNITIES FOR IMPROVEMENT Despite the development and publication of the PD measurement set in 2010, gaps in care remain. Evidence suggests that those with chronic illness have better care coordination when this is done by a health care professional compared to self-managed care and that for people with PD, neurologist care reduces the risk of hip fracture and lower likelihood of skilled nursing facility placement.[8,9] Using the Pacific Northwest Veterans Health Administration Data Warehouse, Swarztrauber et al.[10] found that for patients with PD, depression screening occurred in 16.6%, fall screening occurred in 23.4%, and 67.3% received urinary incontinence management. Baek et al.[11] found that annual review of the diagnosis was documented 7.2% of the time; they examined 1,461 charts from 33 neurologists, and found that movement disorders neurologists were more likely to ask items from the original PD quality measures compared to other neurologists. Of note, the movement disorders nurse practitioner completed the highest number of items. A study of 236 patients with PD who died over a 3-year period in the United Kingdom found that only 3 patients had a recorded discussion regarding their end of life goals/wishes and 7 relatives discussed this with the attending physician.[12] Studies of European countries indicate that most people with PD see general practitioners for their care.[13] Abbott et al.[14] conducted a pretest of general practitioners who scored 51% on average for basic PD motor and nonmotor symptom care knowledge, and following education, knowledge improved as well as self-reported confidence in dealing with PD issues. Given these continued gaps in care and opportunities to improve care, the AAN determined an update to the original measurement set was warranted.

METHODS The AAN aimed to convene a cross-specialty and multidisciplinary expert work group to update the measurement set, and therefore solicited a broad representation of key stakeholders by inviting nominations for expert panel members from physician and nonphysician associations, PD patient and caregiver advocacy organizations, and large group employers.

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Table 1 2015 Parkinson disease measurement set update

Measure title	Measure description
Annual Parkinson's Disease Diagnosis Review[a]	Percentage of all patients with a diagnosis of PD who had their diagnosis reviewed in the past 12 months. (Reviewed is defined as an evaluation of the UK Parkinson's Disease Society Brain Bank Clinical Diagnostic Criteria available at http://www.ncbi.nlm.nih.gov/projects/gap/cgi-bin/GetPdf.cgi?id=phd000042.)
Avoidance of Dopamine-Blocking Medications in Patients with Parkinson's Disease	Percentage of patients with PD provided a contraindicated dopamine-blocking agent (i.e., antipsychotic, antinausea, anti–gastroesophageal reflux disease).
Psychiatric Symptoms Assessment for Patients with Parkinson's Disease[a]	Percentage of all patients with a diagnosis of PD who were assessed for psychiatric symptoms in the past 12 months. (Assessed can be a verbal discussion. Psychiatric symptoms defined as psychosis [i.e., hallucinations and delusions], depression, anxiety disorder, apathy, and impulse control disorder [i.e., gambling, hypersexual activity, binge eating, increased spending].)
Cognitive Impairment or Dysfunction Assessment for Patients with Parkinson's Disease[a]	Percentage of all patients with a diagnosis of PD who were assessed for cognitive impairment or dysfunction in the past 12 months. (Assessed is defined as use of a screening tool [see specifications for recommended tools] or referral to neuropsychologist for testing.)
Querying about Symptoms of Autonomic Dysfunction for Patients with Parkinson's Disease[a]	Percentage of all patients with a diagnosis of PD (or caregivers, as appropriate) who were queried about symptoms of autonomic dysfunction in the past 12 months. (Autonomic dysfunction is defined as orthostatic hypotension or intolerance, constipation, urinary urgency, incontinence, nocturia, fecal incontinence, urinary retention requiring catheterization, delayed gastric emptying, dysphagia, drooling, hyperhidrosis, or sexual dysfunction.)
Querying About Sleep Disturbances for Patients with Parkinson's Disease[a]	Patients with a diagnosis of PD (or caregivers, as appropriate) who were queried about sleep disturbances in the past 12 months. (Sleep disturbances are defined as excessive daytime sleepiness, insomnia/fragmentation [including nocturnal motor features], dream enactment/REM sleep behavior symptoms, restless leg syndrome, or sleep disorder breathing [obstructive sleep apnea].)
Falls Outcome for Patients with Parkinson's Disease	Number of falls that occurred in the preceding 6 months for patients with PD.
Parkinson's Disease Rehabilitative Therapy Options[a]	All patients with a diagnosis of PD (or caregivers, as appropriate) who had rehabilitative therapy options (i.e., physical, occupational, and speech therapy) discussed in the past 12 months.
Counseling Patients with Parkinson's Disease About Regular Exercise Regimen	Percentage of patients with PD counseled on importance of and provided recommendations on regular exercise regimen in the past 12 months. (Regular exercise regimen is defined as at least 150 minutes of moderate-intensity activity each week per the Department of Health and Human Services.)
Querying about Parkinson's Disease Medication-Related Motor Complications[a]	All visits for patients with a diagnosis of PD where patients (or caregivers, as appropriate) were queried about dopaminergic medication-related motor complications (i.e., wearing off, dyskinesia, dystonia, on-off phenomena, and amount of off time).
Advanced Care Planning for Patients with Parkinson's Disease	Patients with advanced PD who have an advance care directive completed or have a designated power of attorney for medical decisions in the last 12 months.

Abbreviation: PD = Parkinson disease.

[a] 2009 measure updated with additional specificity.

Details of the full AAN measurement development process are available online.[7] The selected work group consisted of 21 members (a list of work group members and contributing organizations follows this article). All work group members were required to disclose potential conflicts of interest and completed an application summarizing experiences and interest.

The co-chairs independently select members from the pool of qualified specialists and experts who responded to the nomination call. Each individual application was reviewed and work group participants were selected based on prior experience in performance measurement, quality improvement, and clinical activity. The process involves seating a work group to represent members of a PD treatment team, and as a result requests for nominations were sent to appropriate provider organizations, patient advocacy groups, payers, and large health care organizations.[15]

The work group followed the AAN measure development process, which requires (1) completing an evidence-based literature search, (2) drafting candidate measures and technical specifications, (3) establishing a multidisciplinary work group adhering to the AAN conflict of interest policy, (4) convening members to review candidate measures, (5) refining and discussing the candidate measures, (6) soliciting public comments on approved measures during a 30-day period, (7) refining the final measures according to input received during the public comment period and corresponding technical specifications, and (8) obtaining approvals from the work group, AAN Quality and Safety Subcommittee, AAN Practice Committee, and American Academy of Neurology Institute Board of Directors.[15]

The work group's primary goal was to develop and update measures supporting the delivery of high-quality care and improvement of patient outcomes. A rigorous review of the evidence occurred. The co-chairs and facilitators, guided by a medical librarian, conducted a comprehensive search identifying over 557 abstracts and winnowing results to locate 15 guidelines used as the evidence base for the measures developed.

The work group also strove to balance the burdens of measures on clinicians and patients against the benefit of these measures in guiding quality care. Measures created and updated are designed to be meaningful for patients and obtained by providers through electronic data collection to reduce reporting burdens. The AAN will continue to update these measures on an ongoing basis every 3 years, and thus the updated measure set provides a working framework for measurement, rather than a long-term mandate.

RESULTS: PD UPDATE QUALITY MEASUREMENT SET

An abbreviated version of each of the 11 measures in the final set is included here (table 1). The full description and rationale of each quality measure is provided in appendix e-1. The process began with a review of the initial quality measure set developed and published in 2009–2010. Select measures were reaffirmed and modified, new measures developed,

Table 2 2009 Parkinson disease measurement set[3]

Measure 1	Annual Parkinson disease diagnosis reviewed
Measure 2	Psychiatric disorders or disturbances assessment
Measure 3	Cognitive impairment or dysfunction assessment
Measure 4	Querying about symptoms of autonomic dysfunction
Measure 5	Querying about sleep disturbances
Measure 6	Querying about falls (retired)
Measure 7	Parkinson disease rehabilitative therapy options
Measure 8	Parkinson disease–related safety issues and counseling (retired)
Measure 9	Querying about medication-related motor complications
Measure 10	Parkinson disease medical and surgical treatment options reviewed (retired)

and others retired if warranted. A list of 14 measure concepts was developed by the work group based on the interest in identifying what desired outcomes are for patients with PD. Based on available evidence and gaps in care discussed by the work group they were ranked and voted on, and the top 11 were agreed upon for development.

Three measures were retired by vote of the work group (table 2). The falls assessment was moved to an outcome measure. This is currently the only outcome measure in the set. The safety counseling measure was thought by the panel to lack specificity and as a result it had the lowest adherence rating.[11] A separate driving measure was considered as a new measure and was one of the 14 measures voted on, but work group consensus was not reached for approval given limited evidence. This concept will be retained and considered at the next update in 3 years. Medical surgical treatment options were believed to be covered in another measure (Querying about Parkinson's Disease Medication-related Motor Complications), and after much discussion by the work group was retired.

Seven of the original measures were reviewed and additional specificity added. They included the following: Annual PD Diagnosis Review; Psychiatric Symptoms Assessment for Patients with PD; Cognitive Impairment or Dysfunction Assessment for Patients with PD; Querying about Symptoms of Autonomic Dysfunction for Patients with PD; Querying about Sleep Disturbances for Patients with PD; PD Rehabilitative Therapy Options; and Querying about PD Medication-related Motor Complications. Four new measures were created, including Avoidance of Dopamine-Blocking Medications for Patients with PD; Fall Rate for Patients with PD; Counseling Patients with PD about Regular Exercise Regimen; and Advanced Care Planning for Patients with PD.

As with the prior quality measure set, each measurement statement contains a denominator and numerator with appropriate exclusions provided. A denominator exclusion is a factor supported by the clinical evidence that removes a patient from inclusion in the measure population. A denominator exception is a condition that should remove the patient, procedure, or unit of measurement from the denominator only if the numerator criteria are not met. There are 3 possible types of exceptions for reasons why a patient should not be included in a measure denominator: medical (e.g., contraindication), patient (e.g., declination or religious belief), or system (e.g., resource limitation) reasons. For each measure, there must be a clear rationale to permit an exception for a medical, patient, or system reason. The work group provided explicit exceptions when applicable for ease of use in eMeasure development. Each measure identified the eligible patient population and identifies temporal application, such as annually. Once it is determined that the patient is eligible, then the measure states how it is fulfilled. Note that the measures do not recommend specific assessment tools but, unlike the prior set, do provide options for validated tools. This leaves clinicians with some flexibility within the evidence base in how the measures can be successfully completed. The level of the measure (individual, practice, or system) and applicable care settings were established and settings include outpatient, inpatient, skilled nursing, and emergency department. Finally, also stated is the desired outcome and opportunity for improvement for each based on available evidence.

DISCUSSION The purpose of developing quality measures is to improve patient care and enhance treatment whenever possible. The initial measures published in 2010 represented the beginning of this process for PD. It is necessary, with advances and the accumulation of new evidence, to modify these measures at regular intervals. This represents the first such update. The measures presented here were developed in the hopes of changing practice in a way that would benefit patients. For example, it would be beneficial to monitor accuracy of diagnosis even after several years of follow-up and the development of often unrecognized but impactful nonmotor features. It would also be beneficial to promote healthy practices and safety in this population. The outcome of our process was the development of a set of 11 quality measures, 7 of which were maintained or revised from the original set and 4 that were new.

Much of the current clinical research surrounds the frequency and impact of nonmotor symptoms in PD, which are common but often underrecognized and, in turn, undertreated. For example, depression is present in about 50% of patients, anxiety in 30%, impulse control disorders in 14%, and cognitive change occurs in up to 80%.[16–18] Since the development of the first set, there has been no change in the fact that nonmotor symptoms need to be recognized but compliance with these measures has been low.[11] There continues to be a gap in care. There is increasing evidence that cognitive dysfunction, psychiatric disorders, and sleep and autonomic symptoms are a primary part of the disease process in PD and that many are treatable. Such treatments can have a major impact on quality of life; hence the importance of maintaining these measures. Assessment for these disorders can be made verbally but several tools are provided as options for practitioners.

The annual diagnosis review measure was also maintained as recent literature has confirmed that PD clinical diagnosis can be elusive, even after 5 years.[19] It is also important in terms of optimizing therapy (including avoiding ineffective therapies) and providing important prognostic information for patients and families. In addition, the recommendation for rehabilitation has been maintained as there is growing evidence that rehabilitative therapies, physical, speech, and occupational, are effective in improving motor impairment, activities of daily living, and quality of life in PD throughout all stages.[20–23] There remains clear gaps in care in relation to rehabilitative referrals.[11] Finally, queries regarding medication were maintained as well, which is of great importance as the treatment regimens become increasingly complex.

There were 4 new measures added. In the past, treatment of PD focused on medications and surgeries with a nod to exercise and physical therapies. Recent evidence suggests that exercise has multiple important health benefits that should be leveraged by patients with PD. Exercise improves the physical and mental functioning levels and quality of life for patients with PD,[22–26] and early intervention with exercise can prevent falls.[26] It should be recommended to all patients with PD. The work group declined to develop an exception for this measure as it is believed that all patients can benefit from this counseling and counseling must be tailored to individual patient needs. The new measure of avoiding dopamine-blocking agents in patients with PD is important in ambulatory and hospital practice settings. The prescribing of these drugs is a common medical error that can lead to worsening of motor symptoms of PD and result in further disability and falls. This is particularly important when faced with a patient with PD who is hallucinating but also should be kept in mind when treating sleep disorders and gastrointestinal ailments. There are 2 exceptions—quetiapine and clozapine—but these too should be used with caution.[27] The third was a change in the falls measure from a process to an outcome measure examining the frequency of patients experiencing falls. The desired outcome is to reduce and eliminate falls. Increasing attention is being given to outcome measures, as practitioners, patients, and payers demand this information to make informed care decisions. The work group believed that evolving the falls process measure into an outcome measure was appropriate at this time, and it is anticipated that more process measures will evolve into outcome measures in future updates. An outcome measure provides practitioners data needed to identify outcome variances, but leeway on which processes practitioners should change or improve to affect their patient population's outcomes. Falls are often devastating for this population facing higher morbidity and mortality.[28] Following a fall, there is risk of increased costs of care, fear of future falls, repeated falls, and reduced health-related quality of life.[29] The work group recommends that when any number of falls occur, patients should be referred for multidisciplinary gait assessment including physical therapy and occupational assessment for walking aids and the patient should be encouraged to exercise.

The final new measure is the percentage of patients with PD who have an advance care directive completed or have a designated power of attorney for medical decisions in the last 12 months. It is held that all patients with PD should have an advanced care directive completed.

Advance care directives ensure that a patient's treatment preferences and treatment goals are being considered and if these are adhered to it is anticipated that increased satisfaction with care will result. Multiple studies have shown that patients want their clinicians to discuss advance care planning.[30] There are also data that despite the desires of the patients to discuss advanced directives this is rarely done.[15]

The new quality measure set was developed to promote quality improvement, drive improved outcomes for patients with PD, and assist in establishing threshold performance rates, and through continued data gathering to drive quality improvement. Their selection and development were based on currently available evidence. The AAN encourages the use of these measures by physicians, other health care professionals, practices, and health care systems, where appropriate. It is hoped that through this quality measure set, electronic medical records can incorporate annual reminders for assessing these complex symptoms and medication order entry, including highlighting the avoidance of dopamine-blocking agents for people with PD.

This set should provide opportunities for improvement in gaps in care specific to the PD.

AUTHOR CONTRIBUTIONS

Dr. Factor contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. A. Bennett contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Hohler contributed to study concept and design, acquisition of data, analysis or interpretation of data, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Wang contributed to study concept and design, acquisition of data, analysis or interpretation of data, critical revision of the manuscript for important intellectual content, and study supervision. Dr. Miyasaki contributed to study concept and design, acquisition of data, analysis or interpretation of data, drafting/revising the manuscript, critical revision of the manuscript for important intellectual content, and study supervision.

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Quality improvement in neurology: Parkinson disease update quality measurement set: Executive summary (see p. 2278)

This podcast begins and closes with Dr. Robert Gross, Editor-in-Chief, briefly discussing highlighted articles from the June 14, 2016, issue of *Neurology*. In the second segment, Dr. Binit Shah talks with Drs. Janis Miyasaki and Stewart Factor about the AAN paper on new quality measures developed to improve outcomes for patients with Parkinson disease. Dr. Ted Burns interviews Dr. Ansgar Furst about his editorial on the incidental findings and future of amyloid plaques in traumatic brain injury for our "What's Trending" feature of the week. In the next part of the podcast, Dr. Alberto Espay focuses his interview with Dr. Josep Dalmau on his George C. Cotzias Lecture at the AAN Annual Meeting on the topic of antibody-mediated disorders of the synapse.

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