Qualitative Study: Caregiver Experience of Dementia

Seniors: Emma Kamp, Kayleigh Willett
Juniors: Madison Ling, Keegan Maris, Isabella Portugal
Theresa A. Kessler, PhD, RN, ACNS-BC, CNE, Lynette Rayman, DNP, RN, CNE

Background

- Dementia affects an estimated 5.5 million Americans (Czekanski, 2017) and has ramifications for those affected with the disease as well as their caregivers.
- Approximately 70-80% of people with dementia reside with a caregiver (Roberts & Struckmeyer, 2018).
- More than 15 million Americans currently care for individuals with dementia without pay, most provided by their loved ones (Czekanski, 2017).
- Caring for a loved one with dementia is associated with emotional, physical, and financial repercussions (Warchol-Biedermann et al., 2014).

Purpose

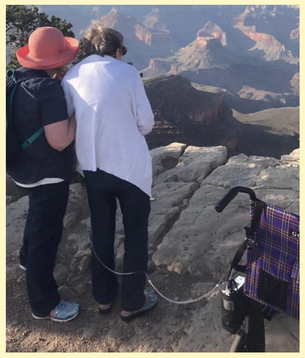
- The objectives of this qualitative study are to assess the physical, emotional, and psychological effects of being a caregiver for someone with dementia and the impact of using an adult day service.

Theoretical Framework

- 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 (Roberts & Struckmeyer, 2018).

Method

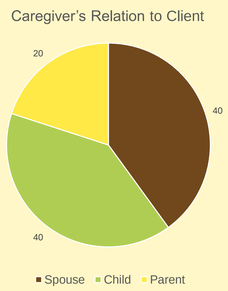
Approval: University IRB
Setting: Private, faith-based, adult day service center
Design: Cross-sectional, descriptive
Sample: Caregivers of those with dementia
N = 10
Qualitative: Two Focus groups:
Structured, open-ended questions
Analysis: Interviews audio recorded and transcribed verbatim

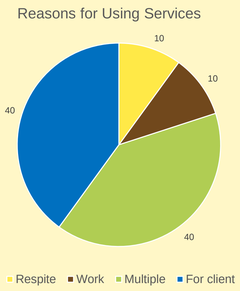


Results

Caregiver Characteristics

Age:	*M* = 65.0 *SD* = 10.58
Gender:	60% male, 40% female
Race:	90% White, 10% Hispanic
Employment:	50% employed outside the home
Years of Providing Care:	*M* = 6.1 *SD* = 6.0
Years of Using Day Service:	*M* = 1.8 *SD* = 0.98





Themes

Following verbatim analysis of the data, four themes emerged:

- Most Common Emotional Responses
- Benefits of Adult Day Service
- Overwhelming Impact on Daily Life
- Caregiver Social Isolation

Most Common Emotional Responses:

The participants described a variety of emotional responses experienced while providing care for their loved one. These emotions included feelings of grief, denial, frustration, and despair.

"Because I think the hardest thing I had to deal with was it's not going to get any better. There is no cure. I have to accept that….it's only going to get worse."
"I'd be crying every day. It's mourning. There's grief. It's a grief, and it's continuous. It's not like the person dies."

Results Cont.

Benefits of Adult Day Service:

When describing the benefits of an adult day service, the participants felt grateful for the security and peace of mind provided. It provided the time they needed to benefit their lives and helped promote resilience.

"I was able to get out and at least run, go to the YMCA. Because as you know, there's a lot of stress. And the physical activity was what saved me."
"They're a godsend, because that's a break for me. I try to work during those hours."

Overwhelming Impact on Daily Life:

Participants expressed concerns with role overload that changed the way they lived their daily lives. Not only did it impact them, but their family members as well.

"And my kids, sometimes I feel bad that it's compromising kind of their I don't know social lives."
"You have to take over everything."
"Grocery shopping, making food, sleeping in a chair next to his bed. I had to you know, learn everything as far as safety in the house."

Caregiver Social Isolation:

A main concern expressed by participants was feeling disconnected from their lives, friends, and social connections. Some even expressed feelings of being a burden to others.

"You have to cut back on things you love. You can't do the hobbies you used to do. You can't do the, you know, meet the friend for lunch on any given day. You can't do those simple things that used to bring you a little bit of joy."
"You don't want to ruin somebody else's time, because usually that topic comes up."

Conclusions/Implications for Practice

- Respite services, such as adult day centers, provide caregivers opportunities for self-care, the ability to perform daily tasks, and a decrease in emotional burden.
- Using respite services promotes resiliency in the caregivers and supports a healthier mental, emotional, social, and physical well-being.
- Education is needed to inform the public of the resources available when caring for someone with dementia.

Future Research

- Investigate barriers caregivers face when learning about an adult day center.
- Further assessment of caregivers' experiences as their loved one's disease continues to progress.
- Explore the impact of adult day services on the person with dementia.

Acknowledgements: Funding from The Kreft Endowment