Nursing Solutions: Improving Caregiver Strain
The Science and a Model Intervention

Moderated by:

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Introduction

- Parkinson’s disease (PD) is chronic and progressive; often spans many years, even decades
- Gradual loss of autonomy of patient impacts the caregiver/family as well as the patient
- Caregivers may experience a negative impact on their quality of life over time
- By recognizing the multitude of caregiver positive and negative factors, nurses and other health care providers can better assess for caregiver strain and help caregivers to develop coping strategies
Objectives

• Discuss a clinically useful research framework to help family caregivers of people with PD.
• Recognize factors or variables that may influence caregiver strain.
• Contemplate interventions that may assist caregivers in coping with their role.
• Become familiar with the use of PHOTOVOICE, an intervention to help caregivers discuss difficult topics.
Caregiver Strain: The Science

Julie H. Carter, RN, MN, ANP
Professor of Neurology
Oregon Health & Science University
Portland, Oregon
Are Families Invisible Patients?

Negative Outcomes

- Decline in mental health
- Decline in physical health
- Decreased quality of life

Greenwell, et.al.2015
Definition of Caregiver Strain/Burden

The perception of emotional, social, financial, physical and spiritual difficulty in performing the caregiver role.
Caregivers Experience Strain at All Stages of Disease

Carter et. al 1998

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Why Do Some Caregivers Do Better Than Others?
Transactional Model of Stress and Coping
The Research: A Framework for Helping Caregivers

- **Predictors**
  - Person with Parkinson’s disease
    - Motor symptoms
    - Neuropsychiatric symptoms
      - Predict more burden than motor symptoms
  - Caregiver factors
    - Demographics
    - Psychiatric symptoms
    - Personality traits
  - DBS

Mosley, et. al. 2017, Greenwall, et. al. 2015
Protective Factors

- Social support
- Personality: optimism and pessimism, sense of meaning, competence (self-efficacy)
- Good mental and physical health
- Mutuality: quality of the relationship
- Preparedness

Greenwell, et. al. 2015
Goal

Identify protective factors that offer an intervention opportunity.
Assessment Before Intervention

- Assessment of strain/burden
- Assessment of capacity
  - Age, other care demands, gender, mental and physical health
- Assessment of preparedness
Caregiver Interventions: What Do We Know From Research?

- Limited evidence for effective interventions in the PD literature.
- Lessons from the dementia literature:
  - Behavioral change requires psychological skills.
  - Interventions should address multiple stressors.
  - “One size does not fit all.”
  - Sufficient amount and duration of treatment has better outcomes.
  - Outcomes should match the caregiver’s agenda.

Corry, M., et al. 2015, Mosely, et.al. 2017
Improving Resources to Counteract Demands

- **Transactional model of stress and coping**
  - Stress is an imbalance between demands and resources or occurs when pressure exceeds one's perceived ability to cope.

  - Resources in family caregiving.
    - Competence
    - Preparedness
    - Adequate information
    - Positive psychology.

Hudson, P. & Payne, S. Jr. of Palliative Care. 2011
Given, B. et. al. 2008
Interventions with Potential Merit


- A standardized patient education program for patients with Parkinson’s disease and their caregivers. A’Campo, Wekking et. al. 2010

Key Points: Take-Home Messages

1. Caregiver strain occurs at all stages of disease.
2. CG strain is heterogeneous making effective interventions complex.
3. Assessment of caregivers is important to know who is at risk and to identify needs.
4. Interventions that teach skills to provide behavioral change hold promise.
Selected References


Improving Caregiving Strain: PhotoVoice Methodology Overview

Joyce Bredesen, DNP, PHN, RN
Associate Professor
Metropolitan State University
St. Paul, MN
PhotoVoice Background

• **PhotoVoice Methodology:**
  • Dr. Carolyn Wang
  • Participatory research method used with various populations (assessment/research/intervention)
  • Elicits in-depth descriptions of realities through pictures

  – Intended outcomes of PhotoVoice:
    • Empowerment of participants
    • Increase community awareness
    • Promote dialogue to bring about change

(Catalani & Minkler, 2009; Hergenrather et al., 2009; Wang & Burris, 1997; Wang et al., 2004)
What Is PhotoVoice?

- A way to express, reflect, and communicate everyday life experiences.
- A technique that uses visual imagery through pictures to tell stories of the participant’s life realities.
- Photographs, as visual images, along with the descriptions of the meanings attached to these photographs, are a powerful method to explore and address the realities and perspectives of life by the participant.
- Brings about more in-depth discussion.

Catalina & Minkler 2009; Fitzpatrick et al., 2012; Goldsworthy & Knowles, 2008; Mayfield-Johnson et al., 2014; Wang & Burris, 1997
PhotoVoice Process

- 2-3 meetings - may direct PhotoVoice assignment
  - 1st meeting - go over use of camera, ethics in taking pictures, consent forms
  - 2nd meeting - develop pictures/may use digital options/computer: discuss process
  - 3rd meeting - review pictures, discuss what pictures mean to the person who took the pictures

- Individual meetings or group meetings:
  - Have used with both Parkinson’s care partners (individual) and also with Parkinson’s support groups
Examples of PhotoVoice as an Intervention

- **Used in support groups throughout MN:** The goal was to utilize PhotoVoice as a therapeutic intervention that could assist in bringing about a deeper discussion and healing to members within Parkinson’s disease support groups.
  - Worked with 12 support groups (approximately 150 participants; both those who had Parkinson’s and their care partners/family).

- Many PhotoVoice projects include a ‘showing of the pictures and stories’ in a public setting.
Example of Questions to Direct Pictures
(Used in Parkinson’s Support Groups)

1. Take pictures of things you do that help you cope with Parkinson’s. What things are helpful for your self-care?

2. Take pictures of the biggest challenges that you face on a day to day basis.

3. Take pictures of your support system and resources that you find helpful.

4. While you can’t change the diagnosis, take pictures of what your hopes and dreams are now.

*(Gave a worksheet to assist in remembering and documenting, as it was a month between meetings)*
“Accepting that my body cannot do some of the things I used to enjoy like running and tennis, and feeling like my mind doesn’t work like it used to. This all affects my relationships with my family and my friends.”

*Learned more about each other and were able to share experiences about what they have enjoyed doing.*
Results of PhotoVoice Use as an Intervention

- A total of 82 evaluation surveys were filled out (some couples completed together).
- 88% found Photovoice to be helpful or very helpful in bringing about more discussion within the support groups.
- 80% felt that taking the pictures and writing down their feelings about the pictures helped them to explore more about PD and how it affects them.
- 94% percent stated that it was helpful or very helpful to have others share their pictures and stories and to talk about their experiences.
Comments from Participants Regarding Use of PhotoVoice

- “I got to know my support group at a different deeper level, it was good.”
- “It brought about more discussion and a better understanding of each other.”
- “The pictures offered an opportunity to talk more in depth about some of our challenges and things that are harder to talk about.”
- “This project offered some time for good self-reflection. It made me think about how Parkinson’s affects my life.”
- “It was a good project to do together (as husband and wife). While he couldn’t take the pictures, he told me what he wanted me to take the pictures of. It helped us to talk about things we might not have talked about.”
References


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ANY QUESTIONS?
Upcoming Educational Programs

**Allied Team Training for Parkinson’s Disease™ (ATTP)**
ATTP is a three-day course designed to increase knowledge of PD and build capacity for comprehensive inter-professional care in the treatment of Parkinson’s disease.
Vancouver, BC Canada from April 4-6, 2018
parkinson.org/attp

**Nurse Faculty Program**
Apply to the Edmond J. Safra Visiting Nurse Faculty Program to help us prepare the next generation of nurses to care for the growing population of people with PD.
parkinson.org/edmondjsafranursing

**Physical Therapy Faculty Program**
Learn from internationally recognized PT experts in an intimate classroom setting and help change the future of physical therapy care in Parkinson’s.
Summer 2018 at Boston University and Oregon Health & Science University
parkinson.org/ptfaculty
Educational Resources

Order Materials
Information about Parkinson’s symptoms, medications, resources and more.
parkinson.org/books

Aware in Care Kit
Includes tools and information for people with PD to share with hospital staff during a planned or emergency hospital stay.
parkinson.org/awareincare

National Helpline
Available at 1-800-4PD-INFO or helpline@parkinson.org Monday through Friday 9:00 AM – 5:00 PM ET.

Podcast: Substantial Matters
New episodes every other Tuesday featuring Parkinson’s experts highlighting treatments, techniques and research.
parkinson.org/podcast