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Hospitalization and Parkinson’s disease: Safety, quality and outcomes

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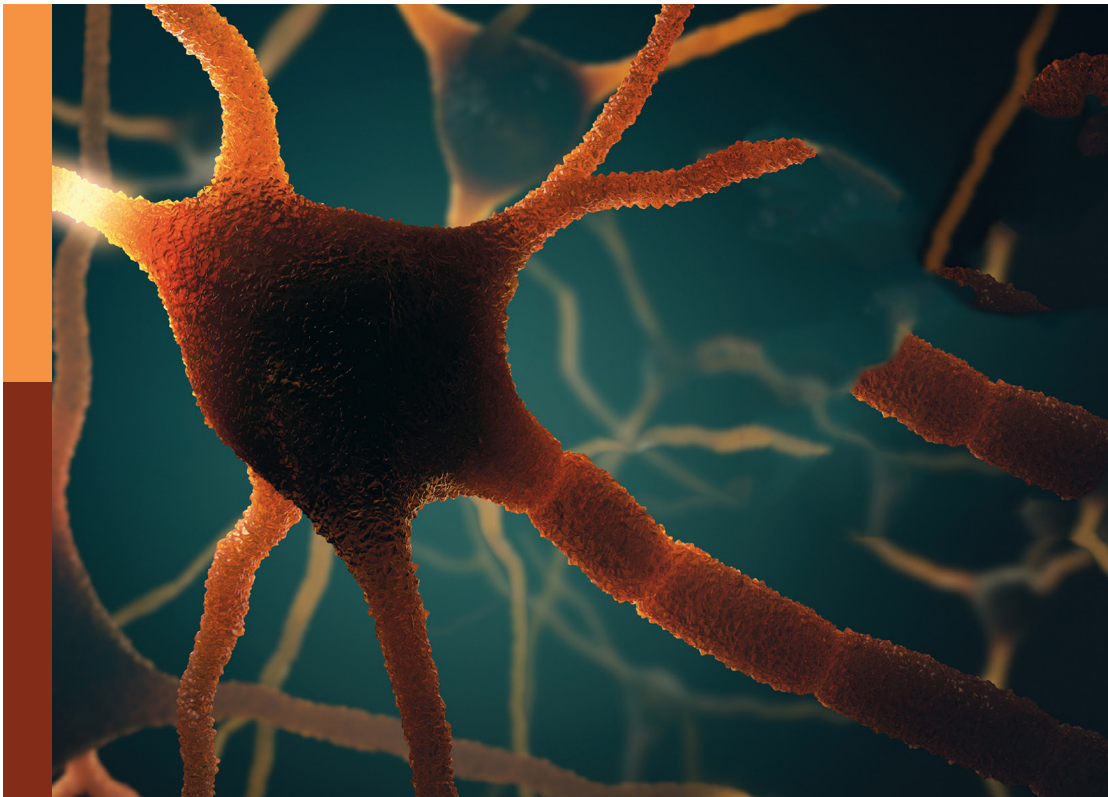

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Hospitalization and Parkinson's disease: Safety, quality and outcomes

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Editorial: Hospitalization and Parkinson's disease: safety, quality and outcomes

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Editorial on the Research Topic
Hospitalization and Parkinson's disease: safety, quality and outcomes

Introduction

For people with Parkinson's (PWP), hospital admissions can be perilous. Nearly 300,000 PWP are admitted to the hospital each year in the US. Following admission, they are at an increased risk of complications that may lengthen their stay and increase the risks of both morbidity and mortality. These preventable hospital-occurring complications occur as a result of many factors.

The majority of PWP enter the hospital for non-PD related issues and are placed in alternative units rather than the neurology floor. Treatment teams may not be cognizant of a patient's PD diagnosis or may alternatively be unfamiliar with special considerations for hospital safety for PWP.

The Parkinson's Foundation Hospital Care Recommendations were recently created as a step toward eliminating preventable harm for PWP in the hospital. To advance this work, we as a field realized that there is a need to demonstrate the prevalence of challenges with both medication administration and overall management of the PWP in the hospital. To achieve meaningful data on patient outcomes and to realize cost savings, we need hospital systems to engage with quality champions and to harness the full potential of information technology and electronic heath records (EHR).

Our Topic series "*Hospitalization and Parkinson's disease: safety, quality and outcomes*" was intended to encourage the discourse surrounding this issue and to further expand the knowledge base. This series includes thirteen publications written from varied perspectives, all centered on the hospitalization of PWP. The articles draw attention to the risks that PWP face in the hospital by providing a clearer idea of the magnitude of existing gaps in care, exploring of the impact of these gaps on both clinical and economic outcomes, and identifying best practices. This editorial is focused on three key themes: (1) understanding risk and outcomes, (2) improving hospital care, and (3) exploring hospitalization through community perspectives.

Understanding risk and outcomes for PWP

For over a decade, the Parkinson's Foundation has worked diligently to shed light on hospital safety gaps and encourage the development of solutions. Significant gains were made through an initiative led by Michael Okun through collaboration among the Parkinson's Foundation Global Care Network resulting in publications of dozens of articles identifying the risks to PWP (Magdalinou et al., 2007; Buetow et al., 2010; Derry et al., 2010; Wood et al., 2010; Aminoff et al., 2011; Chou et al., 2011; Delea et al., 2011; Gerlach et al., 2011, 2013; Hou et al., 2012; Wawruch et al., 2012; Anderson and Fagerlund, 2013; Fagerlund et al., 2013; Hassan et al., 2013; Ahlskog, 2014; Cohen and Smetzer, 2015; Crispo et al., 2016; Shahgholi et al., 2017). Their research also led to the creation of the Parkinson's Foundation hospital safety kits, which have been distributed to over 150,000 PWP. As community awareness increased, investigators better defined the safety gaps and demonstrated the effect on PWP (Gerlach et al., 2012; Oguh and Videnovic, 2012; Martinez-Ramirez et al., 2015).

In this series, we offer a more comprehensive and detailed effort at defining the problem. One review analyzes 35,457 admissions for PWP and explores the complications and outcomes. This article showed an increased risk of delirium and aspiration pneumonia, however interestingly, neither falls nor UTI were cited as a big challenge (George et al.). A smaller study in the series found that while patients with parkinsonism and psychosis had a higher rate of hospitalization, the duration of hospitalization was consistent whether psychosis was active, resolved, or not present (Piat et al.).

Two articles explored the relationship between the end-of-life period and hospitalization for PWP. A large study of Medicare data observed that over 60% of decedents with PD were hospitalized at least once in their last 6 months of life. This data was compared to 18% of non-decedents (Aamodt et al.). Another study also examined the experiences of hospitalized PWP during the end-of-life period, finding that the majority did not receive palliative care consultations. Lack of consultations was correlated with higher healthcare resource utilization, and the lack of provision of this service was inconsistent with patient and family expectations (Bhansali et al.).

Exploring community perspectives

Though presenting hospital care risk and outcome data is essential, it presents an incomplete story. Several articles in the series focused on addressing another essential component less represented in the literature: the community perspective. One qualitative study captured the nuances of complex emotional and physical shortfalls in care as expressed by PWP and their care partners. Aligning directly with several of the Parkinson's Foundation Hospital Care Recommendations, PWP expressed the expectation to be recognized as patients with unique needs, especially needs related to mobility and their Parkinson's medication management. PWP and care partners felt that Parkinson's related challenges should be managed collaboratively (Shurer et al.).

Another study in the Research Topic outlined the perception of safety among PWPs receiving care and identified two relevant themes: (1) the importance of access to interdisciplinary care from inpatient clinicians and (2) the necessity for a care team with an adequate understanding of PD (Pedrosa et al.).

Another article reviewed a case example, as recalled by a Parkinson's care partner. This perspective article explored the role care partners could play as advocates and how hospital staff could utilize care partners as active participants in care, a role that half of care partners "hoped to fill". Communication and a willingness to see the care partner as an expert were identified as primary factors for improving the hospitalization experience. Additionally, this may also minimize risks for aspiration pneumonia (Brooks).

Improving care

Finally, our Research Topic focused on improving care for PWP. As the literature has evolved from early efforts focused mostly on identifying and better defining the hospitalization challenge, more recent efforts have focused on how processes can impact hospital safety gaps and improve patient care (Skelly et al., 2014; Azmi et al., 2019; Hobson et al., 2019; Nance et al., 2020).

This hospitalization issue expands on tangible efforts to improve care. One article reported on improvement across all chosen performance measures by utilizing the Nurse Professional Development Model. The Model included implementation of onboarding policies, multimodal education, competency management tools (such as time-critical alerts in the Medication Administration Record), development of a "nurse champion" role, collaborative interdisciplinary partnerships, and the development of a process for inquiry into the effectiveness of interventions (Bobek et al.). Another article in the series reviewed how the same center was able to impact care through EHR-based interventions. Using this method, when PD medications were placed within a custom schedule (∼14,000 orders), rather than with default options (∼17,000), medications were 1.4 times more likely to be administered within 15-min of the scheduled time (Azmi et al.), in alignment with the Parkinson's Foundation Hospital Care Recommendations.

The impact of using a Best Practice Alert (BPA)—another EHR-based intervention—was highlighted in two articles. In both experiences the method successfully reduced the receipt of contraindicated medications in PWP. In one article, administrations decreased by nearly half from 16 to 8.8% (Chunga et al.). Another article showed similar results in the first 3 months of a program, with less significant impact, though still improved, when followed to 1 year (Goldin et al.).

More comprehensive EHR-solutions with pointers for healthcare system leaders were highlighted in two additional articles. One highlighted default features in the Epic "Foundation System," developed and implemented at medical centers across the country (Wu et al.). Another highlighted a series of recommended policies and tools focused on inpatient pharmacy departments (Yu et al.). Together, these articles provided specific recommendations on how institutions can (1) improve the administration of time-critical PD medications, (2) reduce omissions and substitutions of unavailable medications, and (3) reduce the administration of contraindicated medications.

Conclusion

We believe that the optimal approach to drive improvements in hospital-based care for PWP will be a systematic and nation-wide quality improvement effort. A cornerstone for this effort is the creation, formalization, and meaningful adoption of clinical guidelines driven by new data and innovative methods. Another cornerstone is the formation of a national community of practice to share learning and accelerate adoption of effective interventions, such as the efforts initiated by the Parkinson's Foundation through their national learning collaborative which includes twenty health systems. Delineating the financial impact of costs incurred to ensure compliance and cost savings associated with harm reduction are also critically important. This compilation of articles provides the data and perspectives we will need to continue on the journey toward improvement.

Author contributions

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Conflict of interest

BW has served as site investigator and/or co-investigator for clinical research studies sponsored by grants from Industry to Cleveland Clinic. He has served as a consultant or speaker for Medtronic, Boston Scientific, and Abbott. KA previously served as Investigator and/or medical monitor for clinical trials supported by Aptinyx Inc. Genentech Roche Ltd., EIP Pharma Inc., Michael J. Fox foundation for PD research, NINDS, and Acadia Pharmaceuticals Inc., and Biogene. She previously served as Co-I of a Lewy Body Dementia Association Research Center of Excellence site. IR has served as a site investigator and/or co-investigator for clinical research studies sponsored by grants from Industry to the University of Rochester, currently including F. Hoffmann-La Roche Ltd., Acadia Pharm, and Jazz Pharmaceuticals. MO has received royalties for publications with Hachette Book Group, Demos, Manson, Amazon, Smashwords, Books4Patients, Perseus, Robert Rose, Oxford and Cambridge (movement disorders books). MO is an associate editor for New England Journal of Medicine Journal Watch Neurology and JAMA Neurology. MO has participated in CME and educational activities on movement disorders sponsored by WebMD/Medscape, RMEI Medical Education, American Academy of Neurology, Movement Disorders Society, Mediflix and by Vanderbilt University. MO has participated as a site PI and/or co-I for several NIH, foundation, and industry sponsored trials over the years but has not received honoraria.

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End of life care of hospitalized patients with Parkinson disease: a retrospective analysis and brief review

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Background: Towards the end of life (EOL), persons with parkinsonism (PwP) have complex needs and can present with unique palliative care (PC) challenges. There are no widely accepted guidelines to aid neurologists, hospitalists, or PC clinicians in managing the symptoms of PwP at EOL. We examined a population of PwP at EOL, aiming to describe trends of in-hospital management and utilization of PC services.

Methods: All PwP admitted to two hospitals during 2018 ($N = 727$) were examined retrospectively, assessing those who died in hospital or were discharged with hospice (EOL group, $N = 35$) and comparing them to the main cohort. Their demographics, clinical data, engagement of multidisciplinary and palliative services, code status changes, invasive care, frequency of admissions, and medication administration were assessed.

Results: Among the EOL group, 8 expired in hospital, and 27 were discharged to hospice. Forty-six percent of EOL patients received a PC consultation during their admission. The median interval from admission to death was 37 days. Seventy-seven percent had a full code status on admission. Compared to hospice patients, those who expired in hospital had higher rates of invasive procedures and intensive care unit transfers (41% vs. 75%, in both variables), and lower rates of PC involvement (52% vs. 25%). The transition of code status change for the EOL group from Full code to Do Not Resuscitate (DNR) occurred at a median 4–5 days from admission. For patients that passed in the hospital, the median days from transition of code status to death was 0(IQR 0–1). Levodopa dose deviations were frequent in both EOL and non-EOL group, but contraindicated medications were infrequently administered (11% in EOL group vs. 9% in non-EOL group).

Conclusion: Our data suggest a low utilization of PC services and delayed discussions of goals of care. More work is needed to raise awareness of inpatient teams managing PwP regarding the unique but common challenges facing PwP with advanced disease. A brief narrative review summarizing the suggested management of symptoms common to hospitalized PwP near EOL is provided.

KEYWORDS

parkinsonism, Parkinson disease, palliative care, antipsychotic, hospice, DNR

1. Introduction

Parkinson disease (PD) is a slowly progressive neurodegenerative disorder. Following Alzheimer's dementia, PD is the second leading cause of mortality among the neurodegenerative conditions (Feigin et al., 2019). PD diagnosis is often preceded by years of non-motor symptoms. As the disease progresses, motor symptoms worsen and motor complications, including fluctuations and dyskinesia, may appear. Variable patterns of motor trajectories had been described in PD, but progressive terminal motor decline is common (Poonja et al., 2021). Many motor and non-motor symptoms become treatment-resistant in late-stage PD (Kalia and Lang, 2015). Due to the burden of these symptoms, waning response to dopaminergic therapy and cognitive decline, palliative care (PC) interventions are needed (Richfield et al., 2013; Dawson et al., 2022). A consensus committee perceived PC as an "active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life" (Radbruch et al., 2020). There are several suggested models for the delivery of PC to PwP, including primary PC or neuropalliative/specialty PC model (Tarolli and Holloway, 2020; Margolius and Samala, 2022). Primary palliative care should ideally be provided by the patient's neurologist or family practitioner and should commence at the time of diagnosis. As time progresses, and symptoms become more challenging—such as refractory pain, complex psychiatric symptoms, assistance with conflict resolution in establishing goals of care—a referral to specialty PC or consulting a neuro-palliative physician becomes appropriate. In the inpatient setting, neuro-palliative care can be administered either through inpatient PC services, where patients are admitted for the purpose of managing their symptoms, or through PC consult services that offer guidance to the admitting team on effectively addressing the patients' symptoms. Hospice is a form of PC, typically delivered by an interdisciplinary inpatient or home-based team, that focuses on care at the end of life (EOL). A prognosis of 6 months or less is commonly required for patients to receive hospice care in the United States (Hui et al., 2013). Accumulating evidence, including from a recent randomized controlled trial, suggests that integrating PC in the care of persons with parkinsonism (PwP) leads to an improved quality of life and reduced symptom burden (Wiblin et al., 2017; Kluger et al., 2019).

Towards the EOL, PwP often have complex needs and can present unique PC challenges (Saleem et al., 2013). Interestingly, quality of life and symptom burden concerns are comparable to end-stage cancer patients (Kluger et al., 2019). However, PC for patients with advanced Parkinson's disease and related disorders (PDRD) is underutilized and lacks awareness (Safarpour et al., 2015; Akbar et al., 2021). Additionally, identifying patients approaching EOL is often difficult in PwP (Campbell et al., 2010; Hindmarsh et al., 2021). One study estimated that 17.3% of PDRD patients in the United States died in the hospital, as opposed to 4% dying in hospice (Moens et al., 2015). There are no widely accepted guidelines to determine hospice eligibility for this population. Few studies, however, have attempted to identify predictors of mortality and suggested criteria for hospice considerations (Goy et al., 2015; Akbar et al., 2021).

The inpatient care of PwP is complex. Compared to non-PD, hospitalized PwP are more likely to require longer lengths of stay and experience delirium, infections, pressure ulcers, syncope, falls, and adverse drug events (Gerlach et al., 2011). In a 2011 systematic review, poor PD control and complications related to PD treatment were identified as major clinical concerns (Gerlach et al., 2011). Inappropriate administration of dopaminergic medications can cause significant complications (Magdalinou et al., 2007; Campbell et al., 2010).

Two large reviews highlighted the need for guidelines concerning the management of hospitalized PD patients (Aminoff et al., 2011; Gerlach et al., 2011). There are no consensus guidelines to aid neurologists, hospitalists and PC clinicians in managing the symptoms of PwP at EOL. Moreover, few studies have explored the experiences of PwP at EOL. In one study investigating persons with PD who died while in the hospital, only 10% of patients had documented EOL care discussions with their providers and 14% were referred to the palliative care team (Walker et al., 2014). In this study, we examined a population of PwP at EOL who died in a hospital setting or were referred to hospice care prior to discharge. We aimed to describe: (i) their clinical characteristics, (ii) trends of in-hospital medical and surgical management, and (iii) engagement and utilization of specialized PC services and ancillary services. Additionally, we reviewed the literature to summarize strategies for managing hospitalized PwP near the EOL.

2. Methods

2.1. Study population

Details on the study population and data collection were previously published by Yu et al. (2023). In summary, that study interrogated the inpatient management of PwP. Patients were selected by searching the electronic health records for a past medical history or problem list of PD or parkinsonism. The search included admissions to two Cleveland Clinic sites–Fairview Hospital and Main Campus–for calendar year 2018. Patients diagnosed with primary parkinsonism disorder-IPD and atypical forms of parkinsonism, such as progressive supra nuclear palsy, multiple system atrophy, dementia with Lewy bodies, or cortico-basal syndrome, were included. Patients with drug induced parkinsonism were excluded. The original data set contained 925 hospital admissions from 727 patients over 1 year. For the purpose of the current paper, we queried the dataset for patients who met the following criteria: (i) those who expired during the admission or discharged with hospice care, and (ii) those whose diagnosis of primary parkinsonism was confirmed by a neurologist or a geriatrician. This was done to further confirm the exclusion of secondary parkinsonism, drug-induced parkinsonism, and other neurodegenerative dementias. This group will be referred to as EOL group. Forty-seven charts were reviewed and 35 patients fulfilled the inclusion criteria and were included in the final analysis. All other PwP not meeting the criteria were included in the non-EOL group.

2.2. Data collection

For each admission, the following data were collected: demographic data (i.e., age, sex, race, and ethnicity), age-adjusted Charlson Comorbidity Index, nutrition status on admission, and length of stay. These data were extracted from the electronic health record using a custom Structured Query Language script. The following additional data were collected whenever available: PD duration, days from discharge to death, number of admissions and emergency room (ER) visits in the year preceding their last hospital admission, code status upon last admission, changes to code status during last admission, caregivers'/patients' discharge goals, rehabilitation team's impression of disposition upon admission, final discharge dispositions, utilization of allied health services, such as physical therapy (PT), occupation therapy (OT) and speech therapy (ST), nutrition status, PC team involvement, intensive care unit (ICU) admission, and invasive procedures. The latter was defined as any procedure requiring general anesthesia, including bronchoscopy, biopsies, intubations, hernia repair, palliative ERCP, nephrostomy tube placement, percutaneous endoscopic gastrostomy (PEG) tube insertion, and advanced PD therapy management (DBS, levodopa intestinal gel). The severity of malnutrition was graded based on nutritionists' evaluation, assessing a composite of subcutaneous fat loss, muscle loss, and functional capacity (White et al., 2012; Phillips, 2014). With regards to code status, "Do Not Resuscitate Comfort Care" (DNR CC) is defined here as no cardiopulmonary resuscitation effort or intubation and the provision of comfort care. This data was extracted via manual chart review by two of the authors (SB, EA).

Medication information was reviewed, including levodopa equivalent daily dose (LEDD), deviation from LEDD during admission, and administration of contraindicated medications. Search for contraindicated medications included the following: (1) typical antipsychotics: chlorpromazine, fluphenazine, haloperidol; (2) atypical antipsychotics: risperidone, olanzapine, ziprasidone, aripiprazole, lurasidone, paliperidone, brexpiprazole, asenapine, and (3) antiemetics: metoclopramide, prochlorperazine, promethazine. A manual chart review was conducted by a study team member (JY) to record patients' time-critical antiparkinsonian outpatient medication regimen. These were defined as products containing levodopa. Patients with available medication data and hospital stays longer than 24 h were reviewed for administration of contraindicated medications (835 hospitalizations, 528 patients). Of the dataset of hospital stays greater than 24 h, 366 patients (531 hospitalizations) had complete medication data allowing for LEDD calculation and analysis of deviations from home regimen (Figure 1).

2.3. Statistical analysis

Categorical variables were described in frequencies and percentages. Continuous variables were reported in mean, and standard deviation if normally distributed and in median and interquartile range if skewed. Descriptive statistics were calculated separately for EOL and non-EOL group. Data analysis was carried out using SAS Studio version 3.7.

3. Results

3.1. Demographics of the general inpatient cohort and EOL cohort

Thirty-five PwP at EOL were reviewed. Baseline demographic and some clinical characteristics were compared to 692 patients with parkinsonism who did not meet inclusion criteria (non-EOL group; Table 1). Compared to non-EOL group, patients in EOL group were older (mean of 80 years vs. 76 years) and had a higher age-adjusted Charlson index score (mean of 9.1 ± 2.8 vs. 7.1 ± 3.3). Both groups had a higher proportion of males compared to females. Date of death was known for 34 patients in EOL group (97%) and 218 (32%) patients in non-EOL group. Among deceased patients, the median interval from hospital admission to death was 37 days for patients in EOL group and 425 days in non-EOL.

3.2. Experience of inpatient PwP at EOL

Only 46% received PC consultation (Table 2). Speech therapists, nutritionists, and physical or occupational therapists were involved in the care of 31, 57, and 51% of patients, respectively. Hospitalizations in the year preceding death were frequent with a median of four admissions. Nearly half of the patients (49%) in the EOL cohort underwent invasive procedures, including intubation, nephrostomy tube placements, bowel surgery, biopsies, and bronchoscopies. Forty nine percent of patients received ICU-level care during their admission. Seventy seven percent of patients had a full code or presumed full code status on admission and 23% had a DNR CC code status. During their hospital stay, code status was changed to DNR CC for all the full code/presumed full code patients, except one patient for whom code status was not clearly documented at the time of discharge. At the time of admission, disposition goals as determined by family or patient preferences and by admitting providers were explicitly stated for 22 and 23 patients, respectively. Twenty percent of patients/families expected a discharge to a rehabilitation or skilled nursing facility, while 31% expected a discharge to home. Eventually, the largest number of patients were discharged to hospice facilities or inpatient hospice (40%), followed by home with hospice care (37%). Eight patients (23%) died in the hospital.

Among PwP at EOL, we compared those who expired in hospital vs. those discharged with hospice care. Average age (82 vs. 81), median PD duration (7 vs. 6 years), and median Charlson Comorbidity Score (5 vs. 4) were relatively similar between the two groups. The group of patients that expired in the hospital had a higher percentage of invasive procedures and ICU admissions compared to the hospice group (75% vs. 41%, respectively for both variables). The hospice group was more likely to receive a palliative care consult (52% vs. 25%). The transition from Full Code to DNR CC for both groups occurred at a median of 4.5(IQR 1.5–9) days and 5(IQR 2–10) days, respectively. Unfortunately, death occurred at a median of 0 days from transition to comfort care for patients that expired in the hospital. Out of 27 patients that were initially full code, 6 passed on the same day of the code status change (Table 3).

3.3. Medication administration trends in inpatient PwP cohort

With regards to medication administration trends, both groups were subject to frequent LEDD deviations and underdosing from their home regimen while being inpatient (Table 4). Eighty-five percent of hospitalizations in EOL group involved at least one day of LEDD deviation. The largest LEDD deviation was higher for the EOL group (300 mg vs. 147 mg), but missed doses were infrequent in both groups. Eighty five percent of admissions of patients in the EOL group had LEDD. In the EOL group, 80% of admissions had atleast 1 day of

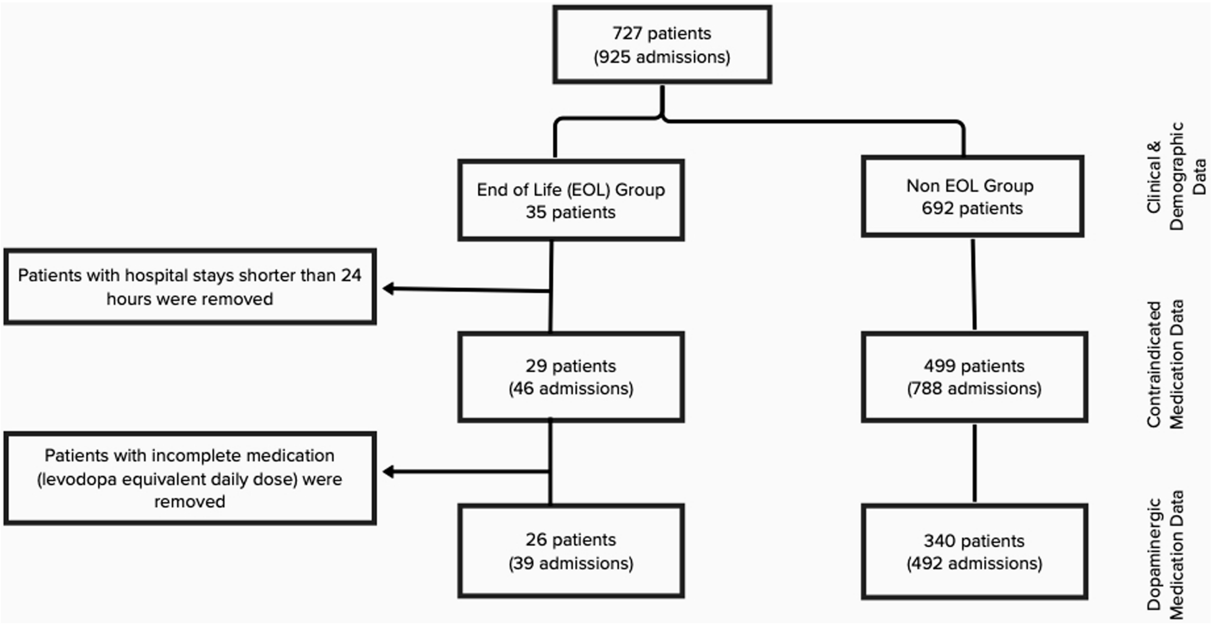


FIGURE 1
Flowchart of patients and hospital visits included in different stages of the study.

levodopa underdosing, 10% had atleast 1 day of levodopa overdosing. The median number of missed doses of levodopa was 1 in both the EOL and non-EOL group. The frequency of contraindicated medications administration was 11% in EOL group and 9% in non-EOL group (Table 5). Both groups received contraindicated medications for a median of 2 days during their hospitalizations. Haloperidol and olanzapine were the most frequently administered medications in both cohorts. While metoclopramide was never given in the EOL group, patients in 21% of hospitalizations in non-EOL group received it during their stay. Among patients in EOL group, three had pre-existing advanced therapies. One patient had a levodopa intestinal gel pump placed *in-situ*, which was not actively used due to malfunction, and two had an active Deep Brain Stimulation (DBS) device placed. One of them died acutely due to intracranial hemorrhage, presumed unrelated to the device. The other patient had an active stimulation upon transfer to hospice. The admitting hospitalist team followed the hospice team's advice to maintain the device on.

4. Discussion

In this retrospective study, we assessed the experience of PwP at EOL who died while in the hospital or were discharged with hospice, evaluating their clinical characteristics, trends of dopaminergic medication use, and interaction with palliative and medical services. Our population of PwP at EOL had a median interval of 37 days separating admission to death. Despite being older, having multiple comorbidities, and having frequent admissions in the last year of life, the majority of patients did not receive a PC consultation. During their admission, invasive procedures were frequent and admission to ICU were not uncommon. At the time of admission, patient/family and providers' expectations on disposition goals were not aligned and the majority had a full code/presumed full code status. Most patients were eventually discharged to home or inpatient hospice. When code status was changed, it occurred at a similar median number of days in the hospice vs. inpatient expired population group (4.5 and 5 days, respectively). The median number of days from this transition to death was 0 in the patient group that expired in the hospital.

Our findings suggest a low utilization rate of PC resources. Discussions of goals of care and involvement of PC services were delayed. This was observed more often in the group that expired in the hospital, which also received more invasive care. Our findings are in line with a prior study which emphasized the underutilization of PC resources for PwP at EOL (Nimmons et al., 2020). Lower awareness from the primary inpatient team of the available palliative resources and the appropriateness of PC referral might be one possible explanation. It is possible that patients could not have had palliative care/hospice discussions due to more critical and urgent medical concerns. In such scenarios, patients and family members may benefit from early recognition of declining course and need for goals discussion. We hope that the narrative review that accompanies this article gives readers an overview of providing primary palliative care and knowing when to seek specialist help.

Moreover, prognostication is often difficult in PD especially with the lack of uniformly accepted criteria for PC or hospice referral. In a study investigating a cohort of patients who died of cancer or non-cancer illness and had received PC, more patients with chronic organ failure and dementia had received PC 30 days or less before death relative to cancer patients (Quinn et al., 2021). Earlier involvement of palliative-oriented care may have facilitated an earlier discussion of advance care planning. A Parkinson Disease Quality Measurement Set, published by the American Academy of Neurology in 2016, recommended an annual review

TABLE 1 Patients' demographic and basic clinical characteristics.

Variable	EOL group (*n*=35)	Non-EOL group (*n*=692)
Gender		
Female	10 (28.6)	294 (42.5)
Male	25 (71.4)	398 (57.5)
Race		
White	25 (75.8)	576 (83.2)
Black	7 (17.2)	69 (10.0)
Multiracial/multicultural	3 (6.9)	15 (2.2)
Asian	0 (0)	8 (1.2)
Other	0 (0)	7 (1.0)
Declined, unavailable or unknown	0 (0)	17 (2.5)
Age, mean (SD)	80.2 (9.9)	75.5 (12.1)
Known death after discharge		
Yes	34 (97.1)	218 (31.5)
No	1 (2.9)	474 (68.5)
Among deceased: the number of days from discharge to death, median (IQR)	37 (10–136.5)	425 (128–865)
Have deep brain stimulation		
Yes	2 (5.7)	79 (11.4)
No	33 (94.3)	613 (88.6)
Charlson index score, median (IQR)	4 (2–7)	2 (1–5)
Age-adjusted Charlson index score, mean (SD)	9.1 (2.8)	7.1 (3.3)

Values presented represent frequency (%), except where otherwise noted. *N* refers to the number of patients. EOL group includes patients with parkinsonism at the end of life. Non-EOL group includes the remainder of patients with the parkinsonism cohort.

of advance directives, but it is unclear how widely this is implemented. Estimated rates of advance directives completion among PwP were reported to vary from 68 to 95% (Kwak et al., 2014; Tuck et al., 2015; Kluger et al., 2018; Lum and Kluger, 2020). The present study did not assess this directly though the rate is postulated to be lower given that the majority of patients at EOL had a full/presumed full code status upon last admission. Similar findings were seen in another study which described that advanced care planning for many patients with PD started as a response to a crisis event like a hospitalization (Nimmons et al., 2020). Our patients who were discharged to hospice had received a PC consultation more frequently. On the other hand, the patients who expired in the hospital, with higher rates of ICU transfers and invasive procedures, were observed to have less frequent interactions with PC services. While the sample was not felt to be powered enough to assess for correlations, previous research had shown that in-hospital PC involvement influenced discharge disposition and improved quality of life (Brody et al., 2010).

In addition to frequent admissions over the last year of life, majority of patients in the EOL group were malnourished and had several comorbid conditions. This is in agreement with other studies showing that recurrent hospitalizations and ED visits increase with longer disease duration (Factor and Molho, 2000; Klein et al., 2009). Some of these factors are among the suggested criteria for triggering hospice referral (Akbar et al., 2021; Centers for Medicare and Medicaid Services, 2023). These trends should be noticed and could be considered as "red flags," triggering the initiation of advance care planning conversations and/or referral to PC programs/resources.

Lastly, with data from over 500 admissions, LED deviations were frequent among admitted PwP, whether or not at EOL. Contraindicated medications were infrequently administered (11 and 9% in EOL and non EOL group; respectively) in both groups. Patients at EOL were more prone to LEDD compared to the Non EOL group (85% vs. 67%). While differences in the group size did not permit comparison studies, underdosing was more common than overdosing in both groups. While previous studies have reported missed and delayed doses as common errors in administering levodopa (Martinez-Ramirez et al., 2015), these errors were uncommon in this cohort. There could be several reasons why admitting teams were underdosing levodopa, such as the unavailability of a specific strength of levodopa, lack of awareness about the need for strict adherence to the home levodopa regimen, and misconceptions about levodopa being a common cause of neuropsychiatric manifestations. However, administering anti-dopaminergic agents to a particularly vulnerable group suggests more work is needed to enhance the awareness of inpatient teams caring for PwP of potential harm. Other reports of medication errors during admissions ranged between 20 and 50% (Lertxundi et al., 2017; Lance et al., 2021). Such errors had been linked to prolonged hospital stays and increased risk of readmissions (Martinez-Ramirez et al., 2015; Shahgholi et al., 2017).

Several limitations are noted here. As a retrospective study, which partly relied on automatic data retrieval from electronic medical records, the design had its inherent biases. A large number of patients had to be excluded from the levodopa deviations analysis for being admitted for less than 24 h or missing an outpatient regimen. Thus, the cohort may or may not be a representative of the inpatient PwP population. Previous discussions about advanced care planning and medical directives have been shown to increase the utilization of hospice services and reduce hospitalizations (Lum et al., 2019). This may have influenced medical decisions for some patients in the end-of-life (EOL) cohort. This study focused solely on the inpatient course of these patients, and this data wasn't consistently available for all patients and was not collected. Additionally, the EOL group was small in size, limiting the ability to conduct meaningful comparative analyses to the main cohort.

In summary, this inpatient retrospective study of PwP highlights areas of concern which may affect the quality of life of PwP in their last days. There is an unmet need to expand advanced care planning discussions, particularly in the outpatient setting. More work is needed to raise awareness of inpatient teams managing PwP regarding the unique, but common, challenges facing PwP with advanced disease, their vulnerability to certain medication omissions/administrations, and the value of involving specialty PC and/or movement disorders services. Future prospective studies are needed to assess PwP, in the outpatient and inpatient settings, aiming to assess the integration of movement disorders and PC services, and enhancing the recognition of those who might benefit from earlier facilitation of such resources.

TABLE 2 Clinical characteristics of PwP at EOL.

Variable	EOL group (N = 35)
Parkinsonism duration in years, median (IQR)*	7 (4–9)
Number of hospitalizations in the last year, median (IQR)	4 (2–6)
Number of ED visits in the last year, median (IQR)	1 (0–2)
Code status on admission	
Full code/presumed full code	27 (77.1)
DNR CC	8 (22.9)
Had consult with diet/nutrition team	
Yes	20 (57.1)
No	15 (42.9)
Had consult with physical/occupational therapy team	
Yes	18 (51.4)
No	17 (48.6)
Had consult with speech therapy team	
Yes	11 (31.4)
No	24 (68.6)
Had consult with palliative care team	
Yes	16 (45.7)
No	19 (54.3)
Had invasive procedure performed	
Yes	17 (48.6)
No	18 (51.4)
Malnutrition	5 (14.3)
Mild	9 (25.7)
Moderate	9 (25.7)
Severe	12 (34.3)
NA	–
ICU admission/transfer	
Yes	17 (48.6)
No	18 (51.4)
Initial disposition goal by caregiver/patient	
Acute rehab or skilled nursing facility or extended care facility	7 (20)
Hospice	4 (11.43)
Home	11 (31.43)
NA	13 (37.14)
Initial disposition goal as judged by admitting providers**	
Acute rehab or skilled nursing facility or extended care facility	16 (45.7)
Hospice	4 (11.4)
Home	3 (8.6)
NA	12 (34.3)
Patient's final disposition	
Home with hospice	13 (37.1)
Hospice facility or inpatient hospice	14 (40.0)
Expired	8 (22.9)

Values presented represent frequency (%), except where otherwise noted. N=35. Not applicable refer to hospital visits in which patients with missing values; EOL, end of life; ED, emergency department, DNR-CC, Do Not Resuscitate Comfort-Care order; DNI, Do Not Intubate; ICU, intensive care unit. *Disease duration data was available for 28 out of 35 patients. **Patients'/caregiver's initial disposition goals and providers estimated disposition were available for 23 patients and 22 patients, respectively.

TABLE 3 Clinical characteristics of patients who died in hospital versus discharged to hospice care.

Variable	Hospice care (N=27)	Expired (N=8)
Age, mean (SD)	80 (10.5)	80.6 (8.2)
Hospital stay duration, median (IQR)	6 (3–11)	2 (1–9.5)
Parkinson's disease duration, median (IQR)	6 (4–9)	7 (6–12)
Whether the patient had an invasive procedure or not		
Yes	11 (40.7)	6 (75)
Whether the patient had a palliative care consult or not		
Yes	14 (51.9)	2 (25)
Whether the patient had a speech consult or not		
Yes	9 (33.3)	2 (25)
Whether the patient had an ICU admission or not		
Yes	11 (40.7)	6 (75)
The number of hospital admissions, median (IQR)	4 (2–7)	3 (2.5–4.5)
The number of emergency department visits, median (IQR)	1 (0–2)	0 (0–0.5)
Code status upon admission		
Full code or presumed full code	21 (77.8)	6 (75)
DNR CC	6 (22.2)	2 (25)
Duration between DOA to DNR CC in days, median (IQR)	2.5 (0–5)	2 (0–9)
Duration between DNR CC to date of death, median (IQR)	16 (3–35)	0 (0–1)
Charlson Comorbidity index, median (IQR)	4 (2–6)	4.5 (2.5–8)

Values presented represent frequency (%), except where otherwise noted. DNR-CC, Do Not Resuscitate Comfort-Care order; DNI, Do Not Intubate; ICU, intensive care unit, DOA, date of admission.

5. Review of management recommendations for inpatient PwP at EOL

The following sections will review available literature pertaining to the care of PwP closer to EOL. We highlight pertinent aspects of the inpatient management of common symptoms of advanced PD at EOL. It is meant to aid trainees, hospitalists, and providers in hospitals, nursing homes, and hospice agencies that frequently take care of PwP, and emphasizes areas in which managing PwP might differ from usual PC symptom management. For simplicity, we will review suggested management which may be applicable to the majority of PwP at EOL (Group A). When necessary, specific management points applicable to patients with shorter life expectancy (days to weeks) is provided as Group B.

5.1. Palliative care or hospice referral

There are no guidelines to indicate when specialty palliative care may be needed for people with Parkinson's (PwP). Complex symptom

TABLE 4 Patterns of parkinsonism medication administration during hospitalizations.

Variable	EOL group (*n* = 39)	Non-EOL group (*n* = 492)
Length of hospital stay in days, median (IQR)	6.3 (3.3–10.9)	3.7 (1.8–7.4)
Patient's LEDD from their home regimen, median (IQR)	600 (300–800)	600 (300–950)
Full hospital days (not including admission and discharge days), median (IQR)	5 (2–8.5)	2 (1–6)
Number of levodopa doses per day, median (IQR)	4 (3–5)	4 (3–4)
Whether the patient had at least one day with an LEDD overdose during stay		
Yes	4 (10.3)	94 (19.1)
No	35 (89.7)	398 (80.9)
Whether the patient had at least one day with an LEDD underdose during the stay		
Yes	31 (79.5)	275 (55.9)
No	8 (20.5)	217 (44.1)
Whether the patient had at least one day with an LEDD deviation during the stay		
Yes	33 (84.6)	330 (67.1)
No	6 (15.4)	162 (32.9)
Largest daily LEDD deviation, median (IQR)	300 (100–560)	146.5 (0–394.5)
Number of levodopa doses missed in the hospital, median (IQR)	1 (1–2)	1 (0–1)
Whether the patient had any days with a missing levodopa dose		
Yes	16 (41.0)	127 (25.8)
No	23 (59.0)	365 (74.2)

For EOL group, *N* = 39 hospitalizations pertaining to 26 unique patients. For non-EOL group, *N* = 492 hospitalizations pertaining to 340 unique patients. Values presented represent frequency (%), except where otherwise noted. LEDD, levodopa equivalent daily dose.

management and challenging discussions regarding end-of-life care and advanced care planning may be common reasons for referral or consultation. Recent studies have highlighted specific symptoms or time points in the disease course that may be used as triggers for palliative care referral. These triggers include a significant decrease in functional capacity or caregiver strain, discussions about feeding tubes, distressing psychiatric symptoms, and communication issues with families (Boersma et al., 2014; Creutzfeldt et al., 2016). That being said, there are several barriers that contribute to the underutilization of palliative care for people with Parkinson's. Underestimating the emotional impact of being diagnosed with PD, insufficient time allocated for advanced care planning, lack of clear responsibilities and roles in introducing palliative care, limited resources, high workloads, and limited communication between healthcare services are some of the common barriers identified that contribute to the underutilization of palliative care in this population (Vaughan and Kluger, 2018; Lennaerts et al., 2019). Neurologists often inform PwP that they will die with PD, not from it. While it is a chronic condition, the age-adjusted mortality ratio is higher in this population, and the leading causes of death are related to complications of PD. Like PC, there are no consensus guidelines to help identify PwP who would benefit from hospice care (Chen et al., 2023). However, a number of experts have suggested recommendations to guide the transition to PC (Goy et al., 2015; Akbar et al., 2021; Margolius and Samala, 2022). Goy et al. suggest that weight loss and shifts in dopaminergic medication prescription trends–reflecting that medication benefits no longer outweigh side effects risk–might be important factors signifying the need to consider hospice referral (Goy et al., 2015). Akbar and colleagues provided a comprehensive list of criteria to determine hospice eligibility (Figure 2). In addition to identifying potential candidates for hospice, it is important to explore patient's and family's goals and wishes and ascertain if hospice is in line with these goals. Familiarity with local eligibility criteria (Vaughan and Kluger, 2018; Centers for Medicare and Medicaid Services, 2023) is necessary, though strict adherence to such criteria might hinder the delivery of care.

5.2. Managing common symptoms in advanced PD

5.2.1. Motor symptoms

5.2.1.1. Group A

It is advisable to consider simplifying medication regimens to reduce medication pill burden, risk of interactions, and side effects (Aminoff et al., 2011). With disease progression, tolerance to trihexyphenidyl, amantadine, and dopamine agonists is reduced and discontinuing these medications is recommended (Friedman and Factor, 2000). Risk of daytime somnolence, neuropsychiatric, and autonomic side effects become more prominent. Moreover, the dose of dopaminergic medications may need to be revised as non-motor symptoms predominate with disease progression.

When PwP are hospitalized, admitting teams are advised to continue their dopaminergic medications following their home regimen. Following the precise timing of medication administration is necessary since advanced motor fluctuations are common. Care should be taken to avoid delays in medication administration. Effective communication is vital between involved medical teams including emergency physicians, consulting teams and nurses. Parkinsonism-hyperpyrexia syndrome is a rare but life-threatening condition which can occur when dopaminergic medications are rapidly reduced or stopped (Apetauerova et al., 2021). When admitted patients are delirious and workup is underway to explore delirium causes, medications which may contribute to confusion, like amantadine, may be withheld. When a medication is non-formulary for an inpatient pharmacy, patient's own supply can be used. Alternatively, consultation with a movement disorders neurologist is encouraged. If the need arises to switch from one agent to another, a levodopa equivalent dose (LED) calculator can be a helpful tool. A recent consensus paper from the International Parkinson and Movement Disorders Society had provided updated recommendations on LED calculation (Jost et al., 2023). LED conversion formulae are, however, primarily designed to inform research and their development is limited by the lack of sufficient trials informing dose equivalency.

A frequently encountered scenario is medication administration interruptions due to concerns about swallowing safety or decreased

TABLE 5 Frequency of contraindicated medications administration across hospital visits.

Variables	EOL group (n = 46)	Non EOL group (n = 788)
Contraindicated medications were given*	5 (10.9)	67 (8.5)
Number of days during the hospital visit when at least one contraindicated medication was administered*	2 (1–4)	2 (1–5)
Among hospital visits where contraindicated medications were given**		
Metoclopramide	0 (0)	14 (20.9)
Aripiprazole	1 (20)	9 (13.4)
Haloperidol	4 (80)	35 (52.2)
Risperidone	1 (20)	5 (7.5)
Olanzapine	2 (40)	14 (20.9)
Promethazine	0	4 (6.0)
Paliperidone	0	1 (1.5)

Values presented represent frequency (%). *Values pertain to 46 visits (29 unique patients) involving EOL group and 788 visits (499 unique patients) involving non-EOL group. **Values pertain to 5 visits (5 unique patients) in EOL group and 67 visits (58 unique patients) in non-EOL group; values represent 'yes' responses, within each cohort, for each medication out. This table includes hospital visits of patients who have medication data and with hospital stays greater than 24 h.

level of consciousness. When PwP lack a safe oral route temporarily, the following options can be considered.

Orally disintegrating carbidopa/levodopa tablet (ODT): the tablets quickly dissolve and can be swallowed with saliva. Unlike sublingually absorbing tablets, these tablets are absorbed in the lower GI tract similar to normal tablets, and are better tolerated in patients with dysphagia especially because it does not require water to swallow it (Morgan and Sethi, 2005; Nausieda et al., 2005). ODT and immediate release carbidopa-levodopa (IR CL) tablets have a similar time to action and duration of action. However, Tmax is achieved faster in ODT compared to IR CL tablets (Ondo et al., 2010). ODT may not be consistently absorbed in patients with ileus. In patients with poor gut motility and severe dysphagia, subcutaneous (SC), sublingual, or transdermal options offer a better drug bioavailability.

Levodopa carbidopa ascorbic acid solution (LCAS): LCAS can be an option for patients with advanced motor fluctuations and limited tolerance to adjunctive medications, patients with dysphagia to pills, or patients requiring nasogastric (NG) feeding (Yang et al., 2017; Sung et al., 2023). One Suggested LCAS recipe is dissolving ten IR CL tablets (100/25 mg) in 1 L of water with ascorbate (2000 mg/L). One ml of LCAS was equivalent to 1 mg of levodopa carbidopa (Sung et al., 2023). The solution can be administered at 1–2-h intervals based on their home LED.

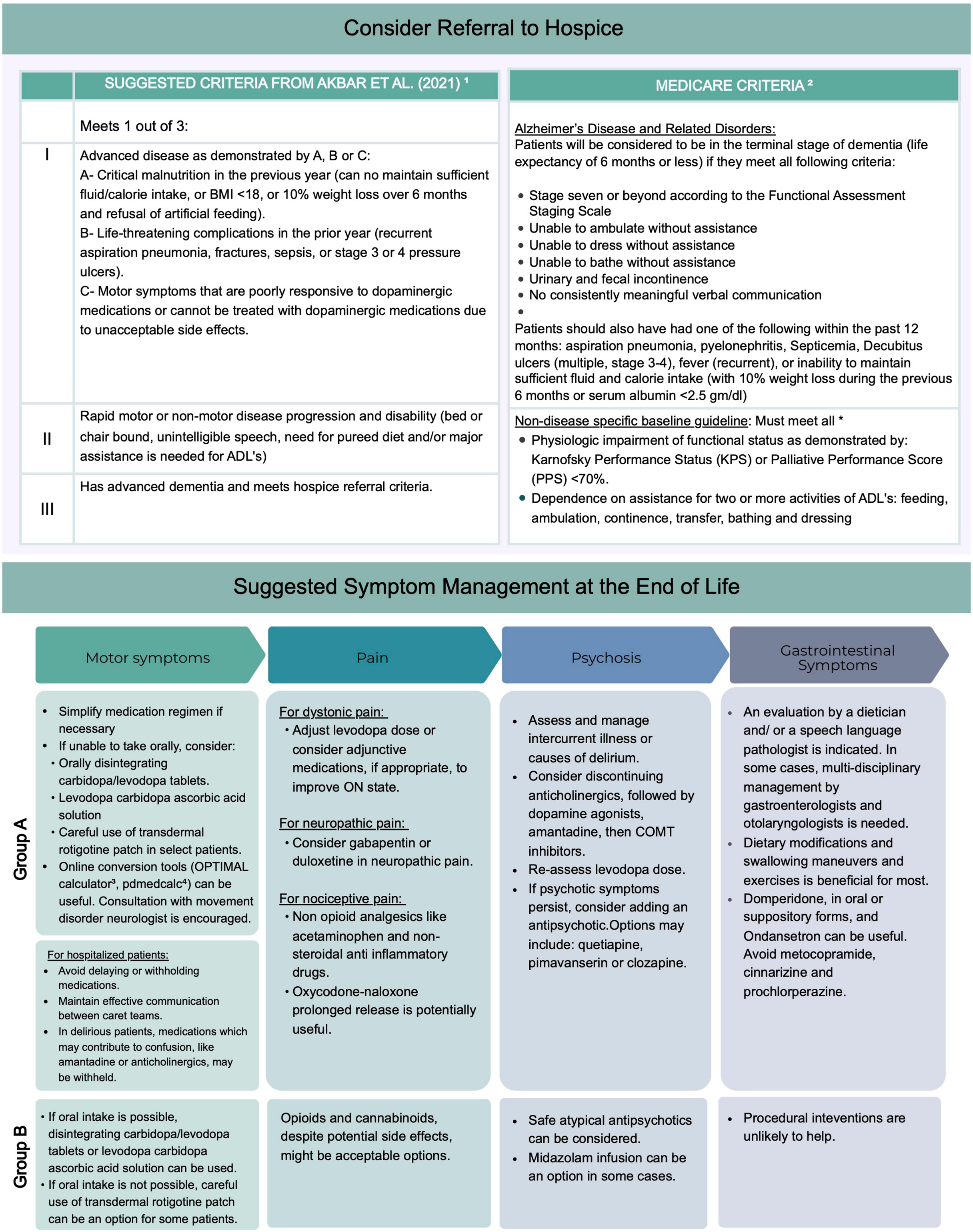
Transdermal rotigotine patch: In cases of poor gastric motility in which patients are not amenable to NG tube placement, transdermal access is the next best strategy. Avoiding inappropriate dosing is necessary especially in patients with dementia. One retrospective study evaluated inpatient use of the rotigotine patch and found that 10% patients had new or worsening hallucinations, and 24% had new or worsening delirium (Ibrahim et al., 2021). The OPTIMAL calculator 2 is publicly accessible and helps calculate rotigotine patch doses based on their prior PD medications (Ibrahim et al., 2021). As part of an initiative to improve hospital safety, the Parkinson Foundation had published a report highlighting the inherent risks of inpatient care(Amodeo et al., 2023). The report includes an NPO protocol summarizing temporary dopaminergic substitutions options.

Some advanced therapies for motor complications can be considered for selected PwP. These include levodopa carbidopa intestinal gel (LCIG) and apomorphine. While they can be utilized for those who had been initiated on these agents previously and temporarily lack safe oral access, initiating such therapies is often not feasible for newly admitted patients for other reasons. Additionally, LCIG initiation is unlikely beneficial in hospice-eligible patients. The guidelines of the European Academy of Neurology and the European section of Movement Disorders Society (EAN-ES MDS) for invasive therapies suggest that clinicians consider offering LCIG to eligible patients with motor fluctuations that are not satisfactorily controlled with oral medications. Based on the results of two trials, LCIG was found to improve both motor and non-motor symptoms across all subdomains, as measured by the non-motor symptom scale (Antonini et al., 2017; Deuschl et al., 2022). In the GLORIA registry, participants had a mean age of 66 years and a mean PD duration of 13 years. Therefore, results may not apply to patients with more advanced parkinsonism. While studies have demonstrated the beneficial effects of motor and non-motor symptoms on patients with LCIG in advanced stages of Parkinson's disease, (Kamel and Al-Hashel, 2020) its applicability to most patients nearing the end of life is unlikely. Firstly, obtaining insurance authorization for this procedure might prove unfeasible or challenging when patients are in an inpatient setting and/or under hospice care. Secondly, the approval process generally spans several weeks, and given the constraints imposed by the advanced nature of their condition, this option may not be viable. Lastly, surgical interventions may often misalign with the patient's goals. Although literature supporting these observations is lacking, these are common pitfalls that the authors have encountered in their clinical practice.

With regards to apomorphine, it was initially licensed in the United Kingdom in 1993 (APO-go®, Britannia Pharmaceuticals Ltd., United Kingdom), which was followed by additional licensure in European and non-Euorpean countries. In the United States, apomorphine subcutaneous infusion, as opposed to apomorphine subcutaneous pen, is not yet FDA-approved (Pietz et al., 1998; Odin et al., 2015). There is insufficient evidence on the safety of apomorphine infusion in PwP at EOL. In the broader context of managing advanced PD, the EAN-ES MDS guidelines suggests offering apomorphine infusion to eligible patients. The recommendation is based on a single randomized clinical trial and a few open label studies (Deuschl et al., 2022). Patients were excluded from the TOLEDO trial if they had atypical parkinsonism, a significant postural instability or orthostatic hypotension, cognitive impairment, or moderate psychosis. Side effects were frequent in the treatment group, including 22% experiencing nausea and somnolence (Katzenschlager et al., 2018). Incidence of neuropsychiatric side effects range was 36–44% and orthostatic hypotension was seen in up to 16% of patients.

5.2.1.2. Group B

LCAS can be used for those who can swallow. Transdermal rotigotine patches can be considered to minimize discomfort and rigidity at EOL when oral intake is not possible, although there might be considerable risks of delirium, agitation and psychosis as previously mentioned (Hindmarsh et al., 2021; Ibrahim et al., 2021).



Consider Referral to Hospice

	SUGGESTED CRITERIA FROM AKBAR ET AL. (2021) ¹
	Meets 1 out of 3:
I	Advanced disease as demonstrated by A, B or C: A- Critical malnutrition in the previous year (can no maintain sufficient fluid/calorie intake, or BMI <18, or 10% weight loss over 6 months and refusal of artificial feeding). B- Life-threatening complications in the prior year (recurrent aspiration pneumonia, fractures, sepsis, or stage 3 or 4 pressure ulcers). C- Motor symptoms that are poorly responsive to dopaminergic medications or cannot be treated with dopaminergic medications due to unacceptable side effects.
II	Rapid motor or non-motor disease progression and disability (bed or chair bound, unintelligible speech, need for pureed diet and/or major assistance is needed for ADL's)
III	Has advanced dementia and meets hospice referral criteria.

MEDICARE CRITERIA ²
Alzheimer's Disease and Related Disorders: Patients will be considered to be in the terminal stage of dementia (life expectancy of 6 months or less) if they meet all following criteria: • Stage seven or beyond according to the Functional Assessment Staging Scale • Unable to ambulate without assistance • Unable to dress without assistance • Unable to bathe without assistance • Urinary and fecal incontinence • No consistently meaningful verbal communication • Patients should also have had one of the following within the past 12 months: aspiration pneumonia, pyelonephritis, Septicemia, Decubitus ulcers (multiple, stage 3-4), fever (recurrent), or inability to maintain sufficient fluid and calorie intake (with 10% weight loss during the previous 6 months or serum albumin <2.5 gm/dl)
Non-disease specific baseline guideline: Must meet all * • Physiologic impairment of functional status as demonstrated by: Karnofsky Performance Status (KPS) or Palliative Performance Score (PPS) <70%. • Dependence on assistance for two or more activities of ADL's: feeding, ambulation, continence, transfer, bathing and dressing

Suggested Symptom Management at the End of Life

	Motor symptoms	Pain	Psychosis	Gastrointestinal Symptoms

Group A	• Simplify medication regimen if necessary
	• If unable to take orally, consider:
	  • Orally disintegrating carbidopa/levodopa tablets.
	  • Levodopa carbidopa ascorbic acid solution
	  • Careful use of transdermal rotigotine patch in select patients.
	• Online conversion tools (OPTIMAL calculator³, pdmedcalc⁴) can be useful. Consultation with movement disorder neurologist is encouraged.
	For hospitalized patients:
	• Avoid delaying or withholding medications.
	• Maintain effective communication between caret teams.
	• In delirious patients, medications which may contribute to confusion, like amantadine or anticholinergics, may be withheld.
		For dystonic pain:
		• Adjust levodopa dose or consider adjunctive medications, if appropriate, to improve ON state.
		For neuropathic pain:
		• Consider gabapentin or duloxetine in neuropathic pain.
		For nociceptive pain:
		• Non opioid analgesics like acetaminophen and non-steroidal anti inflammatory drugs.
		• Oxycodone-naloxone prolonged release is potentially useful.
			• Assess and manage intercurrent illness or causes of delirium.
			• Consider discontinuing anticholinergics, followed by dopamine agonists, amantadine, then COMT inhibitors.
			• Re-assess levodopa dose.
			• If psychotic symptoms persist, consider adding an antipsychotic.Options may include: quetiapine, pimavanserin or clozapine.
				• An evaluation by a dietician and/ or a speech language pathologist is indicated. In some cases, multi-disciplinary management by gastroenterologists and otolaryngologists is needed.
				• Dietary modifications and swallowing maneuvers and exercises is beneficial for most.
				• Domperidone, in oral or suppository forms, and Ondansetron can be useful. Avoid metocopramide, cinnarizine and prochlorperazine.

Group B	• If oral intake is possible, disintegrating carbidopa/levodopa tablets or levodopa carbidopa ascorbic acid solution can be used. • If oral intake is not possible, careful use of transdermal rotigotine patch can be an option for some patients.	Opioids and cannabinoids, despite potential side effects, might be acceptable options.	• Safe atypical antipsychotics can be considered. • Midazolam infusion can be an option in some cases.	• Procedural interventions are unlikely to help.

FIGURE 2

Suggested criteria for hospice referral and suggested outline for management of common symptoms at end of life. Group 1 includes recommendations that apply to the majority of patients with parkinsonism receiving palliative care at end of life. Group 2 includes suggestions that apply to more frail patient anticipated to have shorter life expectancy (Akbar et al., 2021)[1]; (Centers for Medicare and Medicaid Services, 2023)[2], (Fisher et al., 2017)[3]. ADLs, activities of daily living.

5.2.2. Non motor symptoms

5.2.2.1. Pain

5.2.2.1.1. Group A

The PD-Pain Classification System (PD-PCS) helps identify PD-related pain and non-PD related pain. Pain can be neuropathic, nociceptive (musculoskeletal, dyskinesia, or dystonic), or nociplastic (neuropsychiatric, central; Mylius et al., 2021). The success in treating pain is determined by identifying the cause. Unfortunately, many medications used in pain management at EOL (e.g., opioids) can worsen many non-motor symptoms of parkinsonism like hypotension, delirium, and constipation, to name a few. Agents like Gabapentin and duloxetine are reasonable pharmacological options for treating neuropathic pain (Djaldetti et al., 2007). For nociceptive pain, first line agents include acetaminophen and non-steroidal anti-inflammatory drugs (Buhmann et al., 2020) though insufficient evidence was found to support the use of oxycodone-naloxone prolonged-release capsules, it was considered potentially useful in a systematic review (Seppi et al., 2019).

If pain is felt to be related to the OFF state or represents a dyskinetic or dystonic wearing off pain, then increasing the levodopa dose may alleviate the pain. The use of adjunctive medications to prolong the ON period may be helpful (Buhmann et al., 2020). Focal, cramping or dystonic pain can respond well to botulinum toxin A injections. Consulting a movement disorder specialist with expertise in injections is recommended. A trial investigated the utility botulinum toxin A in reducing dystonic limb pain in advanced parkinsonism. Injections were found to be safe although pain reduction was not significantly different from placebo (Bruno et al., 2018). In many practices, there are logistic barriers to implementing inpatient neurotoxin injections.

One meta-analysis investigating the overall effectiveness of different therapies in PD pain found a greater pain reduction with safinamide, followed by cannabinoids, opioids, multidisciplinary pain management, catechol-O-methyltransferase inhibitors, electrical and Chinese therapies (Qureshi et al., 2018). Supplementing vitamins B6, B12, and folate helps prevent homocysteine-induced length-dependent peripheral neuropathy that can occur due to peripheral metabolism of levodopa. Some movement disorders experts suggest a single multivitamin that includes these vitamins should be a part of the daily medications for every PwP who is getting levodopa therapy (Ahlskog, 2023).

5.2.2.1.2. Group B

Although opioids have bothersome side effects, such as constipation and somnolence, they are still acceptable at EOL for PwP in this group. Opioids can be particularly useful in managing not only pain in the last days of life, but also shortness of breath. When unable to swallow tablets, alternative methods of administering opioids like syringe drivers have been used with success (Campbell et al., 2010; Butt et al., 2019; Żylicz, 2022).

Concentrated forms of liquid opioids, such as morphine, oxycodone and hydromorphone, are available and can be administered sublingually. Immediate-release opioid tablets can also be administered intrarectally.

5.2.2.2. Dementia and psychosis

5.2.2.2.1. Group A

Psychosis in PwP could reflect disease progression or be a complication of dopaminergic therapies. Optimal management of motor symptoms may be at odds with managing neuropsychiatric symptoms in advanced parkinsonism. There is paucity of controlled studies examining the comparative efficacy and safety of different algorithms for managing acute agitation and psychosis among PwP in-hospital. This section provides general guidance to manage psychosis which may be applicable to inpatient management. Intercurrent illnesses like respiratory and urinary tract infections, constipation, dehydration, electrolyte derangements must be treated promptly. As a next step in managing hallucinations or other psychotic symptoms in PwP who are treated with complex regimens, medications should be reviewed with the aim of reducing or discontinuing potentially offending medications. Anticholinergics should be stopped first, followed by selegiline, dopamine agonists, amantadine, and COMT inhibitors (Friedman and Factor, 2000). Levodopa dose then should be re-assessed. If psychosis persists and further dose reduction will cause bothersome motor impairment, antipsychotics can be added. First generation antipsychotics should be avoided (Żylicz, 2022). Among atypical antipsychotics, quetiapine and clozapine are the preferred agents. Antipsychotics improve the symptoms of psychosis-hallucinations, agitation, and the confusion that may accompany delirium events. They do not improve the confusional state in PwP which is a result of cognitive impairment. Hence, treating these symptoms should be based on the degree of discomfort the patient and the family experience (Friedman and Factor, 2000). Pimavanserin is a novel antipsychotic that received FDA approval in 2016 to manage psychosis and visual hallucinations in PD Psychosis (Cusick and Gupta, 2023). It has shown to reduce hospitalization and mortality rates compared to quetiapine (Sankary et al., 2020; Layton et al., 2023). Although the average age of the patients in two groups were 80, patients that had claims for hospice or palliative care were excluded from both these studies. Currently, it is only available as an oral formulation. Importantly, it is the first antipsychotic without any dopaminergic antagonism and has no significant drug interactions with carbidopa/levodopa (Meltzer and Roth, 2013). Notable contraindications include QT prolongation. While the manufacturer does not does not suggest dose adjustment in renal disease, caution is recommended when treating those with severe renal impairment.

At EOL, many PwP are on medications to manage cognitive impairment. Rivastigmine has been shown to reduce the decline of PD dementia compared to placebo in a 6 month follow up, with maximum efficacy within 3 months. Rivastigmine may also be beneficial for PwP with hallucinations (Zahodne and Fernandez, 2008; Lokk and Delbari, 2012). Common side effects include gastrointestinal symptoms. Donepezil is sometimes used to manage PD dementia. The Movement disorders Society evidence-based review of non-motor symptoms therapeutics rated donepezil as insufficient evidence but potentially useful (Seppi et al., 2019). The most common reported side effect in the PD population with donepezil is psychosis and dizziness along with GI side effects (Ravina et al., 2005). Careful consideration should be made when continuing these medications, especially when concomitant side effects can hamper QOL.

5.2.2.2.2. Group B

Terminal agitation experienced in PwP can be managed with midazolam. Pimavanserin and preferred atypical antipsychotics (clozapine and quitepine) can be safely used in this population. Cholinesterase inhibitors may be discontinued to reduce pill burden (Żylicz, 2022).

5.2.2.3. Gastrointestinal symptoms

5.2.2.3.1. Group A

Nausea, dysphagia, and malnutrition are quite common in advanced PD. When concerns about weight loss and/or swallowing dysfunction emerge, an evaluation by a dietician and/or a speech language pathologist is indicated. In some cases, multi-disciplinary management by gastroenterologists and otolaryngologists is necessary to guide individualized management. A consensus statement on the management of gastrointestinal manifestations of PD was published in 2021 (Schindler et al., 2021). Most patients will benefit from dietary modifications and swallowing maneuvers and exercises. Domperidone is a peripheral D2 dopamine blocker which only crosses the blood brain barrier in minute amounts minimizing risk of aggravating parkinsonism. It can be considered for the management of nausea or dyspepsia in PwP. Available formulations include an oral tablet and a suppository and it can be administered 30 min prior to a meal. Domperidone is not available in the US. Its use is deemed possibly efficacious and supported by Class II-IV evidence per a review for the Movement Disorder society Task Force (Ferreira et al., 2013; Seppi et al., 2019). On the other hand, metoclopramide, cinnarizine and prochlorperazine, some of which are commonly antiemetics in hospice, carry a significant risk of worsening parkinsonism and should be avoided. Ondansetron, a 5HT3 receptor antagonist, is likely beneficial and well tolerated. Interestingly, several studies have also shown benefit of this agent in PD psychosis (Kwan and Huot, 2019). For persistent nausea, dyspepsia or gastric dysmotility despite pharmacological management, referral to gastroenterology should be considered.

Limited data is available on non-invasive brain stimulation for dysphagia. Published studies on transcutaneous electrical stimulation do not suggest swallowing benefit (Schindler et al., 2021). Procedural interventions might be considered for a subset of patients under the supervision of the multidisciplinary team. With data from Class IV evidence, neurotoxin injection to the cricothyroid muscle, by an experienced clinician, may be an option to manage those whose swallowing dysfunction is primarily related to upper esophageal spasm (Schindler et al., 2021). Nutritional modifications should take into account both the safety aspects as well as nutritional status. Patients with advanced PD receiving LCIG were reported to experience improvements across many non-motor symptoms including gastrointestinal symptoms although weight loss was reported in 6.7% of patients in one large registry (Abbruzzese et al., 2012; Antonini et al., 2017; Kamel and Al-Hashel, 2020). There are no specific recommendations for percutaneous endoscopic gastrostomy (PEG) placement in PD. Similar to other conditions, experts suggest PEG can be considered when severe swallowing dysfunction lasts more than 4 weeks resulting in weight loss (Schindler et al., 2021). Decisions should be individualized, taking into account the patient's perspective, prognosis and overall medical status. For PwP who receive LCIG, enteral nutrition via the gastric port can be provided when needed while monitoring for possible changes in medication absorption.

5.2.2.3.2. Group B

Procedural interventions for dysphagia and PEG are unlikely to help in this population.

6. Conclusion

In conclusion, this study sheds light on the complex and often challenging landscape of providing care to patients with Parkinson's disease (PD) near the end of life (EOL). The study touched on underutilization of PC resources for this population despite the high burden of comorbidities and frequent hospital admissions in the last year of life. Majority of the patients were full code, and less than majority of the patients were seen by PC. Patients who passed in the hospital had a higher health care resource utilization (invasive procedures, ICU transfers) and lower PC involvement. The findings highlight the need for improved integration of palliative care (PC), particularly in the inpatient setting. The delayed involvement of PC services and the mismatch between patient/family expectations and providers' goals of care highlights the importance of early recognition of declining health trajectories and initiating conversations about advance care planning. The study also highlights the complexities of medication management for inpatient PD patients. Frequent deviations from home medication regimens in both EOL and non-EOL group, included underdosing. Fortunately, giving contraindicated medications and missing medications for PD were uncommon errors.

Additionally, efforts to develop standardized guidelines for PC integration, advance care planning, and medication management for patients with advanced PD at EOL are essential to improve patient outcomes and quality of care.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Cleveland Clinic Institutional Review Board, IRB # 21-1128. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

SB: Data curation, Methodology, Conceptualization, Formal analysis, Visualization, Writing – Original draft, Writing – Review & editing. EA: Data curation, Methodology, Writing – Original draft, Writing – Review & editing, Formal analysis, Visualization. JY: Data curation, Writing – Review & editing. NM, CS, OH: Formal analysis, Writing – Review & editing. BW: Writing – Review & editing. RS, AM: Conceptualization, Supervision, Visualization, Writing – Review & editing.

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Conflict of interest

BW serves as Section Head of Movement Disorders at the Cleveland Clinic. Over the years, he has received research grants from the NIH and Parkinson's Foundation. He has served as site investigator and /or co-investigator for clinical research studies sponsored by grants from Industry to Cleveland Clinic. Currently, he site PI for Neuroderm (Mitsubishi Tanabe Pharma), Discern (Great Lakes Neurotech/NIH R44), Tempo2, and Tempo3 studies (Cerevel Therapeutics) and a grant from the Parkinson's Foundation to improve the inpatient care of People with PD. He has served as a consultant or speaker for Medtronic, Boston Scientific, and Abbott for less than $5,000 in the last year.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The author(s) declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

Publisher's note

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Safety perception in patients with advanced idiopathic Parkinson's disease – a qualitative study

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Background: A fundamental cornerstone of quality of healthcare is patient safety, which many people with life-limiting illnesses feel is being compromised. Perceptions of impaired safety are associated with the occurrence of psychological distress and healthcare utilization. However, little is known about how people with idiopathic Parkinson's disease (iPD) perceive their own safety toward the end of life. The aim of our study was therefore to investigate factors that influence the perception of safety of patients with advanced iPD.

Methods: We conducted semi-structured interviews with a purposeful sample of 21 patients with advanced iPD. Participants were recruited at the neurology department of a tertiary care hospital in Germany between August 2021 and June 2022. Data were analyzed using reflexive thematic analysis.

Results: iPD-patients reported relevant impairment of their safety. While most participants expressed safety concerns based on the manifestation of disease, our analysis identified enablers and barriers to establishing safety in patients with advanced iPD, in 10 additional domains: relationship to the disease, informedness, self-perception, utilization of support and care structures, healthcare professionals and structures, treatment, social interaction, social security, spirituality, and environment.

Conclusion: This study provides new insights into safety perceptions of patients with advanced iPD, which extend well beyond the physical realm. The findings suggest that clinicians and policy makers should consider a holistic and multidisciplinary approach to assessing and improving patients' safety taking into account the enablers and barriers identified in this study.

KEYWORDS

Parkinson disease, patient safety, safety, quality of healthcare, palliative care, qualitative research

Introduction

Idiopathic Parkinson's disease (iPD) is a common neurodegenerative disorder that increases with age, and in its advanced stages, is characterized by impairment of activities of daily living, symptom burden, and reduced quality of life (Fasano et al., 2019; Feigin et al., 2019). Given the rapidly growing incidence (Feigin et al., 2019), it is a logical consequence that the disease has been recently declared a public health issue with the aim of improving the care of iPD-patients (World Health Organization, 2022). This seems all the more important as iPD specialists are not confident about the quality of care their patients receive in hospital, leading to the recommendation that hospital staff and clinicians should be thoroughly educated about the disease, including management, potential complications and medications to avoid (Chou et al., 2011).

This knowledge contributes to the understanding that one of the pillars of high-quality healthcare is patient safety (World Health Organization, 2019). According to a white paper, patient safety is defined as the extent, determined from the patient's perspective, to which individuals, professional groups, teams, organizations, associations and the healthcare system

(1) are in a state where adverse events are rare, safety behaviors are promoted and risks are controlled,
(2) are able to recognize safety as a worthwhile goal and implement realistic options for improvement, and
(3) are able to use their innovation skills to achieve safety (Schrappe, 2018).

Consequently, patients are assigned an essential role in defining and advancing patient safety (Schrappe, 2018; World Health Organization, 2021). Patients are thought to provide valuable insights into safety that complement existing measurement of patient safety and challenge common definitions of patient safety incidents that focus on physical risks (O'Hara et al., 2018). In this context, although there is a large number of studies dealing with safety aspects in patients with advanced iPD, they are mostly limited to side effects of available treatment options. However, evidence on patient safety in mixed populations with life-limiting conditions suggests that a patient-centered approach must consider safety issues beyond the physical domain to meet patient priorities in healthcare (Pedrosa Carrasco et al., 2021, 2022). These may include factors (e.g., risk behaviors in informal care, abuse, unsafe neighborhoods, natural disasters) that are not a function of healthcare itself, but which may be essential to consider in order to provide holistic care. This is all the more important given that a perception of compromised safety among patients is not only associated with pronounced psychological symptoms such as anxiety and depression (Vincent and Coulter, 2002), but in populations of severely ill patients has been shown to make the decision to present to hospital more likely (Henson et al., 2016; Robinson et al., 2018).

Nevertheless, despite the fundamental importance of patients themselves in establishing safety in the healthcare system, little is known about iPD-patients' own perceptions of safety. A comprehensive understanding of this could yet be used to promote a differentiated and individualized approach to both safety assessment and the implementation of safety measures. This study set out to examine experiences of hospital patients with advanced iPD to ultimately gain knowledge on how to improve patient safety and, therefore, care for iPD-patients across the care continuum.

Methods

Study design

We conducted a qualitative study to explore the experiences and views on perceived safety in order to identify enablers and barriers. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guided reporting (Tong et al., 2007).

Recruitment

We recruited iPD-patients with advanced disease according to current literature (Antonini et al., 2018) under the care of the Department of Neurology at the University Hospital of Marburg, Germany. Participants were purposefully selected according to key characteristics (age, gender, marital status, living situation and history of migration) (Bowling, 2014) to capture a breadth of views and ensure diversity. Patients were not deemed eligible if they had insufficient German language skills or cognitive inability to give informed consent. Eligibility was determined by the treating physician, but patients were invited to participate by the interviewer.

Data collection

Participants' socio-demographic data were collected prior to the interview. The research team with expertise in neurology, palliative care and medical ethics developed an interview guide for semi-structured qualitative interviews. The guide comprised open-ended questions aiming at the participants' experiences and perceptions of safety (*cf.* Supplementary Table 1 for English translation). All interviews were conducted face-to-face on the hospital premises by AP. In some cases, due to the immobility of the participants, it was necessary to conduct the interview in the patient's room. However, privacy was always ensured. There was no pre-existing relationship between participants and interviewer. Interviews were digitally audiotaped and transcribed verbatim. Care was taken to anonymize any identifiable references to participants, staff or care providers. For publication, illustrative quotes were pseudonymized and translated from German into English by a fluent speaker. The sample size allowed for an in-depth exploration of an under-researched aspect and provided rich data appropriate to answer the research question (Braun and Clarke, 2021b).

Analysis

MAXQDA was used to assist in data management. We performed reflexive thematic analysis following six stages: (1) familiarization with data, (2) development and refinement of inductive codes, (3) constructing of initial themes, (4) development and review potential themes (5) refinement, definition, and naming themes, (6) reporting (Braun and Clarke, 2021a). For the first five interviews, AP and MvM independently created codes from which a coding scheme was reached through consensus discussions. The resulting preliminary coding scheme was applied by AP to the analysis of the remaining interview transcripts and expanded as new codes and themes were identified.

Results

Participants

We approached 22 iPD-patients of whom 21 consented to participate. Interviews were performed between August 2021 and June 2022 and had a median length of 20 min (range 8–59 min). One interview had to be terminated early because the participant suddenly felt too unwell to be able to concentrate sufficiently on the questions being asked. However, the data already collected could be used for our analysis. Detailed participant characteristics are shown in Table 1. Supplementary Table 2 shows the percentage distribution of the individual indicators of advanced iPD identified by Antonini et al. (2018).

TABLE 1 Participant characteristics.

Demographics	
Gender (%)	
Female	11 (52.4)
Male	10 (47.6)
Median age in years (range)	66 (49–84)
Median time since diagnosis in years (range)	9 (1–30)
Civil status (%)	
Married	15 (71.4)
Single	2 (9.5)
Divorced	3 (14.3)
Widowed	1 (4.8)
First-generation immigrants and/or holders of dual citizenship (%)	5 (23.8)
Professional education (%)	
None	3 (14.3)
Non-university degree	11 (52.4)
University degree (including technical college)	7 (33.3)
Living situation (%)	
Own household	17 (81.0)
With relatives	1 (4.8)
Assisted living	1 (4.8)
Nursing home	2 (9.5)
Clinical context (%)	
Inpatient Parkinson complex treatment	15 (71.4)
Emergency hospitalization	2 (9.5)
DBS implantation	1 (4.8)
Medication pump installation	1 (4.8)
3-month follow-up after DBS implantation	1 (4.8)
Routine outpatient visit	1 (4.8)

DBS, deep brain stimulation.

Main findings

We identified barriers and enablers to the implementation of patient safety in iPD-patients. These were related to 11 themes, which are presented in Table 2. Figure 1 shows the multidimensional architecture of patient safety in iPD based on the identified themes.

Relationship to the disease

The relationship to their illness in terms of processing and acceptance was crucial for the participants' perceptions of safety. In particular, coping with the disease itself was associated with an increased sense of safety. This was fostered, among other factors, by optimism, resilience and empowerment through achievement.

> *"I didn't let the illness affect me and I didn't hang my head, in that sense. It was like this: I had the disease in a pocket. It was there, but I still lived normally." (Participant 2, male, 63 years)*

For some, safety meant being open about the disease and its associated symptoms, as hiding the condition from others was associated with fear of discovery.

> *"I always say that if you are open about it and if you also say: Hey, I'm not feeling so well today, that's easier than retreating into a quiet closet." (Participant 11, female, 53 years)*

Disease manifestation

Almost all participants agreed on feelings of insecurity caused by symptoms of the disease. This was mainly the case for motor symptoms, where actual falls or perceived risk of falls were particularly emphasized.

> *"I've already fallen a few times. Sometimes I feel a bit tingly. And my hands, I already have so much pain there, and my arms, I feel unsafe. Not as safe as it should be." (Participant 16, male 76 years)*

However, participants also attributed special relevance to non-motor symptoms in the experience of safety such as pain, constipation and incontinence. However, physical safety was rarely mentioned in this context; the safety affected by these symptoms was mainly deemed to be of social nature, which for some encouraged social withdrawal.

> *"When you go travelling...that's not possible, if only because of the incontinence. I have pads that can absorb most of it. But you can see that the clothes, that it shows through." (Participant 15, male, 72 years)*

Furthermore, some participants reported psychological safety concerns due to symptoms such as depression, panic attacks and delusions. For two participants, the psychological distress even culminated in suicidal thoughts, with one of them being admitted to a psychiatric hospital.

TABLE 2 **Themes and subthemes relevant to iPD-patients' perception of safety divided into enablers and barriers.**

Themes	Enablers	Barriers
Relationship to the disease	Coping	
	Openness	
Disease manifestation		Motor symptoms
		Non-motor symptoms
		Comorbidities
		Uncertain future
Informedness	Own informedness	Lack of information
	Informedness of relatives	
Self-perception	Activity	Everyday dysfunctionality
		Anxiousness
Utilization of support and care structures	Healthcare facilities and services	
	Residential care and assisted living	
	Informal support services	
Healthcare professionals and structures	Professional Expertise	Lack of professional expertise
	Trust in healthcare professionals	Lack of trust in healthcare professionals
	Patient-centered care	Deficits in professional-patient communication
		Structural deficits of healthcare
Treatment	Non-medical treatment	Complications and side effects of medication
	Medical treatment	DBS-Implantation
	Medical aids	
Social interaction	Support from family and friends	Weaknesses in the family structure: Lack of support Family's breaking point Difficulties in living up to the partnership Family conflicts
	Thoughtfulness of others	Hurdles in social life: Lack of understanding and stigmatization Social overstrain Social isolation
Social security	Professional stability	Incapacity to work and job loss
	Financial stability	Financial stress
Spirituality	Drawing from faith	
Environment	Familiar environment	Unfamiliar environment
	Barrier-free living	Physical barriers
	Routine	Discontinuity in routine
		Traffic
		COVID pandemic

> *"Because of these panic attacks that build up, I always think about suicide or 'Is my wife doing what we agreed in the advance directive? Will she make sure that I have a proper death?" (Participant 12, male, 61 years)*

Uncertainties regarding the future were another source of feeling unsafe. This mainly concerned fears about the course of the chronic progressive disease including the end of life, the associated need for care and unpleasant connotations with dependence.

> *"Of course, I'm thinking about the future and how it will go on [...] Those are the two insecurities. So one is experienced insecurities (.) and the other is fear of the future." (Participant 3, male, 67 years)*

Informedness

Being informed about Parkinson's disease, but also having well-informed relatives, was perceived by many as promoting safety as it resulted in mental preparation and empowerment.

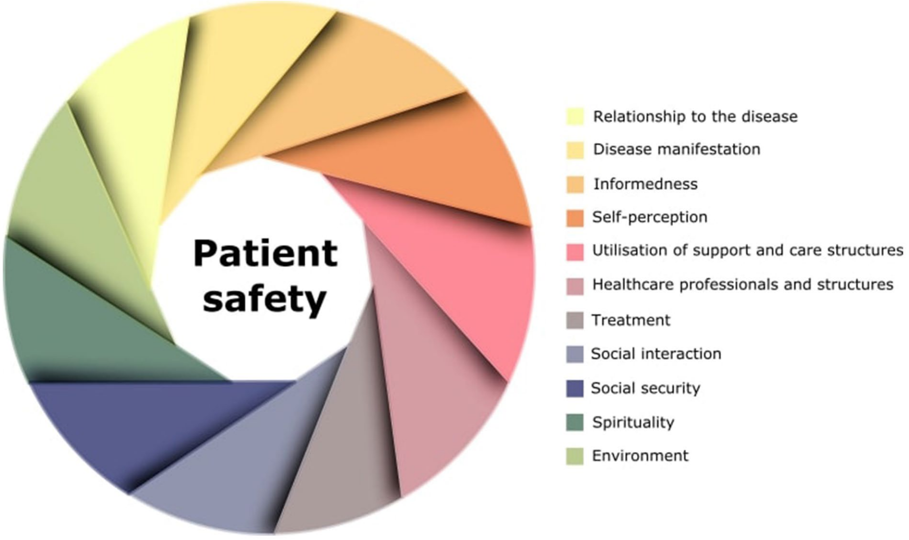

FIGURE 1
Domains relevant to patient safety in iPD.

> *"Yes, it is definitely important […] to say that this is the reason why this is the way it is, this is how it comes about. It's always better to be in the know, because if you only find out about it today or live according to it, you have been given a lot of quality of life." (Participant 2, male, 63 years)*

Conversely, two participants reported that a lack of information about the disease and its treatment led to a relevant feeling of insecurity.

> *"When you are given medication that you don't know, it makes you insecure as to how it is compatible with all the other medication that I have to take every day. I would have hoped for a bit more information, but you don't get a proper answer anywhere." (Participant 21, female, 75 years)*

Self-perception

Participants also reflected on their own nature and role as actors in creating safety or insecurity. Some expressed safety concerns in their daily lives because they found themselves overwhelmed or uncomfortable being dependent on others. Most participants experienced a sense of safety as long as they were physically active as they felt more mobile and were less aware of the physical symptoms.

> *"I usually feel safer when I move properly. When I walk, when I pace, I generally feel safer because then I feel active and I think to myself: 'Parkinson's is actually nothing. It can't affect me'." (Participant 13, male, 49 years)*

However, one participant also stated that she had felt anxious and insecure all her life due to her personality traits, which provided a fragile foundation for her patient safety in the context of iPD.

> *"Yes, it's because I've always been afraid all my life, although it's not a thing to be afraid of. I'm always afraid of Santa Claus in disguise, when I see his face." (Participant 6, female, 78 years)*

Utilization of support and care structures

Utilization of support and care structures was perceived valuable in providing safety. This included healthcare facilities and services, residential care and assisted living as well as informal support services such as support groups and volunteers.

> *"So what gives me safety now is that I'm in a nursing home. I find that quite safe." (Participant 6)*

Healthcare professionals and structures

Interactions with healthcare professional also played a major role in participants' perceived safety. Professional expertise and, closely related to this, the trust placed in staff had a positive effect. In addition, however, patient-centered care encompassing empathy, dedication of time and holistic approaches was considered vital for the experience of safety.

> *Participant: "Yes, they [care team] gave me safety."*
>
> *Interviewer: "What was decisive for that?"*
>
> *Participant: "Humanity, ability, knowledge. (…) Yes, competence and humanity." (Participant 18, female, 54)*

However, when these characteristics were absent in the staff-patient-relationship, patient safety could be compromised. In particular, many participants reported communication deficits, a lack of compassion and a feeling of not being heard. For example, participants reported that healthcare professionals - unaware of the fluctuating symptoms associated with the on–off phenomenon - blamed participants for being lazy when in fact they were suddenly unable to perform certain activities.

> *"I rang the bell and said: "Can you please help me go to the toilet?" She hung her hands and said: "No, you can go yourself! I can't help you! You walk during the day and you can't walk at night." And I said: "Yes, if I can, I'll do it myself". But I couldn't go." (Participant 9, female, 76 years)*

But structural deficits in care, such as work overload, lack of communication between professional groups or discontinuity in care were also among risk factors for reduced sense of safety.

> *"But he [former treating physician] is no longer at the hospital and since he left, I have had different doctors all the time […] Everyone always tries their best and messes around [with DBS]. And that always worse." (Participant 11, female, 53 years)*

Treatment

The therapeutic success of the different non-medical and medical treatment methods alone brought a sense of security for many participants.

> *On the second day after [DBS-]surgery, I danced with my friends in the hospital room. […] This experience that they were able to help me so well with this is the best thing I have against my fears. (Participant 3, male, 67 years)*

However, feared and experienced complications and side effects of the various therapy options could also be a reason for feeling unsafe.

> *Every new [medication] adjustment is associated with a change and this usually makes you feel insecure. (Participant 1, female, 52 years)*

Mobility-enhancing aids, especially walkers, were seen by many participants as a way of improving safety in the face of the risk of falling.

> *"I'm safer with the walker. I'm safer with it in my hand than without it. There's no doubt about that. Also with the wheelchair, if things are not going well you can sit in it. You're also better off with it." (Participant 5, male, 58 years)*

Social interaction

Support of a practical and emotional nature from the personal environment of the participants, especially the family, was perceived as promoting safety.

> *"When the partner is there! That's very safe then! Or if siblings, close relatives or people who are close to me. I'm safe then." (Participant 19, female, 64 years)*

Yet, weaknesses noticed in the family structure could contribute to a feeling of insecurity: lack of support, overburdened family carers, patient's struggle to living up to the partnership, and family conflicts.

> *"So I'm afraid (…) that I won't be able to maintain the minimum with my wife, because I live with her. I am also afraid of that. I don't think she would leave me, but (…)." (Participant 3, male, 67 years)*

While an understanding attitude of others toward the person with iPD was helpful, the participants often felt insecure due to shortcomings in social life. In addition to stigmatization, they frequently experienced the feeling of being overwhelmed when surrounded by other people.

> *"We just choose what I can eat. A bread dumbling, my husband cuts it, he then cuts it into small pieces and I can eat it with a spoon. But that is difficult. At the beginning I thought: 'Uh, now everyone is looking. The world is over." (Participant 19, female, 64 years)*

Participants regretted that they felt alone or socially withdrawn, which had a negative impact on their sense of security.

> *"You feel alone and abandoned. Before I couldn't – I was willing to talk to some people. I don't do that anymore. That questioning, that – I don't know, I have a feeling of being unsafe already. But I don't know what to do about it." (Participant 10, female, 84 years)*

Social security

Some participants mentioned that social security through professional and financial stability gave them a feeling of safety as they believed to be prepared for the contingencies of an uncertain future.

> *"If you have enough dough [money], it's no problem, but that's the prerequisite." (Participant 14, male, 79 years)*

Others, however, saw their safety compromised in this respect due to the illness, complained about financial disadvantages as a result of being unable to work, taking early retirement or losing their job.

> *"Because my job is dangerous, a crane driver. For example, I worked at the top in the cabin and downstairs there were 60, 80 people working at the steelworks and they said: 'You can't come in here, you're not allowed to work.' Well, the factory doctor said I ought to retire." (Participant 17, male, 66 years)*

Two female participants even reported financial losses due to a gambling addiction most likely caused by the medication.

> *"Yes, lots and lots of side effects. For example, shopping. I used to go shopping, I had everything at home, but still I went shopping at the shop. I always wanted to go to the casino. When I was in [city] in [country] I went to the casino twice a week. And I spent a lot of money." (Participant 9, female, 76 years)*

Spirituality

No participants reported spiritual or religious challenges that affected their sense of safety. However, a few participants felt that faith supported their sense of safety in the experience of illness.

> *"People need something to hold on to. Yes, even if you say that not everything can be like that, but I think there is a point, how should I put it, where you can hold on to it." (Participant 21, female, 75 years)*

Environment

Environmental factors played a vital role in safety establishment. Thus, physical barriers in walking routes in the home and the public were perceived as a relevant threat to safety mostly due to increasing the risk of falls.

> *"I have changed flats. Before, I had to go down steep stairs. Then I gave that up because there was too much danger of falling down the stairs and so on." (Participant 15, male, 72 years)*

iPD-patients felt more comfortable in familiar surroundings whereas unknown environments created a sense of insecurity. In addition, routine in daily life beyond regular medication was given special importance whereas discontinuation of routine was perceived as a safety barrier.

> *"Yes, I think that [routine in nursing home] is safety for me. You always have everything on time at the same time and so on. I think so." (Participant 6, female, 78 years).*

Participation in road traffic, especially as a car driver, but also as a pedestrian, was perceived as a safety hazard by some iPD-patients interviewed.

> *"Until last year, I went to visit the children. I went by car, but that's no longer possible, they have to come to me. I don't like risk, I don't like it. It's a risk when I drive a car, if I'm not well adjusted with medication, the day doesn't go well." (Participant 8, female, 59 years)*

Additionally, current world events such as the COVID pandemic were seen as a barrier to an intact sense of safety, as there were fears of an unfavorable course of infection.

> *"Yes, it was all very scary. Although I was one of the first ones to go with this [...] AstraZeneca. And I was actually vaccinated so early and had to wait three months and that made me feel unsafe." (Participant 5, male, 58 years)*

Discussion

Two major conclusions can be drawn from our qualitative study: (i) the perception of safety in advanced iPD corresponds to a multidimensional construct, and based on this, (ii) a holistic and multi-professional approach in iPD care is indisputable to ensure safety.

Advanced iPD is associated with higher disability and mortality (Barer et al., 2022). Our research indicates that patients' safety perception in advanced stages of the disease is compromised and confirms previous assumptions that patient safety toward the end of life is shaped by the care provided by healthcare staff and informal caregivers, but also by patient-related factors and external factors (Pedrosa Carrasco et al., 2021). We identified various enablers and barriers to patients' perceptions of safety at physical, psychological, social, and spiritual levels.

Participants shared challenges in engendering safety, as well as safety-giving measures during their journey through the healthcare system. Undoubtedly, our study revealed that motor and non-motor symptoms associated with iPD, as well as uncertainty and worries about the future course of the degenerative disease, can lead to feelings of insecurity. It is not surprising, therefore, that therapeutic efforts were considered to be of great importance for the generation of safety. In this context, however, thorough education about medication, including potential side effects, could enhance a sense of safety and promote patient empowerment. That being said, healthcare which deviates from patient needs or grievances have led to a loss of safety among iPD-patients (Owen et al., 2022). This phenomenon does not seem to be unfounded, as iPD-patients are prone to inadequate prescribing and complications during hospitalizations (Gerlach et al., 2011; Mantri et al., 2019; Bakker et al., 2022; Richard et al., 2022). In our study, participants frequently described insufficient understanding of the disease and lack of expertise in terms of treatment specifics on the part of healthcare professionals as the cause of feeling unsafe. This underscores the usefulness of early collaboration among disciplines and facilitated short-term access to centers with movement disorder expertise for iPD-patients with specialized therapeutic approaches. In addition, in the community specially trained nurses could provide care coordination, patient navigation, and information to complement existing care structures (van Munster et al., 2022). Palliative care services may offer further support to promote safe care for patients with advanced iPD (Fleisher et al., 2020).

But even as private individuals outside the healthcare system, people with iPD often felt their safety threatened when they were exposed to social challenges in society. Even though social safety schemas are assumed to develop early in life, these perceptions are shaped by the actual situations people face (Slavich, 2020). In this respect, our study reflected that social self-schemas and world-schemas were of prominent importance in the experience of safety of people with iPD. Social overload and experienced or perceived stigmatization as a result of their condition were described as relevant safety barriers, leading to social withdrawal in many patients. In our study, these social safety schemas were closely interwoven with psychological aspects of safety. Psychological safety concerns result in a reduction in feeling comfortable being and expressing oneself, and sharing worries and failures without fear of embarrassment, ridicule, shame or retribution (Torralba et al., 2020). The study participants reported impaired general social functioning, but also narrated more specific insecurities in the family environment. For example, in line with earlier research revealing negative effects on couple and family relationships (Vatter et al., 2018; Perepezko et al., 2019), some participants feared being a burden to their family, reported disputes grounded in the disease and their insecurity about not being able to fulfil their partnership in the future.

In a North American study, higher spirituality was associated with less impairment of quality of life and less anxiety and depression in patients with Parkinson syndromes, suggesting a potential influence on feelings of safety (Prizer et al., 2020). Given that a minority of Germans perceive themselves as particularly spiritual or religious (Statista, 2017; YouGov, 2021), it was, however, not unusual that none of the participants reported spiritual or religious crises that led to feelings of insecurity. Nevertheless, for a few iPD-patients interviewed, faith and the idea of a divine plan gave them a sense of safety which might be explained by a protective effect against psychological distress (Bernard et al., 2017). Other research projects could revisit the influence on perceived safety in populations where religion and spirituality are more prominent in everyday life.

In summary, while the identified enablers and barriers to the safety of iPD-patients should be considered to ensure a holistic approach to care, our study also provides direct recommendations for healthcare professionals to promote patient safety. These include a sound knowledge of the disease and its treatment options, prescription of medical aids, as well as soft skills such as empathy, patient-centered communication, and teamwork. The basic prerequisite for understanding individual patient safety is, therefore, a thorough medical history that goes beyond the patient's physical complaints to address unmet needs.

Strength and limitations

Our qualitative approach supported explorative investigation of a variety of aspects that contribute to and hinder perceptions of safety in patients with advanced iPD. Nevertheless, there are some important limitations. Recruitment under heterogeneous clinical conditions and exclusion of patients with advanced iPD with severe cognitive impairment may have introduced selection bias. Moreover, given that recruitment took place at a single site in Germany, views may not be representative of patients from other geographical regions. Further research outside Germany could identify country- and health system-specific characteristics of patient safety. In addition, our interview study provided a snapshot; a longitudinal study might yield more information about the variability or persistence of feelings of insecurity.

Conclusion

Our study shows that the perception of safety of people with iPD is subject to a holistic concept based on physical, psychological, social, and spiritual needs. In order to identify safety concerns and address safety issues, multidisciplinary approaches to the care of people with iPD should be adopted. This may include systematically assessing safety concerns and developing safety strategies for patients, taking into account individual characteristics and circumstances. The enablers and barriers identified by our research offer promising starting points for improving the quality of healthcare by informing safety-oriented practice. Nevertheless, complementary quantitative research projects are warranted to estimate the prevalence of individual safety concerns and thus their implications for the healthcare system, and to inform quality improvement initiatives by healthcare professionals and policy makers.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Ethics Committee of the Medical Faculty of the Philipps University of Marburg. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

AP and DP conceptualized and planned the study. AP conducted the interviews and drafted the manuscript. AP and MvM were involved in the qualitative analysis of data. All authors provided critical comments on drafts of the manuscript and approved the final manuscript.

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Conflict of interest

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Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fnagi.2023.1200143/full#supplementary-material

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Risk of hospitalization in synucleinopathies and impact of psychosis

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Background: Few studies have investigated the risk of hospitalization among patients with synucleinopathies (Parkinson disease, Dementia with Lewy Bodies, Parkinson disease dementia, Multiple System Atrophy) with associated psychosis and the impact of antipsychotic treatments on hospital admissions and duration of the stay.

Objective: To determine the risk of hospitalization among patients with synucleinopathies and in patients with associated psychosis. To evaluate the impact of antipsychotic treatments on hospital admission of patients with synucleinopathies and psychosis in an incident cohort study in Olmsted County, Minnesota (MN).

Methods: We used the Rochester Epidemiology Project (REP) to define an incident cohort of patients with clinically diagnosed synucleinopathies (1991–2010) in Olmsted County, MN. A movement disorder specialist reviewed all medical records to confirm the clinical diagnosis of synucleinopathies using the NINDS/NIMH unified diagnostic criteria.

Results: We included 416 incident cases of clinically diagnosed synucleinopathies from 2,669 hospitalizations. 409 patients (98.3%) were admitted to the hospital at least once for any cause after the onset of parkinsonism. The median number of hospitalizations for a single patient was 5. In total, 195 (46.9%) patients met the criteria for psychosis: patients with psychosis had a 49% ($HR = 1.49$, $p < 0.01$) increased risk of hospitalization compared to patients without psychosis. Among patients with psychosis, 76 (39%) received antipsychotic medication. Treatment with antipsychotic medications did not affect the risk of hospitalization ($HR = 0.93$, $p = 0.65$). The median length of hospitalization among the entire cohort was 1 (IQR 0–4) day. There was no difference between hospitalization length for patients with no psychosis and patients with active psychosis ($RR = 1.08$, $p = 0.43$) or patients with resolved psychosis ($RR = 0.79$, $p = 0.24$).

Conclusion: Psychosis increases the risk of hospitalization in patients with clinically defined synucleinopathies; however, it does not affect the length of hospital stays in our cohort. Antipsychotic treatment does not affect the risk of hospitalization in our study.

KEYWORDS

synucleopathy, parkinsonism, psychosis, population-based, adverse event, hospitalization

Introduction

Parkinson's disease-associated psychosis (PDP) affects 39%–60% of patients with Parkinson disease (PD) according to population-based studies. Psychosis also affects patients with other synucleinopathies, such as Lewy Body Disease (LBD), Parkinson's disease with dementia (PDD), and Multiple System Atrophy (MSA) (Papapetropoulos et al., 2007; Badwal et al., 2022). Previous studies have linked PDP with an increased risk of mortality (Forsaa et al., 2010; Stang et al., 2022) as well as a greater caregiver burden (Aarsland et al., 1999; Schrag et al., 2006). PD patients with psychosis have an increased risk of nursing home and hospital admission (Goetz and Stebbins, 1993; Goetz and Stebbins, 1995; Wetmore et al., 2019). Although drugs such as pimavanserin and clozapine are available to treat psychosis, off-label use of antipsychotic medication is still common in PDP treatment, worsening motor symptoms for some of these drugs (Schneider et al., 2017).

Our study aims to determine the risk of hospitalization among synucleinopathies patients with or without psychosis and evaluate the impact of antipsychotic treatment on hospital admission of patients with psychosis.

Methods

Database and cohort design

We collected data using the electronic medical records linkage system of the Rochester Epidemiology Project (REP). The REP encompasses all local medical facilities, including private practitioners and nursing homes within Olmsted County, Minnesota (MN) with a catchment rate of over 97% in this population (St Sauver et al., 2011). The electronic index of the REP includes records, diagnostic and procedure codes, health services utilization data, outpatient drug prescriptions, demographics, and additional medical data (St Sauver et al., 2011).

Our incident cohort 1991–2010 was composed of two subcohorts: the first one was population-based and included all synucleinopathies cases in Olmsted County (1991–2005); the second one was composed of patients with synucleopathies with a parkinsonism onset within the 1991–2005 time period, who were diagnosed between 2006 and 2010. The purpose of the latter subcohort is to ensure catchment of individuals with parkinsonian motor symptoms onset in the 1991–2005 timeframe but with diagnosis within the next 5 years (2006–2010); this methodology has been already reported elsewhere (Savica et al., 2013) and its rationale is to maximize true population-based results for the first cohort (1991–2005).

All hospitalizations that occurred following the parkinsonism motor-symptom onset were recorded and categorized based on the reason for hospital admission, based on physicians' history and physical examinations (H&Ps) and on a "principal problem list" as reported in the patients' clinical records. All other contributing causes of hospital admission were also recorded, based on an "active hospital problems" list in patients' clinical records, allowing for each hospitalization to have multiple categories. Hospitalizations were categorized in three time periods relative to the onset of psychosis: non-psychosis hospitalizations, psychosis hospitalizations, and hospitalizations after the resolution of psychosis. All recorded hospitalizations were considered non-psychosis hospitalizations in patients who never developed psychosis.

Case ascertainment

We ascertained cases of synucleinopathies through the REP infrastructure, in a similar fashion to what previously reported (Savica et al., 2013). A movement-disorders specialist (RS) reviewed the medical records of patients with synucleinopathies to confirm their clinical diagnosis. A board-certified neuropathologist reviewed available autopsy reports to confirm the diagnosis when possible. Further details regarding the clinicopathologic characteristics of this cohort appear elsewhere; however, the clinical-pathology concordance was 89.5% of the cases (Turcano et al., 2017).

Diagnosis of synucleinopathies

Synucleinopathies include Parkinson's Disease (PD), Lewy Body disease (LBD), Parkinson's disease with dementia (PDD), and Multiple System Atrophy (MSA). All our patients with synucleinopathies had parkinsonism, and some had additional distinct clinical features relative to the specific clinical syndrome. Parkinsonism is the presence of at least two of four cardinal signs: rest tremor, bradykinesia, rigidity, and impaired postural reflexes. These criteria have proven efficient in a previous study (Savica et al., 2013) where a movement-disorder neurologist blinded to the criteria reviewed a sample of patients with parkinsonism. The agreement on the presence of parkinsonism was 90%, higher than the accuracy of the UK Brain Bank Criteria on parkinsonism (82%) (Hughes et al., 1992). Fourth Consensus criteria and McKeith criteria for Dementia with Lewy Bodies (DLB)/PDD (McKeith et al., 2017) were adopted (Gilman et al., 1998, 2008) for MSA.

Identification of patients with psychosis

We used the NINDS/NIMH Work Group clinical criteria for psychosis to classify patients with psychosis (Ravina et al., 2007). We defined psychosis as the presence of one or more of the following symptoms: illusions, false sense of presence, hallucinations, or delusions. Psychotic symptoms had to last at least 1 month or recur within 1 month and not be explained by another medical condition (Ravina et al., 2007). We excluded all cases of acute change in mental status such as acute dementia, confusion, and delirium due to medical conditions or adverse drug events. If the symptoms persisted for 6 months or more, patients were considered to have unresolved psychosis. Patients with psychosis were regarded as treated if any antipsychotic prescription was used for psychosis at any time after their psychosis diagnosis. Available antipsychotic medications at the time of the study were Quetiapine, Clozapine, Olanzapine, Risperidone, and Haloperidol.

Statistical analysis

Numeric features were summarized with medians and interquartile ranges; categorical features were summarized with frequency counts and percentages. The incidence of hospitalizations among synucleinopathy patients was calculated as the total number of hospitalizations divided by the total years of follow-up recorded for the entire cohort. Comparisons between males and females were conducted using incidence rate ratios (IRRs) with 95% confidence intervals.

Risk of hospitalization was assessed using recurrent-event Andersen-Gill (AG) models. Psychosis was treated as a time-dependent covariate to properly account for the differential onset and resolution of psychosis within the cohort of synucleinopathy patients. The AG models also accounted for patient sex and age at the onset of parkinsonism. A secondary analysis further classified psychosis as either treated with antipsychotic medication or untreated. This predictor was again treated as a time-dependent covariate since patients could have different lengths of untreated and treated psychosis depending on when the medication was prescribed relative to the onset of psychosis.

The length of hospitalization was compared between psychosis time periods using population-averaged Poisson generalized estimating equations (GEEs). The strength of these models over simple regression is that GEEs account for multiple hospitalizations from a single patient which will not necessarily be independent. Models were unadjusted using psychosis as the predictor of interest, as well as adjusted for patient sex and age at parkinsonism onset. Model results are reported as rate ratios (RRs) with 95% confidence intervals.

Standard protocol approvals, registrations, and patient consents

The Mayo Clinic and Olmsted Medical Center Institutional Review Boards approved this study. Participating patients or their legally authorized representatives provided informed written consent for the use of their medical information for research (Savica et al., 2013).

Data availability statement

All the relevant data are shared and published in this article. Data regarding case ascertainment and methodology on case identification have been previously published (Savica et al., 2013; Stang et al., 2022). Data regarding frequency of psychosis, mortality, and other characteristics of patients of this cohort have already been reported elsewhere (Stang et al., 2022).

Results

Demographics

A total of 416 clinically diagnosed synucleinopathy patients were included in this study. Table 1 provides a summary of patients' demographics, parkinsonism characteristics, and hospitalizations. Our cohort was 37.2% female and 63.8% male. The median age of onset was 75 years (IQR = 67–81). The median time of follow-up was 8.5 years (5–12.1). Breaking down by synucleopathy type, 283 (68%) of our patients had Parkinson's disease, 76 (18.3%) Lewy Body Disease, 46 (11.1%) Parkinson's with dementia, and 11 (2.6%) Multiple System Atrophy.

Incidence of hospitalization

The 416 patients included in the cohort had a total of 2,669 hospitalizations. Most patients (409/416, 98.3%) were admitted to the hospital at least once after parkinsonism onset and the rate of admission was similar between males and females ($p = 0.98$).

In the full cohort of synucleinopathy patients, the incidence of hospitalizations following the onset of parkinsonism was 70.6 hospitalizations per 100 person-years of follow-up. The incidence of hospitalization was similar between males (70.5 per 100 person-years) and females (70.6 per person-years; IRR = 1.00, 95% CI: 0.93–1.08, $p = 0.99$).

Psychosis

Of the 416 synucleinopathy patients, 195 (46.9%) developed psychosis. Table 2 provides a summary of patients' parkinsonism characteristics, psychosis characteristics, treatment, and hospitalizations. This subgroup consisted of 124 (47.5%) males and 71 (45.8%) females. The median age at parkinsonism onset and at psychosis onset was 74 years (68–81) and 79 years (74–85) respectively. The median time of follow-up time to psychosis onset was 9.1 years (5.7–12.7). Seventy-six of the 195 (39%) patients with psychosis were treated with antipsychotics. One hundred and thirty eight of 195 (70.8%) had unresolved psychosis.

Risk of hospitalization

In an unadjusted AG model including only psychosis as a predictor of hospitalization, we observed that active psychosis correlated with a 49% greater risk for hospitalization (HR = 1.49, 95% CI: 1.25–1.79, $p < 0.001$). However, the risk of hospitalization for patients with resolved psychosis did not differ significantly from patients without a diagnosis of psychosis (HR = 1.07, 95% CI: 0.74–1.53, $p = 0.72$).

After accounting for patient age, sex, and synucleinopathy subtype, we found comparable results. Active psychosis correlated with a 41% increase in risk for hospitalization (HR = 1.41, 95% CI: 1.17–1.70, $p < 0.001$). Resolved psychosis was not significantly different from no psychosis (HR = 0.93, 95% CI: 0.63–1.37) and was associated with a 34% lower risk of hospitalization compared to active psychosis (HR = 0.66, 95% CI: 0.44–0.98, $p = 0.042$).

There was no difference in risk of hospitalization between males and females (HR = 1.04, 95% CI: 0.87–1.23, $p = 0.69$); however, a 5-year increase in age was associated with a 16% increase in risk for hospitalization (HR = 1.16, 95% CI: 1.14–1.18, $p < 0.001$).

Effect of anti-psychotic treatment on risk of hospitalization

When classifying psychosis as treated by antipsychotic medication or untreated, an unadjusted AG model found both treated (HR = 1.46, 95% CI: 1.21–1.77, $p < 0.001$) and untreated psychosis (HR = 1.58, 95% CI: 1.16–2.15, $p = 0.004$) associated with greater risk for hospitalization. There was no significant difference between treated and untreated psychosis (HR = 0.93, 95% CI: 0.67–1.29, $p = 0.65$).

TABLE 1 Summary of cohort demographics and disease characteristics.

	Female (N = 155)	Male (N = 261)	All patients (N = 416)
Demographics			
Age at onset, years	76 (68, 82)	75 (67, 80)	75 (67, 81)
Race, *n* (%)			
White	150 (96.8%)	250 (95.8%)	400 (96.2%)
Non-White	4 (2.6%)	8 (3.1%)	12 (2.9%)
Unknown	1 (0.6%)	3 (1.1%)	4 (1.0%)
Disease characteristics			
Parkinsonism subtype, *n* (%)			
Parkinson's disease	110 (71.0%)	173 (66.3%)	283 (68.0%)
Lewy body disease	22 (14.2%)	54 (20.7%)	76 (18.3%)
Parkinson's disease with dementia	21 (13.5%)	25 (9.6%)	46 (11.1%)
Multiple system atrophy	2 (1.3%)	9 (3.4%)	11 (2.6%)
Duration of follow-up, years	9.2 (4.7, 12.7)	8.2 (5.2, 11.6)	8.5 (5.0, 12.1)
Psychosis, *n* (%)	71 (45.8%)	124 (47.5%)	195 (46.9%)
Hospitalizations			
Total hospitalizations, median (Q1, Q3)	5 (2, 9)	5 (3, 8)	5 (2, 9)
Any hospitalization, *n* (%)	153 (98.7%)	256 (98.1%)	409 (98.3%)
Neurological	114 (73.5%)	189 (72.4%)	303 (72.8%)
Cardiovascular	102 (65.8%)	182 (69.7%)	284 (68.3%)
Infection	75 (48.4%)	115 (44.1%)	190 (45.7%)
Respiratory	58 (37.4%)	109 (41.8%)	167 (40.1%)
Psychiatric	73 (47.1%)	93 (35.6%)	166 (39.9%)
Nephrological	49 (31.6%)	109 (41.8%)	158 (38.0%)
Fall	61 (39.4%)	80 (30.7%)	141 (33.9%)
Trauma	43 (27.7%)	64 (24.5%)	107 (25.7%)
Other	136 (87.7%)	230 (88.1%)	366 (88.0%)

Similarly, after accounting for patient age, sex, and synucleinopathy type, both treated (HR = 1.38, 95% CI: 1.14–1.69, p = 0.001) and untreated psychosis (HR = 1.47, 95% CI: 1.07–2.03, p = 0.018) were associated with greater risk of hospitalization. There was no difference between the two categories of psychosis on risk of hospitalization (HR = 0.94, 95% CI: 0.67–1.32, p = 0.72).

Duration of hospitalization

The median length of hospitalization among the entire cohort was 1 (IQR 0–4) day. For males the median was 1 (0–4) day and for females the median was 1 (0–4) day of hospitalization. An unadjusted GEE model found no difference in length of hospitalization between males and females (RR = 0.96, 95% CI: 0.78–1.20, p = 0.74).

Hospitalizations for patients not previously diagnosed with psychosis lasted a median of 1 (IQR 0–4) day. Comparatively, patients with active psychosis had a median of 2 (IQR 0–5) days and patients with resolved psychosis had a median of 1 (0–3) day of hospitalization. Relative to the patients not diagnosed with psychosis, there was no difference in hospitalization length for patients with active psychosis (RR = 1.08, 95% CI: 0.89–1.32, p = 0.43) or patients with resolved psychosis (RR = 0.79, 95% CI: 0.52–1.18, p = 0.24). There was also no difference between patients with resolved psychosis and patients with active psychosis (RR = 0.73, 95% CI: 0.49–1.07, p = 0.10).

Adjusting for patient age and sex revealed no difference in length of hospitalization for patients with active psychosis (RR = 1.12, 95% CI: 0.91–1.37, p = 0.29) or resolved psychosis (RR = 0.81, 95% CI: 0.55–1.19, p = 0.29). There was no difference between patients with resolved psychosis and patients with active psychosis (RR = 0.73, 95% CI: 0.50–1.06, p = 0.095). Similarly, males did not have significantly different hospitalization duration compared to females (RR = 0.97, 95% CI: 0.77–1.22, p = 0.76).

Reasons for hospitalization

The most frequent cause of hospitalization was neurological, with 72.8% of all patients hospitalized at least once for neurological reasons. The least common cause was trauma, with 25.7% of all patients having at least one trauma-related hospitalization.

TABLE 2 **Summary of patients diagnosed with psychosis.**

	Female (*N* = 71)	Male (*N* = 124)	All patients (*N* = 195)
Parkinsonism characteristics			
Age at parkinsonism onset, years	74 (65, 81)	74 (69, 80)	74 (68, 81)
Parkinsonism subtype, *n* (%)			
Parkinson's disease	48 (67.6%)	66 (53.2%)	114 (58.5%)
Lewy body disease	16 (22.5%)	44 (35.5%)	60 (30.8%)
Parkinson's disease with dementia	7 (9.9%)	12 (9.7%)	19 (9.7%)
Multiple system atrophy	0 (0%)	2 (1.6%)	2 (1.0%)
Duration of follow-up, years	10.2 (6.6, 14.3)	8.6 (5.6, 11.2)	9.1 (5.7, 12.7)
Psychosis characteristics			
Age at psychosis onset, years	79 (73, 86)	79 (74, 84)	79 (74, 85)
Psychosis symptoms, *n* (%)			
Hallucinations	62 (87.3%)	113 (91.1%)	175 (89.7%)
Delusions	22 (31.0%)	40 (32.3%)	62 (31.8%)
Confusion	29 (40.8%)	40 (32.3%)	69 (35.4%)
Delirium	14 (19.7%)	14 (11.3%)	28 (14.4%)
Treatment for psychosis, *n* (%)			
Any antipsychotic medication	32 (45.1%)	44 (35.5%)	76 (39.0%)
Quetiapine	31 (43.7%)	43 (34.7%)	74 (37.9%)
Haloperidol	3 (4.2%)	7 (5.6%)	10 (5.1%)
Risperidone	4 (5.6%)	0 (0%)	4 (2.1%)
Hospital admission due to psychosis, *n* (%)	5 (7.0%)	25 (20.2%)	30 (15.4%)
Psychosis resolution, *n* (%)			
Unresolved	47 (66.2%)	91 (73.4%)	138 (70.8%)
Resolved	24 (33.8%)	33 (26.6%)	57 (29.2%)

Discussion

Risk of hospitalization

Our study shows that active psychosis increased by 49% the risk of hospitalization of patients with synucleinopathies. This association was significant after accounting for patients' age, sex, and parkinsonism subtype, with a 41% increased relative risk of hospitalization. Resolved psychosis mitigated this higher risk, and patients had the same hospitalization risk as patients without psychosis.

Effect of antipsychotic treatment on hospitalization

In this study, we found that antipsychotic treatment by Quetiapine, Olanzapine, Risperidone, and Haloperidol did not significantly affect the risk of hospitalization compared to patients with untreated psychosis. Similarly, we found that antipsychotic treatment did not significantly affect hospitalization length. Although a relatively small number of our patients with psychosis were treated [76 of 195 (39%)], and none of our patients received Clozapine, this suggests that the other drugs available at the time of our study (1991–2010) may help reduce psychotic symptom burden for both patients and caregivers but are not necessarily effective for reducing the risk or length of hospitalization in patients with synucleinopathies. The findings support a previously published study (Stang et al., 2022), where antipsychotic treatment available at that time did not significantly affect mortality of PD patients with psychosis, even if they helped reduce psychotic symptoms. It is important to note that since our study time-period, other drugs such as pimavanserin have become available, and the use of clozapine is also possible, although rarely used.

Duration of hospitalization

In our study, the median length of hospitalization stay was relatively short [1 (IQR 0–4) day], compared to a study on PD patients from the United Kingdom (Woodford and Walker, 2005) where the median length of hospital stay was 21 days, and another study on Spanish PD patients (Gil-Prieto et al., 2016), where the median length of hospital stay was 10 days. A possible contributing factor of these different hospitalization lengths could be that our study includes Emergency Department admissions, with a vast number of patients discharged the next day.

An interesting result from our study is that the presence of active psychosis does not affect the length of hospitalization, compared to patients with no psychosis or resolved psychosis. An explanation for this finding may be the effort made by healthcare teams to limit hospitalization to the shortest possible duration for parkinsonian patients to reduce the risk of adverse events or higher mortality (Low et al., 2015). Another explanation is that resolution of the acute phase of psychosis may bring patients back to their baseline (even with persistent psychotic features), and a longer hospitalization may not be necessary. As hospitalization itself can cause delirium for PD patients (Ahlskog, 2014), short as possible hospitalizations still offer the safest approach for parkinsonian patients, except when patients are a danger to themselves or others.

Rate of hospitalization

In our study, the median number of hospitalizations for a single patient was 5 (IQR 2–9). This is higher than previously reported (Okunoye et al., 2022).

Reasons for hospitalization

The most common reasons for hospitalization in our cohort were neurological (72.8%) and cardiovascular (68.3%), followed by infections (45.7%). Falls only accounted for 25.7% of hospitalizations. Interestingly, this is in contrast with multiple previous studies on parkinsonism-related hospitalizations where the leading cause of hospitalizations were falls (Hommel et al., 2022; Okunoye et al., 2022; Santos Garcia et al., 2023).

Limitations and strengths

Our study has limitations. First, retrospective data collection is dependent on physician report of symptoms, which can lead to an underascertainment of psychosis. Second, as psychosis rates vary widely in synucleinopathy patients (Forsaa et al., 2010; Stang et al., 2022), and as not all patients with psychosis need medication, the number of treated patients with psychosis was relatively small. This can affect the generalizability of the results. Third, data on antipsychotic treatment adherence were not available so there is risk of bias. Fourth, pimavanserin, a drug proven efficient on PDP (and psychosis-related hospitalizations) was not available in our study time-period (Rajagopalan et al., 2023a,b). The current study can be relevant as a baseline to set the stage for future population-based studies that might confirm our results with readily available pimavanserin. Fifth, although clozapine was available at the time of our study, none of our patients received this medication, which may affect the generalizability of our results. Finally, we had a limited number of pathologically confirmed cases (24 cases) in our cohort. However, a previous study shows that our rate of clinical diagnosis accuracy is 89.5% (Turcano et al., 2017).

Our study also has several strengths. First, the complete review of medical records by a neurologist, to confirm both diagnosis of synucleinopathy and psychosis, insures the good quality of our data and less selection bias seen in studies based on electronic codes only (Peterson et al., 2020). Second, our study is population-based, with our cohort grouping all incident cases of synucleinopathy from 1991 to 2010 in Olmsted County, Minnesota. Third, this study is one of the first to look at hospitalization risk of all synucleinopathy patients and specifically target the influence of psychosis. This is of interest as psychosis is known to increase mortality in parkinsonian patients (Stang et al., 2022) and affect their quality of life (Schneider et al., 2017; Badwal et al., 2022).

Conclusion

Our study shows that active psychosis increases the risk of hospitalization of synucleinopathies patients by 49% but does not affect the duration of hospitalization. Available antipsychotic treatment at the time of the study does not affect the risk of hospitalization. With nearly half (46.9%) of our patients with synucleinopathy affected by psychosis, it is necessary for health professionals, patients, and families to look out for psychosis symptoms throughout the disease course, to prevent deleterious consequences of psychosis on their life and autonomy.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Mayo Clinic Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

CP: Writing – original draft. AM: Investigation, Writing – review & editing, Formal analysis and Performed statistical analysis. CS: Data curation, Investigation, Writing – review & editing. MH: Investigation – review & editing. EC: Data curation, Investigation, Writing – review & editing, Methodology. PT: Data curation, Investigation, Methodology – review & editing. PM: Formal analysis – review & editing. JB: Conceptualization, Investigation, Writing – review & editing. RS: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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More than medications: a patient-centered assessment of Parkinson's disease care needs during hospitalization

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Background: Parkinson's disease (PD) increases the risk of hospitalization and complications while in the hospital. Patient-centered care emphasizes active participation of patients in decision-making and has been found to improve satisfaction with care. Engaging in discussion and capturing hospitalization experience of a person with PD (PwP) and their family care partner (CP) is a critical step toward the development of quality improvement initiatives tailored to the unique hospitalization needs of PD population.

Objectives: This qualitative study aimed to identify the challenges and opportunities for PD patient-centered care in hospital setting.

Methods: Focus groups were held with PwPs and CPs to capture first-hand perspectives and generate consensus themes on PD care during hospitalization. A semi-structured guide for focus group discussions included questions about inpatient experiences and interactions with the health system and the clinical team. The data were analyzed using inductive thematic analysis.

Results: A total of 12 PwPs and 13 CPs participated in seven focus groups. Participants were 52% female and 28% non-white; 84% discussed unplanned hospitalizations. This paper focuses on two specific categories that emerged from the data analysis. The first category explored the impact of PD diagnosis on the hospital experience, specifically during planned and unplanned hospitalizations. The second category delves into the unique needs of PwPs and CPs during hospitalization, which included the importance of proper PD medication management, the need for improved hospital ambulation protocols, and the creation of disability informed hospital environment specific for PD.

Conclusion: PD diagnosis impacts the care experience, regardless of the reason for hospitalization. While provision of PD medications was a challenge during hospitalization, participants also desired flexibility in ambulation protocols and an environment that accommodated their disability. These findings highlight the importance of integrating the perspectives of PwPs and CPs when targeting patient-centered interventions to improve hospital experiences and outcomes.

KEYWORDS

Parkinson's disease, hospitalization, patient-centered care, qualitative methods, focus groups

Introduction

People with a clinical diagnosis of Parkinson's disease (PD) experience more frequent and prolonged hospitalizations than their age-matched peers (Aminoff et al., 2011; Chou et al., 2011; Hobson et al., 2012; Kowal et al., 2013; Shahgholi et al., 2017; Su et al., 2018). Most hospitalizations occur in general wards and result from a comorbid disorder or health crisis, such as respiratory and urinary tract infections, cardiovascular diseases, falls, and fractures (Woodford and Walker, 2005; Braga et al., 2014; Lubomski et al., 2015; Gil-Prieto et al., 2016; Okunoye et al., 2020; Réa-Neto et al., 2021). It is well documented that during hospitalizations, person with PD (PwP) is at a higher risk of complications, including falls, medication errors, development of delirium and psychosis, and overall decline of their pre-existing motor and non-motor symptoms of PD (Derry et al., 2010; Gerlach et al., 2013; Lubomski et al., 2015; Skelly et al., 2017; Magnuszewski et al., 2022). Improved medication adherence during hospital stays, e-alerts to PD specialists upon admission, development of the Parkinson's Foundation Aware in Care Hospital Kit, and recommendations for ward certification programs are among the calls for action and quality improvement interventions that have targeted hospital outcomes for PD (Azmi et al., 2019, 2020; Hobson et al., 2019; Aslam et al., 2020; Nance et al., 2020; Parkinson's Foundation Hospital Safety Kits, 2023). However, to date, only a few studies have reported significant decreases in the length of hospital stay or complications during hospitalization for PD (Skelly et al., 2014; Azmi et al., 2020).

In the context of inpatient hospitalization for older adults and those with chronic and serious medical conditions, patient-centered care (PCC) has revealed benefits in intermediate and distal outcomes, and almost all studies have found positive relationships between PCC approaches and patient satisfaction (Counsell et al., 2000; Wolf et al., 2008; Rocco et al., 2011; Rathert et al., 2013). PCC places patients at the center of the healthcare decision-making process and recognizes the importance of their individual preferences and goals (Berwick, 2009; Institute of Medicine, 2014). Growing awareness of PCC delivery has resulted in the establishment of specialized multidisciplinary teams as the gold standard of outpatient care for PD, as well as the increasing application of palliative care, a traditionally team-based model of care, for the management of the physical, emotional, and spiritual needs of PwPs (Eggers et al., 2018; Connor et al., 2019; Vlaanderen et al., 2019; Bhidayasiri et al., 2020; Kluger et al., 2020; Rajan et al., 2020; Lennaerts-Kats et al., 2022).

Presently, the voices of PwPs and their care partners (CPs) regarding their experiences during hospitalization are not well represented in the literature, and most research on PCC for PD has focused on outpatient care. Studies that qualitatively investigated hospitalization for PD primarily highlighted medication mismanagement, struggles with postoperative confusion, and deterioration of motor symptoms; however, they minimally captured patient-reported needs or experiences of CPs during hospitalization (Barber et al., 2001; Buetow et al., 2009; Gerlach et al., 2012; Carney Anderson and Fagerlund, 2013; Read et al., 2019).

By applying open–ended questions qualitative methods gather detailed and nuanced accounts of participants' experiences, perceptions, and behavior. Compared to quantitative methods, which are intended to achieve the breadth of understanding of a topic, qualitative methods dive deep into individual experiences and the context surrounding them (Patton, 2002).

Unlike quantitative research, which emphasizes data generalization by employing sample size calculation and randomization, qualitative methods place primary emphasis on saturation, which means collecting the information until no new substantive insight emerges (Francis et al., 2010). To achieve saturation, researchers often use purposeful sampling by recruiting individuals who are especially knowledgeable about or experienced with a phenomenon of interest, available and willing to participate, and can communicate experiences and opinions in an articulate, expressive, and reflective manner (Guest et al., 2006). This approach can collect robust and meaningful data per participant, and thus fewer participants within the sample are needed to achieve saturation or "information power" of the sample (Malterud et al., 2016). The choice for qualitative data analysis is dictated by qualitative study methods and the research question. Since open–ended surveys, focus groups, and one on one interviews create information-rich and nuanced datasets, thematic analysis is commonly applied to this qualitative method. This involves creating codes (labels) to organize and describe the data, and then actively synthesizing the data by framing, interpreting, and/or connecting data elements to construct the themes (Kiger and Varpio, 2020). The advantage of thematic analysis is that it offers researchers flexibility concerning the type of research questions it can address, however, it also implies a systematic and iterative process that requires careful attention and interpretation of the data, and then a rigorous approach to identifying and validating themes (Braun and Clarke, 2006, 2012; Kiger and Varpio, 2020).

To expand the scope of patient-centered PD care from outpatient to inpatient settings, we employed qualitative research to gather and analyze valuable self-reported experiences of PwPs and CPs regarding hospitalization.

Methods

Study design

Focus groups were selected as the optimal methodology to capture first-hand experiences of PwPs and CPs, and to generate themes on PD care during hospitalization (Patton, 2002; Busetto et al., 2020). Participants either had a neurologist-confirmed clinical diagnosis of PD or were family members of a person with a neurologist-confirmed clinical diagnosis of PD and were able to participate in the interview. Hospitalization was defined as a planned (e.g., scheduled surgery or procedure) or unplanned (e.g., emergent or urgent admission) hospital stay for at least 24 h between January 2018 and July 2022. Patients hospitalized for deep brain stimulation surgery were excluded. All participants had to be at least 18 years old, with no upper age limit.

This study was conducted in accordance with the Declaration of Helsinki and was approved and overseen by the Office of Human Research Ethics the University of North Carolina at Chapel Hill. The participants provided verbal informed consent prior to any study activity including data collection. This study was supported by a Parkinson's Foundation Community Outreach Resource Education grant.

Data collection

Participants were recruited through clinician referrals, announcements shared with North Carolina-based PD support groups, and flyers placed at the outpatient neurology clinic at the University of North Carolina at Chapel Hill. A purposive sampling strategy was used to recruit a variety of PwPs and CPs with a range of hospital experiences (Table 1). The focus groups were capped at a maximum of five participants to allow for adequate time for each person to actively participate in the focus group discussion and accommodate for inherent challenges with communication and processing speed in PD. Quotas were applied to the patient sample to ensure a diverse representation, including demographic (e.g., sex, age, race) and clinical characteristics (e.g., stage of condition as defined by Hoehn and Yahr score, planned vs. unplanned hospitalization experiences) (Goetz et al., 2004). Half-way through recruitment, additional efforts were made to enroll participants from underrepresented demographics of the study.

A semi-structured discussion guide, developed *de novo* by the research team based on a review of the published literature on hospitalizations in PD, was used to structure the focus groups (Supplementary Appendix S1). As the data collection progressed, the discussion guide was adapted to incorporate new issues raised by the participants. The questions focusing on aspects of hospital admission, inpatient experiences, discharge processes, interactions with the health system and team, and lived experiences of PwPs and CPs thought to be most relevant to patient- and family-centered outcomes. An experienced group moderator (J.S.) used probing questions to further expand the discussion. Prior to the focus groups, all the participants completed a brief questionnaire to capture their demographic information.

All focus groups were conducted virtually on the Zoom platform and were recorded and transcribed verbatim. Each group was 120 min in length. Identifiers were stripped from the transcripts, which were reviewed for accuracy. Participants received $20 honoraria. After conducting 7 focus groups, the research team determined that information power was achieved, and recruitment ended (Patton, 2002).

Data management and analysis

Transcripts were independently reviewed by a multidisciplinary team of three researchers, including a movement disorders specialist (N.B.), a clinical social worker (J.S.), and a qualitative methods expert (S.G.), to identify emerging concepts related to hospital experiences. During the first phase of analysis, two investigators (N.B. and S.G.) independently read 3 transcripts before convening to define initial topics/concepts and develop a preliminary codebook. Coded data and transcripts were maintained in an electronic database, MAXQDA 2020 (VERBI software, 2019). An inductive thematic approach was used for analysis. The respective coded transcripts were compared during face-to-face meetings (N.B. and S.G.) to assess similarities and discrepancies regarding code names and code application. Based on these consensus meetings, researchers developed a final codebook that was systematically applied to the remaining transcripts. The team continued to review and code transcripts independently, meeting regularly to collaboratively discuss coding decisions and to resolve any coding differences through consensus. All coded transcripts were then reviewed by a third researcher (J.S.) to ensure consistency (Busetto et al., 2020). The varied perspectives of team members yielded a nuanced and robust interpretation of the results and all discrepancies among analysts were resolved. The research team (N.B., J.S., P.M.) analyzed each code and assessed conceptual relationships among them to develop higher-level categories and the relevant sub-themes within each category (Table 2). The findings were then condensed, and conclusions drawn.

Results

Participants

Seven focus groups were conducted. Participants included 12 PwPs (69% in the 65–74 age range and 28% non-white) and 13 CPs, including five PwP-CP dyads, for a total of 25 participants (Table 1). 84% of participants had unplanned hospitalizations and 64% of participants had lived with the PD diagnosis between 6 and 14 years at the time of hospitalization. All CPs reported unplanned hospitalizations of their loved one with PD. Ten participants were hospitalized at academic medical centers. During recruitment, participants were identified by their roles in the healthcare system (patient vs. family CP). Initially, the researches planned to create homogenic focus groups that thought would facilitate open discussion (Kaiser, 2009). However, during the recruitment, several PwPs in more advanced diseases stages expressed a preference for their CPs to be present during focus group and help navigate challenges with speech or slower processing speed, which made it difficult for them to fully participate in the discussion. In these PwP – CP dyads, the CP commonly participated in discussion by either voicing their own opinion about hospitalization or helping the PwP express their thoughts, thus playing the role of “patient’s voice.” The study included two focus groups consisting solely of CPs, one focus group with only PwPs, and the remaining four focus groups had a mix of participants (Table 3).

Resulting categories

The focus group discussions revealed rich descriptive and thematic data, however, this paper focuses on two specific categories: the impact of the PD diagnosis on the patient and family’s hospital experiences and perceptions of care, and the emergence of distinctive needs of PwPs and CPs during hospitalization.

Tables 4, 5 present the sub-themes and themes accompanied by the focus group participants’ representative quotes. Each quote is marked with participant number (P#), focus group number (G#), and whether the participant identified as PwP or CP.

In the following section, we outline the major themes of each category.

TABLE 1 Demographic and clinical characteristics of the participants.

Demographics	Total PwP (*n* = 13)	Total CPs (*n* = 12)	Total (*n* = 25)
Age *n* (%)			
Below 55 years old	0	1 (8%)	1 (4%)
55–64 years old	0	1 (8%)	1 (4%)
65–74 years old	9 (69%)	2 (17%)	11 (44%)
75–84 years old	3 (23%)	7 (58%)	10 (40%)
Over 85 years old	1 (7%)	1 (8%)	2 (8%)
Gender *n* (%)			
Male	9 (69%)	3 (25%)	12 (48%)
Female	4 (31%)	9 (75%)	13 (52%)
Highest level of education *n* (%)			
High school	0	0	0
Some college	3 (23%)	1 (8%)	4 (16%)
Associate degree	4 (31%)	0	4 (16%)
Bachelor's degree	1 (8%)	6 (50%)	7 (28%)
Master's degree	2 (15%)	1 (8%)	3 (12%)
PhD	3 (23%)	4 (33%)	7 (28%)
Race *n* (%)			
White	10 (77%)	8 (67%)	18 (72%)
Black/African American	1 (8%)	1 (8%)	2 (8%)
Asian	2 (15%)	2 (17%)	4 (16%)
Multi-racial	0	1 (8%)	1 (4%)
Yrs since diagnosis of PD *n* (%)			
≥15 yrs	1 (8%)	3 (25%)	4 (16%)
11–14	5 (38%)	4 (33%)	9 (36%)
6–10	4 (31%)	3 (25%)	7 (28%)
3–5	3 (23%)	2 (17%)	5 (20%)
Less than 3 yr.	0	0	0
H&Y stage *n* (%)			
Stage 1	0	n/a	0
Stage 2	3 (23%)	n/a	3 (23%)
Stage 3	6 (46%)	n/a	6 (46%)
Stage 4	4 (31%)	n/a	4 (31%)
Hospitalization type *n* (%)			
Planned hospitalization	4 (31%)	0	4 (16%)
Unplanned hospitalization	9 (69%)	12 (100%)	21 (84%)

1. **Pre-existing PD diagnosis affected participants' hospital experience and perception of care: "They acknowledged [PD] immediately… that was great!"**
   1.1. **Acknowledgment of PD diagnosis by the health care team was important to participants.**

Although none of the participants' hospitalizations was directly related to PD symptoms, the presence of a PD diagnosis and whether the health care team (HCT) actively acknowledged the PD diagnosis had a significant impact on the perceptions of care of both for the PwPs and CPs. In both planned and unplanned hospitalizations, trust in the HCT was immediately gained when the team openly acknowledged the patient's diagnosis of PD and demonstrated knowledge about specific considerations during hospital stays, anesthesia, and post-hospitalization rehabilitation.

   1.2. **Hospitalization experience differed according to whether hospitalizations were planned or unplanned.**

Overall, the participants' experiences with planned hospitalization were positive starting from the ability to choose their HCT with previous experience in PD care.

TABLE 2 *A priori* codes, sub themes, themes and categories.

A priori codes	Sub themes	Themes	Categories
Declaring PD diagnosis/establishing PD identity		Importance of active acknowledgment of PD diagnosis by the health care team	The impact of PD diagnosis on the hospital experience and perception of care among PwP and CPs
Knowledge by the team about PD			
Attributes of Health Care Team			
Care partner advocacy			
Care partner experience			
Advance care planning	Preparedness for hospital admission	Different experiences with care during planned and unplanned hospitalizations	
Decision making			
PD comorbidities			
Packing to go to hospital			
Knowledge by the Health Care Team about PD	Communications with health care team before admission/at ER/after admission/on discharge		
Attributes of Health Care Team			
ER experience			
Patient experience			
Care partner advocacy			
Care partner experience			
Emotions about hospital stay	Care during hospital stay		
PD medications			
Hospital environment			
Patient experience			
Care partner advocacy			
Care partner experience			
Knowledge by the Health Care Team about PD			
Rehabilitation/Ambulation	Rehabilitation/ambulation during hospital stay		
Discharge instructions			
Knowledge by the Health Care Team about PD			
Attributes of Health Care Team			
Patient experience			
Care partner advocacy			
Care partner experience			
Emotions about hospital stay	Inconsistent availability of PD medications Delays in medication schedule Substitution of medications	Dissatisfaction with management of PD medications	The unique needs of PwP and CP during hospitalizations
PD medications			
Patient experience			
Care partner advocacy			
Care partner experience			
Knowledge by the Health Care Team about PD			
Care partner advocacy	Self-administration of medications		
Declaring PD diagnosis/establishing PD identity			
Patient experience			
Knowledge by the Health Care Team about PD			
Rehabilitation/Ambulation	Allied health clinician evaluations Encouragement of safe ambulation	Desire for flexibility in hospital protocols regarding falls risk and ambulation	
Hospital environment			
Patient experience			
Care partner advocacy			
Care partner experience			
Declaring PD diagnosis/establishing PD identity	Individualized assessment of falls risks		
Emotions about hospital stay			
Care partner advocacy			
Hospital environment	Preservation of independence in the hospital environment	The need for disability-informed hospital environment	
Discharge instruction			
Rehabilitation/Ambulation			
Declaring PD diagnosis/establishing PD identity			
Patient experience			
Care partner advocacy			
Emotions about hospital stay	Desire for accommodations for PD—specific care needs		
Declaring PD diagnosis/establishing PD identity			
Care partner advocacy			
Care partner experience			

TABLE 3 Composition of the focus groups.

Focus group #	Subject ID	Category of participant	Planned or unplanned hospitalization	Academic or community hospital admission	Gender	Race/ ethnicity
1	P_1_G_1_CP*	Care partner	Unplanned	Community	F	Multi – racial
1	P_2_G_1_PwP*	Patient	Unplanned	Community	M	White
1	P_3_G_1_CP*	Care partner	Unplanned	Community	F	White
1	P_4_G_1_PwP*	Patient	Unplanned	Community	M	White
1	P_5_G_1_PwP	Patient	Planned	Academic	F	White
2	P_6_G_2_PwP	Patient	Unplanned	Community	M	White
2	P_7_G_2_PwP	Patient	Planned	Academic	M	White
2	P_8_G_2_PwP*	Patient	Unplanned	Community	F	White
2	P_9_G_2_CP*	Care partner	Unplanned	Community	M	White
3	P_10_G_3_CP	Care partner	Unplanned	Academic	F	White
3	P_11_G_3_CP	Care partner	Unplanned	Community	F	White
3	P_12_G_3_CP	Care partner	Unplanned	Community	M	Asian
3	P_13_G_3_CP	Care partner	Unplanned	Community	M	Asian
3	P_14_G_3_CP	Care partner	Unplanned	Academic	F	White
4	P_15_G_4_PwP	Patient	Planned	Academic	F	White
4	P_16_G_4_PwP	Patient	Unplanned	Community	M	Asian
5	P_17_G_5_CP	Care partner	Unplanned	Academic	F	White
5	P_18_G_5_CP	Care partner	Unplanned	Academic	F	White
6	P_19_G_6_PwP	Patient	Unplanned	Academic	M	Asian
6	P_20_G_6_PwP*	Patient	Unplanned	Community	M	African American
6	P_21_G_6_CP*	Care partner	Unplanned	Community	F	African American
6	P_22_G_6_PwP	Patient	Planned	Academic	F	White
7	P_23_G_7_PwP*	Patient	Unplanned	Academic	M	White
7	P_24_G_7_CP*	Care partner	Unplanned	Academic	F	White
7	P_25_G_7_PwP	Patient	Unplanned	Community	M	White

Dyads of PwP - CP are marked with*.

"That was really important to me. I wanted to make sure that there was somebody that could do a good job with hip replacement but they have had patients that had Parkinson's, so they knew that that was an element that was different." (P15G4PwP).

PwP chose the date of their planned hospitalization to ensure the presence of CP during the hospital stay and after the discharge: *"And so I actually chose that particular surgery time so that I knew my daughter would be around… It was at Christmas time and… She is a teacher, and she was actually off for the next two and a half weeks." (P5G1PwP).*

During planned hospitalizations, PwPs had support from the rehabilitation services, and were given precise discharge instructions regarding the primary cause of hospitalization. Still, participants admitted to struggling to maintain the timing of their PD medication dosage during the hospital stay and their discharge instructions did not reference their diagnosis of PD.

In contrast, unplanned hospitalizations were described as "*chaotic*," requiring quick decision-making from either PwPs or CPs on whether an ER visit was warranted. For those with unplanned hospitalizations, not one participant mentioned that they had a plan for contacting their neurologist or primary care physician. PwPs and CPs from multiple focus groups commented on delayed access to PD medications in the ER as well as perceived challenges with care delivery (e.g., HCT ability to perform intravenous cannulation placement or chest X-ray) due to prominent PD symptoms such as tremor. CPs were active participants in the decision to go to the hospital for unplanned hospitalizations, and in some cases, drove PwP to the ER. At the ER and once admitted, CP played an essential role in describing the usual state of health of the PwP and helped communicate any changes in their symptoms from baseline to the HCT.

2. The presence of PD-specific care needs posed an additional challenge for participants during hospitalization: "I expect them to be aware of the fact that I'm different."

Specific needs affecting the experience from admission to discharge were identified, including knowledge of PD medications, proper medication management, improved hospital ambulation protocols, and preservation of independence in the hospital environment.

2.1. Numerous hurdles with PD medications management lead to dissatisfaction with hospital care among the participants.

Prior to any type of hospitalization, across all focus groups, PwPs and CPs were concerned about the availability of PD medications and,

TABLE 4 The impact of PD diagnosis on the hospital experience and perception of care among PwP and CPs with representative quotes.

Themes/sub themes	PwP and CPs representative quotes
Importance of active acknowledgment of PD diagnosis by the health care team	The doctor convinced me that they knew what they are doing with Parkinson's as well. So that was reassuring, even though most of the focus was on the hip. I did not have to tell [about Parkinson's diagnosis] anesthesiologist or any of them. They were all aware. And as a matter of fact, he said to me, "Do not worry about it. We've got that under control and we are taking care of you." So he was great. I wanted to make sure that there was somebody that could do a good job with hip replacement, but they have had patients that had Parkinson's, so they knew that that was an element that was different. *(P15G4PwP)* The anesthesiologist was really good. He acknowledged Parkinson's disease diagnosis immediately before I went into the surgery. *(P20G6PwP)* I think there's a big educational deficit with a lot of providers, cause in a lot of instances, you tell them that you have Parkinson's, and they get that deer-in-the-headlights look and they do not quite know how it impacts what it is they are looking at. Or, really, what it is. *(P25G7PwP)* I would end up being the one who bring [Parkinson's diagnosis] up more than anybody [because] the medication [timing] was the issue. It wasn't available in the pharmacy. So then of course now that starts throwing me off on timing wise. I do not think there was awareness of how important timing is of the Parkinson's pills. *(P7G2PwP)* …they were not really that familiar with how it impacted this kind of a situation… The nurse did not ask me, "How often does he have to have the carbidopa?" or "How many pills is he on?" They did not ask anything about that and I felt that they should have. The people taking care of him really had no experience with Parkinson's, and I felt that they needed serious retraining about Parkinson's. *(P1G1CP)* I expected them to—whoever was treating him—to understand what Parkinson's meant. It meant tremors, it meant that he had to take L-dopa on time… and I'm not supposed to sleep there next to him the whole time. So, I expected them to say, "Oh, well we understand, and we will make sure that he gets the proper treatment." That's what I thought. I did not understand that the people taking care of him really had no experience with Parkinson's. I could not trust them. *(P24G7CP)*
Different experiences with care during planned and unplanned hospitalizations	
Planned hospitalization	I think I went and had opinions from three or four doctors, and I wanted to specifically have somebody that can convince me they knew what they had dealt with Parkinson's patients. That was really important to me. [F, hip replacement] *(P15G4PwP)* That was all very organized… They had all my paperwork ready. I had my physical before the surgery and had a chat with the doctor, what they are gonna do and how long it's gonna take and what I'm gonna need and how long I'll be in the hospital. And so, it went very smoothly actually, and a lot of the paperwork I had done ahead of time. After my spine surgery, they were very encouraging, to get up and move and walk around as much as you can. They do not want you to stay in bed. [F, spine surgery] *(P22G6PwP)* I was prepared. Number one, I wasn't alone. My daughter went with me. We had my list of medications and when I take them and how much I take. And even though they told me not to bring them, I brought my medications with me just in case I panicked and did not have them. I was evaluated by physical therapy before discharge, and it was very encouraging to know that I am safe to go home. And to have specific instructions for my knee rehabilitation. [F, knee replacement] *(P5G1PwP)* For my discharge instructions I left there [hospital] … and nobody got in touch with my neurologist—I had to make my appointments by myself. [M, cardiac ablation] *(P7G2PwP)*
Unplanned hospitalization	I had a hard time breathing and went to ER. I mentioned I had Parkinson's disease when it was time to take my medication. I said that I brought medication, but they insisted that they draw it from their pharmacy rather than use my medication. My medication was delayed and eventually I took my own. [M, pneumonia] *(P16G4PwP)* In ER, I had to describe exactly what Parkinson's is because they'll look at my hand shaking… They just kind of look…I kind of had to explain to them and then sometimes they would ask more questions about what exactly the disease is. My medications were always late, but I did not bother addressing it. I was never there long enough to make it worthwhile to change. And all the focus was on my urinary tract infection. [F, urinary tract infection] *(P8G2PwP)* The whole thing [admission] is so hazy. You do not know whether you are being discharged or not, and you do whatever they tell you to do. You're almost sleepwalking, you know? I could tell that some of the nurses were not as cognizant of what Parkinson's really means and the implications of it. [M, pneumonia] *(P19G6PwP)* I brought my own walker. The moment I felt better, I started to move around and out of the bed. I did not want to lose ground. And I did not have physical therapy for a while. I think they came only when it was time to discharge me. My wife helped me with walking. [M, urinary tract infection/sepsis] *(P6G2PwP)* I do not remember physical therapy coming into the hospital at all. And I stayed in bed all the time. It's what they wanted me to do. They were afraid I would fall. [F, urinary tract infection] *(P8G2PwP)* EMT took him to ER but would not let me ride with them. I said to EMT that he may be having a stroke, but ER nurses did not understand that. It was poor communication between the people who were there and the people who were delivering him. I wish that I had been in the ambulance because I would have known how it was said and how he usually looks. I would've been able to advocate for him immediately and say, "This is an emergency. I think he maybe had a stroke. His speech is impaired." But that did not happen. I do not know what they thought he was there for. [M, stroke] *(P17G5CP)* I remember that we were waiting in the ER hallway, and he was extremely agitated. There were six people trying to hold him down and they could not. I thought it was due to the fact that his medication wasn't working so I was giving him his medication. And I remember that one of the doctors got so mad at me that he took the glass of water from me so that [PwP] could not swallow his medication. But anyway, I gave him the medication and he was less agitated. [M, urinary tract infection] *(P18G5CP)* We went to ER probably 2:30–3:00 p.m. Oh and thank goodness I brought some of the pills with me "cause of course we got into the 5:00 pm and then 9:00 pm carbidopa/levodopa dose before he was in a room." And the people in the ER were not willing to do any of that before he got upstairs. So, I gave him his medications in ER. [M, abdominal infection] *(P3G1CP)* Every time you go to a hospital, and you come home from the hospital, there's like 30 doctor visits you have to schedule. You gotta go see a neurologist, you gotta see your GP, you gotta go see your cardiologist, your pulmonologist, and then rehab on top of that. And physically moving her [PwP] around can be difficult for her and for us. And so sometimes it was like we could not even contemplate her having the ability to do all of that. So, with discharge, it wasn't just sometimes what can we do for her at home, but how are we gonna do all of this when she does not even have the strength. [F, pneumonia] *(P12G3CP)*

PwP gender and diagnosis of hospitalizations presented in parenthesis.

TABLE 5 The unique needs of PwP and CP during hospitalizations with representative quotes.

Themes/sub-themes	PwP and CPs representative quotes
Dissatisfaction with management of PD medications	
Inconsistent availability of PD medications	The medication was the issue. I brought my medication with me, they insisted that I could not have my own little stash. I needed to go to the pharmacy. And they took down whatever I was supposed to take. So okay, I take the pills that I've got with me, give them to the nurse who puts them down in the pharmacy and then I have to get them brought back up to me. And all of this is taking time that is pushing me off my normal schedule. *(P15G4PwP)* They said that the hospital did not have it [carbidopa]. They said, "Well, we'll have to see if the pharmacy can get it." And so I offered to bring it and they did not want me to bring it. It was after the third day that they finally got it straightened out, so I do not think he had carbidopa until just before time to leave. *(P21G6CP)*
Delays in medication schedule	Every 4 h, that has to be taken; otherwise, my reaction is awful. Leg starts kicking, the hands start kicking, the body shakes. So, I mean, it's really an awful feeling. *(P19G6PwP)* I can tell when I need to take my medications. That's when my tremors start when I'm not on time. I take it three times a day. As it wears off, I take it. I asked for it, it took them an hour to get it. *(P8G2PwP)* But I would also say when someone with Parkinson's is a patient in the hospital, they are probably under stress due to health issues. They probably need their medication early some of the time, not just on time. *(P14G3CP)* Our biggest problem was the timing. They could not get the idea that the carbidopa/levodopa had to be given at a certain time particularly in relation to meals. *(P3G1CP)* We know they are hospital and they are not gonna be on the dime at the exact timing, so you have to be somewhat flexible. But with Parkinson's patients, especially with someone who's taking medication every 2 h, more than 15 min is very impactful. *(P12G3CP)*
Substitution of medications	They were giving me different looking medications that they assured me were the same thing, just a different manufacturer or whatever it was. Every time they gave me something and I looked at it and questioned it. I was only there for 2 days so it wasn't an extended time period, but it was very disconcerting for me. *(P5G1PwP)*
Self-administration of medications	Now, what happened was that they did not have something I needed—I wanna say some ropinirole—they did not have it in stock. So that was a problem. And I quite honestly had my son and my husband go home and they sort of snuck it in… *(P15G4PwP)* I let my wife know to bring the Neupro patches. It would've been a couple days before it got to the pharmacy, so we just went with mine and I thought that was good cause they normally do not allow you to do that. *(P25G7PwP)* And so I tried to tell them that I spoke to my doctor and that this was all cleared and it was fine, but they were a little hesitant and, at one point, they said, "Well, why do not you give us the medication and we'll give it to you?" And I said, "No…" I said, "I wanna keep the medication in my nightstand here so I do not get it mixed up with anything else," and so they finally said that was fine. *(P22G6PwP)* I wish there was a way for patients who are self - aware to be able to be more self-dosing while they are in the hospital, with some limit per day. They often know their needs better than any staff can. *(P16G4PwP)* …and so a couple times I gave medication to him when he needed to have it and then I just told them that I'd already given it to him. I know they were not happy but we could not wait. It was very hard to get through that this is time sensitive. *(P3G1CP)* I did not trust them [nurses] to give it to him, so I wanted to give him his pills. *(P24G7CP)*
Desire for flexibility in hospital protocols regarding falls risk and ambulation	
limitations in mobility protocols and overall ambulation while in the hospital	It was kind of funny that as soon as I said Parkinson's they put a tag on my hand saying that the fall risk. So after that, they would not let me get off the bed by myself, even though I was pretty able to walk. As long as I'm on the medication, I'm pretty stable. But they put the tag and after that I had to call the nurse every time I want to get off the bed and use the bathroom or anything like that. *(P25G7PwP)* They had fits because I would get out of bed and I'd have to urinate and they would just go ballistic about me getting out of bed but they would not come right away "cause they were dealing with other issues so I took it upon myself to." So finally at about 6 in the morning they brought a port-a-potty into the room. But you know they should have done that sooner if they did not want me getting out of the bed "cause alarms went off left and right." *(P7G2PwP)* "You should continue on moving and get out of the bed" that is not something they [healthcare team] discussed at all. *(P19G6PwP)* It was difficult to convince them that I'm pretty capable of getting up and walking by myself. They just would not listen to me. And I did not make a fight because I knew that they had their protocols and that they are following theirs. And like I said, if my fall risk increases, if I realize that I'm getting weak or I stumble more, I would totally welcome that protocol. I know it is useful. *(P16G4PwP)* To keep someone in bed even two days, my husband has had to relearn to walk twice during the length of his hospitalizations. And it could be prevented if you were able to get out of bed and walk around the room or down the hall every day and it's just not encouraged. They come and do the physical therapy evaluation before discharge. And they should be getting them out of bed every day. It's so quick that you lose the ability to walk. *(P14G3CP)* And they would not let him out [to be discharged] because they said his balance was so bad. But he had been in bed for 3 days. So of course, his balance is bad. That's a long time to be in a hospital where he's totally in bed. He could not get up and walk. He just had to be in that bed. *(P10G3CP)* [for inpatient PT evaluation] he was able to walk across the room and down the corridor. So there wasn't an issue that time. But then when he eventually started doing it at home in a home setting, it was obvious that maybe it was not possible to do. If he would go outdoors, walk down the driveway, and get into the vehicle or drive somewhere and come back, then he could not get out of the vehicle. He would just collapse on the ground.*(P1G1CP)* For Parkinson's, every patient is different and their needs are different. So when I said, "You know, he needs help getting up out of the bed." And he has to have help getting out of a chair even now, and so I had to tell them that because they would come into the room and say, "Okay, it's time to go to the bathroom," and they would take the pole or let him take the pole. He cannot do that, you know? His disability does not allow for that… *(P24G7CP)* Even if not walking but at least just some kind of sitting down exercises, and to take him to have some kind of activities. We really do not have that. It has not been happening in a hospital on its own, is not it? It should happen especially with Parkinson's patients.*(P21G6CP)*
The need for disability—informed hospital environment	
Preservation of independence in the hospital environment	Sometimes it was difficult, especially the dinner, to cut the food up I mean, 'cause my hands start shaking. *(P19G6PwP)* My husband would always try to order finger food that he would rather feed himself and he always had difficulty with that hand coordination after surgery for several days. And so to think about maybe adding items that are finger foods, do not fall apart when you pick them up. *(P14G3CP)* You do not give a Parkinson's person with tremor a full glass of water because it'll be all over the place. You also offer them a straw and always do a half glass of water. Little things like that make all the difference. *(P24G7CP)*
Desire for accommodations for PD—specific care needs	It's hard for me to sleep so when I get to sleep, I'm not really happy when somebody wakes me up and they would come in and have to take my temperature and my blood pressure. *(P7G2PwP)* Every time I've been in the hospital, they keep me fairly close to the nurse's desk and especially during change in shift, you have got all these nurses and everybody congregating at this one spot and they are all talking at once. It gets kind of noisy especially in the middle of the night when they are changing shifts. *(P8G2PwP)* Nurses did not care that I had Parkinson's and, therefore, disabled in ways that they were not familiar with. *(P23G7PwP)* It was hard to use urinal. Needless to say, there were times that he would get wet or whatever and I asked [the nurse] if she would help and she said, "No, he needs to learn to just do it himself." And it kind of threw me off "cause I did not expect that answer." *(P1G1CP)* The problem is as they get older and sicker, we also get older and sometimes also sicker. It was harder and harder for me to spend those nights in the hospital because those chairs that they give you are very uncomfortable. *(P18G5CP)*

as a result, packed and brought their medications to the hospital. All participants reported issues with consistent and timely delivery of PD medications at all stages of hospitalization, from admission to discharge. For some, medications were substituted or re-arranged without explanation, which created mistrust toward HCT.

"They were giving me different looking medications that they assured me was the same thing, just a different manufacturer or whatever it was. Every time they gave me something and I looked at it and questioned it. … it was very disconcerting for me." (P22G6PwP).

Most participants reported needing to have continuous discussions about their medication regimens with their care team. Trust in the HCT further eroded when the PwP perceived that the team lacked knowledge of commonly used medications for PD.

"Everyone had a general understanding of Parkinson's, but not what I would consider, really, decent depth. And especially when it came to the medication, that was a tangible way of judging [the team]- that was something that had to happen and they needed to understand why it was important." (P26G7PwP).

To ensure the correct medications were taken on time and as prescribed, many PwPs and CPs chose to administer their own medications during hospitalization. This was accomplished with or without nursing staff awareness. One CP explained: "*I did not trust them to give it to him, so I wanted to give him his pills.*" *(P24G7CP)* While acknowledging possible limitations, many participants expressed a desire to see protocols around medication self-administration in the hospital. As one participant shared: "*I wish there was a way for patients who are self-aware to be able to be more self-dosing while they are in the hospital, with some limit per day. They often know their needs better than any staff can." (P16G4PwP).*

2.2. The restrictive nature of the hospital fall prevention protocols, along with dissuasion of ambulation, was discordant to participants needs to maintain mobility in the hospital.

Participants who experienced planned hospitalizations for orthopedic issues received prompt postoperative physical therapy (PT) with encouragement for daily ambulation. However, during unplanned hospitalizations, PwPs struggled to advocate for their ambulation needs and reported limited or no evaluation by PT and decreased mobility due to bed confinement. While CPs were commonly present at the bedsides of PwP, they were unsuccessful in advocating for more physical activity. In all focus groups, both PwPs and CPs remarked that the immobility of the PwP was not a concern for HCT. While some participants actively advocated for more physical activity and an assessment by a PT during their hospital stay, others did not, but still expressed their concerns during their focus group.

There were multiple PwPs with good postural stability and no history of falls who were deemed to be a "fall risk" during their hospitalization. "*It was kind of funny that as soon as I said 'Parkinson's' they put a tag on my hand saying that I have fall risk. So, after that, they would not let me get off the bed by myself, even though I was able to walk." (P16G4PwP)* The discrepancy between PwP needs to maintain mobility in the hospital, and the restrictive nature of the hospital fall prevention protocol, along with dissuasion of ambulation, was unsettling to the patients. "*They had me in lockdown mode because I was the fall risk… I would just attempt to escape from Alcatraz.*" *(P25G7PwP)* While participants acknowledged fall prevention as an important aspect of hospitalization, not many PwPs mentioned success in their advocacy to the HCT to revert fall prevention protocols despite obvious distress that such protocols created during their hospital stay.

2.3. Hospital environment was not accommodating toward participants' existing motor and non-motor limitations, indicating the need for disability-informed hospital environment.

Both CP and PwP participants reported feeling that PwP's sense of independence was significantly altered in the hospital. They described the impact of poor fine motor control (due to bradykinesia or tremor) on PwP's ability to attend to daily tasks, such as eating and preferring finger foods on the menu, drinking from half-filled glasses to prevent spillage, and requiring assistance with managing urinals or pushing buttons on bed controls. Both PwPs and HCT preferred CPs to be at the bedside to aid in communication related to PD (e.g., low volume of voice, cognitive issues), although many CPs commented on the lack of accommodations for them, including limited space at the bedside or uncomfortable chairs. Some participants described significantly interrupted night sleep due to vital signs assessments, hearing conversations at the nursing station, or being awakened early to take morning medications. Some CPs observed that sleep interruptions created subsequent confusion and delirium and negatively affected the hospital experience for PwPs. Notwithstanding the reason for hospitalization, when accommodations for PD-specific care needs were included in hospital care, the experience was perceived by PwPs and CPs as more positive than when accommodations were excluded.

Discussion

Our study used an innovative approach to define care needs of PwPs and CPs in the inpatient setting. By gathering first-hand experiences from direct stakeholders, we used qualitative and patient-centered methods to define the challenges and opportunities for improving hospitalization for PD. Thematic analysis revealed unique needs of PwPs and CPs while in the hospital, including the desire for individualized treatment plans and approaches, and the impact of the PD diagnosis on the perception of care during hospitalization.

Consistent with previous literature, the timely provision of PD medications was a key factor in the experience of and satisfaction with care for participants (Barber et al., 2001; Burroughs et al., 2007; Gerlach et al., 2011). In a systematic review examining the prevalence of adverse events related to medication errors, 31% of PwPs expressed dissatisfaction in the way their PD was managed (Gerlach et al., 2011). A more recent study focusing on motor outcomes identified medication errors as the most important factor in motor deterioration during hospitalization (Gerlach et al., 2013). Owing to challenges with medications in the hospital, most participants in our study proceeded with or desired medication self–management. Studies in other patient populations demonstrated the benefits of carefully applying validated medication self–administration protocols during hospitalization and after discharge (Manias et al., 2006; Vanwesemael et al., 2018a,b). The potential benefits and barriers to PD medication self-administration have been explored in outpatient settings; however, no study to date has assessed attitudes toward inpatient medication self-management in the PD population (Tuijt et al., 2020; Armstrong et al., 2021). Strategic and evidence-based medication self-management protocols for PwPs in the early stages or with support of CPs could empower PwPs and CPs and alleviate the workload on hospital staff.

Participants highlighted an important opportunity to improve PCC through individualized assessment of fall risk and flexibility in fall prevention protocols. To our knowledge, the study of falls and fall prevention protocols in hospitalized PwPs does not exist, even though gait and balance deficits were found in 41% of hospitalized PD patients, and prospective studies documented falls in up to 70% of PwPs (Wood et al., 2002; Bernhard et al., 2018). In older adults, a multidisciplinary and patient-centered approach to the development and implementation of hospital fall prevention protocols has been beneficial and could serve as a roadmap for similar quality improvement initiatives for PwPs (Covinsky et al., 2011; Hempel et al., 2013; Matarese et al., 2015). Participants in our study also strongly advocated for safe mobilization and early assessment by rehabilitation therapists during their hospital stay because of their fear or the reality of worsening PD motor symptoms due to immobility. Although there is a lack of literature on the safety and feasibility of early mobilization for hospitalized PwPs on general wards, studies show the benefits of early mobilization after surgery in PD (Macaulay et al., 2010; Schroeder et al., 2015). Walking during hospitalization is effective for older adults, promoting mobility, shortening hospital stays, and increasing likelihood of discharge to home (Hastings et al., 2018). Interventions to encourage mobility in this population show promise in preventing hospital-associated functional decline and maintaining prehospitalization mobility (Wassar Kirk et al., 2018; Cohen et al., 2019; Resnick and Boltz, 2019). Reported barriers to physical activity during hospitalization include insufficient staffing to assist with or encourage mobility, illness symptoms, fear of falls, and a discouraging hospital environment (Brown et al., 2007; Boltz et al., 2011; Koenders et al., 2020). Our study participants alluded to similar barriers to mobilization during their hospital stays. In addition to further research on fall prevention protocols for hospitalized PwPs, identifying patients with low fall risk and encouraging safe ambulation could be the first step to translate the well-established benefits of sustained mobility from outpatient to inpatient care for PD and to empower PwPs and CPs during hospitalization (Ellis et al., 2021).

In our study, nearly two-thirds of participants lived with the PD diagnosis for more than 6 years, and 84% experienced unplanned hospitalizations, emphasizing the complexity of care in the mid- and later stages of PD. The participants' descriptions of challenges with navigating the hospital environment, including but not limited to tremor preventing the ease of intravenous cannulation placement, difficulty picking up and swallowing food that was served, and using hospital equipment like nurse call buttons, were not anticipated by the researchers when this study was designed. These PD-related challenges point to the hidden impact of hospitalization on one's sense of independence. In addition, many CPs mentioned worsening of cognitive function or the development of delirium in PwPs while hospitalized. Our study methods precluded us from identifying specific practices implemented for delirium prevention; however, participants in multiple focus groups mentioned poor sleep protection for PwP during hospitalization. This was similar for CPs, who left the hospital feeling exhausted from reportedly sitting in uncomfortable chairs, monitoring and speaking for their PwP, and continuing to care for their partners once discharged home. Patients diagnosed with PD are fivefold more likely to be treated for delirium than patients from the general population, which may be related to non-motor symptoms in PD, such as dementia, cognitive impairment, and sleep disturbances (Figueroa-Ramos et al., 2009; Stavitsky et al., 2012; Lubomski et al., 2015). Since hospitalization places older adults and PwPs alike at risk for new or worsening disability and reduces likelihood of recovery, several successful interventions have been employed to modify hospital environment and improve patient experience and outcomes (Covinsky et al., 2011; Cohen et al., 2019; Resnick and Boltz, 2019; de Foubert et al., 2021). The hospital environment has a significant impact on patient satisfaction with care, and thus, it could be beneficial to develop and adopt customized hospital accommodations for PwPs to optimize outcomes and decrease risk of complications (Skelly et al., 2014; Rapport et al., 2019).

When patients with chronic conditions are admitted to the hospital, they are expected to switch from being the leader of their own care to being a passive consumer who resumes self-management only upon discharge. Consequently, during hospitalization, the combined stress of acute and chronic illness, set against the background of ongoing pressure to advocate for their unique needs, may be all-consuming for PwPs and CPs. Yet, this can be easily overlooked by HCTs as they are focused on medical management of the acute condition that caused hospitalization. In our study, PwPs and CPs sought active acknowledgement of PD diagnosis by their HCT and adjustment of the hospital communications, protocols or even environment, all of which underscore the impact of PD diagnosis on their perceptions of and experiences with inpatient care. Chronic care advocates argue that hospitals will continue to play a key role in chronic disease care, despite how many acute hospitalizations can be avoided, as most chronic conditions are characterized by acute exacerbations requiring admission (Hernandez et al., 2009; De Regge et al., 2017). Innovative care delivery models, such as the Chronic Care Model, recognize the importance of better preparing hospitals for a role in chronic illness management and demonstrate positive outcomes associated with specialized knowledge of PD among inpatient HCTs (Skelly et al., 2015; Siu et al., 2017). Thus, key findings from our study support acknowledging and accommodating the intersectional needs between the chronic condition of PD and the acute reason for hospitalization of the PwP.

The strength of our study is the use of purposeful sampling, a technique widely used in qualitative research, to identify and select information-rich cases for the most effective use of limited resources (Patton, 2002). Purposive sampling allowed us to identify and select individuals in different stages of PD and ensure that we would capture maximum variation of hospitalization experiences. Qualitative analysis can reveal themes in the data that otherwise may be difficult to identify using quantitative approaches. Focus groups, as a qualitative method, carried an additional strength by creating information—rich data. Focus groups allowed people to discuss the relevant topics with other PwPs and CPs using their own language, to build upon each other's accounts and promoted "memory synergy," bringing forth a "collective memory" of varied perspectives on similar experiences during hospitalization (Kamberelis and Dimitriadis, 2013). One of the limitations of our study is that we were unable to recruit CPs who experienced planned hospitalizations with their PwP, and, as a result, this perspective was not represented in our focus groups. Our sample was largely white, despite having intentionally expanded our recruitment efforts to include PwPs and CPs from diverse demographic backgrounds. Racial and ethnic differences in diagnosis, care experiences, and treatment utilization with PD are well known (Ben-Joseph et al., 2020). Therefore, the findings from this study likely cannot be generalized to the overall PD population and must be further validated in people with varied racial, ethnic, socioeconomic, and clinical backgrounds. Because the focus groups occurred months after their hospital stays, participants' reports were subject to recall bias, and their nonclinical knowledge may have restricted their abilities to identify all factors impacting their hospitalizations. Despite the fact that some of the focus group participants were hospitalized during the COVID-19 pandemic, the discussion did not elucidate robust comments to draw any conclusions about the effect of the COVID-19 pandemic on their experience with hospital care. Despite these limitations, this study provided a novel opportunity for PwPs and CPs to describe their own realities of their hospitalization experiences.

Our study adds to the canon of literature on hospital care for PD. Still, several concepts brought forth by this study warrant further exploration. There is an opportunity to further investigate the role and impact of advocacy by PwPs and CPs on healthcare delivery, as well as explore methodology to capture the real-time experiences of PwPs and CPs during hospitalization, as has been accomplished in other medical conditions (Gualandi et al., 2021). Additionally, the methods and findings of this study serve as good starting points for understanding the hospital experiences of those with atypical parkinsonian syndromes, including progressive supranuclear palsy and multiple system atrophy, given the complexity of symptoms, rapid disease progression, profound lack of awareness of these rarer neurodegenerative diagnoses within the medical community, and the current dearth of research on hospital care for atypical parkinsonism (Dayal et al., 2017; O'shea et al., 2023).

Conclusion

Our qualitative study draws attention to the significant impact a PD diagnosis can have on planned and unplanned hospital stays, even when the reason for care is not directly related to PD. It highlights the plethora of unique needs PwPs and their CPs have during hospitalization. Findings from this study can be used to inform patient-centered interventions aimed at improving the experience with hospital care for PD, including tools that help PwPs prepare for and advocate during hospitalization as well as ensuring flexibility, as appropriate, within hospital protocols. Empowering PwPs and CPs to communicate their questions, concerns, goals, and needs, both generally and regarding PD, with HCT in the hospital setting, thus applying the principles of PCC, could lead to the care they desire and set them up for higher likelihood of positive outcomes following hospitalization.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Office of Human Research Ethics the University of North Carolina at Chapel Hill. The studies were conducted in accordance with the local legislation and institutional requirements. The ethics committee/institutional review board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because the research was deemed to have no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context (e.g., many phone or mail surveys, "man in the street" interviews, etc.).

Author contributions

NB: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Visualization, Writing – original draft, Supervision, Validation. JS: Conceptualization, Data curation, Funding acquisition, Investigation, Project administration, Resources, Methodology, Writing – original draft. SG: Data curation, Methodology, Software, Writing – review & editing, Formal analysis, Validation. PM: Conceptualization, Data curation, Methodology, Writing – review & editing, Supervision.

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Conflict of interest

JS is currently employed by the CurePSP Foundation, although at the time of the study, she was working at the University of North Carolina at Chapel Hill.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fnagi.2023.1255428/full#supplementary-material

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Dysphagia and aspiration during a Parkinson's hospitalization: a care partner's perspective and recommendations for improving standards of care

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People with Parkinson's disease have a significantly increased incidence and risk of aspiration pneumonia when compared to those without. Aspiration pneumonia associated with dysphagia (swallowing issues), which is the leading cause of death among people with Parkinson's disease, accounting for 25% of Parkinson's deaths. There is relatively limited evidence of the most effective strategies to balance the competing needs of each Parkinson's patient as providers aim to prevent, diagnose, and manage dysphagia. Exacerbated, and in part caused, by the intricacies of dysphagia and Parkinson's disease, there is still limited understanding among hospital providers and the Parkinson's community regarding the most appropriate measures to prevent and manage dysphagia in Parkinson's disease. The Parkinson's Foundation Hospital Care Recommendations identified the prevention and management of dysphagia as a care standard necessary to eliminate harm and attain higher reliability in care. This article discusses key components of dysphagia management in the hospital, provides a case example to demonstrate the challenges that people with PD and their care partners experience in the hospital related to dysphagia, and offers recommendations on how to better manage dysphagia and involve care partners in PD hospital care.

KEYWORDS

Parkinson's disease, hospitalization, dysphagia, aspiration pneumonia, caregiving

Introduction

Of the nearly one million people living with Parkinson's disease (PD) in the U.S., an estimated one in six will experience avoidable complications in the hospital often related to medication management, mobility, and dysphagia (Aminoff et al., 2011; Hassan et al., 2013; Zeldenrust et al., 2020). Dysphagia, or impaired swallowing, is a common PD symptom that can lead to serious problems for people with PD in the hospital, including aspiration pneumonia, increased mortality, and longer hospitals stays (Di Luca et al., 2021; Gong et al., 2022). PD medication adjustments that may seem insignificant can lead directly to dysphagia and indirectly to aspiration pneumonia (Lenka et al., 2020). The use of antipsychotic medications is also associated with an increased risk of aspiration pneumonia in older PD patients (Huang et al., 2021). The Parkinson's Foundation Hospital Care Recommendations, which outline optimal hospital care for people with PD, identify dysphagia management as one of the five key standards of quality hospital care (Parkinson's Foundation, 2023).

Bringing a care partner to the hospital who can advocate for one's needs is critical for people with PD because staff may not fully understand PD or know how to properly manage a patient's PD symptoms, including those related to swallowing. This article discusses key components of dysphagia management in the hospital, provides a case example to demonstrate the challenges that people with PD and their care partners experience in the hospital related to dysphagia, and offers recommendations on how to better manage dysphagia and involve care partners in PD hospital care.

Dysphagia management in the hospital

Screening and assessment

Diagnosing dysphagia typically involves three steps—a screening test, a clinical assessment, and an instrumental assessment (Riera et al., 2021). However, the diagnostic approach and the staff involved often vary in the inpatient setting because there is no nationally recognized standard protocol.

Dysphagia is symptomatically multidimensional, and therefore, a multidisciplinary approach to assessment is recommended (Cordier et al., 2023). While speech language pathologists (SLPs) are qualified to lead the assessment, diagnosis, and management of dysphagia (American Speech-Language-Hearing Association, 2016), limitations of SLP staffing and availability make this difficult. As an alternative, initial dysphagia screening tests may be conducted by nurses, with a referral to SLP for further assessment if necessary (Fedder, 2017).

Screening tools that provide optimal diagnostic performance in patients with PD are essential regardless of whether they are being completed by SLPs or nurses. Despite this, two of the most common dysphagia screening tools in use today across settings and patient populations, namely, volume-dependent water swallow tests and subjective patient reports, are both inadequate for patients with PD (Speyer et al., 2021; Dumican et al., 2023). Although there is not yet evidence to support a strong screening tool (Frank et al., 2020), several validated assessment tools do exist (Tomita et al., 2018; Christmas and Rogus-Pulia, 2019).

Care partner advocacy

Parkinson's care partners play an important role during hospital stays. They can assist by providing staff with educational materials, accurately explaining the patient's medication schedule, and conveying the patient's wishes. Having a care partner present can be helpful to all patients as the impact of one's disease can make it more difficult to express one's needs and understand information shared by one's healthcare team (Fenton et al., 2022). Studies have found that the presence of family members during hospitalization increases patient comfort and can even help identify errors that may otherwise be missed (Correia et al., 2020).

The advocate role is also important to many care partners. One study highlighted that nearly 50% of care partners wanted to influence the care provided to their loved ones in the hospital (Lindhardt et al., 2008) as they hold essential information about their loved one's condition, routine, and overall needs. Defining optimal care for each patient often requires direct dialogue with care partners (Bragstad et al., 2014). When healthcare staff work together with patients and families, "the quality of healthcare increases, costs decrease, and patient satisfaction improves (Smith et al., 2022)."

However, care partners are frequently not kept informed while their loved one is hospitalized (Fields et al., 2023) as some providers view family involvement as risky or time consuming (Smith et al., 2022). Families often recognize this hesitance to trust care partner input, which decreases their confidence in staff and satisfaction of care (Whittamore et al., 2014). Among many care partners, there is a sense that hospital policies may contribute to insufficient communication because there are limited established protocols to ensure care partners' access to information (Giguere et al., 2018). When care partners are not kept informed about their loved one's care, they struggle to influence the decisions being made or help improve the care being delivered (Smith et al., 2022).

Case example

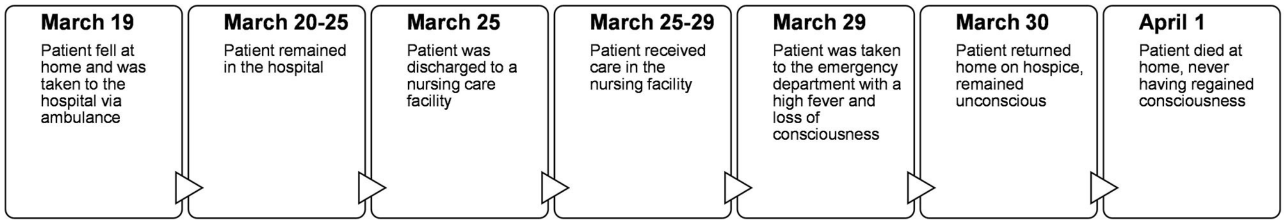
This case example is provided to illustrate the dysphagia-related challenges people with Parkinson's disease and their care partners face while in the hospital as well as the challenges care partners face when attempting to advocate for their loved ones. The interviewee, a Parkinson's Foundation volunteer and care partner to her husband with PD, agreed to participate in a virtual semi-structured interview with the author. The goal of the interview was to describe her husband's experience as a person with Parkinson's disease in the hospital and the interviewee's experience as his care partner.

Case summary

A 74-year-old man with PD diagnosed at 60 years and now with known dementia and dysphagia was admitted to a rural critical access hospital after a fall. The patient was admitted and hospitalized for 5 days for assessment before being discharged to a large continuing care retirement community to receive skilled care and intensive therapy. Four days later, after developing a fever and becoming unresponsive, he was readmitted to the hospital and was subsequently diagnosed with aspiration pneumonia. The following day he was transitioned to home hospice where he died 2 days later (Figure 1).

Care partner perspective

On 19 March 2021, the patient was taken to the hospital *via* ambulance after falling, unable to get up, seeming disoriented and in significant pain. The care partner (CP) accompanied him to the hospital where he was admitted. Due to COVID-19 protocols, she was only permitted to be with him for 6 h per day. This was especially worrisome for the CP because her husband's dementia had progressed to the point that he could not communicate his needs.



March 19
Patient fell at home and was taken to the hospital via ambulance

March 20-25
Patient remained in the hospital

March 25
Patient was discharged to a nursing care facility

March 25-29
Patient received care in the nursing facility

March 29
Patient was taken to the emergency department with a high fever and loss of consciousness

March 30
Patient returned home on hospice, remained unconscious

April 1
Patient died at home, never having regained consciousness

FIGURE 1
Timeline.

CP attempted to advocate for her husband's Parkinson's-specific needs throughout his stay speaking to numerous hospitalists, nurses, and nurse aids. Upon arrival, she explained to the hospitalist that her husband had trouble swallowing and that she typically gave him his medication with either applesauce or yogurt, but medications were withheld rather than given with thickened liquid. As an education and advocacy tool, CP brought and used her hospital safety kit, provided by the Parkinson's Foundation. Included in the kit are tips to share if swallowing is an issue, including "sit up while eating, tuck in your chin each time you swallow," (Parkinson's Foundation, 2022) but she did not see any aspiration prevention measures implemented and received no information about the offsite SLP being contacted.

CP identified nurse aids as particularly crucial team members, given the amount of time they spent with her husband, but felt they were the least receptive to input about her husband's care needs and lacked a sufficient understanding of his risk of aspiration. She viewed her husband's care in the hospital as problematic, acknowledging the impact the pandemic had on her ability to advocate and on the healthcare facilities' capacity to provide quality care. She also felt the lack of staff knowledge about risk factors of dysphagia and aspiration pneumonia was the primary factor leading to his steep decline. She highlighted the key role of the CP in PD management, sharing her frustration that she was unable to be more present as an advocate and that hospital staff were unreceptive to her input, particularly related to his swallowing.

Case example limitations

A key limitation of the case example is the presentation of a single perspective without access to the medical chart or input from medical care providers. Additionally, the impact of the visitation limitations implemented during the height of the COVID-19 pandemic must be considered.

Establishing meaningful channels of communication became especially challenging in the throes of COVID-19 when the physical presence of care partners was discouraged and often significantly limited (Bragstad et al., 2014). An integrative review of 17 articles published in 2021 focused on the impact of COVID-19 visitation limitations identified numerous unintentional consequences of the absence of care partners, including significant decline in health and wellbeing of family members, adverse health effects, and decreased quality of life (Hugelius et al., 2021).

Discussion

As we consider the next steps in improving dysphagia management and aspiration pneumonia prevention among people with Parkinson's disease in the hospital, evidence-based practices for clinicians must be established, ideally as part of nationally recognized standards of care. We also must ensure that the Parkinson's communities—care partners and people with PD—are informed collaborators throughout hospital care. In the next section, we will discuss both.

Recommendations for dysphagia best practices in the hospital

Hospitals need clear best practices for assessing and treating dysphagia in patients with PD. Dysphagia prevention and management is one of the five care standards outlined in the Parkinson's Foundation Hospital Care Recommendations. The standard states that "All people with Parkinson's should undergo screening for dysphagia within 24 h, with measures taken to minimize the risk of aspiration pneumonia, as needed (Parkinson's Foundation, 2023)."

These recommendations represent a step forward in establishing best practices but do not define the standard protocol for institutions to utilize. With consistent protocols, sufficient implementation will be uneven across institutions, and patients with PD will remain at risk. More rigorous research on how to best assess, prevent, and treat dysphagia is needed.

Requirement 1: standard screening of swallowing abilities

To reach consensus on a standard screening protocol, additional research must validate effective screening tool(s) for identifying dysphagia in PD patients, ensuring the feasibility of use across hospital settings. Without appropriate screening tools, hospitals will need support in prioritizing the timely use of validated assessment tools.

Requirement 2: standard protocol for minimizing aspiration pneumonia risk

Generally, it is considered appropriate but is a rarely established policy for people with Parkinson's disease in the hospital to eat only while maintaining an upright posture. Establishing this as a policy would still require the navigation of administrative processes in individual hospitals.

Standardizing hands-on practices, such as supervising meals, may be more challenging. More research is needed to demonstrate when this level of care is necessary.

Requirement 3: standard protocol for medication management when dysphagia is identified

Since PD medications contribute to the maintenance of the ability to swallow, a customized approach to medication management in PD patients with mild-to-moderate dysphagia may prevent the continued deterioration of swallowing function. Clinical tools that can clarify the severity of dysphagia could make this possible. Identification or development of these tools is necessary before we can recommend appropriate medication protocols based on the severity.

Broadscale adoption of standards will require a national dissemination and education plan, buy-in from health systems and quality improvement organizations, and additional research into the areas of limited evidence.

The role of patients and care partners

In addition to the need for reliable tools and evidence-based best practices in PD care, there is also a need to educate the Parkinson's community, and in particular, care partners of people with Parkinson's disease, about what they can do to help prevent aspiration pneumonia in the hospital.

Care partners are essential as advocates during hospitalization and should be acknowledged as an important member of the care team. Without staff respect for care partner input, however, the success of advocacy is limited. For example, in the case example, even though the care partner came equipped with tools in the Hospital Safety Kit, she struggled to impact care. It is important for hospitals to adopt standard protocols that honor the care partner role and create opportunities for their input on the care being provided.

Future research can strengthen care partner advocacy efforts by offering evidence-based answers to complex questions about how care partners can best monitor and advocate for their loved ones needs related to medication management, swallowing, dysphagia, and aspiration pneumonia.

Conclusion

The Parkinson's Foundation, in collaboration with key clinical and community stakeholders, is committed to understanding the challenges associated with dysphagia in the hospital and identifying strategies and best practices for improving care and outcomes. We prioritize the inclusion of care partners and people with PD in our process and invite all healthcare systems and leadership to join us as we work together to eliminate preventable harm in the hospital for people with Parkinson's disease.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

AB: Writing—original draft.

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Conflict of interest

AB was employed by Parkinson's Foundation.

Publisher's note

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Reducing the receipt of contraindicated medications in patients with Parkinson disease

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Background: The administration of antidopaminergic medications to patients with Parkinson's disease (PD) can exacerbate symptoms, and in the hospital setting, can lead to complications and increased length of stay. Despite efforts to improve medication administration through provider education and patient-centered interventions, the problem persists, with an estimated 21–43% of hospitalized PD patients receiving dopamine blocking medications.

Methods: In this study, a best practice alert (BPA) was developed that was triggered when an antidopaminergic medication was ordered in the Emergency Department or hospital for a patient with a diagnosis of PD in the EMR. The primary outcomes were receipt of a contraindicated medication, length of stay (LOS) and readmission within 30 days. These outcomes were compared between the 12 months prior to the intervention and the 12 months post intervention. Data were also collected on admitting diagnosis, admitting service, neurology involvement and patient demographics.

Results: For pre-intervention inpatient encounters, 18.3% involved the use of a contraindicated medication. This was reduced to 9.4% of all inpatient encounters for PD patients in the first 3 months post-intervention and remained lower at 13.3% for the full 12 months post-intervention. The overall rate of contraindicated medication use was low for ED visits at 4.7% pre-intervention and 5.7% post-intervention. Receipt of a contraindicated medication increased the risk of a longer length of stay, both before and after the intervention, but did not significantly affect 30-day readmission rate.

Conclusion: An EMR BPA decreased the use of contraindicated medications for PD patients in the hospital setting, especially in the first 3 months. Strategies are still needed to reduce alert fatigue in order to maintain initial improvements.

KEYWORDS

Parkinson 's disease, best practice alert, quality improvement, electronic medical record, contraindicated medications

Introduction

Parkinson Disease (PD) is a neurodegenerative disorder caused by loss of dopamine-producing neurons in the substantia nigra. Further depletion of dopamine with dopamine antagonists, such as antipsychotics and antiemetics, can lead to worsening PD symptoms, cognitive changes, falls, and infections (Chou et al., 2011). In hospitalized patients, receipt of contraindicated medications has been shown to increase length of hospital stay (Chou et al., 2011). In addition, PD patients who are hospitalized are more susceptible to hallucinations, mental status changes, and nausea, symptoms that are typically treated with anti-dopaminergic medications. These patients often have complicated medication regimens, and inpatient staff may be unfamiliar with the management of this largely outpatient-treated disease. In one study, 70% of inpatient staff were unaware of which medications to avoid in patients with PD (Chou et al., 2011). Due to these challenges, contraindicated medications are often inadvertently prescribed to patients with PD who are admitted to the hospital. Studies in hospitals throughout the US and beyond demonstrate that 21–43% of hospitalized PD patients received dopamine-blocking medications, which was associated with complications and longer hospital stays (Derry et al., 2010; Oguh, 2012).

Several measures could be taken in attempts to improve medication administration to PD patients. Patient and provider education on contraindicated medications in PD is important. While providers may immediately better understand the risks associated with administering certain medications to PD patients, the disconnect between a didactic session and hands-on patient care that may occur months after the session can hamper retaining of the information. The Parkinson's Foundation put out the "Aware in Care" kit, which provides information for patients to hand out to staff members during a hospitalization. This includes the importance of medication timing and a list of contraindicated medications and encourages the patient or care partner to be an advocate. While these kits are certainly helpful, without other interventions, they put the responsibility on the patients and their families to keep this information with them and to recognize when a medication should not be given; efficacy depends on the involvement of the patient and caregiver.

Some hospitals have developed in-chart interventions to address this issue. The Barrow Institute in Arizona and Hutt Hospital in New Zealand implemented EMR notices that alerted prescribing providers if a contraindicated medication was ordered for a patient with PD (Aslam et al., 2020; Lance et al., 2021). The Barrow Institute decreased contraindicated medication use from 42.5 to 17.5% while Hutt Hospital reduced contraindicated medication use from 33 to 5% and reduced length of stay (LOS) by 50%.

Reducing in-hospital complications and LOS was even more important in the COVID-19 era where resources were often limited. In a preliminary data analysis at our institution, 24% of hospitalized PD patients received a contraindicated medication. While this was at the lower end of the above referenced range of contraindicated medication administration at other hospitals, it left plenty of room for improvement. The aims of this study were to determine the effects of contraindicated medication administration in PD patients on ED and hospital outcomes and to develop a tool to reduce contraindicated medication use for PD patients by alerting providers of a possible drug-disease interaction.

Materials and methods

Approvals and research protections

This study was determined to be exempt by the Colorado Multiple Institutional Review Board (COMIRB) at the University of Colorado Anschutz Medical Campus.

Study design

In this prospective cohort study, a best practice alert (BPA) was developed and implemented using a quality improvement "Plan, Do, Study, Act" (PDSA) cycle (Figure 1). It was incorporated into Epic, the electronic medical record (EMR) system at the University of Colorado Hospital. The alert was designed to be triggered when a patient with a diagnosis of Parkinson's disease, identified by ICD-10 code "G20" in their problem list or past medical history, was prescribed an antidopaminergic medication in the Emergency Department or in the hospital. The BPA warned that dopamine antagonists were contraindicated in Parkinson's disease and listed several possible adverse effects as shown in Figure 2. Prescribers were given the option to remove the order, keep the order, or apply a safe alternative that was provided in the alert. In order to provide appropriate alternatives, four versions of the BPA were created for different indications. These included "nausea," "agitation," "promotility agent," and "other." Depending on the indication for the order, appropriate alternatives would be suggested (eg, quetiapine instead of olanzapine for agitation; ondansetron instead of prochlorperazine for nausea). If the order was kept, an acknowledged reason was required, including "inaccurate diagnosis of PD," "home medication," and "previously tolerated." The inpatient pharmacist was notified if the contraindicated medication was ordered, and they were instructed to reach out to the prescriber to discuss the order. Patients were excluded if they had a diagnosis of a secondary or drug-induced parkinsonism, identified by the ICD-10 code "G21".

Prior to implementation of the BPA, in-service trainings were held with the inpatient pharmacists to discuss the BPAs and their role in discussing the orders and alternatives with providers who prescribed a contraindicated medication.

Using the same inclusion and exclusion criteria, a retrospective chart review was performed to determine baseline rates of contraindicated medication use for patients with Parkinson's disease seen in the Emergency Department or hospital and were compared to the 12 months post-BPA.

Study outcomes

The primary outcomes were receipt of a contraindicated medication, length of stay (LOS) and readmission within 30 days. We also collected data on admitting diagnosis, admitting service, neurology involvement, age, gender, race, and ethnicity. For the first 6 months, we also collected data on how often the BPA was triggered, the number of times it was overridden, how often an alternative from the BPA was given and the number of times the contraindicated medication as given.

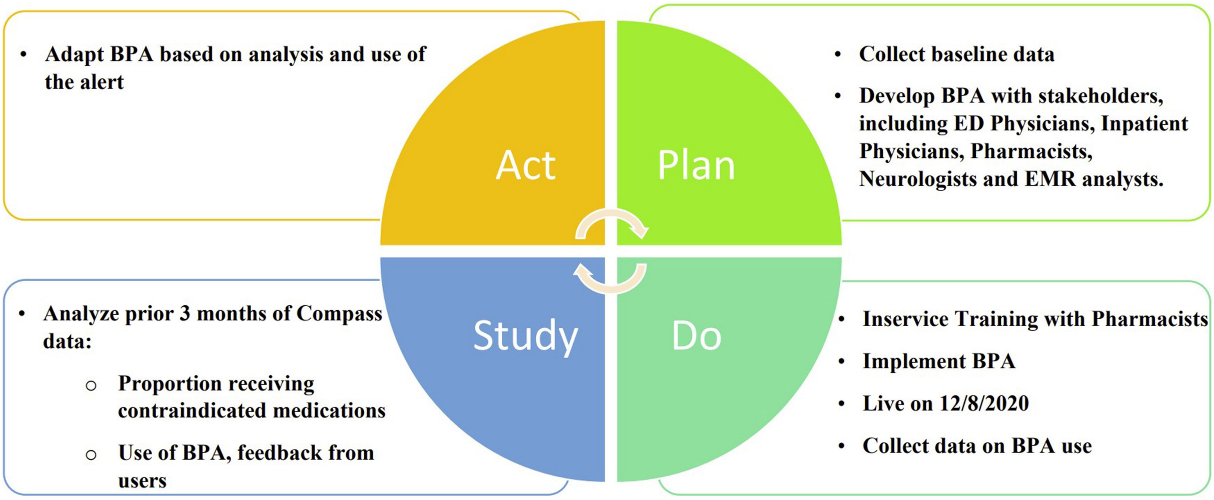
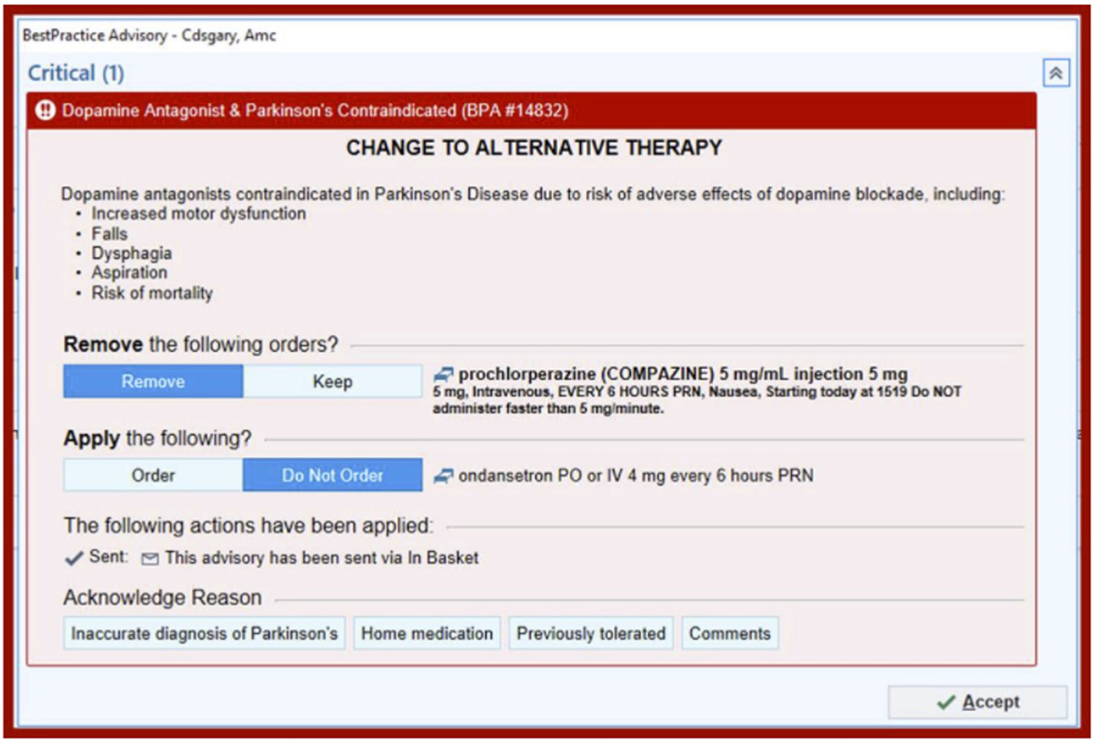


FIGURE 1
Development and implementation of best practice alerts using PDSA Cycles.


BestPractice Advisory - Cdsgary, Amc

Critical (1)

Dopamine Antagonist & Parkinson's Contraindicated (BPA #14832)

CHANGE TO ALTERNATIVE THERAPY

Dopamine antagonists contraindicated in Parkinson's Disease due to risk of adverse effects of dopamine blockade, including:

- Increased motor dysfunction
- Falls
- Dysphagia
- Aspiration
- Risk of mortality

Remove the following orders?

prochlorperazine (COMPAZINE) 5 mg/mL injection 5 mg
5 mg, Intravenous, EVERY 6 HOURS PRN, Nausea, Starting today at 1519 Do NOT administer faster than 5 mg/minute.

Apply the following?

ondansetron PO or IV 4 mg every 6 hours PRN

The following actions have been applied:

✓ Sent: This advisory has been sent via In Basket

Acknowledge Reason

FIGURE 2
Best practice alert for nausea as the indication for the medication order.

Statistical analysis

Statistical methods

Frequency and percentages were calculated for categorical variables, and mean and standard deviation were calculated for continuous variables. Summary statistics were broken down by time period (pre- and post-BPA), and by encounter type (ED Visit or Admission). Patient demographics were assessed on unique patients, while treatment characteristics were assessed at the encounter level. Binary outcomes were analyzed with relative risk models, with generalized estimating equations (GEE) accounting for repeated measures. Length of stay was analyzed with Cox proportional hazards models. All tests were two-sided and statistical significance was set at $p < 0.05$ unless otherwise noted. Statistical analyses were performed using the SAS statistical software package version 9.4 (SAS Institute Inc., Cary, NC).

TABLE 1 Characteristics of PD patients who received care in the Emergency Department or Hospital Pre and Post Intervention.

	Pre-BPA		Post-BPA	
	ED Visit *N* = 176 patients, 318 encounters	Admissions *N* = 147 patients, 229 encounters	ED Visit *N* = 164 patients, 317 encounters	Admissions *N* = 160 patients, 266 encounters
Mean age, SD (years)	72.40 (11.19) (first encounter)	72.22 (11.45) (first encounter)	72.79 (10.62) (first encounter)	73.03 (10.29) (first encounter)
Sex, *N* (percent male)	96 (54.55%)	93 (63.27%)	88 (53.66%)	105 (65.63%)
Race				
White	137 (77.84%)	120 (81.63%)	132 (80.49%)	130 (81.25%)
Black	21 (11.93%)	9 (6.12%)	8 (4.88%)	10 (6.25%)
Asian	5 (2.84%)	6 (4.08%)	2 (2.50%)	4 (2.50%)
Other	10 (5.68%)	9 (6.12%)	15 (9.15%)	11 (6.88%)
Multiple race	3 (1.70%)	3 (2.04%)	7 (4.27%)	5 (3.13%)
Ethnicity				
Non-Hispanic	162 (92.05%)	136 (92.52%)	139 (84.76%)	145 (90.63%)
Hispanic	14 (7.95%)	10 (6.80%)	25 (15.24%)	15 (9.38%)
Patient refused	0 (0.00%)	1 (0.68%)	0 (0.00%)	0 (0.00%)
Neurologist involved (*N*, percent yes)	Patient: 16 (9.09%) (at least once) Encounter: 17 (5.35%)	Patient: 57 (38.78%) (at least once) Encounter: 73 (31.88%)	Patient: 11 (6.71%) (at least once) Encounter: 17 (5.35%)	Patient: 53 (33.13%) (at least once) Encounter: 73 (31.88%)
Length of stay, Mean, SD (days)	Patient total: 0.40 (0.63) Encounter: 0.22 (0.42)	Patient total: 8.78 (9.78) Encounter: 5.64 (5.71)	Patient total: 0.47 (0.80) (N = 163) Encounter: 0.25 (0.48) (N = 311)	Patient total: 9.04 (10.63) Encounter: 5.44 (6.09)
Mean # of encounters per PD patient, SD	1.81 (1.44)	1.56 (0.74)	1.93 (1.76)	1.66 (1.01)

TABLE 2 Frequency of contraindicated medication use by encounter type, pre and post intervention.

	Pre-BPA		Post-BPA	
	ED visit *N* = 176 patients, 318 encounters	Admissions *N* = 147 patients, 229 encounters	ED Visit *N* = 164 patients, 317 encounters	Admissions *N* = 160 patients, 266 encounters
Number (%)	Patients: 15 (8.52%) (at least once) Encounters: 15 (4.72%)	Patients: 37 (25.17%) (at least once) Encounters: 42 (18.34%)	Patients: 16 (9.76%) (at least once) Encounters: 18 (5.68%)	Patients: 24 (15.00%) (at least once) Encounters: 36 (13.53%)

Results

In the 12 months prior to BPA implementation, a total of 318 ED visits and 229 inpatient admissions occurred for patients with a diagnosis of Parkinson's disease (Table 1). Post-intervention, there were a total of 317 ED visits and 266 inpatient admissions. There were no differences in age, gender, race, and ethnicity between the pre- and post-intervention groups. The majority of the patients were white and non-Hispanic. The mean age was 72–73 years old and about 60% were male.

The overall rate of contraindicated medication use was low for ED visits. In the encounters for 12 months pre-intervention, 4.7% of ED encounters involved the use of a contraindicated medication compared to 5.8% of 12 months post-intervention encounters, which was not statistically significantly different ($p = 0.55$). Regarding inpatient encounters, 18.3% involved the use of a contraindicated medication pre-intervention compared to 13.3% post-intervention for a 27.3% improvement (Table 2). However, there was a larger reduction (48.6%) in the use of contraindicated medications for inpatient admissions in the first 3 months post-intervention versus the first 12 months post-intervention (9.4% vs. 18.3%), after which the use of antidopaminergic medications increased again (Figure 3). During this 3-month period, the BPA was triggered 57 times and overridden 21 times. The inpatient pharmacists approved the use of medications 11 times, most commonly because it was a home medication, the diagnosis of Parkinson's disease was in question, or the medication was previously tolerated. After the first 3 months, the BPA was overridden more often at 31 times. In addition, there were several

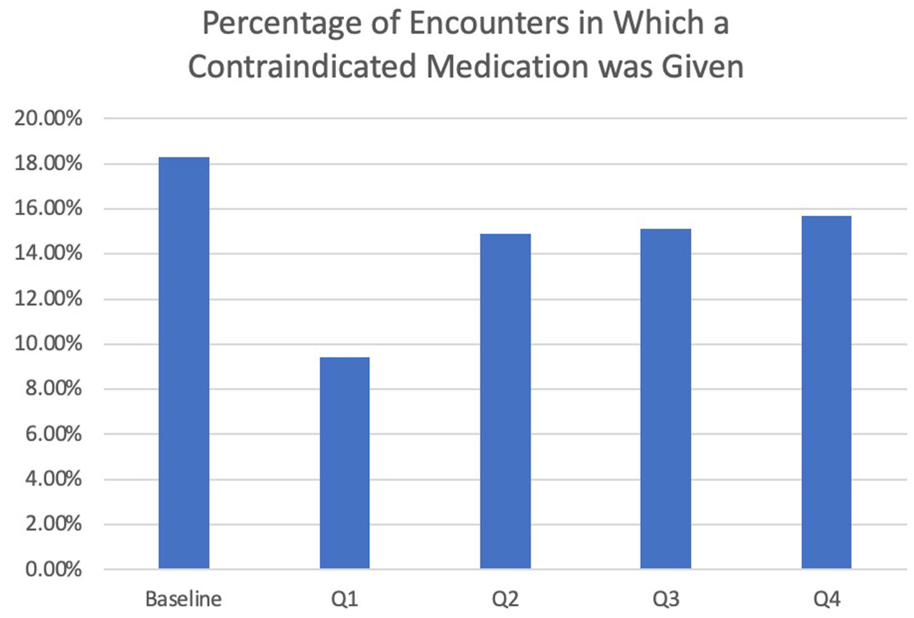


FIGURE 3
Percentage of encounters in which a contraindicated medication was given by time period.

instances in which the pharmacist on shift did not see the alert, leading to more antidopaminergic orders getting approved.

Receipt of a contraindicated medication was associated with a longer length of stay both pre- and post-intervention (Table 1). This outcome was analyzed using hazard ratios. Pre-intervention, the contraindicated medication administration reduced the hazard of leaving the hospital (increased length of stay) with a hazard ratio of 0.62 ($p = 0.0005$). Post-intervention, the findings were similar, with a hazard ratio of 0.64 ($p = 0.0065$). There was no significant difference in mean or median length of stay pre- versus post-intervention. Similarly, there was an increase in 30-day readmission rates with receipt of a contraindicated medication versus not, although the difference was marginally statistically non-significant with a risk ratio of 0.69 ($p = 0.073$). There was an increased 30-day readmission rate in patients who received a contraindicated medication post-intervention with a risk ratio of 1.84 ($p = 0.0001$). There was no difference in readmission rates pre- and post-intervention in patients who did not receive contraindicated medications.

Admitting service and admitting diagnosis were evaluated in the context of whether patients received a contraindicated medication. Patients admitted to a surgery service were more likely to receive a contraindicated medication than patients admitted to a neurology service (22.9% versus 6.9%) post-intervention; however, the omnibus tests were not statistically significant. The percentage of patients who received a contraindicated medication pre- and post-intervention by admitting diagnosis category is displayed in Figure 4. Statistical analysis of this data was limited by low sample sizes in some categories and missing admitting diagnosis in the EMR in many patients.

Neurologist involvement in patient care was assessed by presence or absence of a neurologist's note during the encounter. Pre-intervention, there was a risk ratio of 0.58 ($p = 0.078$) for administration of a contraindicated medication with neurologist involvement versus without. Post-intervention, the risk ratio was 1.14 ($p = 0.58$). While there was a trend toward lower risk of the use of a contraindicated medication when a neurologist was involved in the care of the patient pre-intervention, it was not statistically significant. This analysis is also limited by not accounting for if the neurologist was involved before or after the receipt of a contraindicated medication.

The most commonly prescribed contraindicated medications both pre- and post-intervention are displayed in Table 3.

Conclusion and discussion

In this study, we developed and implemented a tool to alert prescribing providers about potential drug-disease interactions and successfully reduced the administration of contraindicated medications, with the most significant impact observed in the first 3 months after the tool's release. In addition, we found that increased LOS and 30-day re-admission rates were associated with contraindicated medication use.

Our BPA decreased the rate of contraindicated medication administration in admitted patients with Parkinson's disease. In the first 3 months post-intervention, the rate of administration of these agents nearly halved. While the rate of administration continued to trend lower than baseline in the subsequent 9 months, the reduction was much more modest. The first 3 months were also associated with a higher pharmacist involvement and prescriber responsiveness to the alerts, likely accounting for the larger reduction in contraindicated medication use during this time period. As with any repetitive alerting system, there is a potential for practitioners to become fatigued from frequent reminders. This phenomenon could decrease the tool's efficacy over time, resulting in reduced use and possibly undermining its benefits. To address the issue of alert fatigue, several strategies could be employed to increase the engagement of both prescribers and pharmacists. Firstly, periodic education and retraining sessions can serve as timely reminders about the importance of the tool and its

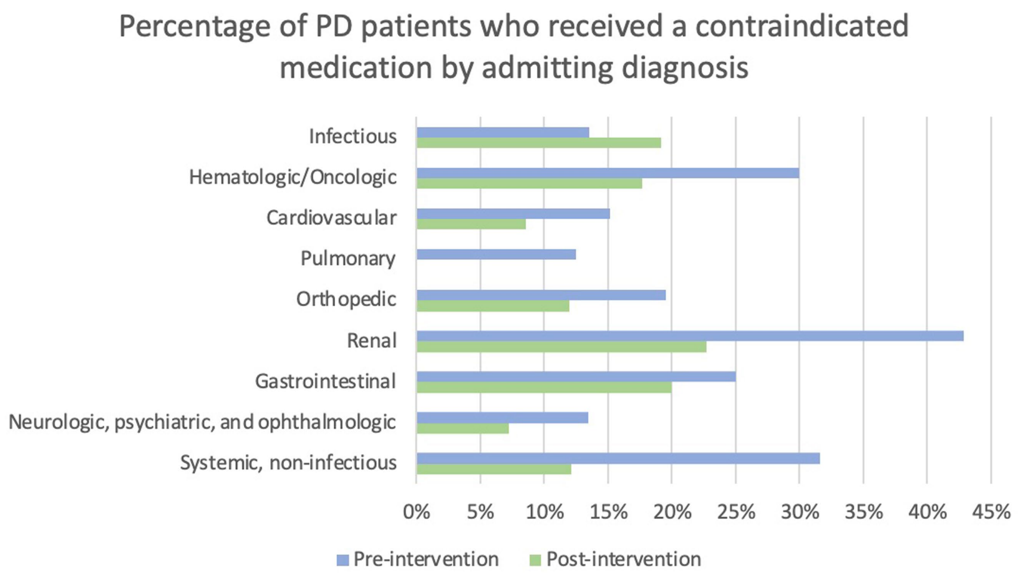


FIGURE 4
Percentage of PD patients who received a contraindicated medication by admitting diagnosis. Note that no patients admitted with a pulmonary diagnosis received a contraindicated medication post-intervention.

TABLE 3 Contraindicated medications by frequency of receipt.

	Pre-intervention (12 months)		Post-intervention (12 months)	
Medication	Frequency*	Percent	Frequency*	Percent
Prochlorperazine	16	2.93	11	1.89
Olanzapine	14	2.56	22	3.77
Hydroxyzine	9	1.65	10	1.72
Haloperidol	8	1.46	6	1.03
Metoclopramide	6	1.10	6	1.03
Promethazine	6	1.10	1	0.17
Aripiprazole	1	0.73	2	0.34
Risperidone	3	0.55	4	0.69
Chlorpromazine	1	0.18	0	0.00
Ziprasidone	0	0.00	1	0.17
Total	64	NA	63	NA

*Number of ER and admissions in which the medication was given at least once.

impact on patient outcomes. Implementing personalized feedback mechanisms to monitor individual prescriber and pharmacist performance may also encourage continued usage of the tool, as successfully executed by Raja et al. (2015).

By providing a tangible solution to the prescription of contraindicated medications in hospitalized Parkinson's patients through the development of a tool, we contribute to the growing body of research on improving medication safety in neurodegenerative disorders. The successful implementation of the tool adds to the literature regarding the potential for technology-based interventions to improve patient care and reduce complications in vulnerable populations. This study replicates findings in the literature of a BPA's ability to reduce administration of contraindicated medications and the association of receipt of a contraindicated medication with length of stay. The study adds to the literature data from a facility with lower-than-average baseline administration of contraindicated medications, suggesting that a BPA is an effective tool in this setting.

Our findings reveal a significant association between the administration of contraindicated medications and increased length of stay and 30-day readmissions in PD patients. By reducing the use of contraindicated medications through the implementation of a BPA, both length of stay and 30-day readmissions can be reduced. This is important for healthcare providers and institutions, as reducing both length of stay and readmissions is important for both optimizing healthcare resources and for improving patient outcomes.

The statistically significant difference between pre- and post-intervention 30-day readmission rates for patients who received contraindicated medications may be due to alternative medications suggested by the BPA being reasonable for less acutely ill patients, while the more acutely ill patients required the originally prescribed antidopaminergic therapy.

In conclusion, this study not only emphasizes the importance of avoiding contraindicated medications in PD patients but also illustrates the efficacy of a well-designed tool in reducing the occurrence of such medication errors, even in facilities where baseline administration of contraindicated medications is lower than average. While alert fatigue remains a potential challenge, proactive strategies to address this issue can sustain the tool's impact and ensure its continued usage among healthcare providers. Overall, our findings hold valuable implications for enhancing patient safety, optimizing hospital care, and promoting medication management practices in Parkinson's disease and other neurodegenerative disorders.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Colorado Multiple Institution Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

CG: Methodology, Writing – original draft, Writing – review & editing. SS: Methodology, Writing – review & editing. EW: Writing – review & editing. JB: Writing – review & editing. RC: Writing – review & editing. KT: Writing – review & editing. MF: Methodology, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Unique characteristics of end-of-life hospitalizations in Parkinson disease

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Introduction: Persons with Parkinson disease (PD) are hospitalized at higher rates, have longer lengths of stay, and are more likely to die in the hospital than age-matched peers. Although prior studies have compared inpatient outcomes between persons with and without PD, little is known about inpatient outcomes across the PD trajectory, or whether hospitalizations occurring in the last 6 months of life differ from earlier hospitalizations.

Methods: This cross-sectional study compared Medicare Part A and B beneficiaries aged 65 and older with a qualifying PD diagnosis who were hospitalized in 2017: decedents who died between 7/1/2017 and 12/31/2017 from all causes and were hospitalized at least once in their last 6 months of life, and non-decedents who were hospitalized between 1/1/2017 and 6/30/2017 and lived 6 or more months after discharge. End-of-life (EoL) hospitalizations were defined as those occurring in the last 6 months of life. Descriptive analyses compared patient-level variables (e.g., demographics, comorbidities, treatment intensity) and encounter-level variables (e.g., length of stay, total charges) between groups. Multivariable logistic regression models also compared rates of intensive care unit (ICU) admission and 30-day readmission between hospitalized decedents and hospitalized non-decedents, adjusting for age, sex, race/ethnicity, rural residence, and Charlson Comorbidity Index Score.

Results: Of 26,492 Medicare decedents with PD, 16,187 (61.1%) were hospitalized in their last 6 months of life. Of 347,512 non-decedents with PD, 62,851 (18.1%) were hospitalized in a 6-month period. Hospitalized decedents were slightly older than hospitalized non-decedents (82.3 [SD 7.40] vs. 79.5 [SD 7.54] years) and had significantly more comorbidities. Compared to non-EoL hospitalizations, EoL hospitalizations were slightly longer (5 [IQR 3–9] vs. 4 [IQR 3–7] days) and more expensive based on total charges per admission ($36,323 [IQR 20,091-69,048] vs. $32,309 [IQR 18,789–57,756]). In covariate-adjusted regression models using hospitalized non-decedents as the reference group, hospitalized decedents were more likely to experience an ICU admission (AOR 2.36; CI 2.28–2.45) and 30-day readmission (AOR 2.43; CI 2.34–2.54).

Discussion: Hospitalizations occurring in the last 6 months of life among persons with PD in the United States are longer, more costly, and more resource intensive than earlier hospitalizations and may stem from medical comorbidities. Once hospitalized, ICU admission and 30-day readmission may aid in prognostication and serve as markers of transition to the EoL period.

KEYWORDS

Parkinson disease, hospitalization, intensive care unit, length of stay, cost, mortality

Introduction

Parkinson disease (PD) is the second most common neurodegenerative disorder worldwide and the 14th leading cause of death in the United States (Marras et al., 2018; Kochanek et al., 2019). There are no disease-modifying therapies for PD, and progressive symptoms contribute to significant morbidity and mortality. Not surprisingly, age and advancing symptoms increase the risk of hospitalization (Woodford and Walker, 2005; Hobson et al., 2012; Hassan et al., 2013), and persons with PD are hospitalized at higher rates, have longer lengths of stay, and are more likely to die in the hospital than age-matched peers (Aminoff et al., 2011; Gerlach et al., 2012; Low et al., 2015; Shahgholi et al., 2017). Despite these data, little is known about PD hospitalizations in the end-of-life (EoL) period, commonly defined as the last 6 months of life (Lamont, 2005; Hui et al., 2014).

A recent study exploring inpatient treatment intensity among hospitalized patients with PD found that the final 6 months of life are a critical period in PD care (Aamodt et al., 2023a). Almost two-thirds of all United States Medicare beneficiaries with PD are hospitalized at least once in their last 6 months of life with high rates of aggressive care (Aamodt et al., 2023a). For example, of 33,107 beneficiaries with PD who were hospitalized in the EoL period in 2017, 16,266 (49%) were transferred to the intensive care unit (ICU) and 7,970 (25%) died in the hospital. Of those surviving hospitalization, 9,892 (30%) were discharged to inpatient or home hospice and 10,046 (30%) were readmitted within 30 days. These inpatient outcomes are considered markers of inappropriate EoL care quality in persons with Alzheimer's disease (AD) and may suggest inappropriate EoL care practices in PD (De Schreye et al., 2017). However, it is currently unknown whether increased rates of hospitalization or inpatient treatment intensity among persons with PD are unique to the EoL period or occur throughout the disease course.

Building upon our existing data, the primary objectives of the current study were to (1) describe and compare the demographic and clinical characteristics of United States Medicare beneficiaries with PD who were hospitalized at least once in their last 6 months of life (e.g., hospitalized decedents) or hospitalized at least once before the EoL period (e.g., hospitalized non-decedents), (2) compare inpatient resource utilization and total inpatient charges between hospitalized decedents and non-decedents, and (3) determine whether rates of ICU admission and 30-day readmission differ between hospitalized decedents and non-decedents after adjusting for key demographic and clinical variables.

Methods

Protocol approval

This study was approved by the University of Pennsylvania Human Research Protections Office and the Centers for Medicare & Medicaid Services (CMS) via a Data Use Agreement and waiver of consent. Data analysis was conducted from January 2023 to April 2023.

Data source

The Medicare program insures more than 98% of United States adults aged 65 and older and provides inpatient, outpatient, and prescription drug coverage (Research Data Assistance Center, 2015). The current study used data from the 2017 Master Beneficiary Summary File (MBSF), 2017 Medicare Provider Analysis and Review (MedPAR) file, and 2015–2017 Carrier files. CMS files contain individual-level data that can be linked across datasets using a unique beneficiary identification code. The MBSF contains Medicare enrollment and eligibility information, validated birth and death dates, demographic data, postal codes, and indicator variables for 27 common chronic medical conditions obtained using validated algorithms (Chronic Conditions Data Warehouse, 2023). The MedPAR file contains information on 100% of Medicare beneficiaries admitted to acute care hospitals and skilled nursing facilities covered by Medicare. These files contain admission and discharge dates, admission and principal diagnoses, procedure codes, total charges, and reimbursement amounts. The Carrier files contain fee-for-service claims submitted by professional providers, including physicians, physician assistants, nurse practitioners, and clinical social workers. The MedPAR and Carrier files contain International Classification of Diseases, Ninth Revision (ICD-9) codes for services provided before October 1, 2015, and International Classification of Diseases, Tenth Revision (ICD-10) codes for services provided on or after October 1, 2015.

Inclusion and exclusion criteria

We conducted a population-based cross-sectional study comparing two cohorts of Medicare Part A (inpatient) and Part B (outpatient) beneficiaries aged 65 and older with at least two validated inpatient and/or outpatient encounter diagnoses for PD (ICD-9 code 332 [paralysis agitans]; ICD-10 code G20 [Parkinson disease]) between January 1, 2015 and December 31, 2017. Hospitalized decedents with PD were defined as individuals with a validated death date between July 1, 2017 and December 31, 2017 from all causes who were hospitalized at least once in their last 6 months of life. Hospitalized non-decedents with PD were individuals who were hospitalized between January 1, 2017 and June 30, 2017 and lived 6 or more months after discharge. These dates were chosen to restrict analyses to a single year of data and allow for cost comparisons. Persons enrolled in both Medicare and Medicaid services, known as dual-eligible beneficiaries, were also included, as Medicare remains the primary source of financing for acute care services (Liu et al., 2006). We excluded Medicare Advantage (Part C) beneficiaries with private insurance benefits whose inpatient care patterns would not be reflected in CMS data, along with beneficiaries who had diagnostic codes for atypical or secondary parkinsonism (ICD-9 code 332.1 [drug-induced parkinsonism], 333.0 [atypical parkinsonism], 094.82 [syphilitic parkinsonism]; ICD-10 code G21 [secondary parkinsonism], G21.0 [neuroleptic malignant syndrome], G21.1 [other drug-induced secondary parkinsonism], G21.2 [secondary parkinsonism due to other external agents], G21.3 [post-encephalitic parkinsonism], G21.4 [vascular parkinsonism], G21.8 [other secondary parkinsonism], G21.9 [secondary parkinsonism, unspecified]).

Study outcomes

Primary study outcomes in descriptive analyses included patient-level variables (e.g., demographics, comorbidities, treatment intensity) and encounter-level variables (e.g., hospital length of stay, total charges), while secondary outcomes included discharge disposition. Primary study outcomes in logistic regression models included ICU admission and 30-day readmission, chosen because they are common among persons with PD in the EoL period (Aamodt et al., 2023a) and considered markers of inappropriate EoL care quality in persons with AD (De Schreye et al., 2017), another neurodegenerative disorder.

Covariates

We extracted demographic data and comorbidities to create covariates and stratification variables based on age, sex, race/ethnicity, rural residence, and Charlson Comorbidity Index (CCI) score (Charlson et al., 1987; Quan et al., 2005). Age was calculated based on birth date. Sex is dichotomized in CMS files as “male” or “female.” Race and ethnicity are mutually exclusive categories and were categorized alphabetically as “Asian,” “Black,” “Hispanic,” “Native North American,” “Unknown/Other,” and “White.” The recorded county of the beneficiary mailing address was used to determine the location of residence in a rural or urban area based on the 2013 United States Department of Agriculture Rural–Urban Continuum Codes, a classification scheme that subdivides counties into 6 nonmetro (rural) and 3 metro (urban/suburban) areas (USDA ERS - Documentation, 2022). Medical comorbidity burden was calculated using the CCI.

Statistical analysis

First, descriptive statistics were used to characterize and compare hospitalized decedents and hospitalized non-decedents with PD. Second, logistic regression models were built to determine whether demographic variables, CCI, or the timing of a hospitalization (e.g., EoL vs. non-EoL) were associated with primary outcomes among PD patients admitted to acute care hospitals. Univariable models examined the relationship between primary outcomes and individual patient factors (e.g., age, sex, race/ethnicity, rural residence, and medical comorbidities). Multivariable models examined the odds of each primary outcome after adjusting for a combination of patient factors. All statistical tests were two-sided with an alpha level of 0.05. Analyses were conducted using Stata (v17.0; StataCorp, College Station, TX).

Results

Demographic and clinical characteristics

There were 400,791 Medicare beneficiaries aged 65 and older with PD in 2017, of which 53,279 died, yielding an age-adjusted all-cause mortality rate of 13.3% with geographic variability (Figure 1). Of decedents with PD, 26,492 (49.7%) died between July 1, 2017, and December 31, 2017, of which 16,187 (61.1%) were hospitalized at least once in their last 6 months of life and formed our hospitalized decedent cohort. Of 347,512 non-decedents with PD, 62,851 (18.1%) were hospitalized at least once between January 1, 2017, and June 30, 2017 and lived at least 6 months after discharge and formed our hospitalized non-decedent cohort (Table 1). The mean age of hospitalized decedents and hospitalized non-decedents was 82.3 (SD 7.40) years and 79.5 (SD 7.54) years, respectively. In both cohorts, beneficiaries were predominantly male, White, and most likely to live in suburban/urban areas. Hospitalized decedents were also more likely to be dual-eligible for Medicare and Medicaid services due to disability or poverty (5,272; 32.6%) than hospitalized non-decedents (18,156; 28.9%). More than one-third of hospitalized decedents with PD had 6 or more chronic conditions (6,048; 37.4%) compared to a quarter of hospitalized non-decedents (17,541; 27.9%). Notably, hospitalized decedents with PD were more likely to be diagnosed with dementia (13,644; 84.3%) than hospitalized non-decedents (43,130; 68.6%). Demographic and clinical data are summarized in Table 1.

Inpatient resource utilization and total charges

Of the 26,492 Medicare decedents with PD who died between July 1, 2017, and December 31, 2017, 16,187 (61.1%) were hospitalized at least once in their last 6 months of life, resulting in 31,415 admissions. Of the 347,512 non-decedents with PD, 62,851 (18.1%) were hospitalized at least once between January 1, 2017, and June 30, 2017, and lived at least 6 months after discharge, resulting in 93,478 admissions (Table 2). The five most common inpatient principal diagnoses for hospitalized decedents were sepsis, aspiration pneumonitis, urinary tract infection (UTI), acute kidney failure, and PD. In comparison, the five most common inpatient principal diagnoses for hospitalized non-decedents were sepsis, PD, UTI, acute kidney failure, and pneumonia (Supplementary Table S1).

Of the 16,187 PD decedents admitted to the hospital in the last 6 months of life, 8,010 (49.5%) had at least one episode of ICU care, 1,575 (9.7%) were mechanically ventilated, 475 (2.9%) received a percutaneous feeding tube, 610 (3.8%) received a blood transfusion, 4,881 (30.2%) were readmitted to the hospital within 30 days, 4,801 (29.7%) were discharged to hospice care, and 3,892 (24.0%) died in the hospital. Of the 62,851 PD decedents admitted to the hospital before the EoL period, 18,047 (28.7%) had at least one episode of ICU care, 813 (1.3%) were mechanically ventilated, 497 (0.8%) received a percutaneous feeding tube, 943 (1.5%) received a blood transfusion,

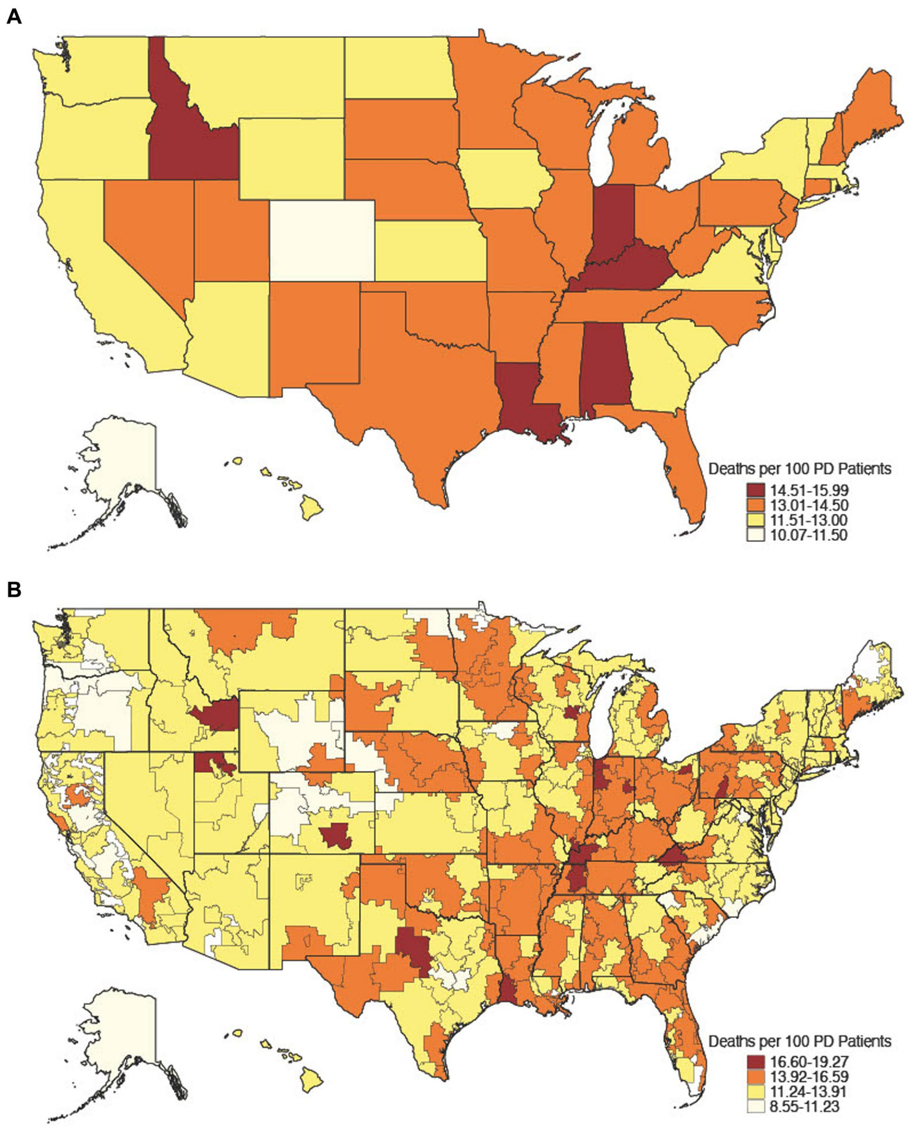

FIGURE 1
Age-adjusted all-cause mortality rate, 2017. All-cause mortality rate among 2017 Medicare decedents aged 65 and older by state [**(A)** *n* = 53,279] and hospital referral region [**(B)** *n* = 53,162], a geographical unit derived from the Dartmouth Atlas of Health Care that defines 306 unique Medicare healthcare market regions composed of 5-digit zip code areas grouped by referral patterns for tertiary care (The Center for the Evaluative Clinical Sciences, Dartmouth Medical School, 1996).

9,204 (14.6%) were readmitted to the hospital within 30 days, 599 (1.0%) were discharged to hospice care, and 0 (0.0%) died in the hospital.

Because some decedents were hospitalized multiple times, other outcomes are reported as encounter-level data (Table 2). Compared to non-EoL hospitalizations, EoL hospitalizations resulted in a slightly longer median length of stay (5 days [IQR 3–9] vs. 4 days [IQR 3–7]) and greater median total charges per admission in United States dollars ($36,323 [IQR 20,091–69,048] vs. $32,309 [IQR 18,789–57,756]). Discharge dispositions are summarized in Table 2.

ICU admission and 30-day readmission

Next, univariable and multivariable logistic regression models were used to estimate the relative odds of each primary outcome occurring in hospitalized decedents and hospitalized non-decedents with PD, adjusting for a combination of age, sex, race/ethnicity, rural/urban residence, and CCI (Table 3). In adjusted models using hospitalized non-decedents as the reference group, those hospitalized in the last 6 months of life had greater odds of ICU admission (AOR 2.36; CI 2.28–2.45) and 30-day readmission (AOR 2.43; CI 2.34–2.54) with notable sex, racial, ethnic, and geographic differences that have been previously reported (Aamodt et al., 2023a). We did not perform regression analyses on demographic, clinical, or encounter-level variables.

Discussion

In this study using comprehensive Medicare data from 2017, we found that persons with PD who were hospitalized in the last

TABLE 1 Demographic and clinical characteristics.

	Hospitalized decedents (*n* = 16,187)	Hospitalized non-decedents[b] (*n* = 62,851)
Age, years; mean (SD)	82.30 (7.40)	79.46 (7.54)
Male	81.72 (7.19)	78.93 (7.34)
Female	83.09 (7.63)	80.05 (7.71)
Age, years; n (%)		
65–69	876 (5.41)	6,832 (10.87)
70–74	1,809 (11.18)	11,060 (17.60)
75–79	2,918 (18.03)	13,777 (21.92)
80–84	3,903 (24.11)	13,842 (22.02)
85–89	3,944 (24.37)	11,146 (17.73)
>90	2,737 (16.91)	6,194 (9.86)
Sex, n (%)		
Male	9,674 (59.76)	33,396 (53.14)
Female	6,513 (40.24)	29,455 (46.86)
Race/Ethnicity, n (%)		
White	14,292 (88.29)	55,233 (87.88)
Black	1,014 (6.26)	3,800 (6.05)
Hispanic	282 (1.74)	1,147 (1.82)
Asian	257 (1.59)	1,023 (1.63)
North America Native	71 (0.44)	300 (0.48)
Unknown/Other	271 (1.67)	1,348 (2.14)
Region, n (%)		
Northeast	3,115 (19.24)	12,405 (19.74)
Midwest	3,706 (22.89)	14,465 (23.01)
South	6,797 (41.99)	25,542 (40.64)
West	2,535 (15.66)	10,334 (16.44)
Other	34 (0.21)	105 (0.17)
Rurality, n (%)[a]		
Urban/suburban	12,910 (79.76)	50,190 (79.86)
Rural	3,262 (20.15)	12,489 (19.87)
Unknown	15 (0.09)	172 (0.27)
Dual eligibility, n (%)		
No	10,915 (67.43)	44,695 (71.11)
Yes	5,272 (32.57)	18,156 (28.89)
Part D coverage, n (%)		
No	3,842 (23.74)	14,297 (22.75)
Yes	12,345 (76.26)	48,554 (77.25)
Chronic condition count, n (%)		
0–1	678 (4.19)	6,349 (10.10)
2–3	3,431 (21.20)	16,595 (26.40)
4–5	6,030 (37.25)	22,366 (35.59)
≥6	6,048 (37.36)	17,541 (27.91)
Chronic conditions, n (%)		
Alzheimer disease and related disorders or senile dementia	13,644 (84.29)	43,130 (68.62)

(Continued)

TABLE 1 (Continued)

	Hospitalized decedents (n = 16,187)	Hospitalized non-decedents[b] (n = 62,851)
Atrial fibrillation	6,289 (38.85)	20,152 (32.06)
Cancer	5,498 (33.97)	16,933 (26.94)
Prostate	2,020 (12.48)	6,175 (9.82)
Breast	903 (5.58)	3,699 (5.89)
Colorectal	949 (5.86)	2,757 (4.39)
Leukemia/lymphoma	732 (4.52)	2,152 (3.42)
Lung	701 (4.33)	1,451 (2.31)
Endometrial	193 (1.19)	759 (1.21)
Chronic obstructive pulmonary disease	8,488 (52.44)	29,604 (47.10)
Ischemic heart disease	12,989 (80.24)	47,378 (75.38)
Congestive heart failure	10,715 (66.20)	35,385 (56.30)
Diabetes mellitus	9,101 (56.22)	34,545 (54.96)
End-stage renal disease	372 (2.30)	1,020 (1.62)
Liver disease/cirrhosis	2,916 (18.01)	10,316 (16.41)
Stroke/TIA	7,595 (46.92)	26,196 (41.68)
Mood disorders, n (%)		
Depression	10,464 (64.64)	40,289 (64.10)
Anxiety	8,978 (55.46)	35,439 (56.39)
Schizophrenia/psychosis	4,612 (28.49)	15,242 (24.25)

Medicare decedents with Parkinson disease died between July 1, 2017 and December 31, 2017 and were hospitalized at least once in their last 6 months of life, while non-decedents with Parkinson disease were hospitalized at least once between January 1, 2017 and June 30, 2017 and lived 6 or more months after discharge. [a]Rural/urban residence was determined using 2013 US Department of Agriculture Rural–Urban Continuum Codes (RUCC), a classification scheme that subdivides counties into 6 nonmetro (rural) and 3 metro (urban) groupings based on 5-digit Federal Information Processing Standard (FIPS) code. [b]Hospitalized decedents and hospitalized non-decedents with Parkinson disease were compared using independent sample *t*-tests for normally distributed continuous variables and Chi-square analyses for categorical variables. Due to the large sample size, all comparisons were significantly different ($p < 0.05$) with the exception of the following: race/ethnicity; residence in the Northeast and Midwest; rurality; Part D coverage; 4–5 chronic conditions; and prior diagnosis of breast cancer, endometrial cancer, and depression. SD, standard deviation; TIA, transient ischemic attack.

6 months of life were slightly older and had more medical comorbidities than hospitalized persons who survived 6 or more months after discharge. Compared to non-EoL hospitalizations, EoL hospitalizations among persons with PD were also longer and more costly. Notably, PD patients hospitalized in their last 6 months of life had twice the odds of ICU admission and 30-day readmission as those hospitalized at earlier time points after controlling for key demographic and clinical variables. Consistent with prior studies, these data suggest that the last 6 months of life are a critical period in PD care and associated with significant, potentially preventable healthcare utilization (McKenzie et al., 2022; Aamodt et al., 2023a).

When comparing the clinical characteristics of hospitalized decedents and hospitalized non-decedents, decedents in our PD cohort were more likely to have 6 or more medical comorbidities and had increased rates of dementia, which likely contributed to group differences in hospitalization rates (Phelan et al., 2012). Not surprisingly, age and comorbidity burden are associated with an increased risk of all-cause hospitalization and mortality in older adults (Miller et al., 1998) and persons with PD (Braga et al., 2014). Hospitalizations among PD patients can also lead to hospital-related complications that may hasten death (Aminoff et al., 2011; Gerlach et al., 2012; Low et al., 2015), underscoring the need to ensure that all hospitalizations are medically necessary and aligned with care preferences. Thus, a multi-disciplinary approach involving general, neurological, and palliative care providers is required to prevent inappropriate hospitalizations whenever possible.

Next, when comparing inpatient resource utilization between hospitalized decedents and hospitalized non-decedents admitted for all causes, inpatient treatment intensity was significantly greater among decedents, with longer lengths of stay and more costly admissions in the last 6 months of life. Our findings support results from prior studies which also showed that persons with PD have longer lengths of stay than individuals in the general population (Gerlach et al., 2011). Longer hospital stays in PD patients have been associated with delayed or missed administration of dopaminergic drugs (Martinez-Ramirez et al., 2015), administration of dopamine receptor blocking agents (Martinez-Ramirez et al., 2015), elective surgery (Kleiner et al., 2019), and post-operative delirium and other complications (Pepper and Goldstein, 1999; Abboud et al., 2020). However, further research is needed to determine risk factors for prolonged length of stay in the EoL period. With regard to cost, hospitalizations account for the greatest

TABLE 2 Inpatient treatment intensity, discharge disposition, and total charges.

	Hospitalized decedents	Hospitalized non-decedents
(A). Total patients admitted, *n* (%)	16,187 (61.1)	62,851 (18.1)
ICU admission	8,010 (49.5)	18,047 (28.7)
Invasive mechanical ventilation	1,575 (9.7)	813 (1.3)
Percutaneous feeding tube	475 (2.9)	497 (0.8)
Blood transfusion	610 (3.8)	943 (1.5)
30-Day readmission	4,881 (30.2)	9,204 (14.6)
Hospice discharge	4,801 (29.7)	599 (1.0)
Discharged to home hospice	2,074 (12.8)	427 (0.7)
Discharged to inpatient hospice	2,727 (16.8)	172 (0.3)
In-hospital death	3,892 (24.0)	–
(B). Total admissions, # (%)	31,415	93,478
ICU admission	11,132 (35.4)	21,592 (23.1)
Invasive mechanical ventilation	1,803 (5.7)	918 (1.0)
Percutaneous feeding tube	476 (1.5)	510 (0.5)
Blood transfusion	696 (2.2)	1,014 (1.1)
Length of stay in days, median (IQR)	5 (3–9)	4 (3–7)
30-Day readmission	7,491 (23.8)	12,227 (13.1)
Discharged to home/self-care	3,201 (10.2)	26,947 (28.8)
Discharged to inpatient rehabilitation	1,041 (3.3)	6,242 (6.7)
Discharged to skilled nursing	11,358 (36.2)	32,147 (34.4)
Discharged to LTAC	685 (2.2)	869 (0.9)
Discharged to other care	6,385 (20.3)	26,652 (28.5)
Discharged to home hospice	2,112 (6.7)	445 (0.5)
Discharged to inpatient hospice	2,741 (8.7)	176 (0.2)
In-hospital death	3,892 (12.4)	--
Admissions/100 decedents or beneficiaries	118.6	26.9
(C). Total charges, USD	1,935,551,428	4,606,930,619
Charges/admission, median (IQR)	36,323 (20,091-69,048)	32,309 (18,789-57,756)

Individual-level (A) and encounter-level (B) data on inpatient treatment intensity and discharge disposition, along with total inpatient charges (C). Of 26,492 Medicare decedents who died between July 1, 2017 and December 31, 2017, 16,187 were hospitalized at least once in their last 6 months of life. Of 347,512 non-decedents in 2017, 62,851 were hospitalized at least once between January 1, 2017 and June 30, 2017 and lived 6 or more months after discharge. ICU, intensive care unit; IQR, interquartile range; LTAC, long-term acute care hospital; USD, United States dollar.

proportion of EoL healthcare spending relative to other spending categories (French et al., 2017). In the United States, Medicare spending in the last year of life accounts for up to 25% of total Medicare costs (Duncan et al., 2019), and increased spending at EoL may reflect inappropriate care practices. Hospitalizations in the last 6 months of life may also be incongruent with care preferences, reiterating the importance of advance care planning for persons with PD to improve quality of life and reduce spending at the national level.

Lastly, we found that hospitalized decedents with PD were twice as likely as hospitalized non-decedents with PD to be admitted to the ICU or experience a 30-day readmission after controlling for age, sex, race/ethnicity, rural/urban residence, and comorbidities. ICU admissions among persons with PD are often unrelated to PD duration or severity (Paul et al., 2019), and ICU mortality data are overall mixed. In one study comparing ICU admissions between persons with and without PD in Brazil, those with PD had longer hospital stays but did not experience an increased mortality risk resulting from their ICU admission (Réa-Neto et al., 2021). However, in a second study involving a random sample of elderly Medicare beneficiaries, ICU length of stay was associated with an increased risk of 1-year mortality among ICU survivors (Moitra et al., 2016). Hospital readmission is also common among persons with PD (Shahgholi et al., 2017). Although we could not determine the exact reasons for readmission in our cohort, other studies have demonstrated that readmissions among PD patients are associated with medical comorbidities, elective surgeries, and caregiver strain (Shahgholi et al., 2017; Fullard et al., 2020). For example, persons with advanced PD become increasingly reliant on caregivers for support, and increasing physical dependence can lead to caregiver burden (Lo Monaco et al., 2021; Aamodt et al., 2023b). Caregiver burden and depression are associated with a higher risk of

TABLE 3 **Frequency and relative odds of ICU admission and 30-day readmission.**

	Frequency *n* (%)	Unadjusted OR	95% CI	Adjusted OR[a]	95% CI
(A). ICU admission (*n* = 26,057)					
Admission type					
Non-decedent (>6 months)	18,047 (69.3)	ref	ref	**ref**	**ref**
Decedent (<6 months)	8,010 (30.7)	**2.43**	**2.35–2.52**	**2.36**	**2.28–2.45**
Age	26,057 (100.0)	1.00	0.99–1.00	**0.99**	**0.98–0.98**
Sex					
Male	14,975 (57.5)	ref	ref	ref	ref
Female	11,082 (42.5)	**0.84**	**0.81–0.86**	**0.91**	**0.88–0.94**
Race/Ethnicity					
White	22,539 (86.5)	ref	ref	ref	ref
Black	1,772 (6.8)	**1.16**	**1.09–1.23**	1.03	0.96–1.10
Hispanic	587 (2.3)	**1.45**	**1.31–1.62**	**1.37**	**1.23–1.53**
Asian	526 (2.0)	**1.45**	**1.30–1.63**	**1.42**	**1.26–1.59**
North America Native	116 (0.5)	0.95	0.76–1.18	1.03	0.82–1.29
Unknown/Other	567 (2.2)	**1.12**	**1.01–1.25**	1.11	0.99–1.23
Rural Residence	4,701 (18.0)	**0.84**	**0.80–0.87**	**0.86**	**0.82–0.89**
Charlson Comorbidity Index	26,057 (100.0)	**1.10**	**1.09–1.10**	**1.09**	**1.08–1.09**
(B). 30-Day readmission (n = 14,085)					
Admission type					
Non-decedent (>6 months)	9,204 (65.4)	ref	ref	ref	ref
Decedent (<6 months)	4,881 (34.6)	**2.52**	**2.42–2.62**	**2.43**	**2.34–2.54**
Age	14,085 (100.0)	**0.99**	**0.99–0.99**	**0.98**	**0.98–0.99**
Sex					
Male	7,853 (55.8)	ref	ref	ref	ref
Female	6,232 (44.2)	**0.94**	**0.91–0.97**	**1.06**	**1.02–1.10**
Race/Ethnicity					
White	12,171 (86.4)	ref	ref	ref	ref
Black	1,064 (7.6)	**1.34**	**1.25–1.44**	**1.12**	**1.04–1.21**
Hispanic	302 (2.1)	**1.26**	**1.11–1.44**	**1.15**	**1.01–1.21**
Asian	214 (1.5)	0.95	0.82–1.10	0.90	0.77–1.05
North America Native	70 (0.5)	1.10	0.84–1.42	1.15	0.89–1.50
Unknown/Other	264 (1.9)	0.92	0.80–1.05	0.90	0.79–1.04
Rural Residence	2,681 (19.0)	**0.93**	**0.89–0.98**	0.96	0.92–1.01
Charlson Comorbidity Index	14,085 (100.0)	**1.14**	**1.14–1.15**	**1.13**	**1.12–1.14**

Frequency and relative odds of intensive care unit admission (A) and 30-day readmission (B) in hospitalized Medicare beneficiaries with Parkinson disease. [a]Multivariable regressions were adjusted for a combination of age, sex, race/ethnicity, rural/urban residence, and Charlson Comorbidity Index score. Statistically significant ORs are in bold. ICU, intensive care unit; OR, odds ratio; CI, confidence interval; ref, reference group for logistic regression model.

emergency department visits (Rashid et al., 2023) and re-hospitalization among persons with PD (Shahgholi et al., 2017), presumably when caregivers are overwhelmed and require additional support. In the general population, 30-day readmission is also associated with age, male sex, comorbidities, polypharmacy, and length of stay at the initial hospital visit (Glans et al., 2020). Because ICU admission and 30-day readmission among persons with PD are significantly more common in the last 6 months of life, these hospital outcomes may signify a transition to the EoL period and aid in prognostication. Interestingly, the principal admission diagnosis was similar between hospitalized decedents and hospitalized non-decedents and may not be a reliable indicator of the EoL period.

Numerous studies have advocated for improved EoL care in the United States (Teno et al., 2013; Committee on Approaching Death: Addressing Key End of Life Issues, Institute of Medicine, 2015).

Although rates of EoL hospitalization declined among United States Medicare beneficiaries between 2000 and 2015 (Emanuel, 2018; Teno et al., 2018), progress is slow and EoL interventions are needed for those at greatest risk of death. Despite the prognostic uncertainty associated with heterogeneous symptoms and rates of disease progression in persons with PD, our findings have important clinical implications. Because PD patients hospitalized in their last 6 months of life have twice the odds of ICU admission and 30-day readmission, these events could trigger automatic inpatient palliative care consultations to clarify goals of care. While advance care planning can reduce unwanted, invasive, and potentially inappropriate EoL care (Kwak et al., 2014), most discussions occur in the outpatient setting and may miss critical opportunities to intervene after hospital admission. Thus, inpatient admissions can offer time-sensitive opportunities to discuss EoL preferences and prompt earlier referral to hospice care when indicated and desired.

This study has several limitations. First, Medicare is an administrative dataset, and studies using Medicare claims data are limited to the diagnoses and treatments documented in the medical record and subject to misclassification bias. Second, although comorbid dementia was determined using a validated indicator variable for Alzheimer's disease and related disorders (Chronic Conditions Data Warehouse, 2023), the exact dementia diagnosis was unknown. Similarly, the cause of death among hospitalized decedents in our cohort was unknown, and hospitalizations among persons with PD may stem from other illnesses. However, sepsis, aspiration pneumonitis, UTI, acute kidney failure, and PD comprised the top 31% of inpatient principal diagnoses among hospitalized decedents. By contrast, these conditions only comprised the top 20% of inpatient principal diagnoses among hospitalized non-decedents (Supplementary Table S1), suggesting that hospitalizations in the EoL period are more often associated with PD-related system failure. Because UTIs and pneumonia are leading causes of acute hospitalization in persons with advanced PD (Okunoye et al., 2020), further work is needed to minimize these risk factors. Future studies should also explore inpatient outcomes at EoL using more granular clinical data. In addition, we could not account for a do-not-resuscitate (DNR) order or pre-existing advance directives that may have influenced resource utilization and treatment intensity. While hospitalized patients with PD have higher odds of DNR utilization than other hospitalized patients (Mahajan et al., 2017), hospitalized decedents in our cohort still had high rates of treatment intensity and readmission, suggesting that new approaches to advance care planning may be needed in acute care settings. Lastly, our study presents data from a large, nationally representative sample of persons with PD who were hospitalized before the COVID-19 pandemic. Future studies should also utilize more recent data, when available, to account for post-pandemic changes in healthcare delivery, acute care utilization, and life expectancy (Balser et al., 2021; Pujolar et al., 2022; Schöley et al., 2022; Huang et al., 2023). Despite these limitations, this study is among the first to describe differences in inpatient outcomes across the PD lifespan.

In conclusion, intensive and frequent hospitalizations among persons with PD are a unique characteristic of the EoL period. Although hospitalizations may stem from non-PD-related illnesses, inpatients with PD are twice as likely to experience an ICU admission and hospital readmission in the last 6 months of life than at other time points. Because hospitalizations among persons with PD may portend a poor prognosis and reflect poor EoL care quality, providers must ensure that all hospitalizations are reasonable, necessary, and aligned with care preferences. In addition, because caregiver burden is a risk factor for re-hospitalization among persons with PD, inpatient admissions may provide important opportunities to address caregiver strain. Further work is needed to reduce hospitalizations in the EoL period, which can lead to improved quality of life, more efficient resource allocation, and reduced healthcare spending for all persons with PD.

Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: all datasets are available to purchase at resdac.org/. Aggregated de-identified data may be shared on request. Requests to access these datasets should be directed to https://resdac.org/.

Ethics statement

The studies involving humans were approved by the University of Pennsylvania Human Research Protections Office and the Centers for Medicare and Medicaid Services via a Data Use Agreement and waiver of consent. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

WA: Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. ND: Conceptualization, Formal analysis, Methodology, Writing – review & editing. WB: Data curation, Methodology, Writing – review & editing. JF: Conceptualization, Methodology, Supervision, Writing – review & editing. AW: Conceptualization, Data curation, Formal analysis, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fnagi.2023.1254969/full#supplementary-material

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Optimization of inpatient medication administration among persons with Parkinson's disease: recommendations on pharmacy technology and workflow

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Individuals with Parkinson's disease (PD) are vulnerable during hospitalizations due to the underlying complexities o1f symptoms, and acute illness or medication changes often lead to decompensation. Complications during hospitalizations are often due to worsening motor and nonmotor symptoms and commonly result from inaccurate medication regimens. Although the accuracy of medication administration relies on an interplay of factors, including patient status, transitions of care, coordination between the hospital prescriber and outpatient neurologist, etc., hospital pharmacists play an integral role in pharmacotherapy. The main aspects of pharmacy strategies aim to achieve timely administration of levodopa-containing medications, reduction of substitution and omissions of antiparkinsonian medications, and avoidance of antidopaminergic medications. This paper highlights critical areas for improvement and recommendations to minimize the impact of other factors from the pharmacy standpoint.

KEYWORDS

Parkinson's disease, inpatient, medication administration, pharmacy, recommendations

1 Introduction

Ensuring the accuracy of medication regimens is paramount in optimizing inpatient care for people with Parkinson's disease (PWP). Inaccurate medication regimens and administration of contraindicated medications are associated with complications and poor outcomes (Martinez-Ramirez et al., 2015; Lertxundi et al., 2017; Yu et al., 2023). With increasing complications such as aspiration due to swallowing problems and falls due to worsened mobility from dyskinesias or orthostasis, which renders them unable to participate in physical therapy, the overall length of stay is prolonged (Martinez-Ramirez et al., 2015). Alternatively, the involvement of non-motor symptoms can result in the administration of contraindicated medications, further worsening motor function. For these reasons, it can be argued that managing PD medication regimen is the cornerstone of inpatient care. Further, the role of pharmacists in establishing a systematic approach to delivering PD-specific care is well recognized (Azmi et al., 2019).

Several factors influence the accuracy of medication administration, including awareness of the time-critical nature of PD medications, medication availability, nothing per orem

(NPO) status, patient to nurse ratios. Nursing staff reported that administration time constraints had compelled them to take shortcuts such as removing medications from storage locations well before administration time or gathering more than one patient's medications at a time, etc., all of which increase errors, hence, calling for a revision to the 30-minute rule (Institute for Safe Medication Practices, 2023). However, revision of the time constraint is not feasible for PWP as levodopa is time critical. In this paper, we highlight key areas utilizing pharmacy workflow and technology to minimize the impact of other factors contributing to inaccuracies in medication administration.

2 Improving the timely administration of time-critical Parkinson's medications

2.1 Categorize levodopa products as "time critical"

Levodopa, the most efficacious medication for PD for over 50 years (Cotzias et al., 1967), has a short half-life, requiring multiple times a day dosing (Nutt, 2008). Accuracy of medication administration times in the hospital is critical as this population is vulnerable to deterioration of symptoms with dosing and timing deviations. Studies have highlighted challenges in adherence to medication administration schedules (Hou et al., 2012; Richard et al., 2022) when comparing administration times to inpatient orders. In a recent study, we examined the deviations between the hospital administration times and the patient's outpatient regimen. We found that 47% had average hospital dose timing intervals that differed from outpatient timing intervals by greater than 30 min, which were associated with a longer length of stay (Yu et al., 2023).

The Centers for Medicare and Medicaid Services (CMS) defines time-critical medications as "those for which an early or late administration of greater than 30 minutes might cause harm or have a significant, negative impact on the intended therapeutic or pharmacological effect" (Department of Health & Human Services Centers for Medicare & Medicaid Services). Longer dosing intervals or delayed doses may result in problems related to wearing off, such as worsening of motor symptoms (tremor, dystonia, dysphagia, freezing of gait, falls) and nonmotor symptoms (anxiety, shortness of breath). On the other hand, dosing too early may result in dyskinesias which limit effective rehabilitation, psychosis, orthostasis and syncope (Aminoff et al., 2011a; Nance et al., 2020).

Administration of levodopa-containing products is time-critical and unique from one patient to another. In accordance with the CMS definition above, we recommend that hospitals label levodopa-containing products as time critical. The Institute for Safe Medication Practices (ISMP) and CMS recommend that time-critical medications be given within 30 min before or after their scheduled due time. Further, the CMS standard for the preparation and administration of drugs states that hospital policies and procedures should facilitate administration within this 1-hour time window. The timing of levodopa administration should be documented, including reasons for doses outside the recommended time window.

Special instructions must be in place to avoid missing doses in cases where the patient is off the floor. For short duration procedures and when time-critical medications are due within 15 min, it may be best to give the dose prior to wheeling patients off the floor. For longer procedures (ex. surgeries, etc.), time-critical medications must be given as soon as patients are transferred to the recovery room. Remaining doses of the day are to be timed based on the patient's home dosing interval. Resume scheduled due times the following day based on the patient's home regimen.

2.2 Emphasize the role of pharmacists in medication reconciliation

Deviation from the home regimen can be due to various shortfalls represented by the *Swiss cheese model* in which multiple gaps align—from order entry to bedside administration–resulting in a medication error reaching the patient (Reaso, 2000). On order entry, prescribers may enter the order based on outdated home medication lists, or the electronic medical record (EMR) may implement default administration times. Pharmacist review of medication orders is integral in double-checking the continuity of dose, route, frequency, and timing of PD medications from home regimens as required by Joint Commission Standard for Medication Management MM.05.01.01. Yet only 43% of hospitals have 24/7 pharmacy staffing with medication orders reviewed in real-time, and 7.5% have no method for prospective order review after hours requiring retrospective review after the pharmacy opens (Pedersen et al., 2021). Hospitals should maintain adequate staffing for prospective order review by pharmacists and ensure that the reviewing pharmacist has access to sufficient information to confirm the outpatient regimens. This includes EMR access to outpatient office visit notes, telephone notes, and outpatient pharmacy dispensing records.

2.3 Employ pharmacists to direct and indirect patient care roles

When feasible, hospital systems should employ pharmacists to fulfill specific roles. Aside from order review, pharmacy consultations on admission may also be considered to assist PWPs in establishing medication dose and timing. Whenever feasible, hospitals should staff decentralized floor-based pharmacists who can speak directly with patients, care partners, and the patient's neurologist to establish an accurate account of home PD medication regimens. A helpful resource for the reconciliation of medication regimens is patient safety kits from the outpatient setting, such as the Parkinson's Foundation Aware in Care kit (Parkinson, 2023). They contain medication forms and medical alert cards that may assist pharmacists with continuing the PWP's outpatient regimen accurately while hospitalized. Floor-based pharmacists can also round with medical teams and assist nursing staff with impromptu medical problems. Hospitals should consider active interventions via PD consultation services with a physician, mid-level provider, pharmacist, and nurse trained in PD care. This serves as a resource for concerns surrounding special circumstances other staff may be unfamiliar with.

In addition to direct patient care roles, hospitals should staff pharmacists who provide institutional support through pharmacy informatics, formulary management, and review of medication safety events. Informatics pharmacists can contribute significantly by improving EMR alerts, pharmacy workflows, order sets, and order mapping to product selection. In addition, they play a role in ensuring that the automated dispensing cabinets (ADC) footprint is optimized for PD medications. Lastly, hospitals should staff pharmacists who are dedicated to formulary management and work with the hospital Pharmacy & Therapeutics committee to ensure all PD medications are on the formulary and available whenever feasible. Medication safety pharmacists collect and trend medication errors for the institution to identify opportunities for workflow or structural changes to prevent future events.

2.4 Consider internal pharmacy technician training programs

Recent pharmacy technician shortages have caused problems in hospitals nationwide. In a recent survey of hospital pharmacies, 73% reported technician staffing shortages, with an average vacancy rate for FTE positions of 13% (Schneider et al., 2022). This shortage has been detrimental to the multitude of functions pharmacy technicians support in our hospitals, including timely fulfillment of medication orders from centralized pharmacies, restocking of ADCs, controlled substance system management, inventory and purchasing, sterile compounding, billing and reimbursement, and re-dispensing medications from nursing or provider requests. A pharmacy technician shortage in these areas has spread staffing thin, making the essential functions of medication procurement and order fulfillment another barrier to the timely administration of medications. Hospitals can implement internal pharmacy technician training programs to promote internal relief from staffing shortages (Pereda et al., 2022).

2.5 Enforce custom order timing entries

Beyond staffing, several pharmacy informatics solutions may assist with accurate order entry. A common error is when the EMR incorrectly transcribes a PWP's specific medication times and intervals. For example, a patient may take carbidopa/levodopa 25/100 mg, one tablet upon waking up, then every 4 hours daily (ex. 8 a.m., 12 noon, 4 p.m., 8 p.m.). The EMR may translate this to a hospital schedule "four times per day" (i.e., 6 a.m., 12 noon, 6 p.m., 12 a.m.), significantly deviating from home use with longer dosing intervals. Problems related to wearing off, such as mobility problems, falls, worsening of tremor, dystonia, dysphagia, freezing of gait, and other nonmotor symptoms, including shortness of breath and anxiety, may arise. Similarly, high protein meals can reduce absorption of levodopa and providers should request meal delivery 60 min after the nearest levodopa administration time, if hospital meal services can accommodate. On the other hand, dosing too early may cause dyskinesias, predisposing patients to falls, inability to participate in therapy, psychosis, orthostasis, and syncope (Aminoff et al., 2011a; Nance et al., 2020). Pharmacy informatics teams should consider removing default administration times for carbidopa-levodopa products on order entry in the EMR and instead force custom hour/minute time orders.

2.6 Utilize EMR overdue alerts

Hospitals may also leverage their EMRs to promote timely administration of levodopa products. For instance, most nursing medication administration records (MARs) have overdue alerts. However, most hospitals permit medications to be given within 1 h of the due time before they are considered overdue. Hospitals should update their MARs to reflect the time-critical window of 30 min, and the MAR should flag nurses of overdue PD medications accordingly. Additionally, hospitals should include carbidopa-levodopa as a time-critical medication in their nursing onboarding and through continuing education. This education can be reinforced by working with pharmacy informatics teams to add administration comments to medication files stating that the medication should be given within 30 min of its due time.

2.7 Optimize dispensing through automated dispensing cabinets (ADCs) and labeling

There are other systems hospitals can implement to reduce deviations. First, the medication must be available to the nurse when due. Most hospitals utilize a mix of order fulfillment from a centralized pharmacy delivery and ADCs on patient floors. In a survey, 75% of hospitals now use ADCs as the primary dispensing method for maintenance medications (Pedersen et al., 2021). Although space is limited in ADCs, and hospital pharmacies must judiciously choose which meds are stocked, we recommend, at a minimum, that immediate-release carbidopa-levodopa be stocked on each floor to minimize delays. For PD medications not able to be stocked in ADCs, hospital pharmacies should ensure their cartfill deliveries dispense at least a 24 h supply of a medication order. Multiple deliveries for the same medication order throughout the day require more pharmacy staffing resources and introduce more opportunities for the late arrival of time-critical medications. Using a charge-on-administration model, rather than a charge-on-dispense model, ensures patients are not charged for supplies sent by the pharmacy and unused. Another strategy to optimize medication dispensing is through barcode labeling. Practices vary across different hospitals. For example, larger hospitals are more likely to utilize barcode scanning to verify ingredients during intravenous medication compounding (Pedersen et al., 2021). Medications can be labeled through an electronic health record-integrated mobile dispense tracking to reduce redispense rates (Bhakta et al., 2022), thereby increasing administration efficiency by reducing redispense associated delays.

2.8 Establish standard protocols for event reporting and data analysis

Standard procedures should be in place if delays in the administration of levodopa-containing medications occur. These include prescriber notification to evaluate the need to change the timing of future levodopa doses and monitoring of any change in motor or nonmotor symptoms (Code of Federal, 2012). Typical scenarios include transitions of care, such as the emergency department and post-anesthesia care unit, which are susceptible to dose omissions and delays. Regardless of intentionality (for example, when patients are tested in the off-mediation state during deep brain stimulation surgery), a standard process for reporting untimely administration of levodopa-containing medications should be established and implemented. For levodopa-containing medications, nursing staff should reference the MARs to establish succeeding dose and timing intervals if the previous dose was off schedule. In addition, medication safety pharmacists can assist with reviewing reported levodopa administration events or coordinate reviews with other area-specific pharmacists. Recommendations are summarized in Table 1.

3 Reducing omissions and substitutions of unavailable medications

Deviations from outpatient regimens may also occur through omissions and substitutions, resulting in differences in levodopa equivalent daily dose (LEDD). In our recent study, LEDD deviation occurred on 43% of days; 68% LEDD underdose where patients received a lower LEDD (median of 150 units less) in the hospital than in their outpatient regimen. Levodopa substitutions were identified in 19% of hospital days. The most common formulation substitutions were substituting an extended-release (ER) tablet of the same dose from the patient's outpatient regimen for an immediate-release (IR).

3.1 Stock appropriate medications in the formulary for common hospital situations

Medication formulation availability contributes to dose omissions and substitutions (Lertxundi et al., 2017). Unfortunately, many hospitals' formularies do not include all PD medications (Lertxundi Etxebarria et al., 2021). The FDA Orange Book defines therapeutic equivalency and specific drug products that can be confidently interchanged while assuming comparable safety and efficacy (US Department of Health and Human Services Food and Drug Administration, 2023). Many PD medications have specific formulations involving release mechanisms that are not therapeutically equivalent. Neurologists should work with their hospital pharmacy and therapeutics (P&T) committee to ensure the various levodopa formulations are added to the hospital formulary and stocked for inpatient use.

Aside from limitations from hospital logistics, medication omissions may occur due to NPO status. Carbidopa/levodopa is dosed several times daily due to its short half-life, resulting in problems when patients are placed on NPO status longer than necessary. A study on perioperative medication withholding found that the levodopa median withholding time was 12.35 h (Fagerlund et al., 2013), equivalent to 2-4 doses missed depending on patient profile. Some PWPs may also be placed on NPO due to nausea or swallowing difficulties, resulting in missed doses while awaiting formal evaluation by a speech-language pathologist (SLP). Hospitals should stock carbidopa-levodopa oral disintegrating tablets for use in such situations. These tablets dissolve before swallowing, and a PWP may still be able to take this when unable to swallow other formulations whole. Other alternatives such as rotigotine transdermal patch, inhaled levodopa, or apomorphine sublingual and subcutaneous injection are also options but limited in formularies (Lertxundi Etxebarria et al., 2021), likely due to cost. Additionally, these options may not be appropriate for many patients due to comorbidities or complications of PD.

3.2 Consider temporarily using the patient's or nearby hospital supply when medications are unavailable

If formulary addition is not feasible, a simple and efficient process should be developed to have the inpatient pharmacy identify patient-owned supplies and re-labeled them for use during the hospital stay. In some situations, borrowing supplies from a nearby hospital in a hub-and-spoke model might be acceptable. Still, this practice is suboptimal since many PD medications are time critical. As a last resort, when levodopa medication is not on the hospital formulary, patient-owned supply is unavailable, and external supply is not quickly available from nearby institutions, an interchange resulting in the equal LEDD (Lertxundi et al., 2015) is preferable to omission.

3.3 Develop user-friendly interchange protocols

Although complete stocking of medications and hospital pharmacist review has improved medication administration (Nance et al., 2020; Lance et al., 2021) this may only be feasible in some hospitals. Furthermore, levodopa formulations are varied and complex, with different pharmacokinetic and pharmacodynamic properties by formulation (Nutt, 2008; Espay et al., 2017). An alternative therapeutic interchange protocol with equivalent levodopa immediate-release dose has been proposed (Tomlinson et al., 2010; Lertxundi et al., 2015). However, converting from a patient's outpatient to a hospital regimen is still error-prone, especially among clinicians inexperienced with PD care (Grissinger, 2018). Neurologists should work with the P&T committee and pharmacy informatics to implement an interchange protocol using LEDD conversion guides between different levodopa formulations (Espay et al., 2017; Tomlinson et al., 2010; Schade et al., 2020a; Julien et al., 2021) and leverage the EMR to guide clinicians in selecting appropriate conversions.

In cases where patients are sedated or mechanically ventilated, early efforts should be made to obtain enteral access as soon as possible by methods such as nasogastric tubes. PD medications should be converted to LEDD (Schade et al., 2020a) and administered as crushed immediate release carbidopa-levodopa tablets in divided doses. Consultation with a PD specialist and/or pharmacist is highly recommended. Close monitoring for PD symptoms and dyskinesias is necessary and

TABLE 1 Modified from ISMP Acute Care Guidelines for Timely Administration of Scheduled Medications. Adapted for time-critical Parkinson's medications[a].

Topic	Description
Maintain Adequate Staffing Levels	• Maintain adequate nursing staffing to allow the administration of time-critical medications that may not align with standard administration times
	• Maintain adequate pharmacist and pharmacy technician staffing to allow for prospective order review and timely dispensing of medications
Use of automated Dispensing Cabinets (ADCs)	• Ensure the number of cabinets allows for the timely removal of medications
	• Stock levodopa products in at least one ADC per floor whenever possible
	• Limit overrides to emergency situations
Justification of early or late administration	• Define justifiable reasons that levodopa medications may be given early or late
	• Require notification of provider to guide possible adjustment of future scheduled doses
MAR documentation	• Require nursing staff to document the exact time the drug was administered in the MAR and provide documentation of reasoning for doses of levodopa-containing products given outside the recommended 1-h window for critical medications
Reference MARs	• Require nursing staff to reference the MAR showing times of previously administered dose to assess if dosing interval is off schedule
eMAR alerts	• Enable eMAR alerts to show when doses of levodopa-containing medications are soon to be overdue (30 min)
	• Highlight previous doses on the eMAR that have been given late or omitted
	• Enable eMAR alerts to alert staff who administer medications when attempting to administer contraindicated medications and document rationale if overridden
Standard Administration Times	• Levodopa medications should be classified as time-critical and custom times (i.e., specific times) should be entered for accuracy of administration times
	• Excluding time-critical medications, utilize standard administration schedules whenever possible to reduce the time burden on staff who administer medications
Procedure to follow if medication administration is early or delayed	• Establish a procedure for staff to follow if levodopa-containing medications will be or have been delayed. This should include prescriber notification to evaluate the need to change the timing of future doses and monitor for any change in clinical condition. Medication errors due to late/missed doses should be reported to the attending physician
Event reporting	• Establish a process for reporting untimely administration of levodopa-containing medications, even if the reason for the delay is justifiable
Data analysis	• Employ dedicated medication safety pharmacists who can assist with reviewing reported events or coordinate reviews with other area-specific pharmacists. These reviews should not be punitive but used to develop system-based process improvement initiatives to prevent further untimely administration
Other Pharmacy Resources	• Employ medication safety pharmacist(s) to assist with medication event reporting and quality improvement initiatives
	• Employ pharmacy informatics pharmacist(s) and technician(s) to improve EMR alerts, workflows, order sets, order mapping to product selection, and ensure ADC footprint is optimized for PD medications
	• Employ pharmacist(s) dedicated to formulary management who can work with the hospital Pharmacy & Therapeutics committee to ensure all PD medications are on the formulary and available, whenever feasible
	• Employ floor-based pharmacists who directly confirm home medications with patients and care partners, reconcile inpatient orders, round with medical teams, and assist nursing staff with impromptu medication problems
	• Implement EMR alerts to appear for contraindicated medications on prescribing, pharmacist verification, and nurse administration
	• Implement EMR alerts to warn nursing staff when a levodopa-containing medication is overdue (<30 min)
	• Remove default EMR administration times for levodopa-containing medications and require prescriber entry of home administration times
	• Implement policies and procedures which empower pharmacists to reduce nursing workload by adjusting MAR due times for non-time critical medications
	• Utilize the EMR to guide prescribers on policies and procedures for using patient-owned supply or a product substitution that best approximates home LEDD if a non-formulary PD medication is ordered

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doses and/or intervals may need to be modified based on response.

4 Reducing administration of contraindicated medications to people with Parkinson's

Due to the fundamental PD pathophysiology involving loss of dopaminergic cells, medications affecting dopaminergic states must be used cautiously. In particular, dopamine antagonists belonging to the antipsychotic (including haloperidol, fluphenazine, chlorpromazine, risperidone, olanzapine, ziprasidone, aripiprazole, etc.) and antiemetics drug classes (including metoclopramide, promethazine, prochlorperazine) have dopamine receptor blocking properties. These further worsen mobility which increases risk for falls, may exacerbate cognitive impairment, possibly increasing risk for psychosis, and swallowing, which increases risk for aspiration (Aminoff et al., 2011a; Gerlach et al., 2011; Ahlskog, 2014). These complications result in extended hospital stays and increased fatalities (Lertxundi et al., 2017; Grissinger, 2018).

Antidopaminergic medications are often given when patients decompensate. In our study, contraindicated medications were administered at least once in 10% of admissions, the top three of which were available in non-parenteral formulations (Yu et al., 2023). We found that 61% (88/143) and 20% (29/143) of haloperidol was given via intravenous and intramuscular routes, respectively, and only 18% (26/143) were given orally as a tablet. However, of those given olanzapine, 80% (76/95) was oral, while only 20% (19/95) was intramuscular, suggesting that factors other than tolerability may play a role in the administration of contraindicated medications.

In cases of acute agitation or psychosis during which patients pose a risk to themselves and others, antipsychotics with antidopaminergic medications (i.e., haloperidol, risperidone, olanzapine, etc.) are used. While this and other studies raise a concern about the safety of high-affinity D2 antagonists in people with PD, there is a paucity of controlled studies examining the comparative efficacy and safety of different algorithms for managing acute agitation and psychosis in PD. Controlled studies examining the ideal management of acute agitation and psychosis in PD are lacking. Current data suggests that one should minimize the use and potency of D2 antagonists in PD and use sound clinical judgment to escalate the potency of medications used only when absolutely necessary. Neurologists should encourage using technical and staffing resources to guide judicious use. We highlight strategies from the pharmacy standpoint to optimize medication selection.

4.1 Avoid ADC overrides

Acutely agitated patients may cause harm to themselves and others, and ADCs are often set up to allow for medication overrides in emergent situations. An override occurs when a medication order is placed, but the medication is removed before the pharmacist reviews the order. However, not all instances of agitation in the hospital warrant this level of urgency, and ISMP discourages the overuse of ADC overrides, as bypassing pharmacist review increases the risk of medication errors (Institute for Safe Medication Practices, 2019). Overriding the use of antipsychotics for acute agitation in PWP removes the opportunity for a pharmacist to intervene and recommend alternatives such as benzodiazepines. Neurologists should work with hospital rapid response and psychiatry teams to discourage the use of the override process whenever possible and educate on alternatives to antipsychotics for managing acute agitation in PWP. Nevertheless, challenges continue to exist in managing acute agitation among PWPs in the inpatient setting, which should be studied further.

4.2 Utilize EMR drug-disease interaction alerts

Other scenarios when contraindicated medications are commonly given include encephalopathic or uncooperative patients and those critically ill or unable to tolerate oral feeding. When necessary, medications that have less extrapyramidal side effects such as quetiapine, clozapine or pimavanserin, are ideal. However, these medications are only available per orem and would not be favorable in scenarios when patients are unable to tolerate oral feeding. In these situations, providers sometimes prefer medications with intravenous or intramuscular formulations, even if they have extrapyramidal side effects. ADC overrides should be avoided so as to allow pharmacist review (Institute for Safe Medication Practices, 2019). Medication safety pharmacists and pharmacy informaticists can assist with clinical decision support for drug-disease contraindications with recommended dose ranges and frequencies. Specifically, EMR alerts can be formulated to remind prescribers on order entry, pharmacists on prospective order review, and nurses on administration that these medications are contraindicated in patients with PD. The American Parkinson Disease Association page contains a list of medications to avoid or use cautiously among PWPs (American Parkinson Disease Association, 2018).

4.3 Exclude antidopaminergic medications in standard order sets

Certain institutions utilize a standard postoperative order set intended for the general patient population. In addition to EMR alerts, teams that frequently see PWP should consider removing these contraindicated medications with dopamine antagonist properties from shared admission order sets and standard peri-operative order sets. This is crucial in perioperative situations such as perioperative nausea when a patient is commonly placed on NPO or given medications containing antidopaminergic properties, worsening motor function. By removing contraindicated medications in the standard order sets, the provider is forced to order the medication, which is subject to EMR alerts, etc. A better alternative is to replace contraindicated medications with PD-safe medications for common scenarios encountered. For example, consider revising standard order sets to indicate the use of ondansetron over metoclopramide, promethazine, and prochlorperazine for antiemetics among PWPs, and removing haloperidol from order sets for those experiencing agitation. Recommendations are summarized in Table 1.

5 Conclusion

In summary, the challenges surrounding the accuracy of administering time-critical PD medications are well recognized. Approaches from pharmacy technology, staffing, and workflow can be utilized to minimize the impact of other factors contributing to inaccuracies in medication administration. Proactive interventions that utilize pharmacists as part of a multifaceted approach are integral in ensuring a safe hospitalization for PWPs.

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Conflict of interest

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Complications and outcomes of hospitalizations for patients with and without Parkinson disease

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Objective: To examine complications and outcomes of hospitalizations for common indications for hospitalization among patients with Parkinson disease (PD).

Methods: We identified and selected the ten most common indications for hospitalization among individuals ≥65 years of age using principal diagnoses from the California State Inpatient Database, 2018–2020. Patients with comorbid PD were identified using secondary diagnosis codes and matched one-to-one to patients without PD based on principal diagnosis (exact matching), age, gender, race and ethnicity, and Elixhauser comorbidity index (coarsened exact matching). We identified potentially preventable complications based on the absence of present on admission indicators among secondary diagnoses. In the matched cohort, we compared inpatient complications, early Do-Not-Resuscitate (DNR) orders (placed within 24 h of admission), use of life-sustaining therapies, new nursing facility requirement on discharge, and death or hospice discharge for patients with and without PD.

Results: We identified 35,457 patients with PD among the ten leading indications for hospitalization in older adults who were matched one-to-one to patients without PD (n = 70,914 in total). Comorbid PD was associated with an increased odds of developing aspiration pneumonia (OR 1.17 95% CI 1.02–1.35) and delirium (OR 1.11 95% CI 1.02–1.22) during admission. Patients with PD had greater odds of early DNR orders [placed within 24 h of admission] (OR 1.34 95% CI 1.29–1.39). While there was no difference in the odds of mechanical ventilation (OR 1.04 95% CI 0.98–1.11), patients with PD demonstrated greater odds of tracheostomy (OR 1.41 95% CI 1.12–1.77) and gastrostomy placement (OR 2.00 95% CI 1.82–2.20). PD was associated with greater odds of new nursing facility requirement upon discharge (OR 1.58 95% CI 1.53–1.64). Patients with PD were more likely to die as a result of their hospitalization (OR 1.11 95% CI 1.06–1.16).

Conclusion: Patients with PD are at greater risk of developing aspiration pneumonia and delirium as a complication of their hospitalization. While patients with PD more often have early DNR orders, they have greater utilization of life-sustaining therapies and experience worse outcomes of their hospitalization including new nursing facility requirement upon discharge and greater mortality.

KEYWORDS

Parkinson disease, hospitalization, complications, outcomes, epidemiology, delirium, aspiration, mortality

Introduction

Parkinson disease (PD) is a progressive, neurodegenerative disease that affects almost one million individuals in the United States, and approximately 8.5 million worldwide (Marras et al., 2018; Ou et al., 2021). Diagnosis of PD requires the presence of bradykinesia accompanied by either rest tremor, rigidity, or both (Tolosa et al., 2006; Bloem et al., 2021). With a projected increase in PD prevalence in the coming decades (Dorsey et al., 2013), it is important to understand the hospitalization burden of the disease and subsequent outcomes of inpatient stays (Yang et al., 2020). One-third of patients with PD experience hospitalization each year (Hassan et al., 2013). Direct medical costs of PD were estimated at $25.4 billion in 2017, which includes post-acute or long-term care, inpatient and outpatient care, medical equipment, prescriptions, and provider office visits (Yang et al., 2020). Inpatient costs for patients with PD comprised over one-quarter of all direct medical care costs at over $7.1 billion (Yang et al., 2020). Factors contributing to greater hospitalization rates in PD include gait abnormalities and orthostasis resulting in falls and injuries, autonomic dysfunction with altered urodynamics potentially leading to greater incidence of urinary tract infections, and dysphagia which can result in aspiration pneumonia (Aminoff et al., 2011; Gerlach et al., 2011; Bhattacharya et al., 2012; Martinez-Ramirez et al., 2015; Suttrup and Warnecke, 2016; Beydoun et al., 2017; Hogg et al., 2022).

In addition to factors that lead to hospitalization in patients with PD, specific health conditions and issues may arise after hospital admission that develop independent of the underlying illness or principal diagnosis (3M™ Health Care Academy, 2023). These complications may lead to unfavorable outcomes of hospitalizations for patients with PD (Gerlach et al., 2012). Venous thrombosis, bladder infections, delirium, and inpatient falls are all issues that may commonly be encountered in hospitalized patients with PD (Aminoff et al., 2011). The use of life-sustaining procedures, Do-Not-Resuscitate (DNR) orders, and discharge disposition in hospitalized patients may also differ for patients with PD (Mahajan et al., 2017). Few studies have used large population-based data to understand reasons for hospitalization, complications, and outcomes for patients with PD (Woodford and Walker, 2005; Mahajan et al., 2016). Additionally, to date, no studies have included hospice discharge when determining the risk of mortality for hospitalized PD patients, and though the Parkinson's Foundation has recently identified dysphagia screening and aspiration pneumonia prevention strategies as recommended care standards for hospitalized PD patients (Parkinson's Foundation Hospital Care Recommendations, 2023), a limited number of studies have investigated aspiration pneumonia as an inpatient complication for hospitalized patients with PD. Due to the potentially fatal risk of complications in hospitalized patients, it is important to elucidate which factors are associated with hospitalization for patients with PD.

We aimed to examine complications and outcomes of hospitalizations for common inpatient conditions among patients with PD compared to matched controls. We hypothesized that patients with PD are at an increased risk of complications and experience worse outcomes of hospitalizations.

Methods

We used the California State Inpatient Database (SID) from the Agency for Healthcare Research and Quality, Healthcare Cost and Utilization Project (HCUP) (Overview of the State Inpatient Databases (SID), 2023) from January 1, 2018 to December 31, 2020 to perform a retrospective observational analysis of deidentified older adult patients admitted for any one of the ten most common reasons for hospitalization among individuals ≥65 years of age and compared complications and outcomes for those with and without Parkinson disease (PD). The University of Rochester Medical Center Research Subjects Review Board approved the study. The study adheres to the STROBE guidelines for the reporting of observational studies.

Data source

There are 58 counties in the state of California, over 300 acute care hospitals throughout the state, with more than 3 million hospitalizations per year (State Inpatient Databases (SID) File Composition, 2023). The California SID includes a complete enumeration of all-payer administrative claims data on hospital discharges from all non-federal acute care hospitals within the state of California in each year. The SID includes patient demographics (age, sex, race and ethnicity, urban vs. rural origin, median household income for ZIP), primary and secondary diagnoses, procedures, and procedure timing (i.e., days from admission), as well as the length of stay, and detailed disposition including death. Race and ethnicity in the California SID are directly reported by HCUP partner organizations and consolidated by HCUP to uniform values which combine race and ethnicity into a single variable. In HCUP methodology, ethnicity took precedence over race. For example, if a patient was identified as Black and Hispanic, they were assigned to Hispanic. Additionally, HCUP consolidates some race categories (i.e., Asian and Native Hawaiian or Pacific Islander).

There is a single principal diagnosis for each hospitalization and up to 36 additional diagnostic fields representing chronic conditions and complications. There are 25 procedural fields each with a respective day of procedure indexed from day of admission. A small percentage of hospitalizations had a documented procedure code for all 25 procedural fields (0.05%). Diagnoses and procedures were identified using the International Classification of Diseases, 10th Revision, Clinical Modification (ICD-10-CM) and Procedure Coding System (ICD-10-PCS), respectively. We used secondary ICD-10-CM diagnoses to calculate an Elixhauser comorbidity index (Elixhauser et al., 1998).

The California SID is the only existing population-level database in the US that contains detailed administrative claims information and captures patient-level "Do-Not-Resuscitate" (DNR) status (Goldman et al., 2013). The presence of DNR status within the dataset indicates that a DNR order was written at the time of hospital admission as indicated by the California source documentation.

Patient selection

We used Clinical Classification Software Refined (CCSR) from HCUP to aggregate ICD-10-CM codes into clinically meaningful categories (Clinical Classifications Software Refined (CCSR), 2023). We identified the 10 most frequent principal diagnoses by CCSR code for inpatient stays among hospitalizations ≥65 years of age: (1) Sepsis [CCSR INF002], (2) Heart Failure [CCSR CIR019], (3) Cerebral Infarction [CCSR CIR020], (4) Myocardial Infarction [CCSR CIR009], (5) Pneumonia [CCSR RSP002], (6) Acute Renal Failure [CCSR GEN002], (7) Cardiac Dysrhythmia [CCSR CIR017], (8) Hip Fracture [CCSR INJ006], (9) Urinary Tract Infection [CCSR GEN004], and (10) Chronic Obstructive Pulmonary Disease (COPD) [CCSR RSP008].

Inclusion and exclusion criteria

The study included individuals ≥65 years of age admitted under non-elective, emergent circumstances to an acute care hospital in California between 2018 and 2020 for any one of the top ten principal diagnoses for older adults. Individuals <65 years of age were excluded from the analysis. Outgoing patient transfers from one acute care hospital to another acute care hospital were excluded from the analysis to avoid double counting the same patient. Observations with missing data for age, gender, race and ethnicity, length of stay, and hospital characteristics were excluded (Figure 1). Our study relies on the reporting of "Present on Admission" (POA) indicators to identify hospital complications. To refine our population and improve accurate identification of complications, our study excludes hospitals failing to report POA indicators for >5% of cases with mandatory reportable POA diagnoses (Hospital-Acquired Conditions (Present on Admission Indicator): Reporting, 2023).

Parkinson disease

We used the ICD-10-CM code G20 present in any one of the 36 available secondary diagnoses to identify individuals with comorbid Parkinson disease.

Potentially preventable complications

Potentially Preventable Complications (PPCs) are harmful events or negative outcomes (e.g., hospital-acquired aspiration pneumonia, deep venous thrombosis) that develop after hospital admission (while inpatient) and may result from care and treatment processes rather than the natural progression of the underlying illness and are, therefore, potentially preventable (Hughes et al., 2006; 3M™ Health Care Academy, 2023). We used ICD-10-CM/PCS codes to identify select PPCs among secondary diagnosis codes. Secondary diagnoses were considered PPCs if they met the coding criteria and did not have a "Present On Admission" (POA) indicator. The POA indicator is a data element on the Uniform Billing form for hospitalizations, available in the California SID, indicating if a diagnosis was present at the time of admission. The database contains diagnosis POA indicators which permit the identification of conditions that develop during the hospital stay (as opposed to those present on hospital admission). The presence of an "N" for POA indicator, specifying a hospital diagnosis was not present on admission, was used to positively identify complications of the hospitalization. We also made clinical exclusions of PPCs if

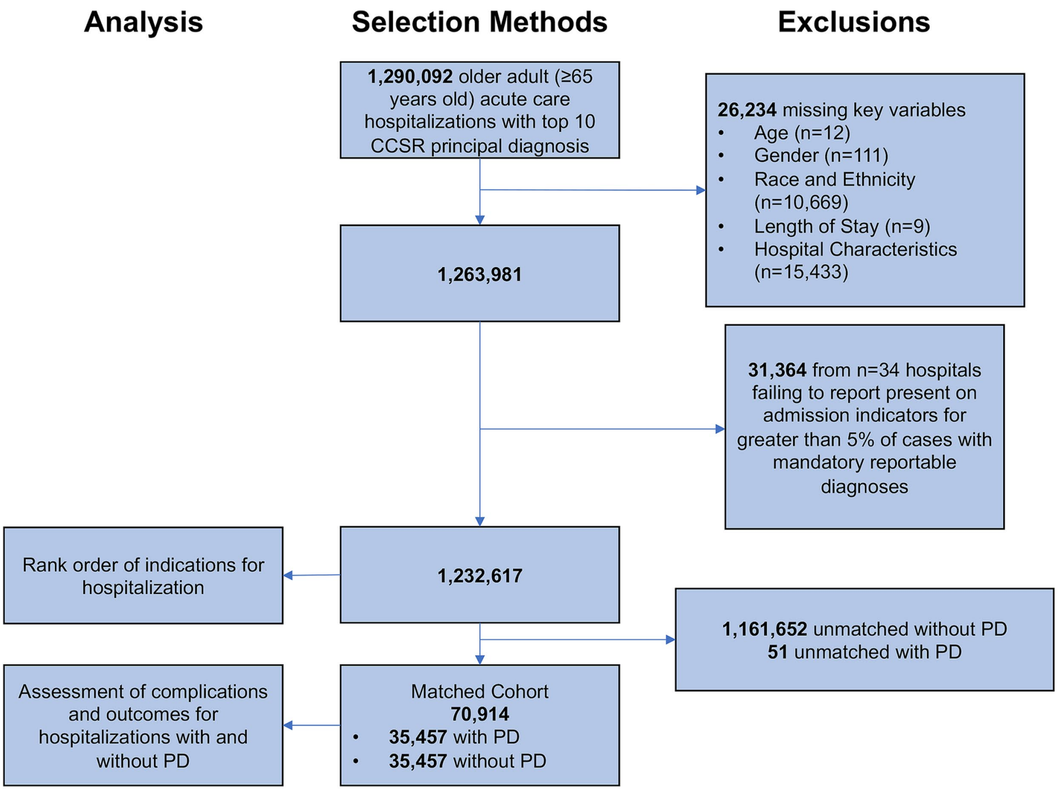


FIGURE 1
Selection methods. CCSR, Clinical Classification Software Refined. Patients with Parkinson disease were matched one-to-one to patients without Parkinson disease on principal diagnosis (exact matching), age, gender, race and ethnicity, and Elixhauser comorbidity index (coarsened exact matching).

complications were thought to be a natural consequence of the reason for hospitalization (e.g., aspiration pneumonia cannot be considered a complication for a hospitalization with a principal diagnosis of pneumonia), or if the complication were unlikely to occur within a short stay. These methods are similar to those previously used to define PPCs (Lagoe and Bick, 2013; 3M™ Health Care Academy, 2023).

Outcome measures

We examined the number of select PPCs: aspiration pneumonia, *C. difficile* infection, deep venous thrombosis (DVT), pulmonary embolism, decubitus ulcer, delirium, ileus and other reduced motility gastrointestinal complications, inpatient fall, urinary tract infection, and in-hospital cardiac arrest. These PPCs were selected by the authors based on their relevance for patients with Parkinson disease considering potential contributions from dysphagia, immobility, encephalopathy, constipation, gait dysfunction, and frailty. PPCs and the respective ICD-10-CM/PCS codes used for the purposes of our study, as well as any relevant exclusions, can be found in Supplementary Table S1. We also examined utilization of life sustaining therapies (LSTs) including invasive mechanical ventilation, tracheostomy, and gastrostomy placement. LSTs and their respective ICD-10-PCS codes used in this study can be found in Supplementary Table S2.

We assessed hospital length of stay as reported by HCUP. New nursing facility requirement on discharge was defined as the presence of skilled nursing facility discharge based on the discharge data element without an indicator of nursing facility point-of-origin on the UB-04 claim form (Official UB-04 Data File, 2023). Death was defined as inpatient mortality or discharge to hospice (i.e., total mortality equivalence) (Asch et al., 2021).

Statistical analysis

We compared the rank order of indications for hospitalization among patients with and without PD in the unmatched cohort using a chi-squared test.

Coarsened Exact Matching (CEM) was used to match patients with and without PD in a one-to-one ratio, to make the outcomes in both groups more comparable. CEM involves temporarily coarsening continuous data into predefined set-width bins, matching of categorical and binned-continuous variables of interest, and then running analyses on the uncoarsened matched data following the matching procedures (Blackwell et al., 2009). Patients were matched on age, gender, race and ethnicity, and Elixhauser comorbidity index. Matching was stratified by principal diagnosis to ensure comparisons were exact across indications for hospitalization.

Categorical variables were evaluated using chi-squared test. Continuous variables were found to be non-normal in distribution, and therefore, a Wilcoxon Rank-Sum test was used for comparisons. Conditional logistic regression was performed to calculate the odds associated with PPCs, LSTs, death, and new nursing facility requirement for patients with PD among matched subjects, reported as odds ratios compared to those without PD. Mortality was examined across subgroups by indication for hospitalization. Statistical significance was set *a priori* at $p < 0.05$. Analyses were performed using Stata version 18.0 (College Station, TX).

Results

Indications for hospitalization

There were 1,232,617 hospitalizations (Figure 1) admitted for any one of the ten most common indications for hospitalization among adults ≥65 years of age including sepsis, heart failure, cerebral infarction, myocardial infarction, pneumonia, renal failure, cardiac dysrhythmia, hip fracture, urinary tract infection, and chronic obstructive pulmonary disease (COPD). The rank order of indications for hospitalization among patients with and without PD were different ($p < 0.001$) (Figure 2). The most common indication for hospitalization among older adults with or without PD was sepsis; 16,468 (46.4%) with PD and 433,113 (36.2%) without PD (Figure 3). The second and third leading causes of hospitalization in all older adults without PD was heart failure ($n = 173{,}849$, 14.5%) and cerebral infarction ($n = 86{,}910$, 7.3%), respectively (Figure 2A). In contrast, the second and third leading causes for hospitalization in patients with PD was urinary tract infection ($n = 3{,}399$, 9.6%) and hip fracture ($n = 2{,}989$, 8.4%), respectively (Figure 2B). There was no difference in admissions for pneumonia ($p = 0.55$) or acute renal failure ($p = 0.93$) (Figure 3). Patients with PD were less often admitted for heart failure, cerebral infarction, cardiac dysrhythmia, myocardial infarction, and COPD ($p < 0.001$ for all).

Matching

We identified 35,457 patients with PD among the ten leading indications for hospitalization in older adults matched based on principal diagnosis (one-to-one exact matching), age, gender, race and ethnicity, and Elixhauser comorbidity index (one-to-one coarsened exact matching) to hospitalizations without comorbid PD (Figure 1).

Patient and hospital characteristics for those with and without PD in the matched cohort are in Table 1. Patients with comorbid PD more often had comorbid dementia and depression, and less often had cancer, hypertension, diabetes, peripheral vascular disease, and alcohol or drug abuse. Patients with PD were less often from rural locations (2% vs. 3%, $p < 0.001$), and more often admitted from nursing facilities (14% vs. 8%, $p < 0.001$). Patients with PD were more often from higher income ZIP codes (53% vs. 51% in top 50th percentile, $p < 0.001$) and more often insured by Medicare as the primary payer (92% vs. 90%, $p < 0.001$). Patients with PD more often received care in larger, teaching hospitals. There was no difference observed in the availability of neurologic services among hospitals in which patients with PD and those without PD received care (84% for both, $p = 0.16$).

Potentially preventable complications

The incidence of complications in both groups was generally low (any complication 7.8% without PD vs. 7.7% with PD, $p = 0.41$) (Figure 4). Hospitalized patients with PD were more likely to experience delirium (Odds Ratio [OR] 1.11, 95% CI 1.02–1.22) and aspiration pneumonia (OR 1.17, 95% CI 1.02–1.35) compared to matched controls. Patients with PD were less likely to develop pulmonary embolism (OR 0.6, 95% CI 0.40–0.92) and ileus or other reduced motility gastrointestinal complications (OR 0.84, 95% CI 0.75–0.95) while in the hospital. In-hospital cardiac arrest (excluding

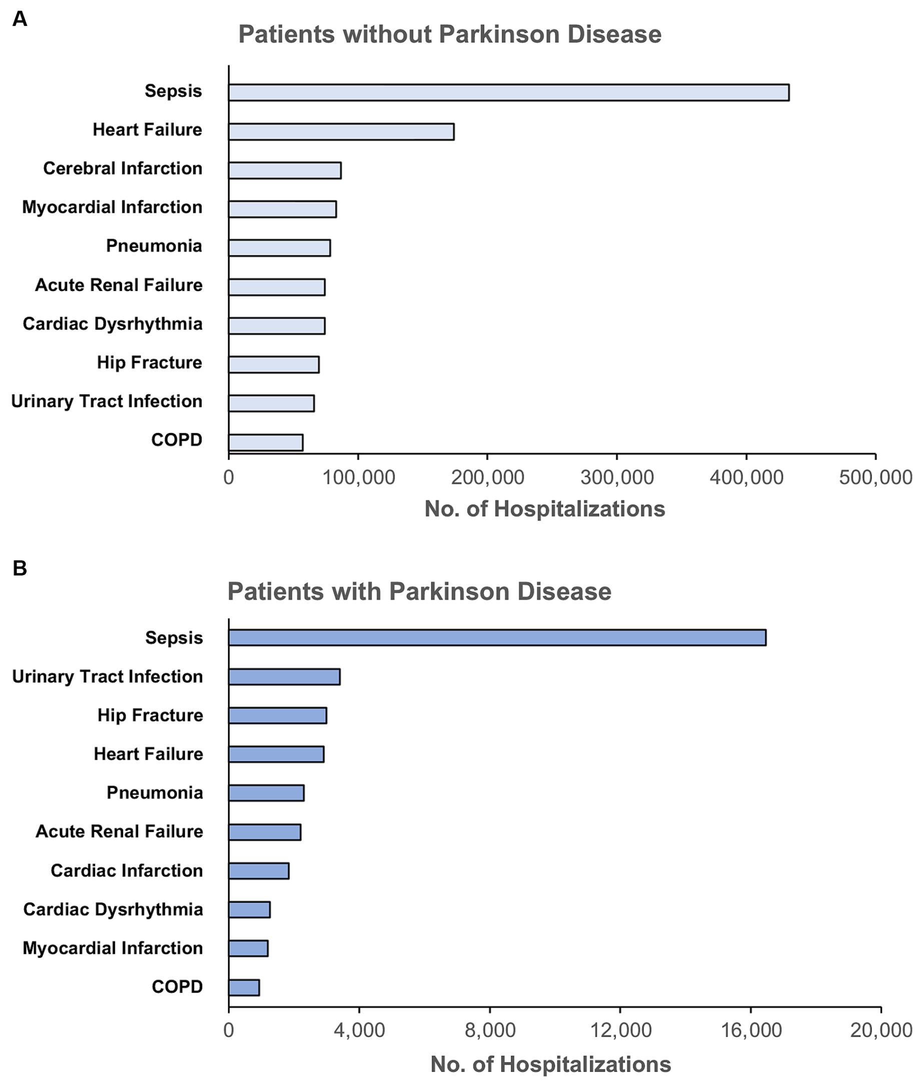


FIGURE 2
Rank order of the top ten indications for hospitalization among unmatched older adults **(A)** without Parkinson disease and **(B)** with Parkinson disease, unmatched. COPD, Chronic Obstructive Pulmonary Disease. Principal diagnoses were grouped based on ICD-10 codes into clinically meaningful categories using Clinical Classification Software Refined from the Healthcare Cost and Utilization Project.

those with DNR orders) was less likely in hospitalized patients with PD compared to those without PD (OR 0.84, 95% CI 0.74–0.96). There was no difference in inpatient falls (OR 0.93, 95% CI 0.77–1.13) or DVT (OR 0.72, 95% CI 0.49–1.06) for hospitalizations with PD compared to those without PD in the matched cohort. Hospitalized patients with PD had similar risk of developing urinary tract infections, *C. difficile* infections, and decubitus ulcers compared to matched controls (Figure 4).

Advance directive and life-sustaining therapies

PD patients who were hospitalized had greater odds of early DNR orders (OR 1.34, 95% CI 1.29–1.39) (Figure 4). Odds of tracheostomy (OR 1.41, 95% CI 1.12–1.77) and gastrostomy (OR 2.00, 95% CI 1.82–2.2) were increased in hospitalized patients with PD, whereas the odds of invasive mechanical ventilation were similar (OR 1.04, 95% CI 0.98–1.11).

Discharge disposition and mortality

There was no difference in length of stay for patients with and without PD (PD: median 4 days, IQR 3–7 days vs. without PD: median 4 days, IQR 2–7 days; $p = 0.18$). Approximately 14.8% of hospitalized patients with PD died compared with 13.6% of hospitalized patients without comorbid PD (OR 1.11, 95% CI 1.06–1.16) (Figure 4). This difference was largely driven by hospice discharge which represented 47% of deaths for patients with PD compared to 37% of deaths in patients without PD ($p < 0.001$). In subgroup analysis, there was greater odds of death for patients with PD compared to those without PD among admissions for sepsis (OR 1.12, 95% CI 1.07–1.19), urinary tract infection (OR 1.32, 95% CI 1.05–1.66), hip fracture (OR 1.35, 95% CI 1.05–1.74), and acute renal failure (OR 1.25, 95% CI 1.02–1.53). Mortality rates by indication for hospitalization can be found in Figure 5. Exclusion of those with early DNR orders did not change the magnitude or direction of the association between comorbid PD and death. Additionally, patients with PD had greater odds of new nursing

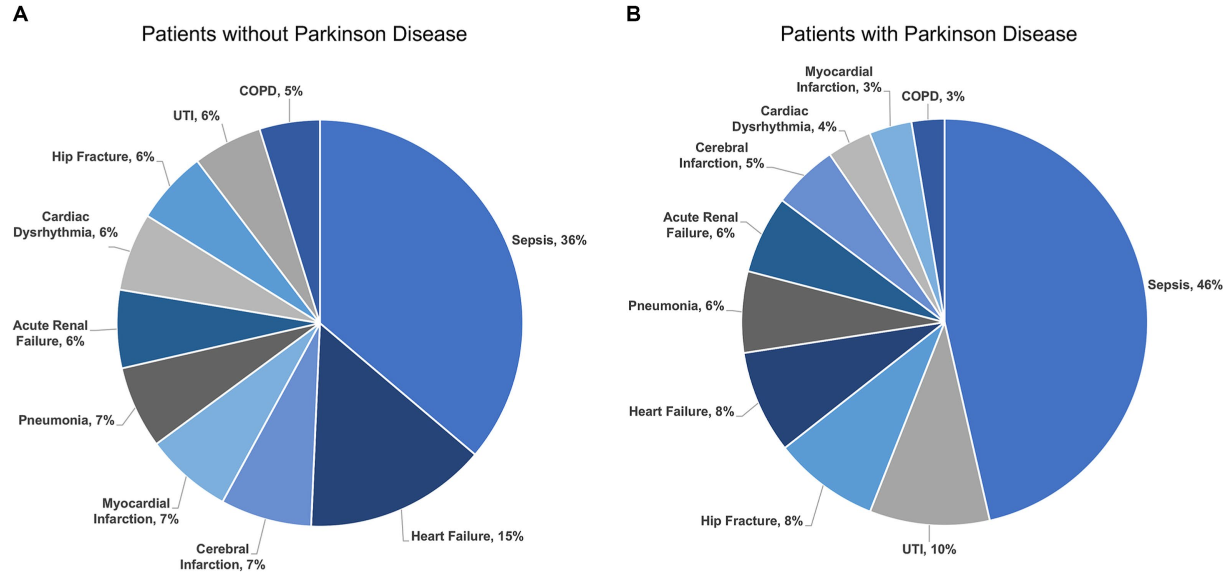


FIGURE 3
Indications for hospitalization among unmatched older adults **(A)** without Parkinson disease and **(B)** with Parkinson disease by percent. UTI, Urinary Tract Infection; COPD, Chronic Obstructive Pulmonary Disease.

facility requirement upon discharge (30.6% vs. 24.0%, $p < 0.001$; OR 1.58, 95% CI 1.53–1.64), excluding those who were admitted from nursing facilities.

Discussion

Several studies to date have found higher rates of hospital admission for patients with PD (Klein et al., 2009; Mueller et al., 2009; Rhalimi et al., 2009); however, prior to this report little was known about inpatient complications and outcomes experienced for patients with PD from large population-based data. In this retrospective observational study of the ten most common indications for hospitalization among older adults in California, we found differences in leading reasons for hospitalization, in-hospital complications, life-sustaining therapy utilization, and outcomes for patients with PD.

First, we found that older adults with PD similarly experienced admissions for sepsis as the leading cause of hospitalization in comparison to older adults without PD; however, sepsis accounted for a greater share of admissions for PD patients. While hip fracture and urinary tract infections represented the 8th and 9th leading causes of hospitalization among older adults without PD, these diagnoses were the 3rd and 2nd leading causes for hospitalizations among patients with PD, respectively. Prior studies used varied data sources and methods to identify indications for hospitalization among patients with PD (Woodford and Walker, 2005; Temlett and Thompson, 2006; Klein et al., 2009; Vossius et al., 2010; Gil-Prieto et al., 2016; Mahajan et al., 2016; Okunoye et al., 2020), however, few had comparisons to patients without PD (Vossius et al., 2010). Based on our results, sepsis, urinary tract infections, and hip fractures related to falls may be important targets for future study on PD-associated hospitalizations.

Additionally, while our cohort of hospitalized older adults with PD and those without PD were matched on Elixhauser comorbidity index (a summary metric which quantifies comorbidity), the profile of comorbidities differed between the two groups. Comorbidities such as cancer, hypertension, diabetes, peripheral vascular disease, and alcohol or drug abuse were more likely to be observed in hospitalized patients without PD, whereas dementia and depression were more common among hospitalized patients with PD. Furthermore, comorbidities among hospitalized patients with and without PD may be different than observations of comorbid disease in the community. For example, PD is associated with an increased prevalence of diabetes in the community (Cereda et al., 2011), differing from our study of hospitalized patients which demonstrates those without PD were more likely to have diabetes.

Second, patients with PD had differences in risk of complications during hospitalization. We found an increased odds of developing aspiration pneumonia as a complication of hospitalization compared to matched controls. Between 32% and 70% of patients with PD have dysphagia, or swallowing difficulties (Miller et al., 2009). Few studies have examined aspiration as a complication of inpatient stays for PD (Temlett and Thompson, 2006; Miller et al., 2009), however, the high risk of dysphagia (Miller et al., 2009; Suttrup and Warnecke, 2016), potential for greater immobility in the hospital (Aminoff et al., 2011; Oguh and Videnovic, 2012), and increased risk of cognitive changes (acute or chronic) (Williams-Gray et al., 2007; Dham et al., 2023) may subject patients with PD to higher risk of aspiration while hospitalized. Based on these results, patients with PD may benefit from routine and rigorous inpatient monitoring of swallow function during their hospital stay and early use of short-term alternatives to feeding when indicated (e.g., nasogastric tubes); similar to the management of stroke patients (Dennis et al., 2005; Dziewas et al., 2021).

Our study also identified an increased risk of delirium for hospitalizations with comorbid PD. Potential precipitants of delirium in hospitalized patients with PD include infections, recent surgery, urinary retention, constipation, pain, metabolic abnormalities, and mismanagement of PD-related medications or administration of contraindicated medications (Golden et al., 1989; Price et al., 2015;

Marcantonio, 2017; Dham et al., 2023). Patients with PD are susceptible to in-hospital medication errors such as missed or poorly timed doses of PD-related medications (e.g., Carbidopa/Levodopa) or abrupt discontinuation of PD medications either unintentionally or due to lack of *Per Os* access (Magdalinou et al., 2007; Buetow et al., 2010; Derry et al., 2010; Hou et al., 2012). Patients with PD may also receive contraindicated medications during their hospitalization, such as centrally-acting antiemetics, neuroleptics, or others (Keyser and Rodnitzky, 1991; Rhalimi et al., 2009). Prevention of these in-hospital medication errors are identified as recommended care standards for hospitalized PD patients within the Parkinson's Foundation Hospital Care Recommendations (2023). Although the clinical granularity of our study is limited in the ability to fully elucidate contributing factors to delirium, our findings are consistent with that of prior studies examining risk of in-hospital delirium for patients with PD (Golden et al., 1989; Dham et al., 2023).

While reduced mobility and motor disturbances is likely a greater issue for patients with PD during their hospitalization (Woodford and Walker, 2005; Klein et al., 2009), we unexpectedly found individuals with PD were less likely to receive a diagnosis of pulmonary embolism and ileus as a complication of their inpatient stay, and they experienced inpatient falls at similar rates compared to matched controls. There is potential for this association to be related to detection or reporting bias. It is possible that patients with PD could be subject to therapeutic nihilism, similar to that observed in other chronic neurodegenerative conditions (Sedney et al., 2019; Maksymowicz et al., 2022). A diagnosis of pulmonary embolism and ileus may require further diagnostics beyond a bedside clinical evaluation (Weledji, 2020; Cafferkey et al., 2022), which is unlikely to be ordered for a patient with an anticipated poor outcome or one who awaits hospice discharge. Inpatient falls in which no injury was sustained may be underappreciated, and may be viewed as a common or expected occurrence rather than an adverse outcome (Oliver, 2004; Haines et al., 2008). Unfortunately, our data rely on recorded diagnosis codes for hospitalizations, and we are unable to account for imaging or other testing during an inpatient stay using the SID.

Third, we found greater odds of early DNR orders and decreased odds of in-hospital cardiac arrest, even when those with DNR orders were excluded. Consistent with prior studies (Mahajan et al., 2017), patients with PD were more often admitted with DNR orders underscoring the typical feelings of patients and their surrogates toward resuscitative efforts on admission in the setting of chronic neurodegenerative illness (Gaster et al., 2017). When patients with DNR orders were excluded, there were still decreased odds of in-hospital cardiac arrest with resuscitative efforts in hospitalized patients with comorbid PD compared to those without PD. While this finding could potentially be a marker for lower overall disease severity despite matching, this more likely represents patient, surrogate, and provider attitudes toward resuscitation in patients with neurodegenerative illness. Further study is needed to better understand the characteristics and decision-making processes for critically ill patients with PD forgoing cardiopulmonary resuscitative efforts.

Fourth, we found that patients with PD receive gastrostomy and tracheostomy more often compared to matched controls. Studies in older adults with dementia have shown no improvement in the risks of aspiration, nutritional deficiency, or death with gastrostomy placement (Finucane et al., 1999; McCann, 1999). Despite the prior

TABLE 1 Patient and hospital characteristics of the matched cohort for patients with and without Parkinson disease.

Characteristics	No Parkinson disease	Parkinson disease	*p*-value
N (%)	35,457 (100)	35,457 (100)	
Age in years, median (IQR)	81 (75–86)	81 (75–86)	0.98
Gender, *n* (%)			
Female	14,810 (42)	14,810 (42)	
Male	20,647 (58)	20,647 (58)	1.00
Race and ethnicity[a], *n* (%)			
Asian or Pacific Islander	4,284 (12)	4,284 (12)	1.00
Black	1,495 (4)	1,495 (4)	
Hispanic	5,971 (17)	5,971 (17)	
White	21,967 (62)	21,967 (62)	
Other	1,740 (5)	1,740 (5)	
Elixhauser comorbidity index[b], median (IQR)	5 (4–7)	5 (4–7)	1.00
Comorbidities, *n* (%)			
Dementia	8,057 (23)	16,865 (48)	<0.001
Cancer	3,769 (11)	1,795 (5)	<0.001
Hypertension	29,871 (84)	27,309 (77)	<0.001
Diabetes	15,397 (43)	12,658 (36)	<0.001
Peripheral vascular disease	7,386 (21)	5,376 (15)	<0.001
Alcohol or drug abuse	1,811 (5)	952 (3)	<0.001
Depression	4,711 (13)	6,400 (18)	<0.001
Patient location, *n* (%)			
Urban	34,211 (97)	34,602 (98)	<0.001
Rural	980 (3)	727 (2)	
Point of origin[c], *n* (%)			
Community	29,704 (84)	27,921 (79)	<0.001
Nursing facility	2,685 (8)	4,940 (14)	
Other healthcare facility	3,035 (9)	2,567 (7)	
Median household income by patient ZIP[d], *n* (%)			
1st Quartile	8,404 (24)	7,810 (22)	<0.001
2nd Quartile	8,753 (25)	8,523 (24)	
3rd Quartile	9,383 (27)	9,819 (28)	
4th Quartile	8,231 (24)	8,839 (25)	
Primary insurance payer, *n* (%)			
Medicare	32,080 (90)	32,590 (92)	
Medicaid	1,601 (5)	1,324 (4)	
Private	1,210 (3)	1,012 (3)	
Self pay/no charge/other	566 (2)	531 (2)	
Hospital bedsize, *n* (%)			
<100	2,348 (7)	2,470 (7)	0.01
100–199	7,962 (22)	7,817 (22)	
200–299	8,290 (23)	8,259 (23)	
300–399	8,665 (24)	8,350 (24)	

(Continued)

TABLE 1 (Continued)

Characteristics	No Parkinson disease	Parkinson disease	p-value
≥400	8,192 (23)	8,561 (24)	
Hospital teaching status, *n* (%)			
Teaching	22,491 (63)	23,129 (65)	<0.001
Non-teaching	12,966 (37)	12,328 (35)	
Neurologic service in hospital, *n* (%)			
No	4,611 (16)	4,702 (16)	0.16
Yes	25,050 (84)	24,748 (84)	

[a] "Other" race and ethnicity includes individuals not categorized by the database, including those identified as multiple race, not classified, or unknown. Individuals identified as Native American or Alaskan Native are included within this group for confidentiality reasons due to fewer than 10 records within the sample.

[b] Elixhauser comorbidity index is a measure of comorbidity for use with large administrative datasets with higher numbers representing the presence of greater comorbidity, accounting for up to 31 categories of disease.

[c] Point of origin is derived from the UB-04 claim form. Other healthcare facilities include clinics, physician offices, ambulatory surgical centers, other acute care hospitals, and non-acute care units within the same hospitals. There were $n = 33$ (0.1%) unknown without PD and $n = 29$ (0.1%) unknown with PD.

[d] Household income quartiles were assigned based on the median income of the patient's ZIP Code where the first quartile is the lowest income and fourth quartile is the highest income.

evidence, patients with PD appear to receive gastrostomy more often in our study, presumably for sustainable artificial nutrition and prevention of aspiration. There is no evidence to date demonstrating outcomes (e.g., aspiration occurrence, survival) specific to patients with PD undergoing gastrostomy placement. However, surgical feeding tube placement is a preference-sensitive decision for patients and surrogates (O'Brien et al., 1997), which is subject to wide geographic and institutional practice variability (George et al., 2014; Hwang et al., 2018). Potential logistical benefits of surgical feeding tubes may include consistent medication administration and eligibility for nursing facility placement which may reduce length of stay (in contrast to more temporary nasogastric feeding tubes) (George et al., 2017).

Little is known about the use of tracheostomy for patients with PD, although there has been a proposed benefit for patients with Parkinson-plus syndromes and airway dysfunction (Sinclair et al., 2013). Our study appears to be the first to date that has found an increased odds of receiving tracheostomy among hospitalized patients with PD. Given the elevated risk of aspiration and potential for accompanying respiratory failure, it may be expected that patients with PD receive tracheostomy with greater frequency. Furthermore, issues with upper airway musculature in PD may play a role in mediating airway dysfunction, further complicating ventilator liberation for patients with PD (Vincken et al., 1984). However, like gastrostomy, indications for tracheostomy are typically accompanied by severe functionally disabling illness as well as considerable healthcare costs (Engoren et al., 2004; Seder, 2019; Wahlster et al., 2021), and could be compounded by a progressive neurodegenerative disorder for patients with PD. Therefore, further study is needed to understand recent clinical practices, patient and surrogate preferences, and the associated value with use of life-sustaining therapies in the setting of hospitalized patients with PD.

Fifth, patients with PD experience death (as measured by inpatient mortality or hospice discharge – i.e., total mortality equivalence) (Asch et al., 2021) more often than matched controls. This association held even with the exclusion of individuals with DNR orders. However, hospice appeared to be an important determinant with nearly half of those counted as PD deaths undergoing discharge to hospice. In this regard, deaths may be overestimated since there are likely some patients who experience "live discharge" from hospice in time (Dolin et al., 2017), but this methodology is needed in light of increasing hospice utilization by hospitals to improve mortality statistics (Marks, 2015). When examined within the subgroups by indication for hospitalization, those admitted for sepsis, acute renal failure, hip fracture, and urinary tract infection demonstrated greater mortality compared to matched controls. There was a non-significant trend towards greater mortality for those admitted with myocardial infarction. These indications for hospitalization may represent reasonable targets for interventions that may aim to improve outcomes for hospitalized individuals with PD.

Previous studies have identified inpatient mortality rates between 4 and 10% for hospitalized patients with PD (Pepper and Goldstein, 1999; Gil-Prieto et al., 2016; Mahajan et al., 2016; Rumalla et al., 2017), compared to our study which identified an inpatient mortality rate of approximately 15% among hospitalized patients with PD. Accounting for hospice discharge in the mortality rate may account for the greater mortality observed in our study compared to prior findings (Sleeman et al., 2013).

Finally, patients with PD demonstrated greater odds of new nursing facility requirement upon discharge. Discharge to a nursing facility is often needed for patients that require a higher level of post-acute care, and greater assistance with activities of daily living, that may not be feasible at home (Quine and Morrell, 2007). This finding indicates a greater loss of independence following a hospitalization among patients with PD compared to matched controls. This highlights a need to better understand loss of independence for hospitalized patients with PD, and to develop interventions that will improve safe living while preserving autonomy and patient satisfaction (Leff et al., 2005; Csipke et al., 2021).

Limitations

There were several limitations to our study. Our study relies on ICD-10 codes for the identification of diagnoses, complications, and procedures within administrative hospital data. These codes are subject to misidentification and under or over-reporting based on the inherent inaccuracies of administrative data. However, we used ICD-10 codes akin to that previously used in studies of administrative datasets for Parkinson disease (Willis et al., 2012; Dham et al., 2023). We used procedure codes associated with highly billable services (e.g., tracheostomy, gastrostomy) which are unlikely to be missed in administrative records (George et al., 2014, 2017; Albert et al., 2023), and the 25 available procedural fields for hospitalizations within the matched cohort were rarely full ($n = 32$ of 70,914 patients with all 25 fields documented). Additionally, we used a coding methodology and adjunct POA indicators that are industry standard in the identification of potentially preventable complications (PPCs) (Hughes et al., 2006; Lagoe and Bick, 2013; 3M™ Health Care Academy, 2023; Health Data NY, 2023). There are a few likely incentives for hospitals to under-report complications (e.g., code actual complications as present on admission): (1) to reduce complication rates, and (2) to increase severity of illness

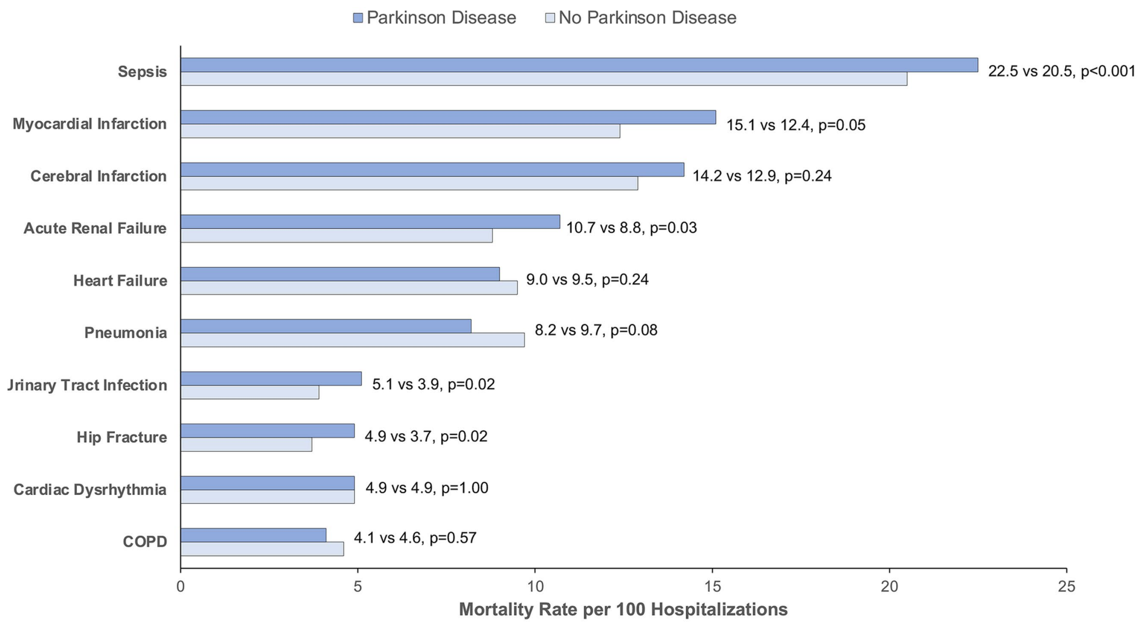
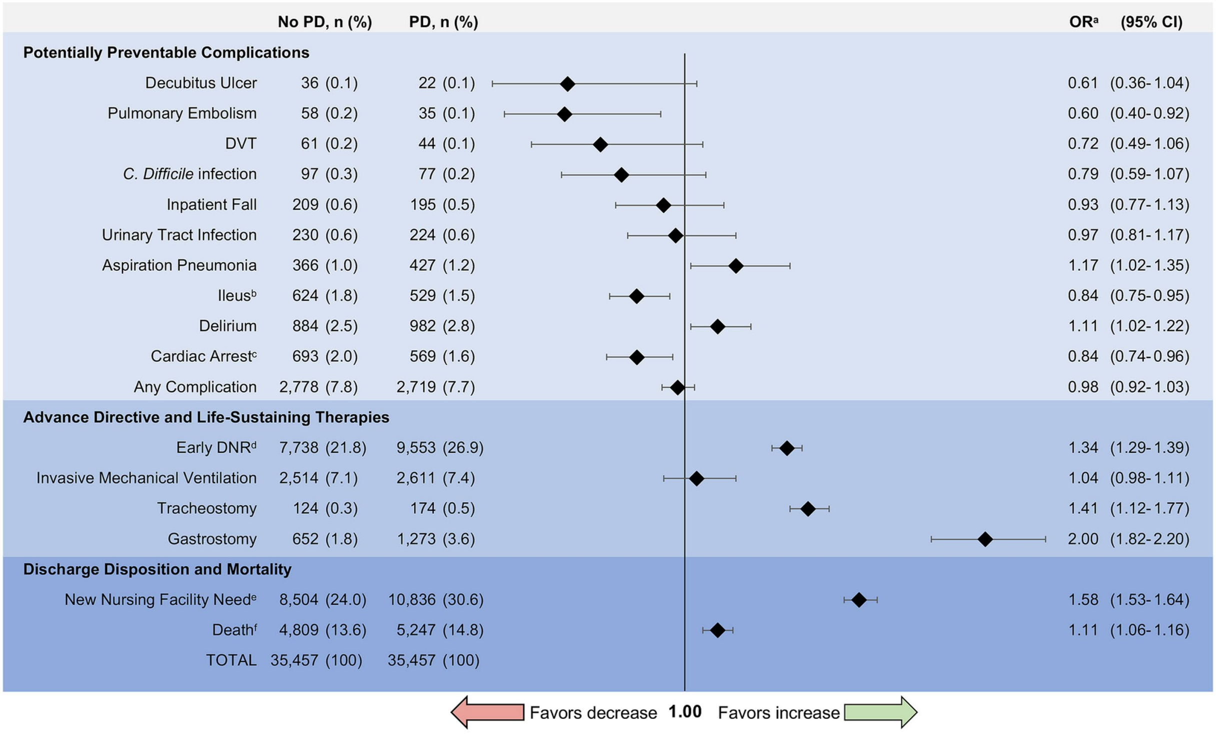


FIGURE 5
Mortality rate by indication for hospitalization for matched patients with and without Parkinson disease. COPD, Chronic Obstructive Pulmonary Disease. Mortality rate is calculated per 100 hospitalizations for Parkinson disease vs. no Parkinson disease. $p < 0.05$ is considered statistically significant.



	No PD, n (%)	PD, n (%)	OR[a]	(95% CI)
Potentially Preventable Complications				
Decubitus Ulcer	36 (0.1)	22 (0.1)	0.61	(0.36-1.04)
Pulmonary Embolism	58 (0.2)	35 (0.1)	0.60	(0.40-0.92)
DVT	61 (0.2)	44 (0.1)	0.72	(0.49-1.06)
C. Difficile infection	97 (0.3)	77 (0.2)	0.79	(0.59-1.07)
Inpatient Fall	209 (0.6)	195 (0.5)	0.93	(0.77-1.13)
Urinary Tract Infection	230 (0.6)	224 (0.6)	0.97	(0.81-1.17)
Aspiration Pneumonia	366 (1.0)	427 (1.2)	1.17	(1.02-1.35)
Ileus[b]	624 (1.8)	529 (1.5)	0.84	(0.75-0.95)
Delirium	884 (2.5)	982 (2.8)	1.11	(1.02-1.22)
Cardiac Arrest[c]	693 (2.0)	569 (1.6)	0.84	(0.74-0.96)
Any Complication	2,778 (7.8)	2,719 (7.7)	0.98	(0.92-1.03)
Advance Directive and Life-Sustaining Therapies				
Early DNR[d]	7,738 (21.8)	9,553 (26.9)	1.34	(1.29-1.39)
Invasive Mechanical Ventilation	2,514 (7.1)	2,611 (7.4)	1.04	(0.98-1.11)
Tracheostomy	124 (0.3)	174 (0.5)	1.41	(1.12-1.77)
Gastrostomy	652 (1.8)	1,273 (3.6)	2.00	(1.82-2.20)
Discharge Disposition and Mortality				
New Nursing Facility Need[e]	8,504 (24.0)	10,836 (30.6)	1.58	(1.53-1.64)
Death[f]	4,809 (13.6)	5,247 (14.8)	1.11	(1.06-1.16)
TOTAL	35,457 (100)	35,457 (100)		

FIGURE 4
Complications and outcomes for matched patients with and without Parkinson disease. PD, Parkinson disease; OR, Odds Ratio; DVT, Deep Venous Thrombosis; *C. difficile, Clostridium difficile*; DNR, Do-Not-Resuscitate. [a]Odds ratios were calculated using conditional logistic regression to assess the association between comorbid Parkinson disease and complications or outcomes in the matched cohort. [b]Ileus includes paralytic ileus as well as other reduced motility gastrointestinal complications. [c]Identifies in-hospital cardiac arrest. Excludes individuals with DNR orders to avoid bias from advance directives. [d]Early DNR includes patients with DNR orders placed within 24 h of admission to the hospital. [e]New nursing facility need analyzes discharges to a nursing facility but excludes individuals admitted from a nursing home to avoid bias from point of origin. [f]Death includes inpatient mortality and discharge to hospice (i.e., total mortality equivalence).

on admission. The extent to which under-reporting occurs is unknown. While we cannot ensure complete accuracy, we ameliorated potential errors by excluding hospitals with poor reporting (<5% of mandatory reportable diagnoses) of POA indicators, selecting only those hospitals with high compliance in POA-reportable diagnoses. Unfortunately, we are unable to determine the exact timing of inpatient complications as they relate to the day of admission, only that they were not present on admission. We cannot exclude the possibility that some PPCs are related to the reason for hospitalization such as a complication that develops in sequence as a result of an admitting diagnosis (e.g., cardiac arrest that occurs days after an admission for septic shock), and there is no way to know the extent to which the admitting diagnosis contributed to the development of a complication using these data. Furthermore, our study lacks granular clinical data such as exam findings, lab values, specific medication administration and dosing, deep brain stimulation status, or disease severity metrics commonly used for PD. Our study was limited to inpatient hospitalization data used in California, and therefore, our results may not be generalizable to larger populations of patients with PD. For our study, we chose to focus on older adults given the large proportion of PD patients within this cohort and the intrinsic differences in common reasons for hospitalization for younger versus older adults. Therefore, our study may not be applicable to the young adult PD population. Finally, our study is cross sectional at the time point of each hospitalization; we are unable to follow patients longitudinally, and therefore, outcomes following discharge are unknown.

Prior studies evaluating PD hospitalization outcomes are often limited by the degree of power and scope of the patient populations investigated. Despite the our study's limitations, this is (to our knowledge) the first study of inpatient complications and outcomes of this magnitude with analysis of over 35,000 hospitalized patients with PD admitted to institutions ranging from large academic centers, non-federal government-owned facilities, and urban or rural community hospitals, encompassing all insurance payers, and including diverse groups who are frequently under-represented in the current literature.

Conclusion

Patients with PD are at greater risk of developing aspiration pneumonia and delirium as a complication of their hospitalization. Patients with PD more often have early DNR orders and they experience in-hospital cardiac arrest less often. However, hospitalized patients with comorbid PD demonstrated greater utilization of life-sustaining therapies. Furthermore, patients with PD experience worse outcomes of their hospitalization including new nursing facility requirements indicating a loss of independence following discharge, and greater odds of death resulting from hospitalization. Further study is needed to identify interventions that will improve care, optimize patient-centered decision-making, and ultimately, generate better outcomes for patients hospitalized with PD.

Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: available for purchase under HCUP licensing agreement. Requests to access these datasets should be directed to HCUP-RequestData@ahrq.gov.

Ethics statement

The studies involving humans were approved by University of Rochester Research Subjects Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

BG: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Resources, Software, Visualization, Writing – original draft, Writing – review & editing. WB: Formal analysis, Investigation, Writing – review & editing. AS: Formal analysis, Investigation, Writing – original draft. IR: Conceptualization, Formal analysis, Funding acquisition, Investigation, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fnagi.2023.1276731/full#supplementary-material

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Effect of best practice advisory on the administration of contraindicated medications to hospitalized patients with Parkinson's disease and related disorders

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Objective: To determine the effect of a Best Practice Advisory (BPA) on the ordering and administration of contraindicated dopamine blocking agents (DBA) to hospitalized patients with Parkinson's disease (PD) and related disorders.

Background: Patients with PD are more likely to require hospitalization and are at increased risk of complications. Administration of contraindicated DBA contributes to worsened outcomes in this patient population. Electronic medical record (EMR) warnings (also referred to as BPA) have been proposed as a way to prevent the administration of contraindicated medications.

Methods: A BPA was launched in January 2020 within the University of Rochester EMR system, which alerts the provider when a contraindicated DBA is ordered in hospitalized patients with PD and related disorders. Patients with PD and related disorders hospitalized at two hospitals affiliated to the University of Rochester during a time period before (*t1*: 1/1/2019–1/1/2020) and after (*t2*: 1/8/2020–1/8/2021) the implementation of the BPA were included in this study. Epic SliderDicer was used to collect the data from the University of Rochester EMR. The number of patients who had contraindicated DBA orders and administrations in both time periods, and the number of patients who had the BPA triggered during *t2* were obtained. We compared the results before and after the implementation of the BPA.

Results: 306 patients with PD and related disorders were hospitalized during *t1* and 273 during *t2*. There was significantly less percentage of patients who had contraindicated DBA orders (41.5% in *t1* vs. 17.6% in *t2*) and patients who had contraindicated DBA administrations (16% in *t1* vs. 8.8% in *t2*) during *t2* ($p < 0.05$ for both comparisons). There was no significant difference between the percentage of patients who had contraindicated DBA orders in *t1* and patients with attempted orders (BPA triggered) in *t2* ($p = 0.27$).

Conclusion: The results of this study increase the evidence of the potential benefit of EMR warnings for the optimization of inpatient medication management in patients with PD and related disorders. In particular, our results suggest that EMR warnings help reduce the administration of contraindicated medications, which is a known contributing factor for hospital complications in this patient population.

KEYWORDS

Parkinson disease, parkinsonian disorders, hospitalization, drug contraindication, dopamine antagonists, electronic medical record

1 Introduction

Parkinson's disease (PD) is a neurodegenerative disorder that affects over 10 million people worldwide, and the prevalence is estimated to continue increasing in the next decades (Kasten et al., 2007; Statistics|Parkinson's Foundation, 2023). People with PD are more likely than the general population to be hospitalized. The most common reasons for admission include elective surgery (e.g., joint replacements), falls, fractures, urinary tract infections, and mental status changes (Chou et al., 2011; Gerlach et al., 2011; Low et al., 2015). Hospitalized patients with Parkinson's disease are at increased risk of medical complications, longer stays and higher rates of morbidity and mortality. As a direct result of the hospital stay, PD patients often experience a significant decline in their level of function compared to pre-hospitalization and require a higher level of care at the time of discharge (Woodford and Walker, 2005; Gerlach et al., 2012, 2013). Several contributing factors have been identified, including adherence to complex medication regimens that require precise timing of administration, susceptibility to delirium, as well as increased risk of aspiration and falls (Aminoff et al., 2011; Low et al., 2015; Martinez-Ramirez et al., 2015). In addition, hospitalized PD patients may be administered dopamine blocking agents (DBA), which are contraindicated in this disease as they can worsen their condition and are potentially fatal in those with PD and related diseases (Lertxundi et al., 2008; Gerlach et al., 2013; Martinez-Ramirez et al., 2015).

The DBA drug class includes antiemetic medications, as well as first and second generation antipsychotics, which are commonly used in the hospital setting to treat, for example, hospital-induced delirium (e.g., haloperidol) or post-anesthesia nausea (e.g., prochlorperazine) (Golembiewski and Tokumaru, 2006; Derry et al., 2010; Schwartz et al., 2021). These medications have high affinity for the dopamine receptors, and thus, they are dangerous for PD patients who have an inherent dopamine deficiency. Serious complications can arise from the use of this drug class in PD patients, including worsening motor symptoms, mental status changes, longer hospital stays, need for a higher level of care, and potentially death (Aarsland et al., 2005; Martinez-Ramirez et al., 2015). Similarly, patients with atypical parkinsonian disorders, such as Dementia with Lewy Bodies, are also at increased risk for complications due to DBA (McKeith et al., 1992; Aarsland et al., 2005).

Considering the significant morbidity and health-related costs associated with hospitalization in people with PD and related disorders, efforts have been made to address the various contributing factors to this problem. Inpatient medication management is a potentially modifiable factor, and electronic medical record (EMR) warnings have been proposed as a potential strategy to optimize it, although they are little used (Grissinger, 2018; Lertxundi Etxebarria et al., 2021; Parkinson's Foundation, 2023). Aslam et al. studied the effect of an EMR alert that was activated when a patient with PD or on PD medications was admitted to the hospital, and they found that patients who had contraindicated medication orders decreased after the intervention, although no significant difference in the hospitalization outcomes was found (Aslam et al., 2020). Beyond this study, there is scarce literature regarding the use of EMR warnings to prevent contraindicated medications in hospitalized PD.

Our group felt it prudent to implement an EMR warning to decrease the potential risk associated with the use of these agents in patients with PD and related disorders. An EMR warning (also referred to as a Best Practice Advisory or BPA) was created within the University of Rochester system to alert about contraindicated medications in hospitalized patients with PD and related disorders. This initiative was part the Parkinson's Disease Hospital Optimization Project (PD-HOP). The goal of this study was to determine the effect of the BPA on the ordering and administration of contraindicated medications among patients with PD and related disorders who were admitted at two hospitals affiliated with the University of Rochester.

2 Materials and methods

2.1 Study design

This was an ecologic study aimed to evaluate the effect of a BPA on the ordering and administration of contraindicated DBA among the patients with PD and related disorders who were hospitalized at Strong Memorial Hospital and Highland Hospital, which are hospitals affiliated to the University of Rochester, located in Rochester, New York.

2.2 Best practice advisory

In collaboration with the University of Rochester Information Technology and Pharmacy Department, a BPA was created within our EMR system. The BPA was designed to alert the provider when a contraindicated DBA was ordered in hospitalized patients with PD and related disorders (Table 1 for the list of medications and diagnoses). For the BPA to be triggered, the diagnosis had to be listed in the EMR. The warning provided suggestions for alternative, safer medications including recommended dosages (Figure 1). The list of alternative medications was standard and the same in all cases; the suggestions were not tailored based on indication, as this information is not always specified in our EMR's orders.

To build a list of contraindicated medications as inclusive as possible, we conducted an internet search and created a comprehensive list of all the DBA. Our team's Movement Disorders specialists and hospital pharmacy collaborators reviewed this list to ultimately include the agents available in the USA and on formulary in our health system. Clozapine and quetiapine were not included in the list of contraindicated medications as they have predominant affinity for serotonin receptors and are less apt to worsen parkinsonism in

TABLE 1 Best practice advisory criteria.

Best practice advisory criteria	
Diagnoses (ICD-10 code)	Contraindicated DBA medications
■ Parkinsonism unspecified (G20) ■ Parkinson's disease (G20) ■ Dementia with Lewy Body (G31.83) ■ Multiple system Atrophy (G90.3) ■ Progressive Supranuclear Palsy (G23.1) ■ Corticobasal Degeneration (G31.85)	*Antiemetics* ■ Droperidol ■ Metoclopramide ■ Prochlorperazine ■ Promethazine *First-generation antipsychotics* ■ Chlorpromazine ■ Haloperidol ■ Loxapine ■ Molindone ■ Perphenazine ■ Pimozide ■ Thioridazine ■ Thiothixene ■ Trifluoperazine *Second-generation antipsychotics* ■ Asenapine ■ Aripiprazole ■ Cariprazine ■ Fluphenazine ■ Lurasidone ■ Olanzapine ■ Risperidone ■ Ziprasidone

The BPA was triggered when a provider ordered contraindicated DBA in hospitalized patients with Parkinson's disease and related disorders, according to the diagnoses and medications listed above. BPA, best practice advisory; DBA, dopamine blocking agents; ICD-10, international classification of diseases, tenth revision.

patients with PD and related disorders (Kyle and Bronstein, 2020). In fact, quetiapine was included among suggested alternative medications.

In order to assess the functionality and determine the need of the BPA, there was a one-month period during which activation was monitored but warning was not visible to the clinicians. The warning was triggered 10 times during this one-month period, leading the University of Rochester EMR Warning Committee to approve its implementation, and the BPA was launched in the clinical setting in January 2020.

The BPA was implemented as part of the PD-HOP, a quality improvement project that also encompassed establishing a hospital-based multidisciplinary PD champion network, creating a PD educational program for hospital providers, and changing the EMR ordering system to allow custom PD medications regimens. All these initiatives were instituted in parallel.

2.3 Study population

For this study, we included all the patients with a diagnosis of PD and related disorders who had a hospital admission at Strong Memorial Hospital or Highland Hospital during a 1 year period before the implementation of the BPA (*t1*: 1/1/2019–1/1/2020) and after the implementation of the BPA (*t2*: 1/8/2020–1/8/2021).

2.4 Data analysis

Epic SlicerDicer was used to collect the data from the University of Rochester EMR. SlicerDicer is an EMR data extraction tool that provides de-identified clinical-epidemiological information on large patient populations with customizable search criteria (Saini et al., 2021). The data was obtained in February 2023.

The patient population was defined following the criteria noted above. We applied the Patients data model in SlicerDicer to obtain the cumulative number of individual patients. We used the search criteria Problem List to identify the patients with diagnosis of PD and related disorders (Table 1). For the two time periods (*t1* and *t2*), we obtained the total number of patients, the number of patients who had contraindicated DBA orders, and the number of patients who had contraindicated DBA administrations. In addition, the number of patients who had the BPA triggered in *t2* was obtained, which was used as a surrogate of the attempted orders during *t2*.

We calculated the percentage of patients who had contraindicated DBA orders and administrations in the two time periods, as well as the percentage of patients who had the BPA triggered in *t2*. Chi-square test was used to compare frequencies. A significance level of 0.05 was used. GraphPad Prism 9.0 (RRID:SCR_002798) was used for the statistical analysis.

2.5 Ethical considerations

This study was approved by the University of Rochester Institutional Review Board. All the data was de-identified and no personal health information was used.

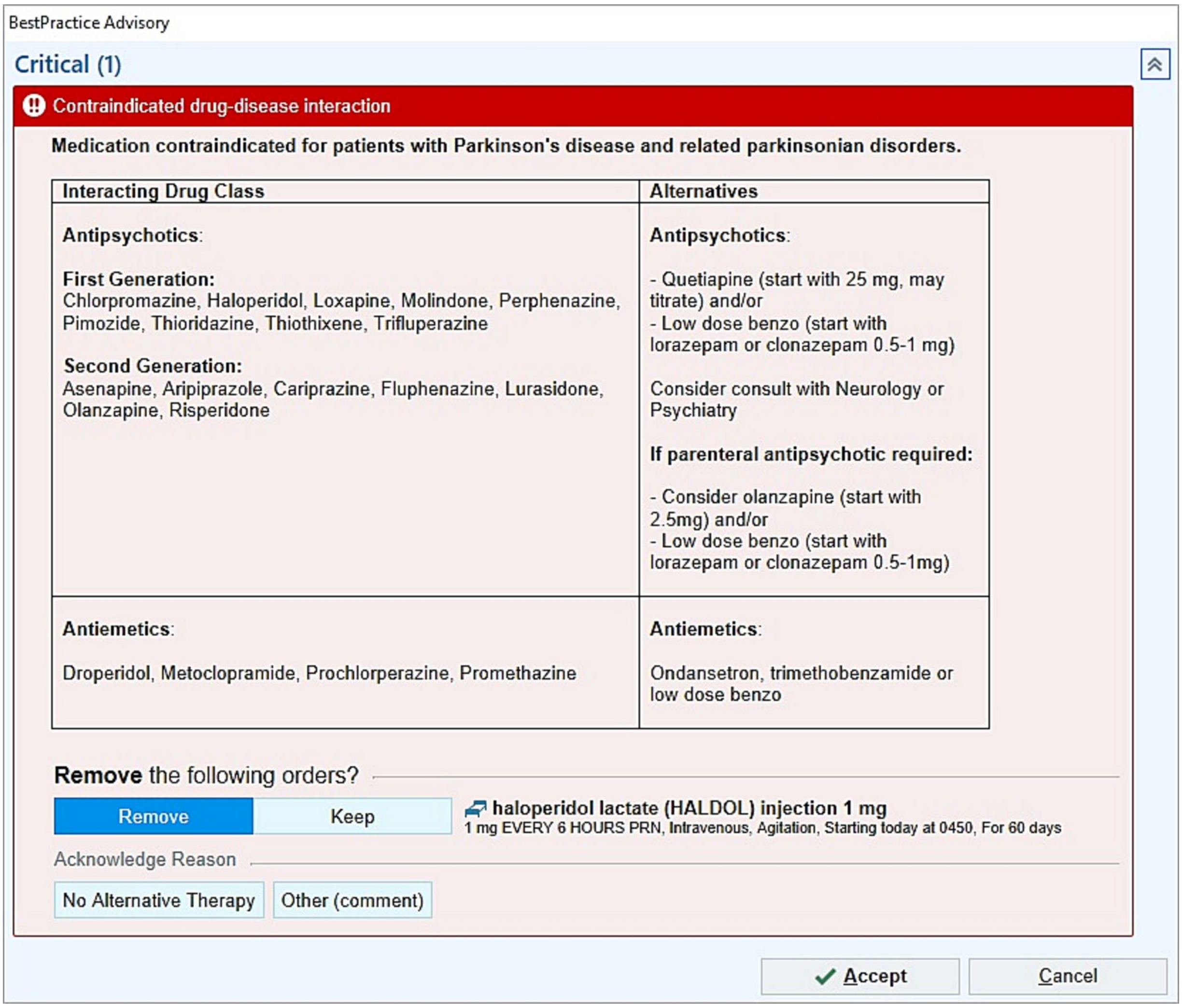
3 Results

306 patients with PD and related disorders had a hospital admission at Strong Memorial Hospital or Highland hospital during *t1* (1/1/2019–1/1/2020), and 273 patients during *t2* (1/8/2020–1/8/2021).

During *t1*, 127 patients (41.5%) had contraindicated DBA orders, and 49 patients (16%) had contraindicated DBA administrations. During *t2*, 48 patients (17.6%) had contraindicated DBA orders, and 24 patients (8.8%) had contraindicated DBA administrations (Table 2). In addition, during *t2*, 101 patients (36.9%) had the BPA triggered.

The percentage of patients who had contraindicated DBA orders was significantly less in *t2* as compared to *t1* ($\chi^2 = 39.15$, $p < 0.0001$), with an absolute reduction of 23.9%. The percentage of patients who had contraindicated DBA administrations was also significantly less in *t2* as compared to *t1* ($\chi^2 = 6.83$, $p < 0.05$), with an absolute reduction of 7.2%. There was no significant difference between the percentage of patients who had contraindicated DBA orders in *t1* and patients who had the BPA triggered in *t2* ($\chi^2 = 1.23$, $p = 0.27$), where the latter was used as a surrogate of the attempted orders during *t2*.

Additionally, among the subgroup of patients who had contraindicated DBA orders, the proportion of patients who had contraindicated administrations was 38.6% in *t1* (49 out of 127) and 50% in *t2* (24 out of 48).



Contraindicated drug-disease interaction

Medication contraindicated for patients with Parkinson's disease and related parkinsonian disorders.

Interacting Drug Class	Alternatives
Antipsychotics: **First Generation:** Chlorpromazine, Haloperidol, Loxapine, Molindone, Perphenazine, Pimozide, Thioridazine, Thiothixene, Trifluperazine **Second Generation:** Asenapine, Aripiprazole, Cariprazine, Fluphenazine, Lurasidone, Olanzapine, Risperidone	**Antipsychotics**: - Quetiapine (start with 25 mg, may titrate) and/or - Low dose benzo (start with lorazepam or clonazepam 0.5-1 mg) Consider consult with Neurology or Psychiatry **If parenteral antipsychotic required:** - Consider olanzapine (start with 2.5mg) and/or - Low dose benzo (start with lorazepam or clonazepam 0.5-1mg)
Antiemetics: Droperidol, Metoclopramide, Prochlorperazine, Promethazine	**Antiemetics**: Ondansetron, trimethobenzamide or low dose benzo

Remove the following orders?

haloperidol lactate (HALDOL) injection 1 mg
1 mg EVERY 6 HOURS PRN, Intravenous, Agitation, Starting today at 0450, For 60 days

Acknowledge Reason

FIGURE 1
Best practice advisory (BPA) example. The BPA alerts the provider when contraindicated DBA are ordered in hospitalized patients with PD and related disorders, and it provides suggestions for alternative medications.

TABLE 2 Contraindicated DBA orders and administrations before and after the implementation of BPA.

	Before BPA[a]	After BPA[b]	*p* value
Total number of patients	306 (100%)	273 (100%)	NA
Patients with contraindicated DBA orders	127 (41.5%)	48 (17.6%)	<0.0001*
Patients with contraindicated DBA administrations	49 (16%)	24 (8.8%)	0.009*

BPA, best practice advisory; DBA, dopamine blocking agents; NA, not applicable; (*) statistically significant ($p < 0.05$).
[a]From 1/1/2019 to 1/1/2020.
[b]From 1/8/2020 to 1/8/2021.

4 Discussion

As part of the Parkinson's Disease Hospital Optimization Project (PD-HOP), supported by a Parkinson's Foundation Community Grant, a BPA was launched within the University of Rochester EMR in January 2020 to alert about contraindicated DBA in hospitalized patients with PD and related disorders. In this study, we found that there was a significant reduction in the percentage of patients who had contraindicated DBA orders and administrations after the implementation of the BPA.

Similar to previous studies, we found that contraindicated medications were ordered in 41.5% and administered in 16% of patients with PD and related disorders before the implementation of the BPA (Derry et al., 2010; Hou et al., 2012; Aslam et al., 2020). The high rate of contraindicated medication usage underscores the importance of implementing strategies to address this problem, especially considering that this is a potentially modifiable factor to improve outcomes in hospitalized patients with PD and related disorders.

EMR warnings have been proposed as a strategy to optimize the inpatient medication management for patients with PD and related disorders (Grissinger, 2018; Lertxundi Etxebarria et al., 2021; Parkinson's Foundation, 2023). Aslam et al. reported that the PD patients who had contraindicated medication orders decreased from 42.5 to 17.5% after creating an EMR alert and doing in-service training sessions (Aslam et al., 2020), which is comparable to our results that revealed a reduction from 41.5 to 17.6%. These findings support the reproducibility of this type of intervention with potentially similar impact across different hospital systems. Furthermore, we found that the number of patients who had contraindicated DBA orders in *t1* was comparable to the number of patients with attempted orders in *t2* (as measured by the BPA triggers), suggesting that the orders reduction in *t2* might have been related to the BPA implementation. On the other hand, contrarily to our results, Morris et al. found no benefit from EMR alerts for preventing contraindicated orders (Morris et al., 2015). Importantly, in our study, the BPA provided suggestions for alternative medications, which could explain these divergent results and prove valuable, especially considering that the detrimental effect of DBA has been previously reported to be under-recognized among non-specialists (Esper and Factor, 2008; Chou et al., 2011).

Additionally, our study showed that not only the orders, but also patients who had contraindicated DBA administrations decreased from 16 to 8.8% after the implementation of the BPA. To our knowledge, this is the first study to show the potential benefit of a BPA on the administration of contraindicated medications in patients with PD and related disorders, which is a contributing factor for hospital complications in this patient population. Aside from the BPA, other components of PD-HOP, including the creation of a multidisciplinary PD champion network and the educational program for hospital providers, may have also contributed to the reduction in contraindicated medications.

Interestingly, the reduction of patients who had contraindicated orders was larger than the reduction of those who had administrations (absolute percentage reduction of 23.9% vs. 7.2%). In addition, among the subgroup of patients who had contraindicated DBA orders, the proportion who had administrations was less in *t1* as compared to *t2* (49 out of 127 [38.6%] vs. 24 out of 48 [50%]). These findings suggest that during *t1*, there was a higher rate of contraindicated medication orders that were ultimately not utilized. A possible explanation is that more as-needed DBA orders might have been placed during *t1*, which are not always required; at the same time, as-needed orders could have been more suitable for discontinuation or change to an alternative medication in response to the BPA during *t2*. Nevertheless, we do not have data from our hospital to support these hypotheses at this time, as we did not explore the underlying reasons for this observation. A previous study looked at the factors associated with discontinuing a contraindicated medication in patients with dopamine-requiring diseases in response to an EMR alert, and use of the medication for nausea or emesis was found to be the strongest predictor (Morris et al., 2015). Further studies would help learn more about the reasons to adopt or dismiss the suggestions of our BPA.

Considering the different impact on the reduction of orders and administrations of contraindicated medications, medication administration appears to be a better outcome measure than medication order when evaluating the effect of EMR warnings. In addition, future studies are needed to determine if the reduction in contraindicated medication administrations translates into better patient-related outcomes. Notably, Aslam et al. reported no change on the hospital outcomes after the creation of an EMR alert, despite significant reduction on contraindicated medication orders (Aslam et al., 2020); however, they did not explore the impact of the EMR alert on the administration of contraindicated medications, which could be a possible reason for their conflicting results.

It is important to note that the BPA aimed to identify patients with neurodegenerative parkinsonism. Nevertheless, other types of parkinsonism might have been captured under the diagnosis of 'Parkinsonism unspecified (G20)', including drug-induced parkinsonism which has been estimated to account for approximately 20% of all the parkinsonism cases (Benito-León et al., 2003). Patients with drug-induced parkinsonism might be on DBA therapy at home, which is typically continued during hospital admissions; thus, this patient group could have contributed to the patients who had contraindicated DBA orders and administrations during *t2*, despite the use of the BPA. Similarly, patients with PD and related disorders might need long-term DBA therapy, especially if they develop psychosis (Bower et al., 2018). As individual patient information was not evaluated in this study, we could not exclude those patients on long-term DBA therapy prior to the hospital admission, nor determine if the proportion of patients with drug-induced parkinsonism was similar in both time periods.

The results of this study increase the evidence of the potential benefit of EMR warnings for the optimization of inpatient medication management in patients with PD and related disorders. This study had several limitations: (1) the ecologic study design limits the extent of the conclusions, as no definitive associations or causality effects can be determined; (2) no individual patient information was analyzed, limiting the evaluation of possible confounding variables and patient-related outcomes; (3) the BPA activation and data collection were based on information documented in the EMR, which is at risk of human error; (4) the data extracted from SlicerDicer can change over time if the variables are modified in the EMR (e.g., if a patient's diagnosis is deleted or changed, they will not be detected in subsequent searches for such diagnosis); (5) information on user experience and potential distress caused by the alert was not collected in this study. Given that the patient populations were comparable and defined by the same variables in the two time periods, we assumed that the potential effect of limitations (3) and (4) was similar in both time periods. Lastly, it is important to recognize the potential risk for EMR warning fatigue, which could lead to reduced benefit over time (Ancker et al., 2017).

In conclusion, EMR warnings are a potential reproducible strategy to improve inpatient medication management for patients with PD and related disorders. In particular, our results suggest that EMR warnings help reduce the administration of contraindicated medications. Further studies are needed to evaluate the impact of the EMR warnings on hospitalization and long-term outcomes, healthcare-related costs, sustainability over time, and combined effect with strategies for other factors leading to hospital complications in patients with PD and related disorders.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by University of Rochester Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

NC: Conceptualization, Methodology, Project administration, Writing – original draft. KA: Conceptualization, Methodology, Project administration, Writing – review & editing. MB: Conceptualization, Methodology, Project administration, Writing – review & editing. BV: Conceptualization, Methodology, Project administration, Writing – review & editing. IR: Conceptualization, Funding acquisition, Methodology, Project administration, Supervision, Writing – review & editing.

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Conflict of interest

KA was supported by the Michael J Fox Edmund J. Safra Fellowship in Movement Disorders from July 2,107–July 2019. She previously served as Investigator and/or medical monitor for clinical trials supported by Aptinyx Inc. Genentech Roche Ltd., EIP Pharma Inc., Michael J Fox foundation for PD research, NINDS, and Acadia Pharmaceuticals Inc., and Biogene. She previously served as Co-I of a Lewy Body Dementia Association Research Center of Excellence site.

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Custom order entry for Parkinson's medications in the hospital improves timely administration: an analysis of over 31,000 medication doses

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Background: Patients with Parkinson's disease (PD) are at increased risk for hospital acquired complications. Deviations from home medication schedules and delays in administration are major contributing factors. We had previously developed a protocol to ensure adherence to home medication schedules using "custom" ordering. In this study we are assessing the impact this order type may have on reducing delays in PD medication administration in the hospital.

Material and methods: We reviewed 31,404 orders placed for PD medications from January 2, 2016 to April 30 2021. We evaluated the orders to determine if they were placed in a Custom format or using a default non-custom order entry. We further evaluated all orders to determine if there was a relationship with the order type and timely administration of medications. We compared medications that were administered within 1 min, 15 min, 30 min and 60 min of due times across custom orders vs. non-custom default orders. We also evaluated the relationship between ordering providers and type of orders placed as well as hospital unit and type of orders placed.

Results: 14,204 (45.23%) orders were placed using a custom schedule and 17,200 (54.77%) orders were placed using non-custom defaults. The custom group showed a significantly lower median delay of 3.06 minutes compared to the non-custom group ($p<.001$). Custom orders had a significantly more recent median date than non-custom default orders (2019-10-07 vs. 2018-01-06, $p<0.001$). In additional analyses, medication administration delays were significantly improved for custom orders compared to non-custom orders, with likelihoods 1.64 times higher within 1 minute, 1.40 times higher within 15 minutes, and 1.33 times higher within 30 minutes of the due time ($p<0.001$ for all comparisons).

Conclusion: This is the largest study to date examining the effects of order entry type on timely administration of PD medications in the hospital. Orders placed using a custom schedule may help reduce delays in administration of PD medications.

KEYWORDS

Parkinsons disease, hospitalization, medication delays, custom orders, complications, safety, timely administration

Introduction

Patients with Parkinson's disease (PD), especially those in more advanced stages, often rely on complex medication regimens to maintain function and quality of life (QoL). Errors or delays in medication administration can have a significant negative impact for this group. The consequences are particularly pronounced when PD patients are admitted to the hospital where rigid medication schedules, lack of PD knowledge among hospital staff, and limited availability of PD medications on hospital formularies can lead to missed or delayed dosing, medication substitutions, or even administration of contraindicated medications (Derry et al., 2010; Chou et al., 2011; Cohen and Smetzer, 2015; Shin and Habermann, 2016; Lertxundi et al., 2017; Mucksavage and Kim, 2020). These errors increase complication rates and prolong hospital stays (Barber et al., 2001; Derry et al., 2010; Gerlach et al., 2012; Carlson et al., 2014; Cohen and Smetzer, 2015; Martinez-Ramirez et al., 2015; Crispo et al., 2016; Lertxundi et al., 2017; Cox et al., 2018; Margolesky and Singer, 2018; Yu et al., 2023). Delays in medication administration of even 15 min have been shown to result in negative outcomes for PD patients (Parkinson's Foundation, 2022).

Attempts to address such errors and delays have had varied success across institutions. Nance et al. demonstrated how nursing alerts in the Electronic Medical Records (EMR) and educational programs could improve timing of medication administration (Nance et al., 2020). Skelly et al. compared outcomes for patients with PD when admitted to general units vs. specialized units and observed a decreased length of stay and fewer medication errors (Skelly et al., 2014). Hobson and colleagues utilized an email alert to notify the specialist team when a PD patient was brought in through the emergency room. The alerts resulted in early interventions to address medications, and other needs of the patients (Hobson et al., 2019). Previously we reported on the design and implementation of a protocol aimed at better adherence to home medication regimens for hospitalized patients with PD, with emphasis on using "custom" orders instead of non-custom hospital defaults (Azmi et al., 2019). We further reported on the protocol's impact in increasing the use of custom orders as well as improving patients' length of stay (Azmi et al., 2020).

Any attempt to tackle such safety gaps for people with PD, need not only address adherence to the home medication regimen, but also timely dosing. To evaluate the effect of our protocol on timely dosing, we evaluated PD medications orders placed over a 5-year period. Herein, we report on the analysis of these orders with specific attention to the differences between dosing due time vs. dose administered time.

Materials and methods

Following IRB approval, a retrospective review of PD medication orders placed from January 2, 2016, to April 30, 2021, was conducted at a single site, at Hackensack University Medical Center. 31,404 doses were analyzed. The primary outcome measure was whether the type of order placed (custom vs. non-custom) had any effect on the timely dosing of PD medications. (Non-custom orders are those which the default schedules such as BID or TID are used, whereas custom orders use a manual entry of specific medication times, ideally to reflect the patient's home regimen). Timely dosing of medication was measured by the difference in the time recorded when the medication was administered by the nurse vs. the actual due time. The absolute value of the time difference was used to compare the two groups. Comparisons of frequency of medications administered within 1 min of medication due time, were modeled using a mixed effects model. Comparisons of median differences in time to medication administration relative to the due time of medication administration were modeled using mixed effects quantile regression.

Additional analyses were conducted for subgroups of medications administered within 15, 30 and 60 min of due time, as well as subgroups of ordering providers and ordering unit clusters. Descriptive analysis of all order types was also conducted.

Statistical analysis

The full statistical methods can be found in the Supplementary Material. Descriptive statistics are reported as mean ± standard deviation, median (interquartile range), or as count (percentage). Normality of data was cross-validated using standard tests (Anderson and Darling, 1954; Shapiro and Wilk, 1965; D'agostino and Pearson, 1973). Medication administration within 1 min of due time was analyzed as a binary event (yes vs. no) using Fisher's exact test. Effect sizes from Fisher's exact test are reported as odds ratios (ORs), along with 95% CIs computed using the Baptista-Pike method (Fisher, 1922). For subgroup analysis multivariable models were used which included the ordering unit, provider type, and time of medication orders as fixed effects.

Multivariable analysis using a hierarchical mixed effects quantile regression was used to model conditional median differences in time to medication administration between groups, adjusted for fixed covariates as well as clustering variables. Additionally, a standard mixed effects generalized linear model was used to compare the conditional mean differences between groups; A mixed effects generalized linear model with a logistic link function was also chosen to compare frequencies of medications administered within 1 min between groups.

Descriptive analyses of frequency of medications administered within discrete time windows by group was also provided; dichotomized time windows included medications administered within 15-, 30-, and 60-min relative to the medication due date/time.

Additional exploratory analyses were performed to evaluate differences in usage of custom orders over time and between provider types and unit clusters (ER, ICU, Medical, Surgical, Psychiatric, Other).

All analyses were performed in RStudio (Version 2022.12.0, Build 353) running on R version 4.2.2. Mixed effects quantile regressions were performed using the 'lqmm' package and other multivariable analyses were performed using the 'lme4' package (Geraci and Bottai, 2014; Bates et al., 2015).

Results

Custom ordering

We reviewed 31,404 PD medication doses. Medications consisted of different formulations of carbidopa-levodopa, carbidopa-levodopa-entacapone, pramipexole, and ropinirole. Of all medication orders, 14,204 (45.23%) were placed using a "custom" schedule (Custom group) and 17,200 (54.77%) were placed using non-custom default schedules (Non-Custom group) (Table 1).

There were no significant differences in the custom vs. the non-custom group when comparing orders placed in the ICUs, the Psychiatric unit or units grouped as "other." (Units grouped as "other" were low census, non-surgical, non-medical units throughout the hospital). On the other hand, there were significantly more orders placed in the non-custom group in the ER and conversely more orders placed in the custom group in the Medical and Surgical units (Table 1). Within the custom group, orders rates were similar across the Medical [42.9% (7,717/18009)], ICU [44.1% (866/1964)], Psychiatric [43.5% (229/526)], and Other [42.0% (167/398)] units; however, the ER had significantly lower rate of custom orders [29.3% (339/1156)] while the Surgical unit cluster had a higher rate of these orders [52.3% (4,886/9351)] and was the only unit cluster to more commonly use custom medication orders over non-custom medication orders (Figure 1).

TABLE 1 Summary of characteristics by group.

Variable	Custom (N = 14,204)	Non-custom (N = 17,200)	Value of p
Median order date	2019-10-07	2018-01-06	<0.001
Earliest order date	2016-01-04	2016-01-02	.
Latest order date	2021-04-30	2021-04-28	.
Unit cluster			
ER	339 (2.4%)	817 (4.8%)	<0.001
ICU	866 (6.1%)	1,098 (6.4%)	0.303
Medical	7,717 (54.3%)	10,292 (59.8%)	<0.001
Surgical	4,886 (34.4%)	4,465 (26.0%)	<0.001
Psychiatric	229 (1.6%)	297 (1.7%)	0.453
Other	167 (1.2%)	231 (1.3%)	0.205
Provider type			
APNP	1,597 (11.2%)	2,296 (13.4%)	<0.001
Physician	8,864 (62.4%)	11,478 (66.7%)	<0.001
Physician assistant	1,008 (7.1%)	966 (5.6%)	<0.001
R1	380 (2.7%)	185 (1.1%)	<0.001
R2	341 (2.4%)	126 (0.7%)	<0.001
R3	1,363 (9.6%)	1,269 (7.4%)	<0.001
R4	232 (1.6%)	246 (1.4%)	0.151
R5	252 (1.8%)	450 (2.6%)	<0.001
R6	71 (0.5%)	107 (0.6%)	0.174
R7	96 (0.7%)	59 (0.3%)	<0.001
R9	0 (0%)	17 (0.1%)	>0.999
Null	0 (0%)	1 (0.01%)	>0.999

The Custom group and Non-Custom groups had similar rates of medications ordered by year 4 resident (R4), year 6 resident (R6), and a year 9 resident (R9); however, the Custom group had a larger proportion of orders by physician assistants, year 1, 2, 3, and 7 residents (R1, R2, R3, R7) while the Non-Custom group had a larger proportion of orders by advanced practice nurses (APN), attending physicians, and year 5 residents (R5) (Figure 2).

When comparing the entirety of orders across the study period, there was a significant difference in the median dates of orders in the custom group vs. those in the non-custom group. The Custom group tended to have more recent orders (median date = 2019-10-07) in comparison to the Non-custom group (median date = 2018-01-06); (Figure 3).

Timely administration

The median difference in time to medication administration relative to the due time was 24 min (IQR: 9–51) in the Custom group compared to 29 min (IQR: 12–53) in the Non-Custom group. This difference was statistically significant, with a median difference of 3 min (95% CI, 3–4, $p < 0.001$).

When comparing the timing of medication between groups, 733 (5.16%) orders were administered within 1 min of due time in the Custom group compared to 522 (3.03%) in the Non-Custom group. This difference was statistically significant, with the odds of medications administered on time being 1.64 times as likely to occur in the Custom group compared to the Non-Custom group (95% CI, 1.55–1.95, $p < 0.001$; Table 2).

Overall, when comparing the two groups of order types, the probability of the medication being administered within 1 min of due time was more when the medication order was "custom" compared to non-custom (Figure 4A). Moreover, the probability of any medication, regardless of order type, being administered within 1 min of due time increased over the study period (Figure 4B).

In addition to our focus on medications administered within 1 min of due times, we also compared subgroups of medications administered within 15 min, 30 min, and 60 min of due times to assess more practical subgroups.

When orders were placed using a Custom format, it was 1.4 times more likely for the medication to be administered within 15 min of due compared to when the order was placed using a non-custom default (95% CI: 1.34–1.47, $p < 0.001$). Similarly, when medications orders were placed in a custom fashion, it was 1.33 times more likely for the medication to be administered within 30 min of due time compared to non-custom ordered medications (95% CI: 1.24–1.39, $p < 0.001$). This effect was not observed when medications were administered within 60 min from due time (Figure 5).

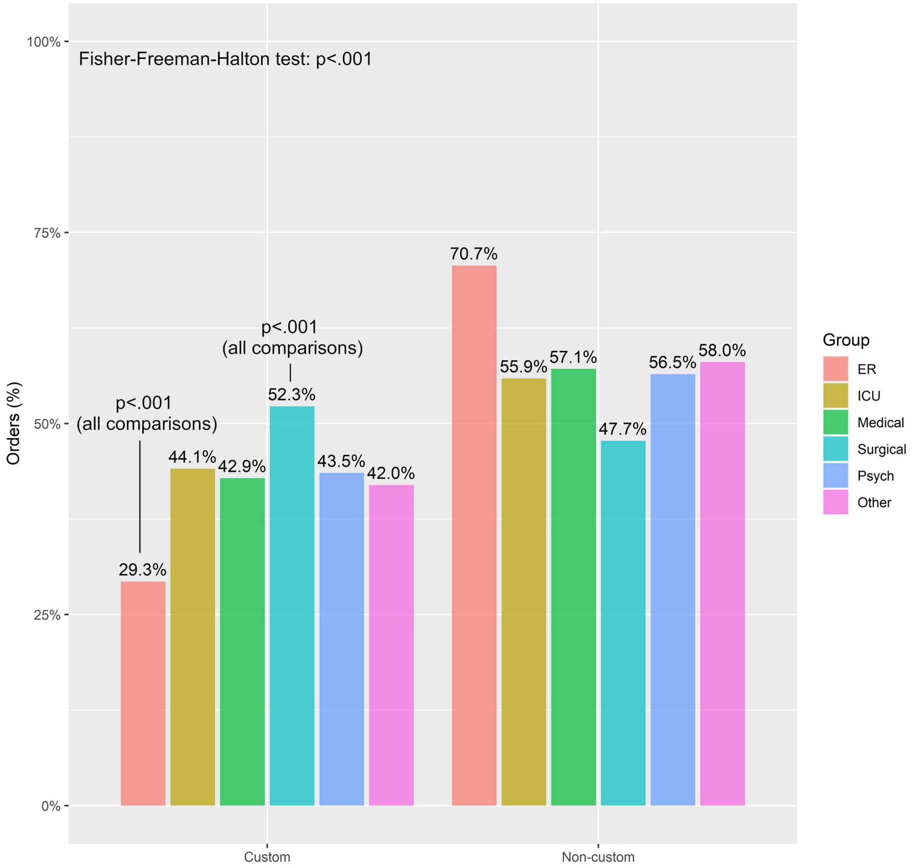

FIGURE 1
Frequency of custom and non-custom medication orders between unit clusters. ER tends to have the lowest amount of medication order, while surgical tends to have the highest amount of medication orders based on a Fisher's exact test corrected for false discovery rate. ER, emergency room; ICU, intensive care unit.

Discussion

Timely administration of PD medications is critical to maintaining the safety of PD patients in the hospital. There is growing literature regarding worsening outcomes, delays in discharge and increased mortality with poorly managed PD medications in the hospital. Efforts to mitigate these issues by several institutions have demonstrated some positive potential, although widespread and universally effective processes have been lacking.

The fundamental challenge in achieving more uniform and comprehensive protocols is the lack of standardized guidelines. The Parkinson's Foundation, one of three main advocacy groups for people with PD, has been actively creating awareness around these safety gaps. They recently put forth their Hospital Care Recommendations[1] (Parkinson's Foundation, 2023) as a tool for institutions to improve quality and safety of people with Parkinson's in the hospital, which hopefully can serve as a steppingstone to development of national guidelines.

This study, To our knowledge, is the largest study to date to examine the effect of Custom order placement in the hospital on the timely administration of PD medications. The analysis did not exclude any hospital units with the objective of capturing the most accurate representation of delays in the administration of PD medications.

It is reassuring to see the findings demonstrate an increase in order placement using "Custom" schedules over time. This validates our educational process and our efforts to encourage adherence to the PD medication protocol, which was officially launched in 2018, as over time we see an increased likelihood of use of "custom" schedule ordering.

This analysis also supports the importance of placing PD orders using "Custom" ordering. Adherence to patients' home medication not only helps reduce the risk of hospital acquired complications and decreases length of stay but may also positively impact timely administration of medication.

While the median administration delay for both groups was under 30 min, the custom group had 3 min less delay when comparing all doses across the time period analyzed. The comparison across subgroups demonstrated medications placed in a custom format were more likely to be administered within 1 min of due time. The same effect was seen when comparing

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[1] https://www.parkinson.org/sites/default/files/documents/hospital-care-recommendations-april2023.pdf

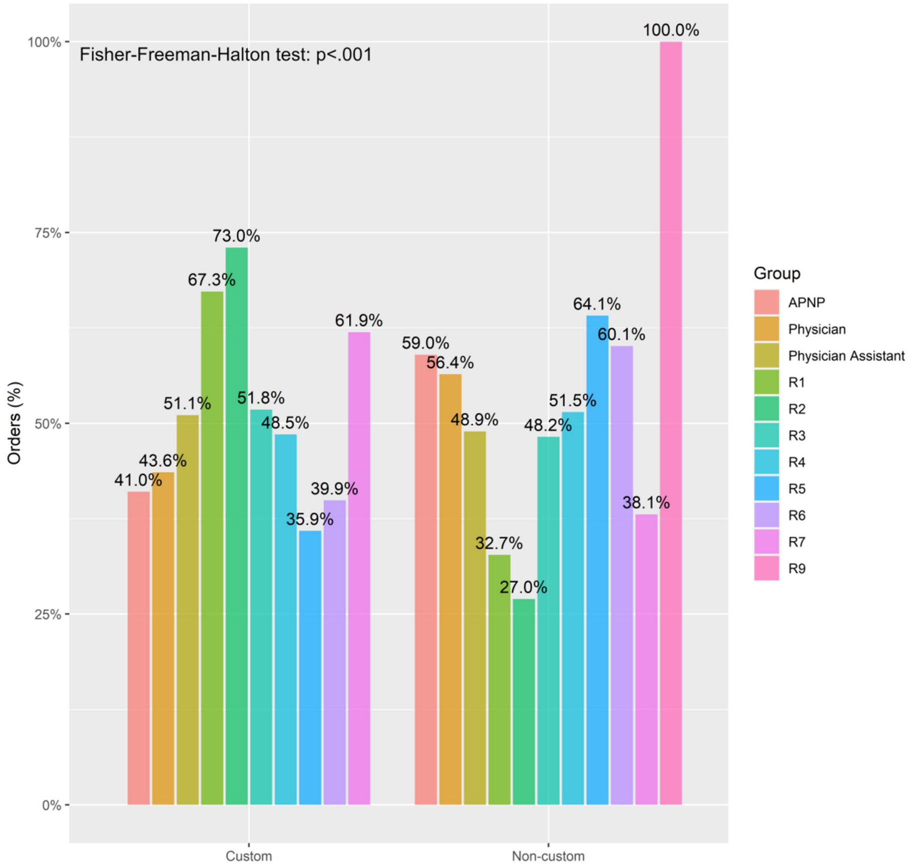

FIGURE 2
Frequency of custom and non-custom medication orders between medication provider types. APNP, advanced practice nurse practitioner.

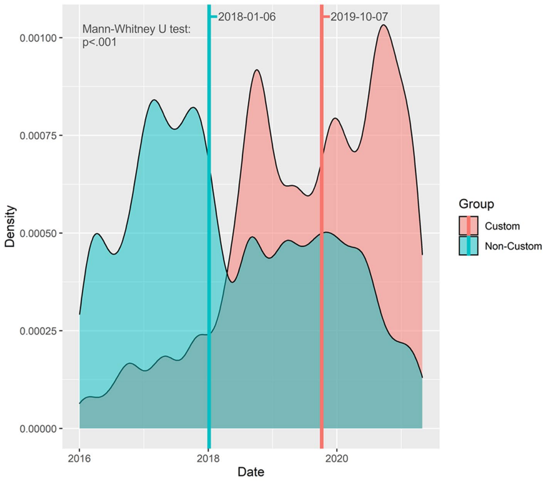

FIGURE 3
Density plot of ordered medication dates between groups. Lines showing the median values for each group are displayed, along with labels of the median values.

medications given within 15 min of due time, as well as those given within 30 min of due time. The differences were statistically significant. These are powerful observations as there is evidence in the literature that even a 15-min delay in administration of PD medications can be deleterious for PD patients. While encouraged by the findings, clearly there is more work to be done as the majority of our medications were administered with over a 15-min delay.

The 60-min subgroup did not demonstrate a difference across custom and non-custom groups. This may be because this subgroup reflects a cohort where the administering nurses were unaware or unable to administer the medications in a timely manner reflected by the degree of delay, and as such the method of order placement may have been irrelevant.

When comparing order entry in various patient units across the hospital, it appears that most units or unit groupings performed similarly except for two outliers. The ER lagged the rest of the hospital in orders placed using custom schedules and the surgical units fared significantly better than other units for the same metric. The former finding is not surprising, given the nature of emergency room visits where the presenting complaint takes precedence. The latter finding may be explained by the origins of our medication protocol as it was developed in an attempt to ensure proper care of post deep brain stimulation surgery (DBS) patients and later disseminated through the entire hospital, and as such at least earlier in the process, the concepts were more familiar to the surgical units.

TABLE 2 **Multivariable analyses of differences in time to medication administration between groups.**

Outcome	Custom ($N = 14{,}204$)	Non-custom ($N = 17{,}200$)	Effect size	Value of p
Frequency of medications administered on time	733 (5.16%)	522 (3.03%)	1.67 (1.43–1.96)	<0.001
Median time difference relative to due time (minutes)	24 (9–51)	29 (12–53)	3.06 (1.48–4.46)	<0.001
Mean time difference relative to due time (minutes)	37.00 ± 46.25	40.57 ± 45.50	2.60 (1.01–4.18)	0.001

Effect sizes are reported as conditional odds ratios for “frequency of medications administered on time,” conditional median differences for “median time difference relative to due date/time” (from mixed effects quantile regression), and conditional mean differences for “Mean time difference relative to due date/time.” for each model, the non-custom is coded as the reference level; as such, the odds ratio of 1.67 implies that odds of medications being administered on time are 1.67 times as likely to occur in the Custom group compared to the non-custom group. Similarly, the median difference of 3.06, implies that the Custom group has a median decrease of 3.06 min in time to medication administration relative to the due date/time compared to the non-custom group. Models are adjusted for ordered date/time of medication, ADT unit, and medication provider type (see Supplementary Tables S1–S3 for detailed summaries showing the effect estimates for all variables included in models).

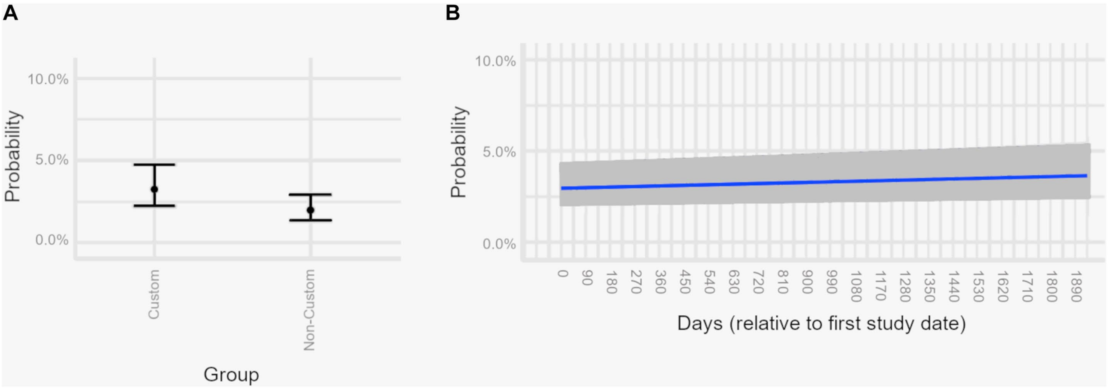

FIGURE 4
Estimated marginal effects plots, showing the predicted probabilities of medications administered on time across different predictor variables from a multivariable logistic regression model. Estimated marginal effects plots provide the predicted values for medications being administered on time at the margin of specific values (for continuous variables) or levels (for categorical variables), while holding non-focal variables constant and varying the focal variables. Medications are considered on time if administered within 1 min of the medication due date/time. Shaded areas and error bars represent 95% confidence intervals. Panel **(A)** Probability of any medication being administered within 1 min of due time if ordered “custom” vs. non-custom. **(B)** Probability of any medication being administered within 1 min of due time, demonstrating improvement over time.

When evaluating ordering providers, it seems that custom ordering was used more commonly among physician assistants, first, second, third year and seventh year residents while non-custom ordering was more common among advanced practice nurses, attending physicians and fifth year residents. While it is not a clear-cut picture, certain patterns can be gleaned: the timeline of our educational process could account for the pattern of residents earlier in their careers being more aware of the importance of custom order placement. And the differences observed in ordering patterns between physician assistants and other advanced practice providers may be related to how these separate groups are organized within our hospital system and with which patient units they are more associated.

Limitations

This study is limited by its retrospective nature. While the findings are encouraging for those institutions aiming to correct the risks faced by people with Parkinson’s in the hospital, they need to be validated in a prospective multicenter study.

There is also the consideration that while this study demonstrates a correlation between custom order placement and improvement in timely administration, this does not prove causation. There may be factors such as overall staff education that help improve timely administration. While this is possible, confounding factors should affect both order type groups equally. What we do observe however is a significant improvement in timely administration of medications when orders are placed using Custom timed schedules vs. non custom default schedules, supporting a more causative phenomenon.

Conclusion

To our knowledge, this is the largest study to date examining the effects of order entry type on timely administration of medication. Based on this review of 31,404 medication doses administered across all units of our hospital, orders placed using a Custom schedule, may help reduce delays in administration of Parkinson’s medications.

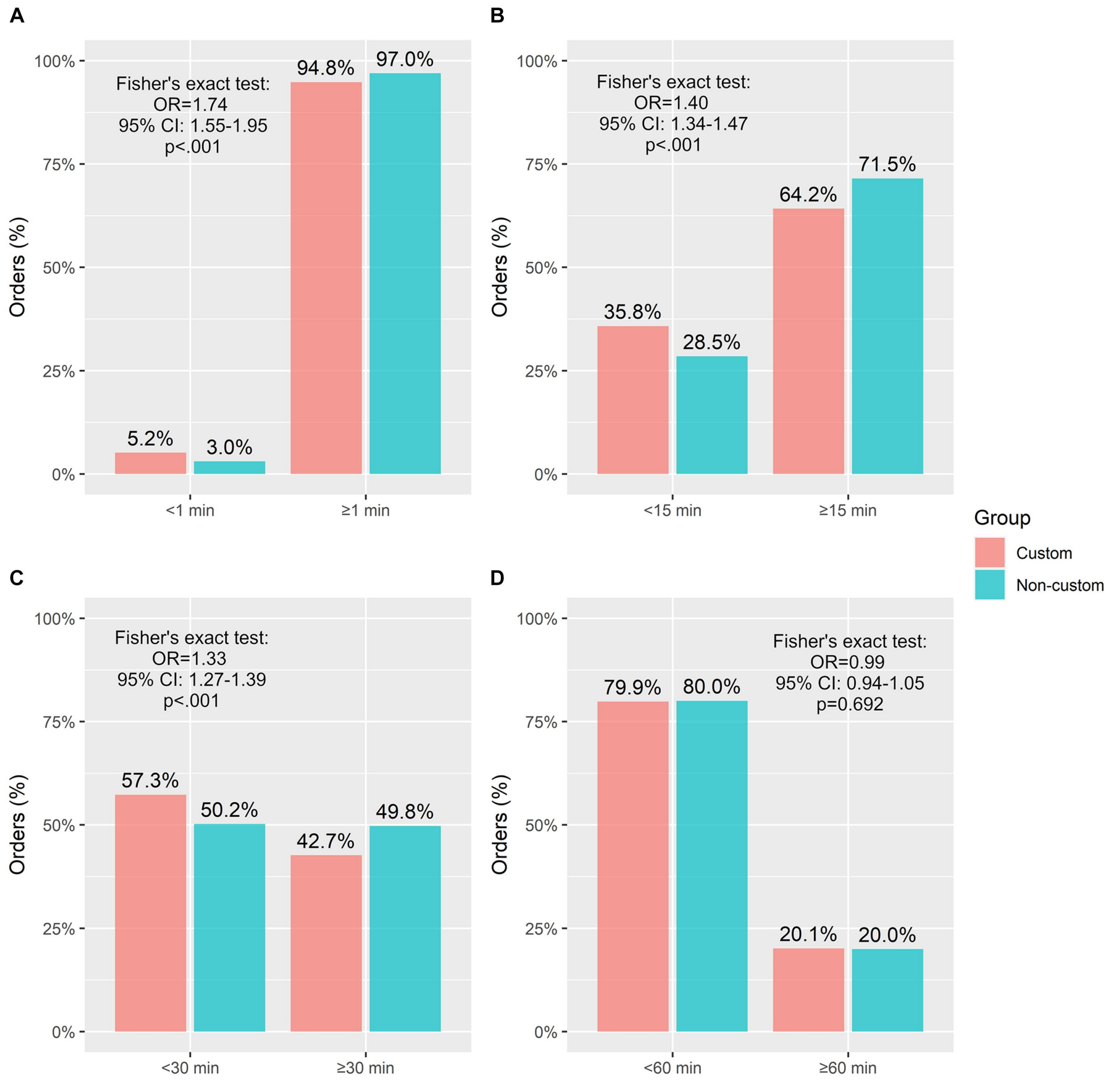

FIGURE 5
Frequency of medications administered within discrete time windows by group. **(A)** <1 min or ≥ 1 min, **(B)** <15 min or ≥ 15 min, **(C)** <30 min or ≥ 30 min, **(D)** <1 h or ≥ 1 h. OR, odds ratio; CI, confidence interval.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Hackensack University Medical Center Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

HA: Conceptualization, Data curation, Investigation, Writing – original draft, Writing – review & editing. LC: Resources, Supervision, Writing – review & editing, Data curation. FR: Writing – review & editing, Data curation. EC: Writing – review & editing, Conceptualization, Methodology, Visualization. JP: Writing – review & editing, Formal analysis, Software. BJ: Resources, Writing – review & editing, Data curation, Project administration. JT:

Data curation, Writing – review & editing, Project administration, Resources. AR: Data curation, Resources, Writing – review & editing. MB: Writing – review & editing. LP-A: Resources, Writing – review & editing. PR: Resources, Writing – review & editing. FPT: Writing – review & editing, Resources, Supervision.

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Conflict of interest

JMP is employed and hold equity in Superior Medical Experts, Inc.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fnagi.2023.1267067/full#supplementary-material

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Standardizing default electronic health record tools to improve safety for hospitalized patients with Parkinson's disease

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Electronic Health Record (EHR) systems are often configured to address challenges and improve patient safety for persons with Parkinson's disease (PWP). For example, EHR systems can help identify Parkinson's disease (PD) patients across the hospital by flagging a patient's diagnosis in their chart, preventing errors in medication and dosing through the use of clinical decision support, and supplementing staff education through care plans that provide step-by-step road maps for disease-based care of a specific patient population. However, most EHR-based solutions are locally developed and, thus, difficult to scale widely or apply uniformly across hospital systems. In 2020, the Parkinson's Foundation, a national and international leader in PD research, education, and advocacy, and Epic, a leading EHR vendor with more than 35% market share in the United States, launched a partnership to reduce risks to hospitalized PWP using standardized EHR-based solutions. This article discusses that project which included leadership from physician informaticists, movement disorders specialists, hospital quality officers, the Parkinson's Foundation and members of the Parkinson's community. We describe the best practice solutions developed through this project. We highlight those that are currently available as standard defaults or options within the Epic EHR, discuss the successes and limitations of these solutions, and consider opportunities for scalability in environments beyond a single EHR vendor. The Parkinson's Foundation and Epic launched a partnership to develop best practice solutions in the Epic EHR system to improve safety for PWP in the hospital. The goal of the partnership was to create the EHR tools that will have the greatest impact on outcomes for hospitalized PWP.

KEYWORDS

electronic health record, Parkinson's disease, hospitalization, safety, Epic Systems

Introduction

In 2009, the Health Information Technology for Economic and Clinical Health Act (HITECH) was passed into law to encourage hospitals to adopt electronic health record (EHR) systems. EHR systems can be configured to support significant improvements in patient care and quality by streamlining processes, consolidating availability/accessibility of information, and providing appropriate clinical decision support. Hospitals can leverage EHR systems to reduce safety risks for vulnerable populations, like people living with Parkinson's disease (PWP).

PWP are hospitalized 1.5 times more frequently than their peers (Gerlach et al., 2011), with studies showing up to 45% of all people with Parkinson's visiting the emergency department annually and up to 28% being admitted to the hospital (Oguh and Videnovic, 2012). During their hospitalization, PWP are more susceptible to hospital-acquired complications (Sauro et al., 2017), including worsening of their motor symptoms (Gerlach et al., 2012, 2013; Fujioka et al., 2016), delirium (Gerlach et al., 2012; Patel et al., 2017; Lawson et al., 2019), and dysphagia (Martinez-Ramirez et al., 2015), and are at increased risk for falls (Wedmann et al., 2019). In addition, they often have longer lengths of stay, are discharged to a facility rather than their home, and have higher readmission rates (Mahajan et al., 2016; Perdomo-Lampignano et al., 2020). The gaps in safety also increase the cost of care. In 2014, inpatient care for PWP (Mantri et al., 2019) was estimated to cost the Medicare program over $2.1 billion. Across all insurance types, PWP were estimated to contribute to over $7 billion in excess medical costs is for inpatient care (Lewin Group, 2019).

There are a number of reasons that PWP are at risk of experiencing hospital-acquired complications. First, patients are not always identified as having PD when admitted to the hospital. Second, because PWP are often not directly admitted for PD, appropriate management of their PD medications may not be a primary focus of care (Shin and Habermann, 2016). Finally, there is a PD knowledge gap in the healthcare workforce and the intricacies of managing Parkinson's disease can be overshadowed by other more common disorders.

EHR systems are often configured to address these challenges and improve patient safety for PWP. For example, EHR systems can help identify PD patients across the hospital by flagging a patient's diagnosis in their chart, preventing errors in medication and dosing through the use of clinical decision support, and supplementing staff education through care plans that provide step-by-step road maps for disease-based care of a specific patient population. However, most EHR-based solutions are locally developed and, thus, difficult to scale widely or apply uniformly across hospital systems.

In 2020, the Parkinson's Foundation, a national and international leader in PD research, education, and advocacy, and Epic, a leading EHR vendor with more than 35% market share in the United States (Blauer and Warburton, 2023), launched a partnership to reduce risks to hospitalized PWP using standardized EHR-based solutions. This article discusses that project which included leadership from physician informaticists, movement disorders specialists, hospital quality officers, the Parkinson's Foundation and members of the Parkinson's community. We describe the best practice solutions developed through this project. We highlight those that are currently available as standard defaults or options within the Epic EHR, discuss the successes and limitations of these solutions, and consider opportunities for scalability in environments beyond a single EHR vendor.

Methods

The Parkinson's Foundation and Epic launched a partnership to develop best practice solutions in the Epic EHR system to improve safety for PWP in the hospital. The goal of the partnership was to create the EHR tools that will have the greatest impact on outcomes for hospitalized PWP and where there is the greatest likelihood for change in the inpatient setting.

Collaborators: the Epic Movement Disorders Specialty Subcommittee

Parkinson's Foundation is a nonprofit organization with a mission to make life better for people with PD by improving care and advancing research toward a cure. They are committed to leading the national effort to improve hospital care through systemic changes in areas of policy, technology, culture and education. Its Hospital Care Initiative aims to eliminate preventable harm and promote reliability in care for PWP in the hospital. The Parkinson's Foundation Hospital Care Recommendations, released April 2023, (Parkinson's Foundation, 2023) outline five standards of care that represent optimal care in the hospital and can be used by hospital leadership to assess and systemically improve the quality of PD care within their institutions. The Recommendations were created in partnership with Hackensack Meridian Health, Henry Ford Health, and the University of Florida Health Norman Fixel Institute for Neurological Diseases, with support from Dr. Peter Pronovost and Manatt Health. The Hospital Care Initiative and Recommendations provided a national, patient-centered, practical starting point for developing the EHR-based solutions.

A Parkinson's Foundation Ambassador, a volunteer living with PD who is specially trained on the topic of hospital safety, facilitated the connection between the Parkinson's Foundation and Epic, which made this project possible. Additional Ambassadors were added to the subcommittee throughout the process as needed.

Epic (Epic Systems Corporation, Verona, WI) is an EHR software vendor with the largest percentage share of acute hospitals beds in the United States (Blauer and Warburton, 2023). Epic develops and maintains an out-of-the-box EHR system called the "Foundation System." Hospital systems use the Foundation System to create their customized EHR, accounting for local workflow and operational requirements. Organizations using Epic can leverage the Foundation System as a vehicle to implement newly available and updated features developed by Epic (build packages).

To support the specific needs of specialty practices, Epic sponsors the Specialty Steering Boards (SSB), consisting of subject-matter experts who advise Epic on best practice workflows, default content, and ideal EHR features beneficial for each specialty. All SSB members are peer-selected volunteers from that specialty. The Adult Neurology Specialty Steering Board (Neurology SSB) was formed in 2016. The collaborative and productive nature of the Neurology SSB, in partnership with advocates within the American Academy of Neurology, has been previously described (Weathers et al., 2019).

The Epic Movement Disorders subcommittee (EMDS) was formed to develop, recommend, and promote Epic EHR solutions to

TABLE 1 Locally developed solutions reducing risks to hospitalized persons with Parkinson's disease.

Target areas for best practice solutions	Identification of hospitalized PWP	Prevent medication errors through medication order entry customization	Care plan for inpatient nursing/support staff
Hackensack University Medical Center (HUMC)	Flags and banners in Chart Review	Default and custom frequency timing for levodopa medication orders.	Care plan integrated as Epic Nursing Care Plan
University of Rochester Medical Center	Best Practice Advisory (avoid neuroleptics)		
Cleveland Clinic	Patient List dashboard	Default and custom frequency timing for levodopa medication orders. Custom After-Visit Summary.	Protocol screening for PD-related medication errors or complications
Northwestern Medicine	Best Practice Advisory (suggest PD Order Set)	Default and custom frequency timing for levodopa medication orders. Custom PD Order set.	Inpatient medication reconciliation nursing in-service training

PWP, Persons with Parkinson's disease; PD, Parkinson's disease; Custom time-based.

reduce risks to hospitalized PWP. The EMDS initially included select members of the Neurology SSB and representatives from the Parkinson's Foundation including staff leadership and Parkinson's Foundation Ambassadors. Additional subject matter experts were identified and added to the EMDS during the review of possible EHR solutions. An Epic facilitator with a neurology nursing background coordinated efforts as the project manager.

Approach and roadmap

Initial state and locally developed solutions

In 2020, the Epic Foundation System had no default features that would specifically reduce risks of inappropriate medication dosing or timing. As such, any existing solutions using the Epic EHR were locally developed by individual hospital systems. The EMDS sought examples of such solutions from hospitals in the Parkinson's Foundation Global Care Network, known national leaders in inpatient Parkinson's care, and Neurology SSB contacts. A series of demonstrations were conducted to review possible solutions.

Roadmap and implementation

A review of existing solutions and discussions with multiple subject-matter experts identified both opportunities for leveraging existing Epic EHR features and highlighted gaps in the existing Epic EHR feature set that limited the development of some proposed solutions. A roadmap was devised, leveraging the best solutions, and balancing feasibility, usability, and clinical prioritization. Through a series of development cycles, the EMDS identified, prioritized, and then designed and built best practice content and workflows that are now available as default build packages in the Epic Foundation System.

Results

Review of locally developed solutions

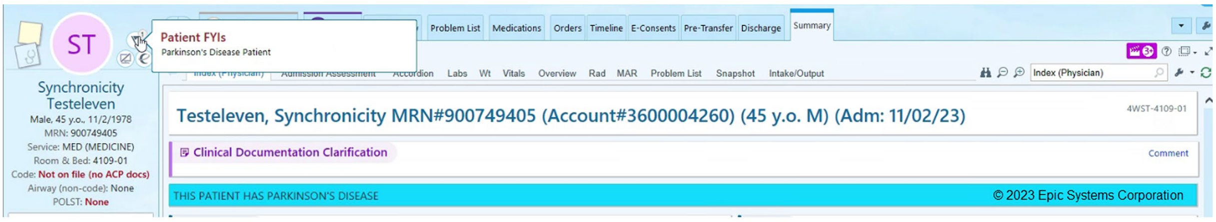
Hackensack University Medical Center (HUMC), Northwestern University, Cleveland Clinic, and the University of Rochester all developed individual solutions to improve safety for hospitalized PWP using the Epic EHR. Presentations of these solutions led to productive discussions and ideas within the EMDS. Key features from each solution considered for the roadmap are summarized in Table 1.

Hackensack University Medical Center

Proper identification of patients is crucial for successful implementation of any protocol. Hackensack University Medical Center (HUMC), with the help of the technology team, developed flags that would alert any provider to the diagnosis of PD when a chart was opened. The flags appear as an icon in the Storyboard and as a banner across the summary report in the chart (Figure 1). The triggers for the flag are the inclusion of PD in the problem list, as well as detection of the keywords including "Parkinson" in any note. While this does result in the inclusion of atypical parkinsonism syndromes, as well as occasional patients that may not have PD, the increased sensitivity was felt important to avoid erroneously missing potential patients in the ensuring protocol.

A protocol for ensuring adherence to the home schedule and timing for PD meds was developed at HUMC with an emphasis on using customized time-based levodopa medication orders. Initially, and common to all institutions, the default options available when ordering PD medications in the inpatient setting were standard default frequency settings (once a day, nightly, twice, 3x, or 4x per day). These standard frequency settings would result in default hospital timings that were rarely aligned with actual timing of PD medications. To order the medication in a custom format, providers would have to follow a three step process: (1) avoid selecting the default, (2) click a search button and search for a particular option called "custom frequency" in the drop-down menu, and after selecting it, (3) insert the appropriate timing for the medication. In addition to the paucity of knowledge about the importance of custom ordering for PD medications, these extra steps were additional barriers to placing appropriate orders for PD medications. The HUMC team was able to successfully add the "Custom" option as a default frequency for selected PD medications for which timing is critical and eliminate the default frequency settings (non-custom) options from being available to choose (Figure 2). With these changes, HUMC saw nearly a threefold increase in appropriate (custom) placement of PD medication orders (Azmi et al., 2020).

Care plans are available options within the Epic EHR for nursing teams to ensure adherence to required standards or locally desired guidelines or protocols. They are step-by-step road maps for care of a specific patient population. Many have been used for older adults,



Patient FYIs
Parkinson's Disease Patient

Synchronicity Testeleven
Male, 45 y.o., 11/2/1978
MRN: 900749405
Service: MED (MEDICINE)
Room & Bed: 4109-01
Code: Not on file (no ACP docs)
Airway (non-code): None
POLST: None

Testeleven, Synchronicity MRN#900749405 (Account#3600004260) (45 y.o. M) (Adm: 11/02/23)
4WST-4109-01

Clinical Documentation Clarification

THIS PATIENT HAS PARKINSON'S DISEASE

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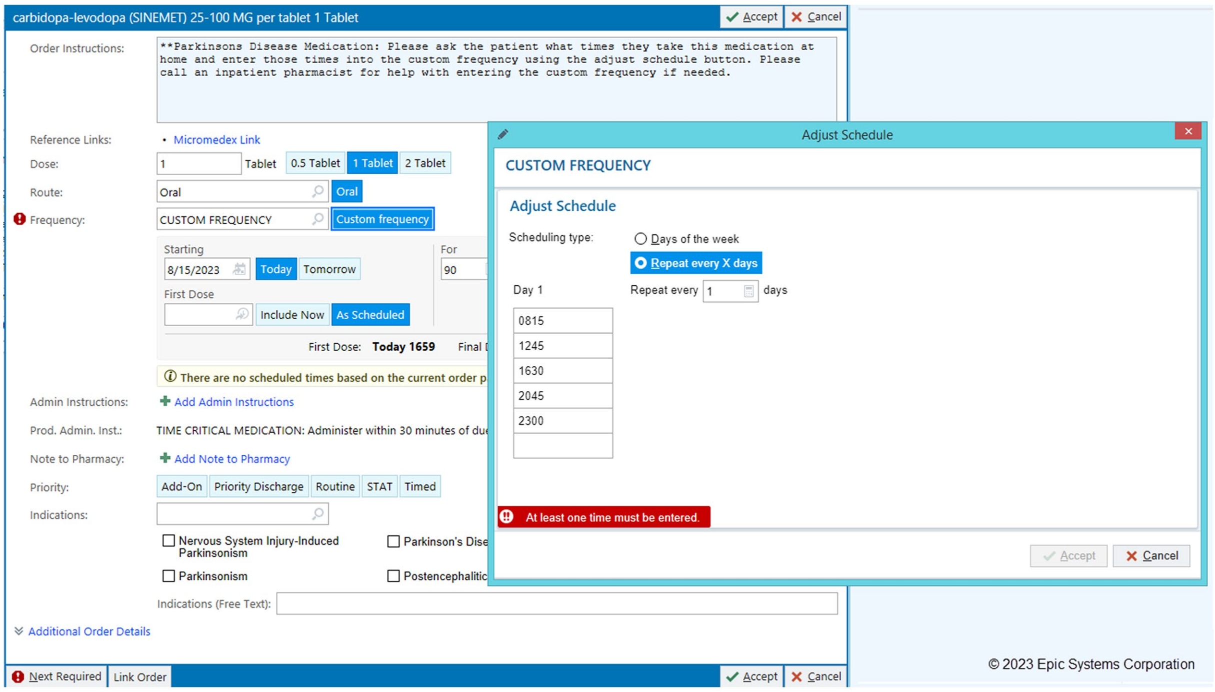
FIGURE 1
Patient identification tools alerting users of a person with Parkinson's disease. Screenshot showing EHR Chart (HUMC) for hospitalized PWP. Parkinson's Disease is highlighted as a banner (blue).



carbidopa-levodopa (SINEMET) 25-100 MG per tablet 1 Tablet

Order Instructions: **Parkinsons Disease Medication: Please ask the patient what times they take this medication at home and enter those times into the custom frequency using the adjust schedule button. Please call an inpatient pharmacist for help with entering the custom frequency if needed.

Reference Links: Micromedex Link
Dose: 1 Tablet
Route: Oral
Frequency: CUSTOM FREQUENCY
Starting 8/15/2023
For 90
First Dose
First Dose: Today 1659
There are no scheduled times based on the current order p
Prod. Admin. Inst.: TIME CRITICAL MEDICATION: Administer within 30 minutes of due
Indications:
☐ Nervous System Injury-Induced Parkinsonism
☐ Parkinson's Dise
☐ Parkinsonism
☐ Postencephalitic
Indications (Free Text):

Adjust Schedule
CUSTOM FREQUENCY
Adjust Schedule
Scheduling type:
○ Days of the week
● Repeat every X days
Day 1
Repeat every 1 days
0815
1245
1630
2045
2300
At least one time must be entered.

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FIGURE 2
Examples of default and custom frequency timing for inpatient levodopa medication orders custom frequency created for levodopa medication, eliminating standard non-custom options, and requiring timing of medication to be entered (HUMC).

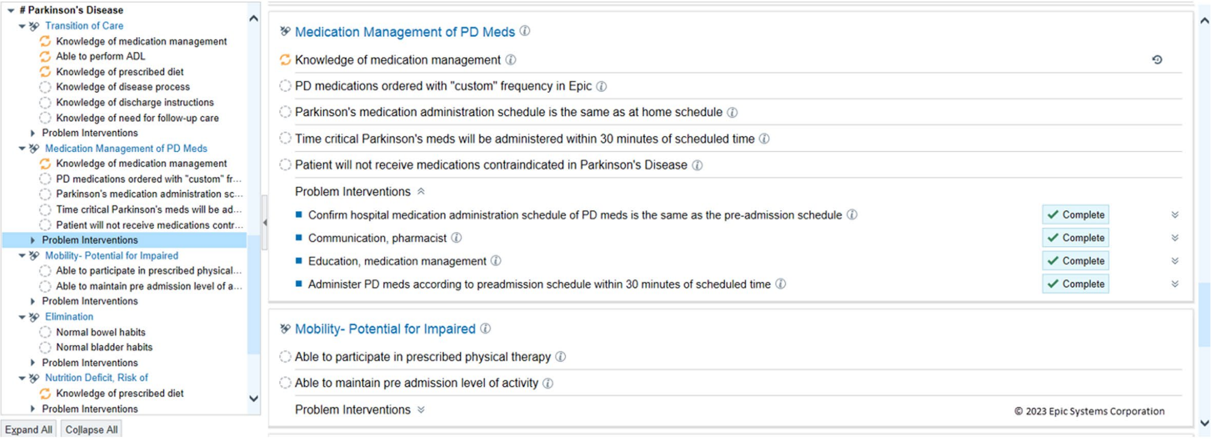
including those specifically with cognitive decline, diabetes, and other complex and long-term needs (Yutong et al., 2023). streamlining care and ensuring adherence to standards. A nursing PD care plan was developed at HUMC to supplement and support our educational efforts to reduce risk for hospitalized PWP. The care plan can be added by nursing intake for any PWP admitted. In addition to existing hospital-wide components of mobility and fall prevention, our care plan incorporates our goals of adherence to patients' home medication regimen, placement of orders for PD medications in custom format, the time-critical nature of PD medications, and avoidance of administration of contraindicated medications. While the use of care plans at HUMC are not required, they are encouraged (Figure 3).

Northwestern University

To address risks of medication errors in the hospital, Northwestern's Movement Disorders team, within the Parkinson's Foundation Center of Excellence, developed a PD-specific Inpatient Order Set, which included prominent advisory text to address two issues. First, the advisory text prominently warned of the need to avoid relatively contraindicated neuroleptic medications (Figure 4A). Second, advisory text noted that certain PD medications, particularly levodopa medications, would require manual entry of exact frequency and dosing schedules as best practice. All inpatient medication orders of levodopa, similar to HUMC and other institutions, had default medication frequencies removed. A 'User Specified' custom default frequency was provided for each levodopa medication order which would then require discrete entry of timings for the medication. This would occur if the medication was ordered within or outside of the order set.

The major limitation was awareness and use of this custom PD Order Set. A best practice advisory (BPA) alert was created to detect the diagnosis or the presence of Parkinson's disease on the problem list (Figure 4B). It would suggest, with one click, the ability to open the PD Order Set with its guidance and suggested PD medication timings and dosings. After releasing this BPA, 33% of PWP who were hospitalized had providers open the PD Order Set, representing the opportunity to see the guidance for ordering inpatient PD medications.

Another limitation identified was that the nursing staff who perform medication reconciliation intake in a prior to admission home medication workflow are unable to access the dosing/timing table required when ordering PD medications with detailed 'User Specified' doses and timings. These nursing staff are in the best position in the workflow to identify exact doses and timing during the intake/admission process. This represents a fundamental limitation in the EHR design in that home medications do not support exact doses or timings that can translate to the inpatient setting. As such, there is an inability to efficiently transfer that outpatient PD doses/frequency information to the appropriate inpatient ordering clinician. A quality improvement process involving nursing informatics designed a workflow where the home medication doses and timing were placed in the comment field, and the clinicians who then continue and order that medication into the hospital encounter are asked to transcribe the free text Comment information into the 'User Specified' table during medication ordering. This workflow was poorly utilized by nursing staff and admitting physicians. The standard workflow requires nursing staff to routinely identify outpatient medications that the patient is taking and then to enter (or reconcile) each medication into the inpatient EHR upon admission. This workflow required the nursing staff to recognize that a medication was PD-related and to enter exact times of day that patient took that medication as outpatient into a free text field. Then, admitting physicians, when writing inpatient orders, were required



Medication Management of PD Meds

Knowledge of medication management

○ PD medications ordered with "custom" frequency in Epic

○ Parkinson's medication administration schedule is the same as at home schedule

○ Time critical Parkinson's meds will be administered within 30 minutes of scheduled time

○ Patient will not receive medications contraindicated in Parkinson's Disease

Problem Interventions

- Confirm hospital medication administration schedule of PD meds is the same as the pre-admission schedule ✓ Complete
- Communication, pharmacist ✓ Complete
- Education, medication management ✓ Complete
- Administer PD meds according to preadmission schedule within 30 minutes of scheduled time ✓ Complete

Mobility- Potential for Impaired

○ Able to participate in prescribed physical therapy

○ Able to maintain pre admission level of activity

Problem Interventions

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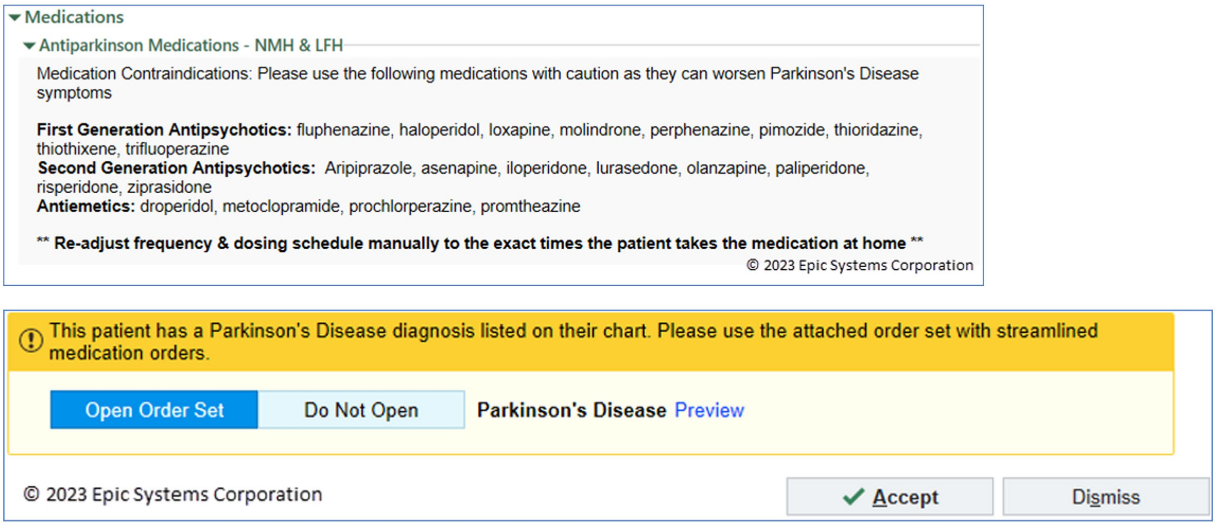
FIGURE 3
Nursing care plan for hospitalized patients with Parkinson's disease. Care Plan for patients with Parkinson's disease regardless of admitting diagnosis (HUMC).



Medication Contraindications: Please use the following medications with caution as they can worsen Parkinson's Disease symptoms

First Generation Antipsychotics: fluphenazine, haloperidol, loxapine, molindrone, perphenazine, pimozide, thioridazine, thiothixene, trifluoperazine
Second Generation Antipsychotics: Aripiprazole, asenapine, iloperidone, lurasedone, olanzapine, paliperidone, risperidone, ziprasidone
Antiemetics: droperidol, metoclopramide, prochlorperazine, promtheazine

** **Re-adjust frequency & dosing schedule manually to the exact times the patient takes the medication at home** **

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This patient has a Parkinson's Disease diagnosis listed on their chart. Please use the attached order set with streamlined medication orders.

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FIGURE 4
Parkinson's Disease Order Set. (Top) PD Order Set with text advisory to avoid contraindicated medications and recommendation to ensure PD medications using exact frequency and dosing (Northwestern); (Bottom) Associated Best Practice Advisory (BPA) Alert, supporting ability to open the PD Order set with a single click (Northwestern).

to remember to look at that free text field for those PD particular medications, and translate those free text notes into discrete exact times into a PD medication order to sign. This workflow imposes extra burden on both nurses and physicians. In spite of promotional materials and tipsheets, this awkward workflow was rarely used and reflects current difficulties of communicating key medication timing information between nurses and physicians within the EHR.

Cleveland Clinic

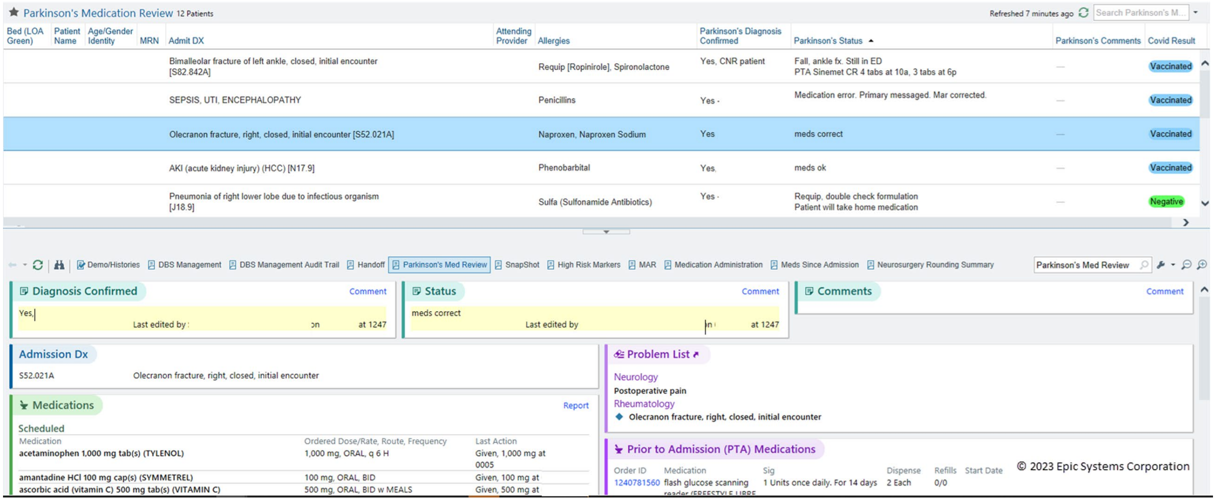
The Cleveland Clinic, a Parkinson's Foundation Center of Excellence, developed a proactive strategy to improve inpatient care for people with PD. This strategy utilizes a team of advanced practice providers from the outpatient movement disorder clinic and heavily leverages IT strategies through the Epic EHR. Using a cross-population approach, Cleveland Clinic developed an automated Patient List which populates in real-time with all hospitalized patients with a diagnosis, past medical history, or problem list identifying PD or parkinsonism (Figure 5). Advanced Practice Providers review this list of patients daily, looking for probable errors in medication orders that do not match home regimens, either based on available EHR outpatient documentation or on patients and caregivers record of the home regimen (if not documented within the EHR). This review also looks for evidence of PD-related symptom exacerbation related to acute hospitalization. An associated custom report displays relevant information and allows comments and status information to be updated and shared with care teams.

A key advantage of this strategy is the additional benefit of skilled PD clinicians ensuring quality care for all people with PD who are admitted. As these skilled clinicians utilize this list they observe the effects of implementation in real time, identifying opportunities to improve clinician-lead as well as EHR-driven quality assurance practices.

Many tools mentioned in this paper are also used, including contraindicated medication alerts and constraints to custom time-based levodopa medication orders. However, additional advice can be given, and further care gaps are frequently identified as we proceed with this quality improvement program. With the collaboration and support of a Parkinson's Foundation grant, the impact of this approach is being studied and compared to a baseline data set in which we could define the frequency of medication timing deviations and contraindicated medications (Yu et al., 2023).

University of Rochester Medical Center

The University of Rochester Movement Disorders Parkinson's Foundation Center of Excellence, with support from a Parkinson's Foundation Community Grant, assembled a team of PD Champions, including neurologists, hospitalists, physical therapists, occupational therapists, speech therapists, and registered nurses at Highland Hospital in Rochester, NY. As part of the initiatives driven by the team, collaboration between inpatient pharmacists, Epic EHR team developers, and neurologists led to the creation and implementation of a best practice advisory (BPA) to define the acronym warning against the administration of dopamine-blocking agents (i.e., antipsychotics and certain antiemetics) to PWP and related parkinsonian disorders. The implementation of the BPA started with a meeting among the BPA committee to discuss the harm associated with exposing PWP to a dopamine-blocking agent. The team then created an inclusive BPA that would be triggered should any antipsychotic other than quetiapine, pimavanserin, or clozapine be ordered on a patient with diagnoses (using linked ICD-10 codes) of either PD, multiple systems atrophy, corticobasal degeneration, dementia with Lewy bodies, or progressive supranuclear palsy. The final push with the BPA "going live" was to demonstrate its need. This was accomplished by showing the BPA was triggered ten times over a one-month period in which the BPA was only visible to the inpatient pharmacy. This was then brought to the BPA committee, and the BPA was approved and went "live." Ongoing data collection and analysis to demonstrate its effectiveness are underway.


Parkinson's Medication Review 12 Patients

Refreshed 7 minutes ago

Bed (LOA Green)	Patient Name	Age/Gender Identity	MRN	Admit DX	Attending Provider	Allergies	Parkinson's Diagnosis Confirmed	Parkinson's Status	Parkinson's Comments	Covid Result
				Bimalleolar fracture of left ankle, closed, initial encounter [S82.842A]		Requip [Ropinirole], Spironolactone	Yes, CNR patient	Fall, ankle fx. Still in ED PTA Sinemet CR 4 tabs at 10a, 3 tabs at 6p	—	Vaccinated
				SEPSIS, UTI, ENCEPHALOPATHY		Penicillins	Yes -	Medication error. Primary messaged. Mar corrected.	—	Vaccinated
				Olecranon fracture, right, closed, initial encounter [S52.021A]		Naproxen, Naproxen Sodium	Yes	meds correct	—	Vaccinated
				AKI (acute kidney injury) (HCC) [N17.9]		Phenobarbital	Yes,	meds ok	—	Vaccinated
				Pneumonia of right lower lobe due to infectious organism [J18.9]		Sulfa (Sulfonamide Antibiotics)	Yes -	Requip, double check formulation Patient will take home medication	—	Negative

Diagnosis Confirmed

Yes,
Last edited by : on at 1247

Status

meds correct
Last edited by on at 1247

Comments

Admission Dx

S52.021A Olecranon fracture, right, closed, initial encounter

Medications

Scheduled

Medication	Ordered Dose/Rate, Route, Frequency	Last Action
acetaminophen 1,000 mg tab(s) (TYLENOL)	1,000 mg, ORAL, q 6 H	Given, 1,000 mg at 0005
amantadine HCl 100 mg cap(s) (SYMMETREL)	100 mg, ORAL, BID	Given, 100 mg at
ascorbic acid (vitamin C) 500 mg tab(s) (VITAMIN C)	500 mg, ORAL, BID w MEALS	Given, 500 mg at

Problem List

Neurology
Postoperative pain
Rheumatology
◆ Olecranon fracture, right, closed, initial encounter

Prior to Admission (PTA) Medications

Order ID	Medication	Sig	Dispense	Refills	Start Date
1240781560	flash glucose scanning reader (FREESTYLE LIBRE	1 Units once daily. For 14 days	2 Each	0/0	

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FIGURE 5
Patient List of PWP with monitoring columns and summary report. Real-time System List of inpatients admitted with PD, monitored by a safety team. An interactive summary report provides key information about the selected patient, and includes areas for comments and status updates that update the columns shown in the Patient List (Cleveland Clinic).

A roadmap and Epic Foundation System

The EMDS identified seven workflows that are essential in reducing safety risks for PWP in the hospital based on a review of the existing literature, the example solutions described above, and care recommendations from the Parkinson's Foundation Hospital Care Initiative. The EMDS focused on developing EHR solutions that could become default features in the Epic Foundation System. A summary of these workflows and associated solutions is shown in Table 2. Many of the solutions described are currently available to Epic users and some remain in active development. Each organization upgrades their instance of Epic to a given dated version on its own schedule. Table 2 indicates which features are available now with the associated version of Epic; which features are being built by Epic for an upcoming release; and which features are on the roadmap for future releases. Features listed as available can be used or turned on without incurring costs for development. All features have default configurations set, and most organizations should review defaults to determine the best way to activate the feature and promote its actual use within local workflows.

Identify admitted PWP and their unique care needs

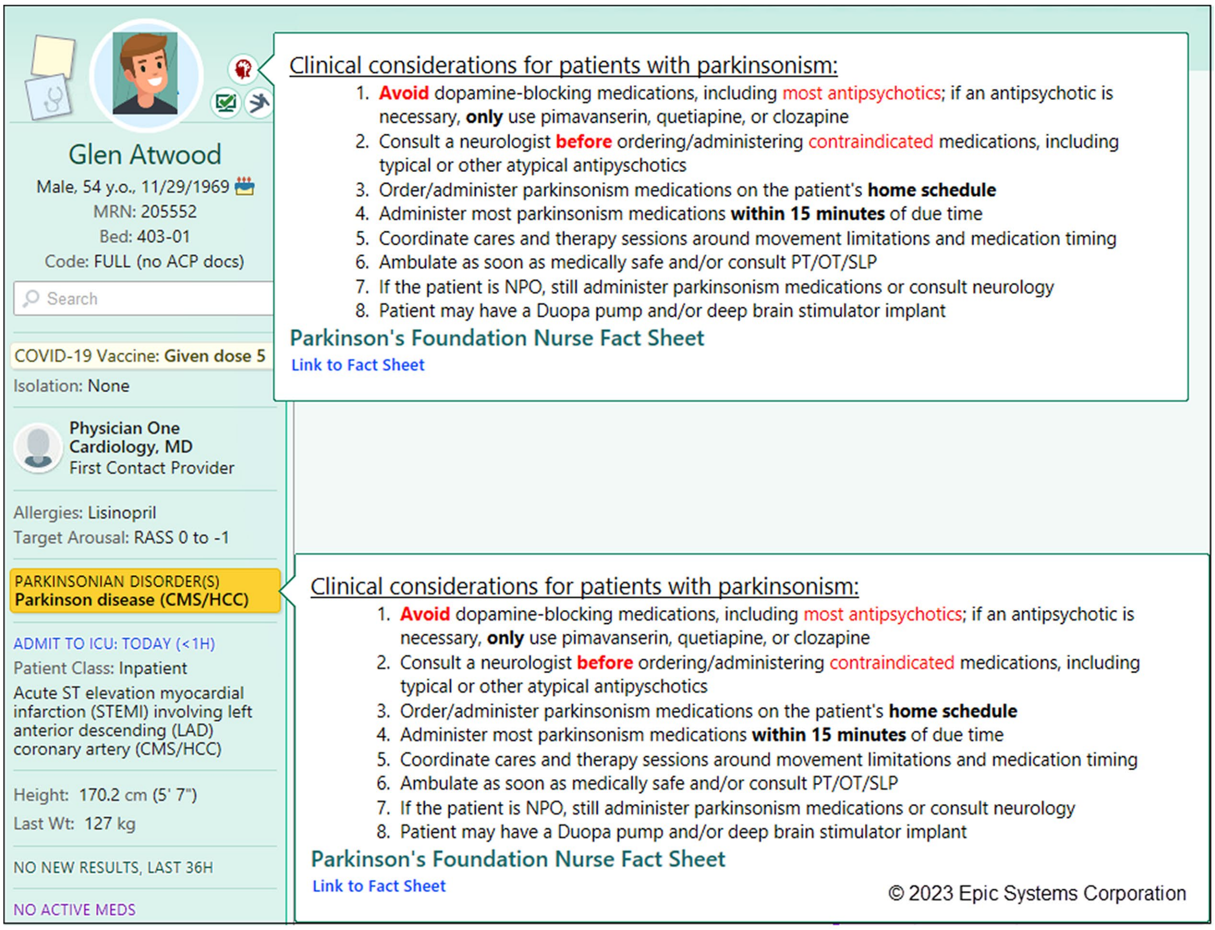
Starting in February 2020, organizations can implement an Epic-provided build package to add three tools:

1. A default Storyboard icon and banner to quickly see that a patient has a parkinsonian disorder. The Storyboard is a default sidebar where all relevant information about a given patient is prioritized with those of most importance near the top. Examples of Storyboard information include icons representing care teams, demographics, allergies, problem list, medications. Hovering over the icon or banner displays a tooltip summary of best practice care guidelines for inpatient care and a hyperlink to the Parkinson's Foundation supporting documentation. Out-of-the-box, these notifications are only visible to neurologists, but organizations can and should consider configuring this feature, so it is visible to all inpatient users' workspaces. Instructions on how to do so are included in the build package documentation (Figure 6).

TABLE 2 Roadmap for tools to reduce risk for hospitalized PWP in the Epic Foundation System.

Roadmap workflows	Epic EHR-based solution	Epic Foundation System Status
A. Identify admitted PWP and their unique care needs	Storyboard icon and report with guidelines and link to Parkinson Foundation resources.	Live since Epic February 2020 version.
	Patient List columns for real-time monitoring of neurology, PT, OT, SLP consults on admitted PWP.	Live since Epic February 2020 version.
	Reports summarizing inpatients with PT, OT, SLP referrals and both home & inpatient PD-related medications.	Live since Epic February 2020 version.
	Reports to identify PWP who are current admitted, recently discharged, and have upcoming pre-admissions.	Live since Epic November 2022 version.
B. Notify patient's neurologist when PWP is admitted	New Care Team relationship of neurologist available to allow users to configure notifications to neurologists of admitted PWP	Live since Epic November 2022 version.
C. Prevent administration of contraindicated meds to PWP	Drug-disease warnings from third party medication vendors (PD-med warnings available)	Live since Epic 2009 version.
	Best Practice Advisory (alert) to supplement drug-disease warnings.	Design in progress (not live)
	Comprehensive medication alerts and warnings for PWP	Specialty organizations to address with third party medication vendors
D. Protect PWP home med regimen during hospital stay	Ability to prescribe outpatient medications to a discrete timed schedule.	Epic development enhancement submitted.
	Updates to PD medications to allow outpatient discrete timing frequencies to be entered discretely into inpatient PD medication timing; updates to orders, preference lists, order sets; prevent PD medications from defaulting to inpatient pharmacy administration times.	Design pending (not live).
E. Enforce timely administration of PWP' PD meds during admission	Add logic to consider PWP medications overdue 15 min after due time.	Design pending (not live).
	Reports to audit timeliness of medication administrations.	Live since Epic 2014 version.
	Report of PD-related medication administrations more than 15 min after due time.	Design pending (not live).
F. Document and display a PWP Nursing Plan of Care	Develop a Nursing Plan of Care for PWP (based on HUMC content).	Design pending (not live).
G. Improve discharge planning and discharge instructions for PWP	Develop default workflow, content, and discharge instructions for PWP (based on Cleveland Clinic content).	Design pending (not live).

Roadmap workflows indicate EMDS identified priority workflows to be addressed in electronic health records. Epic EHR-based solutions indicate Epic-vendor specific tools and workflows recommended to address each roadmap workflow. Epic Foundation System Status indicates whether the solution is a feature already released for organizations to implement (and the earliest available version when that feature was available). Features may be available by default, require enabling or configuration, require a minimum version, or require update packages. Features are best paired with appropriate institutional workflow. Organizations interested learning more or enabling Epic Foundation features should contact their organization's Epic representative for details. PT, physical therapy; OT, occupational therapy; SLP, speech/language pathology.



Glen Atwood
Male, 54 y.o., 11/29/1969
MRN: 205552
Bed: 403-01
Code: FULL (no ACP docs)

COVID-19 Vaccine: Given dose 5
Isolation: None

Physician One
Cardiology, MD
First Contact Provider

Allergies: Lisinopril
Target Arousal: RASS 0 to -1

PARKINSONIAN DISORDER(S)
Parkinson disease (CMS/HCC)

ADMIT TO ICU: TODAY (<1H)
Patient Class: Inpatient
Acute ST elevation myocardial infarction (STEMI) involving left anterior descending (LAD) coronary artery (CMS/HCC)

Height: 170.2 cm (5' 7")
Last Wt: 127 kg

NO NEW RESULTS, LAST 36H

NO ACTIVE MEDS

Clinical considerations for patients with parkinsonism:

1. **Avoid** dopamine-blocking medications, including most antipsychotics; if an antipsychotic is necessary, **only** use pimavanserin, quetiapine, or clozapine
2. Consult a neurologist **before** ordering/administering contraindicated medications, including typical or other atypical antipyschotics
3. Order/administer parkinsonism medications on the patient's **home schedule**
4. Administer most parkinsonism medications **within 15 minutes** of due time
5. Coordinate cares and therapy sessions around movement limitations and medication timing
6. Ambulate as soon as medically safe and/or consult PT/OT/SLP
7. If the patient is NPO, still administer parkinsonism medications or consult neurology
8. Patient may have a Duopa pump and/or deep brain stimulator implant

Parkinson's Foundation Nurse Fact Sheet

Link to Fact Sheet

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Parkinson's Foundation Nurse Fact Sheet

Link to Fact Sheet

FIGURE 6
Epic Foundation System Storyboard icon and tooltip. A Storyboard icon appears when patients are admitted and have either Parkinson's disease or a related parkinsonism disorder. The tooltip shown will automatically appear when the mouse hovers over either icon or problem list item. Users can click the Link to Fact Sheet hyperlink to directly open the Parkinson Foundation Fact Sheet. (Epic).

The icon appears based on a group of PD and parkinsonism diagnosis codes. A default grouper is provided in the Foundation System and can be leveraged by organizations to drive any custom PD-related content, including local solutions as previously described. Using (or updating to use a Foundation grouper) provides standardization for identifying PWP and related parkinsonisms.

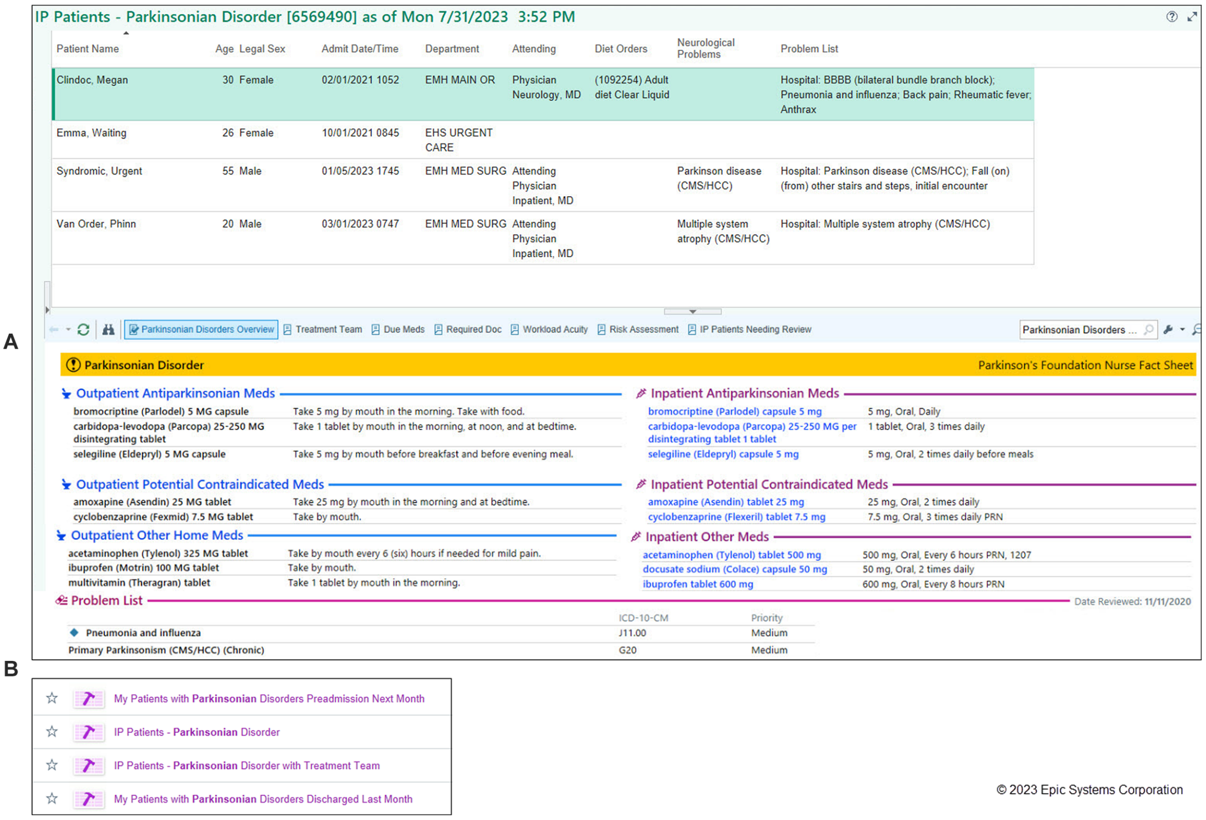
2. An "IP [Inpatient] Parkinsonian Patients" report identifies hospitalized PWP and displays a summary of key clinical information important to caring for a PWP. This includes a comparison view of the patient's outpatient prescriptions against the current inpatient orders and a call-out section of potentially contraindicated medication orders. Out-of-the-box this report is a default for neurologists in the Patient List and Summary activities and available to all users to add independently (Figure 7A).
3. Four new Patient List and Reporting Workbench columns help consulting neurologists, care teams, and PD safety teams see at-a-glance if the PWP has appropriate supportive orders in place. These columns indicate whether consults to neurology, physical therapy, occupational therapy, and speech therapy have been ordered during the current admission: "Neurology Service Consulted?," "PT Consulted?," "OT Consulted?," "SLP Consulted?" Out-of-the-box, these columns are available to all users who choose to add them to their My Lists.

In November 2022, additional tools were added to the build package:

4. Additional reports to find PWP who are currently admitted for a given care team ("IP Patients - Parkinsonian Disorder with Treatment Team"), who were recently discharged ("Patients with Parkinsonian Disorders Discharged Last Month") or have upcoming pre-admissions ("Patients with Parkinsonian Disorders Preadmission Next Month"). Out-of-the-box, these reports are available to all clinical users and can be configured to meet organizational or individual user needs or workflows (Figure 7B).

Notify a patient's neurologist when PWP are admitted

In November 2022, Epic Foundation System added a care team relationship specifically for neurologists. This allows a provider to be listed as the PWP's neurologist. Users can then choose whether to receive patient admission alerts, either by their defined relationship or on a patient-by-patient basis (Figure 8).



IP Patients - Parkinsonian Disorder [6569490] as of Mon 7/31/2023 3:52 PM

Patient Name	Age	Legal Sex	Admit Date/Time	Department	Attending	Diet Orders	Neurological Problems	Problem List
Clindoc, Megan	30	Female	02/01/2021 1052	EMH MAIN OR	Physician Neurology, MD	(1092254) Adult diet Clear Liquid		Hospital: BBBB (bilateral bundle branch block); Pneumonia and influenza; Back pain; Rheumatic fever; Anthrax
Emma, Waiting	26	Female	10/01/2021 0845	EHS URGENT CARE				
Syndromic, Urgent	55	Male	01/05/2023 1745	EMH MED SURG	Attending Physician Inpatient, MD		Parkinson disease (CMS/HCC)	Hospital: Parkinson disease (CMS/HCC); Fall (on) (from) other stairs and steps, initial encounter
Van Order, Phinn	20	Male	03/01/2023 0747	EMH MED SURG	Attending Physician Inpatient, MD		Multiple system atrophy (CMS/HCC)	Hospital: Multiple system atrophy (CMS/HCC)

Parkinsonian Disorder

Parkinson's Foundation Nurse Fact Sheet

Outpatient Antiparkinsonian Meds

bromocriptine (Parlodel) 5 MG capsule	Take 5 mg by mouth in the morning. Take with food.
carbidopa-levodopa (Parcopa) 25-250 MG disintegrating tablet	Take 1 tablet by mouth in the morning, at noon, and at bedtime.
selegiline (Eldepryl) 5 MG capsule	Take 5 mg by mouth before breakfast and before evening meal.

Inpatient Antiparkinsonian Meds

bromocriptine (Parlodel) capsule 5 mg	5 mg, Oral, Daily
carbidopa-levodopa (Parcopa) 25-250 MG per disintegrating tablet 1 tablet	1 tablet, Oral, 3 times daily
selegiline (Eldepryl) capsule 5 mg	5 mg, Oral, 2 times daily before meals

Outpatient Potential Contraindicated Meds

amoxapine (Asendin) 25 MG tablet	Take 25 mg by mouth in the morning and at bedtime.
cyclobenzaprine (Fexmid) 7.5 MG tablet	Take by mouth.

Inpatient Potential Contraindicated Meds

amoxapine (Asendin) tablet 25 mg	25 mg, Oral, 2 times daily
cyclobenzaprine (Flexeril) tablet 7.5 mg	7.5 mg, Oral, 3 times daily PRN

Outpatient Other Home Meds

acetaminophen (Tylenol) 325 MG tablet	Take by mouth every 6 (six) hours if needed for mild pain.
ibuprofen (Motrin) 100 MG tablet	Take by mouth.
multivitamin (Theragran) tablet	Take 1 tablet by mouth in the morning.

Inpatient Other Meds

acetaminophen (Tylenol) tablet 500 mg	500 mg, Oral, Every 6 hours PRN, 1207
docusate sodium (Colace) capsule 50 mg	50 mg, Oral, 2 times daily
ibuprofen tablet 600 mg	600 mg, Oral, Every 8 hours PRN

Problem List

Date Reviewed: 11/11/2020

	ICD-10-CM	Priority
◆ Pneumonia and influenza	J11.00	Medium
Primary Parkinsonism (CMS/HCC) (Chronic)	G20	Medium

☆ My Patients with Parkinsonian Disorders Preadmission Next Month
☆ IP Patients - Parkinsonian Disorder
☆ IP Patients - Parkinsonian Disorder with Treatment Team
☆ My Patients with Parkinsonian Disorders Discharged Last Month

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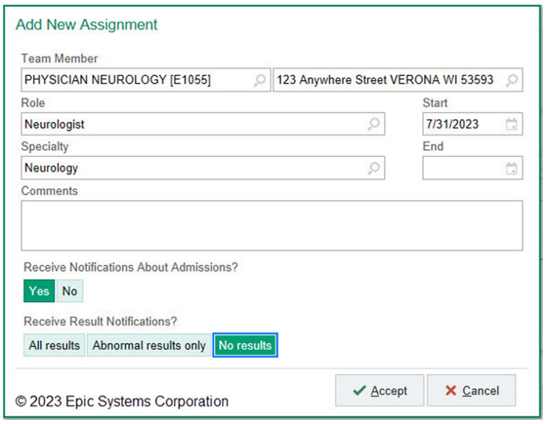
FIGURE 7
Epic Foundation System reports to find hospitalized PWP. Default available Reporting Workbench reports allow ad hoc searches of hospitalized PWP and related parkinsonism syndromes. **(A)** Default report shows relevant outpatient and inpatient medications by category with potential contraindications noted. Additional columns are available in Foundation to add to the report including whether consults to neurology, PT, OT, or SLP services have been ordered (not shown). PT, physical therapy; OT, occupational therapy; SLP, speech/language pathology. (Epic). **(B)** Report on patient status (in-patient, pre-admissions, discharged) which can be customized to institutional needs (Epic).



Add New Assignment

Team Member: PHYSICIAN NEUROLOGY [E1055] | 123 Anywhere Street VERONA WI 53593
Role: Neurologist
Start: 7/31/2023
Specialty: Neurology
End:
Comments:
Receive Notifications About Admissions? [✓ Yes] No
Receive Result Notifications? All results | Abnormal results only | [✓ No results]

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FIGURE 8
Epic Foundation System neurologist Care Team relationship. New Care Team relationship for "neurologist" allows providers to configure their admission notifications. Although admission notification is a standard feature in Epic, the ability to selectively notify neurologists was not previously present. (Epic).

Prevent administration of contraindicated medications to PWP

Drug-disease warnings are clinical decision support tools that can reduce risks of prescribing relatively contraindicated medications (Bhakta et al., 2019). The Epic Foundation System will include an example of a contraindication with haloperidol, a prototype typical neuroleptic and Parkinson's disease (Figure 9). However, an effective BPA would ideally address broader classes of neuroleptic medications with varying degrees of risk.

Drug-related clinical decision support tools in EHRs are provided by third-party medication vendors and include interactions between drugs and drug-disease combinations. These interactions are imported into an organization's local Epic instance and enabled by the local organization to display. After discussion, including the option to adapt the neuroleptic Best Practice Advisory developed by University of Rochester into Foundation System, the current Epic-focused development roadmap does not include a more comprehensive BPA due to challenges in maintenance and lack of consensus on categorization of interaction severity. The EMDS recommends that organizations enable, using standard Epic functionality, at minimum, Parkinson's disease-drug related warnings from third-party interaction warnings labeled with a severity of "contraindicated" (Figure 9).

Protect PWP' home medication regimen during the hospital stay

Unlike inpatient medication orders, although PWP usually take PD medications at stated times throughout the day, within most EHRs, outpatient medications cannot be prescribed at discrete, specific times. As

Medication Warnings for Syndromic, Urgent

New Warnings (1 unfiltered, 1 filtered)

☐ Show filtered (1)

Drug-Disease: haloperidol lactate and **Parkinson disease (CMS/HCC)**

Contraindicated for Parkinsonism

haloperidol lactate (Haldol) injection 2 mg

Hospital medication. **New.**

Immediately override all warnings:

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FIGURE 9
Epic Foundation System example alert of drug-disease clinical decision support alert. The Epic Foundation System includes drug-disease warnings loaded from different third-party medication vendors. This is an example of a warning that shows when the provider attempts to order haloperidol for a PWP. (Epic).

a result, outpatient communication of precise timing of PD medications is in free text comments in the prescription or in separate instructions given directly to patients. The translation of outpatient frequency timing of these medications to the inpatient medication order once a PWP is hospitalized remains a significant gap in safety efforts. EMDS review of individual organizational solutions (Table 1) illustrates a variety of partial solutions including customization of medication frequency, default medication preference list, and order set updates to help neurologists order PWP home medications in a way that prevents inpatient admitting providers from ignoring the schedule. The EMDS identified this gap as a priority. As a result, Epic development of new medication functionality addressing this gap is on the road map as a current enhancement under design and development with EMDS and Epic Neurology Steering Board input. This widely anticipated feature will streamline inpatient admission medication reconciliation to allow direct continuation of discrete timing of PD home medication when PWP are hospitalized.

Enforce timely administration of PWP' medications during hospitalization

The Parkinson Foundation Quality Initiative recommends that all parkinsonian-related medications are administered within 15 minutes of their due time. In the Epic Foundation System, inpatient medication orders are scheduled to discrete due times. By default any medication is considered overdue 60 minutes after the scheduled due time, but organizations can customize this time frame for groups of medications. Organizations can monitor medication administration compliance using out-of-the-box analytic tools. EMDS advises setting PD-related medications to be overdue 15 minutes after the scheduled due time and plans to design more robust analytic tools specific to monitoring timeliness of PWP medication administrations in a future release.

Document and display the PWP's nursing plan of care

The subcommittee plans to review and adapt the nursing care plan from HUMC into Epic's Foundation System in a future release.

Improve discharge planning and discharge instructions for PWP

The subcommittee plans to design workflows and content to improve discharge planning and discharge patient instructions for PWP based on solutions from Cleveland Clinic. In addition, the planned development of an Epic enhancement that supports outpatient medication timing frequency will also support discharge safety by allowing translation of an inpatient medication timing to an outpatient prescription at discharge.

Discussion

Parkinson's disease (PD) patients are commonly recognized to be at risk for deterioration following hospitalization. In a recent comprehensive literature review, Gerlach et al., 2011 reported that PD patients appear to be at both a greater risk for hospitalization with estimations in the range of 7–28% per year, about 1.5 times the general population, and also tend to be admitted for a longer inpatient stay by 2–14 days. This review highlighted the range of issues identified and noted that few systematic solutions for preventing adverse outcomes in this patient population have been identified. This review also indicated that existing literature focused chiefly on perioperative deterioration and emergency room visits and pointed out potential avenues for research, including a better identification of risks involved with hospitalization. In their review, they also found a 31% dissatisfaction rate of PD patients concerning the inpatient management of their condition. A follow-up study by the same group reported results from a survey of 684 PD patients and found that 18% of PD patients were hospitalized within a year (Gerlach et al., 2012). The study reported that 21% of hospitalized PD patients noted deterioration of motor symptoms after hospitalization, 33% had complications during hospitalization, and 26% reported incorrect medication management. In addition, patients with a higher levodopa equivalent dose (LED) of PD medications were associated with an increased risk of post-hospitalization deterioration of PD function.

This report illustrates an approach to scalability to address these issues, albeit limited to Epic Systems, a single major EHR vendor. The Epic Movement Disorders Subcommittee, a collaboration between Epic and the Parkinson's Foundation, worked to develop EHR-based best practice solutions that could become standard within Epic's Foundation System as either default or as available features to address challenges faced by PWP in the hospital. The Parkinson's Foundation contributed a national and patient-oriented perspective and a toolkit to reduce these hospitalization risks. This report contributes to addressing the gap between the resources in the Parkinson's Foundation toolkit and the availability of EHR-based solutions that can be deployed with routine updates to all customers of Epic.

As a vendor, Epic releases many clinical programs, published as implementation and workflow guides that often include specific features built into Foundation System. Examples include tools for sepsis screening, opioid monitoring, fall risk screening, advance care planning documentation, infant feeding best practices, and delirium prevention in ICUs. Most programs are in response to regulatory or certification incentives or requirements. The EDMS plans to create a clinical program publication highlighting the workflows and solutions described in this article.

This report highlights two types of solutions. First, we illustrate a consensus roadmap for development and highlight released features in Epic EHR systems based on this EMDS collaboration. Features released in this roadmap have the advantage of becoming standard within the Epic toolkit, being aligned with a national PD safety initiative, and being deployed automatically via routine Epic upgrades. While a standard toolkit within an EHR can provide features available for implementation and enhance standardization across customer organizations, local configuration and customization are often still needed. Thus, this report also presents examples of practical solutions from different organizations, which can serve readers as further starting points for implementation of features not yet available in the toolkit.

The overall EMDS essential workflows for improving patient safety can be grouped into three categories: identifying admitted PWP, medication management, and PD care plans.

Identify admitted PWP

Though PWP are overall admitted to the hospital more often than peers, there is still limited awareness of the frequency of the hospital care provided to this population due to the fragmented nature of their admissions. One systematic review reports the percentage of admissions due to various concerns as 22.0% infections (primarily urinary tract infection and pneumonia), 19.0% motor symptoms, 18.0% falls and fractures, 13.0% cardiovascular comorbidities, 8.0% neuropsychiatric disorders, and 7.0% gastrointestinal disorders (Okunoye et al., 2020). One can assume that patients entering the hospital for these reasons would be spread across nearly every hospital unit.

Disease-specific real-time patient lists, reports, or dashboards of PWP can be robust tools for population-based interventions or care paradigms once PWP are hospitalized. The Epic Foundation System now contains multiple tools out-of-the-box that support identification of PWP automatically (Storyboard flags and banners), by real-time lists (Patient Lists), or by pre-configured reports and dashboards. These tools enable local organizations to develop and prioritize approaches that can lead to sustainable novel care models that focus on specialized resources for vulnerable patients and, in this case, brings providers that are typically outpatient-focused to the inpatient arena, where most complications occur. As Epic (and other vendors) develop more support for out-of-box alert features for various conditions beyond PD, rather than just turning on all of them, an organization would likely prioritize activating alert features based on follow-up preventative actions that the alert is meant to support, such as the protocol screening implemented by the Cleveland Clinic in Table 1.

Medication management

Avoidable complications in the hospital are frequently related to medication management. The disruption that occurs between a person's home medication regimen and the regimen they receive while hospitalized can lead to a high rate of medication errors that can cause complications. This is often viewed in the context of MODS - Missed, Omitted, Delayed, and Substituted medications (Parkinson's Foundation Hospital Care Initiative, 2022). Medications are frequently missed (unintentionally) or delayed, often because of the typical shift in medication timing from the home regimen to the more rigid, default, standard hospital medication distribution schedules (Shin and Habermann, 2016; Mucksavage and Kim, 2020). Medication omission can occur if a specific PD medication is not available in the hospital's formulary (Derry et al., 2010), or when a patient is not directly admitted for Parkinson's disease and appropriate medication management is not identified as a primary focus (Shin and Habermann, 2016). Inappropriate omissions have been shown to increase the risk of mortality (Lertxundi et al., 2017). The other frequent result of medications being unavailable on the formulary is inappropriate substitution (Mucksavage and Kim, 2020), which also can be detrimental to PD patients. The second category of complications occurs when potentially harmful medications are administered. In particular, we see complications due to the use of commonly used antipsychotic, antiemetic, antidepressant, analgesic, and anesthetic medications that may interact with Parkinson's medications and make Parkinson's symptoms worse (By the 2019 American Geriatrics Society Beers Criteria® Update Expert Panel, 2019), Finally, patients' swallowing function can be compromised when their Parkinson's medications are suddenly and inappropriately stopped, putting them at risk of aspiration pneumonia – the leading cause of mortality among people with PD.

A major contribution of this work is the emphasis of the EMDS to advocate for an EHR-based solution to address the urgent need of ensuring that PD medications are given at the same correct frequency and timing as they were taking as an outpatient. We note that three of four example solutions provided by organizations all faced the same outpatient-to-inpatient medication timing limitation (customized timing of PD medication) (Table 1). Developing a more integrated EHR-supported solution became a priority for the EMDS. After extensive discussion, the primary recommendation of enhancing outpatient medication timing to align with inpatient medication timing would require a core change in how the Epic EHR represents outpatient medication frequencies and timing. Such a change is challenging to undertake, requiring significant research and development costs to the vendor. We note that, in addition to the collaborative advocacy of the EMDS, the vendor, after additional support from other specialty steering boards, not limited to neurology, committed to undertake such a change. Preliminary work supports a promising development roadmap.

Avoiding inappropriate medications (neuroleptics) from being ordered for hospitalized PWP remains a gap in the current roadmap. Epic supports standard clinical decision support tools, which can alert the ordering provider of a drug-drug interaction or a drug-disease interactions. Overall, drug–drug interactions are more often enabled by organizations than drug-disease alerts. Organizations need careful governance and review of clinical decision support tools to minimize potential alert fatigue. In the experience of the EMDS members, few default PD-condition alerts existed at all before undertaking quality improvement efforts. In addition, the alerts are based on lists of drug-disease interactions purchased from third party medication vendors. Engagement these vendors is out of scope for the EMDS project and requires additional collaboration between specialty societies and these vendors. Further review suggested that there is not yet a clear standard at a national level to classify the nature of neuroleptic to parkinsonism interactions, and work to establish such a standard was also beyond the scope of this EMDS collaboration. Subject matter experts in the EMDS continue to pursue this work outside of this collaboration.

PD care plans

As disease diagnosis and treatment paradigms have advanced, so has the complexity of patient management. Translating this complexity into the training of physicians, nurses, and other practitioners can be challenging, with less common neurologic disorders often affected more (Jozefowicz, 1994; Flanagan et al., 2007; Ridsdale et al., 2007; Zinchuk et al., 2010; Willis et al., 2011; Dorsey et al., 2013). With a 1–2% prevalence, the intricacies of managing Parkinson's disease can be overshadowed by other more common disorders. This has left a knowledge gap in the care workforce (Guttman et al., 2004; Shih et al., 2013). In ongoing work by the EMDS, sample content emphasizing nursing care plans, tools to monitor ancillary services (physical therapy, occupational therapy, speech and language pathology), discharge planning, and discharge instructions is being reviewed and adapted as future standardized content for the Epic Foundation System.

Advantages

Other advantages to the approach of developing and standardizing tools at the EHR vendor level go beyond automatic deployment or availability of new features to organizational customers. Most EHR vendors now support tools for organizations to suggest new features, monitor adoption of new features, and allow benchmarking of adoption across organizations. Epic publishes a Neurology Success Guide highlighting content specific to the neurology specialty and including links to build and implementation guides. These resources can also be incorporated into an implementation arm of the Parkinson Foundation efforts to improve safety measures for hospitalized PWP, particularly within their Global Care Network.

The development of standardized toolkits for reducing harm in hospitalized PWP has additional benefits in enforcing standardized data collection. For example, the EMDS and Neurology Specialty Steering Board could maintain a diagnosis grouper in Epic's Foundation System that defines the ICD-10 codes and/or SNOMED terminologies in a standardized definition that all organizations can use. This avoids fragmentation of the cohort of patients that are being addressed by these tools. Across all organizations who use Epic, discrete data fields supporting this toolkit become automatically available to collect information about ancillary services monitored, the activation of a nursing care plan, the benchmarked frequency of inpatient medications ordered with custom timing. These data fields automatically support cross-organizational aggregation of quality metrics.

Challenges

The lack of awareness and appreciation of the potential positive impact of the available EHR tools in the quality and safety of hospitalized PD patients is the biggest challenge to implementing the currently available and forthcoming solutions. Scientific consensus is needed as a basis to implement solutions; advocacy partnerships, such as with the Parkinson's Foundation, are essential to aid in prioritization to decide what to implement. As significant bureaucratic obstacles to enabling, configuring, and implementing EHR tools exist, a concerted effort among the movement disorder and neurologist community is required to overcome them. Local organization champions are critical to not only enable build from Epic's Foundation System in the local EHR, but are also key in adapting the out-of-the-box solutions to fit local organization policies and workflows. Some features require local organizations to develop protocols, policies, and/or procedures to implement changes in workflows or practices to increase the effectiveness of the feature. We hope that the technical development of these features by the EHR vendor can at least reduce some barriers faced for adoption. As a future step, alignment with quality standards or alternative value-based payment models at a national level, could also help incentivize adoption at scale. The current Epic Neurology Specialty Steering Board continues to discuss alignment of future Epic roadmap development with the American Academy of Neurology Quality committees.

Some desired interventions were unable to fit within an EHR vendor roadmap for improvement. There was a limitation in EHR core functionality in aligning medication timing and frequency from outpatient to inpatient settings. Here, we illustrate the importance of collaborative advocacy to help prioritize vendor resources to improve such functionality. Until the development solution becomes available, organizations will continue to struggle with managing PWP medications across the continuum. They will need to design local solutions similar to the three example solutions in Table 1. Another challenge encountered is incorrect or missing drug-disease alerts from third party medication vendors' content. Specialty societies such as the Parkinson Foundation or American Academy of Neurology should advocate to the medication vendors updates needed to their content. Until the content gaps are addressed, organizations will need to create local clinical decision support solutions.

A major limitation of this work is its focus on a single major EHR vendor which took advantage of the vendor-supported specialty steering board of neurology peers. We hope that first, the toolkit and roadmap described here can incentivize and serve as a model for development and/or adoption by other EHR vendors. Eventually, vendor neutral solutions and resources, such as HL7 standards may adopt and promote some of these tools as requirements for EHR certification. For example, the Agency for Healthcare Research and Quality (AHRQ) supports a framework to represent clinical decision support (CDS) artifacts as a vendor-neutral archive[1] with CDS artifacts defined as actionable medical knowledge distilled from various evidence sources (e.g., clinical practice guidelines, peer-reviewed articles, local best practices, and clinical quality measures)

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[1] https://cds.ahrq.gov/cdsconnect/repository

and translated into computable and interoperable decision support. Tools developed here could be translated into a vendor-neutral "artifact" and stored on this repository for any EHR, organization, or third party vendor to implement in a standard way in the future.

This work illustrates the possible solutions but does not report on the effectiveness of any of the tools to affect outcomes, that is, to actually reduce risk to PWP. We anticipate that work to reduce risks to PWP can only benefit from the broader availability of tools that are deployed as available throughout a large community of organizations that use EHRs that have those standardized tools. Such work holds potential to facilitate collaborative outcomes research by facilitating aggregate interventions based on these tools.

Conclusion

Preventable harm in the hospital for people living with Parkinson's disease is often the result of a fragmented healthcare ecosystem in which inpatient care teams may have insufficient PD education and lack recognized care standards and protocols to guide PD treatment. Eliminating these avoidable errors and improving patient safety will require innovation, clinical leadership and commitment, and partnership across healthcare delivery.

With this work, we demonstrated options in use by current organizations, a standardized toolkit of features currently available and forthcoming in the Epic EHR system for improving the safety and quality of care for people with PD in the hospital resulting from the collaboration of an advocacy group with an EHR vendor, with input from subject matter experts across different healthcare systems. We invite healthcare system leaders and other vendors to explore these available tools as a starting point to improve inpatient care for patients with Parkinson's, and to consider the authors of this paper to be a resource for initiating these interventions and tailoring them to each unique care environment.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding authors.

Author contributions

AW: Writing – original draft, Writing – review & editing, Conceptualization, Methodology, Investigation. BW: Writing – original draft, Writing – review & editing, Conceptualization, Investigation. AB: Writing – original draft, Writing – review & editing, Conceptualization. EB: Writing – original draft, Writing – review & editing. KA: Writing – original draft, Writing – review & editing, Conceptualization. IR: Writing – original draft, Writing – review & editing. KM: Resources, Writing – original draft, Writing – review & editing. HA: Conceptualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

AW is a volunteer member of the Epic Neuroscience Specialty Steering Board. BW serves as Section Head of Movement Disorders at the Cleveland Clinic. Over the years, he has received research grants from the NIH and Parkinson's Foundation. He has served as site investigator and/or co-investigator for clinical research studies sponsored by grants from Industry to Cleveland Clinic. Currently, he is the site PI for Neuroderm (Mitsubishi Tanabe Pharma), Discern (Great Lakes Neurotech/NIH R44), Tempo 2, and Tempo 3 studies (Cerevel Therapeutics) and a grant from the Parkinson's Foundation to improve the inpatient care of People with PD. He has served as a consultant or speaker for Medtronic, Boston Scientific, and Abbott. AB Director of Strategic Initiatives, Parkinson's Foundation EB Associate Director of Strategic Initiatives, Parkinson's Foundation. KA was supported by the Michael J Fox Edmund J. Safra Fellowship in Movement Disorders from July 2017–July 2019. She previously served as Investigator and/or medical monitor for clinical trials supported by Aptinyx Inc. Genentech Roche Ltd., EIP Pharma Inc., Michael J Fox foundation for PD research, NINDS, and Acadia Pharmaceuticals Inc., and Biogene. She previously served as Co-I of a Lewy Body Dementia Association Research Center of Excellence site. The work presented here was supported by a Parkinson Foundation Community Grant (awarded to IR). IR serves as Director of the University of Rochester Parkinson's Foundation Center of Excellence and her contributions to this article were supported by a Parkinson's Foundation Community Grant, Parkinson's Disease Hospital Optimization Project (PD-HOP) for which she served as PI. IR has received research and/or training grants from NIH, Parkinson's Foundation and the Michael J. Fox Foundation. IR has served as a site investigator and/or co-investigator for clinical research studies sponsored by grants from Industry to the University of Rochester, currently including F. Hoffmann-La Roche Ltd., Acadia Pharm, and Jazz Pharmaceuticals. KM is an employee of Epic, a health IT software company which licenses electronic health record software and provides related services to health care organizations that pay Epic for such software and services. She and Epic have no financial disclosures or conflicts of interest related to this article.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Utilizing the Nursing Professional Development Model to create and sustain nursing education aimed at improving the care of patients with Parkinson's Disease in the hospital

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The Nurse Professional Development Model (NPD) has been utilized to improve quality of care for several conditions. Patients with Parkinson's Disease (PD) are susceptible to higher risks while in the hospital. Educational efforts for this patient population are challenged by the small, disbursed number of patients as well as increased turn-over and reliance on temporary nursing staff. To properly care for this patient group, any education has to be hospital wide and ongoing for maintenance of competency. We have used the NPD Model to initiate education for new incoming nurses as well as for continued education for a program that requires hospital-wide reach. Our utilization of the NPD Model for this high risk, low volume patient population has helped us improve the safety of this patient population in the hospital. With this manuscript we detail the need and the educational platform with the hope of it serving as a reference for other institutions facing similar challenges.

KEYWORDS

nursing education, medication, safety, Parkinson's Disease, hospitalization, Nursing Professional Development Model

Introduction

Patients with Parkinson's disease (PD) often rely on strict medication regimens to help control their symptoms. Motor fluctuations as well as troubling dyskinesias may develop over time requiring exact timing and doses of medications to maintain mobility and quality of life. Delays or omissions or receipt of inappropriate medication can have a profound negative impact on this patient population (1–3). Approximately 75% of patients with PD admitted to the hospital do not receive their medications on time, (4) and of these, over 60% will experience complications that can be harmful, increase lengths of stays or even increase risk of mortality (5). Compounding the issue is the potential administration of some commonly used medications which can be harmful for PD patients (6). Parkinson's Disease patients can be admitted to any adult in-patient unit and often PD is not the admitting diagnosis (7). Deficiencies in knowledge about the care of PD patients among healthcare providers compounds these issues (8).

Each year over 300,000 PD patients are admitted to US hospitals (9). While this is overall a large number, each of the estimated 6,000 US hospitals may receive a much smaller proportion. The relatively small number of patients scattered throughout the hospital presents a challenge in the development and maintenance of competency for the care of this patient population. Lack of national standards and guidelines for the care of PD patients in the hospital also adds to the obstacles. We have developed a program at our institution centered on ensuring adherence to a patients' home medication regimen when placing orders for PD medications, based on recommendations from the Parkinson's Foundation, which in response to a crisis brought forth by patients and caregivers of dangers of hospitalization, has been advocating for awareness in this arena and for development of safety measures for those with PD in the hospital (5). Our program has had some success, and we have seen a reduction in the length of stay of this patient population after implementation (10, 11). We have utilized the Nursing Professional Development (NPD) Model to educate and to maintain competency for our nursing staff and ensure adherence to the protocol amidst nursing shortages and high turnover rates which are industry wide (12). We are presenting our experience in the use of the NPD model for hospital wide education and maintenance of competency.

Parkinson's Disease Patients are considered a "high-risk, low frequency" patient population as compared to other hospital-wide diagnoses. While 16–45% of PD patients will visit an Emergency Department once a year and 7–28% of these patients will be hospitalized (5). In comparison to diagnoses such as heart failure, PD frequency in the hospital is relatively smaller. From the year 2019–2022 we had a total of 1,517 patients admitted to our hospital who had a diagnosis of PD as a primary or non-primary diagnosis (annual average 379 patients). As a comparison during the same time period, 3,674 patients were admitted for heart failure (average annual admissions 918 patients). Likewise, a primary or secondary Diabetes diagnosis averages 700–800 admissions *per month*. Because of the lower number of annual admissions, nursing staff will encounter a PD patient less frequently compared to other chronic disease processes during an average nursing shift. With more than half of PD patients experiencing a complication while in the hospital (2, 5), nursing education and heightened awareness is crucial in supporting patient care and optimal patient outcomes. This creates an educational challenge for standardizing initial nursing education as well as maintaining competency to ensure nurses can recognize a patient with Parkinson's Disease and care for this high-risk population.

Complicating the matter further, the nursing landscape has shifted nationally, and our institution has not been immune to these changes. Over the past 6 years, the number of new graduate & temporary nurses hired has consistently increased annually (Table 1) as the number of experienced nurses hired has decreased.

TABLE 1 Number of new RNs hired per year, level of experience, and temporary status.

Year	New Graduates	Experienced	Temporary nurses
2016	54	176	33
2017	83	223	65
2018	112	147	43
2019	123	153	61
2020	*	*	*
2021	155	125	192
2022	223	294	192

*Pandemic year, data not collected.

Education opportunity

This high-risk, low frequency population, combined with a less-experienced nursing workforce, has created a significant opportunity for education related to Parkinson's disease. This education included the importance of medication timing and associated complications. PD patients are admitted hospital wide based on their admitting diagnoses; therefore education must extend to all adult inpatient nursing units.

The nurse educator role

Nursing professional development (NPD) is a specialty of nursing practice which is defined by standards, based on research, and critical to quality patient and organizational outcomes (13). This specialty improves the professional practice and role competence of nurses and healthcare personnel by facilitating ongoing learning, change, and role competence and growth with the intention of improving population health through indirect care (14). While this model is more adopted in the US, there are other similar models internationally (15, 16).

The Association for Nursing Professional Development (ANPD) has defined the qualifications of NPD practice. There are two levels of practice which are determined based on degree (Bachelor of Science in Nursing, Master of Science in Nursing, Doctorate) and presence of a national NPD certification. There is evidence of the impact of NPD practitioners ("nurse educator") in an organization and the effect on nursing orientation time, nurse turnover rates, retention, patient satisfaction and organizational outcomes. To assess the impact of NPD practitioners on unplanned hospital visits, Harper, Maloney, Aucoin & MacDonald (17) conducted a replication study of NPD practitioners from 398 participant responses from organizations in 46 states in the US and District of Columbia. Included were those with capacities from 200 beds up to 4,000 beds, stand alone and network systems, profit, non-profit and all levels of care. The study observed that higher numbers of NPD practitioners per hospital were associated with statistically significant ($p \leq 0.10$) lower unplanned visits for heart failure, pneumonia and CABG.

Nursing Professional Development Model

ANPD has defined the scope of practice which is depicted in the NPD Practice Model. This model (Figure 1) is defined by inputs, throughputs and outputs. The model begins with environmental scanning (the assessment) which is a process of systematically monitoring an organization's internal and external environments for

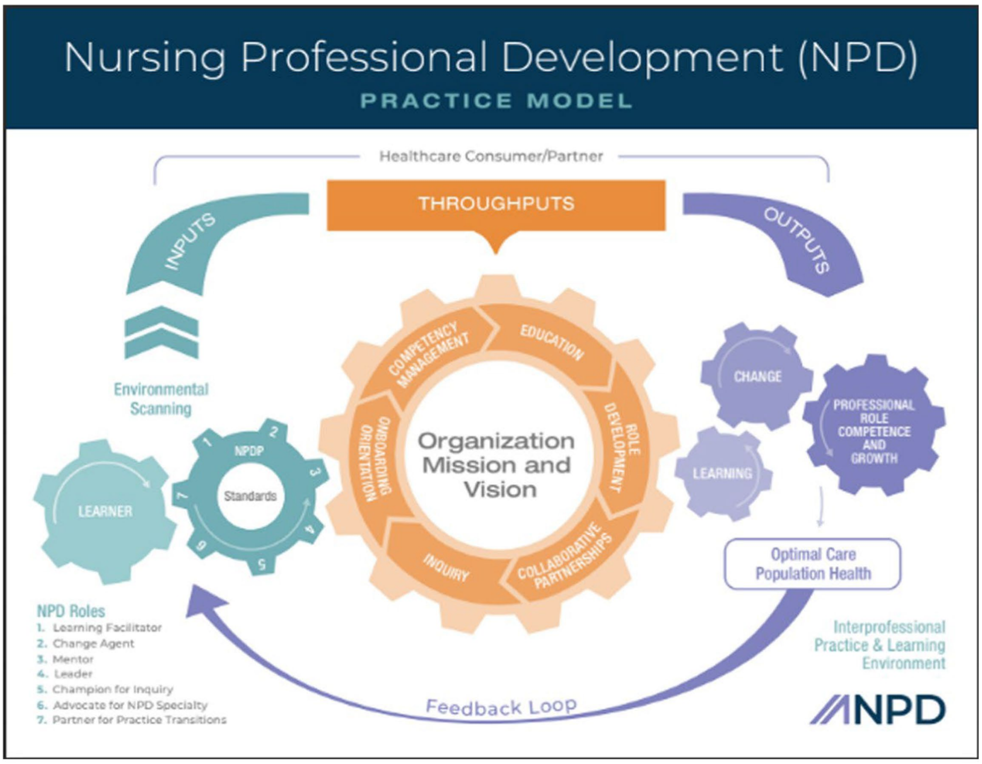

FIGURE 1
Nursing Professional Development Practice Model.

earliest signs of opportunities and challenges that may create or reveal a potential professional practice gap (14). The inputs delineate the "when, who and how" in the scope of practice. NPD practice is a continuous assessment of educational opportunities or gaps in practice. The learner and NPD practitioner interact with the goal of impacting measurable outcomes. The model further defines the roles of an NPD practitioner which are learning facilitator, change agent, mentor, leader, champion for inquiry, advocate for the specialty and partner for practice transitions. The throughputs are the processes that occur in the interprofessional learning environments (clinical, classroom & online) and are facilitated by the NPD practitioner. The throughputs represent the responsibilities of the NPD practitioner or the "what" of the NPD scope of practice and are guided by the "why" which is the organization mission and vision. The major responsibilities are onboarding/orientation, competency management, education, role development, collaborative partnerships and inquiry. Lastly the outputs represent the overall desired outcomes of the NPD practice that align with the mission and vision. Expected outcomes surround learning, change, professional role competence and growth which leads to optimal care in population health (14).

Applying the model to practice

Inputs

Through the process of environmental scanning, we identified nursing education needs related to the changing nursing landscape. As a result of the increase in newly hired nurses, initial education was needed as well as a means to maintain competency caring for this high-risk, but low frequency population. Additionally, we assessed issues that can put PD patients at risk during their hospitalization such as adherence to medication timing and promoting early mobility.

Throughputs: onboarding

All new hires onboarded to our institution attend a full-day course related to clinical practice guidelines for various diseases which includes a presentation on Parkinson's Disease. This class is an introduction to the high standards we hold for patient care and is where nurses receive their initial PD education. This one-hour presentation includes: an overview of PD, nursing assessments and care of the PD patient within the nursing process, common PD medications, contraindicated medications, importance of medication timing, surgical treatment, safety concerns, and the nursing care plan.

Throughputs: education

Education is provided through multimodal platforms. An annual online Parkinson's Disease specific module in our electronic learning management system is assigned to every adult inpatient nurse. This module covers pathophysiology of Parkinson's Disease, the importance of medication timing, contraindicated medications for PD patients, and the importance of early mobility. This education is provided to the nursing team as well as other members of the interdisciplinary team which include Physical Therapy, Occupational Therapy, Patient Care

Technicians, Nursing assistants, Dietary, and Pharmacy. This module can be considered initial education and ongoing competency education for the interdisciplinary team.

Nurses on high volume units such as the neuroscience areas receive additional education. An initial education class was developed for a new medical/surgical neuroscience unit at our institution. It incorporated a one-hour presentation for care of Parkinson's Disease patients. Our Neurosurgical Intermediate Care Unit receives a unit-specific course, taught by nursing peers, which includes a discussion on Parkinson's Disease.

Early mobility initiatives were implemented for all patient populations which further supported the care of PD patients to prevent deterioration of motor symptoms. To help improve mobility, the Bedside Mobility Assessment Tool (BMAT) was implemented in 2016 as well as a "Move to Improve" initiative in 2021 which was a hands-on class to support nursing staff with mobility tools. In 2017 educational webinars were developed with a pre & post assessment for nurses on mobile devices as an additional approach to education. Table 2 summarizes the educational components.

Throughputs: competency management

Maintenance of clinical competency when caring for patients with Parkinson's disease is crucial. Competency is an already expected level of performance that integrates knowledge, skills, and judgment and is considered an outcome and an ongoing process (14). In addition to what was described above, we have created additional methods for maintaining competency.

PD case studies are utilized in our annual adult in-patient nursing competency class. From a safety perspective, laminated posters have been created and displayed near the medication dispensing systems reminding nurses of the contraindicated medication for PD patients. NPD practitioners and a neurosurgery advanced practice nurse also collaborate on unit-based in-services to support competency and raise awareness (Table 2).

Additionally, we have created a Parkinson's Disease awareness "banner" which is an identification tool to alert all health care team members that they are caring for a PD patient regardless of the admitting diagnosis. For nursing specifically, there is also a "Time-Critical" alert in the medication administration record (MAR). The purpose of this alert is to convey the importance of administering the PD medication no more than 30 min before or after the scheduled time as opposed to the standard medication administration range of 60 min or greater.

Throughputs: role development

In our institution, we have developed a voluntary process for nurses to serve as bedside educational support for other nurses. These Nurse Champions act as beside unit resources regarding PD patients to provide real-time and on demand education and support for other nurses. Evidence supports the use of nurse champions to promote best-practice guidelines and close knowledge gaps (18).

Throughputs: collaborative partnerships

Extensive collaboration was required in order to achieve our desired Outputs. Internally, nurses, providers, and pharmacists working together was crucial since medication management is a focus of care for these patients. Key pharmacy members were identified who helped with assuring PD medications were ordered properly; contraindicated medications were discontinued; adding medication administration instructions and alerts to the EMR; adding PD medications and preparations to our formulary; increasing the number of nursing units with access to the medication; and stocking PD medications in the local medication rooms instead of the central pharmacy for quicker availablity. Our Physical Medicine and Rehab department worked with our patients to address PT, OT, and speech therapy needs.

Evidence supports Nursing care plans to guide clinical practice, (19) therefore, we developed and organized a Parkinson's Disease

TABLE 2 Throughputs: educational components.

Educational component	Throughputs	Initial education and competency management	Target audience	Teaching method
PD Presentation for newly hired nurses	Onboarding	Initial	All nurses	Classroom
Neurosurgical intermediate care class	Education	Initial & competency	Intermediate care neuroscience nurses	Classroom
Neuroscience day class	Education	Initial	Neuroscience nurses	Classroom
Annual learning module	Competency management	Competency	All nurses	Online
Move to improve	Education	Initial	All nurses	Classroom
Annual competency class	Competency management	Competency	All nurses	Classroom & online
Unit nurse champions	Role development	Competency	All nurses	On unit support
Time critical medical alert	Inquiry	Competency	All nurses	Electronic medical record (EMR) alert tool
Nursing care plan	Collaborative partnerships	Competency	All nurses	EMR real-time best practice guidance

Patient Care plan to influence practice change and standardize care for Parkinson's disease patients. The Care Plan is discussed during multidisciplinary rounds which includes members from the Nursing, Provider, PT/OT, Case management, and Pharmacy Teams. Representatives from this interdisciplinary team met for monthly meetings to share progress and exchange ideas related to PD care. Also, our lead neurosurgeon visited rehab facilities to educate staff and expand our care initiatives to the community as well.

Throughputs: inquiry

Although there is evidence to direct Parkinson's care such as the Parkinson's Foundation "Hospital Care Recommendations," (4) clear practice guidelines are lacking when compared to other hospital wide diagnoses such as Heart Failure and Diabetes. At our institution, we chose performance measures to prioritize and steer our care. We selected our initial measures and goals when we started our initiative in 2017 based upon environmental scanning. Over time, we went through an ongoing process of developing plans, analyzing outcomes, and revising plans and goals based on our data. Metrics assessing appropriate medication management have been included since the inception of the program. These include ensuring PD medications are ordered using "custom" timing in our EMR to match the patients' home medication schedules, and monitoring whether contraindicated medications were ordered or administered. In addition to medications, mobility has been another area of focus.

Outputs/results

The output is evident in the improvement in compliance with our chosen performance measures. We have increased the rate of custom medication ordering nearly three-fold when comparing 2017–2018, (11) and to nearly 50% of orders in 2023 (unpublished yet as of the submission of this article). Furthermore, as a testament to the depth of the education process, we have observed that over half of the orders that were not initially placed as custom are changed to custom by either pharmacy staff or nursing. For the avoidance of contraindicated medications measure, our rate has ranged from 90 to 97% in 2023. Our OOB (Out of Bed) within 24 hours of admission to the unit rate increased from 32% in 2019 to 75% in 2023 (unpublished data).

Discussion

Evidence supports the role of NPD practitioners in bridging safety gaps with education to improve health outcomes in specific groups of individuals. One of the standards of Nursing Professional Development is health teaching and promotion. NPD practitioners provide education, support, and encouragement for healthcare staff with the overarching goal of promoting population health (14). PD patients are at high risk for development of hospital related complications and are also subject to increased lengths of stay and higher risk of mortality in the hospital. The number of PD patients admitted annually is relatively small compared to other disorders and often they are *scattered* through the hospital based on their admitting diagnoses In order to maintain quality of care in this "high risk, low frequency" patient population, we have utilized the NPD Practice model to introduce initial education and ongoing continuing education with the goal of maintaining competence of inpatient nurses throughout the organization. In this manuscript, we have described the process undertaken by NPD practitioners to support clinical competence in medication management for people admitted to the hospital with PD. Looking to the future, we hope to contribute to the development of practice guidelines to advance the care of Parkinson's patients admitted to the hospital.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding authors.

Author contributions

MB: Writing – original draft, Writing – review & editing. PP: Writing – original draft, Writing – review & editing. LC: Writing – original draft, Writing – review & editing. HA: Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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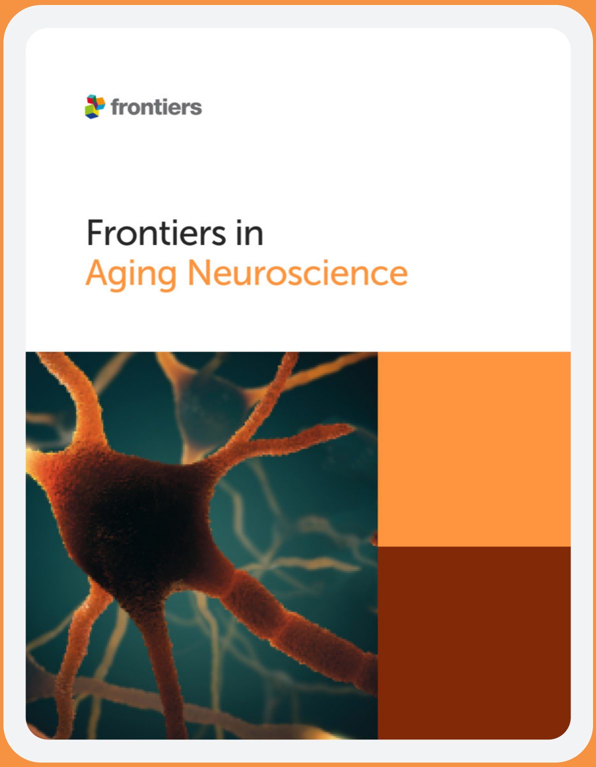

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