Reducing Caregiver Burden: Fostering Healthy Aging and Social Support

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Reducing Caregiver Burden: Fostering Healthy Aging and Social Support

by

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A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science in Public Health
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DEDICATION

I dedicate this work to my parents, Nancy and Jaime. You taught me the value of family as a source of love, comfort, and support; and you continue to nurture our familial foundation. You’ve always strived to make the best choices for our family, many of which were very difficult, to ensure opportunities for our success and happiness. Your selfless sacrifices have paved the way to a brighter future. I am grateful for all you have provided through your love, sacrifice, and instruction. I am honored to have parents such as you. To my siblings, Juan and Stephanie, I have learned much from both of you. You are both unique and have provided me with fascinating and useful perspectives of the world. I cherish the wonderful memories of our times together so far, and happily anticipate the memories we shall make in the future. I look forward to what the future holds for each of us, and am forever in support and encouragement of the pursuit of your goals and dreams. To Brandon, thank you for making our house a home, full of joy and laughter. You gave me comfort and encouragement when it was needed the most. Thank you for my new-found appreciation of the outdoors. I look forward to more log cabins, fishing trips, biking trails, and many other adventures the future holds for us!
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ABSTRACT

Over 43.5 million Americans provide informal care to a fast-growing elderly population in the United States. Informal care allows care-recipients to remain functional members of society. However, research suggests that the demands of informal care can negatively impact the health of caregivers. For example, caregiver burden increases the risk for poor health in caregivers compared to non-caregivers. Caregiving research is on the rise, but the dynamics of informal care in active retirement communities remains widely unexplored. To provide adequate services to lessen caregiver burden and improve the Quality of Life (QoL) of informal caregivers, the various settings in which informal care is delivered must be evaluated.

Aiming to understand the needs of informal caregivers and the protective factors against caregiver burden in active retirement communities, data from the USF Health and The Villages study, conducted from October 2011 and March 2013, were analyzed. Data from twenty-nine focus groups (N=144) was used to explore the challenges faced by seniors in a caregiver role and the availability of resources that decrease caregiver burden. The primary focus was informal care and the challenges associated with the caregiver role; findings revealed a great need for caregiver relief and limited information on existing resources is available to informal caregivers. Consistent with existing literature on caregiver burden, having no personal time, financial burden, physical demands, and poor health were commonly identified as the biggest caregiving challenges. However, findings strongly suggest that the unique structure of The Villages
community encourages high social support that may be the strongest protective factor against
caregiver burden in the community.
CHAPTER ONE:
INTRODUCTION

Unpaid individuals responsible for aiding with activities of daily living (ADLs), instrumental activities of daily living (IADLs), and medical care for care-recipients are referred to as informal caregivers (Reinhard, Feinberg, Choula, & Houser, 2015). ADLs and IADLs include, but are not limited to; assistance with bathing, feeding, toileting, medication management, finances, shopping, and home making (Bakken, Banovitz, Lafrenz & Li, 2015). In the United States, estimates suggest that 43.5 million individuals serve as informal caregivers to adults 50 years old and over – 54% of whom spend an average of 31 hours a week providing care (National Alliance for Caregiving & American Association of Retired Persons, 2009).

Most caregiving responsibilities often fall to family members, predominantly spouses and daughters, who are primarily responsible for providing emotional support, instrumental support (e.g., transportation, meal preparation), and personal care (e.g., bathing, dressing) to their loved ones. Informal caregivers play an important role in the health care system and provide the majority of long term care to adults ages 65 and over. Informal care allows 80% of older adults with limitations in three or more ALDs, to remain active members of their community (Hooyman & Kiyak, 2008).

While the number of adults 65 years and over increases from 46.2 million in the year 2014 to 98 million by the year 2060 (United States Department of Health and Human Services
Administration for Community Living, 2016) the number of informal caregivers across nations is not meeting the demand for elder care (Shahly et al., 2013). Additionally, an increase in the rates of chronic conditions, shorter hospital stays, improvements in home care technology, and changes in discharge planning (Family Caregiver Alliance, 2006; Ibrahim et al., 2017) could lead to an unprecedented caregiving crisis (Carter, 2008).

### Aging Caregivers

Nearly 50% of Americans 55 to 65 years old serve as informal caregivers, far outnumbering the number of formal caregivers (Day, 2014), providing an average of 580 hours of care per year, while caregivers over 75 years old spend an estimated 886 hours per year. Ninety percent of married adults with disabilities are typically cared for by a spouse and 80% of non-married older adults are cared for by adult children (Johnson & Schaner, 2005; Muller & Volkov, 2009; Roth, Fredman & Haley, 2015). Previous research also reports that 16% of the oldest-old (85 years old and over) serving as caregivers provide assistance to a sibling and 20% provide assistance to a friend. Older caregivers tend to experience higher levels of caregiver burden, yet are less likely to receive help from another unpaid individual. Older caregivers are also more likely to use formal support services (e.g., hospice, transportation) more frequently than younger informal caregivers (Wagner & Takagi, 2010).

### Caregiver Burden

Caregivers experience several stressors that have been widely reported to affect their Quality of Life (QoL) (Roth, Fredman & Haley, 2015). For example, the high levels of stress,
which often accompany caregiving duties, result in poor health outcomes for caregivers (Beach et al., 2005; Fauth, Femia & Zarit, 2016; Kim, Carver, Shaffer, Gansler & Cannady, 2015). Other health problems reported by caregivers include: sleep disorders, inappropriate use of alcohol or prescription drugs, headaches, pain, weight gain/loss, panic attacks, high blood pressure, and a higher risk for stroke (Candy, Jones, Drake, Leurent & King, 2011; Evercare & National Alliance for Caregiving, 2006; Haley, Roth, Howard, & Safford, 2010; Silva, Teixeira, Teixeira & Freitas, 2013; Torimoto-Sasai, Igarashi, Wada, Ogata, & Yamamoto-Mitani, 2015). The number of hours invested in providing care, in addition to the number of ADLs and IADLs the caregiver is responsible for, also increases the amount of physical strain experienced by older caregivers (National Alliance for Caregiving & American Association of Retired Persons, 2009).

Mental health can also be affected by the caregiving experience. Anxiety and depression, isolation, and even suicidal ideation are common in informal caregivers (Andren & Elmstahl, 2008; Beach et al., 2005; Burton, Haley, & Small, 2006; Douglas, Daly, O’toole & Hickman, 2010; Haines, Denehy, Skinner, Warrillow & Berney, 2015; Majumdar & Mazaleni, 2010; Neri et al., 2012; Sklenarova et al., 2015). Depression affects one-third of informal caregivers and is most common in caregivers of patients with dementia (Schoenmakers, Buntinx, & Delepeleire, 2010). Older caregivers also report higher levels of emotional stress and limited opportunities for enjoying personal time (National Alliance for Caregiving & American Association of Retired Persons, 2009). Spousal caregivers (wives in particular), individuals new to the caregiving role, and informal caregivers that report higher levels of caregiver burden tend to be especially vulnerable to poor mental health (Lavela & Ather, 2010). Additional feelings that contribute to subjective caregiver burden are resistance, anger, sadness, powerlessness, and uncertainty (Kraiho, Brouwer, de Leeuw, Schrijvers & van Exel, 2012).
The National Alliance for Caregiving & American Associations of Retired Persons (AARP) (2009) reported that more than 25% of individuals providing care to adults reported experiencing some form of financial hardship as a result of caregiving. Many informal caregivers report out-of-pocket spending (Ranji & Salganicoff, 2011) that amounts to an average of $5,000 per year on caregiving expenses (Sisaket, 2015). The cost of managing chronic conditions and re-hospitalizations in the U.S. continue to increase and informal caregivers face enormous financial challenges (Levine, Halper, Peist & Gould, 2010; Vogeli et al., 2007). Healthcare costs for care-recipients with chronic conditions can be as high as $11,284 per year (Alecxih, 2010). Additionally, individuals with limitations are more likely to visit multiple health professionals, utilize different devices for assistance with ADLs, and require longer hospital stays (Feinberg, Reinhard, Houser & Choula, 2011). Working caregivers experience unique financial hardships. The National Alliance for Caregiving and the American Association of Retired Persons (AARP) Policy Research (2015) found that at least 60% of family caregivers are employed either full time or part time – of those working caregivers 40% are 50 years and older. It was also reported that to balance a job and caregiving, working informal caregivers are more likely to reduce the number of work hours, take leaves of absence, or receive disciplinary action. Furthermore, working caregivers over the age of 50 also reported shortening working schedule, leaving the work force, or early retirement as additional challenges; while limited work options for caregivers translates into significant financial loss. For example, family caregivers over the age of 50 can suffer income and benefits cuts, estimated at $303,880 on average, because of leaving the workforce to care for a parent (Feinberg, Reinhard, House & Choula, 2011). In addition, nearly one third of female informal caregivers in the workforce are more likely to retire early (Jacobs, Van Houtven, Laporte & Coyte, 2014) or less likely to return to work (Gonzales, Lee &
Brown, 2015). Further, working caregivers also experience conflicts between work and family responsibilities (Feinberg, Reinhard, Houser & Choula, 2011).

In addition to physical, mental, and financial strains, the challenges faced by caregivers can also affect the quality of care provided. Caregiver burden, more than care recipient’s health status, is a strong predictor for caregiving outcomes (Greenberger & Litwin, 2003; Smith, Williamson, Miller & Schulz, 2011). For example, one study reported that between one third and one half of informal caregivers of cancer patients disclosed not receiving the adequate amount of training to perform duties such as managing nausea, vomiting, fatigue and pain (van Ryn et al., 2011). Schubart, Kinzie, and Farace (2008) also found that poor training in caregiving duties is also a subject of concern for some informal caregivers potentially causing additional stress.

Often, informal caregivers feel untrained or unprepared due to the rapid pace at which the needs of the care-recipient can change. The study reported that as care-recipient needs change, caregivers are forced to take on new roles they may not be properly trained to complete. The continual adaption to new roles over time can increase stress levels, contributing to an overall increase in caregiver burden.

**Positive Aspects of Informal Caregiving**

Research suggests that there are also benefits to the caregiver role. In addition to providing care to loved ones, informal caregivers play a major role in the healthcare system as a major economic factor. The economic value of informal caregivers often goes unnoticed since they are viewed as an “invisible workforce.” For example, estimating the total cost of informal care as fee for service amounted to $470 billion in 2013, using a base of 40 million caregivers.
providing an average of 18 hours per week of care valued at an average of $12.51 per hour (Reinhard, Feinberg, Choula, & Houser, 2015). Conversely, in 2013, Medicaid spending, including long-term services and supports, amounted to $449 billion (Centers for Medicare & Medicaid Services, 2013) and out-of-pocket spending was nearly $339 billion (The Henry J. Kaiser Foundation, 2013). Thus, informal caregiving is an invaluable resource which can translate into cost savings for some publicly funded programs, such as Medicare and Medicaid, as nursing home care is more expensive than services provided at home (Marek, Stetzer, Adams, Popejoy & Rantz, 2012).

Although informal caregiving may be considered burdensome, many caregivers also report satisfaction with their role. For example, some research illustrates perceived intrinsic rewards for caregivers, such as stronger family ties, satisfaction from assisting a family member, and acquiring new skills and competencies (de Labra et al., 2015; Family Caregiver Alliance, 2006). Additional positive aspects of informal caregiving include a sense of purpose and commitment to the caregiver role, increase in patience and tolerance, ability to provide support to other caregivers, and cultivating humor and positive attitudes (Cheng, Mak, Lau, Ng & Lam, 2015). Some caregivers even consider focusing on the positive aspects of caregiver an effective coping mechanism to reduce caregiver burden (Rodakowski, Skidmore, Rogers & Schulz, 2012). As the cost of nursing home care continues to rise, policy-makers and the public continue to seek other alternatives to provide care for older adults in their communities (Bates, Saria, Ohno-Machado, Shah & Escobar, 2014; Cutchin, 2003; Joynt, Gawande, Orav & Jha, 2013; Rocco, 2017). Aging in place (AIP) is often viewed as ideal by adults choosing to continue living at home as they age instead of transferring to establishments that provide formal care (e.g., nursing homes, assisted living facilities) (Fields & Dabelko-Schoeny, 2016). Older adults choosing to
stay at home, rather than relocate to nursing facilities, report many benefits of AIP, such as maintaining independence, feelings of security and familiarity, and continued attachment to families and communities (Wiles, Leibing, Guberman, Reeve & Allen, 2011). Care at home is essential to the notion of Aging in Place and many older adults are able remain at home due to the presence of an informal caregiver (Paganini-Hill, 2013).

The Impact of Social Support on Caregiving Burden

Research on social relationships and health often mention the benefits of social support (Weisz, Quinn & Williams, 2015; Poortinga, 2012). Successful coping during stressful situations and reducing caregiver burden are some of the benefits to caregivers associated with social support (Reeve, Shumaker, Yearwood, Crowell & Riley, 2013; Xia, Ding, Hollon & Wan, 2013; Han et al., 2014; Rodakowski, Skidmore, Rogers & Schulz, 2012). For older adults, late life is full of significant life changes, such as the deaths of friends and family, retirement, loss of independence, and moving. These changes can be softened by the instrumental, emotional, and informational support provided by community members, such as caregivers, family, and friends (Francis, Worthington, Kypriotakis & Rose, 2010; Fredriksen-Goldsen et al., 2013; Kaufman, Kosberg, Leeper & Tang, 2010; Rowe & Kahn, 1997; Ter Meulen & Wright, 2012). Additionally, satisfaction with social support has also been linked to better self-reported health status (White, Philogene, Fine & Sinha, 2009).

Seminal work by House (as cited in Glanz, Rimer & Viswanath, 2008) explains social support as the interaction of four types of supportive behaviors that result in a functional relationship, including: 1) Emotional support (e.g., provision of empathy, love, caring); 2)
Instrumental support (i.e., tangible services); 3) Informational support (e.g., advice, suggestions); and 4) Appraisal support (e.g., information for self-evaluation and improvement). The importance of instrumental and emotional support and its benefits on overall health have been widely documented (Berkman & Glass, 2000; Boutin-Foster, 2005; Chang, Chiou & Chen, 2010; Thoits, 2011; Reblin & Uchino, 2008; Shim, Cappella & Han, 2011). Reciprocal relationships have been shown to have a positive impact on the mental and physical health of older adults, improvements in cognitive functioning, a sense of personal control and meaning, and later onset of disease, disability, and mortality (Berkman, Glass, Brissette & Seeman, 2000; Calvete & de Arroyabe, 2012; Uchino, 2009; Uchino, 2004; Underwood, 2011). Caregivers that receive close emotional support and can discuss caregiver burden benefit from better QoL (Chronister & Chan, 2006; Thoits, 2011).

Lifestyle preference in older adults choosing to live in active retirement communities are becoming more popular (Glass & Skinner, 2013) and the majority of older adults prefer to age in place (Feldman, Oberlink, Simantove & Gursen, 2004; McDonough & Davitt, 2011; Scharlach, Graham & Lehning, 2012). The “Village” model is a non-governmental approach to combat the rising costs of formal care and provide affordable strategies to support aging in place. This grassroots organization provides community-dwelling older adults with a wide range of resources, including emotional and instrumental support (NCB Capital Impact, 2009). In reference to social support, Barker (2002) analyzed the social interactions between friends, neighbors, and non-kin available to aging caregivers. The findings highlight that the quality of emotional connectedness, associations with informal caregivers, and assistance with tasks performed influence the naturally occurring care relationships in community-living older adults. The findings suggest that these relationships are paramount for sustaining community living for
nearly 10% of frail older adults. Further, variances in caregiver burden were significantly associated with the quality and quantity of social support available (Rodakowski, Skidmore, Rogers & Schulz, 2012). Positive views of QoL in caregivers are correlated with social support (Kaufman, Kosberg, Leeper & Tang, 2010). In addition, a sense of value, ability to care, and caregiver satisfaction were associated with caregiver optimism; higher levels in optimism was also associated with higher social support (Brand, Barry & Gallagher, 2016).

**Informal Care in The Villages**

Retirement communities are growing in popularity (Glass & Skinner, 2013), but it is not yet clear what the impacts of informal caregiving is on residents of such communities and nor is it clear how available resources within these communities might mitigate or lessen caregiver burden. *The Villages* fosters high levels of social support and social cohesion (Bach, Mortimer, VandeWeerd & Corvin, 2013) along with a broad range of opportunities for social and physical activities that enhance healthy aging. *The Villages* offers residents the opportunity to engage in over 2,500 interest clubs, more than 2,000 activities, 34 neighborhood recreation centers, and free night entertainment, among other leisure and social activities. The active and dynamic lifestyle available to residents allows for the development of strong social ties through constant interaction. The purpose of this project was to evaluate the residents’ perceptions regarding how living in large retirement community, where social support may be more readily available, would affect caregiver burden. I expected to find that living in a large retirement community would reflect positively in the residents’ responses to questions regarding caregiver burden.
Previous research on caregiver burden relies heavily on assessing caregiver burden through quantitative measures and ignores the significant nuanced contributions qualitative data can offer (Bastawrous, 2013). For example, when rigorous research methods are employed, the qualitative data collected could be more compelling than quantitative data, as issues can be explored in depth in real time (Anderson, 2010). This study aims to fill this gap by further clarifying the impact of caregiver burden and identifying ways to improve the QoL of informal caregivers using rich, contextual qualitative data derived from the lived experiences of older adults in *The Villages*, an active retirement community in Central Florida.

I chose a qualitative approach to pioneer informal care research in a unique active retirement community and to better understand the perceptions and experiences of informal caregivers in *The Villages*. Qualitative research is ideal for exploratory research, where data is collected in a natural environment within a limited geographical context and results can potentially guide interventions for health promotion (Crosby, DiClemente & Salazar, 2006). Qualitative research provides rich contextual data through in depth open discussions on issues of interest, identifying and clarifying new themes as they emerge, and collect responses not gathered through quantitative research (Anderson, 2010). Additionally, qualitative research has been a successful method in geriatric research to better understand older adults’ perceptions on successful aging, aging in place, the importance of social networks, physical environments and physical activity, and physical activity barriers (Gardner, 2011; Reichstadt, Sengupta, Depp, Palinkas & Jeste, 2010; Rosenberg, Huang, Simonovich & Belza, 2012; Van Cauwenberg et al., 2011).
CHAPTER TWO:

METHODOLOGY

Overview

*The Villages* is an active senior-living community located in Central Florida spreading across Sumter, Marion, and Lake Counties and home to over 90,000 residents 55 years of age and over. To further explore caregiver burden and how to reduce its negative effects on older caregivers, data from 29 focus groups conducted with 144 residents of *The Villages* were analyzed. Structured and in depth focus group discussions with residents of *The Villages* allowed for a more detailed examination of experiences and perceptions that offer unique insight into the delivery of informal care to older adults inside *The Villages* community. This qualitative analysis focused specifically on older informal caregivers to identify: 1) perceived challenges, 2) unmet needs, and 3) facilitators and barriers to informal caregiving.

Study Design

The USF Health and *The Villages* study, conducted from October 2011 to March 2013, is part of a larger population health assessment that stems from a community-academic partnership between *The Villages* and the USF Health. The overall population-focused health assessment was conducted in three phases employing a rigorous mixed methods approach. Phase 1, the
formative stage of the study, included 53 focus groups with residents of *The Villages* (N=384) to inquire about perceptions of health, healthy aging, health beliefs, health needs, among other topics of interest to inform the development of a health assessment survey developed in Phase 2. Phase 2 focused on conducting a comprehensive community health assessment of residents of *The Villages* through a population-based survey (N= 33,119). This paper focuses on Phase 3, which included 29 focus groups (N=144) and was designed to validate the survey results and clarify salient themes from Phase 2.

**Recruitment**

Active and passive recruitment strategies were used. In Phase 1, residents of *The Villages* were approached at USF Health sponsored events (e.g., vaccination drives, health lectures) and asked to complete a pre-screener form (See Appendix A). The pre-screener form was meant to collected basic demographic data, health information, and contact information, as well as consent to be contacted about participation in future research. Pre-screener data, stratified by gender and health status using computer software, was used to generate call lists of potential participants. Using the generated call list, residents were contacted over the phone and those interested in participating in the study were enrolled in focus groups based on gender and health status.

In Phase 3, staff increased the number of possible focus group participants by distributing and collecting additional aforementioned pre-screener forms to *The Villages* residents. Pre-screener forms were available to residents at the USF Health satellite office and through the USF Health and The Villages website. The call list of potential participants developed in Phase 1 was also used as a resource to recruit focus group participants for Phase 3.
Pre-screener forms were also used to identify and contact potential research participants, based on age and gender, and invited to enroll in a stratified focus group session.

**Data Collection**

For this paper, only residents that participated in Phase 3 focus groups were included in the analysis. Caregiving in *The Villages* was explored in depth in Phase 3 while Phase 1 focused on a broader approach to health status and QoL in *The Villages*. The 29 focus groups (N=144) from Phase 3 were conducted twice a day, three times a week from February to April of 2013 at The USF Health and *The Villages* satellite office. Focus group sessions typically lasted an hour and a half. Standard focus group protocol (Krueger & Casey, 2014) guided the stratification of focus groups by gender and age. Research staff involved from the inception of the study served as focus group moderators for Phase 3, due to their familiarity with the research design, study population, and previous findings. One moderator guided the discussion while one note taker used Livescribe smart pens to capture and detail residents’ opinions, ideas, and experiences. Additionally, focus groups were audio recorded and transcribed professionally for analysis purposes.

Phase 3 focus groups explored the following domains: transportation, built environment, safety in late life, sexual health in late life, mental health, caregiving, religion and spirituality, advance care planning, end of life care, nutrition, occupational health, and changes in healthcare policy. Given the wide range of topics explored in Phase 3, three different focus group guides were developed and were randomly assigned to individual focus group sessions to ensure all
topics were covered equally across the focus groups. For a list or relevant topics discussed in the focus groups (See Appendix B)

Consent was obtained from participating residents in compliance with the approved USF Institutional Review Board protocol. All data collected was kept strictly confidential, de-identified, and password protected allowing accessibility only to research staff.

The research team met on a weekly basis to debrief on focus group findings. The purpose of the meetings was to identify common themes pertaining to each domain (e.g., caregiving, nutrition, occupational health), identify if saturation had been reached, and to address any issues with the data collection process.

Analysis

A comprehensive code book was developed by a team of four qualitative coders as the basis for analyzing focus group data at the micro level. Codes were formulated through an inductive process that required several focus group transcripts to be carefully read and interpreted until salient themes were clearly defined. Once the preliminary code book was developed, other research staff assisted with the clarification of definitions for existing codes (e.g., caregiver emotional stress, caregiver physical demands, support from friends) and suggested the inclusion of new codes that resulted in a final code book. After the codebook was finalized, coders were assigned five practice focus group transcripts to code to ensure a high degree of reliability (k= 0.89).

Once high reliability was obtained, thirteen trained team members participated in the coding process of the 29 focus groups conducted as part of Phase 3. Qualitative data, including
transcripts from 29 focus groups (N=144), was then coded using the final codebook and analyzed using NVivo 10 software. NVivo 10 software was used to systematically classify relevant quotes from the transcripts based on codebook definitions, identify which topics of discussion were the most salient to determine recurring themes, and provide an organization system for the easy retrieval of important quotes.

For this paper, relevant macro and micro codes that addressed the caregiving domain were carefully analyzed. Codes related to lack of formal resources for caregivers, challenges of informal caregiving, social support from friends and neighbors, and caregiver burden were reviewed for evaluation purposes.
CHAPTER THREE:
RESULTS

Focus Group Demographics

The Phase 3 participant demographics mirror that of The Villages overall population. Females accounted for 57.6% of the sample while males made up the remaining 42.4%. Most participants were between 61 and 75 years of age (83.3%) and retired (87.5%). Most participants were college graduates (72.2%) and all classified themselves as White. Only 1.4% of the participants reported being of Hispanic origin. A significantly large portion of focus group participants (97.2%) indicated having good to excellent health. (See Table 1.)

Focus Group Themes

Qualitative thematic analysis allowed for an in-depth investigation of how caregiver burden is perceived by older adults. Three salient themes emerged pertaining specifically to informal caregivers residing in The Villages: 1) challenges, 2) unmet needs, and 3) available resources. Each theme discussed below is further divided into subthemes to better capture focus group responses and identify key issues.
Challenges of Informal Caregiving

Focus group respondents identified several challenges of informal caregiving such as stress, physical demands, and lack of freedom. Discussions centered predominately on aspects of caregiver burden and highlighted the demanding nature of informal care and high cost of formal elder care.

Caregiver Emotional Stress

Most participants discussed coping with emotional strains associated with caregiving as a major challenge of aging and expressed their views on the poor mental health status of informal caregivers in *The Villages*. Focus group participants agreed that being an informal caregiver significantly impacts emotional stability. As one participant explained “You don’t know unless you’ve been through it. It victimizes the family in ways you can’t imagine. Not only is it heartbreaking, it just strikes you.”

Caregiver depression was a major recurring theme in the focus groups. A great majority of residents pointed out that the physical and mental deterioration of the care-recipient is a very difficult challenge to overcome. One Participant, for example, described the detrimental effects of illness and disability on the care-recipient, citing this as a trigger for caregiver depression “I believe, also, that standing next to every sufferer from Alzheimer’s is a caregiver that is in some stage of depression just because of the difficulty they face every day.” Often, when discussing caregiver depression, many participants highlighted the exacerbated emotional strain associated with caring for an individual suffering from Alzheimer’s disease or other forms of dementia. One individual shared a personal anecdote “My father in law, he’s now passed but he was here, too.
He had dementia…if you’ve lived with anybody with Alzheimer’s or something of that, it just wears you down.”

**A Lack of Caregiver Freedom**

Many participants discussed how caregivers’ inability to manage their own time can lead to a lost sense of autonomy for the caregiver. Interferences with work schedule, limited time to run errands, and missed opportunities for socialization were often cited as instances in which caregivers had their freedom interrupted. A diminished degree of caregiver freedom was consistently discussed as having a negative impact on the QoL of caregivers. For example, one resident elaborated on this notion “Something we all take for granted is daily living skills and ability to go to the grocery store and when this is taken away, you can see people really go down.”

**Caregiver Isolation**

Isolation was identified as a significant and serious challenge for caregivers. Respondents agreed that *The Villages* culture relies heavily on socialization and participation in social activities, yet participants reported that caregivers often feel secluded. Residents also mentioned that the complexity of the caregiver role, due in part to staying at home with the care-recipient, prevents caregivers from interacting with other residents in a social setting. One participant explained “Well, I think that we’ve all bought into the [The Villages] lifestyle. Then when you have someone with dementia or Alzheimer’s your lifestyle is totally altered.” Participants reported “The Villages Lifestyle” revolves around socialization and participation in the many
activities available to the residents and is a positive aspect of choosing this community. Participants agreed that caregivers are less likely to participate in social activities having a negative impact on their social life.

Additionally, participants shared a perception that caregivers are reluctant to leave the care-recipient home by themselves, driving caregivers further into isolation. For example, one participant stated “You can’t do all those things that you enjoy because you can’t leave them alone.” Another resident linked caregiver’s extreme concern for their loved one to caregiver isolation.

I have a friend who’s been a caregiver now for - wow must be about five years and she just never gets out. She’s afraid to leave him. We’ve offered to help her, but she’s afraid because he gets panicky when he’s around anybody he doesn’t know and of course, now he doesn’t know anybody.

Participants also discussed that even if caregivers have an opportunity for socialization, the demands of being a caregiver compromise the quality of the time spent with friends/neighbors. For example, one individual shared concerns that a caregiver may not be able to fully engage in social activities, “They [friends and neighbors] can’t come and visit because you’re too busy taking care of this person. You can’t really have a nice visit.”

Physical Demands of Caregivers

In discussion on the physical demands of caregivers, participants often reported physical strain as a burden associated with caregiving. In general discussion focused on the deterioration of caregiver’s health and limited physical capabilities as caregiving duties intensified, decrease
in the quality of care delivered to the care-recipient, and the safety of caregivers. One participant addressed the physical challenges of providing care to a loved one, “Then you try and transport or transfer someone. You physically may not be able to do some of that or perish the thought.”

Residents often referred to caregivers as being “burnt out” because of their demanding role. Participants mentioned lack of sleep, weakness, emotional distress, and vulnerability to disease affect care givers more than non-caregivers. Additionally, one participant stated that the weathering of the caregiver is not gender specific, “Well, the couple of friends that we have who are in that situation basically they burn out. I think that’s common whether you’re male or female. You just get burned out”

When asked about the physical demands of caregiving and its adverse effects on health, participants also identified being “worn out” as a risk factor for poor health and physical strain that can lead to the death of the caregiver prior to the death of the care-recipient. As one individual said “Being worn out. They say more caregivers die before the actual people they’re caring for.”

**Financial Burden**

Focus group participants identified cost as another major challenge of caregiving. Participants explained how limited existing funds and/or poor healthcare coverage, can hinder caregivers from finding adequate formal care (e.g., nursing homes, respite, assisted living, in-home care) for the care-recipient. Some residents commented that the high cost of respite care prevents caregivers from receiving the support and resources they need to maintain a high QoL for themselves and their loved ones. For example, one participant noted: “If you look in the
Yellow Pages and get somebody from there, you have to pay. For a caregiver, the expenses of taking care of a person is so much that 99% of the people can’t afford to pay somebody to come in and give the caregiver a break.”

Another participant not only talked about the expenses of formal care but also mentioned that limited funds compromises the formal care services provided to care-recipients.

If you need assisted living and/or nursing home, they’re extremely expensive and I don’t think – I see it that there’s nobody that I know in The Villages that could afford to put their spouse there for more than a year max and you would go through almost all your savings to do that.

Participants also challenged the misconception that The Villages residents in general, including caregivers, have sufficient funds to be able to cover the high costs of formal care. One participant in particular illustrated this, “We are living on fixed income. Just because we’re living in The Villages doesn’t mean that we have money running out our ears because we don’t.”

**Unmet Needs of Informal Caregivers**

Residents identified the perceived lack of formal care services in their community (e.g., nursing homes, ALFs, adult daycare, home health) and the limited information for caregivers on the services already available to them as a gap in services. Poor access to formal care and information was said to aggravate the challenge of being an informal caregiver.
Villages Lacks Formal Care Providers

Despite the availability of nursing facilities, ALFs, hospice services, and adult daycares available to The Villages residents, participants discussed their perceived lack of services in the community. Participants primarily focused on the limited number of formal establishments that provide formal care to older adults. Focus group participants perceived lack of certified adult daycare facilities and respite services that relieve caregivers and allow them to “take a break.” For example, one participant referred specifically to the need for respite care in The Villages, “Just make sure that there is more respite and not having to go through a hospice to get respite would be really great because they [caregivers] do need breaks.”

Residents often spoke of the great need for home-nurses to alleviate the burden of caregiving. For example, one resident discussed the presence of community support in The Villages but alluded at the need for more formal care assistance, “That kind of support I don’t think is here. We can see Alzheimer support groups, dementia support groups, cancer support groups, but where is that person who can step in and substitute for that?” Many participants feel there is a lack of formal care resources (e.g., nursing homes, assisted living facilities, respite care) available to residents of The Villages.

Due to the lack of formal care reported by focus group participants, many participants discussed the need to seek resources outside of their community. For example, traveling to neighboring counties in search of assisted living facilities (ALFs) or nursing homes was a common theme noted by participants. Participants often discussed the burdens of traveling outside The Villages in search of formal care as time consuming and draining. One respondent shared the experiences of friends, “Three of my friends who lost their husbands needed daycare
so desperately. They spent 40 minutes driving to Ocala twice/three times a week and back to get them and that’s three hours out of her day.”

**Unaware of Caregiving Resources**

Being unaware of resources for caregivers available at *The Villages* was one of the most common themes revealed when participants discussed the lack of formal resources (i.e., hospice, nursing homes, adult daycare, and assisted living). Residents admitted to being aware of formal care resources that cater to informal caregivers in a general sense; yet, were unfamiliar with any similar services provided specifically to informal caregivers residing in *The Villages*. For example,

I remember hearing of services in South Florida that were caregiver - not replacement but caregiver-break kind of services. If you’re being a caregiver for someone, we’ll come in and you can take a day off kind of thing. I don’t know of anything like that available up here.

Other participants talked about the limited number of conventional channels of information—advertisements, printed information, and media involvement—available to help informal caregivers learn about resources such as home-nurses and respite care. Residents also mentioned how limited information on existing resources may alter resident’s perception of the formal care options at *The Villages* and result in a drastic move back home in search for formal care. Additionally, some participants alluded to “word of mouth” as the only source of information regarding available resources. One resident stated,

I think there should be more advertising for what is available. I mean I think when people get to that point, unless they hear word of mouth from somebody, I don’t think
they know where to turn. I think oftentimes I think that’s why they pack up and go back home, because there’s nothing - what are they going to do here?

Available Resources for Informal Caregivers

When discussing resources available to informal caregivers within The Villages, focus group participants focused primarily on friends and neighbors. Participants emphasized the importance of a strong social support system and how informal caregivers can benefit from being part of a community that fosters social cohesion.

Support from Friends and Neighbors

Focus group participants repeatedly discussed the strong sense of community within The Villages as a key resource for informal caregivers. Participants explained that, despite the lack of formal care available, access to a close-knit community provides caregivers informal assistance with meal preparation, transportation, grooming, and adult-sitting. Throughout the focus groups, participants repeatedly referenced that in The Villages community members are willing to combine resources and volunteer their time to help those in need. Residents reported that social support from friends and neighbors is not solely based on instrumental support. According to participants, strong social cohesion fosters strong emotional support that helps reduce the levels of psychological distress experienced by informal caregivers. As one participant explained,

There seems to be a reasonable amount of support, both psychologically and the rest of it, and a reasonable amount of support logistically - again, for churches, friends, neighbors, some other people. So, caregivers take a little care giving as well. It seems to work and
it’s more on the personal side than it is- I see it more on a personal side than in a hired service.

In addition, participants mentioned the occupational diversity of the population and varying prior professional experiences as a unique asset of The Villages as a contributor to social support. Different occupational backgrounds (i.e., healthcare) and work experiences residents possess were considered discussed. For example,

It’s sort of an extension of really what makes The Villages one of the best places in the world to live and that is the community does possess a remarkably deep level of expertise in almost any subject you would care to name, whether it’s health care or anything else. As a consequence of that, you can get help and people here are willing to help you, and it’s very impressive to see. It’s one of the things that really makes this community great.

Although participants expressed that the lack of freedom is a challenge to caregivers, many participants concluded that strong social ties, unique to The Villages, allow caregivers to retain a sense of self. Participants perceived that caregivers greatly benefit from this close-knit community because other residents step in so the caregiver can run errands or simply enjoy some time to relax and release the stress associated with lack of freedom. Residents believe that the strong social support found in The Villages is a valuable informal resource available to caregivers. One participant explained,

The only thing I know of is neighbors. I know that in our area for example, there are some neighbors who have like a caregiver problem and other neighbors will go over and sit with a loved one who needs help and allow the spouse to get out and maybe just do grocery shopping or maybe go to a movie or whatever, but I think we’re so lucky to live here in The Villages because the neighbors I see step up and help out in so many different ways and that’s one thing.
Caregiver Support Groups

Focus group participants also indicated support groups at The Villages serve caregivers by providing an informal system of adult-daycare. These groups usually offer services on site or have residents that volunteer to go to the homes of caregivers to assist with delivering meals. One resident shared her experience with a support group that allows caregivers to have some personal time,

We’re in our church starting a caregiver review program for people with their caregivers for dementia and Alzheimer’s, cancer, post-surgical. Just come in and let the caregiver get a few hours of the week away from the stress. I’ve been sitting three hours a week with a man who has Alzheimer’s, let his wife get away, and another man goes in another day. [Name] feels very welcome and happy that we’re – I’m not sure that she would feel that way or that her husband would feel relaxed with a stranger.

Residents highlighted the importance of support groups as sources of information for caregivers. It was mentioned support groups provide information to caregivers on various topics (e.g., availability of formal care, how to reduce caregiver stress). A participant mentioned the Alzheimer’s support group inside The Villages as an example “It’s the support group for the Alzheimer’s group as there is a support group for any kind of disease you might have and I think that’s probably where you would get information on how you could get relief, etcetera.”

Faith-based establishments and other groups that perform community service were also frequently discussed as reliable sources of aid. Many participants felt that the services provided by these establishments can provide the same level of care as formal sources and help lessen the impact of caregiver burden. For example,

Our church offers – they have two different Alzheimer’s groups; they also offer another meeting in the adjacent room for the caregivers for those who can leave their spouse by themselves, but they also can stay with them if they want.
Table 1. Focus Groups Demographics (N=144)

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*These data were provided by the student for the purposes of this study*
CHAPTER FOUR: DISCUSSION

While the number of informal caregivers providing long-term care has been projected to grow by 85% from 2000 to 2050, this growth is not meeting the demand for elder care (American Association for Retired Persons, 2016; Department of Health and Human Services and Assistant Secretary for Planning and Evaluation, 2003). The Centers for Disease Control and Prevention (2008) have declared caregiving as a public health priority of national concern based on the principles of burden, impact, and potential for prevention. The purpose of this project was to evaluate the residents’ perceptions regarding how living in large retirement community, where social support may be more readily available, would affect caregiver burden. In general, through rigorous qualitative analysis, I found that the residents’ feel strongly about having extra social support purely due to living in a large retirement community. I also found that the residents are not fully aware of the many resources available to them through the retirement community and the challenges they face are consistent with existing literature.

Specifically, the main results of this project were as follows. First, this qualitative investigation provides new insights on how strong social support abates caregiver burden. The Villages is a retirement community that actively fosters social support and social cohesion (Bach, Mortimer, VandeWeerd & Corvin, 2013) and has incorporated these notions into The Villages culture. This finding is consistent with the popular theory of Successful Aging (Rowe & Kahn, 1997) which identified socialization as having a direct positive effect on health, reducing some
of the health-related effects of aging, and most significantly, diminishes the negative effects of stressful life events. Other aspects of Successful Aging, such as avoiding disease and disability and high physical function were demonstrated by the relatively healthy profile of caregivers from the quantitative phase (Phase 2) of this study. The qualitative data highlights the importance of the third construct in Successful Aging, engagement with life. Focus group participants highlighted how strong social ties provide social support (e.g., instrumental, informational, emotional) for caregivers, and thus, is imperative for reducing caregiver burden. These findings suggest that a strong sense of social support could potentially benefit aging caregivers that do not reside in active-living communities.

Although it has been reported that caregivers over the age of 75 are less likely to receive help from friends or relatives (Wagner & Takagi, 2010), focus group participants reported caregivers at *The Villages* rely heavily on friends and neighbors as their primary source of help. Moreover, most participants agreed that social support from friends and neighbors in *The Villages* provides a safety net for caregivers to rely on to help them meet some of their needs, such as limited time to run errands or availability of information for caregivers. Higher levels of emotional support, frequent visits with friends, and network density are all factors that predict an individual’s satisfaction with their social support (Drentea, Clay, Roth, & Mittelman, 2006; Lai & Thomson, 2011). *The Villages* offers numerous opportunities for residents to develop satisfying and meaningful social relationships that can possibly contribute to a decrease in caregiver burden and an overall improvement in QoL. This finding is supported by the “Village” model, which focuses on promoting aging in place through community involvement (Scharlach, Graham, & Lehning, 2012).
Second, our findings suggest that there is a need for improving the delivery of formal care services available in The Villages. Although participants perceived the existing sources of formal care services as not meeting the demand in The Villages or are underutilized, most participants did, however, discuss a general lack of knowledge of the resources available to them. Existing services may be underutilized because no formal information source, specific for caregivers, is available. Many participants shared that they rely on information from friends and neighbors when trying to find resources, but expressed concerns that this information may not be entirely reliable. This finding is important because knowing how to target the aging population and utilizing the right avenues of communication can help to promote the utilization of existing resources (Grier & Bryant, 2005; Omachonu & Einspruch, 2010) such as home health, ALFs, nursing homes, respite, and adult daycares. Furthermore, participants highlighted the dire need for formal care to elders in general, not exclusively at The Villages, as the population grows at an alarming rate. Given the projections for the rapid growth of the aging population (Howden & Meyer, 2010), and potentially an increase in the number of individuals requiring care at home (Wiles, Leibing, Guberman, Reeve & Allen, 2011), it is important to provide caregivers with the most accurate and relevant information to lessen caregiver burden and allow informal caregivers to benefit from community resources that may already be available to them.

Despite all the opportunities for socialization The Villages offers, a third finding highlights the lack of freedom and withdrawal from social activities associated with informal caregiving discussed by participants. Previous research strongly supports how caregiver isolation can predict an increase in caregiver burden (Butler, Turner, Kaye, Ruffin & Downey, 2005; Hayes, Hawthorne, Farhall, O’Hanlon & Harvey, 2015; Phillips, Gallagher, Hunt, Der & Carroll, 2009). Given that The Villages culture depends highly on socialization and activity participation
(Bach, Mortimer, VandeWeerd & Corvin, 2013), isolation due to caregiver burden not only affects the caregivers’ ability to seek help (Tebb & Jivanjee, 2000), but it can possibly exclude them from participating in the highly-valued Villages lifestyle. Residents rely heavily on each other for social support (e.g. emotional, informational) and not being able to interact with friends and neighbors can lead to depression and have a detrimental effect on the caregiver’s overall health.

Lastly, the high cost of formal care is also of great concern to all residents and is, unfortunately, financially out of reach for many. Some participants challenged the notion that all residents of The Villages have sufficient financial means to cover the high cost of caregiving. Resident’s perceptions on the high cost of formal care are supported by existing literature, which highlights the financial challenges informal caregivers face when seeking formal care (Brem et al., 2010; Demaerschalk, Hwang & Leung, 2010; Ho, Collins, Davis & Doty, 2005; Kopecky & Koreshkova, 2014; Wolff et al., 2006).

Implications for Policy and Practice

The following recommendations to reduce caregiver burden are based on three key findings and supported by literature review: 1) healthcare costs are on the rise and informal caregivers face many financial challenges, 2) social support offers unique opportunities for reducing caregiver burden, 3) perceived lack of formal care resources available can aggravate subjective burden. Further, recommendations not only apply to residents of The Villages but can also improve the Aging in Place experience in different communities.
Reducing Healthcare Spending

The average cost of managing chronic conditions in the U.S. for individuals over 65 years old and over is approximately $300 billion per year, with nearly 93% spent to care for individuals with two or more chronic conditions (Bauer, Briss, Goodman & Bowman, 2014). In addition, the cost of hospital readmissions has been estimated to be $17 billion annually and is often linked to caregivers feeling unprepared for the hospital discharge of the care-recipient and unmet informational needs (Weiss, Yakusheva & Bobay, 2011). A powerful way to offset the high cost of healthcare would be to educate informal caregivers on how to adequately care for their loved ones at home and prevent the progression of chronic diseases, falls, unnecessary emergency room visits, and hospital readmissions (Bauer, Briss, Goodman & Bowman, 2014). In addition, developing and implementing evidence based interventions will promote healthy habits and foster social cohesion (Bialon & Coke, 2012). Educating informal caregivers and healthcare providers can not only improve the QoL of caregivers in The Villages, but can also be an economically efficient approach that can have a positive impact in other communities.

As previously stated, caregiver burden affects the quality of care delivered to care-recipients (Greenberger & Litwin, 2003; Smith, Williamson, Miller & Schulz, 2011). However, research has shown that low cost evidence based interventions and health education, designed to equip caregivers with the skills necessary to care for their loved ones, has a positive effect on their capacity to deliver care at home. Other benefits include improvements in the health and QoL of care-recipients with disabilities and reducing caregiver stress (Adams, Khan, Begum, Wirz, Hesketh & Pring, 2012; Arroyo, Goldfarb & Sands, 2012; Hepburn, Lewis, Sherman & Tornatore, 2003; Potter, Olsen, Kuhrik, Kuhrik & Huntley, 2012). Interventions should focus on falls prevention, medication management, pain management, practical skills, coping
mechanisms, and stress management to prepare informal caregivers for the challenges associated with their role and improve the quality of care they deliver (Haley, 2003; Au et al., 2010; Angelo, Egan & Reid, 2013). Additional interventions should also include: proper use and maintenance of medical equipment, such as feeding tubes, cannulas, and colostomy bags; long-term care financial planning; and mental health counseling.

Ideally, interventions should take place in an environment familiar to caregivers through community-clinical partnerships (Bauer, Briss, Goodman & Bowman, 2014; Freid, Bersntein & Bush, 2012; Morris et al., 2012). Interventions should also incorporate theories of health education and behavior change to assure caregivers are not only implementing the suggested strategies but continue to utilize their newly acquired skills to improve the delivery of care (Meyer, Hill, Dow, Synnot & Hill, 2015;). For example, from a clinical stand point, primary physicians could evaluate caregivers using specific guidelines for a comprehensive assessment of overall health status to diagnose signs and symptoms of caregiver burden. (Bastawrous, 2013; D’Amelio et al., 2009; Gort et al., 2007; Vitaliano, Russo, Young, Becker & Maiuro, 1991; Kinsella, Cooper, Picton & Murtagh, 1998; Elmstahl, Malmberg & Annerstedt, 1996). These evaluation tools should be easy to administer and score, to quickly identify caregivers in distress and immediately address caregiver needs. If caregiver stressors are identified, physicians can then work with caregivers to develop a plan of care to reduce caregiver burden.

If the chosen approach by the physician to reduce caregiver burden includes training and evidence based interventions, caregivers would then work with health educators, local support group facilitators, and/or qualified community members that would be responsible for the implementation of appropriate interventions. Health education programs would be designed to address the specific needs of the caregiver, utilize available resources, and be guided by
theoretical frameworks for behavior change for a more powerful intervention (Glanz, Rimer, & Viswanath, 2008). For instance, The Villages could utilize their existing volunteer nurses network to facilitate the interventions or programs for the caregivers. Sessions would be held in the caregiver’s home to remove participation barriers, such as transportation, location (Syed, Gerber & Sharp, 2013; Andrade et al., 2014), and lack of caregiver freedom, as previously identified by focus group participants. This group of volunteer nurses would be ideal, not only because of their practical expertise managing chronic conditions, but also because they are residents of The Villages and can easily relate to the caregivers’ experiences. It is possible that the caregiver-volunteer nurse relationship could increase the perception of social support, that many residents identified as a major resource to reducing caregiver burden within The Villages. Additionally, the volunteer nurses would be able to provide information about relevant existing resources in the community that benefit caregivers. Because of their active involvement in The Villages through volunteerism and as active residents, the volunteer nurses would be a key component in the community-clinical partnership.

Another practical suggestion, that could extend outside The Villages, would be to develop an interactive intervention that mirrors the Train-the-Trainer model. Geriatric research has shown that a dynamic approach in which trained non-expert individuals train healthcare professionals can have a positive effect on office based practices and increase knowledge about topics such as depression in the aging population (Levine et al., 2007). Individuals with a professional background in healthcare can also serve as powerful trainers to educate community members on identifying signs of caregiver burden and provide information on existing local resources that benefit informal caregivers (Fitzgerald et al., 2009). Trained community members can include neighbors, older adults, volunteers, or other individuals that interact frequently with informal
caregivers. Training sessions could be held at churches, schools, public parks, senior centers, food pantries, or even at home. Additionally, training sessions should be sensitive to cultural and linguistic differences to assure the success of the intervention in more diverse populations (Zeh, Sandhu, Cannaby & Sturt, 2012). The Train-the-Trainer model could help guide the development of the community-clinical partnership, as it has been shown that train the trainer interventions have positive outcomes in healthcare settings, as well as community settings, when dealing with adults with disabilities (Marks, Sisirak & Chang, 2013).

Financial burden has been identified as a major source of stress for informal caregivers and extends beyond formal care, which is estimated at $158 billion (Arno, 2006; Northouse, Williams, Given & McCorkle, 2012; Kusano et al., 2011). While the “invisible” force of informal care can be cost-effective in comparison to nursing home care (Marek, Stetzer, Adams, Popejoy & Rantz, 2012) dismissing the negative effects of caregiver burden, such as poor health, could result in an increase in healthcare spending. Caregivers unable to continue to provide care, as a result of declining health due to caregiver burden, would then face a new challenge: covering their own healthcare costs while simultaneously being financially responsible for the care of their loved one. To prevent declines in health status associated with caregiver burden insurance companies could develop affordable and comprehensive health plans exclusively for informal caregivers. These health plans should expand covered benefits (e.g., physician visits, medications, therapies, mental health). Additionally, care-recipients opting for a more cost effective approach to their care (i.e., informal care) should be entitled to financial assistance for covering items such as incontinence supplies, that can amount to an average of $1825 per year (Ward-Smith, 2009) and medical supplies.
Developing Community Connectedness

The unique environment of *The Villages*, one that revolves around creating opportunities for social interactions, serves as an ideal environment that not only fosters healthy aging, but also nurtures a supportive environment for informal caregivers. Fostering an environment that allows aging caregivers to receive emotional, instrumental, and informational support can serve as an effective tool to reduce caregiver burden. Communities seeking to reduce caregiver burden should be to provide opportunities for meaningful community engagement and socialization at central locations (e.g., faith based establishments, senior or recreation centers, farmers’ markets, public parks) that promote community development. For example, activities could include exercise classes, community gardening, art classes, coffee time, dances, potlucks, pet clubs, support groups etc. As in *The Villages*, the many opportunities for social interaction (Bach, Mortimer, VandeWeerd & Corvin, 2013) has contributed to the perceived high levels of social support and social cohesion. It is possible that by engaging in leisure activities informal caregivers in other communities outside of *The Villages* could see an increase in social capital and diminished caregiver burden (Findlay-King, Nichols, Forbes & Macfadyen, 2017; Graham & Glover, 2014; Hirano et al., 2011; Losada et al., 2010; Karimian, Hosseini, Shekarchizadeh & Nafchi, 2015).

In addition, caregivers should have the option to contribute to the design of local caregiver support groups to address the unique needs of their community thus creating a social space that caters to caregiver needs. Support groups should also focus on developing grassroots advocacy as a powerful strategy to influence policy change. Informal caregivers and community members would be encouraged to organize and mobilize the public to advocate for policy reform that would help reduce caregiver burden (Hall, 2010; Kimberlin, 2010). For example, social
media would be a powerful tool for advocacy, as older adults continue to increase their online presence (Guo & Saxton, 2014; Langton, Bush, Stacy, Howard & Schaffter, 2015; Mashayekhi & Head, 2015) and can be used to engage informal caregivers that are disenfranchised and isolated due to the demanding nature of their role.

**Raising Awareness of Existing Community Resources**

One avenue to increase awareness and utilization of local resources for informal caregivers (e.g., home healthcare, medical supplies providers) would be to organize a vendor fair. This vendor fair could be held at central community locations, to allow service providers in the community to interact face-to-face with informal caregivers to promote services offered. Vendors would include alternatives to formal care establishments that support aging in place, such as home health agencies, meal delivery services, mobile physicians, adult daycares, housekeeping services, mental health counseling, medical supplies distributors, and legal assistance. Vendors interested in attending would pay a small fee, in exchange for free advertisement at the fair, to cover the costs of organizing the event. Funds would then be used to provide incentives for caregivers to attend; such as adult daycare at the event, free lunch, transportation, raffles, etc.

Additionally, the fair should focus around caregivers, and be advertised as such, in a way that would highlight the importance of informal care and recognize informal caregivers as a powerful force in our healthcare system (Reinhard, Feinberg, Choula & Houser, 2015). The fair would also educate attendees on caregiver burden and how to mitigate its effects and empower informal caregivers, allowing caregivers to feel confident and competent in their caregiving abilities (Angelo, Egan & Reid, 2013; Man, 1998; Nomura et al., 2009; Overcash & Balducci, 2003) and informal caregivers to network with one another.
Implications and Future Research

Future research needs to focus on the perceptions, needs, and experiences of informal caregivers through a mixed methods approach. Stratified focus groups with caregivers and qualitative analysis need to be paired with quantitative analysis to assess the QoL of older caregivers. For example, we need a better understanding on how social environments influence health assessed through psychometric testing and consistent processes for data collection (Schaefer-McDaniel, Dunn, Minian, & Katz, 2010). Quantitative data to measure the degree of caregiver burden and the health status of informal caregivers (e.g., BMI, number of comorbidities, nutrition scores) paired with qualitative research to explore the subjective experiences of caregivers can be used to identify a more direct link between the positive aspects of social support, participation in active living environments, and reducing caregiver burden.

Researchers interested in further exploring the dynamics of informal care in aging populations through qualitative research should employ rigorous methods to disseminate results that are valid and reliable (Anderson, 2010). Purposive sampling should be conducted and the following inclusion criteria should be used for focus group stratification: 1) caregiver status to identify themes that are relevant to the informal caregiver population, 2) caregiver health status to identify positive and negative aspects of caregiving, and 3) caregiver age to explore how different aging cohorts describe the caregiving experience and the unique challenges they face. In addition, to make sure discussions are in depth and participants are given the opportunity to clearly share their opinions and experiences, structured discussions should center primarily on the caregiving experience and avoid non-relevant topics. Theoretical and conceptual frameworks could also serve as a guide for the development of focus group guides. For example, the Transactional Model of Stress and Coping could be used to develop questions related to

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caregiver burden. This model focuses on the appraisal of stressors and how psychological, social, and cultural resources can help a person cope with stressful situations (Glanz, Rimer & Viswanath, 2008). Additionally, findings can improve the resources available to reduce caregiver burden and reinforce positive behaviors for a better caregiver experience.

There are several key aging populations that need more attention from researchers and policy makers to create meaningful and relevant care practices. For example, future research needs to harness the unique opportunity to study the Baby Boomers, a rapidly growing cohort of aging adults. As Baby Boomers enter retirement, with health profiles that differ greatly from other generations (Cavanaugh & Blanchard-Fields, 2010), different policies that support informal care may need to be tailored to the specific needs of this population (Rocco, 2017). Research specific to the Baby Boomer cohort is needed to identify not only their health needs, but also their health perceptions to create cost effective care paradigms. Active-living communities and other retirement facilities allow for a convenient sample of Baby Boomers, these environments are full of rich data that could potentially lead to breakthrough findings in efforts to improve the QoL of all Baby Boomers across the nation. Another aging population that needs more attentions from researchers is the oldest-old (adults over the age of 85) who differ significantly from other aging groups. The needs of the oldest-old differ greatly from younger counterparts. For instance, they are not only more likely to suffer from multiple health problems but also more likely to live near or under the poverty line (Hooyman & Kiyak, 2008).
Limitations

It is unknown to what extent these findings are applicable to older adults beyond The Villages, given the predominantly White population. However, the sample of older adults represented in this study provides unique insights into the lives of seniors that serve as informal caregivers residing in the ever-growing number of active retirement communities (Glass & Skinner, 2013). It remains to be seen how these findings would translate into a more culturally and racially diverse population. For example, Hispanics are expected to make up 20% of the total number of older Americans by the year 2050 (Papademetriou & Terrazas, 2009). It is possible that a more diverse population of informal caregivers might experience caregiver burden more closely linked to racial/ethnic health disparities rather than caregiver demands and consider racial discrimination an added stressor. Further, strategies to reduce caregiver burden might require a different approach when dealing with minorities in active retirement communities, as minorities are more likely to already have a stronger built-in social support in comparison to Whites (Michael & Yen, 2014) and report experiencing more discrimination in more advantaged neighborhoods (Dailey, Kasl, Holford, Lewis & Jones, 2010).

Another limitation unique to this paper was the inclusion criteria for focus group participation. Although caregivers and non-caregivers were not identified in the focus groups for stratification purposes, the strong social ties between friends and neighbors enabled participants to share the lived experiences of those in their community, and in some instances, space to share their own personal accounts of the caregiving experience. In the future, studies should stratify by caregiver status, health status, age, and gender, and, if using a mixed methods approach, degree of caregiver burden.
Additionally, the notion that limited formal care resources exist at The Villages should be considered with caution as home health, ALFs, nursing facilities, and adult daycares are available to residents.

Conclusion

The dramatic demographic change taking place in the U.S. calls for an immediate understanding of the aging population and its health needs. As the high prevalence of multimorbidity in older adults increases with age, so does the level of care required to manage health conditions. Since most older adults in need of care and assistance with activities of daily living rely heavily on informal caregivers, future research should focus on obtaining a better understanding of caregiver burden and positive aspects of caregiving, particularly in retirement communities, and the resources that can diminish the negative consequences of caregiving. Identifying challenges faced by aging caregivers and resources available, not only improves the QoL of informal caregivers, but also the quality of care they deliver to the care-recipients. Aging caregivers residing in existing or future active retirement communities can benefit from a setting that resembles the environment of The Villages, as the resources accessible to Villagers (i.e., social support) are, potentially, a tremendous asset to reduce caregiver burden. Strengthened social ties can prove beneficial as a major source of support to help older caregivers cope with the challenges they face. In addition, addressing informal care as a valuable resource can not only lead to cost-effective policy changes but also improve the QoL of informal caregivers and older adults.
REFERENCES


Bakken, N., Banovitz, L., Lafrenz, A., & Li, K. (2015). For low-income adults who experience trouble with one or more activities of daily living (ADL) or two or more instrumental activities of daily living (IADL), does the Community Aging in Place: Advancing Better Living for Elders (CAPABLE) improve performance of ADLs and IADLs?.


Glass, A. P., & Skinner, J. (2013). Retirement Communities: We Know What They Are… or Do We?. *Journal of Housing For the Elderly, 27*(1-2), 61-88.


Mashayekhi, M., & Head, M. (2015). Understanding the Role of Social Media in Health Attitude Change among Older Adults.


APPENDICES
Appendix A: Participant Screener Form

USF Health in The Villages is collecting information on what health and healthy aging mean to residents of The Villages. Completing this form will help us to begin to get to know the residents of the Villages community better so that we can think about ways in which USF Health can partner with the Villages community in the future. Our goal is to help ensure that the quality of life in The Villages remains high for all of its residents.

Additionally, in the future, USF Health may have opportunities for seniors in The Villages to become involved in research studies. If you would be interested in sharing the information you have provided below with members of USF Health Research teams for the purpose of being contacted by members of USF Health at a later date about these studies (this does not in any way oblige you to participate) please provide us with your contact information at the end of this form.

1. What is your gender? Please circle: Male Female

2. What was your age at your last birthday? ________________

3. How long have you lived in The Villages? _______ years _______ months

4. Do you live in The Villages (please circle): Year-round Seasonally

5. Current Relationship Status? Please circle:
   Married  Widow/Widower  Divorced  Never married
   Living with someone

6. Highest grade completed? Please circle:
   K-12   High School graduate   Some college
   Associate/Technical degree   Bachelors degree
   Some graduate school   Graduate/Professional degree

7. What was your primary employment or profession prior to moving to The Villages? ________________________________
8. Are you currently working? Please circle:
   Yes, full-time      Yes, part-time      No

9. Why did you move to The Villages? (Please circle all that apply)
   Weather
   Lower taxes
   Other:__________________________
   To be closer to family/friends
   Activities (golf, swimming, clubs, etc.)

10. Please tell us which, if any, Villages clubs, teams, support groups or interest
groups you currently belong to:
   ________________________________
   ________________________________

11. Would you say that in general your health is _____? Please circle:
    Excellent      Very Good      Good      Fair      Poor

12. What would you say is your most important health concern?
   ________________________________

13. What is your most important lifestyle concern?
   ________________________________

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Would you be interested in participating in a focus group or other research in the next 3
months as part of the USF Health in The Villages Health Study? Please circle:
YES      NO      NEED MORE INFORMATION

Would you be willing to be contacted about participating in future studies by members of
the USF Health Research Team? Please circle:
YES      NO      NEED MORE INFORMATION

CONTACT INFORMATION: (Name, Village, Mailing Address, Email, Phone Number):
Appendix B: Focus Group Interview Questions

Caregiving was also identified in the focus groups and surveys as a present or future concern for many residents of The Villages.

- Presently, do you think The Villages is well prepared to assist older residents who may also be caregivers? Why or why not?
- What current caregiving supports presently exist in The Villages?
- How are people presently coping with caregiving responsibilities?
- Are existing nursing home/assisted living facilities in the area adequate/satisfactory? Why or why not?
- What suggestions do you have for how caregiving services can be improved?
- Overall, how satisfied are you with your caregiving experience in The Villages?
- What aspects of caregiving do you find most challenging?
Appendix C: IRB Approval Letter

9/30/2011

Arthur Williams, Ph.D.
Health Policy and Management
13201 Bruce B. Downs Blvd, MDC56
College of Public Health, USF

RE: Expedited Approval for Initial Review
IRB#: Pro00005610
Title: Health Inventory in The Villages Community

Dear Dr. Williams:

On 9/29/2011 the Institutional Review Board (IRB) reviewed and APPROVED the above referenced protocol. Please note that your approval for this study will expire on 9/29/2012.

Approved Items:
Protocol Document(s):
Study Protocol

Consent/Assent Documents:
Villages Study Informed Consent.pdf

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110 and 21 CFR 56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.
Please note, the informed consent/assent documents are valid during the period indicated by the official, IRB-Approval stamp located on the form. Valid consent must be documented on a copy of the most recently IRB-approved consent form.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval by an amendment.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,

John A. Schinka, Ph.D., Chairperson
USF Institutional Review Board

Cc: Christina Calandro
    USF IRB Professional Staff
Activity Details (IRB Letter Sent to Study Team)  The Committee Chair sends the disposition letter to the study team

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