

**Sigma's 30th International Nursing Research Congress**  
**The Caregiver Role for a Family Member With Dementia**

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**Purpose:**

Worldwide, dementia affects around 50 million people (World Health Organization, 2018). In the U.S., dementia affects an estimated 5.7 million Americans, and this number is expected to rise to nearly 14 million by 2050 (Alzheimer's Association, 2018). Dementia has ramifications for those affected as well as their loved ones (Czekanski, 2017). More than 16.1 million Americans currently care for individuals with dementia without pay, most of this care being provided by their loved ones (Alzheimer's Association, 2018). Caring for a loved one is associated with emotional, physical and financial repercussions (Warchol-Biedermann et al., 2014). Because of these repercussions, caregiver respite is one factor that may sustain resilience over the continuum of care for family members caring for an individual with dementia (Roberts & Struckmeyer, 2018). The objectives of this study are to assess (a) the physical, emotional, and psychological effects of being a caregiver for a family member with dementia and (b) the impact of using an adult day service.

**Methods:**

Caregiver resilience is the successful use of coping strategies that emphasize the perspective of resilience rather than burden (Roberts & Struckmeyer, 2018). Resilience can be defined as being able to maintain normal or enhanced functioning during stressful caregiving experiences. Fitting with the conceptualization of resilience, caregivers experience subtle but long-term role changes, both physical and emotional. The sample will consist of caregivers who have family members that attend an adult day service center. Quantitative and qualitative data will be collected. Quantitative data will be collected with The Kingston Caregiver Stress Scale (KCSS) (Hopkins & Kilik, 2016). The scale contains 10 questions which assess caregiving, family, and financial issues related to the role; the scale has support for reliability and validity. Qualitative data will be collected during at least two focus groups. Undergraduate nursing research assistants will conduct the groups to assess the caregivers' experiences with their loved one. Participants will be recruited at support groups associated with adult day services. Data will be collected through a series of structured, open-ended questions about their experiences with caregiving and the impact of using adult day services. Each group session will begin with the question: Tell us about your experience of caring for your loved one. Each focus group will consist of 6-8 participants and will be audio recorded and transcribed verbatim for analysis. No attempt will be made to connect voices with individual identities. A detailed analysis of themes and interpretations will be provided. All recordings and transcripts will be destroyed after dissemination of data. As a thank you, all participants will be given a \$25.00 gift card to a local merchandise store and be provided refreshments at the focus groups.

**Results:**

Data from the KCSS and the focus groups will be provided. It is anticipated results will demonstrate what caregivers experience while caring for a family member with dementia.

**Conclusion:**

Results may further explain how caregivers cope with potential role overload, role strain, and variable levels of burden depending on their resiliency to manage the care that is needed. Using an adult day service may assist with the role strain and provide respite for the caregivers.

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**Keywords:**

adult day services, caregivers and dementia

**References:**

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**Abstract Summary:**

There are nearly 16 million caregivers for persons with dementia. Through focus group interviews, caregivers expressed their experiences and the impact of the role on their physical, emotional, and financial lives.

**Content Outline:**

I. Introduction

A. Incidence of dementia

B. Number of caregivers in the US

C. Purpose statement

## II. Method

A. Setting – caregivers who use adult day services

B. Quantitative/Qualitative design

C. The Kingston Caregiver Stress Scale (KCSS); assess care-giving, family, and financial issues

D. Focus groups – caregivers, 6 – 8 participants per group

1. focus groups leaders

2. structured and open-ended questions

E. Conceptual Framework – caregiver resilience

F. Verbatim transcription of focus group sessions

G. Analysis of transcripts

H. Analysis of KCSS questionnaire

I. Comparison of focus group and KCSS data

## III. Results

1. Results will be provided

## IV. Conclusions

1. Conclusions will be summarized

2. Connections to theory and further research will be provided

### First Primary Presenting Author

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