

RESHAPING THE FUTURE OF CARE

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The Role of the Caregiver

Caregiving involves attending to another person's health needs and their overall well-being. Caregivers for persons living with Alzheimer's disease and related dementias (ADRD) provide assistance in bathing, dressing, shopping, and bill paying along with emotional support. Additionally, these caregivers provide the communication and coordination with other family members and the health care team while ensuring safety of person with ADRD. Most caregivers are unpaid family or friends of the person living with ADRD.¹



There are over 11.2 million people caregiving for persons living with ADRD in the United States, with over 196,000 of these caregivers residing in Wisconsin. Over 59% of these caregivers rate their stress level as high or very high. When compared with all caregivers, people caregiving for persons living with ADRD have twice the incidence of substantial emotional, financial, and physical difficulties. Caregiving for those with ADRD takes a devastating toll on one's wellbeing.¹

Dr. Ruekert Kobiske PhD, RN is the Director MSN Program/Clinical Associate Professor of Nursing in the College of Health Sciences at Carroll University. She has a personal connection to dementia as her father, grandfather, uncle, and aunt all battled dementia.



Dr. Ruekert Kobiske wanted to have a greater understanding of the role caregivers have in the life of someone with dementia. "I've seen many forms of caregiving," Ruekert Kobiske said. "Before my research, I saw some caregivers that succeeded, and others that struggled. I wanted to understand the difference so we can find ways to help all caregivers."

Caregiver Research

Dr. Ruekert Kobiske's research looked at familial caregivers. "Alzheimer's and related dementias have two victims – not only the individual living with the disease, but also the caregiver and family who support them. My research highlights that if you can help the caregiver, that in turn helps the person with dementia." She conducted several studies including:

Study 1: Caregiver Characteristics

"This study focused on the characteristics of successful caregivers," Ruekert Kobiske said. "It evaluated traits for resilience in caregivers of partners with dementia. Some characteristics that helped caregivers succeed and thrive included an active support system, ability to find humor in situations, and a belief that the caregiver can succeed in the caregiving role. The goal is to be able to translate successful characteristics to caregivers who are struggling, to increase their quality of their life."

¹ Alzheimer's Association 2020 Alzheimer's Disease Facts and Figures

Study 2: Pre-death grief impact on Caregivers

"This research study looked at the long goodbye and the impact on caregivers," Ruckert Kobiske said. "Because Alzheimer's is a slowly progressing disease, life doesn't stop the day of a diagnosis. Pre-death grief is the loss the caregiver experiences during the long goodbye when their loved one is physically present, but emotionally and psychologically no longer able to be active in their relationships. The caregiver is physically still caring for their loved ones, but the previous relationship is gone or changed dramatically. We found that pre-death grief accounted for 42% of the stress caregivers feel, which was a high percentage."

Study 3: Shaping Future Health care workers for Dementia Care

"This is a multi-phase study that is extremely important for the future of dementia health care," Ruckert Kobiske said. "We want to help future health care workers understand what someone living with dementia, and their caregiver experience so that these health care workers can give optimal care to people with dementia. Often, we're educating someone in their early to mid-20's and trying to help them learn that this group of people needs patience, understanding and empathy."

"In order to understand a dementia experience, students completed a Virtual Dementia Simulation, which was developed by Second Wind Dreams. This simulation allows people to experience common challenges faced by a person living with dementia," Ruckert Kobiske said. "For instance, students wore glasses that decrease vision, headphones with white noise, gloves that decrease dexterity and inserts in shoes that are uncomfortable. Then students had to complete five simple tasks such as buttoning a shirt, opening a pill bottle, setting a table, etc."



"Overwhelmingly, students found the simulation to be an 'eye-opening experience' that changed how they delivered care. Students commented that they would have more patience and understanding, after walking in the shoes of someone with dementia. Additionally, the research assessed the impact of the dementia simulation on the nursing students and their level of empathy, which did increase after completing the simulation."

Future of Nursing and Women in Science

"Part of my role as an educator is to recruit future students entering the field of nursing," Ruckert Kobiske said. "There has been a nursing shortage, but COVID has further hit the field. We're seeing nurses retiring earlier and a hesitancy of some to enter the field. But nursing is very rewarding. As the aging population is outpacing other groups, nurses are at the forefront as we are able to look at a person holistically and truly make a difference in the lives of patients. This is the message I emphasize as we recruit."

Dr. Ruckert Kobiske has been involved with the Alzheimer's Association for nearly 30 years as a volunteer and advocate. She is the Alzheimer's Association Wisconsin Chapter Ambassador for District One and has met with members of Congress including, Speaker Paul Ryan, Congressman Bryan Steil, Senator Tammy Baldwin and staff for Senator Ron Johnson to advocate for legislation to support the mission of the Alzheimer's Association. Additionally, she also organizes and recruits nursing students from Carroll University to volunteer at the Walk to End Alzheimer's® Waukesha County and has participated in the Walk both in Milwaukee and Waukesha counties over the years.

