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## Physiological and functional consequences of caregiving for relatives with dementia

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### Abstract

**Introduction:** Dementia caregivers (DCGs) physical and mental wellbeing are seriously impacted by the conditions of caregiving, often contributing to further hospitalizations, higher drug use, and higher mortality rate relative to non-caregiving peers.

**Materials and Methods:** The convenience study included caregivers of a dementia family member who attended an adult day center in a rural/suburban town in the Midwest where there was a clinical rotation for the students. The adult day center provides services regardless of race, religion, gender, or financial means.

**Results:** Fifty percent were employed outside the home. On average, the participant's provided care for four years and brought their family member to the adult day center for approximately one year. One-half of the caregivers (45 %) were responsible for the care of someone else and received assistance in the caregiver role (55 %) beyond the adult day center.

**Conclusion:** There is a growing recognition that chronic stress experienced by DCGs is linked to many physiological changes and changes in behavior and function. Clinicians often consider DCGs healthy adults not requiring special care.

**Keywords:** Physiological, functional consequences, dementia

### Introduction

"Dementia caregivers (DCGs) physical and mental wellbeing are seriously impacted by the conditions of caregiving, often contributing to further hospitalizations, higher drug use, and higher mortality rate relative to non-caregiving peers (Vitaliano *et al.*, 2003) <sup>[10]</sup>. Dementia caregivers' health problems are often neglected and overshadowed by those of their care recipient until a crisis occurs. However, the health and well-being of DCGs are important to caregivers and their care recipients because they may affect the quality of care provided by DCGs, the timing of the recipient's nursing home placement, and overall healthcare costs (Vitaliano *et al.*, 2003) <sup>[10]</sup>. One approach is to mentor students in order to lead research projects. Evidence supports that undergraduate students have the requisite skills to be successful at designing, implementing, and evaluating research when mentored by faculty <sup>[1-3]</sup>. While faculty mentors facilitate student success in the research process, faculty mentors may also provide a stimulus for students to pursue graduate degrees, while simultaneously introducing students to faculty roles <sup>[4]</sup>. Using a student-faculty mentor model promotes immersion in knowledge generation, excitement about the research process, and the development of leadership skills <sup>[2]</sup>. Often times, students become excited about their clinical experiences and wish they could have additional time in those areas or raise questions about what they observed that can lead to research questions. During a clinical rotation at an adult day center for those with dementia, students were positively impacted by the care provided. They were cognizant of the demands of the caregiver position and asked concerns about how respite services affected the caregiver role. Students wanted to have a deeper understanding of the daily demands associated with providing care to a family member with dementia, and how, as future nurses, they could support caregivers.

### Material and Method

Qualitative and quantitative data were collected simultaneously. Simultaneous data collection lends itself to team research and allowed members of the student-faculty collaborative team to weigh both sources of data.

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Eight undergraduate students (3 seniors, 2 juniors, and 3 sophomores) and two faculty advisors were part of the collaborative team. The senior students led the team, guided by mentors from the faculty. Weekly meetings were held to discuss the achievement of the objective and to encourage the students as they carried out the research. Students conducted the literature review, selected a framework, developed the methodology, carried out the data collection process, and disseminated the results. The convenience study included caregivers of a dementia family member who attended an adult day center in a rural/suburban town in the Midwest where there was a clinical rotation for the students. The adult day center provides services regardless of race, religion, gender, or financial means. The director of the adult day center sent a flyer, developed by the collaborative research team, as part of their monthly newsletter. The flyer invited caregivers to join one of two focus groups to gather information about their experiences. During two regularly

scheduled caregiver support groups conducted by the adult day center, a member of the research team also welcomed participants. A total of 11 caregivers responded, and there were 10 caregivers involved.

### Result

The majority of caregivers were over 65 years of age, male (55 %), and white (90 %) (See Table 1). Fifty percent were employed outside the home. On average, the participant's provided care for four years and brought their family member to the adult day center for approximately one year. One-half of the caregivers (45 %) were responsible for the care of some-one else and received assistance in the caregiver role (55 %) beyond the adult day center. Top reasons for the family care-giver to use the adult day center were to socialize (30 %) and work (30%). The persons with dementia receiving care were spouses (30%), parents (30 %), and children of the caregivers (25 %).

**Table 1:** Sample characteristics of family caregivers (N = 20)

Variable	Mean	SD	Range	n	%
Age	65.0	10.58	46-84		
Gender					55
Male				11	
Female				9	45
Employment					25
Full-time				5	
Part-time				6	30
Retired				9	45
Number of years providing care	4.2	3.00	1-10		
Number of years using adult day center	1.3	0.98	0-3		
Received help from another person/service					30
None				6	
Family				7	35
Hired caregiver/assistant				4	20
Blank				3	15
Responsible for the care of someone else					
None				6	30
Handicapped child				2	10
Children				2	10
Mother				4	20
Wife				3	15
Blank				3	15
Reason for using adult day center					
Take care of personal health				3	15
Provide activities/socialization for person with dementia				4	20
Socialize				6	30
Work				6	30
Respite				5	25
Complete errands				4	20
Family responsibilities				2	10

### Quantitative data

Participants reported experiencing moderate levels of caregiving stress according to the KCSS in all three domains (M = 31.4, SD = 9.4). Internal consistency for the KCSS in this sample was  $r = .93$ . Three items related to the domain of care giving issues on the KCSS were most stressful: "feelings of being overwhelmed, over worked, and/or Overburdened" (M = 3.75, SD = 1.16), "changes in your social life" (M = 4.71, SD = .47), and "concerns regarding the future care needs of your spouse/relative" (M = 5.0, SD=.73). Least stressful items were: "having any conflicts within your family over care decisions" (M=2.71, SD=

.91) from the family issues domain and "having any financial difficulties with care giving" (M = 2.71, SD = .91) from the financial issues domain.

### Discussion

The objective outcome measures used in the reviewed studies include markers of sympathetic, HPA axis and coagulant activity, measures of metabolic and immune functioning and cellular aging. During two regularly scheduled caregiver support groups conducted by the adult day center, a member of the research team also welcomed participants. A total of 11 caregivers responded, and there were 10 caregivers involved. The list of possible variables

that can alter DCG's impact on health and function is another significant outcome of this study. Knowledge of factors influencing the relationship between stress and health care will help design and target optimal treatments. In addition to previously known influences of age, SES, and PWD characteristics on DCG health, studies in this review show that access to respite and physical activity levels can also affect the relationship between DCG stress and health (Mills *et al.*, 2004; Von Kanel *et al.*, 2011) [5, 6]. There are also other factors (lifestyle factors) that are of concern and need to be evaluated in the future. Caregiving requires continuous PWD monitoring, which requires endless quantities of time and energy, and DCGs often neglect their own habits of wellbeing, nutrition, sleep, and exercise. More study is warranted to determine the impact of these factors on caregiving and wellbeing. Another interesting finding from a single study that emerges from the review is potential genetic influences on DCG stress reactivity (Brummett *et al.*, 2008) [7]. This finding needs to be confirmed and extended in future research. A common DCG issue not addressed in the reviewed studies is social isolation. Caucasian DCGs are especially prone to social isolation compared to African-American or Latino DCGs who traditionally rely on extended family networks (Schoenmakers *et al.*, 2010) [8]. Both ethnicity factors and isolation are critical to assess in the future as they might increase the risk of DCG depression (Schoenmakers *et al.*, 2010) [8]. In addition, while this research referred to depression as a common risk factor for DCG, the effectiveness of depression therapies in the sense of chronic dementia care stressor and best treatment methods for depression in DCGs remained beyond the reach of this study and should be discussed in future work.

## Conclusion

There is a growing recognition that chronic stress experienced by DCGs is linked to many physiological changes and changes in behavior and function. Clinicians often consider DCGs healthy adults not requiring special care. Dementia caregivers also often neglect their own health by limiting their visits to care providers for their own needs and failing to obtain vaccinations (Thorpe *et al.*, 2006) [9]. The public, clinicians, DCG families, and DCGs need to be educated about the risks involved in dementia caregiving to allow for timely intervention or prevention of the potential problems in DCGs. Societal resources, which are always limited, need to be optimally allocated to maximize the health and well-being of DCGs.

## Conflict of Interest

Not available

## Financial Support

Not available

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### How to Cite This Article

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