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# Women's Work? Gender Differences Among High Need Caregivers

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CAREGIVERS

Women's Work? Gender Differences Among High Need Caregivers

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### Abstract

**Background.** A growing body of research suggests female informal caregivers fair worse physically, socially and emotionally than males. As the prevalence of male caregivers is increasing there is a critical need to understand why some caregivers fair worse than others.

**Aim.** The purpose of this study is to determine what gender and relational differences exist among service-seeking informal caregivers.

**Methods.** This is a retrospective, cross sectional study of 467 caregivers utilizing the Family Caregiver Alliance (FCA) or the University of Southern California Family Caregiver Support Center (USC FCSC) services between January 2017 and March 2018.

**Results.** Twenty percent of caregivers were male. No gender differences were observed in the amount and caregiving tasks provided. More females reported severe levels of burden ( $p=0.013$ ), and we saw no differences in physical health and social connectedness. Compared to adult children, spouses provided higher amounts of care and no differences in burden, physical health, and social connectedness were found.

**Discussion.** Few gender differences were observed, however this sample differed from national estimates. In our sample (versus national estimates) there were half as many males (20% vs. 40%) , caregivers were more likely to provide over 40 hours of care per week (60% vs. 25%) and assist with more activities of daily living (4 vs. 1). Despite these differences, we found caregivers reporting high burden was comparable to national estimates (44% vs. 40%). Our findings suggest service-seeking informal caregivers are performing more intensive caregiving. More research should be done to understand their specific needs.

## **Executive Summary**

### **Background**

Informal caregivers provide unpaid care to a relative or friend with a chronic condition, cognitive disorder or disability. As the population ages, the prevalence of chronic conditions is rising among adults in the United States, resulting in an increased demand for informal caregivers.

While the “typical” informal caregiver is described as a 49-year-old, white female, an increasing number of men may be taking on this role. Female caregivers have typically done worse physically, socially and emotionally, than men, however more recent evidence suggest other factors including the relationship to the care recipient may also be important. Understanding the amount, type of caregiver tasks, care recipient characteristics, and outcomes of caregivers will inform the evolving role of gender in informal caregiving.

### **Project Goals**

In 2016, the Family Caregiver Alliance (FCA) and University of Southern California Family Caregiver Resource Center (USC FCSC) launched CareJourney, an online platform that tailors information, services and resources for informal caregivers. To begin to understand the informal caregiving users of CareJourney, we examined differences in caregiving by gender and relationship to care receiver. Understanding these differences will help improve and tailor agency offerings.

### **Methods**

Data collected from 467 informal caregivers who utilized the CareJourney platform between January 2017 and March 2018 was analyzed in this study. To

understand potential caregiver differences by gender and relationship we examined the amount of care informal caregivers were providing, the type of activities informal caregivers were assisting with, characteristics of the care recipients, caregiver burden, physical health and social-connectedness.

## **Results**

Twenty percent of informal caregivers were male. Male and female caregivers were performing the same amount of care and assisting with equal numbers of activities of daily living and instrumental activities of daily living. Interestingly females were providing care to care recipients with difficult behaviors and behaviors related to memory problems more than male caregivers. More females reported severe levels of burden ( $p=0.013$ ), and we saw no differences in physical health and social connectedness. Notably, 54% of informal caregivers in this study were adult children. Thirty five percent of female caregivers and 40% of male caregivers are caring for a spouse, while 55% of female caregivers and 50% of male caregivers are providing care to a parent. Among females, 75% of spouses compared to 48% of adult children were providing 40 or more hours of care per week ( $p=0.001$ ). The same relational trends in the number of hours of care per week were observed in males, but no statistical significance was seen. No differences were observed in reported burden, physical health outcomes, and social-connectedness by relationship.

## **Discussion**

While there were few differences by gender, we did observe differences between this sample of informal caregivers seeking services from FCA or FCSC when compared to a national sample of caregivers. In our sample (versus national estimates) there were

half as many males (20% vs. 40%)m caregivers were more likely to provide over 40 hours of care per week (60% vs. 25%) and assist with more activities of daily living (4 vs. 1). Despite these differences, we found caregivers reporting high burden was comparable to national estimates (44% vs. 40%). These findings suggest that service-seeking informal caregivers are performing more intensive caregiving. Furthermore, it reveals that fewer male caregivers may be seeking services. Future research is needed to understand the specific needs of this population with a focus as to why this sample of informal caregivers is seeking services and what types of services they are seeking.

The literature has previously reported that adult children are more likely to identify as informal caregiver compared to spouses helping to explain why 54% (n=248) and 36% (n=168) of informal caregivers in this sample were adult children and spouses respectively. Caregiving studies have shown that higher hour caregiving and living with the care recipient have been associated in increased levels of burden. In this study we saw that spouses were providing more hours of care and were more likely to live with the care recipient. We did not see any differences in burden, physical health and social connectedness by relationship to the care recipient. This suggests that spouses may be more resilient to the demands of caregiving compared to adult children and further explain why we see a larger number of adult children in a service-seeking caregiver population.

## **Literature Review**

### **Informal Caregiving in the United States**

Approximately 44 million adults provide informal care in the United Sates (National Alliance for Caregiving, 2015). An informal caregiver is an unpaid relative or

friend providing long-term care for someone with a cognitive impairment, chronic condition, or disability (National Alliance for Caregiving, 2015). Informal caregivers provide approximately 90% of long-term care in the United States playing a critical role in the United States health care system (Centers for Disease Control and Prevention, 2011). As the United States population ages, there will be an increased need for in home care for the elderly.

**Economics of informal caregiving.** In 1997, informal caregiving was valued at \$196 billion dollars and 18% of national healthcare expenditures (Navaie-Waliser et al., 2002; Arno, Levine & Memmott, 1999). Recently, the aging baby boomer population has increased the value of informal caregiving to \$522 billion dollars, more than double the 1997 cost (Chari et al., 2014). The economic value of informal caregiving alone calls for greater support of this population.

**Caregiver burden.** Informal caregiving can be a positive and rewarding experience for both the caregiver and care receiver, however many caregivers suffer enormously, sacrificing their own well-being for their loved one. It has been reported that informal caregivers are less likely to be employed and are more likely to lack health insurance making them vulnerable to financial strain (Ho, Collins, Davis & Dotty, 2005). To better understand this population researchers often evaluate caregiver burden. Caregiver burden is defined as, “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning,” (Adelman et al., 2014). As the population ages and chronic disease becomes more prevalent, caregiver burden is increasing and formal support services and resources are needed to meet the needs of informal caregivers (Adelman, 2014).

**Who are the Informal Caregivers?**

The literature describes the “typical” caregiver in the United States as a 49-year-old white female (National Alliance for Caregiving, 2015). Women have been the predominant providers of informal care across the world and today roughly 60% of informal caregivers are female and 40% are males in the United States (National Alliance for Caregiving, 2015; Sharma, Chakrabart, & Grover, 2016). National surveys including those facilitated by the National Alliance for Caregiving, the AARP and the US Bureau of Labor Statistics report a broad age distribution with one third under the age of 50, 40% between 50-65 and more than a quarter above the age of 65 (Reinhard, Levine, & Samis, 2012).

National surveys report that 73% of informal caregivers are white, yet more recent data suggests that the aging population will lead to diversification (Reinhard et al., 2012). Very little research has been conducted on minority caregivers, but it is know that minorities are less likely to self-identify as a caregiver and therefore it has been difficult to account for minority informal caregivers in national caregiving surveys (Reinhard et al, 2012). Additionally, sampling methods have relied on the use of phone and Internet access that may prevent national studies from reaching minority caregiving populations.

**Caregiver Activities**

The role of an informal caregiver is often a multifaceted commitment. On average, informal caregivers provide care to an individual for 34 hours a week for six years (National Alliance for Caregiving, 2015). Informal caregiver tasks generally include assisting with activities of daily living, managing finances, and communicating and coordinating care with health professionals. Caregivers are responsible for an



increasing number of medical and nursing tasks and 39% report they have not been trained and feel unprepared to perform their caregiving duties (Scharlach, 2003). A national survey revealed that one in five caregivers who assist with medication management have never received any information from a health care professional about the administration of the medication and one in three caregivers assisting with changing dressings or bandages had not been trained to do so (US Committee on the Future Health Care Workforce for Older Americans, 2008).

The complexity of tasks performed by informal caregivers can lead to negative consequences for caregivers including heightened psychological, social, and physical health problems (National Alliance of Caregiving, 2015). Negative health outcomes among caregivers have been correlated with inadequate care, increased health costs, a higher risk for elder abuse, and a decrease in quality of life for both the caregiver and care recipient (Scharlach, 2003).

### **Caregiver Outcomes**

The complexity of care provided by informal caregivers heightens stress and burden making caregivers vulnerable to poor physical, social and emotional outcomes. Consistent reporting of poor psychical and psychological health outcomes among informal caregivers has directed attention to the issue and caregiving has become a public health priority in the United States. Caregivers often put a loved ones care before themselves and it is commonly reported that caregivers experience higher levels of depressive symptoms and mental health conditions compared to those who are not caregivers (National Alliance for Caregiving, 2015).

Caregiving has also been shown to have adverse effects on caregiver's physical health. Twenty-two percent of caregivers report that their health has declined as a result of their caregiving duties (Reinhard et al., 2012). This may be a result due to the lack of preventative care sought out by informal caregivers and the fact that more than half of caregivers report missing doctor's appointments for themselves (National Alliance for Caregiving & Evercare, 2006). Stress, financial strain, lack of social support, and preventative care results in adverse health outcomes for informal caregivers (Reinhard et al., 2012). The adverse outcomes of informal caregiving and the critical role informal caregivers play in the United States long-term care call for increased and improved support for this population.

### **Caregiver Resources, Services and Interventions**

**Evidence based practices.** In response to informal caregivers poor physical, emotional and social outcomes there has been extensive research on interventional approaches. Psycho-educational interventions, emphasizing information and counseling are the most common (Reinhard, Given, Huhtala, & Bemis, 2008). A psycho-educational caregiver cancer program educated caregivers on symptom management, coordination of services, resource support and emotional support including coping mechanisms for dealing with difficult patient behaviors (Kozachik et al., 2001). Results from this study indicated increased self-efficacy among the participating caregivers (Kozachik et al., 2001). Other evidence-based practices include: supportive interventions, respite and adult day care, interventions to improve care receiver competence, and multicomponent interventions (Pinquart, Sorenson, & Duberstein, 2002). Interventions targeted at an individual level are more successful at improving the caregiver's well being, while group

interventions were more successful at improving the care receiver condition (Pinquart et al., 2002). Caregiver interventions have been shown to have a small to moderate effect on caregiver outcomes and psycho-educational programs have proved to be the most successful intervention targeting caregiver (Pinquart et al., 2002).

**Caregiver assessments.** In order to direct caregivers to appropriate services a caregiver assessment, the collection of information about a caregivers specific needs for the well-being of the care recipient and themselves, should be performed (Feinberg, 2012). Using information collected in the caregiver assessment also provides an opportunity to better inform interventionists and clinicians and improve programs and other services available to informal caregivers.

**Technology.** Technology provides increasing opportunities to support informal caregivers. Not only is it cost-effective, it also reaches caregivers who do not feel they have the time to participate in programs that require them to travel and find alternate care for their care recipient (Schulz & Eden, 2016). Informal caregivers living in rural areas have fewer local services available to them and their caregiving duties prevent them from traveling long distances to seek additional services. Online educational and counseling programs have the potential to fill this gap. Despite these advantages, there still remains a digital divide in the United States and technological services and online resources may not be accessible to the caregivers who need them most. Individuals in lower socioeconomic classes are less likely to have access to Internet and more vulnerable to adverse effects of caregiving.

### **Gender Differences Among Informal Caregivers**

Gender norms have portrayed caregiving as “women’s work” (Pinquart & Sorenson, 2006). In the past decades shifts in gender norms have resulted in an increased prevalence of male informal caregivers (Sharma et al., 2016). Caregiving role differences by gender have often been described by traditional gender roles. Male caregivers are described as taking a “project management” or task oriented approach to caregiving while women take an emotional-coping approach (Pinquart & Sorenson, 2006). While male caregivers have typically assisted with managing finances and household tasks, their responsibilities are expanding (Pinquart & Sorenson, 2006). A recent report indicated that on average male caregivers are reported to assist with 1.7 activities of daily living and more than 50% are performing medical tasks in the home (Accius, 2017).

The literature has reported contradicting findings on whether gender differences exist in caregiver stressors, social resources, psychological health and physical health (Pinquart & Sorenson, 2006). There is evidence that women report greater levels of burden than men, however a recent report indicates that 62% of male caregivers found caregiving to be moderate to severely stressful role and 46% experienced moderate to severe physical strain (Bedard, Kuzik, Chambers, Molloy, Dubois, & Lever, 2005; Accius, 2017). Untangling gender differences among informal caregivers is challenging due to the heterogeneity of caregivers and their caregiving experiences. A thorough understanding of both the caregiver and care recipients characteristics can better help understand what gender difference exist (Bedard et al., 2005).

Differences in the caregiver-care recipient gender interaction have provided further insight into gender differences among informal caregivers. Bedard et al. (2005) found that there is a higher prevalence of severe problem behaviors among male care

receivers and that female caregivers had more difficulties handling severe problem behaviors compared to male caregivers. The author's attribute these findings to females feeling concerned about their safety and their ability to control the disruptive behavior (Bedard et al, 2005). These findings suggest that interventions targeted at improving knowledge and coping skills for female caregivers may be important.

### **Relationship Differences in Caregiving**

Eight-five percent of informal caregivers are providing care to a relative (National Alliance of Caregiving, 2015). In the United States spouses are the first in line to assume a caregiving role (Pinquart & Sorenson, 2011). When a spouse is not present to provide care, an adult child is typically next in line. Forty-one percent of caregivers are reported to be providing care to a parent or parent-in-law and 38% are providing care to a spouse (Pinquart & Sorenson, 2011).

Spousal caregivers are more likely to live with the care recipient and provide higher hours of care compared to adult children (Neal, Ingersoll-Dayton, Starrels, 1997). Despite this, little to no differences have been observed in psychological distress between spouses and adult children (Pinquart & Sorenson, 2011). Furthermore, little to no differences in spouses and adult children physical health have been reported (Pinquart & Sorenson, 2011). Research looking at physical health has accounted for age differences between spouses and adult children and researchers believe that differences in physical health are not observed because older adult spouses who are not in good physical health are forced to give up their role as a caregiver (Pinquart & Sorenson, 2011). This suggests negatives consequences of caregiving are driven by the needs of the care recipient rather than the caregiver's relationship to the care recipient (Pinquart & Sorenson, 2011).

There is limited research that looks at both the caregiver gender and relationship simultaneously (Neal et al., 1997). Pinqart & Sorenson (2011) argue that the needs of the care recipient drive caregivers outcomes. This provides insight that gender differences may not exist among informal caregivers. This hypothesis calls for further research on gender differences among informal caregivers that focuses on the needs of the care recipient. However, understanding the full spectrum of informal caregiving will clarify whether gender differences significantly impact caregiver outcomes.

### **Agency Profile**

#### **Family Caregiver Alliance**

The Family Caregiver Alliance (FCA) is a non-profit organization dedicated to improving informal caregivers quality of life. The FCA was created in response to the experienced and observed emotional, social and physical burden faced as a result of providing long-term care in the home. In the late 1970's, a small task force of families, community leaders, and policy makers came together to establish a formal support system for informal caregivers caring for someone with a cognitive disorder. This led to the establishment of the FCA in 1977.

The FCA is one of the first non-profits in the country to address the needs of informal caregivers. The mission of the FCA is, "To improve the quality of life for caregivers and those they care for through information, services, and advocacy," (Family Caregiver Alliance, n.d.). The FCA carries out their mission with the values of: respect, options, quality, innovation, diversity, collaboration, and efficiency (Family Caregiver Alliance, n.d.). While the FCA was established to support informal caregivers who were providing

care to someone with a cognitive disorder, the organization has grown to support any informal caregiver in need of services and support.

The FCA is housed in the heart of San Francisco allowing the FCA staff to be within hands reach of the many diverse communities throughout the San Francisco Bay Area. The success of the organization and improvements in providing support to informal caregivers stems from the vast network of diverse professionals and community members the FCA has established over the past four decades.

The FCA provides caregiver services, but is also a leader in advancing policy and research on informal caregiving. These efforts are housed under four programs within the FCA: CareJourney, Family Care Navigator, National Center on Caregiving and the Bay Area Caregiver Resource Center. CareJourney is an online platform that provides information, resources and support for caregivers. The Family Care Navigator is a state-by-state service aiding caregivers in finding local support services. The National Center on Caregiving was established under the FCA in 2001 to conduct research to better inform policy makers throughout the country. Finally, the Bay Area Caregiver Resource Center provides low cost, family consultation services to the greater San Francisco Bay Area. Family consultants perform a comprehensive caregiver assessment to better understand an individual's situation and best provide them with appropriate resources, education and counseling.

The work of the FCA is made possible by government and private foundation funding. The FCA receives government funding through the Area Agencies on Aging (AAA), and the Department of Health Care Services (DHCS). AAA was established under the Older American Act of 1973 to provide federal funding that flows down to the

community level to support vulnerable adults over the age of 60 (US Department of Health and Human Services, 2017). The California DHCS provides state funding to support the efforts of the FCA. Finally, the Dignity Fund granted the FCA with a 1.25 million award to fund respite care for informal caregivers in San Francisco for 2018 to 2020. This is an example of how the funding received by the FCA goes directly back to the communities and supports the mission of the FCA.

### **Problem Statement**

The FCA launched the CareJourney platform in September 2016 to make services and resources accessible to informal caregivers online. Understanding more about the users of the CareJourney platform, can help the FCA target referrals, services, and outreach efforts. Specifically examining the differences related to caregiver's gender and relationship to the care receiver will also help update our conception of this population.

### **Methods**

#### **Research Questions and Aims**

This study aims to understand what differences exist by caregiver gender and the caregiver's relationship to the care recipient. Specifically, we examined differences among four critical components that make-up informal caregivers experience: the amount of caregiving provided, the tasks and activities the caregiver is performing, characteristics of the care recipient, and self-reported physical, emotional and social outcomes.

#### **Source of Data**

This analysis used data collected through the CareJourney platform at the FCA and the USC FCSC. As part of a collaboration with the FCA, the USC FCSC launched



the CareJourney platform is

Los Angeles County in

parallel with the launch of

CareJourney in the Greater

San Francisco Bay Area.

The CareJourney

platform is a personalized

online, interactive resource

and information center for

informal caregivers. An intake

and assessment evaluation is

completed with a family care

consultant in person or over

the phone or the caregiver may choose to self-administer the evaluations online. Data

collected from the intake and assessment evaluations was analyzed in this study. Data

was de-identified to protect participant confidentiality. This study was reviewed by the

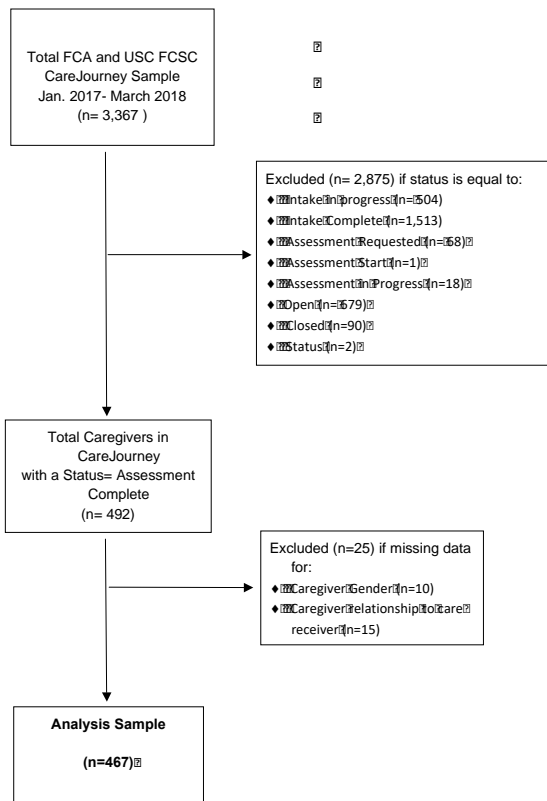
Institutional Review Board for the Protection of Human Subjects at the University of San

Francisco and was deemed as exempt.

**Sample**

This study used data captured between January 2017 and March 2018. The sample consists of adult (aged ≥18) informal caregivers who are seeking services and resources provided by FCA or USC FCSC. A total of 3,367 caregivers utilized CareJourney use between January 2017 and March 2018. Found hundred and ninety-two

Figure 1: Sample Selection



of the 3,367 users completed the intake and assessment (Figure 1). Twenty-five (5.1%) of the 492 caregivers that completed the assessment were missing data for gender and relationship to the care receiver and thus were removed from the study sample (Figure 1). Only the 467 users who completed the intake and assessment evaluation and reported their gender and relationship to the care recipient were included in this analysis.

### **Measures and Variables**

**Demographics.** Caregiver characteristics included age, ethnicity, race, relationship status, employment status, and education level, and relationship to the care receiver. Care receiver characteristics included age and gender.

**Amount of caregiving and help received.** To examine whether there are gender and relationship differences in the amount of caregiving provided the following variables were examined: whether the caregiver is the primary caregiver, whether the caregiver is living with the care receiver, and the average number of hours of care provided per week. Whether the caregiver was the primary caregiving and living with the care receiver were analyzed as part of understanding the amount of caregiving because it is assumed that primary caregivers and those living with the care recipient are higher-hour caregivers.

**Caregiving tasks.** An index of activities of daily living (ADL's) and instrumental activities of daily living (iADL's) were used to assess what types of tasks caregivers perform (see Appendix A). A sum of the total number ADL's and iADL's ("total function") that the caregiver needs assistance with were calculated.

**Care recipient characteristics.** We looked at whether the care recipient had a memory problem (binary variable) and reported problem behaviors associated with having a memory problem. Problem behaviors examined were: asking the same question

over and over, trouble remembering recent events, trouble remembering significant events, losing things, forgetting what day it is, not completing tasks, difficulty concentrating, destroying property, exhibiting embarrassing behavior, waking at night, talking loudly, engaging in harmful behavior, threatening others, verbal aggression, and irritability.

**Self-reported health outcomes.** To address whether there are differences in the consequences of caregiving by gender and relationship, caregiver self-reported outcomes were examined. Physical health was measured by asking CareJourney users to indicate their physical health to be excellent, good, fair or poor as well as indicate whether their health was better, about the same or worse than 6 months ago. This measure does not account for whether or not a caregiver was providing care 6 months ago.

***Lubben Social Network Scale- 6 (LSNS-6).*** The LSNS-6 measure is a self-report measure of social isolation (Lubben et al., 2006) (Appendix B). The self-reported measure consists of six questions about the number of family members and friends the caregiver sees, talks to, and feels close to. Each question has a response ranging from 0-5. The total scale score is an equally weighted sum of the six items, with scores ranging from 0 to 30 (Lubben et al., 2006). Individuals with a score of less than 12 are identified as socially isolated (Lubben et al., 2006). The clinical cut-point for the LSNS-6 has been validated within the literature (Lubben et al, 2006).

***Zarit Burden Interview: Screening Version.*** The Zarit Burden Interview measures caregiver burden and the screening version has been shown to have similar results to the full version (Bedard et al, 2001) (see Appendix C). The screening versions includes 4 questions and all questions are answered as "never" (0), "rarely" (1),

"sometimes" (2), "quite frequently" (3), or "nearly always" (4) (Bedard et al, 2001). The total scale score is an equally weighted sum of the six items, with scores ranging from 0 to 16 (Bedard et al, 2001). The scores indication of burden level can be found in Appendix C.

### **Statistical Methods**

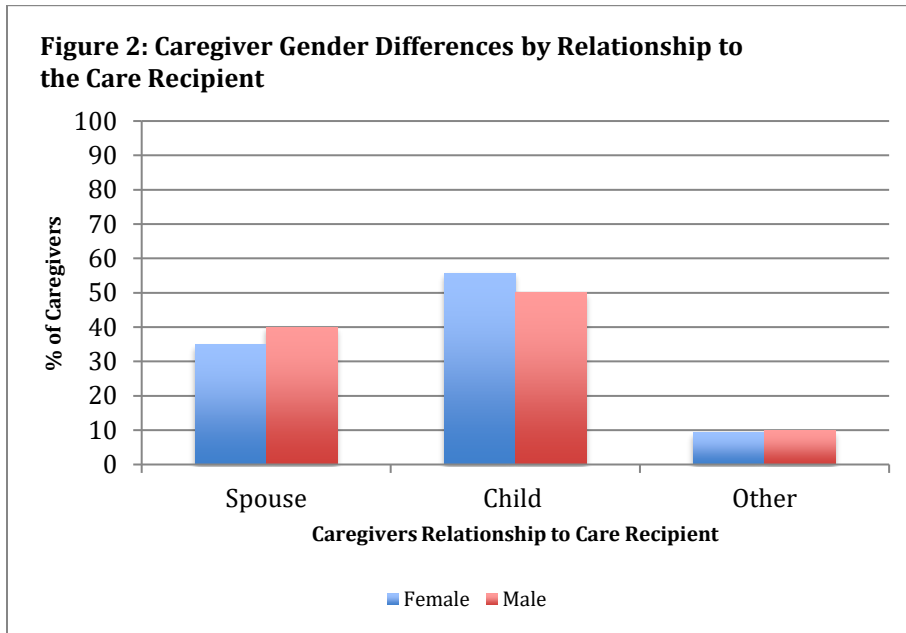
Stata version 15.1 was used for all statistical analyses. The criterion for statistical significance was  $p < 0.05$ . Demographics were reported by gender and results were summarized using descriptive measures. Continuous variables are expressed as a mean and standard deviation. Categorical variables are reported as a frequency and percentage. Bivariate analyses were used to analyze what gender and relational differences exist among informal caregivers. Statistical tests were used to determine whether differences were other than chance. Chi squared tests were used for categorical variables and t-tests were used for continuous variables.

## **Findings**

### **Sample Demographics**

The study sample included 357 (76.45%) female caregivers and 110 (23.55%) male caregivers (Table 1). Caregiver's average age was 60. Thirty-five percent of caregivers in this sample were white, 20% African American, 20% Asian, and 20% Hispanic (Table 1). Adult children account for 54% of the caregivers while 36% are spouses (Table 1). Forty-nine percent of female caregivers are providing care to male recipients, however, 78.7% of male caregivers are caring providing care to female care recipient (Table 1). There were no statistically significant differences by gender in the demographic variables reported in Table 1. Figure 2 shows the percentage of male and female caregivers by

relationship to the care receiver. No statistically significant differences by gender were found by the caregiver's relationship to the care receiver (Figure 2).



**Table 1: CareJourney User Demographics**

	<b>Females N=357 (76.45%)</b>	<b>Males N=110 (23.55%)</b>	<b>Total Sample N=467</b>
<b>Age <i>M (SD)</i></b>	60 (12.79)	61 (13.78)	60 (13.03)
<b>Ethnicity <i>N (%)</i></b>			
Hispanic/Latino	75 (21.37)	21 (19.81)	96 (21.01)
Not Hispanic/Latino	275 (78.35)	85 (80.19)	360 (78.77)
Decline to state	1 (0.28)	0 (0.0)	1 (0.22)
<b>Race <i>N (%)</i></b>			
African American/Black	62 (20.26)	15 (15.46)	77 (19.11)
Asian	59 (19.28)	17 (17.53)	76 (18.86)
Latino/Hispanic	59 (19.28)	18 (18.56)	77 (19.11)
Pacific Islander	4 (1.31)	2 (2.06)	6 (1.49)
White/Caucasian	103 (33.66)	39 (40.21)	142 (35.24)
Other	18 (5.88)	5 (5.15)	23 (5.71)
Decline to state	1 (0.33)	1 (1.03)	2 (0.50)
<b>Relationship status <i>N (%)</i></b>			
Married/Domestic Partners	228 (65.51)	71 (66.36)	299 (65.72)
Separated/Divorced	34 (9.77)	6 (5.67)	40 (8.79)
Widowed	13 (3.74)	2 (1.87)	15 (3.3)
Single	72 (20.69)	27 (25.23)	99 (21.76)
Decline to state	1 (0.29)	1 (0.93)	2 (0.44)
<b>Education Level <i>N (%)</i></b>			
College Graduate	98 (39.52)	44 (56.41)	142 (43.56)
High School Graduate	36 (14.52)	8 (10.26)	44 (13.5)
Post Graduate Degree	39 (15.73)	8 (10.26)	47 (14.42)
Some College	51 (20.56)	13 (16.67)	64 (19.63)
Some High school	24 (9.68)	5 (6.41)	29 (8.9)
<b>Employment status <i>N (%)</i></b>			
Full time	102 (30.00)	36 (36.62)	138 (31.08)
Leave	5 (1.47)	0 (0.0)	5 (1.13)
Part Time	55 (16.18)	12 (11.54)	67 (15.09)
Retired	121 (35.59)	43 (41.35)	164 (36.94)
Unemployed	57 (16.76)	13 (12.50)	70 (15.77)
<b>Care Receiver Age <i>M (SD)</i></b>	79 (11.34)	78 (10.26)	79 (11.37)
<b>Care Receivers Gender <i>N (%)</i></b>			
Male	170 (49.56)	23 (21.3)	193 (57.21)
Female	173 (50.44)	85 (78.7)	258 (42.79)
<b>Caregivers Relationship to the Care Receiver <i>N (%)</i></b>			
Spouse	125 (35.01)	44 (40)	168 (36.52)
Child	199 (55.74)	55 (50)	248 (53.91)
Other	33 (9.24)	11 (10.0)	44 (9.57)

**Gender Differences in the Amount of caregiving provided and help received**

Ninety two percent and 89% of female and male caregivers are the primary caregiver to the care receiver and 68.57% and 69.63% of female and male caregivers live with the care recipient. Fifty nine percent and 51% of female and male caregivers are performing 40 or more hours of care per week. No statistically significant differences were seen in the hours of care provided on average per week.

**Gender Differences in the type of care being provided.**

Female and male caregivers are assisting with an average of 6 instrumental activities of daily living (iADLS) and 4 activities of daily living (ADLs) (Table 4). Male caregivers are providing more help to care receivers with their mobility (p=0.04) than females (Table 4). There are no statistically significant differences by gender in other activities

**Table 4: Differences in Activity Assistance by Caregiver Gender**

	Female M(SD)	Male M(SD)
<b>Activities<sup>1</sup></b>		
Transportation	3.73 (0.73)	3.67 (0.81)
Shopping	3.70 (0.74)	3.74 (0.67)
Managing Finances	3.60 (0.87)	3.54 (0.85)
Household Chores	3.58 (0.84)	3.58 (0.80)
Preparing Meals	3.58 (0.81)	3.57(0.76)
Taking Medications	3.41 (0.96)	3.22 (1.02)
Bathing/showering	2.82 (1.21)	2.97(1.24)
Using the telephone	2.62 (1.31)	2.39 (1.28)
Grooming	2.5q (1.24)	2. 5 (1.31)
Dressing	2.59 (1.21)	2.62 (1.34)
Incontinence	2.30 (1.31)	2.31 (1.37)
Mobility*	2.28 (1.24)	2.58 (1.29)
Using the toilet	2.25 (1.28)	2.38 (1.36)
Transferring from bed/chair	2.10 (1.27)	2.37 (1.33)
Eating	1.92 (1.190)	1.98(1.26)
<b>Number of iADLS</b>	<b>6.37 (1.2)</b>	<b>6.36 (1.01)</b>
<b>Number of ADLs</b>	<b>4.26 (2.5)</b>	<b>4.23 (2.51)</b>
<b>Total number of activities</b>	<b>10.71 (3.27)</b>	<b>10.65 (3.23)</b>

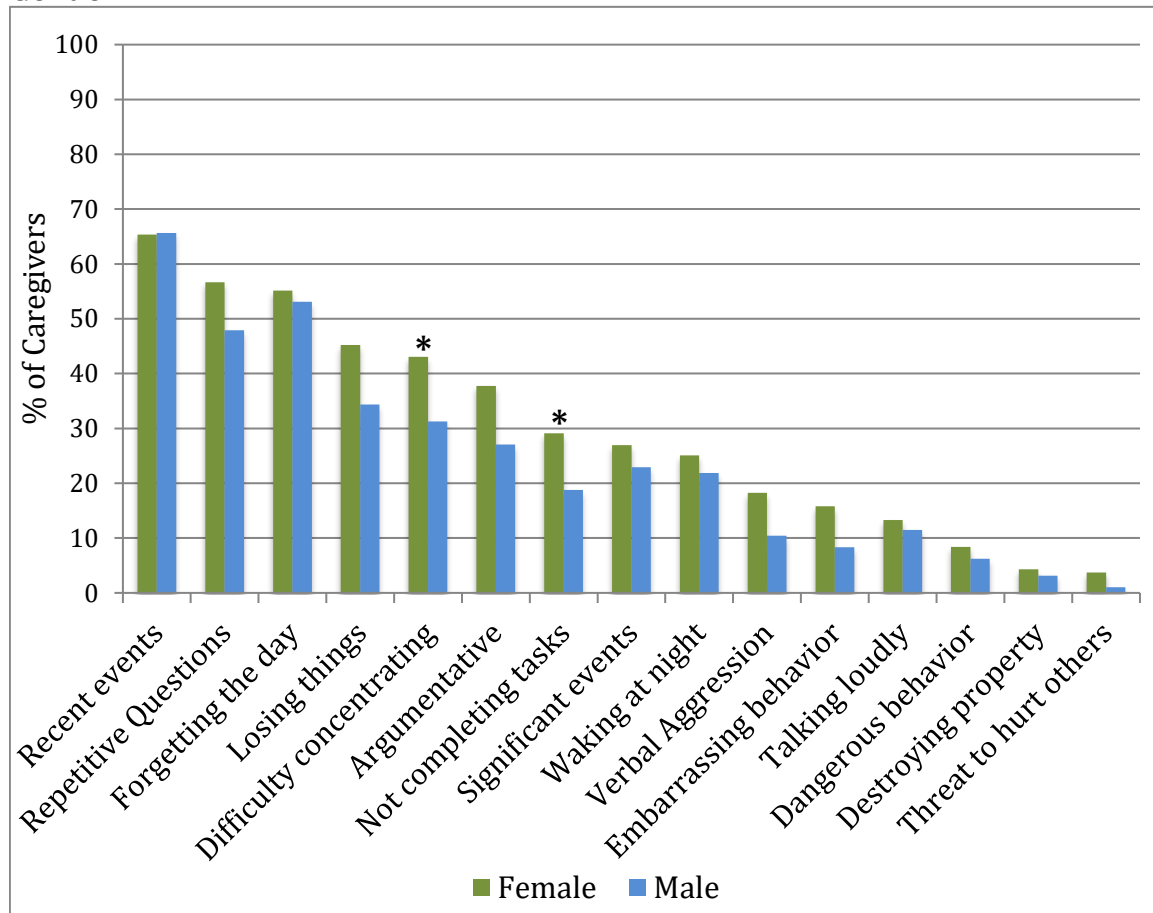
1: 1=Needs no help 2= Needs reminders/little help 3=Needs help most of the time 4= Needs help all of the time

\*= p<0.05

the caregivers are assisting with (Table 4).

Eighty seven percent of females and 83.3% of male caregivers reported providing care to a care receiver with memory loss. Problem behaviors associated with memory loss are shown in Figure 3. More female caregivers are providing care to care recipients across all memory related problem behaviors except remembering recent events (Figure

**Figure 3: Differences in Problem Behaviors of Care Receivers by Caregiver Gender**



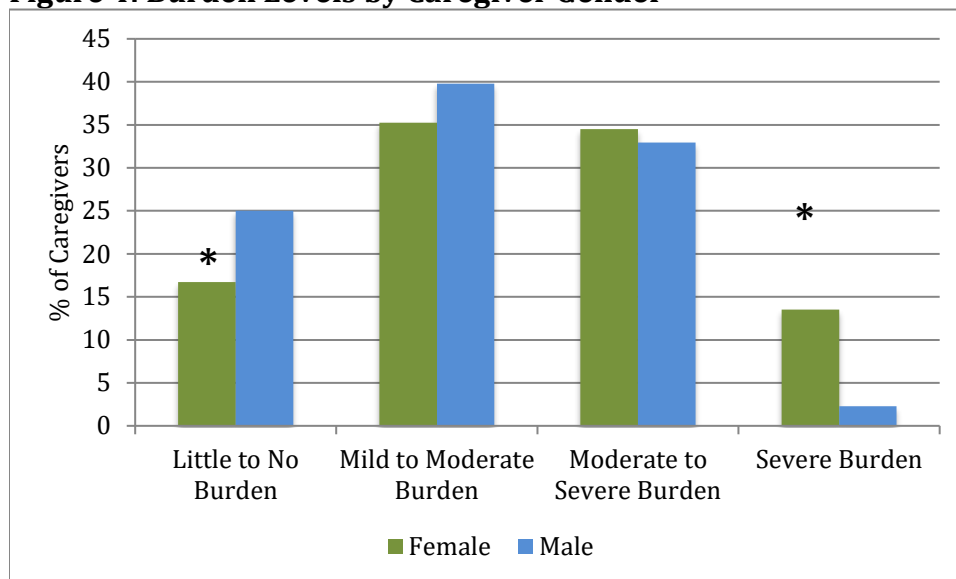
3). 43% and 29% of females are providing care to someone with difficulty concentrating (p= 0.044) and with difficulties completing tasks (p=0.039) respectively.



**Gender Differences in self-reported outcomes**

Female and male caregivers report an average score of 12 on the Lubben Social network scale (Appendix D). As shown in Figure 3, the Zarit Burden Screener showed more female caregivers reported severe levels of burden compared to males (p=0.013).

**Figure 4: Burden Levels by Caregiver Gender**



No statistically significant differences were observed in self-reported physical health outcomes. Ninety percent of female and male caregivers reported their health as fair or good and approximately 70% of female and male caregivers reported no change in their health over the past year due to their caregiving duties (Appendix E).

**Relationship Differences in the Context of Caregiver Gender**

A secondary analysis was performed to examine relationship differences to the care receiver in the context of gender. Ninety-five percent of female spouse caregivers and 92% of male spouse caregivers lived with the care receiver (p=0.001) while 55% of sons and daughters lived with the care receiver (p=0.001). Seventy five percent of wives and 48% of daughters were providing more than 40 hours of care per week (p=0.0013).

Fifty-seven percent of husbands and 46% of sons were providing full time care (40+ hours per week), but the difference was not statistically significant. There were no statistically significant differences by relationship in the activities caregivers are assisting with, problem behaviors of the care receiver, reported physical health, and scores on the Zarit Burden Screening test and the Lubben Social Network Scale.

### **Discussion**

Using data collected through the CareJourney platform, this study analyzed gender and relationship differences in the amount of caregiving provided, type of caregiving activities performed, care recipient characteristics, and self-reported physical health, burden and social connectedness. Notably, among this service-seeking sample of informal caregivers, 20% were found to be male compared to a nationally reported sample that reported 40% of caregivers to be male (National Alliance of Caregiving, 2015). When compared to the national sample this service-seeking sample of informal caregivers also differed in that more caregivers are providing over 40 hours of care per week (60% vs. 25%), they are assisting with more activities of daily living (4 vs. 1), yet comparable levels of high burden were reported (44% vs. 40%). These findings suggest that service-seeking informal caregivers are performing more intensive caregiving. It is encouraging that informal caregivers who are performing high intensity care are seeking services. Previous research has postulated that the most vulnerable caregivers may be the most likely to not seek services due to lack of time and social support in accessing services and resources (Bedard, 2005).

The gender difference in this service-seeking sample compared to the national sample suggests that male caregivers are less likely to seek services than female

caregivers. Traditional gender roles may explain this finding. Pinqart & Sorenson (2006) described male caregivers as taking a “project management” approach while women take an “emotional coping approach”. A “project management” approach focuses more on the tasks that need to be completed and there is less focus and reflection of the impact of these tasks on one’s own health. Being attune to one’s own personal challenges likely will result in the individual reaching out for help. Interestingly, though this service-seeking sample of informal caregivers was found to be providing high intensity care and their burden levels were comparable to a non-service-seeking national population. No conclusions can be made as to whether the FCA and USC FCSC’s services are having a positive impact on this sample as the data collected in this study occurred at the point of initial contact between the caregiver and FCA or USC FCSC. This study examines a unique population of caregivers who are independently seeking out services therefore results from this study cannot be generalized to the overall population of caregivers.

No gender differences were observed in the amount and type of caregiving. 60% of caregivers in this sample are providing more than 40 hours of care per week. Previous research has shown that women are more likely to assist with more activities of daily living (ADL) than males (National Alliance of Caregiving, 2015), however in this study we found that both male and female caregivers are assisting with an average of 4 ADL’s. This is consistent with the literature which has shown that higher-hour caregivers assisting with multiple ADL’s (National Alliance of Caregiving, 2015). These findings suggest that the intensity of caregiving outweighs the affect of gender. It was found that male caregivers are providing more assistance with mobility than female caregivers

( $p=0.04$ ). This could be attributed to differences in tasks performed by gender that have been previously reported in the literature, however because no other statistically significant differences are found in the assistance with ADL's and iADL's by gender this may be the result of confounding.

Previous research has found that females fair worse physically, emotionally and socially compared to male caregivers (Sharma et al, 2016). The results of this study showed that 14% of female caregivers experience severe levels of burden compared to 2% of males. Adelman et al. (2014) defines caregiver burden to be a combination of the emotional, social, financial, and spiritual challenges a caregiver faces. In our findings no differences by gender were found in caregivers physical health or social connectedness. Further research is needed to understand how emotional, social, financial and spiritual aspects affect burden levels. Data collected through the CareJourney assessment do not include financial, emotional and spiritual measure making it difficult to draw conclusions about this samples perceive physical health and social connectedness impact on the reported burden levels.

Higher burden levels have been associated with providing care to someone with difficult behaviors (Pinquart & Sorenson, 2003). We found that females were providing more care to care receivers who had difficulty concentrating ( $p=0.039$ ) and difficulty completing tasks ( $p=0.044$ ). Notably, despite no statistical significance, women were providing care to more care recipients with problem behaviors across all behavior domains except for difficulty in remembering recent events. Male care recipients often exhibit more difficult behaviors and that female caregivers have more difficulty managing and coping with these behaviors (Pinquart & Sorenson, 2003). This helps

explain why female caregivers in this sample are reporting higher levels of severe burden compared to males.

Male caregivers often provide care to a spouse. Compared to adult children, spouses are intrinsically motivated to provide care to their partner while the dyad relationship between an adult child caregiver and parent care recipient is more challenging (Pinquart & Sorenson, 2011). Interestingly, 54% of CareJourney users are adult children. Adult children more often self-identify as a caregiver compared to spouses, and they often have to make more sacrifices to take on a caregiving role (O'Connor, 2006). O'Connor (2006) found that caregivers who sought out services and particularly those who were in support groups were more like to self-identify as a caregiver. Furthermore, O'Connor argues that, "Until one begins to position one's self as a caregiver it is difficult to see the work one is doing and develop self-care strategies," (2006). Our findings did not show any differences in burden levels, social connectedness and physical health by relationship. Thus, the finding that less spouses are engaging with the FCA and USC FCSC resource center may be because they are less likely to position themselves as a caregiver.

Spouses were more likely to provide more than 40 or more hours of care per week and live with the care recipient. Seventy five percent of wives and 48% of daughters were providing more than 40 hours of care per week ( $p=0.0013$ ) and 57.76% of husbands and 46.81% of sons ( $p=0.330$ ) were providing more than 40 hours of care per week. The difference between spouses performing more full time care compared to adult children is more pronounced among women than men. This may be attributed to the smaller sample size of male informal caregiver in this study compared to females. The finding of

spouses providing more full time care compared to adult children can be attributed to relational roles. However, no differences in burden levels, social connectedness, and physical health were found. This suggests that spouses may be more resilient to the demands of caregiving compared to daughters and explain why we see a larger number of adult children in a service seeking caregiver population.

### **Limitations**

Despite the strengths of this study it is important to note the limitations. Missing data was largely due to caregivers declining to answer questions. Future research should examine if there are trends in questions that caregivers are not answering to improve data collection methods. Caregivers either completed the evaluation with a family care consultant over the phone or in person (n=422), or they were able to self-administer the evaluation online (n=45). Research has shown that different modes of administration produce different response rates (Bowling, 2005). Face-to-face interview surveys have shown higher response levels compared to other methods (Bowling, 2005). Self-administration of the evaluation may result in missing data due to caregivers skipping questions. Completing the evaluation with a family care consultant may allow for additional dialogue and provide a more comforting environment that may make caregivers more willing to share sensitive information.

Another limitation for this study is that it is unknown as to why informal caregivers are seeking services. Additional data should be collected to better understand the caregiver's needs in reaching out to the FCA and USC FCSC. Qualitative data collection including focus groups and one-on-one interviews could provide valuable information as to why caregivers choose to interact with the FCA and USC FCSC.

Follow-up data has not yet been collected and will be critical in evaluating the success of the CareJourney platform including the whether it is connecting caregivers with the services they need and the impact of services and resources being provided. The CareJourney platform was launched in September 2016 and as more data is collected the FCA and USC FCSC should closely examine these missing pieces of information.

### **Implications for Practice**

Community-based social service agencies like the FCA and USC FCSC are important assets to our community. Understanding the users of CareJourney will allow for continual improvements of the CareJourney platform and the services and resources they provide. A further understanding of why this sample of service-seeking informal caregivers is engaging with the FCA and USC FCSC is needed. This will help guide the FCA and USC FCSC in how to better support male caregivers. The FCA and USC FCSC have no male family care consultants. This may deter male caregivers from engaging with the FCA and USC FCSC and they should consider hiring male family care consultants. Additionally, continuing to closely examine the users of the CareJourney platform will challenge staff member's assumptions and biases they may have when serving caregivers.

### **Future Research**

Future research on service seeking caregivers and their counterparts is needed. It is likely that some of the most vulnerable caregivers are not receiving the support they need. Language and geographic barriers should be considered, and the Family Caregiver Alliance should continue to leverage the advantage of an online services platform to help reach these populations. Additionally, it will be important to investigate how caregivers

are interacting with the platform using qualitative research methods such as focus groups or one-on-one interviews. CareJourney has the potential to reach a large population, however given current resources the FCA and USC FCSC have limitations of the number of evaluations they can perform administer in-person. It will be essential for CareJourney's success to understand the outcomes of users who self-administer the evaluation and how they can improve access to these individuals.

Informal caregivers are critical to supporting the aging population and those suffering from chronic conditions and terminal diseases. Although caregiving remains a predominantly female role, more men are providing informal care. Informal caregivers are essential to our healthcare system and support and resources must be expanded to keep up with the diversifying aging population in the United States.



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**Appendices**

**Appendix A**

*Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living Questions*

	Activity	Does by self / Needs no help	Needs reminders / A little help	Needs help most of the time	Needs help all the time / Unable to do activity	Do you need more information about this activity?
1.	Eating (cutting food, buttering bread)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
2.	Bathing/showering (washing, getting in/out of tub or shower)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
3.	Dressing/choosing clothes or undressing	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
4.	Grooming: teeth, hair, shaving, cutting fingernails	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
5.	Using the toilet (getting to the bathroom on time, being reminded to go, cleaning himself/herself)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
6.	Incontinence (bladder/bowel accidents)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
7.	Preparing meals (serving or providing meals for himself/herself)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
8.	Taking medications (in correct amounts at the correct times)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
9.	Managing money/finances (paying bills, banking, keeping track of money)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
10.	Performing household chores (laundry, vacuuming, dusting, straightening)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
11.	Using the telephone (looking up numbers, dialing, answering)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
12.	Mobility (getting around inside of the house)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
13.	Transferring from bed/chair/car	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
14.	Shopping	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes
15.	Transportation (driving, getting rides, using public transportation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes

**Appendix B**

**LUBBEN SOCIAL NETWORK SCALE – 6 (LSNS-6)**

**FAMILY:** *Considering the people to whom you are related by birth, marriage, adoption, etc...*

1. How many relatives do you see or hear from at least once a month?  
0 = none    1 = one    2 = two    3 = three or four    4 = five thru eight    5 = nine or more
2. How many relatives do you feel at ease with that you can talk about private matters?  
0 = none    1 = one    2 = two    3 = three or four    4 = five thru eight    5 = nine or more
3. How many relatives do you feel close to such that you could call on them for help?  
0 = none    1 = one    2 = two    3 = three or four    4 = five thru eight    5 = nine or more

**FRIENDSHIPS:** *Considering all of your friends including those who live in your neighborhood*

4. How many of your friends do you see or hear from at least once a month?  
0 = none    1 = one    2 = two    3 = three or four    4 = five thru eight    5 = nine or more
5. How many friends do you feel at ease with that you can talk about private matters?  
0 = none    1 = one    2 = two    3 = three or four    4 = five thru eight    5 = nine or more
6. How many friends do you feel close to such that you could call on them for help?  
0 = none    1 = one    2 = two    3 = three or four    4 = five thru eight    5 = nine or more

*LSNS-6 total score is an equally weighted sum of these six items. Scores range from 0 to 30*

**Appendix C**

*Zarit Burden Screening Questions & Scoring*

		Never	Rarely	Sometimes	Frequently	Nearly always
1.	Do you feel that you don't have enough time for yourself due to the amount of time you spend providing care?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2.	Do you feel stressed between caring for <b>CR</b> and trying to meet other responsibilities (work/family)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3.	Do you feel strained when you are around <b>CR</b> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4.	Do you feel uncertain about what to do about <b>CR</b> ?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Zarit Burden Interview Score	Burden Level
0-4	Little to no burden
5-8	Mild to moderate burden
9-12	Moderate to severe burden
13-16	Severe Burden



**Appendix D**

**Lubben Social Network Scale Scores by Gender**

	N	Mean LSNS Score
Female	230	11.73
Male	70	11.51
Total	300	11.68

**Appendix E**

