The Future of Hospitalization for People with Parkinson’s Disease

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Introduction
The objective is to share the discussion of the December 6, 2019 Parkinson’s Hospitalization Convening. The Parkinson’s Foundation’s (PF) assembled thought leaders in hospitalization and Parkinson’s disease (PD) to understand hospital care needs for people with PD, models of success and best practices that can enable that care, and common barriers, drivers, and strategies for adoption. Estimated annual costs of hospital inpatient services for PD is $7.19 billion, 28.4% of the total direct medical cost of the disease. This cost is due in part to improper medication management for almost 75% of people with PD who are hospitalized, over 50% of whom have complications that could be avoided. Despite significant impact on healthcare quality and cost, hospital care for people with PD varies widely and no nationally recognized standard of care exists.

The Event
The convening gathered leaders in PD care from PF (staff, advisory committee/board members, and the National Medical Director, Michael Okun) and representatives from Hackensack University, Kansas Rehabilitation Hospital, University of Rochester, the Joint Commission and the Edmond J Safra Foundation. Attendees presented progress made in their institutions, challenges and best practices focused particularly on the prescription of contraindicated medications or mistakes in how Parkinson’s medications are distributed when the staff either Missed, Omitted, Delayed or Substituted Parkinson’s medications, from which an acronym is used, MODS.

The History of Aware in Care
Dr. Okun kicked off the event by walking the group through the following timeline:

- **2007**: Chou et al finds: 94% were not confident that patients received meds on time in hospitals; 25% had a protocol for hospital physician to call their center.
- **2011**: Aminoff et al recommends educational programs and the establishment of guidelines around treatment of hospitalized Parkinson’s patients.
- **2013**: Hassan et al finds: 33% of patients report at least one hospital encounter; 51% had a repeat encounter within one year; 25% of those without one had an encounter within a year.
- **2014**: PF Launches Aware in Care Campaign, providing free tools to educate and advocate for better care in the hospital.
- **2017**: PF Launches the Aware in Care Ambassador Program
- **2018**: PF hosts the Hospitalization Convening
- **2019**: Aware in Care Recipient Survey finds: 95% rated the kit as useful; 80% felt confident using the kit; 50% received meds on time

Conclusion
Based on the convening, PF was able to establish clarity of the issues regarding inadequate hospital care for people with PD including key care domains. There was an established consensus on a draft set of core hospital care guidelines, that recognize global guidelines but are unique to the US care system, to be finalized by the Advisory Committee, for all hospitals treating people with Parkinson’s disease and for use by Aware in Care Ambassadors in their local hospital outreach. The Parkinson’s experts in attendance agreed that there is a need for the refinement of the long-term vision for the PF Aware in Care program and its ability to drive nationwide changes in the delivery of hospital care for people with PD. Attendees agreed to work towards establishing standards within four areas: PD Medication Management/Avoiding Missed, Omitted, Delayed and Substituted Medications (MOMS); Special Considerations for Medications; Potentially Inappropriate Medications/Contraindicated Medications; and Fall Risk and Ambulation. It also includes checklists to be used in the following settings:
- Emergency Department Checklist
- Admission Checklist
- Perioperative Checklist
- Discharge Checklist

Acknowledgements
Parkinson’s Foundation would like to thank the Parkinson’s experts who volunteered their time to join us to discuss hospitalization and Parkinson’s and how to improve the hospital experience for people with Parkinson’s disease and the Edmond J. Safra Foundation for their continuous support of the Aware in Care campaign.

**The Event**

**When people with Parkinson’s arrive at the hospital for something unrelated to Parkinson’s, Parkinson’s may not be noted in the Emergency Medical Records and those medications are missed entirely.**

**Often before surgeries, clinicians incorrectly assume that if someone is NPO before a surgery (nothing by mouth) that Parkinson’s medications should be omitted.**

**Clinicians may distribute meds less than an hour too early/late, meeting their legal requirement but likely causing harm. It is also common for medications to be distributed on the hospital’s standard schedule rather than the times determined by the primary Parkinson’s doctor.**

**Typically, clinicians provide an immediate release instead of continuous or generic instead of name brand that is not identical. Clinicians may have assumed that certain Parkinson’s medications are interchangeable when they are not, like substituting the same dose of Rytary for Carbidopa/Levodopa.**

**PF Launches Aware in Care® Campaign, providing free tools to educate and advocate for better care in the hospital.**

**Key Elements in their Approach:**

1. Ongoing conversations with the Parkinson’s community regarding their lived experiences in specific community hospitals
2. Addressing issues with what medications are on formulary
3. Tracking the prescription of Haldol for a month showed hospital leaders that the warnings were necessary

**Key Strategies in their Approach:**

1. Establish a way to identify all Parkinson’s patients within the chart and train staff to understand what it means when a patient is flagged for Parkinson’s
2. Address the availability of medications on formulary with pharmacy
3. Utilize the Electronic Hospital Record (EPIC in their case) to allow for the custom input of each Parkinson’s medication
4. Conduct widespread and ongoing education around the critical importance of medication timing for Parkinson’s patients