

# Exploring Stigma Experienced by People with Parkinson's Disease in Literature and Social Media

Santos, Z. M., Bowlin, A., Castillo, D., Hester, L., Melendez, J., Preston, B., Ramirez, B., Reyes, C., Rojas, A., Santos, J., Mastel-Smith, B., PhD, MS, RN, & Hermanns, M., PhD, RN, PMH-BC, ANEF

## BACKGROUND & SIGNIFICANCE

### Background

- Parkinson's Disease is an incurable progressive nervous system disorder that affects movement, speech, balance and coordination. It is often characterized by tremors, stiffness, and slow movement.

### Significance

- Stigma associated with poor patient outcome
- Depression, physical, mental and emotional health are affected
- Perceived stigma that is experienced is associated with quality of life



Jimmy Choi defeating stigma (and Guinness World Records) after being diagnosed with early onset PD. Used with permission.

## RESEARCH METHODS

### Design

- Multicase qualitative study

### Research Questions

- How do people with PD describe the stigma they experience?
- How is stigma represented in the literature?
- How has social media affected the stigma people with PD face?
- Do findings support the Stigma Theory?

**IRB approval received and informed consent will be provided**

### Setting

- Online video or phone call

### Sample

- 6 adults 30+yo and can read, write, and understand English

### Data collection

- One-to-one interviews audio-taped and transcribed
- Social media posts searched for under "stigma Parkinson's Disease"
- Measures taken to ensure validity and reliability

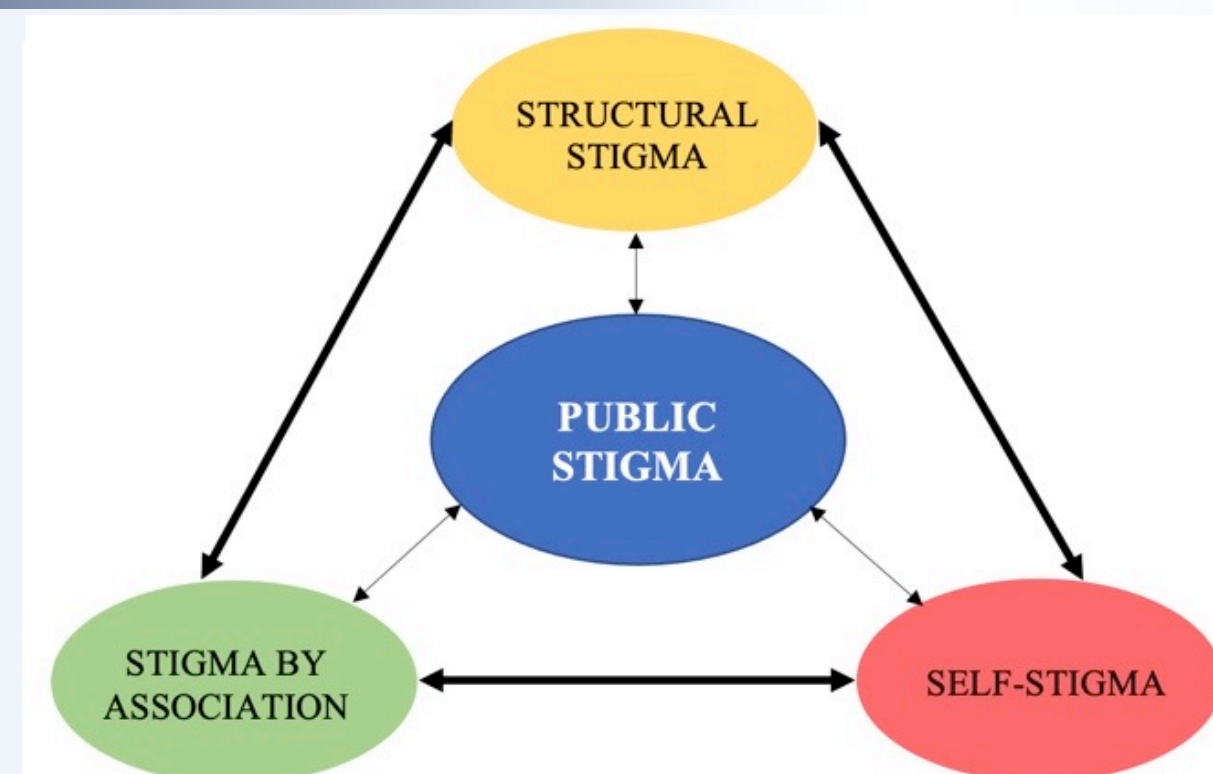
### Data analysis:

- Interview and social media data will be coded, analyzed individually, then compared as a whole
- Search for patterns, explanations, and rival explanations

## THEORY

### Stigma Theory:

- Self
- Structural
- By Association
- Public



Stigma Theory Schematic used with permission from Dr. Arjan Bos

## LITERATURE REVIEW

### Characteristics of PD that result in Stigma

- Early age of diagnosis
- Viewable motor symptoms
  - Dyskinesia
  - Drooling
  - Masking
- Difficulty performing daily activities
- Difficulty communicating
- Hallucinations

### Effects of Stigma for people with PD

- Lower quality of life
- Quickened disease progression
- Dehumanization
- Self-isolation
- Depression
- Frustration and stress
- Altered relationships with environment
- Embarrassment

## CONCLUSIONS

- This study focuses on perceptions of stigma by people diagnosed with PD and how current literature and social media portrays stigma.
- Literature Review Findings:
  - Stigma of PD causes embarrassment, anger, and frustration, and leads to self-isolation
  - The presence of motor symptoms leads to higher stigma
  - Stigma is a major cause of caregiver burnout
- Literature supports the stigma theory concepts of self and public stigma.
- Interviews and data analysis will be completed summer 2021 and published as a multicase study including care partners of people with PD.

## PURPOSE

The purposes of this study are to (a) explore how stigma is experienced by people with Parkinson's disease (PD) and (b) how current literature and (c) social media portray stigma for people with PD and (d) if findings support stigma theory