

Strain among Informal Caregivers of Persons with Parkinson's Disease

- **Thesis:** The purpose of this four-phased study is to develop an instrument to measure caregiver strain.
- **Summary:** A Likert type scale instrument has been developed, pilot tested and is currently in full implementation phase based on Abendroth's published model of caregiver strain.
- **Findings:** The phases of this study have included:
 - Conducted a caregiver focus group on strain
 - Developed a Likert type scale instrument based on dissertation and focus group data
 - Conducted an expert review of the instrument
 - Completed pilot test ($N = 32$) of the instrument
 - Reassessed directionality of items based on the constructs of the conceptual model in light of the quantitative findings using inter-item correlations
 - Used Cronbach's alpha to assess internal consistency of the four conditions/domains of the model
 - Modified instrument as needed to clarify constructs and enhance reliability
 - Assessed feasibility of research using this instrument
 - Identified recruitment issues
 - Identified more realistic time frame for future instrument development research
 - Launched full implementation study using the refined instrument
 - Currently in final phase of instrument development, collecting nation wide sample for a factor analysis
- **Data:** Qualitative and Quantitative data that have been used to refine and enhance the tool include:
 - **Focus Group:** The focus group confirmed the model and emphasized the fact that a multifaceted support system is crucial to mediate caregiver strain.

"Sometimes when it's bad I feel like my head's in a vise. Pressure, and it just sometimes feels unrelenting like I can't get a break. When I try to do something for myself I get interrupted". (Quote from a Caregiver)
 - **Pilot data:** The reliability analysis was substantially constrained due to small sample size ($N = 32$). However, reliability was indicated in three of the four domains
 - Pre-illness life circumstances: Alpha = .478 (6 cases lost due to missing data)
 - Support Systems : Alpha = .729 (3 cases lost)
 - Self-Preservation: Alpha = .760 (8 cases lost)
 - Managing imposing life events: Alpha = .883 (6 cases lost)
 - Five items were revised based on inter-item correlations that gave insight into the conceptual clarity of the model
 - Identified directionality of items for quantitative coding purposes
- **Long Term Goals:**
 - To promote understanding of caregiver strain and effective intervention
 - To publish a valid and reliable tool for use in the research community
 - To develop a scientifically refined diagnostic tool for use in primary care practice

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