

45th Biennial Convention (16-20 November 2019)

Will a Self-Compassion Intervention Improve Rural Caregivers of Persons With Early-Stage Dementia Quality of Life?

Dorothy J. Dunn, PhD, RN, FNP-BC, AHN-BC

School of Nursing, Northern Arizona University, Flagstaff, AZ, USA

Michael J. McCarthy, PhD, MSW

School of Social Work, Northern Arizona University, Flagstaff, AZ, USA

Yolanda E. Garcia, PhD

College of Education, Northern Arizona University, Flagstaff, AZ, USA

Dementia is a human and global problem. As people live longer the number of people who have dementia is rising rapidly in low and middle income countries. Worldwide, one case of dementia is identified every three seconds (World Alzheimer Report, 2018). According to the World Alzheimer Report of 2018, fifty-million people around the globe are living with dementia. By 2050 the number of people with dementia is expected to triple to 152 million and the estimate cost currently is one trillion U.S. dollars and will double by 2030 (World Alzheimer Report, 2018).

Alzheimer dementia is the sixth leading cause of death in the United States and the fifth leading cause of death among people aged 65 years and over in the state of Arizona (Alzheimer's Association, 2018). An estimated 5.7 million persons in the United States have Alzheimer's dementia. The cost of care for people with Alzheimer's dementia and other dementias was estimated to be \$232 billion dollars. The southern and western parts of the United States are expected to experience 50% and greater increase in number of people with Alzheimer's dementia. In Arizona the change in Alzheimer's incidence in 2025 is projected to be an increase of 42.9% (Alzheimer's Association, 2018).

The increasing number of individuals with Alzheimer's dementia will have a marked impact on health care systems both locally and globally, as well as on families and caregivers. Caregiving provided by family members of people with Alzheimer's dementia is somewhat similar to help provided by caregivers of other diseases. However, dementia caregivers tend to provide more extensive assistance with instrumental activities of daily living and provide care for a longer time period on average than caregivers of older adults with other conditions. The progression of the disease may occur in different ways, but the most common symptom in the early stage of the disease is diminished short-term memory (Alzheimer's Association, 2018). For example, difficulty remembering names, and the details of recent events are often early clinical symptoms of Alzheimer's dementia. Early disinterest in activities and depression may also occur. These symptoms impact the quality of life of both the caregiver and care recipient.

The changes in caregiving over time of the disease progression can result in caregivers experiencing increased emotional stress, depression, impaired immune system response, health impairments, loss of wages due to disruptions in employment, and depleted income and finances (Kiecolt-Glaser, Preacher, MacCallum, Atkinson, Malarkey, & Glaser, 2013).

The demands for caregiving increase as the disease progresses, many caregivers are not prepared for dealing with symptoms that evolve such as agitation, resistance to care, emotional lability, delusions, hallucinations, repetitive vocalizations, wandering, anger, and paranoia. Dementia

caregiving is associated with potentially decreasing a caregiver's quality of life. Family Caregiver Alliance recently stated that 63% of caregivers will predecease their care recipient (Family Caregiving Alliance, 2016).

A caregiver who practices self-compassion can experience what is considered a protective factor, fostering emotional resilience (Neff, 2015). Self-compassion can be viewed as a useful emotional regulation strategy, in which painful or distressing feelings that caregivers may experience are not avoided but are instead held in awareness with kindness, understanding, and a sense of shared humanity (Neff, 2015).. Having compassion for one-self implies that caregivers will try to prevent the experience of suffering in the first place, giving rise to proactive behaviors aimed at promoting or maintaining well-being and improving quality of life. Caregivers who reported higher level of preparedness for caregiving experience lower levels of caregiver stress and higher levels of health and well-being (Allen, & Leary, 2013). The goal is to better understand the associations of dementia caregiver knowledge, quality of life, and self-compassion via an innovative psychoeducation intervention program for rural caregivers of persons with early-stage dementia and mild cognitive impairment.

Interventions aimed at addressing the needs of caregivers of persons with dementia could have important positive impact on the caregiver and care recipient's quality of life. Providing education and support for caregivers has been shown to improve or maintain the quality of life of caregivers of persons with dementia and help caregivers cope with stressors (Bell, et al., 2006). Studies have shown that increased knowledge about dementia and the use of positive coping skills significantly diminished the daily struggles with the illness (Bell, et al., 2006; Goldberg-Arnold, Fristad, & Gavazzi, 1999). Caregivers of persons with dementia who participated in a multicomponent caregiver intervention that included psychoeducation intervention along with respite and counseling, demonstrated lower rates of depression and improved quality of life (Bell, et al., 2006). There are a growing number of psychoeducation interventions programs (PIPs) that provide skill-building education to those who are diagnosed with a mental illness such as dementia and have been used with caregivers of persons with dementia (Goldberg, 1999). Recent studies have shown positive results with psychoeducational interventions on caregiver's increased dementia knowledge, use of positive coping skills, and reduction of caregiver stress that significantly improve caregiver well-being (Bell, et al., 2006; Schulz, et al., 2002; Sorenson, Pinquart, & Duberstein, 2002). However most programs are provided in urban medical center and not available or easily accessed for rural caregivers. Four themes were identified from a literature review conducted regarding rural caregivers of persons with dementia: 1) access to health care, 2) unique rural needs, 3) application of knowledge, and 4) rural cultural competence (XX, Price, & Neder, 2016). There is a possible comparison of these four rural caregiver's and caregiver's challenges to low and middle resource countries in how they may experience, obtain knowledge and support needs in order to address health care issues that many providers, caregiver's and care recipients are currently experiencing. Therefore, the overall objective of this research is to implement the psychoeducation intervention program (PIP) to measure changes in rural caregiver knowledge of dementia, quality of life, and self-compassion.

The purpose of this descriptive quantitative one-group pre-test-post-test intervention study is to determine if there is a relationship between self-compassion, increase in caregiver knowledge of dementia, and improvement of quality of life. The implementation of the five-week PIP is for rural caregivers of Northern Arizona of Navajo county who identify as a caregiver of a person with early-stage dementia and mild cognitive impairment.

Hypothesis 1: What is the significance of the PIP on rural caregiver's dementia care knowledge and quality of life?

Hypothesis 2: Will the PIP improve rural caregiver's quality of life after learning and practicing self-compassion strategies?

This study will predict that rural caregiver's quality of life will improve by learning and using self-compassion strategies. Utilizations of the Carpenter's Alzheimer's Disease Knowledge Scale (ADKS), Neff's Self-compassion Scale-Short Form (SCS-SF), Logsdon's Quality of Life-Alzheimer's Disease Scale (QOL-AD), and the World Health Organization Quality of Life Scale (WHOQOL_BREF) for the five-week self-compassion PIP will demonstrate the benefits for caregivers in the rural and underserved region of Northern Arizona. The PIP will provide knowledge of dementia, support and education of caring for self and self-compassion strategies to enhance resilience and improve rural caregiver's quality of life.

Title:

Will a Self-Compassion Intervention Improve Rural Caregivers of Persons With Early-Stage Dementia Quality of Life?

Keywords:

Alzheimer's dementia, Rural caregivers and Self-compassion

References:

Allen, A. B. & Leary, M. R. (2014). Self-compassion responses to aging. *The Gerontologist*, 54(2), 190-200.

Alzheimer's Association (2018). *Alzheimer's disease facts and figures*. Retrieved from https://www.alz.org/media/HomeOffice/Facts_Figures/facts-and-figures.pdf
Alzheimer's Disease International (2018). *World Alzheimer Report 2018*. Retrieved from <https://www.alz.co.uk/research/world-report-2018>

Belle, S. H., Burzio, L., Burns, R., Coon, D., Czaja, S. J., Gallagher-Thompson, D., & Gitlin, L. (2006). Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: a randomized controlled trial. *Annals of Internal Medicine*, 145(10), 727-738.

Family Caregiving Alliance (2016). *Caregiver resources*. Retrieved from <https://www.caregiver.org/health-issues/dementia>

Goldberg-Arnold, J. S., Fristad, M. A., & Gavazzi, S. M. (1999). Family psychoeducation: giving caregivers what they want and need. *Family Relations*, 48(4), 411-417.

Kiecolt-Glaser, J. K., Preacher, K. J., MacCallum, R. C., Atkinson, C., Malarkey, W. B., & Glaser, R. (2013). Chronic stress and age-related increases in the proinflammatory cytokine IL-6. *Proceedings of the National Academy of Sciences of the United States of America*, 100(15), 9090-9095.

Neff, K. (2015). *Self-compassion: The proven power of being kind to yourself*. New York: NY: HarperCollins Publishers.

Schultz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Matrie, L. M., & Belle, S. H. (2002). Dementia caregiver intervention research. *The Gerontologist*, 42(5), 589-602.

Schumacher, K. L., Stewart, B. J., & Archbold, P. G. (2007). Mutuality and preparedness moderate effects of caregiving demand on cancer family caregiver outcomes. *Nursing Research*, 56(6), 425-433.

Sorensen, S., Pinquart, M. & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356-372.

X.X., Price, D. E., & Neder, S. (2016). Rural caregivers of persons with dementia: Review of literature guided by Rogers' science of unitary human beings. *Visions: The Journal of Rogerian Nursing Science*, 22(1), Manuscript 2, 24 pages. Retrieved from <http://www.societyofrogeriansscholars.org/>

Abstract Summary:

This descriptive quantitative intervention study is to determine if there is a relationship between self-compassion, increase in caregiver knowledge of dementia care, and improvement of quality of life. Rural caregivers of a person with early-stage dementia will be recruited for this five-week intervention.

Content Outline:

Introduction

Dementia is a human and global problem. As people live longer the number of people who have dementia is rising rapidly in low and middle income countries. Worldwide, one case of dementia is identified every three seconds (World Alzheimer Report, 2018). According to the World Alzheimer Report of 2018, fifty-million people around the globe are living with dementia. By 2050 the number of people with dementia is expected to triple to 152 million and the estimate cost currently is one trillion U.S. dollars and will double by 2030 (World Alzheimer Report, 2018). There is a crisis level need identified to support caregivers of persons with dementia.

Body

The increasing number of individuals with Alzheimer's dementia will have a marked impact on health care systems both locally and globally, as well as on families and caregivers. Caregiving provided by family members of people with Alzheimer's dementia is somewhat similar to help provided by caregivers of other diseases. However, dementia caregivers tend to provide more extensive assistance with instrumental activities of daily living and provide care for a longer time period on average than caregivers of older adults with other conditions. The progression of the disease may occur in different ways, but the most common symptom in the early stage of the disease is diminished short-term memory (Alzheimer's Association, 2018). For example, difficulty remembering names, and the details of recent events are often early clinical symptoms of Alzheimer's dementia. Early disinterest in activities and depression may also occur. These symptoms impact the quality of life of both the caregiver and care recipient.

The changes in caregiving over time of the disease progression can result in caregivers experiencing increased emotional stress, depression, impaired immune system response, health

impairments, loss of wages due to disruptions in employment, and depleted income and finances (Kiecolt-Glasser, Preacher, MacCallum, Atkinson, Malarkey, & Glaser, 2013).

The demands for caregiving increase as the disease progresses, many caregivers are not prepared for dealing with symptoms that evolve such as agitation, resistance to care, emotional lability, delusions, hallucinations, repetitive vocalizations, wandering, anger, and paranoia. Dementia caregiving is associated with potentially decreasing a caregiver's quality of life. Family Caregiver Alliance recently stated that 63% of caregivers will predecease their care recipient (Family Caregiving Alliance, 2016).

A caregiver who practices self-compassion can experience what is considered a protective factor, fostering emotional resilience (Neff, 2015). Self-compassion can be viewed as a useful emotional regulation strategy, in which painful or distressing feelings that caregivers may experience are not avoided but are instead held in awareness with kindness, understanding, and a sense of shared humanity (Neff, 2015). Having compassion for one-self implies that caregivers will try to prevent the experience of suffering in the first place, giving rise to proactive behaviors aimed at promoting or maintaining well-being and improving quality of life. Caregivers who reported higher level of preparedness for caregiving experience lower levels of caregiver stress and higher levels of health and well-being (Allen, & Leary, 2013).

Conclusion

The goal is to better understand the associations of dementia caregiver knowledge, quality of life, and self-compassion via an innovative psychoeducation intervention program for rural caregivers of persons with early-stage dementia and mild cognitive impairment. The PIP will provide knowledge of dementia, support and education of caring for self and self-compassion strategies to enhance resilience and improve rural caregiver's quality of life.

First Primary Presenting Author

Primary Presenting Author

Dorothy J. Dunn, PhD, RN, FNP-BC, AHN-BC
Northern Arizona University
School of Nursing
Associate Professor
Flagstaff AZ
USA

Author Summary: Dr. Dunn is an associate professor at the Northern Arizona University (NAU), School of Nursing (SON). She is a board certified family nurse practitioner and advanced holistic nurse. Dr. Dunn is the owner and founder of Dunn Family Wellness, LLC providing comprehensive memory evaluation and psychoeducational treatment for patient and families for persons concerned with memory loss. Her research is centered on informal and formal rural caregivers, including Dunns' theory of compassion energy.

Second Secondary Presenting Author

Corresponding Secondary Presenting Author

Michael J. McCarthy, PhD, MSW
Northern Arizona University
School of Social Work
Associate Professor
Flagstaff AZ
USA

Author Summary: Associate Professor of Social Work from University of Cincinnati and now Northern Arizona University who is involved currently with American Heart Association Mentored Clinical and Population Research Award. Development and Validation of a Quality of Relationship Intervention to Prevent Depression in Stroke Survivors and Caregivers. The goal of this project is to develop, content validate, and pilot test the materials and procedures for an intervention for stroke dyads.

Third Secondary Presenting Author

Corresponding Secondary Presenting Author

Yolanda E. Garcia, PhD
Northern Arizona University
College of Education
Associate professor
Flagstaff AZ
USA

Author Summary: Dr. Garcia is an associate professor and psychologist at Northern Arizona University and past President (2017), of the National Latina/o Psychological Association. Her specialty is in educational psychology. She has a passion for older adults and am looking to expand both in treatment and research areas.