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Title

Understanding the role of social capital in the lives of caregivers in rural California, a qualitative study

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BACKGROUND

Alzheimer's disease (AD) and other dementias affect more and more people and families each year. (Mace & Rabins, 2017) According to the Centers for Disease Control and Prevention (CDC), AD is the 6th leading cause of death in the United States and is now the 3rd leading cause of death in California. Recent systematic reviews emphasize how there are greater health needs, chronic disease and comorbidities than years prior, increasing the need for innovative preventative strategies. (Marengoni, Rizzuto, Wang, Winblad, & Fratiglioni, 2009) The barriers to addressing issues like AD are exacerbated in rural areas that lack the medical infrastructure to meet the needs of these individuals and their families, including provider and service shortages. (Innes, Morgan, & Kostineuk, 2011; Rainsford et al., 2017) Based on Office of Statewide Health Planning and Development (OSHPD) data, AD patients in rural San Joaquin Valley (SJV) counties are not discharged to long-term care facilities when needed compared to those in more well-resourced counties like Los Angeles. Instead they are sent home. As a result, the need for paid and unpaid caregivers is increasing with an aging population and families are left to make care arrangements for these older adults, (Anderson et al., 2013) often in environments with limited access to health and support services. (Innes et al., 2011)

Family caregivers, also referred to as informal caregivers, are those who are responsible for and provide ongoing care for a family member. Most often this care takes place in the home (Grunefeld et al., 2004) and is commonly unpaid (Macdonald, Martin-Misener, Helwig, Weeks, & MacLean, 2017) The roles of informal caregivers are diverse, ranging from spouse or partner, child(ren), sibling, "next-to-kin" (referring to other relatives), or a friend. Much of the existing

literature focuses on spouses or partners providing care. (Pozzebon, Douglas, & Ames, 2016)

The range of caregiving status or level of care provided also varies, as some family caregivers are retired and provide fulltime care, while others are still employed and caring for multiple family members (e.g. child and older parent). These caregivers play an essential role in older adults' and elderly individuals' ability to remain at home and in their community, which often affects one's quality of life and allows aging in place (AARP, Bookman, 2008).

To provide context, aging in place is the ability live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level. (Centers for Disease Control and Prevention, 2017) According to the World Health Organization (WHO), aging in place is a common preference among older adults, especially remaining in their local community and maintaining their social networks throughout the aging process. (World Health Organization, 2018) Similarly, the ability for an older adult to remain at home is the preference of many family caregivers, if the individual is capable of handling demands of their environment (Cassarino, O'sullivan, Kenny, & Setti, 2016; Lawton, 1986) . Aging in place may also be moving into a place that is safer or more adapted to meet an older adult's needs, while maintaining vital connections with their community, family and friends. (Fong & Law, 2018)

Fong et al. describe how remaining at home or in a familiar place helps elderly individuals maintain their identity, dignity and enjoy the last phase of life (2018). Aging in place may be preferable for both the caregivers and those in their care, as long-term care may not be financially feasible. (Levine, Halper, Peist, & Gould, 2010; Qualls, 2016) Also, historically, families, specifically Black and Latino families, have not desired or trusted long-term care placement. (Cruz-Oliver et al., 2016; Henning-Smith & Shippee, 2015; Musa, Schulz, Harris, Silverman, & Thomas, 2009; Schapira, Shea, Duey, Kleiman, & Werner, 2016) These

perceptions are often attributed to cultural values or “familism”. Adversely, in order to achieve successful aging in place, supporting services are needed, including health, medical, and food services (e.g. grocery stores). (Fong & Law, 2018)

The ability to age in place may depend, in some cases, on the depth and quality of social capital caregivers and family members are able to acquire and deploy. Family caregiver support, adequate financial resources, and access to social and community resources are important factors for caregiver health and well-being, (Benfield & Holtzclaw, 2014) as caregiving presents numerous challenges and strains. (Cantor, 1983; Roth, Fredman, & Haley, 2015; Zarit & Zarit, 2015) Some of these challenges include insufficient caregiver support, absence of eldercare leave, inflexible work arrangements, and significant stress. (Chin & Phua, 2016) As the nature of providing care is challenging, (Bengtson, 2018; Fong & Law, 2018) it is increasingly important to understand how caregivers identify resources and where family caregivers go for social, emotional, and financial support, in rural environments with limited access to resources and services. In other words, it is essential that we understand the quality and character of social capital to which rural caregivers have access.

Social Capital and Caregiving

Social capital refers to one's social environment and the features of that environment, such as trust of those close to you, norms of reciprocity, and membership to specific groups (Bourdieu, 1985; Kawachi & Berkman, 2000; Kawachi, Kennedy, & Glass, 1999; Kawachi, Subramanian, & Kim, 2008; Portes, 1998; Putnam, 2000). Social capital has two parts: social (e.g. social networks and social support) and capital, referring to how these ties are transformed into tangible and economic benefits and resources or challenges through relationships and interactions over time. (Bourdieu, 1985; Burke et al., 2009; Portes & Landolt, 1996) In Robert

Putnam's book, *Bowling Alone: America's Declining Social Capital* (1995), the author discusses the changing social capital environment in the United States and concludes that a decline in social trust may be a factor. Sources of social capital become evident when interview and focus group participants are asked about their social networks and whom they ask for help (e.g. family, friends, religious organizations). Examples of social capital for caregivers may be neighbors letting you know your family member with dementia left the house or another family offering to help so the caregiver can go on a vacation. In many communities, individuals have various forms of social capital available through relationships with and within: neighbors, churches, schools and community organizations. The social environment is enhanced when these networks are available, trusted, and culturally appropriate.

Social Support and Social Networks

Research suggests social networks and social support are two of the most important resources for family caregivers, (Cattell, 2001; Kaufman, Kosberg, Leeper, & Tang, 2010; Wilmoth & Silverstein, 2017) especially in an environments where providers and support services are scarce, such as rural and low resource areas. (Wedgeworth, LaRocca, Chaplin, & Scogin, 2017) Wedgeworth et al. found that family member and caregiver social support satisfaction and enhanced social network satisfaction were associated with quality of life. Individuals offer and share health-related resources and information to help family caregivers solve health-related problems for those they care for and themselves through social networks. (Kim, Kreps, & Shin, 2015; Nguyen, Chatters, Taylor, & Mouzon, 2016; Roth et al., 2015) For example, Roth and colleagues illustrated the importance of a caregiver support group for emotional support and solving daily problems. In a study of the role of social support and social networks in health-seeking information, Kim et al. demonstrated how important personal

networks are in the dissemination of health information, specifically for those who confront cultural challenges.

Also of great importance are informal and formal social support, defined broadly as the mechanisms that enable one to feel supported by family, friends, co-workers, and others. (Rozario & Simpson, 2018) In areas with limited formal support services, and the sheer challenging nature of providing ongoing care, caregivers often turn to their social network(s), if available, for resources such as, health and caring information, advice, social support, and “exchange of services.” Neighbors are a common source of social support and social capital, especially for those who are far from family or who have limited family support. (Fong & Law, 2018; Waverijn, Heijmans, & Groenewegen, 2017)

Conversely, there may be implications to social support. A growing body of literature examines the impact of problematic social relations and the deleterious effects of negative interactions, and how these may have more of an effect than the positive impacts of social support. (Gray & Keith, 2003; Lincoln, Chatters, & Taylor, 2003, 2005; Nguyen et al., 2016) Nguyen et al. describe how negative interactions that involve members of one's social network can complicate the help-seeking process. Further, these negative interactions “interfere with and restrict the use of emotional and tangible support resources from others.” (Glanz, Rimer, & Viswanath, 2008; Nguyen et al., 2016)

Caregiving relationships represent both strong and weak social ties. (Gulia & Wellman, 2018) Social capital is often divided into two major categories: close or strong ties and loose or weak ties. The concept of weak versus strong ties refers to connections between individuals. “Weak ties” are characterized as loose connections between individuals who may provide useful information or social support to a degree, but are typically not emotionally close. (Granovetter,

1983) An example of a weak tie may be the barista who sees you every day at the local coffee shop. They know your name and you two have talked at length on many occasions.

Alternatively, “strong ties” between individuals are tightly knit, emotionally close relationships, such as family, close friends, pastor at church, and neighbor(s) known for 20 years. These ties are often longer-lasting and consistent.

An important barrier to note is the potential difficulties forming and maintaining both strong and weak ties, especially as social capital and ties are often elastic and change over time. For example, when one moves away from an area where they have established strong ties and rich networks, they lose social capital and must build new relationships and establish new networks. Granovetter outlines the “strength of weak ties” as it allows to access non-redundant information via individuals outside one’s close circle. (1973) Researchers also describe these weak ties as foundation for bridging social capital. (Putnam, 2000) Moreover, weak ties provide more benefit when the weak tie is not associated with stronger ties. (Granovetter, 1983)

Another challenge caregivers face is locating and accessing services such as support groups, meal services, respite care services, and skills training. (Shapiro, 2015) Many caregivers are unaware of formal and informal services and resources available to them (Keith, Wacker, & Collins, 2009; Wacker & Roberto, 2013) and services go unused or underutilized (Angus, Kontos, Dyck, McKeever, & Poland, 2005; Qualls, 2016; Schulz, Eden, & National Academies of Sciences and Medicine, 2016). While it is important to acknowledge that support services, like respite care, meal programs and in home support services, are helpful (Innes et al., 2011; Shapiro, 2015), they may be culturally and linguistically inappropriate, unavailable, inaccessible, or unaffordable, (Schulz et al., 2016; Zarit & Zarit, 2015) and may not take into consideration the limitations of caregivers and families. Schulz and colleagues argue that research and practice

“too often assume the availability of family caregiving without adequate support services that take into account both the individual and the family”. (Schulz et al., 2016)

Adequate financial resources are one of the greatest challenges for those providing care, (Cantor, 1983; Levine et al., 2010; Zarit & Zarit, 2015) especially for families with low socioeconomic status. There are economic risks associated with family caregivers of older adults such as: loss of income and substantial out-of-pocket expenses. (Schulz et al., 2016) Social and family support may serve as buffers for these sorts of financial burdens and economic risks (social capital). In contrast, the financial burdens that come with the caregiving of older adults may have an impact on family and social support (e.g. economic strain).

Despite these factors, family caregiving is a cost saving strategy due to the high costs of long-term care services and an estimated economic value of \$450 billion in 2009, including unpaid contributions. (AARP) This emphasizes the need for more services for caregivers and the older adults in their care. (Anderson et al., 2013; Innes et al., 2011; Wedgeworth et al., 2017) In addition to family caregiving being cost effective, family caregiving has countless other benefits to both the caregiver and the individual receiving care and thus, it is important to know how caregivers navigate ensuring their family members receive the care they need and understand the challenges and barriers in order to intervene effectively and support caregivers.

Culture and caregiving

Caregivers within diverse cultural and rural areas have distinct experiences (Cottrell & Duggleby, 2016) and it is imperative to consider the rural experiences and perspectives of those persons and families receiving care. (Bakitas et al., 2015) In 2017, Rainsford et al. published a systematic review (studies published from January 2006 through January 2016) in

which they identified major gaps in the literature, including a lack of studies describing experiences of rural and ethnically diverse caregivers. Existing research most often describes diverse families, specifically Black, Latino/a and Asian, as groups that are the most supportive and accepting of the responsibility of caregiving (Dai et al., 2015; Mahoney, Cloutterbuck, Neary, & Zhan, 2005; Powers & Whitlatch, 2016) and groups that have the strongest feelings against long term care options. (Nelis, Clare, & Whitaker, 2014; Patterson, 2015)

A growing body of qualitative research has focused on understanding the spousal caregiver perspective of living with a partner diagnosed with dementia, (Dam, Boots, van Boxtel, Verhey, & de Vugt, 2017; Pozzebon et al., 2016) while less has focused on other family members providing care. For the purposes of this analysis, I was interested in identifying social capital resources caregivers access and how social capital, in turn, affects caregivers' health and well being.

As there is a gap in research on the experiences of rural, ethnic family caregivers, this study explores the unique experiences of family caregivers in rural California, through in-depth qualitative interviews and participant observation. This study seeks to build on literature linking social capital and family caregiving.

RESEARCH DESIGN

This study utilized a grounded theory approach (Charmaz, 2014; Glaser, Strauss, & Strutzel, 1968) to examine the lived experiences of family caregivers, allowing for insights to emerge. The research design for addressing questions is presented and includes a description of the participants, the data collection process and the data analysis process. The purpose of this study is to understand how caregivers access and deploy social capital using social support and social networks.

The guiding questions for this study were:

1. How do rural family caregivers describe social network/support?
2. How do they use social network/support?
3. How does their social network/support help or hinder their ability to care for themselves?
4. How does their social network/support help or hinder their ability to care for their family member?

This study was conducted in Merced County, California, located in the San Joaquin Valley. According to the July 2016 United States Census estimates, there are approximately 268,672 people living in Merced County. The racial makeup of Merced County was 82% White, 4% African-American, 2% Native America, 8% Asian, and 59% of the population is Hispanic or Latino. The median household income (in 2016 dollars) was \$44,397, and 20% of the population is living in poverty. 30% of the population is under the age of 18, while 11% are 65 years and over. In addition, Merced County is considered a medically underserved, health professional shortage area (HPSA). (OSHDP)

Prior to beginning this research project, institutional review board (IRB) approval was received from the University of California, Merced.

METHODOLOGY

Participants

For this research, the target population was family caregivers of older adults in the San Joaquin Valley, California. Participants were identified and recruited through community contacts, a local senior center, and an adult day health center. We gained entrée through previously established relationships and partnerships with several community and institutional stakeholders. Participants were given a gift card to a local grocery store in appreciation of their

time. Interviews and focus groups were scheduled at a time and location that was convenient for both the participant and interviewer.

After collecting informed consent from each participating family member, demographic information was gathered including: year born, zip code, gender, race/ethnicity, language(s) spoken at home, marital status, number of children and socioeconomic status. The caregiver specific questions asked were: (1) are you responsible for the care of someone else, (2) if yes, who are you caring for, and (3) how long have you been a family caregiver? This was given either before or after the interview. Lastly, participants completed the Kingston Caregiver Stress Scale (KCSS) at the end of each interview (Hopkins, Kilik, & Day, 2006). This scale was designed for family caregivers versus institutional care staff, to assess the level of stress they experienced and to monitor changes overtime (Sadak et al., 2017). The survey has ten questions in three categories: caregiving issues, family issues and financial issues (Appendix I).

We conducted in-depth qualitative interviews (n=11) and focus groups (n=2) with caregivers in English (n=17) and Spanish (n=2), at a senior center, adult day center, and community leader's home between August and November 2017. Participants were very diverse in SES, race/ethnicity, gender, age and role as family caregiver (e.g. son, daughter, sibling). Family members also represented a range of AD diagnosis/stage of condition, gender, and relationship (e.g. parent, sibling, child). These differences seemed to shape the relationships with each other and other family members and friends.

Qualitative Interview Questions (focused)

Interviews explored each family caregiver's challenges, needs, strategies, and support systems (e.g. social support, family support, financial support, self-efficacy, social capital).

Similar topics were discussed in the individual interviews and focus groups. Table 1 details questions that guided individual interview and focus group conversations.

<i>Can you tell me about the person you are caring for?</i>
<i>What are some of the challenges you have had to deal with?</i>
<i>Is there anything that would make this easier for you?</i>
<i>What is the level of care provided? How has this developed during your time providing their care?</i>
<i>Can you tell me if you have used any support services for your family member or yourself?</i>
<i>How do you define social network?</i>
<i>Can you tell me about your social network and community?</i>
<i>Are there friends or organizations you connect with each week? (e.g. church, volunteering)</i>
<i>How do you feel about asking friends or family for help?</i>
<i>Can you give me an example of a time when your social network was helpful? Or a time when a social network would have been helpful?</i>
<i>What about living in a rural community helps or makes it more difficult to care for your family member?</i>
<i>How has being caregiving had an impact on your own health?</i>
<i>What else do you think I should know to better understand the experience of a caregiver?</i>

Several interviewees responded to questions in the form of stories and examples, helping to illustrate their experiences. One benefit to having the questions structured in an open-ended manner is that interviewees often answered the questions prior to us specifically asking and discussed diet, nutrition and changes to the home when talking about challenges and mechanisms of support.

Data Collection

This study collected many sources of data: (1) qualitative interviews were recorded and later transcribed, (2) demographic survey data, (3) caregiver stress scale, (4) detailed field notes were taken of observations, perspectives, experiences, and conversations that occurred prior to, during and following interviews and focus groups, and (5) two analytic memos and one

reflexivity memo were written during the process of collecting data. A member of the research team or myself collected the data and a number of interviews and both focus groups were conducted as a team. Interviews and focus groups were digitally recorded and lasted between 35 minutes and an hour thirty minutes. Some caregivers talked at length about a given topic, while other provided short and concise responses. Observations were conducted at the senior center and adult day center; notes were taken by hand and later typed for further analysis. Pseudonyms were assigned to all participants.

Each of the recordings were reviewed and transcribed using Word. This was a time consuming process and several undergraduate researchers were hired to help with this process. The undergraduates were trained and each recording had no identifiable content to ensure participant privacy was maintained. The undergraduates worked in teams to crosscheck their transcriptions and verify if these were as close to verbatim as possible. I then checked transcripts against the audio recordings for accuracy.

Data Analysis

Interpretation began during data collection and continued throughout the course of this study. Each of the transcribed interviews was read in preparation for the following interview and to begin the interpretive process. These steps helped to identify gaps and avenues needing further clarification and exploration.

Using a coding and conceptualization process rooted in the grounded theory method of Glaser and Strauss (1967) and further developed by Charmaz (2006), narratives and exemplars of particular situations pertaining to the presence or lack of presence and utilization of social capital and/or social networks were analyzed in detail and viewed in the light of the individual's and

family's overall experience. Each narrative was compared and contrasted and detailed field notes were used to explore the lived experiences of caregivers more holistically, taking into account culture, setting and context and setting myself as a learner in order to try and eliminate power differences.

A codebook was developed and reviewed by researcher and fellow research lab members. Feedback on coding was incorporated prior to finalizing the codebook. Categories of codes included *emotion and feeling codes* (positive, negative, confusion, concern, etc.), *conceptual codes* (barriers to providing care, challenges, successes, etc.), *relationship codes* (partnerships, family role), and *caregiver perspectives* (social support, self-efficacy, sense of responsibility, level of difficulty, etc.) Qualitative data was coded and analyzed ATLAS.ti 8 (2017).

FAMILY CAREGIVER DEMOGRAPHICS

A diverse sample of caregivers were interviewed; (14) female caregivers, (5) male caregivers, 7 identified as African American or Black, 6 identified as Hispanic/Latino, 5 Non-Hispanic White, and 1 Hmong. Two caregivers were Spanish speaking. The majority of caregivers were married or in a committed relationship and were caring for more than one family member (e.g. child and parent or sibling and parent). The majority of caregivers interviewed were clients of an adult health center. This center provides respite care for caregivers for 4 hours each weekday, physical therapy for family members in need of those services, lunch and snacks, recreation time and psychological services for caregivers and their family members. Table 1 describes additional demographic information for caregivers interviewed.

Table 1. Descriptive Characteristics of Family Caregivers (n=19)	
<i>Demographics</i>	
Female caregiver	14
Male caregiver	5

<i>Race/Ethnicity</i>	
African American/Black	7
Hispanic/Latino	6
Non-Hispanic White	5
Hmong	1
<i>Marital Status</i>	
Married/Committed Relationship	13
Divorced/Legally Separated	4
Single, never married	2
<i>Family Member Caring For *</i>	
Spouse	7
Child	5
Parent	7
Sibling or other family member	7
<i>Adult Day Health Center Use</i>	
Yes	14
No	5
<i>Years Caregiving</i>	
>1 years	-
2-5 years	3
5-10 years	1
11+ years	5
Unknown	10

* Several caregivers were providing care for more than one family member

FINDINGS

Our interviewees discussed their experiences, thoughts and feelings through descriptions of their daily routines and perceived support or lack of support. They narrated past and present experiences and how these shaped the different relationships and interactions in their lives and the access to resources and support or networks.

Analysis of interview and focus group transcripts suggests the importance of social networks and social support, or the lack of a social connections, on caregivers' perceived stress and perceived self-efficacy for coping with stress and providing care. Caregivers also identified changes to their own health and relationships with those around them and how limited access to providers and support services impacted their levels of stress. Six (6) themes emerged during the

coding and analysis process indicated below in table 2. The role of social capital is the overarching theme throughout the interviews and focus groups. Social capital is evident in the family caregiver narratives and both past and present experiences. The forms of social capital described are (1) neighborhood social capital, (2) church as a source of capital, and (3) family as a source of social capital and social support.

Table 2. Emerging Themes - Family Caregivers and Family Members
The role of social capital in caregiving
Neighborhood social capital
Church as a source of capital
Family as a source of social capital and social support
Family caregiver self-efficacy
Limitations and lack of social support

The Role of Social Capital in Caregiving

In these qualitative interviews social capital emerges in different forms and functions differently based on relationships. For example, social capital may be in the form of health care access, social support, financial support, useful information, and connections to care assistance. These resources and benefits were obtained through neighbors, churches, health care providers and through other sources. Some participants talked about their own access to resources, while others described their family members access to resources. This is important, as these indirect forms of capital seemed equally beneficial for both. My findings will be presented according to the form or source of social capital (themes) identified.

Neighborhood social capital

Neighbors and neighborhoods as a source of capital was a topic that emerged from a few of the interviews. Vicky, who cared for her mother with Alzheimer's and disability due to diabetes, described scenarios where her mother's social capital enabled her to provide better care

and had a great impact on her mother's quality of life. Vicky's mother was mobile and used a scooter to get around her neighborhood, and was well known. Vicky shared her mother's experience at the farmer's market close to her home.

“She [my mother] liked vegetables, mostly fresh, uh, okra. And she would go to the farmer's market over there, you know, umm, where Starbucks is on Yosemite? Well I live one block behind there. And so when she was with me, she would take her scooter and she could scoot around. And she went every Wednesday, the people knew her, and they would save certain things for her, special grapes... and yams, or uh, uh the okra. Just different things like that.” – *Vicky, Black female caregiver, caring for mother with Alzheimer's and disabilities*

Marie, who cared for her husband with Alzheimer's on her own struggled with the change his illness wrought on their relationship, and the progressive difficulty providing care for her husband. Although she named several challenges and barriers to providing care, Marie also emphasized the importance of her neighborhood and neighbors. She relied on neighbors she had known for 15-20 years, especially since most of their children lived out of town. And despite her husband's declining health and memory, she said she felt reassured by her safe and familiar neighborhood. Marie was also one of the few caregivers interviewed who attended a caregiver support group. Attending this group, she reported, helped her feel at ease about the caring process, specifically because it was becoming harder for her and she felt she was “running out of options”.

“I have neighbors that are very supportive. They all said “if you need something just ask...” It's been a neighborhood that, it's been the same neighbors umm, over 20 years I would say, about 15 years. And so but the other day I went in, I took [my husband] and I got his hair all cut off to make it easier cause he didn't want to take showers. So I took him over to the neighbor's house, I said, “I want you to see what he looks like now in case he gets out” [laughs]. But, sometimes it's really hard, sometimes [sighs]... It's just getting harder and harder.” – *Marie, White female caregiver, caring for husband with Alzheimer's*

Church as a source of capital

One of the most frequent examples of formal social networks and social capital resources identified were churches. Throughout the interviews, participants mentioned churches as a form of support for themselves and their family member. In rural, ethnically diverse settings like Merced and Atwater, churches are often one of the few support services available to people and serve as a gathering point for specific ethnic groups. Vicky commented on the importance of church for both her mother and herself.

Vicky: "I was raised in the church, and so was she [my mother]... So church has always been in our life, 100%, always, always. So I don't know not to go to church. She [my mother] went to church on Sundays and knows who to call [if she needed anything]... You just do the best you can and you have to stay prayerful, you really do, and to have a place to vent... I don't have an association or you know a place, I have friends, I have church. And that's where churches are helpful too, you know 'cause there's somebody who knows what you are going through and they can always help you. Just like what I've been through, I will be able to share with somebody else. 'Cause people think that they're—that nobody else has that experience. Oh yes, they do."

Beverly, a Black female caregiver was providing care for a church member, Brother Maxwell (kin). She had also had experience as a family caregiver for both her mother and father throughout the years. The gentleman in her care is elderly and has several comorbidities (e.g. diabetes, high blood pressure, requires a walker to dress). His family was unable to care for him due to financial constraints, thus she moved him in with her, as she was his pastor in a different city. Beverly recently purchased a home and prior to doing so, made sure her home was wheelchair accessible (e.g. wider doors, no stairs, wider halls, etc.) She is a pastor at a local church and elaborated on the benefits of the church for those in her care and for herself. She described getting supports from other people in order to do her caregiving. When asked about the type of help she has or has had in the past that helped make care easier, she stated:

Beverly: "I go to the faith based community. You know what I mean. I'm the pastor for church. I know people need to work...in the church and if I have the financial resources to put them to work or I can write a grant for help then I'm gonna hire people who I already

know need work. So Natalie cooks for me three days a week because she's a chef [laugh] but she's an unemployed chef. Her mom...I had a little bit of difficulty because of my own cultural biases asking her to help clean but because of my own disability that's a problem for me - so I would have hired somebody anyway umm but her thing was "nope I got this!" and so she cleans three days a week. I have handy person, in my church, who comes over two days a week to make sure light bulbs are in, ramps or things everything is safe for him. But that financially I pay for those services but I do pay people in the church. I tend to pay people in the church." – *Beverly, Black female caregiver, caring for family friend and past caregiver of mother*

Lidia has been caring for her daughter, Kelly, for the past 55 years. Her daughter was born with Down syndrome, is legally blind and has been diagnosed with early onset Alzheimer's. Lidia expressed mixed emotions of love and sadness because of her daughter's condition getting progressively worse. Lidia, who is in her 70s, spoke about the challenges and barriers she faced. Lidia described the role church played in her family's life in great detail. The pastor and other church members supported Kelly's hobby of making jewelry with beads, and served as a social group for Lidia. The support provided in this setting benefited both of them, and this was made clear throughout the interview.

Lidia: "It's sad to see what she's going through, but we make the best of it. And she loves to go to church. She just loves—and the pastor loves her so much. She says, 'Kelly you want to sing a special?' and of course she don't sing it by herself, I go with her and she sings her special there. And so, she's—everybody loves her. It makes us—makes us . . . what we're going through a little bit easier. Yeah to see that the people just love her and they're always getting her little gifts and things you know. The other day a lady at our church she went by and said, 'this is for Kelly.'" – *Lidia, Latina female caregiver, caring for older adult daughter with special needs and Alzheimer's*

Family as a source of social capital and social support

Several caregivers who acknowledged there were family members (often their spouse, kids or siblings) they could ask for help, chose not to ask for a number of reasons, primarily: (1) they did not want to burden them, because it was "their responsibility" or their other family members were "also busy with their own families" and (2) they did not live as close.

When Lidia was completing the stress scale survey, she repeatedly stated that she “did not feel stress because she was very supported”. She attributed her “low level of stress” to having the help of her husband Ernesto. She stated, “I don’t know what I would do without him.” He played a significant role in caring for their daughter and supporting her [Lidia].

Lidia: “It’s just tiring you know. So, the four hours she’s here [at the adult daycare center], I take advantage. My husband and I go out to breakfast or you know. Because we know she’s so happy here we’re not—we don’t worry that she’s not with us at that time...She’s a happy girl. That’s what I...that’s what I always strive for. My husband and I.”

Interviewer: “Would you tell me a little about your own health? Has providing care impacted your own health? You or your husband’s?”

Lidia: “Uh not really. I do, I do have arthritis. But that’s uh had it for a long time. So no because my husband helps me a lot. I’m the provider but he helps me a lot at home. And then sometimes he says, ‘don’t cook we’ll just go out.’ He loves Panda that’s why. It’s good for him. Yeah right, yesterday he was a little bit busy he said, ‘Would you like to go and get Panda,’ I said, ‘Why don’t you go and I’ll stay with her?’ He says, ‘No I want you to go’ [laughs] ‘ok’ I said, ‘I’ll go.’ We try to share the work with her.”

Interviewer: “And so, has it changed the relationship with you and your husband?”

Lidia: “The only way that it has changed is that I do not sleep with him anymore. I sleep with her because she needs me there sometimes at night.”

Lidia also described support she had from other family members, specifically one of her daughters who moved closer in order to be there for her parents and sister [Kelly], which was a welcome and pleasant surprise. The support of one of her daughters was extremely important and beneficial for Lidia. She described, at length, how impactful it was for her daughter to be close and willing to help.

Lidia: “Yes, she [Kelly] and I have a great support system and of course I have uh four different daughters other than her. They’re all married in different—one lives in Minnesota. Her brother, her only brother lives in in Miami, Florida. Uh, another daughter lives in Bakersfield, another one in Los Angeles, so they are all scattered. And the youngest one just moved from San Jose to live here closer with us. She bought a new house and we’re very happy that we have the youngest grand kids.”

Interviewer: "Yeah, that's great and is she helpful when she's around."

Lidia: "Oh! Yes, yes! Uh-huh (affirmative). She's very helpful, she invites us about 3 times a week to go eat at her house. And then she says, 'Mom if you need to go to the doctor I'll go with you,' you know. She's really helpful. Or if her sister needs to be taken care of she will. ... Yeah, we have great help now that she lives around us... And now that my daughter is here she takes me out while she's here. She takes me out and we go either to eat or she has taken me to two little restaurants here in Atwater that I didn't even know they existed."

Interviewer: "That's nice."

Lidia: "Yeah. [Laughs] Yes now that my daughter is here that has been nice. We go to Ross like I said [laughs] only that's a bad thing for her because she just bought a new house and every time she goes, she buys to decorate her new house. But we have a lot of fun together. Yeah so, I, I have my good times to that I have to take advantage when she's here. Because otherwise I take her [Kelly] with me but it's hard for me to, to uh. . .to be holding on to her and to be holding the cart."

"As long as as long as we try our best. And in our case, we depend a lot on God, we ask him for help and he provides help for us. Like now I wasn't expecting my daughter to move over here . . .because she would always say, 'Go to the valley, oh no I would never go to the valley.' But now she's here. [laughs] and she loves it."

When asked about family support, Marie sighed deeply and discussed the difficulties she had faced. Being the sole care provider for her husband, she did not feel could ask her own or his children for the help and support she seemed to desperately need. This sense of responsibility and obligation to provide his care on her own revealed underlying family conflict that may have added to the difficulty of providing care and decision making.

Marie: "Uhh, it's a second marriage, so all of Marvin's children live out of state and I have a son in Atwater and a son in Merced and one in Mariposa. So I mean I have [some help], I can call..." ... I'm basically, my family comes a little bit, but it is basically me and him at home and I am close to looking at placement because I just do not know what else to do. But right now I can't afford it."

Joseph, who participated in the first focus group, is caring for his wife with Alzheimer's. He is in his 70s and also experiencing health issues. He is receiving care from the VA Hospital for ulcerative colitis, as well as managing the care of his wife. He described his daily life as

“unpredictable” and felt he did not “have all the needed to skills to do this [provide care]”, but stated, “I am doing the best I can.” Similar to Marie, this was a second marriage for him, which for him meant, his children were more help, while his wife’s children weren’t as much help.

“I got three kids of my own and she has two. And my kids here help me, her kids live in Lake county so they aren’t much help. But they do care, I mean they are not the type that don’t umm so it’s me basically that like right now my daughter’s got her to take her to her doctor’s appointment and uhh, but basically here she is a, she is a handful and you never know.” – Joseph, *White male caregiver, caring for wife with Alzheimer’s*

When asked if there is currently any support he’d like, Joseph contemplated for a moment. He had just described the lack of help, referring to the adult health center as his primary support.

Joseph: “Well I don’t know of anything, I’m new to the area uhh the neighbors I know or I don’t so anyways I couldn’t think of anything that would help me. Her kids live here, my kids live here, whenever I need help, they’ll come so.”

Greg has been caring for his mother for the last 6 years. He moved in to help her when his siblings were having difficulties. Being the oldest, he felt it was his responsibility to step in. He expressed that despite family conflict between siblings living in the home and the difficulty of care increasing, he was grateful for his family and that they all supported each other. When asked about support, he referenced his family numerous times. He illustrated his experiences throughout the focus group.

“I constantly get told that you’re doing a great thing but I don’t see it like that. I see it as I am the eldest son this is where I belong and I don’t belong anywhere else so I don’t understand that why people say it like that, not so many people do it. So I’m like okay great, whatever.” – Greg, *Black male caregiver caring for mother with Alzheimer’s*

Greg: “Alright uhh family. My sister you know, we’re definitely family orientated. Um, if I need days off, she hooks me up you know, I don’t take em because she has a family and a husband and jobs and she also, not only that she has, she is the uhhh what do you call it... power of attorney with my mother but also with my uncle. So I’m just saying that we have a total family connection here.”

Greg also described the impact caring was having on his own health, and that he does not prioritize his health. He has put off his own health care and taking vacations in order to care for his mother. Since he did live with family, he was able to get away once in a rare while and he used the time his mother spent at adult day center as a break to get things done. When asked about what he does to cope or de-stress he stated, "Mine is a couple of beers and a couple shots of tequila. I don't get to do that very often but every now and then..." Greg cared a lot for his mother and siblings, and the way he spoke highlighted the importance of family and how he knew it was a difficult task providing care, so he took responsibility for the role.

Greg: "... I haven't been to the doctors in forever but I'm basically in good shape. I mean I'm not in physical good shape but I'm basically in spiritually good shape. When I came down here to give up my life, I gave up six years of my life, I knew what I was getting into, I didn't have a problem with it. My sister continuously is like "Greg let me know when you need to go on a vacation and what not" or "how you doing" I say "I'm good man I'm good". I do need to go on a vacation but uh uh I can handle it. I just always knew I could handle it. Just knowing my sisters' personality and my brothers' personality, I can handle the hard stuff. I could take it, I could take in strides more than they could. My sister is a big worry wart, my brother is kind of, you know his biggest problem is he's arrogant fucking asshole. [Laughs]"

Roger, a white male caregiver, cares for his wife who had a stroke and has early onset Alzheimer's. He expressed feeling overwhelmed and depressed throughout the focus group session. The tasks of providing care and managing the household were beginning to take a toll on his health. He stated that he would like a gardener and housekeeper to help him keep up with everything. He feels that it is his responsibility to take care of his wife, and doesn't want to ask their kids. There was the potential for family support, but not the desire to use it. When discussing his reluctance asking for help, members of the focus group commented.

Roger: "I'm pretty much doing everything by myself, I have three kids...(applause) I have a son that works in..he lives in Salida, my daughter lives in Salinas, my other son lives in Merced. I haven't really asked them to do anything because I don't want to burden them."

Randy: "It's hard isn't it?"

Roger: "I don't want to ask them..."

Greg: But its family though dude? It's still family.

Marie: "That's hard..."

Roger: "I know, I know... but I mean, for them to be so young and then have them.. I don't want to ask for help. Right now I'm dealing with it. If I wanted to, they would probably do it but I'd be worried that she wouldn't be receptive to them. So I'm not saying I never will. So prior to coming to [adult day center], [I used] Valley Caregiver Resources for a short time and [they] talked to me."

Tammy is a Hmong caregiver providing care for her father with dementia. Both she and her sister switch off with taking him to the adult day center and caring for him. She elaborated on the how important it is for family to be there for aging family members, provided an example of what the routine is taking care of their dad.

"My siblings are very helpful too. Even though my all my four of my brothers, they run their own business. But then they, they are their own boss, so whenever I know that they're always busy, so whenever I call them they're always like you know, every time I say, 'Hey, you know, I can't make it'. My sister... I have two (2) sisters. We have a big family. I have two (2) sisters and my self. So, basically right now, me and my sister are the ones that you know, that rotate back, today is your day, today is my day, today is your day. You know we have a care provider that we hired to take care of my dad on the day that she has school. Because she is a full time student at Stanislaus. So she'll come home, and then after the DayBreak, drop him off, the care provider takes care of my dad for two (2) hours and then my sister will come and take care of him for the rest of the day. Vice versa, every other day you know, I will do the same thing. I won't take my lunch, I'll work through my lunch, which I have a super nice boss that allows me to do that. And I will go early or I will not take my lunch, or work through my lunch and hmm leave early just to be there, right on time when the care provider drops my dad off at home. So I have a very supportive family too." – *Tammy, Hmong female caregiver caring for father with Alzheimer's*

Tammy's parents had separated prior to his dementia diagnosis and were not on speaking terms. When her dad was initially diagnosed, her mom wanted nothing to do with him or his care. This created a significant strain within the family as he needed care and supervision, but

there was no availability in nursing facilities. She described that even through navigating family conflict, they were able to come together to do what is best for their dad.

Tammy: "I cannot imagine my dad for example, what if he doesn't even have kids? And my mom said 'No, I'm not going to let you come in my house anymore, you're the one who that walked away from me.' Where is he gonna go? You know, and uh we you know, in the beginning it was very tough because my mom said 'No, I don't want him in the house anymore cause' he's the one who walked away from me.' And it took us like quite, almost a year just to you know, for my mom to accept in the end. But then I said, 'Okay then, you know, maybe we'll just take him to a nursing home.' But then the nursing home said, 'We have a waitlist.' But what if, what if this family, this guy don't even have a family? Where is he going to stay? Where is he going to stay if there is no one to take care of him? He can't live on the street, he has dementia... Where else can he stay? You know, like who would be taking care of him if he doesn't have kids or a spouse to take care of him? So that's my big concern you know, for those that are in this situation that have no loved ones."

Beverly spoke of the importance of family and supporting family. She believes even those who are not related should be treated like family, thus she took in Brother Maxwell. When asked about her experience as a caregiver, she stated:

Beverly: "**Being a caregiver I think it's a label that kind of doesn't really exist in the community I'm from. Its just family!** That's just what you do."

"So when you delve into that whole psychology when it comes back down to family and you look at families of color particularly and I can really speak to mine and my network, it is not a caregiving situation. It's just family. You know what I mean? You do what you have to; my mother raised a whole lot of people. There were always people in our home. My mother cared for my grandfather... There were people who lived with us that my mother cared for that I found out later weren't really related to us. Which is why I didn't even trip for them when I started caring for people who weren't related to me or my sister started letting people in her home who needed to be there for a minute - or my brother, doing the same thing. It's just natural and our nieces and nephews kind of do the same thing. Cautious about who you let in your home of course but you don't not do it. You know? So, so it's hard for me to think of it as a caregiving although I understand the word. The term doesn't quiet apply. You know just... it's what you do!"

Limitations and lack of social support

Caregivers talked at length about the challenges and barriers to providing care, and would often ask for advice from the interviewer (in individual interviews) or the other caregivers (in focus groups). Several caregivers also described situations of family conflict, especially between siblings or in cases where caregivers had remarried, and their children were distant and/or didn't want to help.

When we asked focus group members "what kind of support would make it easier for you or your family member and what kind of support(s) do you have," participants identified the adult center facility and staff as social support and a source of information and resources. Some identified the center as the only outside support they had available. The staff was not only there for them, but for their family members as well. And the facility provided as much-needed breaks for the overwhelmed caregivers.

Roger : "My wife... and I love this [adult day center]. I think it is kind of more for her, she doesn't have any close friends or old coworkers...they don't visit. So I like the social interaction she has with the staff and the people around her."

Randy is a White male caregiver providing care for his mother-in-law. He is retired and the primary caregiver, as his wife still works. During the focus group he was very vocal and described his limited social support and how dramatic this change has been for his life and his relationship with his wife. He highlighted the significance of having the adult center and adult center staff for his mother-in-law and for himself.

Randy: "Well our support is this here [adult day center] four hours a day. Really that's it, that's what we have. For us this is a Godsend... for me...more me than my wife I guess, because I'm the one with her [my mother-in-law] most of the time, so it gives me an opportunity to get out. Like I said, go to the gym and do things and relieve some [stress]-I get rid some of the stress lifting weights [laughs]. So I feel better you know? And you don't realize how much that helps, you really don't. Something little like that [having a break a few hours a day]."

Carol is taking care of her husband with early stage Alzheimer's and he is on dialysis. When arriving at the adult center, a staff member mentioned she was "concerned about Carol" as her health was not good and she was becoming forgetful. The staff member also stated, "I am not sure how long she'll be able to continue providing care, she [Carol] needs to start looking at placement [long term care]." Carol is another one of the caregivers who talked about the lack of support she has from family and the lack of social life or social outlets. Throughout her interview she described interactions with medical providers, as her husband was being seen at the Veteran's Hospital (VA) and had physical therapy. These relationships with doctors and medical staff seemed to be a consistent form of social support and she interacted with them at least three times a week at various appointments her husband had.

Carol: "He has nice shoes, but he won't put them on. So... He is very difficult, he's very stubborn, and his doctor told him today that you gotta be nicer to your wife, she's all you got, you know, you don't want to piss her off. So you gotta be a little bit nicer to her. [Her husband] "Well I don't trust her," the doctor said well why don't you trust her? [Her husband] "Because she tries to tell me what to do," he said [the doctor] well that's a good thing, she's trying to help you, you know, you need to listen to her, she wouldn't tell you anything wrong, she's trying to help you, after 59 years you don't trust her? [laughter] He said [the doctor] that's a good thing, I wish I had a wife with me for 59 years. He said [her husband] he'll try. So that was today's conversation, and so I will wait and see if it improves. [laughter]"

A surprising finding was Lidia had access to support that other caregivers did not, but does not use them because Kelly [her special needs daughter] "won't allow it". From the conversation, it seemed Lidia's worries also played a role in not utilizing other support services. Kelly was vulnerable for many reasons, and her mother [Lidia] and father were understandably protective.

Lidia: "Reginal Center has told us that if we need time out or time to ourselves to go, that we—that they would provide someone to come. But she won't allow it, she's so attached to us. So everywhere we go it's the three of us. We don't mind taking her with us."

Social life and interpersonal relationships were discussed in interviews even when caregivers were not directly asked. During the first focus group one of the caregivers asked Randy (male caregiver of mother-in-law) how his social life was, and his response was “what social life?”, while laughing lightheartedly. This is one of many times Randy in particular brought up the impact caregiving has had on his social life.

Randy: “Uhh I used to like shooting competitions, I used to like reading. Just you know, just on a Saturday, hey I might run over to Chuck’s house for a minute... do those things, you know now, I don’t do so, which is you know... I’m pretty blaze [blah-zay] about it, I mean it’s one of those things where it’s like hey this is what happened, this is what I’m dealing with, it’s not like it’s the end of the world but you know I do, there are some things I miss doing.”

Randy was especially concerned with not being able to spend quality time with his wife: “Well I’m supposed to be in Florida buying a home right now... that’s... we were moving there. That is what we were doing and uhh we’re not doing it... we are staying here.”

Greg followed with his feelings about changes to his social life. When asked if he noticed changes to his own health and his social life since providing care, he replied:

Greg: “Anyway I’m fine, health mentally. You know, I definitely do need a vacation. I am a person that went out, I’ve been going out since I was 12 years old, always out. So now I’m completely a home body so I do read when I can, I watch tv when I can.”

Impacts on social life often came up when discussing time and lack of help. Caregivers described the impact this had on their relationships with their spouses and friends. When asked to rate the stress based on the question, “To what extent... has there been a change in your relationship with your spouse/relative?” responses varied from feelings of no stress to feelings of extreme stress. Most who reported feelings of extreme stress were caring for a spouse or family member diagnosed with Alzheimer’s disease or dementia. Marie in particular is caring for her husband with Alzheimer’s on her own and has struggled with the change in their relationship.

Marie: “You know I think...what’s so hard is... is you know how they were before, but It’s so hard because I think for me...everything has just changed and he [her husband] used to be the one that would [do everything]...”

Wanda, who is a Black caregiver providing care for her brother with Alzheimer’s and elderly mother, spoke about the difficulties with providing care and the limited support she had from other family. She had left her life in another state to come and care for her brother and mother. Her mother was struggling with providing care, so as the eldest she felt it was her responsibility to help her mom with her brother. Wanda expressed the toll caregiving takes on personal relationships, because for her “family comes first, before my own happiness.” She also stated:

“I just met somebody in June and... really nice guy. He’s a Vietnam vet, I’m a veteran as well. So we have a lot in common that way, and he understands. I had to tell him, I said ‘you know, my family comes first. There’s nobody else that’s gonna you know, be able to do this but me, right now’. I have a sister here, but she’s got her own little world. She comes over when she can to give me a break but it’s not often. But she’s always saying, ‘Oh you know, when you need a break..’ I said ‘I shouldn’t have to ask you. I’ve been doing this for three (3) years, [Smacking sound in the background] I need a break! ALL the time I need a break.” – *Wanda, Black female caregiver caring for brother with Alzheimer’s and elderly mother*

Veronica is a Latina caregiver, providing care for her son Max who is wheelchair bound and cognitively impaired. Veronica had a strained relationship with her other daughters, as she felt they did not care and did not support her and their brother. She stated:

“My kids used to be supportive this was before they got married. But when they started making their own lives they kind of withdrew. They don’t help me like they used to. They have their own family, their husbands and every once in a while we call them. ‘Can you come and help me with [Max] a little bit?’ ‘oh we’re gonna do this..’ So I just completely stopped asking them for their help.” – *Veronica, Latina female caregiver caring for son with disabilities and cognitive impairment*

DISCUSSION

The emerging themes from these interviews converged under the role of social capital in caregiving. Neighborhood support, church support, family support and social support are each forms of social capital, where the support and resources flow through these networks.

Caregiver's access to services and socially supportive networks increased the forms social capital available to them. Through relationships and connections, caregivers had increased access to resources or knew who to ask and where to go for assistance. These networks were necessary for rural caregivers, who had limited access to health care and often lacked one or more form of support (e.g. family, social, neighborhood). There were clear differences in family and outside network ties. It is relatively easy to distinguish which sort of ties (social capital) caregivers had access to and utilized. In several cases, it seemed as though caregivers had primarily weak ties (e.g. had moved, family distant) or strong ties (e.g. lived with family, lived in same neighborhood for 20 years). The shared experiences help us to see the complex relationships and dynamics between caregivers, their family members and their support systems.

Feelings of trust and belonging in one's neighborhood also greatly impacted caregiver's quality of life. However, these benefits were not accessible to or utilized by everyone and this depended on a number of reasons. For example, several caregivers interviewed didn't use support(s) offered by family members if they perceived their family member being cared for as "too vulnerable or sick" and if they did not trust their support system or outside resource (such as respite care). Also important to note, they did not want to burden other family members, as it "was his/her responsibility". This reason for not accepting help was especially true if their family members had families and children of their own and were working.

The differential benefits of social capital also depended on the quality and intensity of ties. Family ties and relationships within families varied tremendously, in some cases familial

relationships were detrimental to the caregiver and the person they were caring for. For many caregivers, family was the key to successfully providing care, as family was there to give the caregiver a needed break and provide financial resources and social support. Culture was an important factor in the caregiving relationship and often impacted decisions that were made. Culture refers to several aspects: family culture (e.g. eldest expected to have the responsibility, promises made to not place loved ones, culture within communities—faith based community, cultural norms), culture based ethnic background, and culture based on region and environment (e.g. from the South, military upbringing, rural farming community). The idea of expectation and responsibility was clear throughout the interviews, especially for caregivers who described themselves as the eldest child or only daughter. Some felt being a family caregiver was an obligation and burden, while others described it as an opportunity, something they wouldn't think twice about, often relating this positive outlook to "the meaning of family".

The results of this study challenge many preconceptions about family-based informal support using empirical data collected in a rural setting, specifically within Black and Latino/a families. Current research on caregiving in communities suggest that Black and Latino/a families are the most supportive and against sending their family members to long-term care facilities, and these perceptions are often paired with caregiver's feelings of sacrifice, expectation, and obligation.

Consistent with the current understanding, caregivers expressed concerns about trust and many stated how long-term care was undesired, a "death sentence" and the "last resort", however this study demonstrated that many family caregivers "stepped up" to provide care for a parent or sibling because "no one else would" or it was a promise made to their family member in the past, prior to their declining condition. Both Black and Latino/a caregivers discussed interest in long-

term care, but it was not financial feasible, they were criticized by other family members, or felt guilty. Others stated they would consider long-term care if the level of care required surpassed what they were physically able to do. These aspects have important implications for our understandings of families providing care and emphasize the need for resources and long-term care services. (Crouch, Probst, & Bennett, 2017; Ehrlich, Emami, & Heikkilä, 2017)

Caregivers in our study identified the centrality of social life to their senses of well-being. The concept of social life loss was emphasized and was often a result of change in relationship(s), role(s) in the home and changed over time. Social life concerns were also highlighted when stress and coping came into conversation. Most people had used social connections and social activities for coping, but as a result of the demanding nature of providing care, often full-time, caregivers could no longer access these social networks and forms of social capital. Although these shared experiences of select caregivers, these narratives provide an important and unique insight into the lived experiences of family caregivers in rural settings and how they encounter barriers and facilitators in accessing and using resources. Additionally, instead of generalizations we are presenting what this phenomenon looks like in family caregiving.

CONCLUSION

With a consistent shift in demographics, were baby boomers and older adults, individuals age 50 and above, are a growing majority and we have begun to see more health needs, chronic disease and comorbidities, it is necessary to understand what forms of social capital and social support are beneficial for family caregivers in rural settings. There is not a “one size fits all” solution, so exploring the lived experiences of those directly impacted may help inform future support services and interventions, and highlight the implications when caregivers lack social

support and support services. Family caregivers need greater recognition, information, and meaningful support to help them care for older relatives or friends, and to maintain their own health, financial security, and well-being. It is crucial to understand the support systems available for rural, minority caregivers to allow us to better deploy interventions and to understand how to support this growing population.

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Appendix I.

Caregiver Stress Scale

