Hospitalization: An Action Plan to be Aware in Care

Michael S. Okun, MD
NPF National Medical Director
Anhar Hassan, MD
University of Florida
Agenda

• Overview
• What NPF has learned
• What you can do to be *Aware in Care*
• Questions & Answers
Hospitals are Safe, Right?

“They will call my neurologist.”

“The pharmacy will have my Parkinson’s disease meds.”

“Staff will understand Parkinson’s disease symptoms.”

“They will bring me my meds on time.”

“They will know the drugs that are unsafe.”
3 out of 4 people with Parkinson’s disease do not receive medications on time in the hospital\(^1\)

61% of patients who did not get their medications on time had serious complications from it\(^1\)

The Reality

- People with Parkinson’s are hospitalized 50% more than their peers without Parkinson’s\(^1\)

- People with Parkinson’s suffer avoidable complications at a higher rate than non-PD patients\(^1,2,3\)

- This yields longer hospital stays than non-PD patients\(^1,3\)

- This results in a 44% higher risk-adjusted mortality\(^1,3\)

Why is this Happening?

• Lack of understanding of Parkinson’s disease - symptoms, treatment, etc. *even in the very best hospitals in the U.S.*

• Lack of awareness about the critical importance of Parkinson’s medication timing

• Lack of awareness that many common medications for pain, nausea, depression, and psychosis are unsafe for people with Parkinson’s

• Hospital pharmacies that do not stock the full array of PD medications

• Lack of awareness that poorly-managed PD might result in mental confusion and other serious symptoms
How to Survive HOSPITALIZATION

Being a patient is very hard. Here are a few tips to get you out alive.

SET DAILY GOALS.

Wear slippers & wash hands often.

You don't have to know what those signs are. Your nurse or doctor will tell you.

Insults are very clean and very dirty.

DO WHAT THEY SAY - BUT NOT BLINDLY.

YOU HAVE CHOICES.

Look, I really don't want to hear a story. I can walk to the bathroom just fine!

But not too much.

HAVE A PERSONAL ADVOCATE.

(If they know what they are talking about)

Terry on Monday.

DON'T MESS WITH MY BABY!

Oh! I love him!

GET THE NURSES FOOD.

But when she needs anything.


teach me how to

GET OUT AS SOON AS YOU CAN.

3 South

Thank you for not telling me.

Enjoy the perks.

Can I help you?

Yes! Can you bring me a glass of water before "bedside nursing" starts?
Five Frequently asked Questions about Hospitalization

1. When I am in the hospital, why don’t I always get my medications on time?

2. Why can’t I take my own medications in the hospital? Why do they substitute some medications for me?

3. My mother has Parkinson disease and was recently hospitalized. However, she seems to be moving much worse in the hospital than at home. Why is that?

4. My husband has Parkinson disease and became confused in the hospital last time he was there. How can I prevent this?

5. I had deep brain stimulators (DBS) placed two years ago. I now need to have knee replacement surgery. Will the doctors know how to take care of me?
• NPF formed a committee to explore issues related to hospitalization of the Parkinson’s disease patient

• The group penned two articles:
  – Review article
  – Survey of NPF Centers
Management of the Hospitalized Patient with Parkinson’s Disease: Current State of the Field and Need for Guidelines*

*Based on a review of the literature on PubMed covering issues of hospitalization and Parkinson’s disease between 1970-2010
Results of the Review

- Patients with Parkinson’s disease are admitted to hospitals at higher rates, and frequently have longer hospital stays than the general population.

- Little is known about outpatient interventions that might reduce the need for hospitalization and also reduce hospital-related complications.
Problems with mobility in people with Parkinson’s disease are believed to be a causal factor in the higher rates of admissions and complications.
Common Reasons Why People with Parkinson’s disease are Hospitalized

- Elective surgery
- Fall/Fracture
- Infection
- Changes in mental status
- Pneumonia
- Heart problems
- Parkinson’s disease-related symptoms (for example, problems with mobility)
What is Important

• Medications, dosages and specific dosage schedules

• Staff training regarding medications and medication management may help to avoid complications, particularly those related to reduced mobility, and aspiration pneumonia

• Treatment of infections and a return to early mobility
Conclusions of the Review

- Educational programs, recommendations, and guidelines are needed.
- Train interdisciplinary teams.
- Potential for cost savings and for improved outcomes through prevention and management.
Hospitalization in Parkinson Disease:
A Survey of National Parkinson Foundation Centers

* To explore current practices and opinions regarding hospital management of Parkinson disease patients in specialized Parkinson’s disease centers
Reasons for Hospital Visits
Most Common Reasons for Hospitalization

- Elective surgery
- Fall/Fracture
- Infections unrelated to pneumonia
- Mental status change/Psychiatric issues
- Aspirational pneumonia
Perceptions of Care

- Not confident about the quality of PD-specific care provided to their patients when hospitalized

- Not confident received medications on time

- Not confident general knowledge regarding more complex PD-specific contraindicated therapies
Perceptions of Care

• **Not confident** knowledge that anti-emetics such as metoclopramide and prochlorperazine could worsen PD

• **Not confident** knowledge that clozapine and quetiapine preferred antipsychotics

• **Confident** knowledge that infections could cloud mental status
Half of Centers

• Felt the hospitalization practice appreciated PD medication may affect mental status
  • Dopamine agonists
  • Amantadine
  • Anticholinergics

• ....and that reductions may improve psychosis/behavior
Admissions
Admissions

• For unplanned admissions or emergency room visits, few centers had a mechanism in place that would trigger a call from the hospital physician to their Center
• Usually notified by patient or family
• Almost one-fifth of those surveyed learned about hospitalization at a follow-up clinical visit
DBS Hospitalization
DBS Hospitalization

- Approximately 80% of NPF Centers perform DBS surgery.

- Only 18% of Centers overall could admit patients to the hospital for prolonged initial programming, with no difference between US and International Centers.

- There were no differences between US and international Centers in the ability to admit for DBS programming issues, caring for patients implanted at other sites, or providing guidance on handling DBS issues.
Conclusions

- Concern about the quality of PD-specific care provided to their patients when hospitalized.
- Concern about adherence to the outpatient medication schedule.
- Poor understanding by hospital staff of the medications that worsen Parkinson’s disease.
- Few centers had a policy with their primary hospital that “notified” them when their patients were admitted.
Conclusions

- Notification of hospitalization came frequently from the patient or a family member.

- Several centers reported not finding out about a hospitalization until a routine clinic visit after discharge.

- Quick access to outpatient PD care following discharge was a problem.

- Elective surgery, fall/fracture, infection, and mental status changes, were identified as common reasons for hospitalization.
Conclusions

- A “perceived need” for Parkinson’s disease (PD) specialists to be involved during hospitalization
- Improvement in communication between hospitals and PD centers is necessary
- Education of hospital staff and clinicians regarding management of PD, complications of PD, and medications to avoid in PD is critical
- Outpatient access to PD specialists needs to be improved, and this may prevent unnecessary hospitalizations in these patients
Quality Improvement Initiative (QII)
Additional NPF Research

• We reviewed the NPF-QII information over 2 years
  – Demographic, clinical, questionnaires, ER and hospital visits.

• Year 1: ER/Hospital visit: Yes or No?
• Year 2: Repeat admission? New admission?

• What are the risk factors for ER or hospital visits?
Summary of Findings

• Parkinson’s patients have a high risk of ER visits or hospitalization

• Overall Risk:
  – 1 in 3 patients
  – Especially if you move slower, medications wear off, need a lot of assistance, other medical conditions (heart, respiratory, etc), caregiver or spouse feels stressed
  – [DBS requires hospital stay anyway]
Prior admission?

• If you go to hospital/emergency room, you have a 50% chance of this happening next year

• Risk: Very advanced Parkinson’s disease
No prior hospital visit?

• If you attend an NPF center, your chance of admission is lower (1 in 4)

• Risks: Other medical conditions, lower quality of life (PDQ-39), DBS
## Can I avoid an ER/Hospital visit?

<table>
<thead>
<tr>
<th>Issue</th>
<th>Avoidable or treatable?</th>
<th>How?</th>
</tr>
</thead>
</table>
| Advanced Parkinson’s  
  – Slow mobility  
  – Poor balance | Not yet  
  Perhaps  
  Perhaps | Medications to slow disease  
  Medications, exercise, physical therapy, balance/gait |
| Fluctuations | Yes | Medications, DBS |
| Other medical conditions | Yes | Primary/specialist care |
| Caregiver strain | Yes | Additional caregiver, social worker, psychologist, |
| Poor patient quality of life | Yes? | Optimizing Parkinson’s (medication, counseling, DBS) |
Recommendations

- Tell your neurologist if recent ER/hospital visit
- Ensure medical conditions (for example, heart, blood pressure, diabetes) are well controlled
- Review your medications (especially new ones!) with your Parkinson’s doctor each visit
- Bring your spouse/caregiver to your clinic visits
- Spouse or caregiver should tell your doctor if feels stressed or burned out
- Physical, occupational, speech/swallow therapy could help
Aware in Care Hospitalization Kit
What’s in the Kit?

1. Aware in Care Kit—Big enough to carry *Aware in Care* materials and extra bottles of Parkinson’s medications

2. Hospital Action Plan—Details about how to prepare for the next hospital stay—whether it is planned or an emergency

3. Parkinson’s Disease ID Bracelet—Designed to be worn by people with Parkinson’s at all times in case of an emergency situation

4. Medical Alert Card—Designed to be placed in the wallet in case of an emergency

5. Medication Form—Intended to be filled out prior to a hospital visit so there is a complete list of all medications ready to share with hospital staff
Aware in Care Hospitalization Kit

Medications on Time and Contraindications

- Medication Form
- Parkinson’s Disease Fact Sheet
- “I have Parkinson’s disease” Reminder Slips
Planning in Advance

Review Hospital Action Plan
Aware in Care Hospitalization Kit

After a Hospital Visit

- Contact your neurologist and share your discharge instructions from the hospital
- Review the Hospital Action Plan
- Review the contents of your Aware in Care kit

Make sure your Aware in Care Kit is up-to-date.
Aware in Care Hospitalization Kit

Help you plan and advocate for better care

- Get an *Aware in Care* kit
- Familiarize yourself with the kit and contents
- Create your personalized kit
Thank you

Questions?
Upcoming Programs

• Webinar - Building Your Healthcare Team May 17, 2012

• Kripalu Wellness Retreat - Stockbridge, MA June 4-8, 2012

• Young Onset Parkinson’s Conference - Orange County, CA June 15-16, 2012
Aware in Care is Made Possible By:

The Eleanor M. and Herbert D. Katz Family Foundation

...And individuals like you. Thank you for your support.