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**EXPLORING PERCEPTIONS AND EXPERIENCES WITH RESOURCES AMONG
RURAL ALZHEIMER'S DEMENTIA FAMILY CAREGIVERS IN THE MIDWEST**

by

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A DISSERTATION

Presented to the Faculty of

The University of Nebraska Graduate College

In Partial Fulfillment of the Requirements

For the Degree of Doctor of Philosophy

Nursing Graduate Program

Under the Supervision of Karen Schumacher, PhD, RN

University of Nebraska Medical Center
Omaha, Nebraska
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EXPLORING PERCEPTIONS AND EXPERIENCES WITH RESOURCES AMONG RURAL ALZHEIMER'S DEMENTIA FAMILY CAREGIVERS IN THE MIDWEST

Rita M. Million

University of Nebraska, 2017

Supervisor: Karen Schumacher, Ph.D., RN

Background. Despite vast amounts of research on informal caregiving in the Alzheimer's dementia (AD) population, research on the experience and perceptions of rural caregivers is limited. A better understanding of rural caregivers' knowledge, use, and nonuse of resources is essential to offset the impact of caregiving. **Purpose.** This study explored Alzheimer's dementia family caregivers' experiences and perceptions with resources in rural Midwest communities. **Design.** A descriptive qualitative approach with one-time semi-structured interviews was used. **Setting.** Recruitment took place in rural Nebraska and Iowa communities. **Sample.** Twenty-three family caregivers, with a mean age of 65 (SD=13.9), participated. **Findings.** Qualitative results included four broad themes: Perceptions of Rurality, Caregiving Experiences, Resources Used, and Perceptions of Resources. Caregivers' experiences with resources were inseparably tied to their particular rural contexts and their experiences of caregiving. Five subthemes were found in Caregiving Experiences: relationship bonds, changes in family roles, care settings, care provided, and impacts on caregiver. These themes were not mutually exclusive. The Social Ecological Model guided the description of Resources Used that included six subthemes: self, family and friends, neighbors, community, healthcare system, and the Internet. Six subthemes were identified in the Perceptions of Resources theme: limited awareness, knowledge, need, value, fit, and accessibility. Care provided, resources used, and perceptions of resources were strongly related. **Conclusions.** Caregivers perceived things as resources that are not usually perceived as resources. Caregivers, who were able to, would drive long distances for services that met their individual needs. Those who did not have knowledge or accessibility to the individualized resources they perceived as needed would use substitutes that

are not usually thought of as resources. Services provided to rural family caregivers need to be individualized for the caregivers. Programs and support groups cannot fully meet the needs of rural family caregivers as each has a unique experience in their role and, therefore, interventions have to fit their needs.

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Chapter One

Background and Significance

The impact of Alzheimer's dementia on the healthcare system as well as on individuals and families is growing. In the Healthy People 2020 (2015) list of goals, dementia (including Alzheimer's disease) was added as a priority to reduce the cost and morbidity of the disease while improving the quality of life of those with dementia. Alzheimer's is the most common cause of dementia (Hebert, Weuve, Scherr, & Evans, 2013) and the sixth leading cause of death in adults in the United States (U.S.) [Centers for Disease Control and Prevention (CDC), 2014], which contributes to why it has become a priority.

The number of individuals in the U.S. diagnosed with Alzheimer's dementia is estimated to triple by 2050 from 5 million to approximately 13.8 million (Hebert, Weuve, Scherr, & Evans, 2013). Experts believe that the actual number is higher but estimated low due to inconsistencies in the diagnosis of Alzheimer's dementia (Alzheimer's Association, 2015; C. Freeman, personal communication, May 22, 2015). With the increasing age of the U.S. population and improved diagnosis, the number of people with Alzheimer's dementia is only expected to grow over the next ten years. Currently there are 33,000 estimated cases of Alzheimer's dementia in Nebraska and 63,000 in Iowa in individuals over the age of 65. Alzheimer's dementia is projected to increase by 21% (Nebraska) and 15.9% (Iowa) by 2025 (Alzheimer's Association, 2015). As the incidence of Alzheimer's dementia has grown, a recent study identified Alzheimer's dementia among the top three reasons cited by caregivers for providing care to a care recipient [National Alliance of Caregiving (NAC), 2015].

The incidence of dementia in individuals 80 years old and older and the increased number of aging baby boomers in the U.S. will account in part for the expected rise in dementia (Corrada, Brookmeyer, Paganini-Hill, Berlau, & Kawas, 2010; Kasper, Freedman, Spillman, & Wolff, 2015; Larson, Yaffe, & Langa, 2013; Tom et al., 2015). The expected increase in dementia will

have an impact on the number of family caregivers needed in coming years. Recently, 32% of Alzheimer's dementia caregivers report providing care for over five years compared to 28% of non-dementia caregivers (Alzheimer's Association, 2015). The combination of the increased number of individuals with Alzheimer's dementia and the longevity associated with being family caregivers for these individuals is creating the need for greater understanding of the needs and outcomes of these family caregivers.

There are an estimated 39.8 million caregivers for adults in the U.S. and of these 34.2 million provided informal (unpaid) care in the past year according to the National Alliance for Caregiving (NAC, 2015). Alzheimer's dementia was among the top three reasons for providing informal care with fifteen million caregivers providing informal care to individuals with Alzheimer's or dementia (Alzheimer's Association, 2015). Of Alzheimer's dementia caregivers, 85% provide care for a relative, with 49% providing care for a parent or in-law while one in 10 cares for a spouse. The average hours a week providing care is 24.4; however, 23% of caregivers state they provided over 40 hours of care in a week. The yearly cost of informal Alzheimer's dementia caregiving has been estimated at 17.9 billion hours of care at a cost of \$217.7 billion (Alzheimer's Association, 2015). The per person yearly cost for informal dementia care ranges from \$41,689 to \$56,290 (Hurd, Martorell, Delavande, Mullen, & Langa, 2013). According to the National Health and Retirement Study (HRS), the total cost of care (formal and informal) for dementia in 2010 was valued between \$157 billion and \$215 billion (Hurd et al., 2013).

Differences in defining informal caregivers, valuing informal caregiver time, type of care provided, and severity of disease have been identified as discrepancies in informal care costs (Hurd et al., 2013; Zhu et al., 2008) with the overall cost of dementia remaining high by any estimation compared to care for other diseases. Dementia care cost estimates are higher than for heart disease and cancer. Researchers have found a correlation between higher informal care costs and the higher need for assistance with activities of daily living (ADL's) as well as more

“cognitively demanding” care for individuals with dementia (Hurd et al., 2013; Kasper et al., 2015; Zhu et al., 2008).

Alzheimer’s dementia caregivers face numerous challenges in addition to the longer duration of the caregiver role, emotional and financial burden, and negative health outcomes. Many of these challenges have been associated to the care recipient’s behavior, amount of supervision required, and level of dependence on the caregiver for ADL’s (Fonareva, & Oken, 2014; Dauphinot et al., 2015). Seventeen percent of Alzheimer’s dementia caregivers reported giving up their job either before or after assuming the caregiver role, 9% reported quitting their jobs due to their role as a caregiver, 54% had to modify their work hours, and 15% had to take a leave of absence (Alzheimer’s Association, 2015). Using 2010 Behavioral Risk Factor Surveillance System (BRFSS) data, Bouldin and Andresen (2012) found that Alzheimer’s dementia caregivers reported providing more care with activities of daily living as well as providing care for a longer period of time when compared to non-Alzheimer’s caregivers. They also found that Alzheimer’s dementia caregivers reported worsening of their current health problems or the development of health problems by being a caregiver (Bouldin, & Andresen, 2012). Overall the increased stress associated with being an Alzheimer’s dementia family caregiver has received a great deal of attention in caregiving research.

Alzheimer’s dementia family caregiving has been associated with stressors that have led to increased burden and poor health outcomes. The financial burden of being an Alzheimer’s dementia caregiver has been well documented. Financial burden has been linked to inability to work or having to reduce hours at a job, and the cost of providing Alzheimer’s dementia specific care (Alzheimer’s Association, 2015; Kannan, Bolge, del Valle, Alvir, & Petrie, 2011; NAC, 2015). Care recipient behavior and memory problems were linked to higher self-report of depression by Alzheimer’s dementia family caregivers as well as caregiver cognitive impairment and poorer physical health (Pinquart, & Soresnen, 2004; Zarit, Femia, Kim, & Whitlatch, 2010). Depression, coronary heart disease, arteriosclerosis, and metabolic changes in caregivers have

been linked to providing informal Alzheimer's dementia care (Bouldin, & Andresen, 2012; D'Aoust, Brewster, & Rowe, 2014; Fonareva, & Oken, 2014; Roepke et al., 2012; von Kanel et al., 2013; Shaw et al., 1999; Triveldi et al., 2014). Higher caregiver health care use and cost were also related to informal caregiving for Alzheimer's dementia care recipients (Gilden, Kubisiak, Kahle-Wroblewski, Ball, & Bowman, 2014; Vitaliano, Zhang, & Scanlan, 2003; Zhu et al., 2015).

The use and availability of resources by Alzheimer's dementia family caregivers as well as caregiver outcomes related to resources has received little attention. Caregivers residing in rural communities and their knowledge, availability, and use of resources have received even less attention in research. McCabe and colleagues (1995) reported on the lack of resource use and the need for resources in the rural communities of the Midwest over 20 years ago. Current literature has stated that many Alzheimer's dementia rural caregivers do not use resources even if they are available (Carpentier & Grenier, 2012; Friedemann, Newman, Buckwalter, & Montgomery, 2013; Johnson et al., 2013). Whether caregiver resources, especially those specific to Alzheimer's dementia caregivers, are available or not can depend on where the caregiver lives. Rural dwelling caregivers have reported unmet service needs that they felt lead to a decrease in all ADL's in their care recipient (Li, Kyrouac, McManus, Cranston, & Hughes, 2012).

Statistics indicate that 3.4 million individuals over the age of 65 live in rural or outside of metropolitan/micropolitan areas in the U.S. and 9% of these individuals live in poverty (West, Cole, Goodkind, & He, 2014). The relationship of poverty and rural residency, therefore, may have an impact on use of resources by family caregivers and impact both the health of the care recipient and family caregiver. Family caregivers with higher incomes had a higher use of resources compared to lower income caregivers (Sorensen & Pinquart, 2005). The findings from research suggest that the availability of resources and use of resources by Alzheimer's dementia caregivers may be a multifaceted phenomenon that is not clearly understood. With the predicted rise in people age 65 and over coupled with the rise in the incidence of Alzheimer's dementia, developing a deeper understanding of the availability, access to and use of resources by rural

Alzheimer's dementia family caregivers and their reported outcomes related to resources is essential to determining what is needed by rural caregivers.

Research Problem

The availability of resources may play a significant role in how caregivers perceive their role and outcomes associated with being a rural Alzheimer's dementia family caregiver.

Researchers have discussed the impact that lack of access to resources may have on caregivers in rural communities (Bowen, Gonzalez, Edwards, & Lippa, 2014; Jensen & Inker, 2014; O'Connell, Germaine, Burton, Stewart, & Morgan, 2012; Stewart et al., 2014) but little is known about caregivers' knowledge and use of resources. Family caregiver lack of resources has been identified as a potential source of burden for family caregivers as well as being linked to poor health outcomes (Gaugler et al., 2004).

Whether the availability of resources differs in rural versus urban communities is also not fully understood. According to the Alzheimer's Association of the Midlands, zip codes are used to identify resources for individuals calling their hotline seeking resources in their community. Zip codes in the rural community can encompass large areas, and areas that have limited to no formal services. Using the zip codes can provide little immediate help to the rural caregiver seeking help and, if resources are located by zip code, the formal services may be long distances from where the caregiver lives. Understanding the rural family caregivers' experiences with resources is critical in developing a more in depth understanding of caregiver knowledge of resources and their perceptions of resources.

Whether rural family caregivers have available resources or even use available resources may impact how caregivers view their role and how well they can perform their role. Research has linked lack of resources as a source of caregiver burden as the caregiver lacks the skills and tools to perform their caregiving work but this phenomenon has not been fully researched in the rural Alzheimer's dementia family caregiver population (National Academies of Sciences, Engineering, & Medicine, 2016). First, the experience and meaning to rural Alzheimer's

dementia family caregivers of available and used resources needs to be explored and described to increase understanding of what is available and utilized in rural communities. Second, Alzheimer's dementia family caregivers in rural communities perceptions of resources needed and outcomes associated with resources needs to be understood in more depth in this unique population of the Midwest U.S.

The value of family caregiving (estimated at \$217.7 billion a year), the rise in caregivers' medical costs, and the impact with the anticipated increase in diagnosing Alzheimer's dementia, makes the need for a better understanding of what these caregivers need and value as resources essential to offset the deleterious effects associated with the family caregiving role. Because few studies in the literature explore rural family caregivers' experiences with resources in their role as a caregiver, a qualitative descriptive study was proposed.

Purpose

The purpose of this study was to explore Alzheimer's dementia family caregivers' perceptions and experiences with resources in rural Midwest communities.

Research Questions

- 1) How do Alzheimer's dementia family caregivers describe resources in rural Midwest communities?
- 2) What knowledge do Alzheimer's dementia family caregivers have about resources?
- 3) What are Alzheimer's dementia family caregivers' attitudes about resources available in their rural Midwest communities?
- 4) How do Alzheimer's dementia family caregivers use the resources in rural Midwest communities?
- 5) How do resources available and not available impact caregiver perceived outcomes?

Definitions

Family Caregiver. Who is a caregiver has been defined in multiple ways in research literature. The inclusion criteria for the present study were drawn from a widely referenced

national survey for consistent identification of caregivers (NAC, 2015). Family caregivers can be spouses, partners, adult children, or siblings and provide any type of assistance with personal needs, household chores, finances, outside services, or visit regularly to monitor the individual's wellbeing.

Resources. What a resource is can vary by the individual seeking assistance in their caregiving role. An important question for this research was what is a resource as defined by the rural Alzheimer's family caregiver. For a beginning definition, a resource can be either formal or informal. Formal resources would include adult day services (ADS), a structured caregiver support group, home health services, a privately hired professional care provider, and volunteer organizations. Informal resources can be extended family, friends, and other non-professional caregivers in the community.

Rural. Rural-Urban Commuting Area (RUCA) codes will be used to define rural in the proposed study. These codes were developed by the Federal Office of Rural Health Policy as a way to identify rural communities. Commuting distance determines a code which identifies areas with larger traveling distance to work as more rural on a scale of 1 to 10. One through 3 would indicate an urban area while a code from 4 to 10 would be rural. These definitions will be addressed in more depth in Chapter 2.

Chapter Two

The increasing number of Alzheimer's dementia family caregivers and the aging population especially in the rural communities, as described in Chapter One, will have a large effect on the healthcare system but more importantly on the health of family caregivers. For over 30 years, researchers have been exploring the caregiver role and seeking effective interventions to offset the stress reported by Alzheimer's dementia caregivers. Research continues today but family caregivers continue to report high stress and burden, which have been linked to poor health outcomes. Rural family caregivers have received attention in research but there is still a gap in knowledge in this population. A feasibility study conducted by this researcher in the fall 2015 brought to light the struggles and needs reported by a rural caregiver in availability and access to resources. In a review of literature, there is little research into rural caregivers' perceptions of resource availability and use by rural caregivers. This study builds on Alzheimer's dementia family caregiver research as it explored the rural family caregivers' perceptions of resources from their knowledge of, use of, and reasons for not using resources.

Theoretical Background

Miles and Huberman (1994) describe the importance of utilizing a conceptual framework to allow selection of data and information through questions related to the topic to be studied through a qualitative approach. However, a conceptual framework that can be used for the current study does not exist. The current state of the science in Alzheimer's family caregiving does not include a conceptual framework or model that includes both the individual caregiver outcomes associated with stress and resources in the context of rural communities. Two models that provided some direction for this study are Pearlin's Stress Process Model and McLeroy's Social Ecological Model. However, neither model fully encompasses both concepts of stress and resources. Therefore, these models were used to inform this researcher on stress and resources but the study attempted to gain deeper insight from the rural family caregivers' experiences and

perceptions of resources from their knowledge of, use of, and reasons for not using these resources as well as their perceived outcomes in relations to resources.

The impact of stress on Alzheimer's dementia family caregivers has been the focus of researchers for many years. Researchers have linked the stress of being an Alzheimer's dementia caregiver to both perceived poorer health, increased negative health behaviors, and increased use of health services (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Son et al., 2007). Alzheimer's dementia family caregiving stress has been associated with cardiovascular disease, depression, lowered immune status, and metabolic syndrome (Fonareva & Oken, 2014; Roepke et al., 2012; Shaw, et al., 1999; Triveldi et al., 2014; Vitaliano et al., 2002; Vitaliano et al., 2005; von Kanel et al., 2013). Increased behavior problems by the care recipient have been linked to higher stress in family caregivers.

Stress in caregiving has received much attention in research over the past 30 years. Researchers continue to describe the impact of stress on family caregivers' health and yet researchers are still attempting to find interventions to offset this stress to improve the caregivers' outcomes from their very important role in their family members struggles with Alzheimer's dementia.

Alzheimer's dementia family caregiver stress was described as multidimensional over 25 years ago (Pearlin, Mullan, Semple, & Skaff, 1990). The Stress Process Model (SPM) developed by Pearlin and colleagues (1990) outlines the multiple components that over time have an impact on the stress reported by Alzheimer's dementia family caregivers. The SPM describes the Alzheimer's dementia caregiving stress as having three levels: primary stressors (i.e. behaviors, activities of daily living & instrumental activities of daily living), secondary role strains (i.e. family conflict, economic problems), and secondary intrapsychic strains (i.e. self-esteem, loss of self). These levels of stress can lead to caregiver perception of burden from their caregiving role (Pearlin, Mullan, Semple, & Skaff, 1990). Pearlin's Stress Process Model has been used as a conceptual framework for numerous studies of Alzheimer's dementia family caregivers over the

years including Hilgeman and associates (2009) study to test the model. Pearlin's SPM is still widely used today in Alzheimer's dementia caregiving research.

Pearlin and colleagues (1990) identified the Alzheimer's dementia family caregiving role as a process that occurs over time with the stress resulting from this process being dependent upon the caregiving challenges that evolve over time. The SPM includes resources available or unavailable to Alzheimer's dementia family caregivers in the "Background and Context" but provides little attention to the impact of resources on the stress process. These resources that include family support differ from social support. Social support is considered a mediator in the SPM and defined as the assistance from a portion of the "network" from which the caregiver gains support. Program availability is included in the contextual elements and is described as different for each caregiver depending upon the community in which the caregiver lives. Over all program availability, included in the background, does not receive much attention in the stress process.

Aneshensel and colleagues (1995) used the SPM in the context of the "unexpected career" that Alzheimer's family caregivers experience over the years. In their groundbreaking longitudinal study, resources were included in analysis to determine their impact, both positive and negative, on the caregivers' stress. Resources were described as both formal and informal. Formal services were considered more instrumental and there was less emphasis on these resources as they were measured by asking the caregivers how often they used services from a list of 16 formal resources. Informal resources were considered coping resources and included: 1) social assets in the form of social support; 2) personal assets in the form of mastery. Resources and rural communities were not a central focus in either Pearlin's early work with the SPM nor in his continued work with Aneshensel and colleagues' (1995) longitudinal study of Alzheimer's dementia family caregivers. As resources and rural communities were not a focal point in the SPM, a model to better define resources at different levels in a rural community was needed for this study.

A model that includes resources and provides a context for including resources into this study is the Social Ecological Model (SEM). The Social Ecological Model (SEM) provided a framework for describing resources at different levels in the environment as well as interactions between the levels. This model grew from earlier work on child development in Bronfenbrenner's Ecological Systems Theory of Development.

The influence of environmental factors on human development and behavior is rooted in Bronfenbrenner's (1977) Theory of Human Development. Human development according to Bronfenbrenner (1977) is influenced by multiple factors at different individual and environmental subsystems. These subsystems were complex systems with interrelationships between the subsystems that impact human development. According to Bronfenbrenner (1977), research in child psychology focused on individuals and their characteristics while overlooking the influence of context on human development and behavior. Bronfenbrenner's initial findings evolved into the Ecological Systems Theory of Development (1989) that provides a framework for how an individual's behavior is influenced by environmental factors in a person's social and environmental ecology. The Ecological Systems Theory of Development consists of four environmental system influences that Bronfenbrenner (1977) labeled microsystem, mesosystem, exosystem, and macrosystem.

The Social Ecological Model used today for research and program planning is rooted in Bronfenbrenner's Ecological Systems Theory but has evolved into a model for health promotion. McLeroy and associates (1988) described the transition in health promotion from an individual's responsibility for personal health promotion to a more inclusive way to describe an individual's health being impacted by five distinct levels of interactions in a social context. These five social environmental levels were based on Bronfenbrenner's four environmental systems in the Ecological Model. Interpersonal, intrapersonal, institutional factors, community factors, and public policy all have an impact on the health of an individual according to McLeroy's Social Ecological Model (1988). This model has been applied in health promotion programs for

population aggregates by the Center for Disease Control and Prevention (CDC) and in community assessment as well as to develop and implement programs to promote healthy choices and lifestyle modifications to offset deleterious choices and promote overall health in the community. Cho and associates (2015) used the Social Ecological Model (SEM) as a framework in identifying the positive aspects of being an Alzheimer's disease caregiver by racial and ethnic groups. A recent literature search, found no further application of the SEM to Alzheimer's family caregiver research and rural resources.

The Social Ecological Model is built on the premise that changes and especially behavioral changes are impacted on many levels in the community and begin in the individual and family. This framework, although used sparsely in prior rural Alzheimer's dementia family caregiving studies, provides a succinct format to explore rural caregivers' perceptions of resources from the different levels. The context of this study is the rural environment and the different levels of the Social Ecological Model were applied in respect to the levels of resources in a rural community.

The Stress Process Model and the Social Ecological Model informed this researcher as to where the gap in knowledge for Alzheimer's dementia family caregivers lies in terms of the rural community context and individual family caregivers' experiences and perceptions with resources. Within the Stress Process Model, resources may be underestimated on the effect they may have on the caregiver outcome of burden. Also, the type of resources used or available in a rural community could have the potential of increasing burden depending upon the type and level of the resource in relation to the individual.

This study took an in depth look from the family caregiver's perceptions of resources from both the contextual (rural community) and individual's view as Alzheimer's dementia family caregivers. A deeper understanding of the experiences and perceptions of rural Alzheimer's dementia family caregivers through the descriptive qualitative approach will provide the foundation for interventions specific to the needs of these caregivers. An in depth qualitative

exploration of individual experiences and described outcomes within the socio-ecological levels in the rural area was completed.

Literature Review

Resources have been described in numerous ways by researchers in literature. More consistently resources have been identified as being either formal or informal services, organizations, support groups, counseling, or people who provide assistance to the family caregiver in their role. The differentiation between formal and informal has been described as whether the resources are paid for (formal) or a resource is provided without a fee (informal) (Jarrott, Zarit, Stephens, Townsend, & Greene, 2005).

Researchers have identified a need for caregiving resources for Alzheimer's caregivers but actual measurement of available resources and correlation of rural resources with caregiver outcomes is limited (McKenzie, McLaughlin, Dobson, & Byles, 2010; O'Connell et al., 2012). Access and availability of resources for family caregivers in communities has been identified as a growing need for Alzheimer's dementia caregivers (Bowen et al., 2014; Jensen and Inker, 2014; Stewart, Laskutova, Galliher, Warshaw, Coombs, et al., 2014).

Use of resources has been identified as an issue in Alzheimer's dementia family caregiving literature and research is very limited in terms of reasons family caregivers do not seek support. Caregivers have reported knowing about resources available but stated they did not use the resources (Brodaty, Thomson, Thompson, & Fine, 2005; Cheng et al., 2012). Brodaty and colleagues (2005) found that dementia caregivers' reasons for not seeking help, in an Australian population, included not thinking they needed services, the care recipient was reluctant to use services, and lack of knowledge of services. Innes and colleagues (2011) in a systematic review found that formal service use by rural caregivers was low as well as a gap in services available, and that available services do not meet the perceived needs of the dementia caregivers. Overall, the review found that rural caregiver experiences were "neglected" in comparison to other caregivers' experiences. To describe what is currently known about rural caregiver resources, the

proposed study will use the Social Ecological Model to explore types of resources by the different social ecological levels.

Types of Resources

Intrapersonal resources. These resources are the skills and characteristics that exist in the family caregiver. This could include many personal traits that the family caregiver possesses or does not possess. An individual's openness to seeking help or accepting help in their role as a caregiver may have a large impact on the use of resources in the caregiver's role. The rural family caregiver's perception of Alzheimer's dementia has been identified as a barrier to these family caregivers seeking resources as well as the perceived loss of privacy (Morgan et al., 2002). In a systematic review of informal family caregiving, researchers identified the need for a greater understanding of rural family caregivers' perceptions of dementia to better understand how the rural culture views dementia as a stigma (Innes et al., 2011). Innes and colleagues (2011) identified a need for learning more about the lack of participation of rural caregivers in Alzheimer's education programs as well as the use of formal services.

Aneshensel and colleagues (1995) focused on two types of psychosocial resources: coping resources (social support) and mastery. Mastery was found to correlate with positive outcomes when the caregiver felt they had control over the caregiving situation. Increased mastery was correlated with decreased stress and caregiver reports of less depression in Alzheimer's disease caregivers for a spouse (Mausbach et al., 2012).

Although mastery is not a focal point of the proposed study, the caregivers' perceptions of personal resources may include characteristics that imply mastery as being present or absent. Haley and colleagues (1996) found that black family caregivers reported higher self-efficacy in "managing caregiving problems" and reported overall less depression than white family caregivers. Black caregivers had lower appraisal of the stressfulness of caregiving stressors; whereas, white family caregivers had higher reports of approach and avoidance coping. Researchers found that these differences in coping did not have an overall effect on the stress

reported by black and white caregivers. Rather they described culture as potentially having a higher impact on caregiver reported stress.

A deeper understanding is needed of the caregivers' perceptions of their ability to provide care to their family member with Alzheimer's dementia in a rural community. Just as Pearlin and associates (1990) viewed stress as a multidimensional process, resources for rural caregivers are multidimensional and need to be explored in a systematic process through the lens of Social Ecological Model starting with the caregivers' self-identified strengths and weaknesses as caregivers. As a "culture", rural caregivers share many common traits and experiences that are unique to the context of their caregiving that is not found in urban caregiving experiences by family caregivers. This study encouraged caregivers to describe their perceptions on the conceptual aspect of their individual characteristics in the context of being a rural family caregiver.

Interpersonal resources. These resources are assistance from, communication with, and relationships with family and friends in rural communities. This would include the relationship that the family caregiver has with the care recipient, other immediate and extended family members as well as with their neighbors and fellow church members. Typically, these would be the informal resources close to the family caregiver.

Research on family and friend support has had contradicting results. Jarrott and associates (2005) found that informal help (that received from family and friends) had less of an impact on caregivers' distress when compared to formal services (respite, Adult Day Services, home health). Other researchers have found a link to increased distress and coping in a study of the stress process with family functioning as a mediator (Mitrani et al., 2006). A comparison of urban and rural informal resources found that rural family caregivers received less assistance from family members and non-family members in comparison to urban family caregivers (Chadiha, Feld, & Rafferty, 2011).

Community and Institutional resources. These resources are the services and providers located in the local rural community that can provide more structured or formal services that typically are associated with a fee for service. Respite care including both in-home care (sitter) and adult day services, and transportation services would be considered community resources and availability in rural communities may vary. Alzheimer's dementia caregiver support groups, if available in the community, would be considered a formal service and can be dependent on the availability of staffing and support from the local community for the services. Meals-on-Wheels is a formal service that delivers meals to homes of elder individuals and is available in both rural and urban areas. Home health services to assist the caregiver in the home by providing assistance to the care recipient with activities of daily living are community specific resources but again availability may be limited due to rural location or funding. Family caregiver access to counseling would be community specific and less likely to be available for rural caregivers. Formal service needs were identified as a need for rural Alabama dementia family caregivers that was consistent for both African-American caregivers and white caregivers (Kosberg, Kaufman, Burgio, Leeper, & Sun, 2007). A "sitter service" for respite care was linked to higher mental health well-being in urban versus rural family caregivers which researchers predict is due to the lack of consistent "sitter services" being available in rural areas (Tomms et al, 2007).

Structured services (support groups, information) obtained without a charge are also considered formal as they are from national organizations and often supported by donations and fund raising. These services provided free of charge can include non-profit organizations such as the Alzheimer's Association (AA), American Association of Retired Persons (AARP), National Alliance for Caregiving (NAC), and local long-term care facilitated support groups. These resources are available to all Alzheimer's dementia family caregivers without a fee but require the family caregiver reaching out to these organizations either in person, by phone, or through websites. The Alzheimer's Association of Nebraska has an increased need for group facilitators

for rural caregiver support groups and finds it difficult to find these facilitators (E. Chentland personal communication, November 19, 2015).

Adult Day Services (ADS) have received greater attention in recent research. Liu and associates (2014) identified the use of Adult Day Services (ADS) by Alzheimer's family caregivers as decreasing caregivers' perception of burden in their role. The existence of ADS is an example of a resource that may have an impact on a caregiver's wellbeing. The correlation of ADS use and caregiver hours spent providing care as well as the care recipients' level of function identified a benefit to both the caregiver and recipient (Gaugler et al., 2003). Positive effects of ADS on dementia care recipient behavioral and psychological symptoms with decreased caregiver distress were described in an Italian study (Mossello et al., 2008).

Policy and resources. The National Family Caregiver Support Program (NFCSP) was created by Congress in 2000 as part of the Older Americans Act Reauthorization to support families who are caring for an older family member and older adults who care for young children (Whittier, Scharlach, & Dal Santo, 2005). States are expected to provide five types of service: information about available services; assistance to caregivers in acquiring services; counseling, support groups, training; respite care, and supplemental services (Administration for Community Living, 2015). Each state has flexibility in how they implement and meet the five services for family caregivers. Nebraska has eight Area Agencies on Aging regions throughout the state and each offers a different range of services/resources to their region. According to Whittier and associates (2005), rural resources are not as well funded as urban resources that create an inequitable distribution of needed caregiver support.

O'Connell and associates (2012) found that rural and urban family caregivers mental well-being was not dependent upon the amount of resources available; however, they also state that measuring the differentiation between resources is lacking in their study as well as previous research on family caregivers and resources. Rural family caregivers, in O'Connell's study, were hypothesized to reach out to different resources when formal support was lacking. Researchers

suggest finding a way to describe rural resources needed by rural family caregivers (Jarrott et al., 2005; Kaufman et al., 2010; McKenzie et al., 2010; O'Connell et al., 2012) to be used to better identify the impact or lack of impact these resources have on rural caregivers, what is needed by these caregivers to facilitate their mental and physical health, and how to improve the caregiving experience while keeping the care recipient safe and at home.

A systematic review of rural and remote family caregiving found that there is very limited research in these caregivers' experience, education, and support needed (Innes, Morgan, Kostineuk, 2011). Although the concept of family caregiving was of interest, Innes and associates found that the limited research identified focused on "experience, use and barriers to formal service provision." Morgan and colleagues (2011) in a systematic review of formal services found that there is still a discrepancy in the services available to rural communities as well as how they are delivered. Rural caregivers having to commute for formal services, outreach programs to rural communities, and use of technology to provide services were found in the literature but these services still have barriers to use by rural caregivers and provision of services for the aging rural population and especially for those with Alzheimer's dementia (Morgan, Innes, & Kosteniuk, 2011). The development of policy and resources to meet the rural Alzheimer's dementia population needs was hampered by the lack of research specific to the rural population (Morgan, et al., 2011).

Overall, research in rural Alzheimer's dementia family caregiving does not fully explore the concept of resources from the individual caregivers' perceptions of resources and what they know about resources as well as why they use or do not use resources. Resources have been assessed in quantitative studies in limited ways such as the use of checklists asking if the caregiver uses the resource or not. This is not an in-depth account of the individuals' experience of resources and especially their perceptions of resources. As identified in systematic reviews, there is also limited research in the use of resources in rural populations of Alzheimer's dementia caregivers.

Rural Populations

Definition. No one definition is agreed upon in the literature and used consistently in caregiving studies. Frequently researchers fail to identify a definition for “rural”, describe rural by the population size of the community, distance to a larger community, or by a US government definition of rural (Morgan et al., 2011). From 46 identified rural studies of formal Alzheimer’s dementia resources, 23 studies did not provide a definition for rural in the description of their sample (Morgan et al., 2011).

The United States (U.S.) Census definition of rural versus urban communities uses the size of a community. Some communities may qualify for rural status according to the Census definition but be within an hour drive to a large urban metropolitan area. Other communities may qualify for urban (>2500 persons) as urban clusters but be a large distance from resources and healthcare professionals and facilities.

The Office of Management and Budget (OMB) assigned designations for counties based on the size of the largest urban area in the county. Metropolitan counties have a core urban area of 50,000 or greater. An urban core of at least 10,000 but less than 50,000 would qualify a county as micropolitan. If a county’s core urban area is less than 10,000, it would be considered “neither” metropolitan or micropolitan. Rural is considered any county that is not designated as part of a Metropolitan Statistical Area (MSA) which means that a micropolitan county would be considered rural too.

Rural-Urban Commuting Area (RUCA) codes is a method used by the Federal Office of Rural Health Policy. RUCA codes are based on Census data and codes are assigned to Census Tracts. A RUCA code of 4 to 10 indicates that an area is rural. RUCA code designations can be given to areas located in urban counties that, for this study, identified areas considered rural even though they are located within a county with a larger metropolitan area. For example, western Pottawattamie County in Iowa is considered a Metropolitan county by use of the Census definition and the OMB but the eastern portion of the county is considered rural with a RUCA

code of 10. Defining rural for this study using RUCA codes facilitated the recruitment of individuals from within these Metropolitan counties to gain insight into these Alzheimer's dementia caregivers' perceptions of resources as well as rural counties that are not Metropolitan counties.

RUCA codes define areas within counties as rural by the commuting distance that individuals must travel for work. Those living farther from larger metropolitan areas are considered rural. Support for defining rural by distance to services/work was found in a recent Canadian study. Results suggested that distance to dementia specific services may have a large impact on the stress and burden reported by rural dementia caregivers (O'Connell et al., 2012). Just as O'Connell and associates (2012) identified the impact rural definition choice can have on research findings, they also urged future rural researchers to consider a definition based on access to resources.

Disparities. Rural Nebraska counties are comprised of on average 20% of individuals over the age of 65 (Rural Health Plan, 2008). The state average in 2000 was 12.6% (Rural Health Plan, 2008) which indicates that the older adult population in rural communities is continuing to rise, which is consistent with the increase of older adults throughout the US. This is a similar population trait in Iowa with 21.5% of the rural population being comprised of adults over the age of 65 (Iowa Department of Public Health, 2011). Iowa Department of Public Health (2011) is projecting that the number of adults over the age 65 will increase by 50% over the next two decades.

The number of individuals with Alzheimer's disease is projected to grow over the next ten years. Currently there are 33,000 projected cases of Alzheimer's disease in Nebraska and 63,000 in Iowa in individuals over the age of 65. Alzheimer's disease is projected to increase by 21% (Nebraska) and 16% (Iowa) by 2025 (Alzheimer's Association, 2015). It is difficult to identify the exact number of individuals with Alzheimer's disease by counties in Nebraska and Iowa. A search of statistics through the Alzheimer's Association, Center for Disease Control

(CDC), and national databases did not identify just rural US counties statistics of Alzheimer's disease or estimated cases in rural areas. With the large number of individuals identified in each state and the growing projection of cases in both states, family caregivers for the proposed study exist but will need to be identified with the assistance of key informants in the rural counties.

Nebraska's overall poverty level in 2013 was 12.9% with rural counties having higher poverty levels averaging from 14% to 23% in northern counties (American Fact Finder, 2015). With an aging population and an overall larger number of low-income individuals living in rural areas, the family caregivers from rural counties in this study would definitely have health disparities based on income.

The family caregivers recruited in rural counties in Nebraska and Iowa may be experiencing the lack of availability of healthcare professionals in general practice as well as specialized services such as geriatricians. As of December 2014, Nebraska has 104 designated total primary care Health Professions Shortage Areas (HPSA's) and Iowa 118 (Kaiser Family Foundation, 2014). When dealing with aging health issues, and especially the needs of an individual with Alzheimer's dementia, family caregivers may be stressed and forced to drive long distances to access needed services. This supported the use of RUCA codes for defining rural counties to be included in this study.

Caregiver resources can be non-existent in rural communities resulting in a disparity when compared to available resources in urban areas (C. Freeman, personal communication, May 22, 2015). Unmet service needs and less access to formal services in rural dwelling caregivers was identified as a source of increased caregiver burden (Li et al., 2012; Bedard, Koivuranta, & Stuckey, 2004). Kosberg and associates (2007) found that use of formal services by dementia family caregivers in rural Alabama was low compared to urban counterparts. Use of informal support was higher among the rural dementia caregivers but researchers were unsure if this was due to lack of formal resources or family caregivers just not utilizing formal resources (Kosberg et al., 2007).

A recent literature search identified studies in caregivers for individuals with Alzheimer's dementia and included rural subjects or rural versus urban comparisons. Many of the studies were outside the U.S. with the majority conducted in Canada. In the U.S., rural family caregivers were found to provide care for a longer period of time in the home when compared to urban caregivers (Innes et al., 2011). Morgan and colleagues (2002) identified a lack of professionals in rural communities who were able to diagnosis Alzheimer's disease as well as experts in the area of older adults' health needs especially in Alzheimer's disease care. Distance to professionals who have the expertise needed for rural caregivers in Canada was identified as a barrier to support systems for rural family caregivers (Morgan et al., 2002). The cost-of-services in rural Canadian communities were identified as an additional barrier to accessing services and resources, which were also an issue for rural US family caregivers (Morgan et al., 2002; Whittier et al., 2005). These challenges for rural family caregivers differ from urban-dwelling family caregivers, as distance and variety of services are less likely to be an impact in the urban setting (Innes et al., 2011). Lack of availability of and long distance to services have been associated with increased burden in rural caregivers (Bowen et al., 2014; Jensen & Inker, 2014; O'Connell et al., 2012; Stewart et al., 2014).

Summary

Researchers have discussed the impact that lack of access to resources may have on caregivers in rural communities but little is known about caregivers' knowledge and use of resources and the impact that living long distances from larger metropolitan areas may have on rural Alzheimer's dementia caregivers. Identification of caregiver resources for rural Alzheimer's dementia caregivers can be difficult and require travel or use of technology by these caregivers to access resources (C. Freeman, personal communication, May 22, 2015). Lack of use of resources by Alzheimer's dementia caregivers, even when they are available, has also been identified as an area for future research. Further research into the knowledge and use of resources in rural communities is also needed. These considerations point to the need for greater understanding of

the rural Alzheimer's dementia caregiver's perceptions of resources and outcomes related to resources both used and not used which can be gained through a qualitative study. This study aimed to fulfill that need.

Chapter 3

Methods

Family caregivers for an individual with Alzheimer's dementia provide care that becomes more complex over time. In order to provide care specific to the family member's stage of Alzheimer's dementia, the caregiver needs resources to accomplish the tasks as well as respite services for the caregiver's well-being. Rural family caregivers may not have the resources available and, in some instances, may not use available resources. The purpose of this study was to explore Alzheimer's dementia family caregivers' perceptions and experiences with resources in rural Midwest communities.

As noted in Chapter One, the research questions were: 1) How do Alzheimer's dementia family caregivers describe resources in rural Midwest communities? 2) What knowledge do Alzheimer's dementia family caregivers have about resources? 3) What are Alzheimer's dementia family caregivers' attitudes about resources available in their rural Midwest communities? 4) How do Alzheimer's dementia family caregivers use the resources in rural Midwest communities? 5) How do resources available and not available impact caregiver perceived outcomes?

Design

A descriptive qualitative approach was the design for this study. One-time semi-structured interviews with adult family caregivers in rural Midwest communities caring for an individual with Alzheimer's dementia were conducted. A follow-up phone call could have been made if needed for an opportunity by this researcher to gain clarification of the caregivers' responses from initial interviews.

Descriptive qualitative approach was described by Sandelowski (2000) as a way for researchers to explore a topic or issue of importance to a specific population or individuals sharing similar experiences and challenges. With the focus of this study being rural Midwest

adult family caregivers, valuable insight into the knowledge, attitudes, use, and perceived outcomes from caregiver resources in the rural community was gained.

Much debate is in the literature as to whether the descriptive qualitative approach is a distinctive research method (Sandelowski, 2010). Sandelowski (2010) argued for the value of qualitative description as a method that produces new knowledge but also noted its use being a “vehicle for presenting and treating research methods as living entities that resist simple classification” (p. 83).

Sample

Rural Midwest adult family caregivers for individuals diagnosed with Alzheimer’s or unspecified dementia were recruited in rural communities in both Nebraska and Iowa. Inclusion and exclusion criteria are outlined below. The care provided by adult family caregivers could include assistance with one or all of the following areas (NAC, 2015) of caregiving: 1) personal needs; 2) household chores; 3) individual’s finances; 4) arranging outside services; 5) visiting regularly to monitor the individual’s well-being.

Inclusion criteria. 1) A spouse/partner, sibling, or adult child of the care recipient and 19 years of age or older. 2) Lived within one hour of the care recipient. 3) Able to read, write, and speak English as well as able to provide written informed consent. 4) Care recipient may be homebound, enrolled in an adult day program. 5) Care recipient who has been residing in a long-term care or assisted living facility for 12 months or less would still qualify the family caregiver. 6) Residing in a county area with a RUCA code of 4 or greater (see Chapter 2 for definition of RUCA’s). The RUCA code was changed during the study to RUCA code 2. This change occurred after discussion with the caregivers on the distance to urban areas as well as the rural conditions in their community. For example, one caregiver residing in a RUCA code 2 county travelled gravel roads for miles to reach a paved road.

Exclusion criteria. 1) Caregivers who appear to have a cognitive impairment that precludes providing informed consent, based on the assessment of the referring person or

dialogue with the Principal Investigator (PI) during the recruitment process. 2) Paid caregivers for an individual with Alzheimer's dementia. 3) No exclusion criteria related to gender.

Sample Strategies

Purposeful sampling is selecting individuals with specific knowledge or experiences to assist the researcher in better understanding the problem or issue being researched (Creswell, 2014; Flick, 2014). Purposeful convenience sampling (Creswell, 2007; Sandelowski, 2000) was utilized to recruit a homogenous sample of rural Alzheimer's dementia family caregivers. In the study, this researcher sought to gain rich information and understanding of the knowledge and use of resources in rural communities; therefore, purposefully enrolling rural Alzheimer's dementia family caregivers recruited in rural communities provided deeper insight into their knowledge, use, and perceived outcomes related to resources. Recruitment included contacting the Alzheimer's Associations of Iowa and TrialMatch. The associations informed their support groups and workshop facilitators of the study. Once permission to share the participants' contact information was received, this researcher contacted the participant directly for recruitment into the study. This researcher also attended and introduced her study to support groups and workshops in Iowa and Nebraska.

Recruiting a sample for a feasibility study in Fall 2015 brought to light how difficult recruitment of family Alzheimer's dementia caregivers can be in rural communities. In the present study, a second sampling strategy, snowball sampling, was used to facilitate recruitment of participants. When someone in the rural community identified a potential participant, the referring individual was asked to contact the potential participant for permission for this researcher to contact them.

Sample Size

A sample size of 20 was an estimate for the study but would be dependent upon when informational redundancy (Lincoln & Guba, 1985; Patton, 2002; Sandelowski, 1995) or "saturation" (Charmaz, 2006) is achieved. Creswell (2014) estimated that a sample size for a

phenomenological study would be 20 participants but this is not an agreed upon method for determining sample size by experienced qualitative researchers. However, sample size is even less well defined for a qualitative descriptive study. Determining a sample size in advance is a “futile task” according to Morse (2015) and is dependent on several factors including the phenomenon, complexity and scope, and current knowledge of the phenomenon. Sample size for this descriptive qualitative study was not defined by a number but rather by the richness of the data collected from the participants and well-developed themes leading to informational redundancy. Informational redundancy is reached when well-developed themes recur in the data (Creswell, 2014; Sandelowski, 1995). This researcher identified well-developed themes and determined a good understanding of the major themes which determined when informational redundancy or “saturation” had been reached. Enrollment of participants continued after information redundancy was identified to ensure that the themes were consistent in a larger sample of rural family caregivers. Data collection continued throughout the data analysis.

There is much ambiguity in determining a sample size for a qualitative study. Theoretical saturation was identified by Charmaz (2006) in grounded theory as the point when no further data were needed as the themes in the data were repeating in newly collected data. In 2006, Charmaz’s description of saturation had led many to use this term in qualitative approaches other than grounded theory. In 2008, Charmaz described saturation as specific to grounded theory and thus not applicable to other qualitative designs. Guest and colleagues (2006) propose that the meaning of theoretical saturation has become “vague” and propose defining “saturation.” The proposed definition of the term saturation is “point in data collection and analysis when new information produces little or no change” in respect to codes or thematic exhaustion (Guest, Bunce, & Johnson, 2006, p. 65). These researchers also found that from a sample of 120 semi-structured interviews that thematic exhaustion was reached in the first 12 interviews.

Twenty-three rural family caregivers were enrolled and interviewed. Caregivers lived throughout Nebraska and Iowa spanning a distance of 590 miles. This researcher obtained

informed consent prior to the interviews. Interviews occurred in the homes of all but seven caregivers. Four caregivers were interviewed at the assisted living facility where their family member currently resided. The other three caregivers were interviewed at a site of their choice where a quiet, private environment would allow them confidentiality during the interviews.

Recruitment through the local Area Agency on Aging (AAA), one assisted living and long-term care facility, and the Alzheimer's Association as well as TrialMatch occurred in two ways. The AAA and care facility would approach potential caregivers and provide this researcher their contact information if they agreed. Once their information was received, this researcher would contact the potential participants. Alternatively, the Alzheimer's Association allowed this researcher to attend caregiver support groups. In addition, this researcher was invited to present at workshops to identify potential participants. Individuals referred to the study through TrialMatch did not meet the inclusion criteria for the study. These caregivers had either lost a family member due to death or lived outside of the Midwest. Snowball recruitment occurred as the flyer and information about the study was shared among support groups, workshops, and organizations in the rural community. Rural caregivers contacted this researcher for additional information and inclusion as well as exclusion criteria were reviewed. Once the caregiver was identified as eligible for the study, a date and time for the interview was established. Upon meeting with the caregiver, verification of eligibility was again completed. Informed consent was then obtained. The semi-structured audio-recorded interviews then occurred. Interviews ranged from 45 to 120 minutes.

Settings

Nebraska and Iowa communities in portions of counties identified by use of the Economic Research Service Rural-Urban Commuting Areas (RUCA) definition were where this researcher concentrated on enrolling the adult family caregivers. Rural Midwest communities in Nebraska and Iowa with RUCA codes 2 or greater were the settings where adult family caregivers were recruited to participate in the proposed study. Some of the social service

agencies serving these rural communities in Nebraska and Iowa were located in cities with RUCA codes smaller than 4 indicating non-rural; however, these agencies served many counties in their respective states.

Nebraska and Iowa have Area Agency on Aging (AAA), as described in Chapter Two, which serve specific counties within their region (see Appendix A). The two AAA's used for the study were the Nebraska Blue Rivers Area Agency on Aging and the Iowa Connections Area Agency on Aging which are located in non-rural communities. The Alzheimer's Association of Iowa and TrialMatch were utilized in identifying local Alzheimer's caregiver support groups in the rural communities as well as workshops for family caregivers.

Procedures

Approvals

The University of Nebraska Medical Center (UNMC) Institutional Review Board (IRB) was the only IRB approval required for the study. The sites identified by the researcher did not have IRB's that would require an additional approval process.

Authorization from each rural organization was secured for the study. These authorizations were secured from the administration for the organization where study participants were recruited. Once letters of authorization were received these were submitted to the UNMC IRB as part of the approval process.

Recruitment Procedures

Recruiting strategies for the present study were informed by lessons learned in a feasibility study. Relationships with key individuals begun during the feasibility study proved to be important in this study. The feasibility study provided entrée into various agencies and facilities and laid the groundwork for the commitment to the research by key individuals and gatekeepers.

Recruitment was through attendance at caregiver support groups and workshops sponsored by the Alzheimer's Association of Iowa, as well as those sponsored by social services

departments in long-term care and assisted living facilities, and Area Agency on Aging senior services programs located in Nebraska. The social services departments at the identified rural long-term care facility were contacted in person by this researcher regularly to discuss potential family caregivers who had placed their family member with Alzheimer's dementia in their facility within the past 12 months. These potential participants were first approached by the Social Worker for permission for this researcher to contact the individual. This researcher contacted the potential participants, determined that the individual met the inclusion criteria, and informed the individual of the study purpose and procedures.

When an individual was identified at a caregiver support group, this researcher reviewed inclusion and exclusion criteria to be sure the individual met the criteria for the study. Once the caregiver was identified as a potential study participant, a meeting was arranged either at the caregiver's home or at the location of the support group meeting. A private office or room was utilized for the interview. Information about the study was provided to the potential participant and informed consent was obtained.

When an individual was contacted by a case manager at the local Area Agency on Aging and agreed to be in the study, this researcher contacted the family caregiver by phone and reviewed the inclusion/exclusion criteria. A meeting was arranged either at the long-term care or assisted living facility, or the caregiver's home. A private office or setting was used to meet with the caregiver. Informed consent was obtained after reviewing the study protocol.

Regular, routine visits to the identified sites aided in recruiting in rural Iowa and Nebraska counties as well as regular contact by phone and email. Continued visits and communication with those individuals and organizations previously identified in the feasibility study were maintained to aid in recruiting the rural Alzheimer's dementia family caregivers. Establishing relationships with the additional key community members, in Nebraska and Iowa, were a priority. The Alzheimer's Association of the Midlands' Regional Director of Programs and Public Policy, Clayton Freeman, agreed to assist this researcher with recruiting family

caregivers, who attend support groups and workshops in rural communities, once the study was accepted to TrialMatch. The Nebraska Respite Network contacted this researcher and distributed the recruitment flyer to rural offices. TrialMatch is a service provided by the Alzheimer's Association that links individuals to clinical studies. The service is free for researchers.

Informed Consent Process

This researcher in a face-to-face meeting at the caregiver support group, family caregiver's home, assisted living facility, or the long-term care facility obtained informed consent after verifying that the individual met the inclusion criteria. When meeting with potential study participants, this researcher provided information regarding the study as well as reviewed both the "What Do I Need to Know Before Being in a Research Study?" and "The Rights of Research Subjects." A copy of the signed informed consent was provided to the caregiver at the time of enrollment. Once the informed consent was signed, this researcher began the audio recorded, semi-structured interview.

Data Collection

The family caregiver was asked to complete a demographics questionnaire prior to beginning the interview. The demographics questionnaire (see Appendix B) provided general information regarding the caregiver. Upon completion of the demographics questionnaire, a semi-structured interview with the family caregiver was conducted. The interview questions (see Appendix C) guided the interview. The interview was audio recorded on a digital recorder with the family caregiver's permission. Interviews ranged from 45 to 120 minutes. Observations were made before, during and after the interviews and recorded in field notes by this researcher. Digital audio-recorded interviews were uploaded to an encrypted laptop and transcribed verbatim by One Transcription. Transcribed interviews were kept on the encrypted laptop computer for analysis. The demographics questionnaires, recording device, and transcribed interviews were stored in a locked file cabinet in the researcher's home office.

Data Analysis

Thematic analysis, using an inductive approach, was used for data analysis (Braun & Clarke, 2006). Analysis began as this researcher became familiar with the data beginning at the interview and continuing through the re-reading of the transcripts using an iterative approach. Initial codes identified in the data were collated. Collated codes were then sorted into rich themes that captured the latent meanings in the data. Detailed field notes were collected during the interviews and were included in coding as part of thematic analysis.

Ensuring reliability and validity throughout the study was a priority using Morse (2002) criteria and triangulation. Triangulation was achieved through methodological coherence, recruiting a sample that is representative of the phenomenon of interest, analyzing data beginning with data collection and continuing throughout each step of thematic analysis (Morse, 2002). Coherence between the descriptive qualitative method and thematic analysis was maintained by continued assessment for unity between the two. Purposive convenience sampling was used to recruit rural family Alzheimer's dementia caregivers. These caregivers were located in Nebraska and Iowa and had experience caring for a family member diagnosed with Alzheimer's dementia as this was the phenomenon of interest. Data analysis began during semi-structured interviews, documentation of field notes, and throughout the process of code identification and collation leading to rich themes. Revisiting the theoretical background, identified in Chapter Two, during data collection and analysis ensured that a theoretical approach was maintained throughout the study.

Data validity began with the collection of interviews, observations, and participants reporting of resources they used or were aware of on the demographic form. Validity checks included the use of different data analysis methods that included comparison of reports and observations to seek consistency in the findings (Creswell, 2014). Transcribed interviews were also compared to the audio recordings for reliability with the identification of errors that occurred during the transcription process. Constant comparison of codes to the data ensured that codes

were being identified consistently and that the definition of a code is maintained throughout data analysis. Follow-up with study participants for clarification of interview data could have been used. No follow-up with study participants was needed for clarification of participants responses in the interview data. Debriefing with an experienced qualitative researcher was included for validation of codes (Creswell, 2014).

Reflexivity

It is important for a researcher to be aware of the impact their experiences and background can have on a qualitative study (Creswell, 2014). This researcher's personal and professional experiences have had an impact on the topic of Alzheimer's dementia caregivers as well as the rural context. Personal awareness of my beliefs, experiences, and biases was important throughout the research process in the study. Being a registered nurse for over 27 years working in both long term care and home health in rural communities with an emphasis on care for individuals diagnosed with Alzheimer's dementia means that I have knowledge and experiences that could have had a direct impact on my research. In some instances, I had experiences similar to the family caregivers especially in respect to rural resources. These experiences influenced the decision to conduct the study and the importance of expanding knowledge of the experiences of Alzheimer's dementia family caregivers. Reflecting on the differences in Alzheimer's dementia family caregivers' experiences and my skilled experiences was important in both data collection and data analysis to be aware of my preconceived ideas and biases.

This researcher has also lived and worked in rural Midwest communities for more than 20 years. The knowledge of the rural population and personal experiences with individuals living in rural communities may make this researcher more attuned to findings in the study. However, this deeper awareness could have also made this researcher blind to findings that have become common occurrences, acceptable practices, or assumptions based on prior experiences. Reflecting on the experiences and biases during the qualitative research process was important as

the researcher's experiences, biases, and knowledge could have impacted each step in the research process.

Limitations

Recruitment, observation data, and interview data may all have limitations for the proposed study. Recruitment of family caregivers who are not currently using or have never used resources may be difficult. Access to these individuals will rely on the strategy of snowball sampling. Observations can be affected by the researcher being present in the field which alters the participants' "normal" interactions and patterns of behavior. Participants may alter their behavior because they are being observed. Also, observation only provides a view of "external behaviors" and provides no insight into the internal patterns and motivators of behavior (Patton, 2002, pg. 306).

Interview data limitations include the potential for participant bias, differing emotional states of the participants, varying relationships between the participant and the care recipient, and length of time as a family caregiver. Interview data can be affected by family caregivers reframing of caregiving events as they recall their role prior to placement of their family member in respite services or long-term care. The relationship between the family caregiver and the researcher can also affect the data collected.

Chapter 4

Sample

Twenty-three rural caregivers participated. They included 13 spouses, nine adult children, and one sibling. The age of these caregivers ranged from 33 to 82 with a mean age of 65 (SD=13.9). Gender included females (n=16) and males (n=7). Spouses included both female (n=8) and male (n=5), adult children included female (n=8) and one male, and the only sibling was female.

There were three different caregiver care recipient relationships. Spouses were the most frequent relationships (n=13). Adult children were the second most frequent relationship (n=9). Only one sibling participated in the study. One adult child cared for a parent as well as grandparents. Three adult children were also providing support to their parent without AD. Of the nine adult children caring for a parent with Alzheimer's dementia, two were caring for their own children.

The education attained by caregivers was high school (n=3), some college (n=8), college graduate (n=6), and graduate school (n=6). All but one reported race as white non-Hispanic. One caregiver identified two races (white and Native American) and Hispanic ethnicity. Religions identified by caregivers included, Protestant (n=10), Catholic (n= 6), Nondenominational (n=2), Episcopal (n=1), Jewish (n=1), and Christian (n=1) with one reporting other and one with no response.

Care recipients included husbands (n=8), wives (n=5), fathers (n=4), mothers (n=5), grandparents (n=2), and one brother. The age range for care recipients was 62 to 94 with a mean of 78 (SD=3.4). Individuals' time from diagnoses of Alzheimer's disease or dementia ranged from three months to over 10 years.

Financial demographics included caregivers reporting not being able to make ends meet (n=2), just enough money no more (n=5), enough money with a little extra (n=8), and always

having money left over (n=8). Nine caregivers were still working while 11 were retired and two reported “other.” Only one caregiver worked from home. Of those still working, only two reported changing their work to provide care for their family member with one adult child leaving a job to be a full-time caregiver.

Care recipients included husbands (n=8) and wives (n=5). Nine care recipients still lived with their spouse at home, while three spouses were living in assisted living and one in long-term care at the time of the interview. Prior to placement they did live at home with their spousal caregiver.

Care recipients also included mothers (n=5), fathers (n=4), brother (n=1), grandmother (n=1), and grandfather (n=1). Four adult children provided care to their parent in the parent’s home. One individual was providing care to their sibling in the person’s own home. At the time of the interviews, two parents were residing in long-term care facilities and two parents as well as two grandparents resided in assisted living. One father was living with an adult child in her home with her immediate family. Two adult children described how they had their own home with their husbands but stayed with their parent at night to keep the individual safe. Both of these parents were in assisted living at the time of the interview. All names are pseudonyms to ensure the confidentiality of the participants.

Although all family caregivers lived in rural communities, the community setting differed among all with caregivers living on farms and acreages (n=11) and others living in town (n=12). Adult children (n=7) lived distances ranging from 3 to 60 miles from their parent(s). For caregivers living on farms and acreages, they lived distances ranging from two to 40 miles from the nearest town. The RUCA codes also differed with a range from RUCA code 2 to 10 (see Appendix A).

Overview of Qualitative Results

The qualitative results are organized according to four broad themes: Perceptions of Rurality, Caregiving Experiences, Resources Used, and Perceptions of Resources. Caregiver

interviews provided deep insight into the experiences of rural family caregivers use, non-use, and need for resources as they cared for their family members diagnosed with Alzheimer's dementia. Their experiences with resources were inseparably tied to their particular rural contexts and their experiences of caregiving.

Although all family caregivers lived in rural communities, there was considerable diversity in caregivers' experiences and their use and perceptions of resources in their community. Community settings were very different as well as the family caregivers' perceptions of their communities. Community was viewed as supportive by some caregivers while other caregivers voiced distrust of their local communities.

Caregivers were very open about their experiences with resources but spoke of the perceptions of resources in relation to the care they provided and the problems encountered or potential problems they were trying to avoid. Caregivers' descriptions of their roles are essential to understanding their perceptions of resources in rural Midwest communities. The rural family caregivers found unique ways to deal with the problems or were unable to solve the problems. Across the themes there was an underlying problem-solving process caregivers used to identify resources, available or unavailable, to deal with perceived issues in their role.

Perceptions of Rurality

As noted in Chapter 3, the determination of rural status for family caregivers was determined by a RUCA Code of 2 or greater. However, a mere number does not fully describe or even align with caregivers' perceptions of the rural nature of their lives and the seclusion encountered by the caregivers in the study. Prior to expanding the inclusion criteria to include RUCA Code 2, one potential participant was astonished that her home might not be considered "rural" for the study purposes. After the inclusion criteria were expanded and she enrolled in the study, driving to her home involved driving on gravel roads through farmland. There were long distances between some caregivers' homes and paved roads. The significant distances to neighboring farms and homes varied from a mile to several miles.

Some caregivers described living in the rural area in terms of by distance to the nearest town or medical services. Caregivers living in zip codes associated with a RUCA Code 2 did have shorter distances to metropolitan areas. However, once they left the metropolitan area and travelled on black top, gravel, and narrow winding roads, it was evident that travel even the shorter distance to the metropolitan area could be difficult, especially if the weather was precarious. Ellen stated that weather had an impact on her ability to reach the paved highway. The need to travel on gravel roads made the time required to reach resources (or for resources to reach caregivers' homes) a consideration, even when the distance in miles was not particularly far.

The rural communities in which caregivers lived differed. Some lived in towns while others lived on farms and acreages. One difference noted among the caregivers was the distance traveled to larger metropolitan areas where resources were viewed as more available. Distances travelled varied from 25 minutes to 6.5 hours for caregivers to reach a metropolitan area. These differences could be perceived as affecting the experiences and use of resources by the caregivers in relation to access to resources. Another difference among the caregivers was in the perceived availability of resources in the larger towns. For example, two caregivers who lived in towns located on a major interstate and had access to larger healthcare systems, stated that they had access to many resources and choices of service providers in their communities.

Challenges encountered with resources included difficulty obtaining information about resources, limited choices, and limited availability of resources; however, each caregiver's experience with resources was unique to the care they provided as well as the care recipient's stage of Alzheimer's dementia. Family caregivers' experiences were also dependent upon the relationship each caregiver had with the individual with Alzheimer's dementia as well as the family dynamics.

The rural settings as described by the caregivers, as stated above, varied from living in a larger town to a farm. Two caregivers living in larger towns stated that they had access to

resources. Living on a farm for one spousal caregiver was not seen as a detriment to obtaining resources, but Ned stated that they “didn’t need much right now.” The availability of resources for some caregivers was viewed as more dependent on the stage of Alzheimer’s dementia rather than the rural setting they lived.

Living in rural communities was one similarity they all shared but the individuality of each situation required different resources and skills from the family caregivers. Although they did not consider many of the things they used as “resources,” during the interviews it was very clear that they were all creative in using what was available and familiar to them to assist in meeting the day-to-day needs as well as the more complicated demands of their role. The individuality of each unique situation was shaped not only by the nature of their rural environment but also by the nature of their caregiving experiences which will be described next.

Caregiving Experiences

Five subthemes were found in caregivers’ descriptions of their experiences: relationship bonds, changes in family roles, care settings, care provided, and impacts on caregiver. These themes are not mutually exclusive as the relationship between each was intertwined with the caregivers’ descriptions. The caregiving experiences described provide details of the hands-on care as well as the family relationships and roles that were intricately related to the care setting.

Relationship Bonds

Relationships between caregivers and family members diagnosed with Alzheimer’s dementia influenced the overall experience of caregivers. Just as there were three distinct family relationships reported, there were distinctions in the “caregiving” relationship that were influenced by this family bond. Spouses viewed their caregiving as a commitment that extended from their marriage or relationship whereas adult children described owing care to their parents.

Spouses were more likely than adult children to not view themselves as caregivers. One spouse, Adam, did not think he qualified for the study because he was just doing what a husband would do for his wife. He stated, “I haven’t minded and have no regrets and I wouldn’t have it

any other way.” Adam said his wife would do it for him. Ned stated his hopes as a spousal caregiver:

I hope I can do a good enough job taking care of her. She, you know, she needs that. She’s been a nurturer all her life, now what goes around comes around and we have to take care of her.

Keeping a spouse at home was the goal of caregivers and Rhonda stated she hoped to but knew it might be difficult. “What I really would like is to be able to take care of him at home until the end of his life. I know I may not be able to do that, and if I can’t, that will be the time that we’ll sell the house and move to the city.”

The commitment of spouses was evident in interviews. Ned related how he also went through the cognitive testing with his wife to decrease the anxiety for her. He explained, “I was tested too, at the same time. I wanted to go as far as I could with her in this ordeal, and understand what she was going through on the testing. Well, my tests came back ‘normal’ and hers didn’t.”

Frustration with the disease tested the patience of Adam but stated he kept it in perspective and remembered that it was his wife. “I guess in the long scheme of the past year, the only thing that sometimes bothers me, I get a little short because I say, ‘Isn’t this the fifth time I’ve told you that same damn thing?’”

Spouses provided physical care as part of their commitment and hoping to avoid placement in assisted living or long-term care. Love for her spouse is what fueled Kaye’s commitment to provide care, even though caregiving had become difficult due to her spouse’s behaviors and his need for increasing assistance with personal care.

Just something you have to do. That’s...that’s about all I can say. It’s just something you have to do. He was a good man, a good person, and I loved him dearly. And so, I just had to do it.

Commitment was also described by Harry as not using respite, “We go to everything together you know, I feel like I was letting her down if I didn’t...I don’t think I would feel too comfortable letting somebody else [respite].”

One adult child described her sense of obligation to provide care for grandparents and a parent differing from spousal commitment. “It was my job to take Grandma and Grandpa shopping for whatever they may need and make sure the little things in their house had been taken care of,” stated Sally.

Adult children were more likely to believe placement was inevitable for their parent when the care became too much. Cassie was very open with her parent, “So, I said, if and when you do go somewhere, you’ll probably have to go to assisted living. So, I think she’s kind of come down to the fact that, yes, someday I will have to.” Adult children also had multiple commitments in addition to the parent with Alzheimer’s dementia. Balancing care for her parent, Maria stated, “My kids are age 3 to 11, so they don’t know what’s going on, but my husband is supportive.” Spouses were less likely to have these multiple care responsibilities. The type of bond between the spouse or adult child and the care recipient had an impact on the caregivers’ perceptions of their role.

Changes in Family Roles

All caregivers, regardless of their relationship to the care recipient, described their perceptions of being a caregiver and some identified how their role in the family had changed or was changing since becoming a caregiver. Spouses described how they now had responsibilities that they did not have before which included Rhonda taking a full-time job: “I could not continue in my practice because I was going to have to go to work full time somewhere so we would have insurance benefits.” Harry stated that he found it difficult taking on tasks his wife had always done. “Cooking’s been a challenge, because I pretty much do the basic stuff.”

Adult children perceived their role as a transition from care recipient to caregiver. As Faye explained, “Mom and I always had this bond and now it’s switched, because Mom is more

distant and far away, now, so to speak, whereas now Dad and I, we're going through this whole connection thing." Instead of their parent caring for them, adult children were protecting and caring for their parent. For Vera, the care included physical care and she stated, "There are things that I have had to do that a daughter should not need to do for a father."

The adult children's perceptions of their role was impacted by their relationship with the parent diagnosed with AD. For one daughter, it was her responsibility to take care of her mother where her brothers would have been the caregivers for their father. This was a perception of several adult children. As Daniel stated,

I had to literally kind of retrain him to, at least take care of himself. Those were big signs for me to know that Dad is not Dad anymore. Dad's gone. This is the person I'm dealing with that needs some special care.

One adult child, Barbara, had to stop working to provide care and oversight, "It got to a point where he did wander outside and was walking around the yard, so I knew then that I couldn't leave him by himself so I had to give my two weeks' notice for both the jobs."

Care Settings

Caregivers provided care in various settings that the family caregiver perceived as impacting the care provided. Spouses were more likely to be providing care in the home where adult children commuted to provide care in their parents' homes. Two adult children found it easier to stay at their parent's home especially overnight. As Wanda described, "She was in her home, and so that kind of removed me a lot from my home. I would stay with her at night. She was afraid to stay alone. After my dad died, she did not want to stay alone, so there was a lot of night care."

Several caregivers had placed their family member in long-term care or assisted living within a year of being in the study. For these caregivers, they described not only the care provided prior to placement but also their perceived role as caregiver now that their family member resided in a care facility. Four adult children whose parents were in assisted living or

long-term care described how they still provided care just in a different way. Their perception was that they were caregivers no matter the care setting. As Brenda whose husband lived in assisted living said, “I go once a day. I go to check on it (husband’s health), because I can’t give up that role.”

Placement of their family member in memory care or long-term care was viewed as very difficult for those who had decided on placement for their family member. For those still providing care at home, they were hoping to not have to seek placement. This was evident as Ned stated, “And, ah, 48 years ago I made a commitment to this lady, and it still stands...and, uh, it takes, you know...it takes some adjustments and as we make each little step in her progression, you have to make another adjustment.”

Care Provided

Each caregiver described in depth what it has been like both day to day and over time being the caregiver for a family member with Alzheimer’s dementia that was directly related to the care they were providing. Care provided for the family member with AD was a large part of caregivers’ descriptions during the interviews. Descriptions of the things caregivers did for their family member were rich and included the impact of caregiving on themselves, on their extended family, and relationships between family members. Although the rural resources were the focus of the interviews, the family caregivers did not separate the resource from the care provided. This was evident in the interviews, as caregivers’ exploration of resources was put in context with the care they provided or needed help with in their role.

Nine spouses and three adult children reported that they provided care 24 hours a day seven days a week. Three spouses reported hours of care ranging from five hours to 70 hours per week. Adult children (n=2) reported 40 to 50 hours per week while four adult children and the one sibling reported 3 to 15 hours per week providing care. One spouse did not report how many hours a week care was provided but had indicated that the spouse was able to remain at home during her workday. Just as each caregiver differed so did the care they provided which related to

the family member's stage of AD. This care provided by caregivers included managing: physical care, household tasks, appointments, safety, medications, and finances. Family caregivers also provided cognitive care, and emotional care.

Managing physical care. Family caregivers described how they provided hands-on care for their family member. Physical care included hands-on assistance that ranged from encouraging the family members to do their own personal care to hands-on bathing and toileting. Those in the early stages required little to no assistance with personal care whereas those in middle to late stages required greater assistance that increased with disease progression.

Caring for the family member ranged from occasional assistance to complete assistance with all activities of daily living. The need for help with personal care was dependent on the progression of the AD. Early stage caregivers were providing little to no physical care but did provide more guidance. Maria described the care she provided for her parent in early stages, "I don't know. For right now, I think just keeping my mom on track with appointments and organizing shit and stuff like that." Ned stated, "Might need a suggestion once in a while, towards something. Or ask for a suggestion, she does that. And, ah, you know, but she can still do it on her own."

As the disease progressed, caregivers gradually increased the care provided from minimal assistance with dressing to complete care of their family member. As one adult child, Barbara, explained:

It got to where I would put the toothpaste on the toothbrush and set it on the counter, and he would pick it up and brush. Then it got to where I had to put his hand on the toothbrush and put it to his mouth. Now I have to do it all.

She left her job due to the increased personal care she needed to provide for her parent. In doing physical care, Barbara described how she tries to keep her parent involved in the process:

It's like well you just went to the bathroom, you need to do this, and he's like well I don't know if I can, and it's like yeah you can. So, you have to be

persistent with them even if you make them mad, even if you aggravate them because if you just give into him and just do it for him, then you see him get weaker and weaker all the time as far as their ability to be able to do stuff. So, you have to kind of push at them even when you think at times, Oh I should just do this.

Faye stated that she assisted her mother with all personal care tasks but that her father would help as much as he could. However, the daughter realized that her father and brothers were not comfortable providing personal care. "I was the one who ran and took care of a lot of the girl things. And that kind of stuff." She also stated, "It's kinda like I help Mom because I'm the daughter, and my brother helps my dad because there's that guy bond there."

Other adult children described providing some assistance with personal care but with only one son in the study, daughters were the primary caregivers helping or performing personal care for their parents. Daniel encouraged his father to take showers. "Okay, time to take a shower, you know? Cause I knew he did not do a shower."

The amount of physical care provided by family caregivers depended on the stage of the disease. Early stage caregivers were providing little to no physical care but did provide more guidance. As the disease progressed, caregivers gradually increased the care provided from minimal assistance with dressing to complete care of their family member. Spouses provided physical care as part of their commitment and hoping to avoid placement in assisted living or long-term care.

Adult children provided physical care for their parents. The only son in the study did not provide physical care but did hire an individual and later placed his parent in a care facility. The daughters, however, were very involved in the physical care of their parents. As one daughter explained, "It's kinda like I help Mom because I'm the daughter, and my brother helps my dad because there's that guy bond there." Caring for her father, Barbara described the difficulty in doing so:

You start seeing where the adults need to be taken care of like my dad and stuff, but I have to admit, it's a lot harder and a lot more stressful to take care of an adult than it is to take care of a child.

Just as daughters tended to take the role of providing personal care for their parent, several stated that it does not seem right to be doing the care. Vera stated her feelings about providing care for her parent very plainly, "There are things that I have had to do that a daughter should not need to do for a father."

Managing household tasks. Household chores included cleaning, laundry, and cooking. These chores were either supplemented or entirely done by the spousal caregiver. The need to assist with household chores was dependent on the progression of the family members' dementia. For some husbands learning to cook or do laundry was a change that was difficult. One husband, Harry, understood the need to take over the cooking but had not done it before. Lois wanted her brother's apartment to be clean and clothes washed but felt he was still able to do these things himself. Therefore, she did not help him with cleaning and cooking. However, she did hire an individual to provide some assistance to him in his own home.

Adult children identified problems associated with their parent's ability to do household chores. One son, Daniel, described how his wife cooked and brought meals to his parent who lived 40 minutes from their home. They also hired an individual to do light household chores. Barbara, who brought her parent into her home, did all of the cooking and cleaning with support from her husband. This caregiver had to leave her employment to meet the increasing needs of her parent.

Managing appointments. Caregivers scheduled and took their family members to appointments whether they were a spouse, adult child, or sibling. Five spouses still working described their experiences providing the physical care needs for their spouse. Two spouses were still working full-time and had to take time off work that made balancing work and appointments difficult. However, one of these spousal caregivers stated that her work allowed her flexibility in

her hours. For Greg, transporting his spouse to appointments was challenging due to mobility problems. Lois was retired but stated she wanted to keep her sibling as independent as possible. Thus, she encouraged him to attend some of his appointments by himself and use a cab service available in their town.

Four adult children had to schedule time away from work for parents' appointments and all adult children took responsibility for scheduling appointments. Sally who cared not only for a parent but also grandparents, made appointments for each and had to schedule time off work to take them to the appointments. "And he's (physician) out of North Platte. So, I try and set those appointments up on the same day." Lois and Cassie were also more likely to schedule as many specialist and primary care appointments at one time to decrease time away from work.

Cassie stated that it was 60 miles to her parent's house and then over an hour to the larger city where her appointments were located. "Except for those specialists. Like the heart doctor will come in. Mom's hearing aid lady, she comes in once a month. So, we schedule those appointments every 3 months, you know. And it's got to be on the day that they come." Maria had changed her work schedule to part-time so she could be more available to her parent for scheduling and attending her appointments.

Managing safety. The safety of their family member was a priority for all caregivers. Caregivers described the importance of keeping their family member safe. As Ned explained, "I kinda have to stand in the background to watch, if you will, and step in if needed, which happens occasionally." He also described the importance of planning ahead when you live in the country. "If I'm going to be gone for a lengthy period of time, I better have something for her to do or somebody to come visit with her or something to keep her...you know, don't let her alone." Cassie began staying overnights to keep her parent safe, "I would go up probably, oh 3 or 4 months ago I started going up every 3 to 4 days, depending on when we mowed and what Sunday came around and try to work in a little extra. And then now I'm going up...last week I started going up almost every other night."

Living in a rural community meant that at times the safety issue was unique compared to an urban setting. For example, the potential of wandering is an issue in urban areas but, in a rural farm setting, an individual could become lost in a cornfield or wander off long distances in desolate areas. Caregivers described vigilance and forethought in attempts to prevent the wandering of their family member. The rural community's awareness of a family member's diagnosis provided some safety for Adam whose wife would wander or become scared:

She had a few crying episodes and when she called the police. I was downstairs.

So now I've talked to the gal, I mean being a small town, you know everybody, so I just call her and now if she ever calls, they call back, so when the phone rings I know that she's upstairs on the phone, and we haven't had that happen, so I'm sure that they still remember.

Wandering in a rural town still held potential risks for family members. Neighbors and community members, however, were more likely to notify a caregiver if they saw the family member wandering. Also, neighbors were likely to intervene to prevent potential injury to the person. As one spouse stated, "We've had some episodes where she left the house and I was even there and she walked up the street to one of our friends, and then she called me and I came up and got her and brought her back, and she's probably gone next door to the neighbor four times."

For those living outside towns, the risks of wandering were accentuated by the lack of available oversight from neighbors and community members. However, one caregiver described assistance from "renters" as she explains, "My mom lives on a farm. So, the guys that rent the farm ground, they haven't ever called me and said, hey, you know, this is going on at home, but I think they would. In the wintertime, when I'm not up there, they scoop her driveway and they scoop the sidewalks." Another farm-dwelling caregiver had concerns about her spouse wandering in the cornfields. She described how "renters" help her with her spouse's wandering, "I did get a chance the first time they came to, you know, let them know what was going on and

stuff. I had their phone, they had my number, you know, and so I just called and said, ‘Can you see my husband down there?’”

All caregivers identified driving as a safety issue. One son tried to tell his parent that he needed to stop driving but it did no good. It was not until the parent was found sleeping in his car far from his home that his driver’s license was taken away. “He had to take a nap halfway between where the horse track north of town there, and a guy said, ‘I thought your dad was dead.’” Caregivers stated that it required the physician or specialist telling the family member that it was time to stop driving.

Communication with their family member was identified as a learned process to prevent accidents from happening. Ellen stated she knew her husband so well that if she told him to stop something he would try to prove her wrong. She described an incident that could have resulted in an injury:

He had this hand down, clear down inside the garbage disposal hole.

And that’s what I could hear. He was twirling those blades in there. And I come around the corner. I didn’t want to startle him. I just kind of walked up there and I said, “Dad, what are you doing?” And he said, “Fixing this thing.” I said, “It doesn’t need to be fixed.” And as I said that, I thought, I shouldn’t have said that. I could just picture him reaching up here with this hand and flipping that switch to show me that it didn’t work.

Managing medications. All caregivers described their role in ensuring their family member received their medications as prescribed. For some caregivers, managing medications to be sure the correct dose was taken was the extent of the assistance. One caregiver described how he worked with the local pharmacist to have his spouse’s medication in single dose packaging to prevent medication errors. This spouse identified that a shape change in her medication would be a problem. “This isn’t going to work, because she works off of shapes.” So, after speaking with the local pharmacist in his small town, they came up with an alternative for dispensing her

medications to keep her doing it herself safely. “These things are actually like little containers. Twenty-eight little containers. You tear them apart. They’re perforated.” Another spousal caregiver, who did not see himself as a caregiver, described giving medications (which included eye drops) and ensured she had the proper dose. “The eye drops especially because she only takes three eye drops but they’re divvied up over four time periods.”

Managing finances. Paying bills, managing and budgeting money, and controlling checking and savings accounts was included in the care provided by caregivers. For some spouses this was a change in roles but for many these tasks were the natural thing to do. Adult children found it difficult in managing the finances for their parents. For some adult children, obtaining Power of Attorney to manage their parent’s finances was necessary. Caring for her father, Barbara managed and budgeted her father’s finances to provide the essentials necessary for his care while trying to manage her immediate family’s budget with financial loss due to her not working which caused her stress. “When you’re taking care of yourself and him to kind of come up with the income that you lost from quitting your jobs, so you always kind of have that in the back of your head, is something going to happen to where they’re going to check you and just not believe that all this stuff is going” for his care. Concern for her sibling’s finances was causing stress for Lois, “So, we have to stay on a strict budget. So, that’s stressful for me because I would love to give him everything.”

Vera was concerned for future needs of her parent and explains, “I really have to keep track of Dad’s money, so that if the time comes, we will be able to do a skilled care.” This financial concern for the future was also important for spouses. As Jane stated, “And, you know, I keep hearing that this diagnosis will bankrupt you. And that’s one of the reasons I’m trying to work so hard now, so as I can put money aside to take care of his...”

Cognitive care. Maintaining their family member’s ability to make decisions, remember events and people, and socialize with friends and family was a priority for many of the caregivers as they attempted to maintain cognitive function. Playing games such as cards was important to

one adult child as well as playing games on a phone. As Barbara said, “It’s like I think if things were done sooner and you keep their mind busy, I think it helps with them keeping their mental status a little bit longer.” Reading the newspaper was important to Wanda, an adult child, “I made sure she had her newspaper every day, and the kids were in the paper a lot, and she would always find those. She would try to find them. We had these little word things, where she would circle.” Another spouse downloaded games from the Internet for her parent to play and encouraged him to beat her score. Allowing her brother to retell stories is how Lois made her brother feel secure, “He wants to wander a bit more. I’ve learned to let him tell the stories. I’ve heard them 55 times. Does not matter. And to pass the time, he’ll tell the same jokes.”

A voice-controlled speaker connected to the Internet was used by Rhonda to provide activities for her spouse, “It does, but he’s very attuned to music and so he’s been able to pull up all these bizarre radio stations on the Alexa and then he also can pull up his audio books. He stays very current with things that are going on politically and nationally.”

Reminding their family members of current events and people was important to caregivers. One husband used quizzing in an attempt to delay the onset of dementia symptoms. Both spouses and adult children described how they encouraged and questioned their family member to remember events and names. As Adam explained,

I quiz her about where the granddaughters go to school, what their names are, what their boyfriends’ names are, where she went to high school, where I went to high school, just to try to get her to remember specific things.

Vera explained how she cued her parent, “Cognitive. Cueing at that point; ‘You haven’t had a shower for two days’, and there were points where you could hear the shower running but you knew by the sound of the water he wasn’t doing . . .”

Although it became harder to do, Barbara quizzed her parent as a way to keep her father’s mind working. Caregivers also identified the need to encourage their family member to continue to do things for themselves as long as possible. As Barbara stated, “So basically what I started

doing was I'd put shampoo in his hand and I'd watch him, make him wash his head, and then I would just do basically the rest of his body, but I would still wet him, or make him do at least some of what it is."

Several caregivers identified socialization as key in keeping their family member active and cognitively involved. Encouraging extended family to visit and spend time with her husband was important to one spouse.

Emotional care. Reassuring and protecting their family member were important aspects of the care provided by family caregivers. Caregivers, attempting to decrease emotional upset experienced by their family member struggling with their diagnosis, described reassuring their family member that they were still important. Caregivers tried to reassure their family member and protect them. Ned explains how he did this, "Allow her as much independence as she can have, but yet step in whenever it looks like it's not going to work. You know, and do it in such a way that she maintains her dignity." Faye and her family made the decision to not place their mother through the rigor of testing as they viewed it as potentially causing more anguish and held no value. "We made the decision that we were going with our doctor's diagnosis that this is dementia, Alzheimer's, whatever you want, how you want to plug it in. And we made, as a family, a decision that we would, we were never, we were not going to put Mom [through testing]."

Protection of their family member emotionally was a priority for several caregivers. Preventing everyone in the community from knowing about her spouse's diagnosis was a priority for one caregiver to protect her husband emotionally. In contrast, another caregiver was very open with the community about his spouse's diagnosis. Both caregivers had concerns but took different approaches. As one spouse stated, "Our family support is good. The community is not, and I don't want us to be out there in this community because, again, of his privacy, his dignity, and that's how we've always been. It would be so completely different from how we've conducted our entire lives and I don't want that, especially for him." Whereas Ned stated, "We

didn't want to go shout it from the mountaintops, but we started, decided right from the beginning that we weren't going to try and keep it a secret."

Emotional protection for Maria was being respectful of her parent's request of keeping the diagnosis of Alzheimer's disease private and she stated wanted to help preserve her parent's dignity. "My mom is very, very reluctant in telling anybody. She has five siblings and she doesn't even want any of them to know." She was so protective of her parent that her own children were not aware of the diagnosis.

Impacts on Caregiver

Caregiver's health. Concern for their own health was identified as an issue expressed by several caregivers. Being very clear, Paul put it bluntly, "It's killing me. It's killing me. I don't get enough sleep by any means. I rarely get more than three or four hours sleep per night. I sneak in and out a nap whenever I can." For some caregivers, they could not recognize the effect caregiving was having on their health. "Sometimes it takes other people to tell you because you don't put that on yourself to think how your health is or anything like that" explained Barbara. For Kaye trying to keep her husband at home, it took a health scare and a physician telling her she had to place her spouse in a care facility.

I wouldn't have done it if the doctor hadn't have told me... My cardiologist told me when I went in that day, my blood pressure was 230/98, and he said 'You're gonna have to do something different.' And my kids told me all along, said, Mom, whenever it's time you'll know. You pray about it and you'll know when it's time. And it just happened that there was an opening and we could get him in and the doctor told me I needed to do something different.

The 24/7 care provided by some caregivers was taking a toll on their health and as Barbara stated, "It's very easy for me to get tired. It's very easy for me to get depressed. It's very easy for just feeling like throwing your hands up, so I mean, it's a very tiring, a very stressful type thing. There are times that I would have problems a little bit with my back." The physical care

was increasing for Greg and he stated when he could no longer provide the care he would seek placement for his spouse. “I think my health has been as good as it can be. Some of the physical things, in having to move her when she gets stubborn, that’s getting harder. And I don’t know what else to do. Again, that’s that tipping point...when does she have to go into another facility.”

Isolation. As the disease progressed, caregivers felt the loss of friends or found it more difficult to socialize outside the home. As Rhonda explained, “I did tell the one couple at one point exactly what’s going on, and they don’t call. They don’t come over. In two years, there’s been no one that has called my husband to say, ‘Hey, can I come over and have lunch with you,’ just by me asking them to.” Although socialization was viewed as important, some caregivers realized that as the disease progressed it was more and more difficult to maintain social contacts. The loss of social outings had made caregiving more isolating as Donna explains:

He won’t go outside. There’s where it is, see. This is what I am missing the most is, just um, and he doesn’t like me on the phone. He doesn’t want you out of the room. He just gets kind of fearful, or something I guess. And so, really, my activity has been cut down to close to zero.

Kaye stated that her husband was always a private person and that the disease did not change that. They were more reliant on family for socialization and had an adult child that lived nearby. Another spouse, Rhonda, found that friends were less likely to visit and felt it was due to their not understanding the disease. These impacts on caregivers suggested the need for resources to assist and support them. The resources used will be described next.

Resources Used

The care provided differed based on their family member’s needs and the rural community resources available. Just as the care provided was linked to the resources used, caregivers’ perceptions of resources impacted how they used, did not use, or sought resources to help in the care they provided. Perceptions of resources will be discussed further in the next section of this chapter. All caregivers reported higher use of their own resourcefulness and the

support of family. Reliance on formal community resources was not a priority. They did describe the difficulties accessing formal resources such as specialists who were only available at a distance, which is linked to caregivers' perceptions of resources to be discussed in the next section. The Social Ecological Model guided the description of resources used.

Self

Providing care for their family member as described previously was closely tied to resources in the sense of things caregivers were able to draw on in themselves and ways they problem solved as well as the personal knowledge they possessed. This resource of "self" was what the family caregiver brought to their role. Although caregivers were not seeing themselves as having a unique ability, it was evident in the interviews as they described the care they provided.

Knowledge, in relation to "self," includes knowing one's capabilities as well as those of the family member. Caregivers used this knowledge to provide care. Care provided based on knowledge was described by Ned in terms of when he knew things were changing for his wife,

It takes some adjustments and as we make each little step in her progression, you have to make another adjustment. I, ah, allow her as much independence as she can have, but yet step in whenever it looks like it's not going to work.

Being able to remove oneself from the care situation mentally or physically helped some caregivers to provide care. As Vera explained, "I have been blessed with a gift of detachment." She also stated, "There's just a part of you that just automatically you deal with the task at hand and then you move on, and if you have to deal with it later mentally, you do." For Teresa, it was even bigger than her self, "It's not because you're embarrassed that your loved one needs this care. It's just that we've been taught, in America, to take care of business. I can do this."

Barbara talked about how she knew when she needed a break from 24/7 care. She explained, "You just can feel when you start getting kind of burned out, and it's just not so much

that when you can really afford it as when you know it has to be, the caregiver just needs to get out and get away from things.”

Caregivers knew their family members and were able to identify behaviors that would lead to bigger problems. For Barbara there were clues to when changes in behavior were going to occur,

I can see the signs, even if they're a teeny tiny little, teeny things, I can start seeing certain attitudes and certain little changes in the voice and you really get to know the disadvantages to the things that are going through the one you're taking care of.

She also stated, “I know whenever sun downing starts, and it changes even the changed person a lot. You see a lot of anger.” This was similar to Daniel knowing his father was changing, “Those were big signs for me to know that Dad is not Dad anymore. Dad's gone.” He also pointed out the changes to his father's physician, “I had to confirm a lot of things thereof, ‘Hey, Dad really has changed a lot.’” Ellen stated she knew her husband's behavior and tried to inform healthcare professionals, “He doesn't want help. And he doesn't want you to tell him what to do.”

Knowledge included knowing the activities that a family member enjoyed. For Barbara, this included games, “He liked playing 500 rummy, so we would play some of that and things were good with that, and then he loves playing checkers.”

Donna identified her strength as a caregiver. “Things don't upset me, because I have been in the health business for quite a while.” For Ellen, patience was her strength. She explained, “I've been complimented on having patience, but you know what patience is, don't 'ya? It's idling your motor when you really want to strip your gears.”

Being creative in the care she provided, Donna described how she prevented injuries with her husband, “I rearranged the room. He would not be falling out into space. So, I kind of put up

barriers.” Another spouse described how she created a planner for other family members to know what to do if something happened to her. Brenda explained,

I actually have done a planner thing where our daughter is the next person, power of attorney type thing, because of the fact that if something happened to me, it would be so difficult for somebody to walk in the door and – okay he has to be catheterized, where’s his medicine, how many times a day does he take this, where do I get the supplies. The unending things, so I actually had a whole book that I made up for the children in general, but specifically I showed my one daughter, and all the things that go with it that you would need because I just knew that this was coming. What if I fell down the stairs. What if I had a stroke.

Family & Friends

Caregivers identified their family and friends as sources of support as they managed and provided care. However, caregivers tended to not want to burden or bother family and friends or distance prevented hands-on assistance from family and friends. When asked if her adult child was able to provide assistance, Jane stated, “Not on a daily basis. It’s like he lives in a nearby town about 30 miles, 35. So, it would be once in a while if you need him.” Distance was an issue for Faye receiving assistance from a sibling, “I have my two brothers that one is 900 miles away, but he’s available, just moral support and that kind of stuff. And, he’ll fly out when we need him, he can be here.” Ned explained, “We get a number of people, you know, that have offered some assistance. And what I have told them is we’re doing pretty good right now, but I’ll put you in the memory bank. At some point in time, we may need some help.”

At times the help was just being there to listen or showing they cared. A common comment from caregivers was that family and friends were “supportive” but that support was not associated with assistance with the 24/7 care. As Kaye stated, “Without my family’s support, I don’t think I could have done it as long as I did. They didn’t come and stay with him.” Cassie described how her spouse supports her as she cares for her mother,

My husband is very giving. In fact, he's the one that said, you know, maybe it's time to do a little more with Mom and go up and spend a little more time. So, I don't have that stress of trying to have a married life.

Daniel was very clear that support was from his immediate family, "You got absolutely nobody other than your close-knit...my wife, my kids. I owe it all to them, because they kept me focused enough to stay on track." For Faye, assistance from family was support also. She stated,

I have the support of my husband. And, then, my other brother that lives right in the same town with Mom and Dad, he is very diligent about taking care of, of being there, of being the guy for Dad.

Faye also stated that friends are supportive, "Me and my siblings, the support that we're just getting from our own network of friends and that's very supportive. Not that they do anything to assist with my parents, but they help keep us sane, which helps our parents in the long run."

For some spouses and adult children caring was a shared experience. This shared care, however, fell heavily on daughters. Adam stated, "I have a little help from a nurse friend of mine, which is my daughter." As Faye stated, "I mean, my dad's the caregiver for her, but me being there to help, also, and help both of them. I'm glad I was able to take that part of the journey with my father." Harry relied heavily on her daughter for help with caring for his spouse, "She's (daughter) always around and does anything we want, you know. She'd do anything. She's overworked and underpaid." For Barbara, her daughter was able to help with medication administration, "I have a daughter that's a CNA and at that time she lived here and she would come out and of course she'd be satisfied being paid \$10 an hour, so that helped. I knew she would give medication."

Adult children were considered supportive by spousal caregivers. Distance, however, had an impact on the amount of support adult children could provide. For some spouses, children living close by were able to provide more than just support. For example, Ellen stated that her

sons (who lived on farms in close proximity) could respond immediately if she needed assistance. This assistance was not with personal care rather it was to help with keeping her spouse safe. As Ellen described when her husband had wandered into the cornfield,

It was like a short hour before dark, and so I thought, how are you going to look in the dark? So, I called my son that lives here (on an adjacent farm) and my other son that lives in (town). I called both of them, because I thought they'd be about on their way home from work, which they were and they both said they'd be right here.

This same caregiver has a cousin who provides respite care and her adult children encouraged her to do so after her husband came home from assisted living. Ellen stated,

This cousin I have come down last week when I had doctor's appointment, and the boys are stressing that when we brought him back home again, that I needed to do that. At least once every, or couple times a week maybe, and just like get groceries or whatever. And then, of course, the one keeps saying, or go have coffee with a friend. But, I haven't done that."

For some caregivers, friends were available and provided some respite for the caregiver as well as socialization for the family member. As Ned stated, "If we go outside the family, we have a couple of people who are just outstanding support. She has a friend from work that takes her to shows and things like that." Faye stated, "It's good to be able to lean on other people, be it friends, family, whatever. I don't think we could get through it if we didn't have this support we have, it would just be a very different picture." Harry described his wife's friends, "They'll pick her up, most times, and take her out and they'll be gone a couple of hours, then for her ice cream and coffee. Ned spoke of his wife's friends, "Her friend from work, in particular, has really stepped up to the plate. She used to work with her, and she was a caregiver herself, so she knows the routine, so to speak."

Friends were also helpful resource for a family that was seeking placement for their mother. As Faye explains, “I have friends who are nurses, I have friends who have worked in the retirement community, retirement condo kind of things, and I think they get a feel for other places. I trusted their input and her different stories about different things.”

Neighbors

Caregivers identified neighbors in their community as providing oversight for their family member. These individuals also would intervene to keep the person safe. For Donna neighbors helped her with her husband first when he was ill and second when he fell, “She (neighbor) ran over, then went and got a neighbor who came over. Another time he was walking down the block and he fell, and the gal (a rehab nurse) happened to live right at that house.” She also stated she had a police officer and sheriff who lived nearby. Wanda also described having a “safety net” with her mother’s neighbors, “Then she would sometimes just have to stay there alone, but we were fortunate we had a nurse on one side and a nurse on the other side. And they were both good friends so that was helpful.”

Neighbors were also available for another caregiver who lived in a small town. Adam described the assistance neighbors provided him in caring for his wife, “We’ve had some episodes where she left the house and I was even there and she walked up the street to one of our friends, and then she called me and I came up and got her and brought her back, and she’s probably gone next door to the neighbor four times.”

Farmers who rented farmland (renters) were a resource to caregivers living in the country or an adult child whose parent still resided on a farm. As Ellen states, “I let them know what was going on and stuff. Well, I had their phone, they had my number.” For this caregiver, the threat of her husband wandering into a cornfield and becoming lost was a real concern. As described earlier in this chapter, living in the country has unique dangers. Cassie knows the renters who

farm around her mother's house, "The guys that work the farm ground, I think, kind of keep an eye on it."

Community

Community resources used by family caregivers were dependent on the family member's stage of the disease and perceptions of the caregiver. These perceptions will be further discussed in the section below. For some caregivers, community resources used included Meals-on-Wheels, support groups, churches, and Area Agency on Aging. Use of these resources was limited as many caregivers did not seek or feel the need for the services that will be described later in this chapter.

Meals-on-Wheels was used by two spousal caregivers. Paul stated, "The resource we have been relying on, we get Meals-on-Wheels that helps with the cooking." This caregiver also attended his churches "open table" one day a week for a congregate meal. For Harry, Meals-on-Wheels provided a break from cooking, "it works alright for us. It's kinda nice to have 3 meals, don't have to worry about it when you get up that day." One adult child, Faye, stated that her parents lived in an apartment that included Meals-on-Wheels daily for lunch.

Support groups were identified as having been attended by six caregivers. Three caregivers in the study (two spouses and the one adult child) attended support groups regularly. Two caregivers had attended support groups but no longer did so. Two caregivers identified Alzheimer's Association workshops that they had attended. One of these caregivers presented at workshops for early stage caregivers. An adult child stated that finding the support group was difficult, "It wasn't like there was a flyer like, hey cool, found it." Use of the Internet assisted this caregiver. Lois stated her opinion of the support group she had attended in her community, "Actually we get much better information when we're on with another group, because the times we've gone here (Alzheimer's Support Group), they keep repeating the same programs and we've heard them, we've heard them."

Several caregivers identified their churches as resources. However, the assistance received varied from spiritual guidance to emotional support. Respite care was not identified as being available through churches. Vera stated, “My emotional support, yes. I do make the time to go to a weekly bible study and to the church choir.” This was similar to what Barbara stated, “The pastor is really good about praying with us and stuff like that, so I think more emotional things they are able to help with more than the physical things.”

Three caregivers stated they used their local Area Agency on Aging. Vera received information on the local caregiver support group, “I did call the Office of Aging because I felt like I needed a support and wanted to see if there was anything.” They were able to provide her with a support group in her town. For another daughter, “They (AAA) have been amazing in trying, learning where to go and find that stuff.” She also stated, “And, they sat down with me and worked with me in regard to, okay, what care level do you need?” In addition, the local AAA was able to help Faye and her father with the financial impact of respite for her mother,

We went through (local AAA). They get grants and all these other things and Dad would get checks saying, ‘okay, this month we’re able to give you this much back.’ And sometimes it was the full amount. Sometimes it wasn’t. So, I mean, it was little things like that.

Healthcare System

There were several healthcare facilities that caregivers used as resources. As stated previously ten family members were residing in assisted living, memory care or long-term care facilities at the time of the interview. Teresa explained that she moved to her childhood home in the Midwest especially for the memory care unit that was available.

Six caregivers indicated that they had used home health services for their family member. Five caregivers utilized respite services. Explaining how difficult care can become, Teresa stated, “At a certain time, it becomes very overwhelming and you’d better find somebody, some respite care some of the time.” Lois stated that her brother’s respite was as good for her as it was her

brother, “He loves the person that comes and if she ever changes, we’re in trouble.” One spouse, Kaye, also found respite a benefit but the rising cost made it difficult, “She contacted this Home Health up there. And that’s where we got the respite care. And when it first started, it was only \$15 an hour.”

Family practice physicians and specialists, neurologists and geriatricians were resources used by caregivers. Family practice physicians were the providers of care for 12 family members. Two caregivers stated they were searching and considering options for specialized care. Neurologists or geriatricians specializing in dementia care were providing care for 11 family members with AD. Brenda stated, “I would recommend that (Geriatric Clinic) to anybody because there I got my support group. I had somebody; as well, he got a lot of attention and care.”

Internet

The Internet was acknowledged as providing information about the Alzheimer’s disease as well as resources they were seeking. In addition, one caregiver found a Blog on the Internet that was her support group. Jane stated, “The group (support group Blog) that’s on Facebook is a really good group.” Caregivers were able to connect with and locate resources from a distance. For example, Faye stated, “It was looking on the cities website. I mean, just the city website, and googling and trying to find elder care.” Faye also stated, “I couldn’t have done it without the Internet. Because we literally were searching for places, and we were looking in the rural community where they are at, trying to find something so that they could stay home.” For Harry, his daughters used the Internet to find a specialist in AD. “Our daughters got together and was talking about it and everything, and so they looked it up, I suppose on the Internet, and go this bio and that, and searched it and everything.”

Perceptions of Resources

Caregivers’ use of resources was strongly tied to their perceptions. Six subthemes were identified within the larger theme of perceptions of resources. These subthemes were: limited awareness, knowledge, need, value, fit, and accessibility. Just as stated previously, there was a

strong relationship between care provided, resources used, and perceptions of resources. Caregivers' use and perceptions of resources were linked to the highly individualized care they provided and their unique perceptions of need. This meant that caregivers could hold multiple perceptions of resources simultaneously. For example, they might perceive the meals available at a local fast food restaurant to be of great value, while the local respite services were not perceived as a good fit, and specialized geriatric care for Alzheimer's dementia was not perceived as accessible because of the distance. Thus, the themes outlined below are not mutually exclusive and a continuum of perceptions was not found in the data. The links between themes pertaining to care provided by individual caregivers and his or her perceptions of resources are highlighted below. Caregivers had positive perceptions of some resources and used them, while other resources viewed by caregivers as not being needed, holding no value, not a fit, or inaccessible were not used, even if they were available. Caregiver knowledge of resources had an impact on each of these perceptions: need, value, fit, and accessibility.

Caregivers' perceptions of resources provide a deeper understanding of the availability and use of these resources in rural communities. Rather than health professionals "telling" family caregivers what they need, listening to what caregivers perceive as important based on knowledge, perceived need, value, fit, and accessibility might have an impact on the caregivers' and care recipients' experiences and outcomes.

Limited Awareness

One theme identified was limited awareness and it meant the caregiver had a vague belief a resource might exist without any concrete knowledge to support their belief. There was a fine line between developing knowledge and limited awareness. The distinction was large when a caregiver stated they knew it was probably available versus knowing where it was located and what it offered. Limited awareness included assumptions about resources that caregivers had no interest in. This was evident when Ellen responded to a question asking her if she had enough resources,

I guess I can't think off hand, of something I don't think I really needed that isn't available, even though I know there's a lot of stuff I don't even know about, probably. I don't know there is, but I'd imagine there probably is.

The inability to identify resources both available and unavailable was shared by other caregivers. When asked if support groups were available, several caregivers expressed limited awareness. As simply stated by Alice, "I think there is." Another caregiver, Barbara, stated she had been given information but not looked into support groups.

I have kind of thought about that (support groups). Like I said, when we first went there, they (respite provider) kind of gave you some names of different places and stuff like that, and I just didn't. I set it aside and just kind of forgot about it.

Wanda stated "I would like it if it were just a simple thing (support group) and it was easy to get to and knew about it." For Kaye, the rural area she lived impacted her awareness of support groups and resources,

Not that I'm aware of. There could be. Most of the stuff is either over that way, or over that way. Because, we're at the very edge of the county, and this is a different area over here. We have an Area for Aging over here and one over there. But we're just as far away from both places as you can get.

Other caregivers were given information about a resource but were not aware of what it might actually offer as a resource. For example, Adam stated he had no awareness if a resource that would answer his questions exists even though he was given a phone number for a resource. He stated, "I've just never done it (called the number) and I don't know whether they might have a person there on call that can answer. I probably should do that just in case something I don't anticipate."

The limited awareness was identified in how caregivers stated assumptions. In regards to respite services in her mother's small town, one caregiver reflected, "I really don't think respite

care would be available in that town (near mother's home). If they were here in this town (near caregiver's home), I'm sure we could find respite care here, just for the simple fact you can find respite care for kids that have special needs here." For Jane, she knew of a support group but not an Alzheimer's specific group, "Not that I know of. A little group has started, but it's for all supports."

The limited awareness has implications in the rural community. As caregivers provide care, there is an assumption that they will seek and use resources in their community. However, this has not been the finding in the interviews. For example, if a caregiver "believes" a support group or respite service is available, the caregiver may not have knowledge and see value or a fit with the service even when a need is present. As stated above, the themes identified are not mutually exclusive as each theme relates to several other themes. As Kaye stated, "I don't know...I probably didn't take advantage of all I could have, but you're busy doing what you're doing, instead of on the phone trying to get something else done."

Knowledge

Another theme identified was knowledge and it meant the caregivers had concrete information about the existence of resources in their rural communities. For some caregivers, they had a developing knowledge of a resource. Developing knowledge could include being able to identify where the resource was located or how to contact the resource, or what the resource offered. Although the caregiver had not used the resource they were in the process of deciding if it met their need, held value, was a fit, or was accessible.

Developing knowledge. Developing knowledge differed from limited awareness because caregivers were able to state specific details related to a resource. Attending a workshop held by the Alzheimer's Association was important for two caregivers, Ned and Brenda, both caring for spouses. Both stated they were gathering information by attending the workshop. Ned described his need for information, "I say I'm still in a discovery phase. I have to find out how I'm going to handle this. Figure out my options, my resources, if you will." He went on to

compare what he was doing for his wife to his farming, “So...just like when you farm, you want to know what the weather’s going to be next week so you can plan for it.”

Early stage caregivers were especially interested in developing their knowledge of the disease. Faye used the Internet to learn more about Alzheimer’s dementia. Most caregivers were still working and the knowledge needs were consistent between adult children and spouses. Caregivers for family members with early onset Alzheimer’s dementia all stated they would like more information. Information about resources and Alzheimer’s disease were Maria’s biggest concern. Her mother had just recently been diagnosed. Maria stated, “I just want to be able to have the knowledge of how to care for her when we really need to and have the knowledge there for my dad, too.”

Family caregivers for early stage Alzheimer’s dementia individuals were seeking knowledge and wanting to know more about the process of the disease. Frequently they expressed the desire to know how the disease was going to progress for their loved one and how they were going to cope with the disease over time. Knowledge was a key thing they all wanted more of as they were beginning the caregiver role.

Fine-tuning knowledge. Middle and late stage caregivers were fine-tuning their knowledge in a way that focused specifically on obtaining information for their unique needs. For example, they expressed the need to know specifically about availability and cost of resources such as respite or assisted living. Barbara knew the cost of respite for her father and only used it when necessary due to the high cost. Vera knew the cost of daily versus overnight care for her father, “It was going to be \$35,000 a year. To have someone spend the night, from 6:00 at night to 6:00 in the morning, was \$75,000 a year. In addition to the nearly \$4000 a month that we pay here already.”

Rhonda, whose husband was in middle stage AD, had identified respite services available in her small town even though she had not used them. “There is, also, the visiting nurses and there are some people that do in-home services privately.” Faye described how she found the

local AAA to help her find respite services, “I did some more research and talked with AAA, and they sat me down and we talked.”

Perceptions of Need

The perceptions of need was another theme reflecting a caregiver’s view that a resource could provide him or her help with some aspect of care as well as be helpful to the family member. Perceptions of need may have been linked to knowledge that the caregiver has about a resource and the problem being experienced at the time. Perceptions of need in the interviews included identifying resources because of a real or potential problem.

Retrospective perceptions of need. Looking back, several caregivers described resources that would have been helpful in the past. Kaye reflected on how she wished she had kept her husband home longer. “I still feel like I should’ve kept him home longer. And, if I’d have had somebody to come in at night.” Kaye became tearful as she described her past need for a resource that was not available to her, leading to nursing home placement for her husband.

Faye and her family had difficulty finding respite services that could adequately address the specific services her mother needed. “We also needed to go with a more nursing type thing. We wanted somebody to come in and help more with bathing and stuff. It was more than just a friend to sit with Mom.”

Barbara identified knowledge as something she needed when she first started caring for her father 2 ½ years ago. She stated, “I think another thing too, we were talking about resources and stuff like that. Books with experiences and stuff like that, things that people can read up on.”

Current perceptions of need. Caregivers described many current needs, including the following: time away from caregiving; financial assistance to pay for services, a way to replace lost income, supplies needed for care; ways to provide a safe environment; healthcare services (especially specialists), appropriate placement options near caregivers. Caregivers also expressed the need for more specific diagnoses, going beyond the generic diagnosis of “dementia.” Carla, caring for her spouse, was unaware of where to find the services as well as identified an overall

lack of mental health services in her community. She needed a diagnosis for her husband. She stated, “Well, it seems like when you try to find help for mental health things, even the depression and anxiety, there is none available.” She also stated, “We need a good doctor.” Carla also stated she tried finding a specialist through another doctor, “My daughter’s doctor is down there (larger city), and I spoke to him one day when I just didn’t know what to do. I called him and he said, ‘Well, let me see what I can do for you.’” For Adam, a specialist in his community would have been helpful. He described the lack of a specialist in his community,

Obviously, there’s none in my town, and we only have basically one doctor that’s a ‘real doctor’, and he comes from another town, and we see some other nurse practitioners and we see some others that are qualified, and they can administer, nurses and so forth, but we don’t have anybody that’s qualified or has had any studies in Alzheimer or dementia.

Five caregivers had expressed the need for respite services. Donna said that having a “skilled” respite provider in the home at night would be helpful for her to keep her husband at home. Her husband would have frequent falls and would wander at night in the house. She said at times he would wake her to ask a question. She felt that the lack of sleep was making her more stressed and worried for her health.

Three caregivers expressed the need for privacy and confidentiality. These caregivers described the prominent role their family member held in their small communities over many years. The need for maintaining the diagnosis of Alzheimer’s dementia private was important. Keeping all information about their family member confidential was a priority need also. Rhonda described the need for privacy in her small community: “I don’t want this to be out there in this community because, again, of his privacy, his dignity, and that’s how we’ve always been. It would be so completely different from how we’ve conducted our entire lives and I don’t want that, especially for him.” For Marie, her mother was concerned about even extended family knowing about her diagnosis: “My mom is very, very reluctant in telling anybody.”

There were times when a caregiver had a perceived need but the resource was not accessible. Brenda described how difficult the lack of a resource to meet her needs was for her. She explained how she needed a service to provide someone to sit with her husband, “There would be times when I had to do something else, and I would be on the phone, which I don’t do very often, calling and crying to the (visiting) nurse because I had these problems and I needed help.”

Lack of what the caregiver needed led Kaye to place her husband in long-term care. Kaye said she needed help at night as her health was suffering, “Somebody that could stay at night and, um, so I could get some sleep. So, I could go to bed and go to sleep and know that I wasn’t going to be jolted awake by a seizure.” Donnas also identified respite as a need. She identified times when having respite on-call would have been helpful.

A caregiver thinking ahead to the future knew that adult day services would not meet her needs in terms of services offered and the distance to obtain the services. Often a service was not accessible, as both Kaye and Rhonda stated. The perceptions of accessibility will be described later in this chapter. Rhonda’s husband had early onset Alzheimer’s disease and she stated she would need a place that offered services specific to a younger person. “We need something specific for younger people, people under 65, because we’re at a different place in life than people that have been retired for a few years.”

Although caregivers described many needs for which there were no resources, some caregivers were successful in finding a resource for an identified need. The resource meeting the perceived need had positive outcomes for these caregivers. For example, Barbara needed a place for her father to stay when she had to be away for extended periods of time. Her need led her to locate to a respite service offered at a long-term care facility in a larger city. “We would drop him off on a Thursday and then pick him up either that Monday or Tuesday, so he was here close to a week. It could be anywhere from 4 to 6 days.” She also needed someone to sit with her

father while she was still working. She decided her need was worth paying friends and her daughter to assist with this care.

Perceptions of Value

Another theme identified was the perceptions of value. Perceptions of value captured the worth or importance that a caregiver attributed to a resource. Faye perceived value in the local AAA as it was important to her in her role as a caregiver, “I am thankful that Blue River was there. They’ve done well.”

Value increased if the resource was a fit for the need identified by the caregiver. Although these themes are presented separately, they each impact the other as stated earlier. A resource being viewed as having value by one caregiver may have been perceived as having little value for another. For example, some caregivers’ valued support groups whereas others did not perceive that support groups would meet their particular needs. Donna found value in a resource that was able to help her connect to local resources: “Aging and Disability Resource Centers. That was a big help. There’s a lot of things that I can get from that.” With the help of the local AAA, Faye found value in a resource that increased her father’s comfort level compared to a prior service. “We had someone coming in, you know, just to sit with Mom, and maybe do a little exercise stuff. But it was the same concept as what (previous respite service) was doing, but it was through the hospital, and I think that was more of a comfort for Dad.”

Faye also described how she perceived her mother’s family practice physician, “The local doctor was very...very...very efficient in helping us take care of things, and still is.” For Ned and his wife, the neurologist who specialized in dementia care was valued, “But we finally got to see the guy, where I feel that we were blessed, he’s good.” Brenda also expressed the value of a geriatric clinic in terms of its benefits for her and her spouse, “I would recommend that to anybody because there I got my support group. I had somebody; as well, he got a lot of attention and care.” Receiving care from a healthcare provider that was helpful and provided important

services was valuable for these caregivers. Harry and his wife valued her physician, “She sees this Alzheimer’s doctor. We really think he’s such a good guy.”

Perceptions of value were related to perceived quality of care for some caregivers. For example, one caregiver questioned the quality of care provided by her grandparent’s primary care provider. Lack of confidence had occurred after trying to manage her family members’ disease with their provider. Sally stated, “If the doctors would work with people more, it would be a huge help.” She further expressed her disappointment with the provider, “Unfortunately, my grandma thinks that their doctor just walks on water. I wouldn’t let her treat my cat. She has had them hospitalized more times over (medications interaction) ‘Oh, well I didn’t know those medications couldn’t go together’ and little stuff that a doctor should know.” This caregiver found little to value in the healthcare system in her small town, and this was a source of stress.

Some caregivers expressed the value of having respite services. Respite provided some time for them to do what they needed or allowed some free time. Caregivers who used and had access to respite valued the service even when it was not a perfect fit. However, often the respite service as described in the previous section was at best a “somewhat” fit.

Meals-on-Wheels was perceived as a valued resource and worth the cost by some caregivers. A husband, who had to take over the cooking, found that Meals-on-Wheels gave him a break from the stress of cooking. Bob stated, “I get them three days a week, just so it gives me a break.” He further stated, “It’s kinda nice to have 3 meals, don’t have to worry about it when you get up that day.” As stated in a previous section, Paul used Meals-on-Wheels for his wife and himself. He stated, “Helps with the cooking.”

Perceptions of Fit

Another theme identified was perceptions of fit, which entailed the caregiver’s perceptions of how well a resource matched their need or provided support to the caregiver. Some resources were perceived as being a good fit because they provided what the caregiver needed or did not cause problems for the caregiver. Other resources were perceived as somewhat

of a fit when they only partially met needs or created some problems for the caregiver. Still other resources were not a fit at all.

Not a fit. The caregiver's view of the resource as not a fit included both resources that had been used as well resources the caregiver chose not to use. For example, Paul found that the respite he received was very limited and did not provide enough services to be a fit, "The lady comes. She sits in the chair. They watch the game show channel for two hours and then she goes." Carla did not consider respite a fit either. The thought of having someone else, a stranger, in her home was more stressful even though the respite service was available. "To trust somebody roaming around my house all day, I couldn't stand that!" Teresa shared this same perception. She was concerned also about finding a person trustworthy who had a "background check" completed. The stress of having a stranger in the house was not worth it for her so she chose not use respite services.

Respite for two other caregivers was not a fit due to lifting restrictions. Greg explained his frustration with the respite service he used, "She's (respite provider) got a weight limit of 25 pounds. That's the maximum that she can lift is 25 pounds. I said, what happens if she falls out of the chair? 'We're told to call 911'."

Daniel hoped Meals-on-Wheels would be a way to meet his perception of a need for socialization for his father. However, Daniel realized that it was not a fit, "Meals-on-Wheels, I thought 'Well, here's somebody that's going to bring a warm meal to him and, great.' But, Dad developed a very angry side to him. If something wasn't just right, he would be mad as heck about it."

Formal support groups were not consistently perceived as a fit. As Faye stated, "My support group is my family and my friends. And, for me, that's a better fit right now." For Sally the local Alzheimer's dementia support group made her uncomfortable, as she was not able to attend as a caregiver. She explained, "It was at the nursing home, so when I go, I end up being a presenter." Teresa stated that a support group would not be a fit for her because of the time

involved: “I just don’t see myself being one to go to it to be honest, because I’m going to have to have time to go to it.”

When seeking long-term care for her mother, Faye could not find a place in her mother’s small town that fit her perceived needs. She stated, “They don’t have the activities, or your mom’s just going to be sitting there. They don’t interact. She’s not going to get that stimulus that she needs to give her a better life.” Ultimately they found a long-term care facility that was a better fit with their perceived need. This was a better fit for Faye’s mother despite the distance from her mother’s hometown. There was a trade off because it better met her mother’s need for activities and interaction.

Although she was not seeking placement at the time, Rhonda was aware of a memory care and long term care facility. However, these were not a fit for her husband with early onset Alzheimer’s disease. She stated, “As far as here in town, the other facility has opened a dementia care unit but again, even to go into assisted living, we’re looking at being a population that’s 25 years older than we are. Activities here are wonderful if you’re in your 80s and 90s, sing-along songs from the 30s. I don’t think they’re going to play Aerosmith and AC/DC for sing-along here.”

Several caregivers did not identify any benefits with medications specific for Alzheimer’s dementia. As Faye stated, “We tried the meds. I do know when we took her off everything, and she takes nothing for it, and I think she’s better for it. I think she’s better.” For Kaye, medication for Alzheimer’s dementia was not a fit for her husband due to side effects. “They changed his medicine, because he had trouble with the medicine, too. The Namenda gave him diarrhea and different things. You know, there’s side effects to all that medicine. And, we tried 2 or 3 different one.” Medication was perceived as having a negative effect on Jane’s husband. She stated, “I’ve seen a decline. But when he first started taking the medication, it wasn’t like I could see (a change). And that’s why you kind of wonder what would it be without it.”

Meals-on-Wheels were available to many of the caregivers but several stated they were not a fit. As one adult child stated, “I had Meals-on-Wheels just for a brief time, and I thought they were terrible. I never, ever complain, because they were doing a service, but they also charge, so we had to pay, and I didn’t have them very long.” She also stated that she thought the service would provide socialization for her parent but that was not what happened.

Somewhat fits. Resources available and used were not always a perfect fit or match for the caregivers’ needs. Several caregivers that used respite services found that the services were not always what was needed for the family member. Limitations in what respite care providers could do in the home or for the family member made the resource not a match for the need, even though it was available. Although respite was viewed as necessary, the service did not fully meet the needs of some caregivers and that made it somewhat of a fit. As Faye described a respite provider, “I don’t want to badmouth (respite provider), because it is a very incredible organization. It just turned out that where the AAA sent us seemed like a better fit.”

Limitations in what respite care providers could do in the home or for the family member made the resource available but not a match. One daughter, Barbara, found respite care did not meet all the needs of her parent, “They could set the medication out in front of him, but they could not give it to him. They could not. He would have to take it upon himself to take it.” The inability to give medications was also a problem with respite services in Carla’s community. She stated, “I know there’s lots of places that have in-home care. But a lot of them cannot do medications. You know, they can come and sit with somebody and try to redirect them, but they can’t help you with medication at all.”

Barbara described respite care as not quite a fit for her needs, “They can come in, they can do all kinds of things for him, but medically, there’s things that they can’t do.” She also would use the skilled nursing facility for overnight respite care; however, this was not a complete fit either due to the cost, “The only thing, it’s out of pocket, so nothings covered.” Lois described how respite did not fully meet her expectations. Cleaning was also not allowed by

respite providers which was frustrating for a caregiver: “I think that they don’t want her doing cleaning? They want her to do more socializing or, if he needed to go shopping.”

Fit. Some resources were perceived as a good fit by caregivers in caring for their family member. This fit was expressed in different ways. As Faye described the local AAA, “I just liked what we saw and felt trusting with them and comforted with them and where they could send us where others were not.” Faye also described the local AAA, “I think that personal connection was, for me, very important. Because, I felt like I could get some good information. I got a feel for the people there and that helped me.” When Faye and her family had to find long term care for her mother, she found the facility in the large urban area better met their expectations. “The smaller community wasn’t blessed with somebody coming in and creating this wonderful facility that we felt was the fit for us.”

Jane was seeking a support group meeting and had difficulty connecting with the one in her small town. However, the support group that she felt provided what she needed was on the Internet. She found an Internet group on Facebook through the Alzheimer’s Association and stated,

The group that’s on Facebook is a really good group. It’s a fabulous support. And just their stories out there. Then you can see, either how they handle that and how you could handle it then. Or recommendations. Everybody’s trying to give different recommendations. Or I have to be prepared for this. This could happen. Or that could happen.

Compromise was required to find the best fit for Brenda’s husband as his disease progressed and she sought a nursing home. Although there was a facility close to her home in the country, she chose a facility that was a long distance from her home. As she stated, “He fit in better than if we had gotten my first pick, which would have been a faster, easier drive for me, would not have been as good a fit for him, and I will drive.”

Medications were a resource that provided a useful fit for several caregivers. Decreased wandering and anger were just two benefits of dementia medications. Medications, although not a perfect fit for all caregivers, were very helpful for many. As Adam stated, “She has been on medication, it’s been much better and we haven’t had any of those problems.” The problems included wandering and confusion, which included phone calls to the local police department by his wife.

For Ellen, medication is what allowed her to continue to care for her husband at home. His anger and wandering in the fields around their country home were alarming and made her consider placement in a care facility. She stated, “Since we’ve had a medication change and he’s getting medicine for the dementia, I’m much more comfortable with it (caregiving).” She also stated, “Getting disoriented and confused and not knowing where he’s at or what he’s needing to do, a lot of the time. And right now, that’s somewhat better since he’s on different medication.”

For Daniel’s father, medication was making his father better and he felt it might have been helpful before his father was placed in long-term care. “Before we had a lot of behavioral issues that could have been better. I know that we had talked about the Exelon patch before, but had that been utilized, with him being up in independent care here, I think that that would have made a huge difference.” Although medication has not been described as a resource previously, the use of medication specific to Alzheimer’s dementia was a resource for family caregivers in rural communities.

Fit was sometimes for the care recipient. As described by Daniel who was seeking to decrease his father’s social isolation because he lived on a farm, he hired someone to clean his father’s house while also making him less isolated. Fit of the person hired to clean his house was important for the father and Daniel stated it worked well. “We had a gal clean his house once a week, because that was involvement with somebody else, and she was a trusted person that he felt comfortable with. Dad reminded her a lot of her father, so, you know just the things that he would say, so it kind of made it a good fit there.”

Perceptions of Accessibility

Another theme identified was caregiver perceptions of accessibility. Perceptions of accessibility meant caregivers perceived that a resource was within reach or attainable. The caregiver's perceptions of reach could include whether a resource was within a feasible distance. Some caregivers indicated that although resources were technically available they were out of reach because getting to them was impractical. Sometimes distance was an issue even if it was not a great distance. Caregivers' perceptions of reach were at times determined by degree of fit regardless of the distance. Caregiver perceptions of accessibility (or the lack of accessibility) of resources were found in descriptions of specialized care, information and support services, and cost.

Family caregivers described how they were able to access some resources but others were difficult to reach or completely out of reach. Resources within reach could be those used by the caregivers or perceived to be available but not used. Difficult to reach resources could have been related to distance to obtain a service or a strain on the caregiver and care recipient to obtain a service. Resources that were perceived inaccessible could have been related to distance but were also related to caregiver's perceptions that resources were not available. There was a link between those that were perceived accessible and concepts related to the type of care provided by the caregiver.

Specialized care. A resource that was identified as accessible but required long drives by 13 caregivers included dementia-specific neurologists, geriatricians, and geriatric clinics. Two other caregivers reported that these specialized services were not accessible. Wanda stated, "I don't believe that anyone is a specialist in that area (dementia) here, but we do have neurologists. It is very difficult to get in to see them."

Maria, whose mother had just been diagnosed recently with Alzheimer's disease, stated she was not sure where to take her mother for the best care. She stated, "We even maybe

discussed the possibility of the Mayo Clinic.” Distance was not viewed as a barrier to getting the care she felt was needed.

Many of the caregivers stated that neurologists and geriatricians specializing in dementia care were not available in their communities but did not view them as inaccessible. Rather these caregivers would drive to obtain the specialized care with a drive that ranged from 20 to 490 miles. Again, the combination of perceived need, value, and fit of specialized care motivated caregivers to access such services, despite the distance. For one caregiver and his wife, the one-hour drive was well worth it. Ned stated, “The neurologist, we hit the jackpot on that. I think there’s a good repertoire there. You know, and his staff. His nurse, or contact nurse or whatever I call it, is also available. Just a phone call away if I need something.” Harry was in the process of changing his physician to one in the town closer to his wife’s neurologist that was 80 miles from their town.

Our daughter that lives here in town, she doctors in a (city), and so her thinking was, might as well change now as keep running to both places. We’re just in the process now of changing to our doctor, getting doctors in (city) to make it easier down the line.

Caregivers’ perceptions of accessibility were not always determined by distance. For example, Adam and his wife traveled over 400 miles for a geriatric clinic and did not perceive it as too far. As he explained, “Oh, it’s all interstate and it’s just set it on autopilot and outside of three or four construction areas, it’s pretty much an easy trip.” Traveling for dementia-specific care from a neurologist meant a drive for Sally also. “For the Alzheimer’s (doctor) we actually have to go to (a larger city). So, it’s 72 miles to get there, but that’s the closest neurologist we have. There is no neurologist that comes into (our town).”

On the other hand, another spouse found travel to a specialist in dementia care was difficult with a drive of only 20 miles. Paul stated: “We have a GP that we go to all the time and he’s very good. We like him a lot. He has referred us to specialists quite often in (larger city),

which is fine, but if we want to see a doctor about anything really important, we have to track up to the city, oxygen bottles and all, and it's a bit of a nuisance." Again, the link between need, value, and fit are tied to accessibility for some caregivers.

Caregivers' perceptions of accessibility of assisted living, memory care, or long-term care, specializing in dementia care, were different from their perceptions of access to specialized medical care. Caregivers visited their family members in care facilities as often as daily so they needed to be as close as possible. In contrast, distance was not always perceived as a problem when accessing specialized medical care because they made the trip only periodically. While a willingness to drive long distances for medical care made such services accessible, assisted living, memory care, or long-term care was not perceived as accessible when only available at a distance.

Kaye expressed her relief that her husband did not have aggressive behavior. Her relief was related to the lack of a facility nearby for his care. She stated, "He'd have to go to a regular Alzheimer's unit, and there's none close that we can get into." Adult day services were a concern due to distance that Rhonda was facing. Rhonda attended a community town hall meeting and expressed her concern that adult day services were not available in her town. She stated,

I just said there's no adult daycare, and the people from the city said 'Yes there is. We have it.' Well, that's great if you live there. I'm 35 miles away, so for me to access adult daycare would mean I would have to drive my husband there in the morning, come back here, go to work, go back to pick him up.

Information and support. Access to information and support were very important to all early stage caregivers whether they were a spouse, partner, sibling, or adult child. Early stage family caregivers expressed disappointment with their communities as they sought additional information, as they were concerned about what the future would bring. These caregivers voiced frustration with the community.

Lack of available information was identified as an issue by caregivers living in areas considered more rural. Unfortunately, Maria's local hospital could not provide information: "I just remember when we first starting to talking to mom about this, like a year and a half ago, I went to the hospital here and I asked them and the clinic, "Do you have a brochure about Alzheimer or something?" because I just wanted to highlight some things that I thought mom related to, so that mom could see it and maybe keep the brochure and read it herself and think oh man maybe there is an issue, but nobody had that." Maria's motivation to be involved in this study was to gain knowledge about the Alzheimer's disease and how to access additional information.

Support groups specifically for caregivers of individuals with Alzheimer's dementia were lacking in one caregiver's community. Sally explained, "At the hospital, they have diabetes support group. They have, you know, children support group when you're about to have...you know, prenatal support group. You know, for the family. They have death counseling support groups. But they don't have anything for dementia. At all."

Respite service for overnights was important for Kaye as she wanted to keep her husband at home. However, overnight respite was not available and she had to place her husband. She explained, "If I'd have had somebody to come in at night, but in the rural area, you can't get something like that. It's just, that's just the way it is."

The accessibility of Meals-on-Wheels was dependent on the rural setting that a caregiver lived, as they were not available to individuals outside of towns. For example, Ned who lived on a farm described the inaccessibility of Meals-on-Wheels: "They (Meals-on-Wheels) don't go to the country. There is a number of things like that that don't...and we only live a mile and a half from town." Greg, one mile out of town, stated, "They have Meals-on-Wheels in town, but they will not deliver outside of city limits." While Maria explained, "Yeah, it's (her mother's home) out in the country. It's not just on the highway or something. I haven't heard of them delivering out of town anyway."

Caregivers also identified the impact of rural setting on resource accessibility. Barbara, interested in a sitter for her parent, described the difficulty of connecting to services from her small town, “There were also some places where they said you can call these people and meet with them and everything but with us living in our town everything was in the bigger city, so that would mean that I would have to find somebody with him during that time or whatever to be able to come into those meetings.” Lack of services in her small community prevented her accessing services available through a larger city.

Cost. Cost affected perceived accessibility. Caregivers identified cost as being prohibitive in reaching out for services, continuing services, or accessing affordable services. Cost of services, as described by caregivers, was a barrier for respite and home health services. For some caregivers, there was the perception of a resource being financially inaccessible due to criteria that rendered them ineligible for benefits. These eligibility criteria prevented these family members from having access to support or services.

Respite costs were a barrier to access for many caregivers, even when the services existed. Respite was described as something you planned for or only used for special occasions according to Barbara. She was already experiencing financial strain as she had left her job to provide 24/7 care for her father. Barbara described the difficulty, “So it’s kind of one of those things where it’s like you can’t do that too often because you can’t afford it.”

Two daughters identified a service that was too expensive for them to access for their parents. Wanda stated, “Well, I think (national company) are some options, but they’re so expensive that they’re not an option.” Unable to afford the service, she explored another option but it was financially inaccessible.

Then I did interview a few ladies that wanted work, and that was almost prohibitive, and then I thought, well they have to make a living too, so you can’t expect them to come free, but it left you without. They were probably worth what they were asking, but if you can’t afford it, it doesn’t matter.

Vera was seeking assistance for her father in the assisted living facility where he lived. She stated that she could not afford to pay for the additional service due to the cost. She explained:

Last week, because I am getting burned out, some of this has gotten to be too much, we haven't had a lot of those big problems, messy problems, since we've curtailed the eating and changed the portion size, but I checked into what's called (national company). I don't know how they can afford it, because for three hours a day I wanted somebody just to come in from suppertime until he got into bed, to get him to bed so I wouldn't have to make a third trip up here, and it was going to be \$35,000 a year. To have someone spend the night, from 6:00 at night to 6:00 in the morning, was \$75,000 a year. This was in addition to the nearly \$4000 a month that we pay here already.

In addition to the financial inaccessibility of care services for their parents, both of these caregivers were disappointed with the lack of access to Veteran benefits for which their parents were denied. Wanda's mother received her father's VA pension but did not qualify for all of the health services her father received. "When he (father) was alive, we had more resources, but some of those went away because of the VA. The VA was no longer there. She has a pension from the VA, but there were a lot of thing she didn't qualify for that he did." Vera's father retired from the military. He received VA benefits but did not receive full benefits. "The sad thing with my dad is that my dad put in many years with the (armed services). He does not qualify to go to the Veteran's home."

Summary

Rural caregiver knowledge and use of resources in the interviews were as unique for each caregiver as the communities that they lived in. Similarities within the themes, however, provided insight into the way caregivers decide what they need in their role. Caregivers had to decide what was needed in their situation. Resources that held value for the caregivers were more likely to be used even if they were at a distance. Cost played an important part of the decision-making as caregivers reached out for resources. Rural family caregivers' perceptions of need, value, and fit were not mutually exclusive as caregivers chose which resources to use and not use in their role as caregivers based on all in combination.

Chapter 5

This qualitative descriptive study explored AD family caregivers' experiences and perceptions with resources in rural Midwest communities. The 23 family caregivers provided extensive descriptions of care they provided and this care was strongly tied to caregiver perceptions of resources. The findings were organized in four categories: Perceptions of Rurality, Caregiving Experiences, Resources Used, and Perceptions of Resources. Within these categories, themes were identified based on rural caregivers' rich descriptions.

Rural family caregivers' use and perceptions of resources were unique to each caregiver and strongly associated with their specific caregiving experiences including the care provided. In other words, the needs of the care recipient and the nature of the care provided shaped how caregivers thought about and sought resources. As they described the care they provided, caregivers concurrently described how they identified what they needed and used to provide care based on their perceptions of accessible resources. Perceptions of resources included limited awareness, knowledge, need, value, fit, and accessibility. These perceptions are important for future planning, development and implementation of programs and resources in the rural communities of the Midwest.

Family member's stage of Alzheimer's disease shaped the caregiver perceptions. Early stage caregivers were seeking knowledge and perceived their current role as identifying resources for future need. Middle and late stage caregivers had concrete knowledge related to the disease and resources they needed or were using. These caregivers described succinctly their perceptions of resources either not meeting a need or holding no value. Also, they could identify why a resource was not a fit for the care they were providing or not a fit for their family member. Distance was not directly related to accessibility. Accessible resources included those the caregiver was willing to travel to, such as specialized care. Lack of information and support meant that caregivers had tried to access information but it was non-existent or support needed

was not available. Although support groups were reported as lacking, caregivers also stated that they would not use an existing support group. They did not perceive the support group as a fit or meeting their needs. Respite care services were identified as available but the specific types of respite care services needed were not consistently accessible. Caregivers reported the cost and lack of needed services made respite less desirable as a resource.

Caregivers perceived things as resources that had not been identified in previous research. Fast food restaurants, “renters,” and dementia medications were examples of resources caregivers perceived as having value, meeting their needs, and accessible. Health professionals need to better understand resources from the rural family caregivers’ perspectives in order to better meet their needs.

Contribution to Knowledge

Choosing which resources to use or not use included the combination of the caregivers’ perceptions of need, value, and fit as stated previously. The unique characteristics of the caregiving experience in rural communities also shaped the perceptions of these caregivers. Keeping the family member safe for rural caregivers included unique threats not faced by urban caregivers. For example, the dangers associated with wandering takes on new meaning when faced with the threat of a family member becoming lost in a cornfield. Also the urban view of rural communities being open and sharing with all aspects of their lives was not substantiated in this study. Alternatively, caregivers in this study identified the need for privacy and as Ned stated: “a need to know basis” for informing community members of his wife’s dementia diagnosis.

Support groups existed or were known to be available in larger cities by caregivers in this study. However, only six caregivers of the 23 participants had attended support groups while only 3 regularly attended support groups. Meals-on-Wheels were identified as available to those residing in towns, but were only used by one caregiver in this study. Respite care services although used by many in the study did not fully meet the needs and were not a fit for the

caregivers. These findings suggest that how healthcare providers, urban communities and organizations view and react to rural Alzheimer's dementia caregivers' needs must change to align with the caregivers' perceptions and needs.

Design of resources for rural communities needs to be better aligned with the perspectives of caregivers who will actually be using them. Assumptions of what the population needs can no longer drive policy and programming for rural caregivers whose numbers are expected to rapidly increase over the coming years. Healthcare inequity in terms of resource suitability, accessibility and affordability in this study was strongly related to lack of resources to meet the perceptions of rural caregivers in the Midwest.

While receiving an Alzheimer's dementia diagnosis can be overwhelming to individuals and their families, providing accurate information about the diagnosis, treatment, and resources available to support caregivers and care recipients can mitigate the burden. It should not be a struggle to receive a diagnosis or become so overwhelmed by behaviors that can be modified by education and medication.

The care provided by rural caregivers was similar to the care reported in previous Alzheimer's dementia family caregiving studies. The physical care provided by family caregivers as well as the effect on their health has been well documented in the literature (National Academies of Sciences, Engineering, and Medicine, 2016; NAC, 2015) and was also identified in this study.

Earlier work in AD caregivers and resources found that caregivers would use different resources when formal resources were not available (O'Connell, 2012). This was similar to the findings in this study. Support received from "renters" (individuals who farmed on land rented from the caregiver) was a resource similar to neighbors or friends providing oversight and keeping the individual safe. Several of the perceived resources described by caregivers in the current study were used not to replace a lacking resource but to better fit their needs. For example, Meals-on-Wheels was available but two caregivers chose to use fast food restaurants,

which provided socialization in addition to a meal. Medications provided control of deleterious behaviors that alleviated stress for caregivers.

A recent study by Martindale-Adams and associates (2016) found an association between urban caregiver characteristics and the use of services for self in an urban sample. Researchers did find that those who used services reported higher burden, more upset with behaviors, and more likely to seek placement for the care recipient. Support groups were the most frequently used service followed by physicians or psychologists.

The type of services used by urban caregivers in Martindale-Adams' and associates (2016) study were similar to the resources identified by caregivers in this study. However, urban caregivers reported using support groups more than any other service that contrasts with the findings for rural Midwest family caregivers in this current study. Rural family caregivers, in this study, identified respite services, even though they were not an exact fit, more frequently and only three caregivers attended support groups. Overall Midwest rural family caregivers did not see a need or find value in support groups.

Research is limited in family caregivers for AD in identifying their needs and perceptions. Bowen and colleagues (2014) studied psychosocial needs of both patients with memory disorder and caregivers. Participants completed a needs assessment. Findings indicated that caregivers need education, access to clinical trials for individuals with AD, sleep, exercise, and help with ADL's as well as IADL's for their care recipients. Although they were not seeking the perceptions of the caregivers, they suggested further research into the perceptions and outcomes related to needs, which would provide additional information to plan and implement programs for families. Psychosocial needs were not the focus of the current study; however, caregivers did identify the need for help with ADL's and IADL's. Rural family caregivers' perceptions, in the current study, were closely tied to the physical care as well as emotional and cognitive care they provided. Although research was limited, findings from these previous studies provided support for the current study.

Previous research suggested that caregivers lacked knowledge of resources, were reluctant to use resources, and thought they did not need them (Brodaty, Thomson, Thompson, & Fine, 2005). However, in this rural Midwest family caregiver study, caregivers were using family and friends and community services to assist them in providing care for the care recipient. These rural caregivers also used the Internet and workshops to gain knowledge about resources. The knowledge of resources was linked to the care family caregivers provided and the “need” is what drove caregivers to locate resources. Use of resources by rural family caregivers was found to be dependent on the individual caregiver’s perceived value of a resource, the fit of a resource to what was needed, and accessibility of a resource.

Innes and colleagues (2011) reported a gap in services in rural communities as well as low use of formal services by rural caregivers in a systematic review. Findings in the systematic review identified barriers to use of formal services to include a perceived stigma associated with dementia. Rural family caregivers, in the current study, were protective of their family member diagnosed with Alzheimer’s disease or dementia and described emotional care to protect them. This emotional care included keeping the diagnosis of Alzheimer’s disease or dementia private or as one caregiver stated, “A need to know basis.” This breaks with traditional views of rural communities being open and sharing. However, this view was not held by the family caregivers in this study nor in the findings of Innes and colleagues (2011) systematic review. Caregivers in the current study did use formal resources when they met a need and were a fit. However, rural family caregivers in the this study would use, as stated previously, resources not identified as resources previously.

Bouldin and associates (2017) in an urban rural comparison of barriers and difficulties among caregivers that rural caregivers reported less difficulty in family relationships and did not identify less time for themselves as a difficulty. Although the current study was not a comparison of urban and rural family caregivers, the rural family caregivers in the current study perceived family and friends as resources. The perceptions of resource in relation to family and friends was

not as direct support but rather supportive of the family caregiver. Rural family caregivers in this study perceived family and friends as helpful. However, they were reluctant to ask for help with physical care of their family member with AD from family and friends.

Financial concerns were a barrier to care identified in Bouldin and associates (2017) comparison study as well as Porock and colleagues (2015) survey of individuals living with dementia and their caregivers. These findings support the perceptions of the rural family caregivers in this study. Accessibility of resources was associated with cost especially for respite services and in-home assistance with personal cares for care recipients. Rural family caregivers perceived these services available in their rural Midwest communities but cost prohibitive.

Knowledge and support of caregivers was identified as a priority for early stage caregivers in the current study. Porock et al. (2015) reported a need for more supportive services and as well as public awareness of resources by study participants (those living with dementia as well as caregivers) across the US. The perceptions of family caregivers in the current study support the findings in Porock and associates (2015) national survey in relation to the need for funding to provide services to assist in caring for individuals diagnosed with Alzheimer's dementia.

The current study found that rural family caregivers were aware of both resources available in their communities or accessible outside of their community. The family caregivers, however, perceived many of the resources available as not fitting their needs as well as lacking value. Funding of resources to better fit the needs of rural Midwest family caregivers both in services needed and cost would align with the perceptions described by rural family caregivers in the current study.

Medications specific to the treatment of Alzheimer's disease and dementia were perceived as a resource by several rural family caregivers. Only one caregiver did not see disease specific medication as a fit for her parent with Alzheimer's disease. Side effects hindered the use of dementia medications for one care recipient. Several reported that they were not sure that the

medication was a benefit for their family member with AD. According to Henkel and Marvanova (2017), there is a shortage of pharmacists in rural communities in the US and rural pharmacists were less likely to educate care recipients and caregivers on the dementia specific medications. The lack of caregiver dementia medication education, although not the focus of the current study, is supported by the perceptions of the rural family caregivers.

Deeper insight into caregivers' knowledge and perceptions of resources has been lacking in research. The Social Ecological Model guided this study in highlighting relationships between the use of resources and perceived needs of caregivers. Being able to identify resources relevant to the needs of the caregiver including what the caregiver brings to the role, receives from family and friends as well as neighbors, accessible in the caregiver's community, provides a framework for examining resources. Use of the model for the interviews with rural family caregivers provided rich descriptions of resources at the different levels that included: self, family and friends, neighbors, community, healthcare system, and internet. Caregivers described resources and how they related to the care they provided or were not a match for what was needed.

Implications

Research

Further research is needed regarding resource suitability, accessibility, and affordability to support rural Alzheimer's dementia family caregivers. The purposive sample was not representative of races other than white and the education level attained was higher in this sample than anticipated. Future research using the perceptions identified by the rural caregivers in this study need to be further explored in other settings with a more socioeconomically and educationally diverse population to further healthcare providers, community organizations, and the public of the resources needed.

There remains no clear definition of rural that can provide consistency between research studies of rural populations in the US. Use of RUCA codes for the current study was found to not fully capture the rurality perceived by the caregivers. A caregiver living in a RUCA code

designated zip code of 2 was located on a gravel road or secluded black top roads with no neighboring homes in view. However, a RUCA code designated zip code of 4 could be in a city of 30,000 people. Although the perceptions of caregivers were similar between all the rural caregivers in this study, there were inequities in access to specialists that were greater for those in higher RUCA code areas. Perhaps use of more than one measure of rural status needs to be used to further identify rural status in future research.

Practice

Healthcare providers, social services, community services, and Alzheimer's organizations have lacked insight into the reasons rural caregivers do not use resources available in their communities. The perceptions of these rural family caregivers, regarding healthcare services and resources needed to provide care, provided a better understanding of the need for useful resources that are suitable, affordable, and accessible. Rural family caregivers' use of resources using a systematic approach, guided by the Social Ecological Model, provided insight into rural Alzheimer's dementia family caregivers growing need for resources and support.

Rural family caregivers need information and decision-making involvement for the management of the care of their family member with AD. Nurses and all healthcare providers need to look at accessibility of resources from the rural caregivers' point of view. As found in this study, accessibility is not always about distance but rather need, cost and fit.

Rural community resource providers and healthcare providers need to consider the needs described by rural caregivers. Programs and services that are created to reach larger numbers of caregivers are not necessarily what caregivers in this study identified as needed, valued, or a fit. Healthcare providers, especially nurses, may be able to provide more individualized care and service to these caregivers. As caregivers were willing to travel long distances to receive the individualized and specialized care from a specialist or clinic, community healthcare providers and local healthcare systems need to identify ways to make this individualized specialized care more available to the rural caregivers in their communities. Harnessing innovative technology

such as telehealth could have direct implications in providing this type of care in the rural communities as well as training and education for the healthcare providers to better meet the needs of these caregivers.

Policy

Changes in allocation, accessibility, and appropriateness of resources need to be addressed through public policy to better match the needs of rural family caregivers. Only through policy can funds be appropriated to decrease the burden family caregivers and their family members experience as they struggle to deal with the financial inaccessibility of resources. In addition, resources identified as needed in the rural communities need to be given priority by policymakers to offset the deleterious effects of being a caregiver without the resources to do the 'job.'

Strengths

The study sample included 23 caregivers encompassing a wide geographic area of the Midwest. The caregivers were spread over 590 miles between Nebraska and Iowa. The representation of family caregivers from 19 counties across Nebraska and Iowa provided a broader sample of participants. Thus a deeper understanding of caregiver perceptions of resource knowledge, use, and outcomes was obtained from the Midwest.

When informational redundancy was identified, this researcher continued to enroll and interview participants. This continued enrollment allowed the researcher to verify that the themes identified were recurring in a larger sample. Enrollment of participants continued throughout data analysis.

Sixteen interviews were completed in caregiver homes. Seven interviews were completed at sites in the caregivers' communities that they selected. This researcher travelled to the communities of each of the participants. Completing the interviews in the caregivers' settings allowed this caregiver to experience the rural aspect of the community as well as identify the rural status in which the caregiver resided.

Limitations

There were three significant limitations associated with this study. Purposive convenience sampling was used to recruit rural family caregivers and, therefore, may not represent a broader sample outside the local Midwest area. The lack of diversity in race reported by participants may be a limitation as races other than white may have unique experiences and thus differing perceptions of resources in rural communities. Nationally reported urban educational attainment rates for Bachelor's degrees or higher is 32%, which is higher than nationally reported rural education attainment rates of 19% (USDA, 2016). The educational attainment rates of Bachelor's degrees or higher for the rural participants in this study were 52%, which is well above both the national urban and rural educational attainment rates. This higher educational attainment rate among study participants may have influenced the perceptions of the rural Midwest family caregivers.

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Appendix A

Comparison of Rural Categories for Iowa and Nebraska Regions

STATE	CATEGORIZATION				
	Square Miles*	Population* (2016 Est.)	Pop/Sq mile*	RUCA CODES**	USDA CODE RURAL-Urban Continuum Codes**
Iowa	55,857	3,134,693	54.5		
	564	13,157	24.7	7	6
	554	33,189	60.1	7	6
	437	14,972	34.4	7.1	2
	535	15,391	29.8	7	6
	950	93,582	98	2	2
	591	11,800	20.6	7	6
	569	49,691	81.1	4.1	2
	525	6452	12.2	10	9
	Nebraska	76,824	1,907,116	24	
968		49,383	47.6	4	4
557		25,767	45.3	2	2
528		36,757	69.4	4.2	4
546		61,705	107.3	4	3
569		6429	11	10.2	3
952		3679	4	7	8
837		309,367	340.8	2	2
540		9266	17	7	7
717		10,722	15.4	7	7
574		14,331	24.7	7.3	6
739		36,422	50	4	5

*United States Census Quickfacts.

**United States Department of Agriculture: Economic Research Service

Appendix B

Demographics Questionnaire**TELL US ABOUT YOU**

Please fill in the blank or CIRCLE the answer that describes you.

1. What is the zip code for your home address? _____
2. How old are you? _____
3. Are you male or female?
 - Female.....1
 - Male2
4. What is your relationship with your family member with Alzheimer's disease?
 - Spouse/Partner1
 - Adult Child2
 - Sibling.....3
 - Other.....4
5. What is your race?
 - Asian/Pacific Islander..... 1
 - Black/African American..... 2
 - Hispanic3
 - Native American4
 - White.....5
 - Multi-Racial6
 - Other7
6. What is your ethnicity?
 - Hispanic or Latino1
 - Not Hispanic or Latino2

7. What is the highest grade in school that you completed?
- Completed 8th grade or less1
 - Attended high school2
 - Completed high school3
 - Post high school Vocational training4
 - Attended college5
 - Completed college6
 - Graduate/professional training7
8. What is your current marital status?
- Married.....1
 - Long term commitment.....2
 - Widowed.....3
 - Divorced or Separated.....4
 - Never married5
9. What is your religious affiliation?
- Buddhist.....1
 - Catholic.....2
 - Jewish3
 - Protestant.....4
 - Nondenominational5
 - None.....6
 - Other7
 - Do not wish to state a religious affiliation8
10. Which of the following four statements describes your ability to get along on your income?
- I can't make ends meet1
 - I have just enough; no more2
 - I have enough with a little extra sometimes3
 - I always have money left over.....4
11. Do you have any out-of-pocket expenses for the care you provide?
- Yes..... 1
 - No 0
12. If yes, is your income sufficient to meet these additional expenses?
- Yes1
 - No0

TELL US ABOUT YOUR WORK

Please fill in the blank or CIRCLE the answer that describes you.

1. What kind of work have you done most of your working life?

2. Are you currently employed at a paid job?
Yes..... 1
No..... 0

3. If yes, are you working
Full time 1
Part time (change) 2
Part time (no change) 3

4. If you are not currently working outside the home, are you
A homemaker 1
Retired 2
On family leave 3
On disability 4
Unemployed 5
Other 6

5. For how long have you been providing care for the person (in months and years)? _____

6. How many hours per week on average do you provide assistance to your family member with Alzheimer's disease? _____

7. Do you provide care for anyone else? If yes, please describe.
Yes..... 1
No..... 0

TELL US ABOUT THE PERSON YOU PROVIDE CARE FOR
Please fill in the blank or CIRCLE the answer that describes the person you care for.

1. How old is the person you care for? _____
2. Is the person you care for male or female?
 - Female..... 1
 - Male 2
3. What is the race of the person you care for?
 - Asian/Pacific Islander 1
 - Black/African American 2
 - Hispanic 3
 - Native American 4
 - White..... 5
 - Multi-Racial 6
 - Other 7
4. Approximately what year was the person diagnosed with Alzheimer's disease dementia? _____
5. What is his/her ethnicity?
 - Hispanic or Latino1
 - Not Hispanic or Latino2
6. What is the highest grade in school that he/she completed?
 - Completed 8th grade or less.....1
 - Attended high school2
 - Completed high school3
 - Post high school
 - Vocational training.....4
 - Attended college.....5
 - Completed college.....6
 - Graduate/professional training7

Appendix C

Interview Questions

Introduction

Thank you for agreeing to participate in this study. The experiences you share will help nurses and other health professionals better understand family caregiving in a rural community for a family member diagnosed with Alzheimer's disease. I am interested in resources family caregivers use and are aware of as well as how these resources are perceived by family caregivers. How we think about resources can be in a number of ways such as the kind of help your family provides to the kind of help the community provides such as one's church or a support group. Also, it will be helpful to know what kinds of resources one chooses not to use. I appreciate very much your taking the time to participate in this interview and assisting me to better understand resources for you as a family caregiver living in a rural community.

1. To begin could you share with me what it has been like for you caring for "spouse/partner/parent/sibling's" with Alzheimer's?
2. What resources are available to help you as you care for your family member?
 - If unable to identify resources available to them: Is there a support group in your community?
 - A congregate meal site, Meals-on-Wheels, home health services, church resources, or friends or family?
 - State or local agencies? Perceptions of these services?
 - Services in your community? Perceptions of these services?
 - Family and friends' assistance? Perceptions of these services?
 - How would you describe what you personally bring to your role?
 - How would you describe the overall availability of resources?
 - What resources would you most like to have?
3. Resources can be helpful and not helpful to caregivers. Overall what has your experience been with resources in your role?
 - How have resources or lack of impacted or effected:
 - Your "spouse/partner/parent/sibling's" behavior, physical needs, and how you deal with the cognitive changes?
 - Your relationships with family? Your job? Your finances? Your social life?
 - You personally?

Checklist for Resources

- Adult Day Care** _____
- Alzheimer's Caregiver Support Group** _____
- Alzheimer's disease center/specialist** _____
- Area Agency on Aging** _____
- Educational resources** _____
- Family assistance** _____
- Home Health Care provider** _____
- In-home care attendant/homemaker** _____
- Meals-on-Wheels** _____
- Religious affiliated assistance** _____
- Respite Care (in or outside home)** _____
- Transportation** _____

Appendix D
Resources Used

Self	What the caregiver brought to their role Problem solving and creativity Identifying when a break from role needed Insight into behaviors Personal abilities to deal with role
Family & Friends	Supportive of caregiver Listening to caregiver Adult children helped spousal caregivers (often daughters) Respite
Neighbors	Oversight and safety “Crop Renters” provided oversight
Community	Local offices of the Area Agency on Aging Respite Support groups Meals on Wheels
Healthcare System	Specialists: Neurologists specializing in dementia care, Geriatricians Family practice physicians Assisted living, memory care, long-term care facilities Respite services
Internet	Gain knowledge and services Online support group blog “Google”

Appendix E
University of Nebraska Medical Center
Institutional Review Board Letter of Approval



NEBRASKA'S HEALTH SCIENCE CENTER

Office of Regulatory Affairs (ORA)
Institutional Review Board (IRB)

August 8, 2016

Rita Million, MSN, RN
CON-Omaha Division
UNMC - 5330

IRB # 515-16-EX

TITLE OF PROPOSAL: Exploring Knowledge, Use, and Outcomes Related to Resources in Rural Alzheimer's Dementia Family Caregivers in the Midwest

The Office of Regulatory Affairs (ORA) has reviewed your application for *Exempt Educational, Behavioral, and Social Science Research* on the above-titled research project. According to the information provided, this project is exempt under 45 CFR 46:101b, category 2. You are therefore authorized to begin the research.

It is understood this project will be conducted in full accordance with all applicable HRPP Policies. It is also understood that the ORA will be immediately notified of any proposed changes for your research project.

Please be advised that this research has a maximum **approval period of 5 years** from the original date of approval and release. If this study continues beyond the five year approval period, the project must be resubmitted in order to maintain an active approval status.

Sincerely,

Signed on: 2016-08-08 13:13:00.000

Bryan Ludwig, BA
IRB Administrator II
Office of Regulatory Affairs

cc: Bruce G. Gordon M.D.
IRB Executive Chair