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Reciprocity: Caring for America's Caregivers

Courtney Dunn
Cleveland State University

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Reciprocity: Caring for America's Caregivers

Cover Page Footnote

I am endlessly grateful to my mother, who allowed me to use her as not only an example, but also a driving force behind my writing. I would like to thank my professor, Jessica Schantz, for her encouragement in choosing a topic so close to my heart and helping me throughout the editing process.

She hunches over her desk in the muggy office, slides her short, brown, unwashed locks behind her ear, and with her bloodshot eyes she glances at the clock for what must be the fifteenth time in ten minutes. “Stop worrying, Susie,” she whispers to herself. “He’s going to call. He’s probably still sleeping.” A minute goes by as she stares at the spreadsheet on the computer screen, unmoving fingers resting on the keyboard. Finally, as if she cannot hold herself back any longer, she lunges at her phone, frantically dialing the numbers. After about ten seconds there must be a response because you can see the relief overwhelm her face. She warily reveals a smile.



Photo 1: Charly and Susie celebrated their anniversary with a train ride in Dollywood, TN. July 2015

Welcome to a day in the life of Susie Dunn. She is 54-years-old and the sole provider for her family: her husband, Charly, their college-going daughter, and their lively four-year-old Boston Terrier. This might sound like the classic American family; however, Charly is 84-years-old and in 2014 he was diagnosed with dementia from Alzheimer’s disease. Susie works about 50 hours per week, but while at work she constantly worries about Charly driving and getting in a car accident or falling down the stairs at home. She comes home from work to try to get housework done, but has to spend hours cooking, organizing his medications, and helping him complete whatever task he considers most important. At the end of the day she is

exhausted, but is kept up all night by him talking about work he needs to do or non-existent money problems. Susie works two careers, a day shift in the office and a night shift as a home caregiver – and she never gets a day off. I would know; I am her daughter.



Like my father, approximately 5.3 million Americans have been diagnosed with Alzheimer’s disease (Gaugler et al., 2015, p.16). Experts have categorized the disease into three stages defined in the “2015 Alzheimer’s Disease Facts and Figures.” First is the “preclinical” stage when individuals suffer measurable differences in the brain indicating signs of the disease but the patient has yet to

experience obvious symptoms. The second stage involves mild cognitive impairment (MCI). Small changes in thinking and decision making become evident but do not affect the individual's ability to perform everyday tasks. The final stage is dementia, when the individual has increasingly severe symptoms which affect his or her ability to function in everyday life (Gaugler et al., 2015, p.13). Once someone is diagnosed with dementia, it is likely that her or she will need assistance to carry out complex tasks such as organizing medication and paying bills. As the disease progresses, the patient will even need assistance walking, bathing, and eating.

Despite the difficulty of managing these symptoms, 15.7 million people provided unpaid care for someone with Alzheimer's disease in 2014, 85% of these people being family members (Gaugler et al., 2015, p.31). Susie is one of these millions, and she can account for the impact it has had on her both physically and mentally. She reports persistent feelings of anxiety which can negatively impact her ability to focus at work, eat healthy, or feel energized enough to exercise. "Each and every day I worry about Charly. I never know how he will be when he

wakes up, so I actually worry constantly." Though the impact is different for each individual, surely all Alzheimer's care providers experience some burden of care. The Alzheimer's Association reported that about 40% of dementia family caregivers suffer depression, with increasing rates as the disease progresses (Gaugler et al., 2015, p.38). As further demonstrated by Figure 1, caregivers experience both physical and emotional stress from caregiving.

These levels of stress vary for each caregiver, calling for research to determine what factors of Alzheimer's caregiving lead to different forms of emotional and physical burden.

In 2010, two researchers from Virginia Polytechnic Institute's Center for Gerontology, Rosemary Blieszner, PhD and Karen A. Roberto, PhD, published their research examining characteristics, responses, and psychological well-being of family care providers to people diagnosed with mild cognitive impairment. In

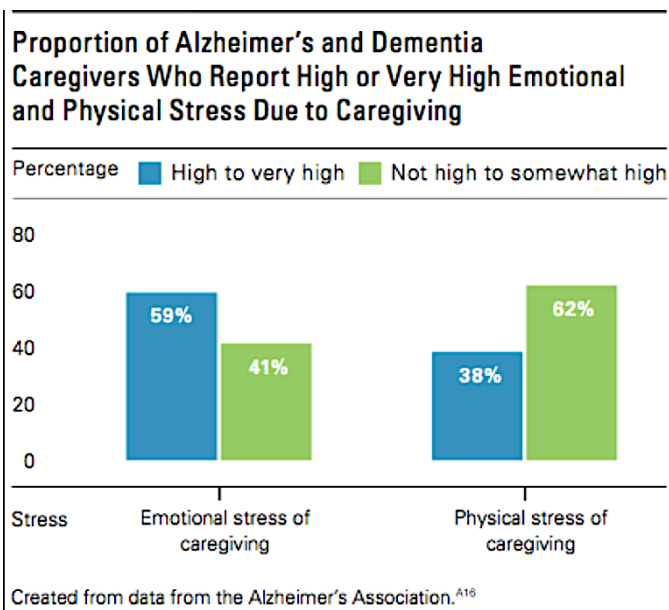


Figure 1: From the "2015 Alzheimer's Disease Facts and Figures"

the article, “Care Partner Responses to the Onset of Mild Cognitive Impairment” (2010), narratives from each of the test subjects revealed various levels of stress, strain, and frustration (p.11). Their results also indicated that several factors contributed to depressive symptoms such as being more bothered by cognitive symptoms, more perceived burden, less caregiving skill, and less knowledge about dementia (Blieszner & Roberto, 2010, p.11). These factors vary for each individual – and they are preventable.

The little research about resolutions for caregiver burden that has been conducted suggests each of these negative influences can be altered or lessened through some form of intervention for the caregiver. One primary example of supporting research, “Impact of a Community Based Implementation of REACH II for Caregiver of Alzheimer’s Patients,” was conducted by K. Lykens et al. (2014). The Resources for Enhancing Alzheimer’s Caregiver Health (REACH II) program was designed to examine the differences in caregiver burden, self-care, depression, and social support after participating in a support program. After the 6-month program, subjects showed significant decreases in depression and caregiver burden. Self-care and social support demonstrated some improvement; however, these changes were not considered statistically significant (Lykens et al., 2014, pg.5). There are several substantial conclusions that can be made by reviewing these results. First, interventions such as REACH can help to decrease the negative outcomes for family caregivers, demonstrating the need for implementation of similar programs. Second, this program showed success in some areas, but not all, indicating the need for research on the most effective forms of mediation. This research validates the need for community-based intervention programs that are specially designed and implemented to benefit caregivers. In turn, these programs would lead to improvement of the quality of life for people with Alzheimer’s disease and their families.



Considering the huge population directly affected by Alzheimer’s disease, it is not surprising that a plethora of research has been conducted to prove the negative consequences of being a family care provider. L. Garand et al. (2005) from the University of Pittsburgh tested the psychiatric outcomes of family members providing care for a MCI patient in “Caregiving Burden And Psychiatric Morbidity In Spouses Of Persons With Mild Cognitive Impairment.” Researchers conducted a series of interviews with 27 people whose spouses had recently been diagnosed with MCI. The results showed raised levels of task-related responsibilities and caregiver burden along with depressive and anxiety symptoms. Specifically, two caregivers demonstrated symptoms possibly indicating clinical depression, two demonstrated potentially significant anxiety symptoms, and one

caregiver experienced symptoms suggesting clinical depression and anxiety (Garand, 2005, pg.518). More recently, Blieszner and Roberto made similar conclusions regarding caregiver depression. After interviewing 106 caregivers of MCI patients, a total of 79% of caregivers reported depressive symptoms; 12.5% reported nine or more symptoms, indicating clinically significant depression (Blieszner & Roberto, 2010, p.18). It is important to note that the subjects of these two reports were caring for persons still in the second stage of Alzheimer's disease. Symptoms of Alzheimer's become increasingly worse as the disease progresses and, as confirmed by the Alzheimer's Association, depression in family caregivers worsens as the patient advances into dementia (Gaugler et al., 2015, p.38). Because most cases of Alzheimer's disease are diagnosed during MCI, these studies establish the need for caregiver intervention resources immediately after the Alzheimer's diagnosis of a family member. Such programs could prevent the negative impacts of caregiving such as anxiety or depression from developing or progressing.



Photo 2: I visited my dad in the hospital following a school event. February 2014

While it would have been ideal for my mom to receive intervention during my father's advancement of Alzheimer's disease, she did not have the opportunity because of my father's abrupt diagnosis. She was not aware that my father had the disease until he suddenly needed constant care. It was a snowy Thursday night in February when my mom took my dad to the hospital because of excruciating ear pain. Although his complaining about the pain was unusual, we didn't really worry; it was probably just an ear infection. An overnight stay revealed shingles in his inner ear, but still this wasn't too bad; a lot of older people

get shingles and they recover. However, this overnight stay turned into six weeks in the hospital – and we worried. During this time, my dad tried to escape from the hospital. Twice. He was promptly awarded an ankle bracelet and a bed alarm. Suddenly, one day the side of my dad's face was drooping and immobile. He developed Bell's palsy, indicating damage to his nerves and brain. We worried constantly after that. My mother was rarely at work because he wanted her to be with him and I lost motivation to compete my homework. There were days when he was very confused, he couldn't hold a conversation, or he didn't remember who

he was talking to. Yes, he was on a substantial amount of pain medication, but something else was causing these strange symptoms. Finally, after conducting several tests the doctor revealed dementia, probable Alzheimer's. The stress and pain he had experienced from the shingles and staying in the hospital had likely progressed the disease. Suddenly my mother became a full-time caregiver. Now she worries about my dad and I worry about her.

"I am sure it would help me to go to some kind of support group," she says almost a year and a half later. "Talking to people going through the same thing would help me." When investigating options at our local Wooster Community Hospital, we discovered there is an Alzheimer's support group that "provides information for caregivers as well as current research developments" ("Support Groups"). This material could be helpful, but in some cases simply receiving information may not be enough. Although there is not sufficient research to identify the best form of intervention, several studies indicate that people with depression or anxiety would benefit from other forms of intervention such as counseling or support groups. Like my mother, there are millions of caregivers who deserve to live a high-quality life. For this reason, support programs need to become a standard option for those caring for someone with Alzheimer's disease.



While there is certainly a lack of research regarding the most impactful forms of intervention to prevent specific factors of caregiver burden, there have been several tested support programs. For example, Stephens et al. (2011) from La Trobe University in Australia evaluated Well Ways, a family education program designed to improve the health of family caregivers for someone with a mental illness. The program featured eight, three-hour group sessions which tested subjects for worrying, tension, urging, supervision, and general health (Stephens et al., 2011, p.47). The results demonstrated a significant decrease in the areas of distress, worrying, tension, and urging, leading Stephens to rule Well Ways an effective program in reducing negative consequences for family caregivers of someone with a mental illness. Yes, this information is positive and useful; however, the research studies that have been conducted have focused on different factors of caregiver burden, making it difficult to come to a general conclusion.

The REACH II intervention included numerous strategies: providing information to the caregiver, didactic instructions, role playing stress management techniques, problem solving, skills training and telephone support groups. The 6-month intervention included 12 sessions (nine in-home and three telephonic) and five structured telephone support group sessions (Lykens et al., 2014, p.2). The program by Stephens et al., Well Ways, applied completely different techniques. Participants attended eight, weekly group sessions with 9-14 caregivers where they

were given information and had a discussion. While participants in REACH II were tested for caregiver burden, depression, self-care, and social support, Well Ways analyzed subjects for levels of distress, worrying, tension, and urging (Lykens et al., 2014, p.1) (Stephens et al., 2011, p.45). Figure 2 defines the eight forms of intervention mentioned in the “2015 Alzheimer’s Disease Facts and Figures” (Gaugler et al., 2015, p.41). Only three of the eight methods (psychoeducational, support groups, multicomponent) were used in the REACH II and Well Ways programs. Additionally, the use of multicomponent approaches makes it difficult to determine which intervention best reduced each symptom experienced by the caregivers. The discrepancies in factors and support methods tested in research demonstrate the need for further investigation to create a solid conclusion on the most effective forms of intervention for caregivers.

Type and Focus of Caregiver Interventions	
Type of Intervention	Description
Case management	Provides assessment, information, planning, referral, care coordination and/or advocacy for family caregivers.
Psychoeducational	Includes a structured program that provides information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (that is, cognitive impairment, behavioral symptoms and care-related needs). Includes lectures, discussions and written materials and is led by professionals with specialized training.
Counseling	Aims to resolve pre-existing personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
Support groups	Less structured than psychoeducational or therapeutic interventions, support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of social isolation.
Respite	Provides planned, temporary relief for the caregiver through the provision of substitute care; examples include adult day services and in-home or institutional respite for a certain number of weekly hours.
Training of the person with dementia	Includes memory clinic or similar programs aimed at improving the competence of the care recipient, which may also have a positive effect on caregiver outcomes.
Psychotherapeutic approaches	Involve the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, cognitive-behavioral therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviors to deal with caregiving demands, and fostering activities that can promote caregiver well-being).
Multicomponent approaches	Are characterized by intensive support strategies that combine multiple forms of interventions, such as education, support and respite into a single, long-term service (often provided for 12 months or more).

Figure 2: From the "2015 Alzheimer's Disease Facts and Figures"

Despite inadequate research on the benefits of caregiver interventions, the need for support is still quite apparent. Caregivers of persons with Alzheimer's disease should not be forced to choose between their own health and that of a loved one. According to the Alzheimer's Association (2015), most people choose to provide care for a family member with Alzheimer's disease due to the desire to keep that person at home, their personal closeness to that person, and their perceived obligation as that person's spouse (p.31). Along with these factors, research has proven another incentive for keeping loved ones in the home. "Long-Term-Care Placement and Survival of Persons With Alzheimer's Disease" is a product of the University Memory and Aging Center at Case Western Reserve by McKee McClendon et al. (2006). Their research found that long-term-care placement tripled the risk of death for patients, but the longer the person remains in the home, the smaller their risk of death. 15 additional years in their home can half that person's risk of dying at a care facility (McClendon et al., 2006, p.225). Therefore, keeping an Alzheimer's disease patient in their own home will likely prolong that person's life. This research surely encourages family members to care for their Alzheimer's disease patient for as long as possible, but they should not have to sacrifice their own health.

Mary Mittelman et al. at New York University's School of Aging Studies agrees. Her research assigned people taking care of a spouse with Alzheimer's disease to an intensive counseling group and therapy session specializing with memory loss. These spouses were able to put off nursing home care for eighteen months and save approximately \$90,000 in nursing home care fees (Mittelman et al., 2006, p.1598). "Most family members would like to keep their loved one at home as long as possible," said Mittelman in an interview for *USA Today* (Fackelmann, 2006). Her research proposes that a balance between patient health and caregiver health is achievable, but only when the caregivers receive support.

Various research studies establish the need for, and positive impact of, intervention for caregivers. While the best form of intervention for each symptom of caregiver burden is still unknown, research by Mittelman et al., Stephens et al., and Lykens et al. demonstrates that multicomponent interventions help relieve some depressive or anxiety-based symptoms (p.1598) (p.48) (p.6). For example, these studies demonstrate that a support group accompanied by education and respite would be more successful than a support group alone. Nonetheless, it is quite difficult to locate programs that provide more than one component of intervention. Many cities have small support groups located at community hospitals and nursing homes, but these groups are not always accompanied by other forms of intervention.

One example of an organization which provides support for care providers is the Alzheimer's Association. The charity's online Caregiver Center provides a range of information on care training, dealing with stress, and community support

("Alzheimer's and Dementia Caregiver Center," 2015). They also sponsor the most prevalent support group specifically for Alzheimer's caregivers in the United States. The free caregiver support groups are led by a trained facilitator and designed to help caregivers solve problems and make difficult decisions by hearing the stories of others who are coping with similar circumstances ("Alzheimer's and Dementia Caregiver Center," 2015). There is at least one support group in every state and often many more (there are 40 in Ohio). While the effort put into these groups displays potential – and surely benefits many people who attend – they are still not specially designed to relieve specific forms of caregiver burden or to be accessible to all caregivers. For those who are committed to caring for their family members who can no longer care for themselves, one key aspect to successful intervention is accessibility. In fact, this problem has prevented my mother from seeking out intervention more than anything else. The closest Alzheimer's Association support groups for my mother are 30-40 minutes from home ("Alzheimer's and Dementia Caregiver Center," 2015). This may not seem far to some, but it is for a caregiver. My mother would have to be away from home for at least 2 hours in the evening. She thinks that leaving my father alone while being this far from home would likely cause her more stress than the support group would relieve. Still, these are her best options to receive support specifically for Alzheimer's disease care providers.

Support groups like the ones found in small communities and those implemented by the Alzheimer's Association may benefit some care providers; however, current research suggests that care plans or counseling to manage specific symptoms of caregiver burden would be more beneficial (Stephens et al., 2011, p.50) (Lykens et al., 2014, p.6). The already established support groups are centrally located, but still not easily accessible for those providing full-time care for another person. Perhaps additional research could work toward designing a new form of intervention that could benefit caregivers of all ages and levels of education on Alzheimer's disease. Perhaps a government-led program could reach individuals located outside of large cities and be better implemented throughout the United States. No matter the requirements, as a daughter of a man with Alzheimer's disease and his caregiver, I know that there needs to be a change when it comes to the United States and its caregivers. There needs to be reciprocity.

"I know there is a lot to caring for a person at home, but I am going to try to keep him at home as long as I can," says Susie. Surely many spouses, children, and friends of someone with Alzheimer's disease share this purpose. Although I know my mom would do anything for my dad in a heartbeat, she should not have to sacrifice her job, her social life, and her mental health. The current lack of caregiver support forces people to choose between allowing the suffering of the dementia patient or the suffering of the caregiver. This is not fair, and I for one refuse to choose between my mother and my father. Research confirms that the

best way to ensure they both have a long, high-quality life is for my mother to seek out intervention. The same goes for *all* care providers. For my mother, and for caregivers of family members with Alzheimer's disease across the nation, support programs based on detailed research need to be implemented in communities across the United States so that *all* caregivers have access to the intervention that they need.



Photo 3: Charly, Susie, Courtney, & Delilah. 2015

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