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#### Interpretive Phenomenological Analysis [IPA]: Examining the Impact of Sleep Disturbances on Lived Experiences of Persons with Parkinson's Disease (PwPD)

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# Examining the Impact of Sleep Disturbances on Lived Experiences of Persons with Parkinson's Disease (PwPD)

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### Background

- Sleep disturbances affect 60-96% of PwPD, which significantly:
  - Reduces Health Related-Quality of Life (HR-QOL)
  - Positively correlates with disease severity & duration
  - Increases the disease burden of care (Politis et al., 2010; Sobreira-Neto et al., 2017; Suzuki, 2020)
- Based on a stakeholder meeting of community dwellers with Parkinson disease, it was determined that typical sleep hygiene protocols may not be effective for the Parkinson's disease population due to the nature of the disorder.
- However, recommended sleep hygiene protocols for PwPD do not differ from that of the typical population.

## **Problem Statement**

There is lack of understanding of the lived experience of PwPD with sleep management.

### **Purpose Statement**

To examine the lived experiences of PwPD who suffer from sleep disturbances to better address their needs & challenges.

### **Research Question**

What are the lived experiences and challenges of PwPD with sleep management?

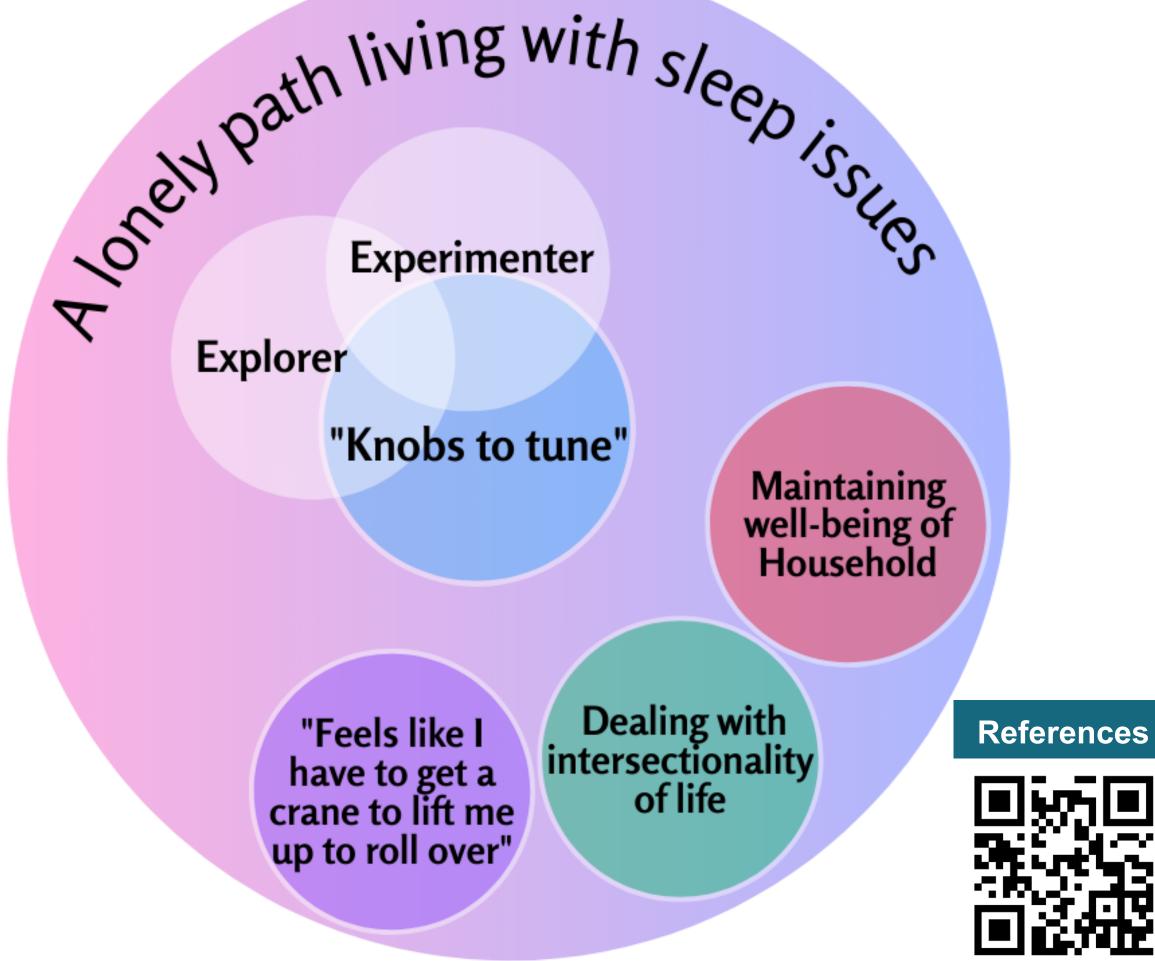
## **Theoretical Framework**

Occupational Adaptation was utilized as a framework to guide the understanding of PwPD & issues with sleep management that challenge their press for mastery.

Interpretive phenomenological analysis Constructivist approach

### **Inclusion criteria:**

- Diagnosis of PD •
- Age > 50 up to 85 years old •
- Score >18 on the Mini Mental State • Examination-1 (Tsoi et al., 2015)
- Report sleep disturbances identified • on the Parkinson's Disease Sleep Scale (Chaudhuri et al., 2002)
- Attend one in-person focus group
- Speak English •



## Methodology

**Participants: N= 9**, communitydwelling adults aged 57 – 75 years old (3 females, 6 males).

- Focus group 1: (n=4)
- Focus group 2: (n=5)

**Data collection:** semi-structured interview schedule/group & field journal.

Data analysis: open coding, memoing, fracturing the data, & examining emerging themes.

Reliability & validity: member checking & peer review, study audit.

The following themes emerged: **Superordinate Theme** A lonely path living with sleep issues **Subordinate Themes** 

- "Knobs to tune" (Strategist) • Explorer
  - Experimenter
- Maintaining the well-being of the household
- Dealing with the intersectionality of life
- "Need a crane to lift—to roll over"

Overall participants felt it was left to them to get help.

- issues if the participant brought it up.
- strategize & find a solution. • They were experimenting
- of life, symptoms of Parkinson's, & were issues that they juggled as they addressed their sleep management.

### Limitations

- Small sample size
- Lack of ethnic diversity

### Strengths

- Provided insight into the complexity of sleep management with Parkinson's disease

## **Implications for OT practice & research**

- tailored to the unique needs of PwPD.
- Healthcare professionals should

#### Results

#### Discussion

• Physicians addressed or acknowledged sleep • They felt the burden of constantly having to • They were exploring sleep solutions • Age-related issues, comorbidities, pressures maintaining the well-being of the household

• Implemented rigorous data analysis methods There is a need for a sleep hygiene protocol approach sleep issues utilizing a holistic approach inclusive of the person's context, performance patterns & skills, & client factors.