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The Perioperative Experience of Patients with Parkinson's Disease: A Qualitative Study

An exploration of the patient perspective.

The difficulty of medication management in patients with Parkinson's disease who must undergo surgery and hospitalization gained national attention last February, when the National Parkinson Foundation (NPF) launched its Aware in Care initiative (www.awareincare.org). The initiative is designed "to address the growing problem of poor hospital care" for people with Parkinson's disease, in part by educating patients and clinicians about the importance of ensuring that hospitalized patients receive their antiparkinson medications when they need them. According to one study cited by the NPF, three out of four patients with Parkinson's disease don't receive their antiparkinson medications on time during hospitalization and 61% of these patients suffer "serious complications" as a result.[1] Indeed, research has shown that when surgical patients with Parkinson's disease miss scheduled doses of these medications, they can suffer from exacerbations of Parkinson's disease symptoms such as rigidity, tremor, and confusion.[2-4] And in comparison with hospitalized patients who don't have Parkinson's disease, those with the disease also tend to have a higher incidence of postoperative complications such as falls, respiratory infections, and urinary tract infections, as well as longer hospital stays.[4-7]

Last month we reported on findings from a quantitative study exploring antiparkinson medication withholding times during hospitalization and symptom management (see "Perioperative Medication Withholding in Patients with Parkinson's Disease: A Retrospective Electronic Health Records Review," January). In this second article, we report on findings from a qualitative study of patients with Parkinson's disease that focused on their perioperative hospitalization experiences, particularly with regard to medication withholding. (Although medication withholding is an issue that can affect hospitalized patients with other chronic conditions such as asthma, diabetes, and mental illness, both studies focused on those with Parkinson's disease.)

PERIOPERATIVE MEDICATION TIMING

The timing of antiparkinson medications has profound implications for motor and cognitive function. Patients with more severe Parkinson's disease may require these medications (particularly carbidopa-levodopa [Sinemet]) as often as every two hours and can tolerate delays of no more than a few minutes. If perioperative surgical staff aren't sufficiently aware of the importance of minimizing disruptions to patients' antiparkinson medication regimens, prolonged medication withholding of several hours' duration can occur.[8]

And patients with Parkinson's disease whose doses are delayed may deteriorate quickly.[7,9] For example,

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ABSTRACT

Objective: The goals of this study were to hear from patients with Parkinson's disease about their perioperative experiences and to describe those experiences using the patients' own words, particularly with regard to antiparkinson medication withholding and symptom exacerbation.

Method: We conducted a descriptive, qualitative study of patients' perioperative experiences with Parkinson's disease symptom management, performing 14 semistructured interviews with 13 participants who had Parkinson's disease and had undergone any type of surgery excepting Parkinson's disease surgeries.

Results: Patients' responses indicated concerns that hospital routines aren't flexible enough for their complex medication regimens; that hospital staff may not recognize a patient's own expertise in Parkinson's disease; and that hospital staff need more education about Parkinson's disease, especially regarding the interactions between the disease and surgery or anesthesia (or both).

Conclusions: Participants' comments made it clear that the actions of nurses could affect the perioperative experience for better or for worse. Our findings further highlight the need for clinical care guidelines for hospitalized patients with Parkinson's disease. Nurses should take the lead in the development of guidelines for Parkinson's disease symptom management.

Keywords: anesthesia, antiparkinson agents, medication management, Parkinson's disease, perioperative symptoms, postoperative symptoms, surgery, symptom management

if rigidity is exacerbated, this can compromise respiration and the ability to swallow, often to the extent that the patient can no longer swallow oral medications. In postsurgical nursing units, patients may become rigid and confused, needlessly suffering before a neurologist is consulted. In addition to medication withholding, other factors that can exacerbate Parkinson's disease symptoms perioperatively include age, comorbidities, disease severity, and other drugs administered during the perioperative period.[9]

Researchers and clinicians who study and care for patients with Parkinson's disease have expressed a need for more research concerning best clinical practices for this population.[2, 8, 10] The development of clinical guidelines for the perioperative care of surgical patients with Parkinson's disease is essential to improving the quality of their care. But the development and successful implementation of such guidelines will require that researchers and clinicians consider the perspective of these patients and their families. To the best of our knowledge, that perspective is missing from the literature. Thus the specific aims of this pilot study were to hear directly from surgical patients with Parkinson's disease about their perioperative experiences and to describe those experiences using the patients' own words, particularly with regard to antiparkinson medication withholding.

METHODS

Design. This descriptive study used interviews with surgical patients with Parkinson's disease to collect data regarding their perceptions about antiparkinson medication use and Parkinson's disease symptoms during the perioperative period. For the purposes of this study, the perioperative period was defined as from midnight prior to surgery until the time of postoperative discharge from the hospital. A semistructured interview format was used, and participants received a $25 honorarium after the interview was completed. Before the study began, all procedures and protocols were reviewed and approved by the University of Minnesota's institutional review board.

Sample and setting. The population of interest was adults with Parkinson's disease who were having an elective surgery, excepting Parkinson's disease surgeries (such as deep brain stimulation surgery). Participants were recruited through flyers distributed at Parkinson's disease support groups or posted in neurology clinics, a Parkinson's disease newsletter, a newspaper advertisement, and referrals from clinicians who care for patients with Parkinson's disease. Inclusion criteria were a diagnosis of Parkinson's disease requiring treatment with carbidopa-levodopa; having a surgical procedure requiring NPO (*nil per os*, or nothing by mouth) status for at least six hours prior to surgery; age between 50 and 80 years; residence within a Midwestern, seven-county metropolitan area; and a score of 7 to 10 on the Short Portable Mental Status Questionnaire (SPMSQ). The exclusion criterion was having surgical procedures for Parkinson's disease.

Thirteen participants, 10 men and three women, met the inclusion criteria. Two participants were recruited preoperatively and 11 were recruited postoperatively. They provided a total of 14 interviews (one man was recruited postoperatively and interviewed for two separate surgeries). Interviews were conducted at the convenience of the participants in their homes.

Instruments. A screening and intake script developed by the investigators was used to screen prospective participants for eligibility and to gather baseline data on those found eligible. The script also incorporated the SPMSQ and the Hoehn and Yahr scale for the staging of Parkinson's disease.

The SPMSQ, a 10-item scale, was used to determine cognitive status. This questionnaire has been validated for telephone administration with older adults.[11] In general, a score of 8 to 10 indicates normal mental functioning; however, in people with a grade school education or less, a score of 7 indicates normal mental functioning. The Hoehn and Yahr staging scale, an ordinal scale, was used to stage the severity of each participant's motor symptoms of Parkinson's disease.[12,13] This instrument categorizes symptoms using five stages that range from stage 1 ("unilateral involvement only, usually with minimal or no functional disability") to stage 5 ("confinement to bed or wheelchair unless aided"). For this study, the Hoehn and Yahr staging scale was modified for telephone administration by the investigators in consultation with a neurologist who specializes in Parkinson's disease research (see Figure 1).

Participants made it clear that the actions of nurses could affect the perioperative experience for better or for worse.

For the in-home interview, a postoperative interview script developed by the investigators was used for collecting data on participants' perioperative experiences. The interview script contained semistructured, open- and closed-ended questions about antiparkinson medication use and Parkinson's disease symptoms before and after surgery, up to the time of hospital discharge. However, when we asked participants whether there was anything else they'd like to tell us, they often discussed issues that extended beyond the time of discharge, and we included those comments in our analysis. Participants were also asked if they felt they'd had a change in symptoms, and if not, what had helped them to manage their disease process during surgery and hospitalization. The interview script also incorporated the SPMSQ and the modified Hoehn and Yahr staging scale. (Our modified scale differs from the original in that the questions are designed to be answered directly by the patient, rather than by an observing clinician; we used it for both the intake call and the in-home interview.)

Data collection. Patients who received recruitment materials were instructed to call a telephone number and leave a message expressing interest in the study. A research assistant who was also a graduate student called interested patients and performed an intake screening to determine eligibility. Eligible participants were read a consent form; those who agreed provided verbal consent. During either the intake call or a second, postsurgical call, an appointment for an in-home interview was made. After the initial phone call, all patients were mailed a copy of the consent form and the investigators' contact information in case they had further questions.

Each interview was conducted by one of three research assistants, all of whom had received interview training from the principal investigator (LCA) or coinvestigator (KF). A day before each scheduled in-home interview, the research assistant called the participant to confirm the interview appointment, answer questions, and administer the modified-for-telephone version of the Hoehn and Yahr staging scale. The research assistant then traveled to the participant's home. Once there, the research assistant first read the consent form aloud to the participant, answered questions, and had the participant sign the consent form. Then the research assistant conducted the interview using the postoperative interview script. The participant's comments were recorded, transcribed, and analyzed. All data materials were secured in the principal investigator's office.

Data analysis. All transcripts were read by both the principal investigator and the coinvestigator to gain an understanding of the entirety of the content. Next, one of the investigators read the transcripts aloud while the other took notes on content that was deemed pertinent by both. The pertinent content was recorded and linked to the coded participant. Coding was performed by hand. This was appropriate because the sample size was small and patients with Parkinson's disease are not able to talk at length because of their disease. Next, we reviewed the coded content and looked for emerging themes. All relevant comments were rearranged under the emerging themes and placed in a table for ease of contrast and comparison.

RESULTS

Fourteen interviews of 13 participants were conducted for this study. Ten participants were male and three were female. All were white and non-Hispanic. The median age was 66.5 years (range, 44 to 80 years). Of the 14 surgeries, 10 were orthopedic surgeries (hip replacement, lumbar fusion, rotator cuff repair, and others). Two were cardiac surgeries (ablation for ventricular tachycardia and pacemaker replacement). One was a hernia repair, and one was a battery replacement for a neurostimulator. Although we didn't specifically ask how long each participant had been living with Parkinson's disease, at the time of interview, one participant was at stage 2, eight were at stage 3, four were at stage 4, and one was at stage 5. None were newly diagnosed.

Figure 1. Hoehn and Yahr Scale for the Staging of Parkinson's Disease, Modified for Telephone Use

Hoehn and Yahr script

Stage 0

1. Do you experience Parkinson's disease symptoms like slow movements, tremor, rigidity, balance problems? Y or N

(If answer to initial question is no, stage 0; if answer is yes, continue questions.)

Stage 1

2. Would you describe your symptoms as mild? Y or N
3. Do you have a tremor or rigidity? Y or N
4. Are your symptoms only on one side of your body? Y or N

(If 4 is yes, stage 1; if no, continue questions.)

Stage 2

5. Are your symptoms on both sides of your body? Y or N
6. Has Parkinson's affected the way you walk? Y or N
7. Are your movements slower because of your disease? Y or N

(If 7 is no, stage 2; if yes, continue questions.)

Stage 3

8. Do you use a cane or walker? Y or N
9. Do you ever lose your balance when you walk or stand? Y or N
10. Would you describe your symptoms as severe? Y or N
11. Would you be able to live alone? Y or N

(If 11 is yes, stage 3; if no, continue questions.)

12. Can you stand or walk for a bit without help? Y or N

(If 12 is yes, stage 4; if no, continue questions.)

13. Do you need a wheelchair to get around? Y or N

(If 13 is no, confirms stage 4; if yes, stage 5.)

Hoehn and Yahr staging scale

Stage 0	No visible disease
Stage 1	Disease that involves only one side of the body
Stage 2	Disease that involves both sides of the body but does not impair balance
Stage 3	Disease that impairs balance or walking
Stage 4	Disease that markedly impairs balance or walking
Stage 5	Disease that results in complete immobility

Hoehn and Yahr stage: _____

The primary aim of this pilot study was to have patients with Parkinson's disease describe their surgery experience in their own words. Analysis of the interview data produced four emerging themes, as follows:

- medication timing may not fit with hospital routine
- patients know their own bodies and the best medication regimen
- education is needed for hospital staff
- there is an interaction between surgery or anesthesia and Parkinson's disease

The theme that emerged most often in comments was "medication timing may not fit with hospital routine." As one patient reported, "OK, so I refused the pill one time, and then an hour later needed it, and the nurses had a hard time understanding why." While there were negative comments from some participants indicating that they were stressed by not being able to manage their own antiparkinson medication regimens, there were also positive comments from others about their experiences with nursing care following surgery. For example, some participants noted that they received their medications on time and when they needed them, and not necessarily according to the hospital schedule. Some participants mentioned specific nurses who recognized that antiparkinson medications were needed and saw to it that these were given. For example, one participant said, "I found one nurse who was willing to fight for me. She was great. She was really making a point of making sure I got my meds, and leaving notes for the next shift."

Patients with Parkinson's disease know their own bodies and are experts on their own medication regimens.

A second theme was that patients with Parkinson's disease know their own bodies and are experts on their own medication regimens. Comments by several participants indicated that they've learned when their worst symptoms are likely to occur and how to recognize signs that they're ready for the next dose of antiparkinson medication. As one participant passionately stated:

> Probably the time frame of medication isn't hard and fast. But normally there is about a half-hour leeway to 15 minutes or so on either side. And it's something that long-term Parkinson's patients have dealt with for quite a few years and is experimented with, with doses and time frames. And your body kind of tells you what works and doesn't work. And so what I was trying to emphasize to them, the time frame I gave you for the medications is what has worked. So for you [the nurses] to arbitrarily put in a different time frame is not what my body is accustomed to. It doesn't just adapt like that.

The third theme to emerge concerned a need for better education about Parkinson's disease for hospital staff. Some participants expressed dismay that the nurses and other clinicians caring for them didn't know more about the disease. For example, one participant stated, "I'm still surprised at how many staff don't understand Parkinson's. You run into a wall, and they don't know anything. And it's been going on a long time. You'd think they'd get the word." The patients in our sample also expressed concern about deficits in nurses' knowledge of antiparkinson medications. For example, one participant noted that nurses didn't seem to know the difference between Mirapex (pramipexole), an antiparkinson medication, and Miralax (polyethylene glycol 3350), a laxative—or, as another participant noted, even the difference between a "slow-release and an immediate-release form of Sinemet."

The fourth theme that emerged from participants' comments was that surgery and anesthesia can interfere with Parkinson's disease symptom management independently of disruptions to medication regimens. For example, patients with Parkinson's disease may be immobile for a short time as they recover from surgery, and that immobility, rather than withheld medication, can be what exacerbates symptoms. Adequate pain management is another important factor in disease management, because the stress associated with pain can worsen Parkinson's disease symptoms. One participant stated, "Because of the pain, I was hallucinating. My wife was there. I threw things at her." Another participant simply said, "If I could control my pain, it works itself out."

The benefit of having another person (typically a spouse or an adult child) serving as a patient advocate, though not explicitly stated, was an important finding. For example, one participant's spouse told the following story:

> Later, she came back with his Mirapex, and she was giving it to him, and she said, "Here's your Miralax—for constipation." And I said, "Excuse me, what are you giving him?" "Well, Miralax for constipation." And I said, "Well no, that's not—he doesn't have constipation. He has Parkinson's, and it better be Mirapex." And she kinda said, "Oh no, no, no, no." And I just said, "OK, please go check. What are you giving him?" And she came back and said, "You're right. It's Mirapex."

Primer for Nurses Caring for Hospitalized Patients with Parkinson's Disease

- The half-life of carbidopa-levodopa (Sinemet) is only one to two hours, and medication timing varies for each individual.
- Patients with Parkinson's disease often need their medications at times that differ from those in the hospital schedule.
- Hallucinations and vivid dreaming are common symptoms in patients with Parkinson's disease.
- The adverse effects of anesthesia drugs may be potentiated in Parkinson's disease. For example, some anticholinergics (such as atropine and glycopyrrolate [Robinul]) can cause confusion, a condition to which Parkinson's disease patients are already prone. There is limited evidence that the therapeutic effects of levodopa may be decreased by midazolam (Versed).[15] An adverse effect of desflurane (Suprane) and sevoflurane (Ultane) is emergence delirium; this could be amplified in a patient with Parkinson's disease.[15] Respiratory depression, a common effect of narcotics, may be exacerbated in patients with Parkinson's disease,[9] in whom muscular rigidity and akinesia can cause respiratory depression.
- Metoclopramide (Reglan), promethazine (Phenergan), prochlorperazine (Compazine), haloperidol (Haldol), droperidol (Inapsine), and—in patients taking MAO inhibitors such as selegiline [Eldepryl] and rasagiline [Azilect])—meperidine (Demerol) are among the drugs contraindicated for patients with Parkinson's disease.
- Immobility during hospitalization and inadequate pain management can exacerbate symptoms of Parkinson's disease.
- Fluctuations in levels of dopamine (a neurotransmitter) can increase rigidity and exacerbate swallowing problems, autonomic dysfunction, urinary problems, and confusion.[10]
- Acute confusion and hallucinations can arise after general and regional anesthesia, even when antiparkinson medication is given close to the patient's normal schedule.[16]

Symptoms such as rigidity, loss of range of motion, and pain, as well as the effects of pain medications, can affect the ability to communicate. Patients with Parkinson's disease tend to speak very softly and quickly, and their speech can be difficult for others to understand.[14] A spouse or an adult child can advocate for the patient simply by interpreting for the hospital staff what their loved one is saying. In our study, we learned from participants' comments that spouses brought medications from home, showed nursing staff the medications their loved ones were taking, alerted nursing staff to patients' needs for medication, and watched to make sure that the medications given were correct.

Though the participants in this sample had some unpleasant experiences, only one participant reported a worsening of symptoms as measured by the Hoehn and Yahr staging scale. Furthermore, in addition to noting the importance of antiparkinson medication timing, several participants reported on the importance of adequate pain management in the management of their Parkinson's disease symptoms.

DISCUSSION

The themes and suggestions that emerged from participants' comments are all within the purview of nurses who work in the perioperative setting. The study participants made it clear that the actions of nurses could affect the perioperative experience for better or for worse.

Participants' comments suggested that there are two actions nurses could take that would immensely improve the perioperative experience: advocate flexibility in the patient medication schedule; and rely on patients' self-knowledge regarding antiparkinson medication, dosing, and timing. Parkinson's disease patients are keenly aware of when their symptoms are worsening or subsiding; on a unit with more flexible nursing practices, it's likely they would be allowed to time their own medications.

Participants' comments also indicated that Parkinson's disease patients benefit from having a family member or a friend serve as an advocate during the hospitalization, helping to communicate the patient's needs to hospital staff during the perioperative period. Family members and friends who know the patient well are likely to be better able to understand her or his speech patterns. Hospitalization is stressful, and this stress can amplify speech difficulties. Allowing liberal visiting hours for family and friends can facilitate better communication between patients and nursing staff.

Our findings also indicate that hospitals should provide nurses with enhanced education about Parkinson's disease in general, and about symptom management during the perioperative period specifically. To that end, we developed a primer for nurses caring for hospitalized patients with Parkinson's disease (see *Primer for Nurses Caring for Hospitalized Patients with Parkinson's Disease*[9, 10, 15, 16]). Periodically

reviewing the disease basics and the latest relevant research can improve the quality of care for all hospitalized patients with Parkinson's disease.

Lastly, our recruitment data indicated that personal contact with a clinician (particularly a nurse) or a support group facilitator was the most successful means of recruitment. Indeed, researchers often count on nurses to refer patients to studies and educate patients about studies. This finding underscores the importance of a nursing presence in conducting research.

Limitations. The major limitation of this study was the small sample size; although we sought 25 participants, recruitment was difficult, and we were only able to recruit 13 participants. Several times during the study we reminded those helping with recruitment (support group leaders, neurology clinic nurses, and other clinicians) to continue promoting the study, but we couldn't be sure if they followed through. Had we been allowed to do our own recruiting, we would likely have recruited a larger number of participants. A second limitation was that because each interview was conducted by one of three research assistants, we can't rule out the possibility of interrater differences.

FUTURE DIRECTIONS

Nurse researchers and clinicians must work together to improve the clinical care of hospitalized patients with Parkinson's disease. First, nursing education must provide both practicing nurses and students with the necessary resources to provide optimal care. Such resources include current information about the pathophysiology of Parkinson's disease and common comorbidities, as well as antiparkinson medications and the complexity of such medication regimens. Nursing education should also emphasize the need to incorporate the patient's input into her or his care. As do patients with other chronic illnesses such as diabetes or asthma, Parkinson's disease patients know their own bodies best.

It's also essential that we develop evidence-based guidelines for the care of people with Parkinson's disease in the United States. We need to utilize nurses and advanced practice nurses who are experts in geriatrics or neurology to optimize symptom management in Parkinson's disease patients, much the way Parkinson's disease nurse specialists coordinate care in the United Kingdom.[2, 17, 18]

Finally, the scientific knowledge gained through Parkinson's disease research must be brought to bear on clinical practice. Research has found that antiparkinson medication withholding leads to numerous difficulties for hospitalized patients with Parkinson's disease,[2-4, 8, 10] and the findings of this study add further support. Interventions to help these patients must be tested. Such interventions include scheduling surgeries earlier in the day, using nonoral routes to administer antiparkinson medications, and perhaps most important, having policies that allow patients to manage their Parkinson's disease symptoms with their own medications. ▼

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