



# Undergraduate Research Symposium May 17, 2019 Mary Gates Hall

## Online Proceedings

### POSTER SESSION 3

Commons West, Easel 35

2:30 PM to 4:00 PM

#### **Operationalization of Resilience for Family Care Partners of People Who Are Living with Dementia**

*Avery O'Hara, Fifth Year, Nursing*

*Mary Gates Scholar*

*Mentor: Tatiana Sadak, PCH*

Dementia impacts 4+ million older adults in the United States. The majority of patients with dementia (PWD) are cared for at home by family/friend care partners (CP). While this caregiving role can be highly meaningful, it is also a demanding responsibility. Resilience, or the ability to recover from stressful situations, has been shown to be protective for CP of PWD. There are three major models of resilience, describing resilience as: 1) an outcome, 2) a trait or 3) a process. Currently, there is no consensus on the best way to operationalize and measure resilience in the context of dementia caregiving. My project focuses on addressing this gap. My hypothesis is that: 1. Resilience in the context of dementia caregiving has specific characteristics, reflecting the complexity of caregiving; 2. CP likely over-estimate their resilience; 3. Resilience is a dynamic process related to positive functioning that fluctuates across time and situation, rather than a personality trait or outcome. 4. Optimal assessment will combine CP self-report with more objective, observable, or CP-reported behaviors. Our initial focus was understanding different approaches of defining and measuring resilience in CP of PWD. We used two data sources to code behaviors linked with resilience: 1. relevant literature; 2. 30 semi-structured interviews with CP of PWD evaluating resilience-related behaviors. We identified relevant behaviors and organized data from both sources using thematic coding. We used key identified behaviors to create a behavior-based model of CP resilience—Care Partner Resilience (CPR). Our hypotheses were confirmed. Our next steps are to validate CPR. Dementia is one of the major health conditions faced by the geriatric population, and CP burden from dementia can take a devastating toll the capacity to continue providing care. Thus, an accurate operational definition of resilience is essential in targeting interventions and developing long-term support tools for CP.

### POSTER SESSION 3

Commons West, Easel 34

2:30 PM to 4:00 PM

#### **Formalizing Care for the Caregiver in Hospice**

*Sandra Renae (Sandy) Kolberg, Fifth Year, Nursing*

*Mary Gates Scholar*

*Mentor: Tatiana Sadak, PCH*

*Mentor: Emily Ishado, Biobehavioral Nursing and Health Informatics*

Everyone dying at home requires help from a care partner (CP). For most people, these CPs are family members and friends who help their loved ones with daily tasks, medications, and comfort measures. Those who engage hospice services also benefit from the support of experienced medical/social service teams. By definition, the focus of hospice care is on a family unit, although currently there are no broadly disseminated systematic methods for assessing the needs of CPs or offering preventative interventions. My mentors, Dr. Sadak's team, conducted a pragmatic trial of assessing CP needs in hospice by adapting "Managing Your Loved One's Health" (MYLOH), a 29-item self-report measure of CP activation: readiness, knowledge, skills for meeting their care recipient's healthcare needs and maintain personal wellness for use in hospice. I reviewed and thematically coded: 1. Video interviews with RN case managers and administrators, 2. Researcher's field notes, and 3. All other documented communication between the research and the hospice teams; created a timeline and documented the rationale for adaptations that were made in MYLOH. Methods: A Sample of N=50 CP of people receiving hospice care; N=14 RN Case Managers; N=6 Hospice Administrators. MYLOH and several other brief CP assessment measures were administered by RN case managers to CPs on baseline, week 4, and week 12. Measures were used as a guide for conducting CP/Patient needs assessment, and to plan and assess effectiveness of interventions. Case managers took process notes and offered feedback via video-recorded interviews with the research team. Adaptations to MYLOH were made based on this iterative feedback. MYLOH-Hospice is a 12-item measure that is a useful tool for guiding assessment and interventions for CPs in hospice, it has strong face validity and acceptability, but is found to be too long for iterative routine use.