## EFFECTS OF SOCIAL NETWORKS ON THE HEALTH OF FAMILY CAREGIVERS IN LATER LIFE: A CROSS-SECTIONAL STUDY

By

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## A DISSERTATION

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#### ABSTRACT

## EFFECTS OF SOCIAL NETWORKS ON THE HEALTH OF FAMILY CAREGIVERS IN LATER LIFE: A CROSS-SECTIONAL STUDY

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The purpose of this study was to better understand the social value of family caregiving in later life by examining the effects of social networks and family caregiving on the health of older adults aged 65 and over. Based on positive gerontology, the study asked the overarching research question: "Are there significant mean differences in health for different levels of social networks and for different family caregiving status after controlling for demographic factors?" In this study, the independent variables were three-dimensional social networks and family caregiving status. The dependent variables were levels of self-rated health, physical function, absence of chronic diseases, and mental health.

This was a cross-sectional, explanatory survey study. It drew a probability sample from a regional representative population of older adults aged 64 and above in three Michigan communities. The survey resulted in a response rate of 36.6% and a final sample of 358 community-dwelling older adults: 136 were caregivers, and 222 were non-caregivers. The questionnaire contained a total of 58 quantitative measures and two open-ended questions. Five standardized measures used in the study had high internal consistency. They were Bakas Caregiving Outcomes Scale, Lubben Social Networks Scale, Berkman-Syme Social Networks Index, Life Events Survey, Instrumental Activities of Daily Livings, and Geriatric Depression Scale.

Multiple data collection and data analysis methods were used to enhance the validity of the results. Between-methods triangulation primarily included a survey instrument that integrated open-ended questions and a consequent combination of descriptive statistics and content analysis. Within-methods triangulation included multiple scales used for the social networks construct as well as the health construct.

Multivariate Analyses of Variance and Covariance were performed. Results indicated significant mean differences in the health for social networks and family caregiving independently. Specifically, high levels of functional social networks significantly predicted better self-rated health and higher physical function. The study also found that family caregiving significantly affected the health of the older family caregivers. Results highlighted that being family caregivers in later life significantly predicted lower levels of physical function and mental health, but social networks positively affected well-being of family caregivers in later life.

The nature of cross-sectional study and a regional representative sample limited generalizability of the results to populations beyond the study population. However, several implications were identified regarding methodology, research, and practice. The results suggested the functional dimension was the most important factor in social network analysis, but there was not similar prior research to which a comparison could be made. More inquiry is needed to assess conceptualization and measurement of social networks in social work and gerontology. Although the study made efforts to combine quantitative and qualitative methods, two open-ended questions were not adequate to fully understand the social networks of older family caregivers. More research is needed to collect social network-specific qualitative data to obtain in-depth understandings regarding health effects of social networks among older family caregivers.

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## **CHAPTER ONE: INTRODUCTION**

The health care system in the United States is increasingly dependent on sustainable and quality family caregiving (Calasanti & Slevin, 2001; Feinberg & Newman, 2006; Goodman, Potts, & Pasztor, 2007; Heller, Caldwell, & Factor, 2007; Talley & Crews, 2007). Available data have shown that the number of older adults who provide unpaid care to their family members, friends, and neighbors across the life span is growing in recent decades (McGarry & Arthur, 2001; Moren-Cross & Lin, 2006; Pinquart & Sörensen, 2006). The 2000 U.S. Census documented approximately 2.4 million grandparents raising 4.5 million grandchildren younger than age 18, a 30% increase from 1990 (Simmons & Dye, 2003; Hayslip Jr. & Kaminski, 2005). Over 15% of 4.7 million persons with intellectual disabilities received care from older family caregivers in 2006, an estimated 10–20% increase in demand for residential services over the past three decades (Braddock, 2002; Braddock, Hemp, & Rizzolo, 2008). In 2007, older adults accounted for about 30% of 34 million family caregivers, and on average they provided 20 hours of care per week, increased from an estimated 25.8 million family caregivers and 17.9 care hours weekly in 1997 (AHRQ, 2001; Houser & Gibson, 2008; Arno, Levine, & Memmott, 1999). Thompson (2004) depicted the critical position of family caregiving in the health care structure as 78% of community-based long-term care recipients receive care exclusively from unpaid family and friends, while 14% receive some combination of family care and paid assistance, and only 8% rely on formal care alone.

The intensified demand has raised great concerns about sustainability of family caregiving in later life and quality of life among older family caregivers. Efforts have been made to better understand needs of older family caregivers (Beach, Schulz, Williamson, Miller, Weiner, & Lance, 2005; Teschendorf, Schwartz, Ferrans, O'Mara, Novotny, & Sloan, 2007; Weeks,

Nilsson, Bryanton, & Kozma, 2009). It is evident that a better understanding of economic, physical, mental, social, cultural, and spiritual needs of older family caregivers could greatly contribute to the sustainability of family caregiving and quality of life of older family caregivers (Carpentier & Ducharme, 2007; Krause, 2009; Netto, Jenny, & Philip, 2009; Sim-Gould & Martin-Matthews, 2007; Traustadóttir, & Sigurjónsdóttir, 2008).

## **Statement of problem**

Despite an increasing dependence on older family caregivers in overall health care system, a risk perspective has exclusively dominated research on family caregiving in later life. It is evident that research has disproportionally focused on negative health outcomes of family caregiving burden, increased risk for mortality, decreased immunity function, cardiovascular disease, depressive symptoms, and potentially harmful caregiver behavior and elder abuse (Kiecolt-Glaser, Preacher, MacCallum, Atkinson, Malarkey, & Glaser, 1991, 1996; Schulz & Beach, 1999; Beach et al., 2005; Nakanishi, Hoshishiba, Iwama, Okada, Kato, & Takahashi, 2009). Pinquart and Sörensen (2003) reviewed 228 family caregiving studies in 1986–2006. They suggested that 151 studies assessed caregiving burden, stress, and strain, and 120 studies measured depression, and that only 28 studies assessed uplifts of caregiving such as satisfaction, enjoyableness, and perceived gains. Additionally, older family caregivers have been treated as co-users of services or "hidden patients" (Fengler & Goodrich, 1979; O'Mara, 2005). Furthermore, this disease-focused research has pathologized older family caregivers by categorizing them with the diseases that their care recipients have (Alwin, Öberg, & Krevers, 2010; Gideon, 2007; Jankauskiene, Lesauskaite, & Naumaviciene, 2007).

A review of family caregiving literature suggested that family caregiving research has identified problems with aging and family caregiving as the following: (1) Increasing old age

dependency ratio: The emphasis on old age dependency ratio refers to older adults as dependents of the family and the society; (2) Disease and disability of older adults were identified as key reasons for family caregiving and care burden: By focusing on one or many elder care-related physical, functional, cognitive, or mental ills, family caregiving studies detailed the dependency of older adults and referred to older adults as "patients" (Eaves, 2006; Gilley, McCann, Bienias, & Evans, 2005; Kim & Schulz, 2008); and (3) Cost of institutional care: Research has consistently estimated the total cost of aging and subsequent demands for institutionalization. Using U.S. Census data, Schneider and Guralnik (1990) made a compelling argument that the aging of America has a direct impact on escalating health care costs. This argument provided a framework for the cost of illness studies of dementia (McDaid, 2001; Guentin, Riedel-Heller, Luppa, Rudolph, & König, 2010). For instance, Harrow et al. (2004) estimated the total annual cost per care receiver as \$23,436 for informal caregiving and \$8,064 for formal service in 1997 dollars, based on a national sample of 1,200 family caregivers for people with Alzheimer's disease.

Epistemologically, a pathology-oriented framework pays little attention to conditions and characteristics that contribute to a full understanding of older Americans and family caregiving in later life. Positive gerontology in this study highlights four counterpoints of a pathological framework. First, the majority of older Americans, including the oldest old, increasingly remains independent and remains in the home and community as long as possible (Raphael & Cornwell, 2008). Secondly, a complete picture of 21st century older Americans must include the fact that older adults have become increasingly active actors in the workplace, civic engagement, and private relations (Hinterlong, Morrow-Howell, & Rozario, 2007). Older adults are not only care receivers, but they are also care providers to people across all age groups, particularly older

family members and friends suffering geriatric diseases and/or disabilities, adult children or siblings with chronic disease and disability, and grandchildren under age 18 whose birth parents are absent from parental responsibilities (Brown et al., 2009; Fujiura, 2010; Standing, Musil, & Warner, 2007). Third, family caregiving delays or reduces institutionalization of dependent older adults or disabled people (Van Houtven & Norton, 2008). In the case of grandparents raising grandchildren in skipped generational households, family caregiving avoids the involvement of the foster care system. Equally important, it is generally agreed that family caregiving provides care that is of high quality, consistent with care recipients' preferences, has better care outcomes, and costs less (Raphael & Cornwell, 2008). Finally, family caregiving helps reduce overall health care costs. Arno et al. (1999) estimated that the economic value of family caregiving was equivalent to approximately 18% of the total national spending on health care. Harrow et al. (2004) estimated family care cost per care recipient with Alzheimer's disease was almost three times the cost of formal services. In 2007, the annual economic value of family caregiving was estimated at \$375 billion, which far exceeded public expenditures for home health and nursing home care combined and approached total expenditures for the Medicare program (Houser & Gibson, 2008; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009).

Since a pathological framework often appears in scientific language and in forms of policy documents, research and human services of family caregiving in later life are constructed and organized by what we have known through pathological lenses rather than by what little is known about the productive roles of older family caregivers or positive features of family caregiving in later life (Gopalan & Brannon, 2006; Zarit & Femia, 2008). What literature has best documented and what we know best can be described as (1) the notion of "the adverse physical and psychological health effects of family caregiving" is well established (Vitaliano,

Zhang, & Scanlan, 2003; Fortinsky, Tennen, Frank, & Affleck, 2007; Pinquart & Sörensen, 2003, 2007); and (2) family caregivers, especially older family caregivers, are at higher risk for physical and psychosocial health problems than noncaregivers (Beeson, 2003; Carter & Clark, 2005; Pinquart & Sörensen, 2003).

The current study observed that incomplete knowledge about health outcomes of family caregiving in later life has provided biased evidence that contributed to public meanings of being old and being an older family caregiver. This observation is supported by strong evidence that family caregiving in later life is not the single determinant of negative health outcomes among older family caregivers (Letiecq, Bailey, & Kurtz, 2008; Pinquart & Sörensen, 2007). Psychology has well established that psychological states contribute to physical outcomes. Negative psychological states such as grief, stress and sense of powerlessness more likely lead to negative physical and psychological health outcomes, while positive psychological states such as love and gratitude more likely result in positive health outcomes (Edwards & Cooper, 1988; Fredrickson, 2004; Ong, Bergeman, Bisconti, & Wallace, 2006). Family caregiving research can minimize biases by examining positive aspects of family caregiving in later life beyond its risks, stress, and negativity.

Evidence from recent quantitative and qualitative data has suggested that older family caregivers recognize social, psychological, cultural, and spiritual values of caregiving (Jankauskiene et al., 2007; Netto et al., 2009). A five-year longitudinal study of 166 caregiverdementia patient dyads found that higher levels of satisfaction with social support networks among dementia family caregivers predicted fewer depressive symptoms and higher levels of life satisfaction (Clay, Roth, Wadley, & Haley, 2008). Based on a random sample of 339 Canadian-Chinese family caregivers, Lai (2010) examined the effects of filial piety on the appraisal of

caregiving burden and suggested that filial piety as a cultural belief served as a protective function to reduce the negative effects of stressors and to enhance the positive effect of appraisal factors on caregiving burden. A strength-based gerontological approach has called for advancement of our understanding of family caregiving experience in later life, with the focus on its social recourses and positive outcomes.

Based on the Changing Lives of Older Couples sample, Brown, Nesse, Vinokur, and Smith (2003) found that mortality was significantly reduced for individuals who reported providing instrumental support to friends, relatives, and neighbors, and individuals who reported providing emotional support to their spouse. This finding suggested that helping behavior and social contact influence health and longevity. Using a national sample of 1,229 older dementia caregivers, Tarlow, Wisniewski, Belle, Rubert, Ory, and Gallagher-Thompson (2004) tested a newly developed measure for the positive aspects of caregiving and found that caregivers perceived their caregiving as providing them with a variety of positive and satisfying experiences. These caregivers frequently reported that caregiving made them feel important and good about themselves. Most caregivers also reported that caregiving enabled them to develop a more positive attitude toward life and strengthened their relationships with others. Based on three empirical studies on the role of positive emotions in the stress process in late adulthood, Ong et al. (2006) found that the occurrence of daily positive emotions served to moderate stress reactivity and mediate stress recovery and suggested that over time, the experience of positive emotions functioned to assist highly resilient individuals in their ability to recover effectively from daily stress (Ong et al., 2006).

It is observed that the pathological family caregiving research failed to identify factors that contributed to positive and negative health outcomes among older family caregivers, which

further contributed to drawing clear conclusions about the nature and the prevalence of negative health outcomes (Pinquart & Sörensen, 2003). This observation is supported by the fact that sources of stress and depressive symptoms existing among family caregivers are complicated (Carter & Clark, 2005; Gopalan & Brannon, 2006; Kiecolt-Glaser et al., 2003; Montoro-Rodríguez, Kosloski, Kercher, & Montgomery, 2009). Without consideration of the roles of socioeconomic and psychological factors in the family caregiving context, any attempt to generalize particular health effects of caregiving stress would be unscientific. Given, Sherwood, and Given (2008) addressed the sense of lack of preparation as a source of stress for family caregivers of people with chronic illnesses and multiple comorbid conditions. They proposed knowledge and skills that gerontological social work should possess to prepare caregivers. Feelings of unpreparedness as well as a sense of lack of mastery, grief, loss, prior conditions, "patient suffering" or certain lifestyle could lead to stress among family caregivers (Jansen et al, 2007; Neundorfer, McClendon, Smyth, Strauss, & McCallum, 2006; Noyes et al., 2010; Roepke et al., 2009; Schulz et al., 2007). Failing to control for unmeasured confounding variables has been a major threat to the validity of inferences made about health effects of family caregiving.

Family caregiving literature generally considers caregiving as a predictor of social isolation among older family caregivers. However, recent evidence has presented different aspects of social positions of older family caregivers and has demonstrated the importance of including various social, psychological, and cultural resources in studying family caregiving in later life (Phillips & Christ, 2008; Sanders, 2007). Observations about positive features of family caregiving in later life can provide opportunities to examine conditions and characteristics that contribute to a full understanding of strengths, capacities, and strongest qualities of older family caregivers. On the other hand, positive gerontology of family caregiving is relatively new and

less documented. Using four waves of the *Asset and Health Dynamics* (AHEAD) cohort of the Health and Retirement Study, Brown et al. (2009) recently reexamined the relationship between caregiving and mortality. They reached the conclusion that caregiving behavior was associated with decreased mortality risk rather than increased mortality risk, but a generalizable conclusion between caregiving and mortality of caregivers was far from being reached. More empirical evidence is needed to test positive gerontological assumptions, especially what and how social relations play roles in the health of older family caregivers when they become more emphasized in family relationships and mastering social networks (Brown et al., 2009; Carpentier & Ducharme, 2007; Gergen & Gergen, 2003).

## Trends of family caregiving in later life

Traditionally, caregiving was a natural component of the family system and community identity in the United States as well as in the rest of the world (Ruggles & Browner, 2003; Holzman, 1998; Stack, 1974; Whyte, Alber, & Geissler, 2004). Unpaid informal caregiving was no longer the only social protection as profound sociodemographic changes occurred beginning in the late 19th century (Elmore & Talley, 2009). The most notable shifts were population aging, urbanization, household living arrangement, increasing number of women in the paid workforce, and the establishment of public protections and advocacy systems (Glasgow, 2000; Alwin, Converse, & Martin, 1985; Costa, 1999; Haber & Gratton, 1994).

In 1900, 4.1% of 76 million Americans were age 65 and over, and 57% of them lived in a multigenerational family household and shared the responsibility and protection of kinship networks (Ruggles, 2003). In 1910, only 20.6% of elderly whites lived alone or with a spouse (Ruggles, 1994). Over the last century, people age 65 and above were the most rapidly growing segment of the national population. In 2010, the number of older Americans grew to 40.3 million

Americans, or 13.0% of the total population in the United States (US Census, 2011). More importantly, population aging was concurrent with industrialization. As early as 1910, Addams had recognized that industrialization had deconstructed the traditional family support system for children, the disabled, and the aged in rural American communities (Addams, 1910). Assistance and protection provided by kin and neighbors were not sufficient. This was due to declining multigenerational households and unavailability of family care resources (Ruggles, 1994; Chappell & Blandford, 1991). Multigenerational households were no longer a norm. More people lived alone or lived in nuclear households than before. In 2008, 50.5% of older adults lived alone or with a spouse (US Census, 2010), a near 30% increase from 1910. All these changes have gradually reshaped family caregiving context and family caregiving itself (Szinovacz & Davey, 2008; Elmore & Talley, 2009; Copen, 2009; Weeks et al., 2009). *Family caregiving, a public agenda* 

As Addams (1910) advocated and fought for, a new protection and advocacy system was established to respond to a faded traditional social support system. Caregiving increasingly become a public agenda. Social Security, Medicare, and other preventions were enacted to insure economic security and health of older adults and their families. To date, family caregivingspecific federal initiatives have provided a necessary policy environment for family caregivers (Elmore & Talley, 2009; Leos-Urbel, Bess, & Geen, 2002).

The National Family Caregiver Support Program, the Aging and Disability Resource Centers, the *Lifespan Respite Care Act of 2003* (H. R. 6893) and the *Fostering Connections to Success and Increasing Adoption Act of 2008* (P. L. 110- 351) were established to deliver direct services for family caregivers. For example, the Older American Act Amendments of 2000 (P.L. 106-501) created a federal caregiving program called the National Family Caregiver Support

Program. The *Older American Act Amendments of 2006* (P.L. 109-365) established three amendments: (1) family caregivers of persons with Alzheimer's disease or a related dementia may be served regardless of the age of the care recipient with dementia; (2) grandparents and other relative caregivers providing care to children under age 18 years may receive services at 55 years of age and older; and (3) grandparent or relative caregivers providing care for adult children with a disability between 19 and 59 years of age may be served under the program.

The federal family caregiving agenda has employed policy approaches beyond direct services. They include financial incentives and compensation, consumer-directed approaches, and employment-based mechanisms (Elmore & Talley, 2009). They foster community-based long-term care for the disability and the aging communities as well as kinship child care (Kearns & Andrews, 2005; Berrick, 2008). Ongoing extensions of federal initiatives have led predictions that the art and science of caregiving has made a meaningful transition (Whittington, 2010). *Family caregiving, an aging experience* 

The *Older American Act Amendments of 2006* specifically respond to the fact that an increasing number of older adults has been involved in family caregiving. The prevalence of family caregiving among older adults suggests that a better understanding of family caregiving should become a gerontological social work mission. It is simply because family caregiving has become a part of the aging experience not only for older care receivers but also for all older adults.

## Social capital, a continuity of family caregiving

The prevalence of family caregiving in later life addresses the continuity of family caregiving, which is often ignored when focus has been on changes and differences from an historical perspective (Uhlenberg & Cheuk, 2008). Although family protection is no longer a

solo social protection mechanism, individuals and families still use their social capital to provide much needed family care. Kin, neighbors, and friends play important roles as much as policy measures and professional care providers (Keating & Dosman, 2009). Existence and use of social capital in contemporary American society partially explain why an estimated 12.1% of non-institutionalized Americans with a disability were able to enjoy community living (US Census, 2010). Although institutionalized long-term care has been a hot topic since the 20th century, the fact is that the majority of older Americans, with or without disabilities, are aging in place with their family and community. According to the 2010 U.S. Census, only 4.9% of older Americans lived in nursing homes and other group facilities (US Census, 2010). Even for institutionalized older adults, family caregiving continues as a complement to professional services (Chappell, & Blandford, 1991; Yeh, Wierenga, & Yuan, 2009).

#### **Theoretical framework**

Positive gerontology has fundamentally shaped and defined this study. This theoretical framework is derived from two lines of inquiry—critical gerontology and positive psychology (Estes, 1999; Calasanti & Slevin, 2001; Ong & Bergeman, 2004). Primarily based on critical theory and political economy, critical gerontology emphasizes the broad implications of political, economic, and social relations for the aging and for treatment of older adults in the society. It illuminates topics such as the social construction of caregiving and the impacts of the current politics of retrenchment on minority older adults.

A positive psychology emphasis is based on the fact that the disease model does not move psychology closer to the prevention of physical disease, mental illness or social problems. Seligman and Csikszentmihalyi (2000, p. 7) declared that: "Psychology is not just the study of pathology, weakness, and damage; it is also the study of strength and virtue." In its quest for

what is best within individuals and institutions, positive psychology does not base its positive orientation on wishful thinking (Seligman & Csikszentmihalyi, 2000). Rather, positive psychology has accumulated enormous empirical studies on how positive features promise to improve quality of life and prevent pathologies (Gable & Haidt, 2005; Salove, Rothman, Detweiler & Steward, 2000; Vaillant, 2000).

Positive gerontology challenges the assumption that aging is a life stage of decline, disengagement, and disease. It critically examines the socially constructed dependence status of older adults and the pathology model of gerontology. It commits to change the course of aging in more positive ways (Calasanti & Slevin, 2001; Holstein & Minkler, 2007; Minkler & Estes, 1999). As Gergen and Gergen (2003) proposed, positive gerontology reconstructs the discourse of aging as a time to return to self-growth and relationships. By adapting positive gerontology in research on family caregiving in later life, this study rejects the notion that caregiving can be isolated from larger political, social or economic realities. It emphasizes the relevance and significance of social relations for understanding how family caregiving in later life is socially constructed and processed in particular social contexts. Two propositions that redefine family caregiving in later life are emerging.

First, under the framework of positive gerontology, this study conceptualizes family caregiving in later life as a socially constructed product. My assumption implicit in socially constructed caregiving is that family caregiving in later life is shaped by social structure and by those social factors that influence the individual's position in that structure. More specifically, this study analyzed social factors such as age, gender, race, ethnicity, and social relations in questions such as how older family caregivers engage in caregiving in contemporary America, and what family caregiving means to older caregivers and their social network members directly

or indirectly involved in family caregiving. It is expected that the meaning of caregiving for a white, middle-class married man is different from the caregiving experience of an African-American single woman, a Latino immigrant woman in a three-generational family, or other older adults in other social contexts. People in caregivers' social networks constantly and deeply form the caregiving experience not only through resources but also through interpretation. Identifying characteristics of older family caregivers' everyday social networks and the ways that everyday social networks link to family caregiving in later life, will help to understand how family caregiving in later life as older caregivers and their social network members see it, which may contribute to the demystification of family caregiving in later life.

Second, contrasting with ageism assumptions, this study moved the research focus to a positive vision of family caregiving in later life (Hunt, 2003; Johnson-Dalzine, 2007). My argument in positive family caregiving is that the availability and sustainability of family caregiving as well as quality of life among older family caregivers may rely on their strengths and capacity. Gerontology is not just a branch of human medicine concerned with illness of older adults. It is also about better understanding of strengths and growth among older adults. From positive gerontology perspectives, research on family caregiving in later life can contribute to identifying and nurturing older family caregivers' strongest qualities and can empower them to find niches in which they can best live out these strengths (Seligman & Csikszentmihalyi, 2000). Empirical evidence indicates that family caregiving involves both positive and negative features. Positive features include positive emotions, beliefs, and attitudes like reward, gratitude, satisfaction, closeness, and growth (Brown, 1993, 2007; Grant, 1998; Robertson, Zarit, Duncan, Rovine, & Femia, 2007). When investigating the relations between psychosocial predictors and the course of illness in men with HIV infection, Taylor, Kemeny, Reed, Bower and Gruenewald

(2000) suggested that psychological beliefs such as meaning, control, and optimism act as resources, which may not only preserve mental health in the context of traumatic or life-threatening events, but be protective of physical health as well.

## Purpose of the study and research questions

The debate on health outcomes of family caregiving presents the core proposition of contemporary geriatrics that shapes older adults' images and the social environments in which older adults live. There has been a consistent focus on health costs for older family caregivers. An emerging understanding of family caregivers, however, argues that values and gains are also evident in being part of family caregiving experiences and that social networks link to health outcomes of caregivers (Gerard, Landrey-Meyer, & Guzell, 2006; Goodman et al, 2007; Netto et al., 2009; Nijboer, Triemstra, Tempelaar, Sanderman, & van den Bos, 1999; Nijboer, Triemstra, Tempelaar, van den Bos, & Sanderman, 2001; Pinquart & Sörensen, 2006; Yap, Luo, Ng, Chionb, & Lim, 2010).

The purpose of this study was to better understand the social value of family caregiving in later life by examining effects of social networks and family caregiving in later life on the health of older adults aged 65 and over. Drawing theoretical support from positive gerontology and methodological efforts of social networks analysis (Cohen & Wills, 1985; Kawachi & Berkman, 2001; Minkler, Driver, Roe, & Bedeian, 1993), this study expected to not only revisit the significance of social networks in family caregiving in later life, in particular, and in positive gerontology, in general, but also called for strength-based geriatric social work research and health care policies.

In line with existing research on social networks and the health of family caregivers in later life, the study examined the following three research questions:

Question 1: What are the demographics, social network characteristics, and health status of older family caregivers, compared to other older adults who do not provide family caregiving?

Question 2: How do older family caregivers perceive family caregiving in later life?

Question 3: Are there significant mean differences in health for different levels of social networks and for different family caregiving status after controlling for demographic factors?

#### **Conceptual definitions**

Based on positive gerontology, the current study identified four key concepts respectively older family caregivers, family caregiving, social networks, and health—are the key aspects of the study.

### Older family caregivers

In the current study, *older family caregiver* was defined as any community-dweller who is aged 65 and over and has provided unpaid care for a family member, friend, or neighbor with chronic illness, disability, or other dependent characteristic on a regular basis in the last 12 months. As a concept of positive gerontology, the notion of older family caregivers in this study described caregiving as community-based caregiving, intergenerational caregiving, and family caregiving. As community-based caregiving, the notion of "older family caregiver" highlights the social and physical location of the caregiver, no matter whether the family care receiver is community-dwelled or institutionalized. Literature has suggested that the subjective responsibility of caregiving remains with family caregivers after family care receivers were institutionalized (Hibbard, Neufeld, & Harrison, 1996). In intergenerational caregiving, three groups of older family caregivers are commonly differentiated in research: caregivers of older family members suffering geriatric diseases and/or disabilities, caregivers of adult children or siblings with chronic disease and/or disability, and caregivers of grandchildren under age 18

whose birth parents are absent from parental responsibilities (Greenberg, Seltzer, & Greenley, 1993; Standing et al., 2007). Family caregivers in later life include primary caregivers, secondary caregivers, and other caregivers with different degrees of care involvement. Penrod, Kane, Kane, and Finch (1995) noticed that approximately 7% of the 242 primary caregivers reported caring for the family member alone. Tolkacheva, van Groenou, Boer, and Tilburg (2011) argued that larger caregiving network size, more shared care tasks in the network, and longer periods of shared care contributed to caregivers' lower care burden.

## Family caregiving

An older family caregiver is defined as anyone involved in unpaid care for a kin or a non-kin person. The current study highlighted family caregiving in later life as a social event in which social network members collectively contributed to care responsibility. For gerontological social workers, the social meaning of *family caregiving* contains much potential for resources to be discovered and utilized for better understanding and better services.

It is essential for family caregiving research to define what constitutes care. Literature has contributed to a hierarchy of care that embraces a range of family caregiving activities (Nolan, Keady, & Grant, 1996; Ekwall, Sivberg, & Hallberg, 2004). At the base of this care hierarchy, "personal care" refers to informal help with instrumental activities for daily living. On the next level of the care hierarchy, "instrumental care" is usually defined as informal and nonprofessional help with personal activities for daily living. Although personal care and instrumental caregiving are two dimensions universally accepted by family caregiving literature, what constitutes instrumental caregiving has remained controversial. The majority of geriatric caregiving literature most commonly referred to it as care for activities for daily living or instrumental activities for daily living, especially Activities of Daily Living (ADLs) or

Instrumental Activities of Daily Living (IADLs) (Katz, Ford, Moskonitz, Jackson, & Jaffe, 1963; Lawton & Brody, 1969). Others argued that a geriatric perspective of care dimensions could not reflect a broader notion of family caregiving, which involves child-specific care as well as disabled advocacy (Oktay, 2006). Some researchers have looked beyond personal care and instrumental care in the hierarchy of care. They addressed the importance of care dimensions such as preservative care, anticipatory care, preventive care, supervisory care, protective care, emotional care, reconstructive care, and reciprocal care (Nolan et al., 1996; Oktay, 2006). Based on a sample of 783 older family caregivers, Ekwall et al. (2004) found only a small percentage of the sample provided help with personal care, and the hierarchy of caregiving was described as anticipatory, preventive, supervisory care, instrumental care, personal care, reconstructive care, and reciprocal care. Using gender analytical lenses, Campbell and Martin-Matthews (2003), on the other hand, categorized care activities as traditional gendered care and gender neutral care.

For the purpose of the current study, *care* was defined from five dimensions: personal care, instrumental care, emotional care, informational care, and advocate care. This definition included care from caregivers' daily activities to macro influence. It covered not only the scope of family caregiving research, but also the range of gerontological social work interventions.

## Social networks

In this study, *social networks* were defined as older family caregiver-centered multidimensional social relationships that cut across traditional kinship, residential, and class groups (Barker, 2002; Berkman, Glass, Brissette, & Seeman, 2000; Bott, 1957; Chatters, Taylor, & Jackson, 1985). Social networks is a measurable term for the total of social connections that most often consist of the caregiver's spouse or partner, friends, neighbors, relatives, and members from religious or spiritual and community organizations (Berkman & Syme, 1979;

Lubben, 1988). More specifically, social networks are considered from three distinct dimensions. First, the structural dimension comprises its size, composition, frequency, density, strength of ties, reachability, and reciprocity of the network relationship. Secondly, the content dimension consists of information, values, and behaviors conveyed by network members. Finally, the functional dimension refers to the network's support, conflict, and social control. A supportive social network could be described in terms of connectedness and social integration. Egocentric social network connectedness includes seven network properties: marital status, co-residence, network size, volume of social interaction with network members, closeness to network members, network composition, and network density. Social integration includes three network properties: religious participation, organized group involvement, and volunteering.

As Carpentier and Ducharme (2003) pointed out, a theoretic and empirical distinction should be made between social network and social support. The notion of a social network calls attention to social contexts of social relations among network members and is defined by its structural parameters. On the other hand, the notion of social support emphasizes interpersonal help among network members and is defined by helping behavior from one network member to another to meet physical, psychological, and social needs (Scott & Roberto, 1985). While social network analysis examines how social relations in the caregiver network function through information, values, and behaviors, it targets social support as well as social conflict and social control in which gerontological social work researchers identify and advocate for the strongest qualities of the caregiver and her/his networks.

#### Health

*Health* was defined as highly self-rated health, a high level of physical function, absence of chronic diseases, and absence of depressive symptoms. Social networks analysis of health in

later life concentrates on the structure and composition of the networks, the resources that are embedded within the networks, and their influences on the health of actors in the networks (Berkman et al., 2000; Moren-Cross & Lin, 2006). In this study, the health effects of social networks were linked to actual and perceived physical and mental health of older caregivers. The health effects of social networks contributed to the perceived value of older family caregivers.

#### **CHAPTER TWO: LITERATURE REVIEW**

It is evident that social networks are crucial to understanding how the needs of older adults are met, and how older Americans achieve positive physical and psychological health outcomes (Christakis & Fowler, 2007; Cornwell & Waite, 2009; Lubben & Gironda, 2003; Newsom, Mahan, Rook, & Krause, 2008). Literature has argued that strong social networks are significantly associated with low mortality, high self-rated health, and high levels of cognitive functioning among older patients (Blazer, 1982; Crooks, Lubben, Petitti, Little, & Chiu, 2008; Lyyra & Heikkinen, 2006), and that social support networks play a preventive role in chronic diseases, cognitive decline, and mental diseases (Beeson, 2003; Boden-Albala et al., 2005; Cornwell, Schumm, Laumann, & Graber, 2009; Crooks et al., 2008; Nijboer et al., 2001; Schulz & Beach, 1999; Weiss, 1973). Less is known about family caregivers' social relations and health effects of their personal social networks (Edwards, Higgins, & Zmijewski, 2007). Attempts to examine the intersection among social networks, health, and family caregiving in later life have been rare.

Methodologically, there has been inconsistency in available literature as to how to conceptualize social networks and the mechanisms through which social networks affect healthy aging. For instance, when Pinquart and Sörensen (2007) explained why a meta-analysis of 176 studies indicated weaker associations of social support with physical health than with burden and depression, they considered that most social support instruments were assessing emotional support, which was more likely to correlate with psychological than physical health. While many have referred *social networks* to social network structure, even simply to size of social networks, an effort to integrate the multidimensional concept of social networks has been persistent since the 1970s (Berkman & Syme, 1979; Cornwell et al., 2009; Ekwall, Sivberg, & Hallberg, 2005).

Inconsistency in the understanding of social networks in family caregiving literature has made it even more difficult to determine which social relations older family caregivers have in everyday life, whether or not these relations are different from those of non-caregiving older adults, and how social networks affect health of older family caregivers.

Review of the literature on health effects of social networks of family caregiving in later life suggested that social network analysis of health and family caregiving is an emerging social work approach. Gerontological social work has used social network analysis to study caregiving networks, the role of social support and social capital, and the influence of personal networks on health behavior and information transmission, particularly on help-seeking behavior. However, most network investigations have centered on the elder patient rather than the family caregiver (Barrett & Lynch, 1999; Keating & Dosman, 2009). It was also notable to mention that many recent available family caregiver network data have come from Canada and Europe (Carpentier & Ducharme, 2005, 2007; Lai, 2010; Tolkacheva et al., 2011). In limited caregiver network literature, social network analysis investigated social network structural characteristics and the relationships in the network to determine how social ties influence care burden and stress, health, and the organization of resources of family caregivers.

#### **Caregiving networks**

The current study distinguished *social networks* of family caregivers and *family caregiving networks*. *Social networks* include all network members with whom family caregivers have connections and interactions, regardless of whether or not they were active connections. *Caregiving networks* are also referred to as "helper networks" (Chatter et al., 1985) and "care networks" (Fast, Keating, Otfinowski, & Derksen, 2004; Keating & Dosman, 2009; Keating, Otfinowski, Wenger, Fast, & Derksen, 2003). Caregiving networks, on the other hand, only

focus on those who are involved in family caregiving in the social networks of family caregivers. Keating and colleagues (Fast et al., 2004; Keating & Dosman, 2009; Keating et al., 2003) made a similar distinction between *support networks* and *care networks* and called care networks a functional subset of a support network. In other words, a personal social network served as a pool of caregiving assets, and a caregiving network was an activated care resource within the network. Research and policy could not assess care resources only by size of personal social networks or support networks of family caregivers.

Existing literature on caregiving networks attempted to move research attention from primary caregivers and care receiver dyad to informal caregiving networks. This was a critical shift for family caregiving research because it challenged the assumption that family caregiving was strictly a one-to-one relationship and that the primary caregiver provided a lone and continuous care, isolated from his or her everyday social relationships (Traustadóttir & Sigurjónsdóttir, 2008). Efforts have been made to understand the collective contribution of the family caregiving network to the care receiver as well as to the primary caregiver (Keating et al., 2003; Ray & Street, 2005). Research has demonstrated the key to quality and sustainable family caregiving is its collective nature. More specifically, caregiving networks comprise primary caregivers, secondary caregivers, and helpers of caregivers and it has become part of caregiving networks research (Tennstedt, McKinlay, & Sullivan, 1989; Connidis, 2001; Sims-Gould & Martin-Matthews, 2007).

Literature on the dynamics of caregiving networks reveals that networks were not merely a static social reality. Two themes were particularly important for family caregiving research: the changing caregiving networks and the impact of relational influences within networks. Drawing data from the *Longitudinal Study of Aging* (LSOA), Peek, Zsembik, and Coward (1997)

described changes in caregiving networks of older adults over a two-year period and patterns of network evolution, which were characterized by both stability and change. Carpentier and Ducharme (2005) further investigated support network transformations in the first stages of family caregiving for individuals with dementia. Although this case study could not be generalized to all family caregivers across the life span, it observed two meaningful networks in transition: an adjusted caregiving network that better served the family caregiving function, and a diminished network that exhausted the spousal caregiver. This observation suggested that our understanding and utilization of caregiving networks could have meaningful impact on caregiving capacity and sustainability as well as health of caregivers. Jewell and Stein (2002) demonstrated how parents of individuals with severe mental illness could influence network members, siblings in this case, to be involved in caregiving and caregiving plans.

#### Network characteristics of older family caregivers

Available literature on family care networks has been most interested in structural properties of social networks in relation to the health outcomes of family caregivers. Although social network analysis has investigated network characteristics beyond network structure, the two network properties that have caught most research attention are size and composition of social networks among older family caregivers.

#### Network size

Network size of older family caregivers holds special importance in gerontology. Literature has reached a general consensus that decreased social participation is a common early response to caregiving, which results in feelings of isolation, loss, and frustration (Hibbard, Neufeld, & Harrison, 1996; Carpentier & Ducharme, 2003, 2005; Szinovacz & Davey, 2006, 2007). Based on qualitative data of 30 elderly men caregivers for spouses with cognitive impairment, Russell

(2004) described radical changes in social networks of retired male family caregivers as a shift from a visible and interactive world to an invisible and isolated one.

Across studies, the majority of family caregivers reported having two to three people in their networks who were immediate family members, distanced family members, friends, or neighbors. In a sample of 242 Medicare beneficiaries from 52 hospitals in Pittsburgh, Houston, and Minneapolis/St. Paul, Penrod et al. (1995) documented an average of 2.33 social network members per primary caregiver, with an average of 2.1 network members who shared care responsibilities, and .25 and .69 network members assisting financially and with decisions, respectively. When exploring network characteristics of 602 Dutch caregivers, Tolkacheva et al. (2011) indicated a caregiving network size of 2.76 in the sample. However, other studies reported a larger network size. Greenberg et al. (1993) reported a network size of 7.9 among 313 aging mothers of adults with disabilities. More recently, Haley, Roth, Howard, Monika, and Safford (2010) reported a similar network size (7.2) in a sample of 767 spouse caregivers for whom the authors examined the relationship between caregiving strain and stroke risk.

Although sampling and other study characteristics might contribute to the difference in the reported sizes of caregiver networks, inconsistency in defining networks as well as family caregiving activities have excluded or included some network members in family caregiving studies (Nolan et al., 1996; Ekwall et al., 2004; Oktay, 2006). In a pioneer caregiver network study, Chatter et al. (1985) innovatively portrayed patterns of informal helper networks of elderly blacks. It argued that the majority of the sample (56%) reported a network size of three. Since the study only measured care help in the instrumental dimension, the actual size of social networks among family caregivers would be larger when emotional help is included. More recently, Phillips and Crist (2008) found that over a one-year period network sizes for caregivers

in both Mexican American and non-Hispanic white groups remained the same, while changes happened within network throughout the year of caregiving: loss of about three network members and gain of three new members.

Even though inconsistency exists in caregiver network size, literature has shown that family caregiving in later life, in general, is not isolated. According to Chatters et al. (1985) and Penrod et al. (1995), both national and regional representative data reported a low percentage of caregivers (7%) for family members with post-acute care with no help from anyone else. Chatters et al. (1985) further examined the differences in caregiver network size and found that sex, marital status, and region were significant predictors of helper network size, with older women having larger networks than older men, married persons having significantly larger network sizes than widowed and never married persons, and persons in the South having larger size networks than people in the North Central and Northeast regions.

## Network composition

Caregiving network composition was another area of interest in social network analysis of family caregiving in later life. However, how network composition was structured varied across studies. Sociology and anthropology tended to categorize network composition as kin and non-kin networks. Social capital theory tended to make distinctions between bonding social capital and bridge social capital. In the case of gender studies, literature sometimes used the feminist perspective to define network clusters. For instance, in order to explore the association of gender, sibling network composition, and patterns of parent care, Coward and Dwyer (1990) separated sibling network composition into three types: only-child networks, single-gender networks, and mixed-gender networks. Through this approach, the study found that daughters from mixed-
gender networks reported significantly higher levels of the association of gender and patterns of parent care than daughters from only-child networks and single-gender networks.

Literature most commonly employed sociological approaches when differentiating network composition and concluded that networks composition of older adults could be characterized as family-based, friend-based, diverse, and limited. Chatters et al. (1985) found that the majority of the sampled elder blacks (56%) had immediate family only networks, one-third had mixed networks with immediate family members and others, and the minority (11%) had relatives/nonkin networks. The study also found that lack of close kin network members affected helper network composition, from few kin members to more distant relative and non-kin members, but did not affect the size of helper networks. Since the study only measured care help in the instrumental dimension, the actual size and composition of social networks among family caregivers would be different when emotional support was included in helper network composition. Fiori, Smith, and Antonucci (2007) derived six social network types from the Berlin Aging Study data. Family based and friend based networks emerged as two basic network compositions in all six network types. Using a social capital framework, Keating and Dosman therefore called family members and friends "the building blocks of social capital" in care network of frail seniors (2009).

Literature explained the reason why family members and friends were the building blocks of elderly network composition from sociological approaches. A preference order in the choice of support in caregiving networks is always for the closest available person, cascading through spouse, children, other relatives, and non-kin friends and neighbors (Chatters et al., 1985; Carpentier & Durchame, 2003). Although parents, spouses, and children have been the core of family caregiving networks, recognition and inclusion of siblings, in-laws, friends, and neighbors

in caregiving networks were critical developments in understanding care availability and capacity (Barker, 2002; Fast et al., 2004; Lohrer, Lukens, & Thorning, 2007). Weeks et al. (2009) investigated future plans of parental caregivers for adults with intellectual disabilities and suggested that siblings and other family members were reported as the top candidates of informal caregivers in parents' plans after they died. Based on a random sample of 23,588 from the 2001–2007 Southern Australians Health Omnibus Survey, Burns, Abernethy, Leblanc and Thomas (2011) identified older women acting as friends and neighbors caring for the frail and old. The study related the contribution of friend caregivers to sustainable community living, which was measured by the increased likelihood of the care receiver being able to stay at home.

Social capital theory offered another view of network compositions of family caregiving in later life. Social capital approaches categorized network members as homogenous groups and heterogeneous groups (Keating & Dosman, 2009). According to social capital approaches, homogenous groups had strong and intimate ties, which were well suited to providing social and psychological supports to meet group members' everyday needs. In the past, family groups were typical homogenous groups. They shared a strong sense of identity and reciprocal services. They spent high amounts of time together and exhibited emotional intensity and mutual confiding. Due to homogeneity, close-kin might have been less likely to have new and alternative access for family caregiving. While homogenous groups provided intense levels of family care over time, they also may have mitigated against information exchanges and formal community services (Furstenberg, 2005; Zacharakis & Flora, 2005). In contrast, heterogeneous groups showed more potential for connecting caregiving networks with external assets as well as service information. Therefore, they were better suited to bringing new network assets, including instrumental and informational resources. Non-kin network members, such as friends and neighbors, were typical heterogeneous groups in the network. They often moved between groups and were more likely to provide links to external support. In short, homogenous groups and heterogeneous groups in a caregiving network functioned as two distinct social capitals: *bonding social capital* and *bridging social capital* of family caregiving. As Putnam summarized, these two social capitals reflected various needs of family caregiving in later life: "Bonding is good for getting by, but bridging is crucial for getting ahead" (Putnam, 2000, p.23). Obviously, a resilient and resourceful social network should have diverse social capital to meet emotional, instrumental, and informational needs of family caregivers.

Carpentier and Ducharme (2009) offered empirical evidence that demonstrated how changes in network composition carried significant impact on network care capacity and the well-being of caregivers for family members with Alzheimer's disease. In the first case, the caregiver's network size had remained at eight over nearly two years. The primary caregiver gained one heterogeneous network member while he lost his mother as a close tie due to the development of her Alzheimer's disease. The new friend functioned as a confidant who provided information about the disease and related services, something which his family members were not able to offer. In the second case, the size of the network of a wife caregiver had been downsized from seven to four over a 19-month period while the network composition was changed from two groups (family and friends) to one group (family). Lack of diversity in network composition jeopardized the sustainability of family caregiving, even though the caregiver wanted to believe that she could cope with caregiving challenges without outside assistance (Carpentier & Ducharme, 2005).

## Health effects of social networks

Prior literature has suggested a general consensus that social networks were associated with physical and mental health outcomes. Supportive and diverse social networks were significantly associated with high self-rated health, high levels of physical functioning, and low vulnerability to mental disorders among older family caregivers (Bergman & Haley, 2009; Brown et al., 2003; Crooks et al., 2008; Robison et al., 2009). Early applications of social networks in gerontological studies have claimed that social networks had a direct and independent effect on health in later life (Berkman, 1984, 1986; Berkman & Syme, 1979). More recent empirical evidence has explored the association between family caregiving in later life, social networks, and health. Attempts have been made recently to understand how social networks influence physical and mental health outcomes, including the relationship between health and social network aspects other than network size and/or composition (Carpentier & Ducharme, 2003; 2005; Newsom et al., 2008). Available empirical evidence indicates that the nature of connectedness and social integration, as well as information, values, and behaviors that flow in the network, might explain physical and mental health of older family caregivers as network size, strength of ties, reachability, and reciprocity of the network relationship might do (Gerard et al., 2006; Kim & Knight, 2008; Sit, Wong, Clinton, Li, & Fong, 2003).

Social network literature has indicated mixed results about conventional assumptions that caregiving restricts the social networks of family caregivers and that caregivers experience higher rates of physical, mental, and emotional health problems than non-caregivers. Using a large and representative sample in Australia, Edwards et al. (2007) discovered that family caregivers for individuals with disabilities reported a low level of face-to-face social contact with friends or relatives not living with them. On the other hand, this study also reported that the selfreported hours of family caregiving did not associate with face-to-face social contact among

family caregivers for individuals with disabilities, nor were they associated with their need for more face-to-face social contact with friends or relatives outside of the household. Drawing postal survey data from a probability sample of 4,278 older adults aged 75 years and over in Sweden, Ekwall et al. (2005) found that caregivers had larger social networks and were healthier than non-caregivers. Meanwhile, results from a quasi-experimental study conducted in the U.S. Midwest documented that spousal caregivers of persons with Alzheimer's disease presented greater loneliness and depression, and that loneliness significantly contributed to the explanation of caregivers' depression (Beeson, 2003). This study reported that loneliness was predictive for spousal caregivers of those with Alzheimer's disease, explaining 49% of the total variance. Comparing fathers of adult children with schizophrenia to age-matched peers who did not have children with schizophrenia, Ghosh and Greenberg (2009) indicated that caregivers showed a pervasive pattern of poorer mental health and perceived their health as worse. Some explained that different care conditions and other complicated factors predicted the different associations between family caregiving, social networks, and health. On the basis of a random stratified sample in Italy, Magliano et al. (2006) compared social networks of family caregiving for relatives with schizophrenia and physical illnesses. It suggested that social support is significantly lower for caregivers of relatives with schizophrenia than caregivers of relatives with physical illness and general population.

Available literature has proposed a diverse explanation of the association between social lives and health of older family caregivers. Greenberg, Seltzer, Krauss, and Kim (1997) argued that effects of social networks are not uniform on psychological well-being across groups of aging family caregivers. Their study indicated that, although aging mothers of adults with mental illness had smaller social support networks than aging mothers of adults with mental retardation,

social support network was a more prominent predictor of changes in care burden and depressive symptoms in mothers of adults with mental illness. Magliano et al. (2006) confirmed that the more support the caregivers perceived in a crisis from their social networks, the better their mental health. More specifically, the study measured social support as the perceived crisis support, the perceived routine support, the received crisis support, and the received routine support. It suggested that the perceived crisis support might provide caregivers with a sense of security to mobilize psychological and physical resources to handle the crisis, and that the perception might enable caregivers to receive advice, aid, and affect through their social network to produce positive psychological states, including a sense of purpose, belonging, and recognition of self-worth.

#### Structure dimension

Literature has debated whether family caregivers have a smaller or larger social network than non-caregivers, but generally it has agreed on a significant association between small social networks and low levels of physical and mental health among older caregivers. Greenberg et al. (1997) found evidence that certain social network ties predicted declining well-being and increasing subjective burden. Weeks et al. (2009) reported that when thinking of future plans for the adult child with intellectual disabilities, the first concern of the aging mother was the care capacity within her personal social network. Aschbrenner, Greenberg, Allen, and Seltzer (2010) indicated that a higher number of confidants were positively associated with personal gains among older parents of adults with serious mental illness. Parents who provided more assistance with activities of daily living to their adult children reported higher levels of gains. Lee et al. (2006) assessed direct and indirect effects of social support on health of family caregivers for individuals with schizophrenia. The results of the study suggested that perceived social support was positively related to the health of caregivers, while received crisis support had a positive effect on the caregivers when the care receiver had severe symptoms. Ekwall et al. (2005) found that compared to non-caregivers, caregivers have had not only a higher chance of having a confidant to trust (96.4% of caregivers vs. 94.9% of non-caregivers), but also a larger size of networks (58.5% of caregivers and 52.0% of non-caregivers with three or more persons in their social network). The authors also reported that caregivers had feelings of loneliness less often than non-caregivers and that loneliness and weak social network are significantly associated with low mental quality of life among caregivers as well as in the total sample. Another crosssectional study of 64 family caregivers for individuals with dementia suggested that social interactions with family and non-family social network members have differential effects on the emotional well-being of caregivers (Gideon, 2007). More specifically, higher levels of emotional support from family might tend to reduce overall caregiver emotional distress, while emotional support from non-familial sources might bolster caregivers' optimistic outlook on the experience of caregiving. Rozario, Chadiha, Proctor, and Morrow-Howell (2008) examined the influence of social resources on depression symptoms among 358 urban African-American wives and daughters as primary caregivers. The authors measured social resources by social participation, satisfaction with family functioning, and perceived instrumental support. Multivariate regression indicated that for the older group, satisfaction with family functioning was the only social support variable that was significantly predictive of depressive symptoms, a different pattern of association between social resources and depressive symptoms from the younger group. However, the cross-sectional nature of the study limited its ability to determine whether depressive symptoms were a function of social resources or vice versa (Rozario et al., 2008). *Function dimension* 

Family caregiving literature has long been interested in supportive networks and their health implications. Ample empirical evidence has documented that higher levels of perceived and actual social support was associated with better health, especially fewer depressive symptoms among spousal caregivers, parental caregivers and grandparents raising grandchildren (Gerard et al., 2006; Greenberg et al., 1997; Williams, Williams, Zimmerman, Munn, Dobbs, & Sloane, 2008). Sit et al. (2004) categorized social support into four functional dimensions. Their cross-sectional study found that family caregivers for a relative with stroke received more emotional support and social companionship than tangible support and informational support. It documented that tangible support and social companionship along with physical independency of care receivers explained 36% of variance in the psychosocial health of 102 family caregivers. Clay et al. (2008) provided longitudinal evidence that higher levels of satisfaction with social support were associated with fewer depressive symptoms and increased levels of life satisfaction for African American and white dementia caregivers over a five-year period.

A review of literature on social networks and health of older family caregivers has found an emerging research interest in effects of conflict networks, including positive impact of conflict networks. Some have developed a social network model that employs *ecomap* to visually present supportive and tensioned relationships between caregivers and network members (Neufeld & Kushner, 2009; Ray & Street 2005; 2011). Neufeld and Kushner (2009) conducted an ethnographic study of 39 male primary caregivers for a relative with dementia. They emphasized that observation of family caregivers' experience about supportive and non-supportive interpersonal interactions could sensitize social network members as well as professionals to the context of male caregivers' experience. In a longitudinal sample of 351 adults and older adults in Hong Kong, Fung, Yeung, Li, and Lang (2009) reported positive effects of negative social

exchanges: more negative social exchanges were associated with more positive change in emotional closeness over a two-year period, even after statistically controlling for social support and structural characteristics of the sample and their social partner. Drawing data from the *Late Life Study of Social Exchanges*, a national longitudinal study of 666 older adults, Newsom et al. (2008) provided opposite evidence with more specific measures. They demonstrated that higher levels of stable negative social interactions were significantly predictive of lower self-rated health, greater functional limitations, and a higher number of health conditions over two years after controlling for initial levels of health and sociodemographic variables.

Although literature has not uniformly used social network approaches to explore functional social networks of family caregivers, it has moved empirical inquiry further by employing more cause-specific network measures. Among these measures, co-residence and proximity have been used to explore health effects of social networks. Others have explored social participation, civic engagement, and other variables and their health outcomes. Some of these variables were originally included in the *Berkamn-Syme Social Network Index* (SNI) (Berkamn & Syme, 1979). Among 12 social relationships assessed by SNI, marital status, employment status, religious group membership, organizational participation, and volunteering were often ignored by social network literature in geriatrics, social work, and other related fields. Ekwall et al. (2005) indicated that caregivers in later life were more likely to live together with someone (74.1%)than non-caregiving older adults (34.5%), which contributed to higher self-rated health status and less frequency of the intense feeling of loneliness among family caregivers. Using secondary data from the 1996 Family Caregiver Survey, Chou, Yeung, and Chi (2001) investigated the effect of physical distance between caregivers and care receivers in family caregiving experience, including caregiving strains. Their study indicated different results: caregivers

sharing the same household with care receivers reported higher levels of physical, emotional, and financial strain than other caregivers. It further explained that impact of distance remained after controlling demographic characteristics of family caregivers in this representative community sample of 1,509 caregivers.

Drawing data from the 1998 and 2000 waves of the *Health and Retirement Study*, Choi, Burr, Mutchler, and Caro (2007) used a volunteerism framework to investigate volunteer activities among family caregivers. They found that spousal caregiving was not significantly associated with the likelihood of formal or informal volunteering for men; however, female caregivers were found to be less likely than non-caregivers to have engaged in formal or informal volunteering. It was noticed that the health effect of volunteering was not in the scope of the study.

## Content dimension

Empirical evidence about health outcomes of the content dimension of social networks among family caregiving has been rare, although literature commonly has recognized the importance of health behavior, shared social values, and access to information about services to family caregiving in later life as well as to health of caregivers. More specifically, literature has suggested that health behavior, information channeling, and service use have had direct or indirect effects on health of older adults (Christakis & Fowler, 2007; Lee et al., 2006).

Traditional social network analysis has studied how the ego's health behavior and health were influenced by alters in her or his networks. In the *Alameda study*, Berkman and Syme (1979) found that shared norms around health behaviors within social networks might be powerful sources of mutual influence with direct consequences for the behavior of networks members. They especially examined alcohol and cigarette consumption, health care use, and dietary patterns. In the same line, Christakis and Fowler (2007) observed a densely

interconnected social network of 12,067 people over 32 years and found that obesity spread through social ties. The explanation was that socially close network members shared social norms about the acceptability of obesity and related negative health behaviors (Smith & Christakis, 2008).

Despite proposals for healthy aging and social networks (Berkman et al., 2000; Carpentier & Ducharme, 2007), literature has failed to provide strong empirical evidence about content network characteristics and the association between health and the content dimension of social networks among older family caregivers. For instance, when Castro et al. (2007) conducted an epidemiologic survey study on rural family caregivers and health behaviors it was the first empirical research that focused on information about health behaviors, and self-care habits among rural caregivers. It found that family caregivers reported lower fruit intake, more walking for exercise, and more advice about stress, fruits, and vegetables than non-caregivers, while the two groups did not differ in smoking, dietary fat, and obesity.

Literature recently has paid more attention to the association between information shared in social networks and health of family caregivers. Sit et al. (2004) found that not only was informational support the most lacking area within caregivers' social networks, but also information provided by professionals was not effectively retained. When explaining indirect effects of social support on health of family caregivers for individuals with schizophrenia, Lee et al. (2006) explained that social support might provide information about the disease and clinical knowledge about services, which might alleviate caregivers' mental burden and benefit their mental health. Caldwell (2008), on the other hand, documented that poorer access to health care contributed to poorer mental and physical health among female family caregivers of adults with developmental disabilities.

There has been lack of consistency across studies about how to posit the content dimension of social networks in conceptual and operational models of family caregiving in later life. For example, Sit et al. (2004) and others identified information as one of the functional dimensions of social support. Carpentier and Ducharme (2003; 2005), on the other hand, treated information as one of the network contents that circulated in social networks and shaped caregivers' health. Other examples included health effects of help-seeking behaviors and service use. Available evidence has suggested low rates of service use among older family caregivers. Keith, Wachwe, and Collins (2009), for instance, found that among 224 studied family caregivers, the mean score of utilization of 19 formal elder care services was 2.11 and that family member influence attributed to caregiver resistance to service use.

However, some have argued that debates over health and social network dimensions could be meaningless or lead to prejudice and cultural incompetence if social contexts were not considered in conceptual and operational models (Castro et al., 2007; Hayslip et al., 2006; Letiecq et al., 2008; Neufeld, Harrison, Stewart, & Hughes, 2008; Phillips & Crist, 2008). This argument emphasized that the meaning of certain health behavior and information about certain health conditions and services might vary by gender, racial-ethnic identity, cultural-social values, socioeconomic boundaries, or other social contexts (Kim & Knight, 2008; Kohn & Smith, 2006; Valle, 2004). Umberson and Montez (2010) claimed that social relationships, measured by network size and quality of relationship within the network, have short- and long-term effects on health. They also stressed the importance of social variation in the link between social relationships and health outcomes. Evidence provided by Christakis and colleagues (Christakis & Fowler, 2007; Smith & Christakis, 2008) supported the argument that the meaning of specific health behaviors varied within social contexts.

In summary, a review of literature indicated that knowledge about social networks and health of older family caregivers has been developing over the last two decades, especially in conceptual modeling and methodological inquiry (Ekwall et al., 2005; Keating & Dosman, 2009). Efforts have been made to provide empirical evidence from specific social network characteristics to cultural variations to health effects of social networks (Caldwell, 2008; Fast et al., 2004; Newsom et al., 2008; Phillips & Crist, 2008; Ray & Street, 2011), which will prove valuable for further research.

## Limitations of existing literature

Despite progress in understanding the relevance of social networks to healthy aging of family caregivers over the last few decades, many questions remain unanswered. Little is known about social influence on health of individual older family caregivers at empirical levels, including non-primary caregivers. Attempts to examine the intersection between social networks and health of older family caregivers have been scarce. Available empirical evidence was based on description of structural network characteristics, which was derived from insufficient understanding of the multidimensional nature of social networks. Inconsistency in operational modeling to assess health, social networks, and family caregiving have contributed to limitations in generalization of findings from large representative samples. I describe each of these research gaps briefly below.

#### *Caregiving network*

While literature has come to recognize family caregiving as a collective event, what we know about social networks and their health effects on family caregiving in later life has been narrowed, for the most part, to primary caregivers, particularly family primary caregivers for older adults. There has been lack of evidence about social network characteristics and their

health effects among older adults caring for adult individuals with disabilities and grandparents raising grandchildren. As table 2.1 suggests, little is known about siblings, in-laws, friends, neighbors, and other underrepresented social ties in the caregiving network and their caregiving experience.

## Multidimensional social networks of family caregivers

Many family caregiving studies have failed to capture the multidimensional nature of social networks of older family caregivers. Studies often solely focus on one social network dimension. Social network structure and social support networks were used interchangeably with social networks. Evidence about content and functional dimensions of social networks was rare. Even in the structural dimension, we knew very little about social network structure of non-primary family caregivers, for instance, friend or neighbor caregivers. It was also noticed that research has contained little agreement about size, composition, frequency, strength, reachability, and reciprocity of social networks, social support networks, and caregiving networks.

## Sampling

In their meta-analysis of 176 family caregiving studies, Pinquart and Sörensen (2007) found that only 13% of studies used probability samples while 87% of studies were based on convenience samples. Table 2.1 indicates that only four (22%) studies used probability sampling in this review of a total of 18 published empirical studies on social networks and health of family caregivers. It was noticed that among reviewed studies, only nine studies drew samples from American populations, and two of them used probability sampling.

# Table 2.1

# Research Gaps: Population, Sampling, and Measures of Social Networks and Health

Study	Country	Population	Sampling	Social Networks	Health
Beeson, 2003	U.S.	49 spousal caregivers and 52 non-caregiving spouses	Convenient sampling	Relational deprivation; loneliness measured by the UCLA Loneliness Scale	Depression measured by CES- D
Carpentier & Ducharme, 2005	Canada	2 family caregivers of person with dementia	Non-probability sampling; case study	Relational structure: size, density, and homogeneity; content of interaction: attitudes, values, and behaviors; and functional properties: social support and conflict.	N/A
Carpentier & Ducharme, 2007	Canada	49 older family caregivers of persons	Convenient sampling; interviews	Network size through a name generator; informal and formal	N/A
Castro et al., 2007	U.S.	147 family caregivers for a frail older relative	Probability sampling; regional behavioral risk factor survey	Physical activity, nutrition, tobacco use, preventive health care behaviors	BMI; self-rated health
Edwards et al., 2007	Australia	998 paid primary family caregivers for a person with disability	Convenient sampling; interview the <i>Families</i> <i>Caring for a Person with</i> <i>a Disability Study</i> (FCPDS)	Levels of face-to-face social contact outside of the household	N/A

# Table 2.1 (cont'd)

Study	Country	Population	Sampling	Social Networks	Health
Keith et al., 2009	U.S.	224 primary family caregivers for community elderly with dementia	Probability sampling; regional	Family norms that influence on primary	N/A
Kim & Knight, 2008	U.S.	87 pair Korean American caregivers and non- caregivers	Convenient sampling; interview survey	The quantity and quality of informal instrumental and emotional social support	Physical health measured by self- reported general health, blood pressure, and cortisol levels
Newfeld & Kushner, 2009	Canada		Purposeful sampling; ethnography	Size, composition, strength and direction of social ties, change over time, and the presence of non-supportive and supportive interactions with kin and friends as well as professionals	N/A
Nijboer, 2001	Netherland	148 couples of cancer patients and primary caregivers	Convenient sampling; interview survey	Social support measured by the Social Support List of Interactions	Depression measured by the CES-D
Rozario et al., 2008	U.S.	358 aging African American primary caregivers	Convenient sampling; interview	Social participation satisfaction with family functioning, perceived instrumental support, and availability of secondary informal help	Depressive symptoms measured by CES- D

Table 2.1 (cont'd)

Study	Country	Population	Sampling	Social Networks	Health
Valle, 2004	U.S.	89 dementia caregiver- care recipient pairs (39 Latino and 50 Euro- American)	Convenient sampling; interview	Composition and size of potential and utilized social network; 6 network help- seeking behaviors.	N/A

It is not surprising that findings of health effects of social networks of family caregiving in later life vary depending on study characteristics. For instance, gender differences were larger in probability samples than convenience samples, where they were often biased toward caregivers at high risk. Unfortunately, non-probability sampling prevented the majority of social network studies from inferences about health effects of social networks among older family caregivers. Although small, purposive samples of ethnic groups provided valuable information about populations who were often invisible and challenging to recruit, small and non-random drawn samples made them difficult to make inferences about the characteristics of the population. Future research requires probability samples with established instruments and measures to test health effects of older family caregiver-specific social networks.

### Measures across studies

The examination of social networks and health among older family caregivers has been hampered by the different measures being used to assess social networks and their health outcomes across studies. As table 2.1 indicates, nine relevant studies have investigated the association between social networks and health, but there was no study that used measures of social networks and health that were identical with any others. The only exception was that five studies used the 20-item CES-D to measure depressive symptoms of family caregivers among six studies that examined health effects of social networks in the last two decades. Although CES-D is not specifically designed for the aging population, its wide recognition in gerontology makes it worth considering for future research on social networks and health of older family caregivers in the United States.

In summary, future research can add new empirical evidence to knowledge advancement in social networks and health of older family caregivers. Specifically, research emphasizing the

following four aspects can contribute to our new understanding of social value of family caregiving in later life: (1) identifying contributions of all older informal caregivers to quality and sustainable family caregiving; (2) recognizing multidimensional nature of social networks; (3) using probability sampling in the United States; and (4) contributing to new understanding of the effects of such social networks on physical and mental health of all informal caregivers.

## **CHAPTER THREE: METHODS**

The purpose of this study was to better understand the social value of family caregiving in later life by examining the effects of social networks and family caregiving in later life on health of older adults. This chapter describes the operational model of the study as well as methods employed in its implementation. First, the health effects model of social networks and family caregiving in later life is discussed. This chapter then specifies the research design, survey instrument and measures, and data management and analysis strategies. Population, sampling and human subject protection are addressed.

## **Operational model**

Emerging awareness of inquiry into the health effects of social networks in later life was one of the most significant scientific advances in the field of gerontology at the turn of the 21st century. Various models have provided empirical evidence of the complicated relationships between social networks, health outcomes, and sociodemographic factors of older adults (Cantor, 1991; Sims-Gould & Martin-Matthrews, 2007). Together they have contributed to our conceptual and methodological understanding of social networks and health among older family caregivers.

Originating in Moreno's sociograms (Moreno, 1953), social network analysis models have investigated the relationships among social entities. By focusing on relational patterns and their implications for family and community, social network models have provided theoretical definition and explicit measures of social structural properties (Bott, 1957; Wasserman & Faust, 1995). Since the 1980s, gerontological social work has applied personal, egocentric network models in family caregiving to trace social resources of older adults through kinship and community networks (Chatter et al., 1985; Penrod et al., 1995; Tolkacheva et al., 2011).

Carpentier and Ducharme (2003) gave particular attention to a three-dimensional social network model. This model distinguished and integrated caregiver network structure, content, and function. The authors articulated the explanatory power of the network model as centered on the associations between the structure of the network and the content of the ties. Social ties between the actors created information channels through which knowledge, opinions, and norms flowed, which conceptualized social networks in a way that linked formal and informal support networks of family caregivers (Carpentier & Ducharme, 2003). This multidimensional model indicated that social networks of family caregiving involved transformation in which networks regulated the behavior of their members so that formal and informal supports were complementary to each other (Carpentier & Ducharme, 2003; 2005; 2007).

Berkman et al. (2000) proposed a main effect model of social networks that integrated macro-social context of social networks and micro-psychosocial mechanisms. This model was rooted in community-based studies of health effects of social networks in the 1970s and 1980s (Cassel, 1976; Cohen & Wills, 1985; Kawachi & Berkman, 2001). Evidence from these longitudinal studies confirmed that social ties were significant predictors of lower risk of mortality and mental illness for older adults, independent of age, gender, race, baseline health status, and health behaviors (Berkman, 1984, 1986; Seeman, Kaplan, Knudsen, Cohen, & Guralnik, 1987). It further found that ties with close friends and/or relatives assumed greater importance for older adults than was true for their younger counterparts. This main effect model employed Burt's definition of network models so as to embed egocentric networks in the network structure. Despite its theoretic ambition and statistical infeasibility, this overarching model confirmed that the health effect of social networks could not be assessed without consideration of complex relationships among social networks, family caregiving, and

demographic factors (Berkman et al., 2000). The authors made efforts to examine the influences that structural networks and functional networks had on physical and mental health of individuals at the behavioral level.

The multidimensional social networks model and the main effect model have contributed to our conceptual and methodological understanding of social networks and health among older family caregivers. In the current study, several important aspects from each model were integrated into an operational model, as shown in figure 3.1.

The core of this operational model is that older adults do not perform informal caregiving in isolation, but they are embedded in a network of social relations (Granovetter, 1985). The model conceptualizes social networks as older adult-centered three-dimensional social relationships that affect their physical and mental health. Much effort has been made in this model to investigate how the individual older adult (*ego*) exchanges services and information with his or her network members (*alters*) and how the ego benefits from resources in the network as well as negotiates and challenges social norms and values of the social network (Granovetter, 1973). The model considers age, gender, race, and SES as social-structural conditions of social network influences. Methodologically, this operational model simplifies the main effect model in the way that multidimensional social networks and their health effects are statistically measurable. This model allows the study to determine patterns of network structural characteristics among older family caregivers and non-caregiving older adults, as well as other network factors that predict physical and mental health outcomes.

Figure 3.1

Operational Model of Health Effects of Social Networks and Family Caregiving in Later Life



Adapted from Carpentier and Ducharme (2003) and Berkman et al. (2000).

## **Research design**

In this population-based survey study, a cross-sectional, explanatory survey study design was used to better understand social values of family caregiving in late life by examining the effects of social networks and family caregiving in later life on the health of older adults, aged 64 and over. The data collection method for this study was a paper-pen mail survey. It was administered in three Midwest communities from July to September 2010. The decision to use the selfadministered mail survey as the data collection mode was based on coverage consideration. Research has observed that mail surveys have higher response rates than surveys using a webbased mode, postcard mode, or a web-postcard mixed mode (Kaplowitz, Hadlock, & Levine, 2004). With the increase of households with unlisted telephone numbers and cell-phone-only, a mail survey became a better option to cover more older adults, especially when computer-based, large-scale mailing lists were available (Dillman, Smyth, & Christian, 2009). Although research has studied web-based family caregiver support programs (Glueckauf, Ketterson, Loomis, & Dages, 2004; Marziali & Donahue, 2006), response to an Internet survey would still be limited by relatively low rates of access to a computer, Internet service, and high-speed services among older adults (Czaja & Rubert, 2002; Dillman et al., 2009).

A mailing list of 6,514 non-institutionalized, community-dwelling older adults aged 64 and above in the three research sites was provided by USADATA, a computer-based mailing list provider. USADATA used cut-off ages with two-year intervals. Between two closest cut-off ages, 64 and 66, I choose 64 as the cut-off age for this sample. Using stratified random sampling strategies, I randomly selected 1,000 potential subjects from a total of 6,514 older adults from urban, suburban, and rural areas. Of the 1,000 individuals contacted, 366 completed and returned the questionnaire, which yielded a 36.6% response rate. Two participant selection criteria were

community dwelling and age of 64 and above. Of 366 respondents, 358 met inclusion criteria and were considered as eligible participants. Six respondents were excluded due to being under 64 years old. Two institutionalized respondents were also excluded from the study. The questionnaire consisted of variables of interest in social networks, health status, health care, family caregiving experience, and demographics. The questionnaire is presented in appendix D.

I analyzed the study population using descriptive and multivariate analyses to examine health effects of social networks among older family caregivers. Variables measuring age, gender, race and ethnicity, and SES of older adults were included. Group comparisons were implemented to identify whether caregivers and non-caregivers had different patterns in social networks and health.

## Research sites

This study was conducted in Michigan. Three communities were selected as the research sites for the purpose of maximum representation in geographic regions, residence types, population aging rates, and racial and ethnic diversity. According to the U.S. Census definition, Site 1 Ypsilanti Township (YT) was categorized as a metropolitan area, Site 2 Grand Rapids (GR) suburban, and Site 3 Powers Village (PV) rural. They were located in Southeast, Southwest, and Upper Peninsula regions of Michigan, respectively. The communities' aging rates ranged from 6.1% to 27.5%, and rates of non-white population ranged from 2.0% to 34.7%. The demographic comparison of three research sites is presented in Appendix E.

## Stratified random sampling

Based on the mailing list of 6,514 community-dwelling older adults aged 64 and above, I used Excel 2007 to generate the random numbers for each research site and then sorted the numbers from the smallest to the largest. In order to ensure the most representative data available

that included diversity in race, ethnicity, and residence type, I equally selected the first 15% of the random numbers from Site 1 and Site 2, then oversampled Site 3 by 35% of the random numbers, which created 1,000 potential subjects: 553 in Site 1, 407 in Site 2, and 40 in Site 3. The stratified random sampling process applied in this study resulted in a response rate that varied between 33.1% and 45%, with Site 1 the lowest and Site 3 the highest.

## **Participants**

Community-dwelling older adults aged 64 and above completed and returned 358 mail survey questionnaires. The mean age of the sample was 73.71, ranged from 64 to 95; 95.3% aged 65 and above, and 25.5% aged 80 and above. The sample was 51.4% female, 85.2% non-Hispanic white, and 51.7% urban older adults. Other demographic factors—marital status, education, employment status, and income—are reflected in table 3.1.

Four self-identified groups emerged from a total sample of 358 participants: 82 family caregivers without receiving care (22.9%); 32 caregivers who also received care (8.9%); 21 care receivers who did not provide care (5.9%); and 210 older adults who neither gave nor received care (58.7%). There were 13 participants (3.6%) did not answer the self-identified family caregiving status question.

### **Data collection procedure**

The survey was 12 pages long and used a 14-point font size. It included brief instructions for completion and two open-ended questions. The pretest estimated that on average it would take about 15 minutes to complete the survey. A multiple contact strategy resulted in a total of 366 returned questionnaires, with an estimated 33% increase following the postcard contact.

## Table 3.1

# Demographic Characteristics of the Sample (n = 358)

Demographics	(n)	(%)	
Age			
$<65 \\ \ge 65-79 \\ \ge 80$	16 237 86	4.7 69.7 25.5	
Gender			
Male Female	169 179	48.6 51.4	
Race/Ethnicity			
White/Non-Hispanic Black Native American Multiracial Hispanic	296 34 2 6 9	85.2 9.9 .6 1.7 2.6	
Marital Status			
Single Married/Live with Partner Separated/Divorced Widowed	16 181 70 80	4.6 52.2 20.3 22.9	
Education			
≤ High School High School Some College ≥College	14 72 111 150	4.0 20.9 31.9 43.2	
Employment Status			
Retired, not Work or Schooling Retired, Working or Schooling Working or Schooling Homemaking	267 14 72 12	73.0 3.9 19.8 3.3	

Table 3.1 (cont'd)

Demographics	(n)	(%)	
Income			
<\$25,000 \$25,000–\$74,000 ≥\$75,000	78 161 68	25.4 52.4 22.2	
Residence			
Urban Suburban Rural	185 155 18	51.7 43.2 5.1	

## Recruitment

Based on social exchange theory, I used seven recruitment strategies to influence response rates identified by Edwards et al. (2002) and Dillman et al. (2009): personalized questionnaire, personalized consent letter, multiple contact, first class postage, providing stamped return envelope, a small token, and providing incentive without condition. First, I sent a personalized invitation letter to 1,000 selected subjects to introduce the research study and to pre-notice the upcoming questionnaire. Three days after the invitation letter I sent the survey package to 1,000 subjects. The survey package included the informed consent, a small token of a one-dollar bill, the questionnaire, and a pre-stamped return envelope. A week later, I sent a thank-you postcard to all subjects. The thank-you postcard was served as a thank-you note, a reminder, and notice of availability of replacement questionnaires. Of 366 returned questionnaires, 103 were received after the postcard was sent. I received 19 phone messages and one email to request replacements. I also received five phone calls and four emails to clarify eligibility criteria and sampling strategies. Another 24 returned questionnaires resulted from these phone calls and emails. Figure 3.2 shows the final sample of family caregivers in the study.

## Figure 3.2

The Final Sample of Family Caregivers (n = 358)



## Protection of human subject

An informed consent letter was sent to the randomly selected 1,000 survey subjects. The consent letter used Institutional Review Board (IRB) language, including an explanation of the purpose of the research, procedures used, the time required, the extent of confidentiality, any potential risks and benefits, and the condition that the study would involve entirely voluntary participation. The Michigan State University Institutional Review Board (MSU IRB) for the Protection of Human Subjects had reviewed and approved the proposal, including the study design and procedure, the survey questionnaire, and the informed consent letter. All documents, from the consent letter to the questionnaire, used a 14-point font size. Using the Word Readability Test, the Flesch-Kincaid grade levels of the consent forms and the survey instrument were rated at 5.5.

Additionally, USADATA as a mailing list provider identified older adults aged 64 and above as one of its protected vulnerable groups. Before obtaining the mailing list, I processed its protection procedure to ensure that no older adult's interest was violated.

## Survey instrument and measures

The survey instrument consisted of demographic background, parameters of personal social networks, and parameters of physical and mental health. This survey instrument had been developed and pretested. It contained a total of 58 quantitative measures, seeking to obtain quantitative data regarding health effects of social networks among older family caregivers. All variables were self-reported. Multiple indicators were used to measure independent variables of social networks and family caregiving in later life as well as dependent variables of health. Table 3.2 indicates internal consistency of standardized instruments used in the study (Emlet, 2006; Bakas & Champion, 1999).

## Family caregiving measures

Family caregiving measures identified caregiving status, the relationship between caregiver and care recipient, the primary reason for caregiving, duration of care, care intensity, care distance, and gain of caregiving. Family caregiving measures are presented in table 3.3.

A single-item question was used to investigate perception of family care status: "Do you consider yourself a caregiver for or a care receiver from a loved one (a family member, relative, friend, neighbor or other)?" The response options were caregiver, care receiver, both, and neither. A dichotomous item was created to indicate that the respondent identified himself or herself as a family caregiver (1) or a non-family caregiver (0). To cross examine family caregiving status, respondents were also asked to answer questions as to whether he or she has regularly helped a loved one with 13 caregiving activities over the past 30 days. A summed score of caregiving ranged from 0 to 13. A caregiving score of 1 or greater indicated a caregiving status in this study.

A comparison was drawn between perceived family caregiving status and actual family caregiving status to explore perception of family caregiving among older adults. A dummy variable was created to measure family caregiving status. Those who helped one or more caregiving activities were coded 1, and all others were coded 0. In this study, this variable was the base of group comparison between family caregivers and non-caregiving older adults.

Caregivers were asked the number of care receivers to whom he or she has provided family care. They were also asked the reason for the care and the duration of care. The reasons for care included absence or unavailability of birth parents of grandchild, chronic illness, and disability. Since caregivers might care for more than one family member, relative, friend, or neighbor, three care types were not applicable for percentage calculation.

# Table 3.2

Summary of variables by Name, Instrument, and Esychometric Froperite	Summary o	of Variables b	y Name,	Instrument,	and P.	sychometric	<b>Properties</b>
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Variable	Description	Туре	Instrument	Range	Scale	α	N
Family Caregiving	Caregiving status; 13-item caregiving activities of daily living 10-item Bakas Caregiving Outcomes Scale (Bakas & Champion, 1999)	IV	Perception of caregiving 13 basic activities of daily living Changes in caregiving experience	0–1 0–13 -30–30	Categorical Ordinal Ordinal	.84 .77	346 143 100
Social Networks	18-item Lubben Social Networks Scale (Lubben & Gironda, 2003), 9-item Social Networks Index (Berkman & Syme, 1979), and 10-item Life Events Survey (Holmes & Rahe, 1967).	IV	Naturally occurring personal social networks related to kin, friends, neighbors, church, and community organizations and other informal social groups	0–90 0–12	Ordinal Ordinal	.82 .66	354 310 200
Health Behavior	4-item	IV	Nutrition intake, absence of alcohol misuse, absence of smoking, and physical exercise	0–4	Ordinal	.33	303
Info Channel	2-item human and health service information channel	IV	Information from social networks and professionals	0–1	Ordinal		58
Physical Function	IADL (Lawton & Brody, 1969).	DV	A score of 1 and lower indicates high daily function	0–7		.80	334
Depression	15-item Geriatric Depression Scale (Yesavage et al., 1983).	DV	A score of 5 or above suggests mild to severe depression	0–1		.84	352

## Table 3.3

Family Caregiving Measures

Measures	n	%
Perceived Caregiving Status $(n = 345)$		
Yes No	114 231	33.0 67.0
Caregiving Status ( $n = 358$ )		
Yes No	136 222	38.0 62.0
Number of People Care for $(n = 127)$		
1 2 3–5	82 29 14	64.6 22.7 11.7
Solo Caregiver ( $n = 122$ )		
Yes No ≥ 1 hour	61 61 5	50.0 50.0 3.9
Reason for Care $(n = 136)$		
Grandparents raising grandchildren Elder care Adult child with disability	15 95 34	N/A N/A N/A
Weekly Care Hour $(n = 113)$		
< 9 9–20 21–40 >40	59 24 15 15	52.2 21.2 13.3 13.3

Measures	n	%
Length of Care $(n = 123)$		
< 6 month 6–11 month 1 or 2 years 3 or 4 years 5–9 years $\geq$ 10 years	11 8 30 23 23 26	8.9 6.5 24.4 18.7 18.7 21.1
Other Bakas Caregiving Outcomes Scale (n = 100)	2	1.6
<0 0 > 0	30 17 53	30.0 17.0 52.0

Care distance between the care receiver(s) and the caregiver was measured by co-residence (0), nearby (<60 minutes), and long-distance ( $\geq$ 1 hour). Care intensity was defined by care hours last week. Care duration was measured by the shortest duration (<6 months) to the longest ( $\geq$ 10 years).

*Bakas Caregiving Outcomes Scale-10.* In this study, the 10-item Bakas Caregiving Outcomes Scale (BCOS-10) assessed personal changes, changes in relationship, and higher level gains of family caregivers. The instrument used a 7-point Likert scale from -3 (changed for the worst) to 3 (changed for the best). A summed score ranged from -30 to 30. A score of 0 indicated no change since serving in the family caregiving role. A score <0 suggested negative changes in caregiving experience. A score >0 indicated gains in caregiving. Higher positive scores denoted higher gains in caregiving.

## Social networks measures

Social networks of community-dwelling older adults aged 64 and above were measured by three dimensions within social networks: structure, function, and content.

*Structural dimension.* In this study the Lubben Social Networks Scale-18 (LSNS-18) and Life Events Survey-Short Form (SF-LES) were used to measure the structural dimensions of social networks. They identified participants' network size, composition, strength of ties, reciprocity, and change in networks over time. The LSNS-18 contained three 6-item subscales. They extensively measured the size, frequency, intimacy, and reciprocity of personal social networks related to kinship, friendship, and neighborhood (Luden & Gironda, 2003). The scale utilized a 6-point Likert-type scale, ranging from 0 to 5 to measure. It provided a summed score ranging from 0–90. Individuals with LSNS scores below 36 were considered socially isolated while LSNS scores above 54 were socially highly connected (Lubben, 1988; Emlet, 2006). Meanwhile, this cross-sectional study used a revised SF-LES in an effort to examine changes in social networks over the last two years. The respondents were asked to identify the number of major life events which occurred during the previous two years. Ten life events were categorized as marriage, family and friends, work, finance and residence, health, and learning.

*Functional dimension*. Based on research findings regarding the relationships between health, religion/spirituality-based networks, and community participation, a revised Berkman-Syme Social Networks Index (BSNI) was used to measure social networks related to marital status, quantity and quality of close relationships with relatives and friends, religious/spiritual community membership, and community organization and group membership. Based on the marital status question, a dichotomous item of marital status was created to assess whether the respondent was 1 (currently married) or 0 (currently not married). One dichotomous item was

used to assess whether the respondent had attended religious services in the last four weeks, with 1 (yes) and 0 (no). Three questions were asked to assess intimate relationships with relatives and friends: (1) How many friends do you feel at ease with that you can talk about private matters? (2) How many relatives do you feel at ease with that you can talk about private matters? and (3) How many relatives and friends do you see or hear from at least once a month? The responses to these questions were rated on a 6-point scale: (1) 0, (2) 1, (3) 2, (4) 3–4, (5) 5–9, and (6) 9 and more. Answers of 0–2 then were re-coded as 0, 3–4 re-coded as 1, and other re-coded as 2. Three dichotomous items were used to identify social and civic engagement of the respondents in organizational participation, group membership, and volunteering other than religious membership. If the respondent answered yes to any of questions about organization or group membership or volunteering, the respondent was scored 1. Nine items were summed to create BSNI scores, which ranged from 0 (least connected) to 12 (most connected). Marital status was weighted as 0 (no) or 2 (yes).

*Content dimension*. Information channel and health behavior measures were used to measure the content dimension of the respondents' social networks. The respondents who identified themselves as family caregivers were asked what information channels they used to obtain information about human and social services for family caregivers. Options listed for information channels were social network members, human and health professionals, and media.

Health behavior measures consisted of exercise, nutrition, absence of alcohol misuse, and absence of cigarette smoking. One dichotomous question was asked to measure whether the respondent exercised regularly. The respondent was then asked the type of exercise and the frequency of exercise he or she did each week. Four-item questions were used to assess nutrition intake. A single-item question asked the respondents, "How many full meals do you eat daily?"
The response options were 1–3 and other. The respondents also were asked three dichotomous questions about whether or not they ate or drank three types of dairy products and food within the measured unit and period.

Three questions were asked to identify levels of alcohol drinking within the last month. Alcohol drinking was defined as consuming alcoholic beverages such as beer, wine, or liquor. A dichotomous item was used to identify whether the subject ever drank alcoholic beverages. The responses were 0 (no) and 1 (yes). Two follow-up questions were asked of those who answered "Yes." The first question asked the frequency of drinking: "In the last four weeks, on average, how many days per week have you had any alcohol to drink?" The second question asked the quantity of drinking: "In the last four weeks, on the days you drank, about how many drinks did you have?" As table 3.4 shows, absence or presence of alcohol misuse was determined based on the level of drinking, with response options ranging from 0 to 4 (0=None, 4=Heavy, and 5=Very heavy). The drinking level 4 was defined as presence of alcohol misuse, and all lower levels were indicated as absence of alcohol misuse.

Absence of smoking was assessed by two dichotomous questions: "Have you ever smoked cigarettes?" and "If yes, do you smoke cigarettes now?" Presence of smoking was identified when both answers were 1 (yes). Absence of smoking then was defined as either never smoked or currently not smoking.

### Health measures

Health of older family caregivers was measured by self-rated health, self-reported level of physical function, total number of 13 chronic diseases, and perceived depressive symptoms. The first health measure was self-rated health that was scored on a 5-point Likert scale, based on the question: "In general, would you say your health is excellent, good, neutral, poor, or very poor?"

#### Table 3.4

### Levels of Alcohol Use Based on the Number of Standard Drinks Consumed

	Number of Standard Drinks a Session						
Frequency	0	<1	1	2	3	4	5
≤1 a month	None	Very light	Very light	Light	Moderate	Heavy	Heavy
2–4 times a month	None	Very light	Very light	Light	Moderate	Heavy	Heavy
2–3 times a week	None	Light	Light	Moderate	Moderate	Heavy	Very heavy
$\geq$ 4 a week	None	Light	Light	Moderate	Heavy	Very heavy	Very heavy
Daily	None	Light	Moderate	Moderate	Heavy	Very heavy	Very heavy

Source: Adapted from Moore et al., 1999; Berks & McCormick, 2008.

*Revised Instrumental Activities of Daily Living (IADLs-R).* IADLs-R was used to assess physical function of participants. Seven dichotomous items identified were difficulty of driving, grocery shopping, hot meal preparation, making phone calls, taking medicine, conducting housework, and money management (Lawton & Brody, 1969). Reversed items were summed to produce the IADLs-R scale (alpha=.80). The IADLs-R scale indicated a high daily function and absence of dependency when it was 6 and greater.

*Absence of chronic conditions.* Thirteen dichotomous items were used to assess whether or not a doctor had ever told the respondent that he/she had the following conditions: high blood pressure, diabetes, cancer, chronic lung disease, congestive heart failure, heart attack, stroke, arthritis or rheumatism, hip problem, falls, persistent back pain, persistent headaches, and severe fatigue or exhaustion. The reversed items were summed to produce a scale of absence of chronic conditions (alpha=.65). When the IADLs-R scale and the absence of chronic conditions were summed, the physical health scale measured physical health of the respondents.

*Geriatric Depression Scale-15.* The Geriatric Depression Scale (GDS) was designed specifically for geriatrics. It measures mood, cognitive complaints, and social behavior (Yesavage et al., 1983). The GDS-15 allowed the study to examine a key concern of mental health in family caregiver studies. The GDS-15 in this study contained 15 dichotomous items, each scored 0–15. Responses of 0 (no) suggested absence of depressive symptomatology, while 1 (yes) suggested presence of depressive symptomatology. There were five reversed items in which 0 (yes) indicated absence of depressive symptomatology and 1 (no) indicated a presence of depressive symptomatology. The GDS-15 scores were reflected by the number of 1 (yes) responses. The cut-off score for clinical purpose was 5. A score greater than 5 points was suggestive of depressive symptoms. Scores higher than 5 points warranted a follow-up interview. A score greater than 10 almost always indicated depression.

#### Demographic measures

Large studies have supported the argument that health effects of social networks vary by age, gender, race, and SES factors. In this study, the demographic variables of age, gender, race, and SES were used as control variables. Covariance variables are presented in table 3.1.

The participants were asked their age: "What is your date of birth?" Three age groups were created by ranging respondents' age: under 65, 65 to 79, and 80 and above. One single-item question was used to identify gender of the respondent: "What is your gender?" The responses were 1 (male) and 2 (female). A dichotomous item was used to identify whether or not the respondent was Hispanic: "Are you Hispanic or Latino?" The responses were 0 (no) and 1 (yes). The respondent also was asked, "What is your race?" The responses were coded as 0

(Caucasian/White, non-Hispanic), 1 (Black/African American), 2 (American Indian and Alaska Native), 3 (Asian), 4 (Native Hawaiian and other Pacific Islander), and 5 (Multiracial). In this study, a single-item question was used to assess the level of socioeconomic status: "What is the highest education you have completed?" The responses were coded from 0 (none) to 7 (post master's).

### Data management

Data management strategies were used to ensure voluntary participation, anonymity, and confidentiality. A one dollar bill was included in the survey package, independent of any commitment on the part of the receiver to participate in the study. This was an effort to not influence participants with the small token. All multiple contacts were sent to 1,000 potential participants. Although this action increased the cost of the survey, it ensured anonymity because no identification of the participants was associated with the returned questionnaires in any way. The completed survey questionnaires were mailed to me in a pre-addressed, stamped envelope. As questionnaires were received by me, each was given an identification number and coded according to the research site. The research site of all returned questionnaires was identified from the zip code on the postal stamp outside of the return envelope. The sending date was observed and recorded to monitor the return rates. Eleven participants put his or her return address on the outside envelope. All return envelopes were shredded after the research site information was recorded. The questionnaire data were entered and stored by me in a secure computer, for which a password was required. The returned questionnaires were stored in a locked cabinet. Access to the computerized data and cabinet-stored data was limited to me, the dissertation committee chair, and potentially the university institutional review board for the protection of human subjects.

Questionnaires were reviewed for quantitative and qualitative responses. Qualitative responses included additional notes attached to the questionnaires. All quantitative and qualitative data were entered into the PASW Statistics 18. Quantitative data cleaning was performed for eligibility and missing data. Frequencies were examined to screen for unusual values that would indicate incorrect data entry.

#### Data analysis

The unit of analysis was "individual older adult." In order to test the hypothesized operational model as presented in figure 3.1, I conducted descriptive statistical analyses, simple and multiple regression analyses, and content analysis to answer three research questions. Qualitative data were transformed from a PASW-18 dataset to a Word document. I reviewed and evaluated the data for content analysis. Emergent themes were identified during the data collection period.

Quantitative data were analyzed for caregiver and non-caregiver demographic characteristics, network characteristics, and health. For question one—"What are the demographics, social network characteristics, and health status of older family caregivers, compared to other older adults who do not provide family caregiving?"—I split data by caregiving status comparison between older family caregivers and non-caregiving older adults. Frequencies and measures of central tendency were obtained for demographic and social network characteristics and health status of older family caregivers and non-caregiving older adults. One-way analyses of variance (ANOVA) were performed to test whether there were significant differences in structural social networks and content social networks between caregivers and non-caregivers. *F* values were used for six social network structural variables and the total LSNS scores independently. Chi-

squared tests were used to assess the relationships between functional social networks and family caregiving in later life.

A mixed methods analysis was used to answer question two: "How do older family caregivers perceive family caregiving in later life?" A descriptive statistical analysis of BCOS in family caregiving was conducted to observe quantitative data on changes in family caregivers. A content analysis was conducted to review and code qualitative data on how family caregivers interpreted their caregiving experience. Positive and negative changes were triangulated between BCOS scores and emerging themes to gain both statistically significant and in-depth understanding of perception of family caregiving using older family caregivers' own words.

Question three—"Are there significant mean differences in health for different levels of social networks and for different family caregiving status after controlling for demographic factors?"—was addressed through bivariate correlation analyses, Multivariate Analysis of Variance (MANOVA), and Multivariate Analyses of Variance and Covariance (MANCOVA). First, bivariate correlation analyses were used to examine the relationship between social networks, family caregiving, health, and demographics of participants. Caregiving statuses were entered as dummy variables as the baseline category. Second, MANOVA and MANCOVA were performed to evaluate the effect model of social networks on health of family caregivers in later life if the assumption of homogeneity of regression slopes was assumed. To test the null hypothesis in MANCOVA that the population mean vectors are equal, the research question three was further broken down into three questions, as table 3.5 presented. Finally, a series of univariate ANOVA was performed to test whether there were significant mean differences for each health measure due to social networks and family caregiving after removing the effects of age, gender, race, and SES.

### Table 3.5

# Research questions and data analysis strategies

Research Question	Data Analysis Strategy
1. What are social network characteristics of older family	Descriptive statistics
caregivers, compared to other older adults who do not	ANOVA
provide family caregiving?	F value
2. How do older family caregivers perceive family	Descriptive statistics
caregiving in later life?	Content analysis
	Ecomap
3. Are there significant mean differences in health for	Bivariate correlation analysis
different levels of social networks and for different	MANOVA
family caregiving status after controlling for	MANCOVA
demographic factors?	
3.1. Are there significant mean differences in the	
combined health, as measured by self-rated health,	
physical function, absence of chronic diseases, and	
mental health, for the different levels of social networks	
after removing the effect of age, gender, race, and SES?	
3.2. Are there significant mean differences in the	
combined health, as measured by self-rated health,	
physical function, absence of chronic diseases, and	
mental health, for family caregivers and non-caregivers	
after removing the effect of age, gender, race, and SES?	

Table 3.5 (cont'd)

Research Question	Data Analysis Strategy
3.3 Is there a significant difference for social networks	
and family caregiving on the combined health, as	
measured by self-rated health, physical function,	
absence of chronic diseases, and mental health, for	
family caregivers and non-caregivers after removing	
the effect of age, gender, race, and SES?	

### **CHAPTER FOUR: RESULTS**

Results of the study are illustrated in three parts, organized by three research questions. Research question one is addressed using results from descriptive analyses, ecomap, and oneway ANOVA analyses. Question two is answered through results from triangulation between quantitative and qualitative data of changes in caregiving experiences. Question three is answered through results from effect models of social networks and family caregiving on health of older adults before and after controlling for age, gender, race, and SES.

### Descriptive statistics and preliminary analyses

Tables 4.1 through 4.6 show descriptive characteristics of 136 older family caregivers and of 222 non-caregiving older adults, answering research question one of this study: "What are the demographics, social network characteristics, and health status of older family caregivers, compared to other older adults who do not provide family caregiving?"

### **Demographics**

Table 4.1 reflects four age structural characteristics. The sample had an average age of 73.71. Caregivers were slightly older (72.1%) than non-caregivers (68.6%), and 24.8% of caregivers were oldest old, which was 37.2% of oldest old in the sample. The majority of older adults in both groups were between 65 and 79 years of age. Among all caregivers, male caregivers shared nearly half of family caregiving (45.7%) with female caregivers (54.3%). In the total sample, 48.6% were male, and 51.4% were female, with an estimated gender ratio of 96. Gender ratio among caregivers dropped to 83, while it increased to 102 among non-caregivers. Table 4.1 also shows that older adults across racial and ethnic groups and SES experienced family caregiving with distinctive characteristics.

# Table 4.1

Variable	Caregiver	Non-caregiver	Total
Age	n = 129	n = 210	Mean = 73.71
<65	4 (3.1)	12 (5.7)	16
65–79	93 (72.1)	144 (68.6)	237
≥80	32 (24.8)	54 (25.7)	86
Gender	n = 129	n = 219	
Male	59 (45.7)	110 (50.2)	169
Female	70 (54.3)	109 (49.8)	179
Race	n = 130	n = 217	
White	108 (83.1)	188 (90.9)	296
Non-white	22 (16.9)	29 (9.1)	51
Education	n = 130	n = 217	
≤High school	40 (30.8)	46 (21.2)	86
Some college	36 (27.7)	75 (34.6)	111
≥Bachelor's degree	54 (41.5)	96 (44.2)	150

# Demographic Characteristics of the Sample by Caregiving Status (n = 358)

Table 4.1 (cont'd)

Variable	Caregiver	Non-caregiver	Total
Income	n = 120	n = 189	
<\$25,000	40 (33.3)	38 (20.1)	78
\$25,000-49,999	32 (26.7)	62 (32.8)	94
\$50,000–74,999	25 (20.8)	43 (22.8)	68
≥\$75,000	23 (19.2)	46 (24.3)	69
Marital status	n = 130	n = 217	
Married	77 (59.2)	104 (47.9)	181
Not married	53 (40.8)	113 (52.1)	166
Residence	n = 136	n = 222	
Urban	68 (50.0)	117 (52.7)	185
Suburban	57 (41.9)	98 (44.1)	155
Rural	11 (8.1)	7 (3.1)	18
Co-residency	n = 136	n = 205	
Live alone	41 (30.2)	81 (39.5)	122
Not live alone	95 (69.8)	124 (60.5)	212

Note. Statistics presented in the table are numbers and percentages.

In contrast to non-caregivers, caregivers were more likely non-white (16.9 % *vs.* 9.1%) and low household income (33.3% *vs.* 20.1%). Caregivers were less educated than non-caregivers, with a higher rate of high school education or less and a lower rate of higher education. Caregivers were lower in the levels of the household income, with one-third at the level lower than \$25,000, in comparison to one-fifth of non-caregivers at the same level.

Descriptive analysis found that caregivers were more likely married and not living alone than non-caregivers, with 52.1% of not married non-caregivers and 40.8% of not married caregivers, and 39.5% of non-caregivers living alone and 30.2% of caregivers living alone. Among married respondents, 12.7% of non-caregivers co-resided with people other than their spouse, while this number was 9.1% among married caregivers.

#### Social network characteristics

Table 4.2 presents descriptive characteristics of three-dimensional social networks of caregivers and non-caregivers. Overall, no statistically significant difference was observed in social networks between caregivers and non-caregivers.

### Table 4.2

Dimension	Caregiver	Non-caregiver	Total	Range
Structural	n = 135	n = 221	n = 343	
LSNS	46.90	47.44	47.24	0–90
LSNS-Relative subscale	20.61	20.13	20.31	0–30
LSNS-Friend subscale	16.84	16.99	16.93	0–30
LSNS-Neighbor subscale	11.48	11.16	11.28	0–30

#### Descriptive Statistics of Social Network Variables by Caregiving Status

Table 4.2 (cont'd)

Dimension	Caregiver	Non-caregiver	Total	Range
Size	9.61 (3.42)	10.00 (3.56)	9.85	0–15
Frequency	9.10 (3.13)	9.33 (3.38)	9.24	0–15
Strength	6.44 (3.29)	6.02 (3.22)	6.18	0–15
Help	7.93 (3.43)	8.09 (3.59)	8.03	0–15
Reachability	7.72 (3.72)	7.74 (3.44)	7.73	0–15
Reciprocity	5.49 (3.02)	5.41 (2.92)	5.44	0–15
Content				
Health behavior	2.81 (.98)	2.99 (.91)	2.93 (.94)	0–4
Service use	.73 (.44)	.69 (.46)	.71 (.47)	0–1
Information	n = 32	n = 4		
Network numbers	.55 (.51)	.50 (.58)		0–1
Professionals	.69 (.47)	.50 (.58)		0–1
Functional				
BSNI	6.28 (2.81)	6.13 (2.94)	6.17 (2.89)	0–12
Co-residence	.59 (.49)	.48 (.50)	52 (.50)	0–1

Table 4.2 (cont'd)

Dimension	Caregiver	Non-caregiver	Total	Range
Religious/spiritual participation	.61	.61	.61	0–1
Organization participation	.38	.45	.42	0–1
	(.49)	(.50)	(.49)	
Group membership	.52 (.50)	.58 (.50)	.56 (.50)	0–1
Volunteering	.50 (.50)	.60 (.49)	.56 (.50)	0–1

Note. Statistics presented in the table are means and standard deviations.

Table 4.2 reports descriptive statistics of other structural social network variables. Caregivers and non-caregivers had LSNS frequency scores of 9.10 and 9.33, respectively. They often saw or heard from relatives, friends, and neighbors with whom they had the most contact. Caregivers had higher scores of LSNS strength (6.44) than non-caregivers (6.02). This suggests that caregivers had about six or more confidants with whom they could talk about private matters. LSNS scores for the number of relatives, friends, and neighbors they could call for help were 7.93 for caregivers and 8.09 for non-caregivers. Both groups perceived there were 6–9 relatives, friends, and neighbors whom they could call upon for help. Data revealed that caregivers perceived their network members and confidants had a reachability of "sometimes" or "often" when caregivers had an important decision to make. Reciprocity scores of 5.49 among caregivers and 5.41 among non-caregivers showed that both groups felt their network members "seldom" or "sometimes" talked to them about their important decisions. Generally, descriptive statistics indicated that network size of caregivers was 9–12, but care network size was smaller, at the level of 6 or more. Frequency of network contact was "often," but frequencies of reachability

and reciprocity were only "sometimes." In comparison to non-caregivers, caregivers had slightly lower scores in network size, frequency, help, and reachability, and slightly higher scores in network strength and reciprocity.

Table 4.2 also reports that caregivers had a moderately higher BSNI score (6.28) than noncaregivers (6.13), indicating a relatively higher degree of overall social function. Table 4.2 also indicates that higher percentages of non-caregivers had engaged in organizations, groups, and volunteering than caregivers, while, on average, both had exactly the same degree of religious participation. In line with table 4.1, table 4.2 further suggests that caregivers (mean=.68) were more likely to not live alone than non-caregivers (mean=.61).

*Structural social networks*. Figures 4.1 and 4.2 show the overall differences of structural social networks between caregivers and non-caregivers. They indicate that caregivers have a slightly lower LSNS score (46.90) than non-caregivers (47.44). An estimated 32% of caregivers and non-caregivers were found to have LSNS scores greater than 54; 23.1% of caregivers had an average LSNS score lower than 36, 2.7% higher than non-caregivers. Data indicate caregivers generally presented a similar level of social connectedness as non-caregivers while a higher risk of social isolation among family caregivers was observed.

A close look at three LSNS subscales in figure 4.3 reveals that caregivers and non-caregivers had a similar sized group of relatives, friends, and neighbors in their social networks. Among three network components, relatives were scored highest, with 20.61 for caregivers and 20.13 for non-caregivers, and neighbors were scored lowest with 11.48 for caregivers and 11.16 for non-caregivers. While LSNS subscale scores of relatives and neighbors were slightly higher among caregivers than non-caregivers, LSNS subscale scores of friends were slightly higher among non-caregivers (16.99) than caregivers (16.84).

### Figure 4.1

### LSNS Frequency among Caregivers (n = 134)



Note. Mean = 46.90, SD=16.00. Dotted lines are LSNS cut-off points.

Figure 4.2

LSNS Frequency among Non-caregivers (n = 216)



Note. Mean = 47.77, SD=15.41. Dotted lines are LSNS cut-off points.

Descriptive data analysis found that caregivers and non-caregivers had network size LSNS scores of 9.61 and 10.00, respectively. Every caregiver and non-caregiver, on average, had 9–12 relatives, friends, and neighbors in his or her network. This network size had taken into consideration changes within networks during the prior two years. Table 4.3 shows changes in social network structure in the last two years between caregivers and non-caregivers. It indicates that caregivers generally experienced more radical changes in social networks during the past two years: 42.2% of caregivers and 32.5% of non-caregivers had lost an immediate family member; 62.6% of caregivers and 51.2% of non-caregivers had lost one or more close friends. Meanwhile, higher percentages of caregivers gained new family members (63.7%) and had started school, training, or other learning (12.8%) than non-caregivers (45.8% and 10.6%, respectively).

#### Figure 4.3



Average Social Network Structural Characteristics by Caregiving Status

Note. All variables recoded on 15-point scale.

### Table 4.3

# Changes in Social Network Structure by Caregiving Status

Change	Caregiver	Non-caregiver
Loss of spouse		
No	70 89.7	125 89.3
Yes	8 10.3	15 10.7
Loss of an immediate family member		
No	52 57.8	104 67.5
Yes	38 42.2	50 32.5
Loss of a close friend		
No	37 37.4	79 48.8
1	39 41.5	63 38.9
2	10 10.6	13 8.0
3–6	8 8.5	7 4.3
Gain in new family members		
No	33 36.3	83 54.2
Yes	58 63.7	70 45.8

Table 4.3 (cont'd)

Change	Caregiver	Non-caregiver
Beginning school, training, or other learning		
No	68 87.2	126 89.4
Yes	10 12.8	15 10.6
Change in number of family get-togethers		
No	53 63.9	101 68.2
Yes	30 36.1	47 31.8
Change in social activities		
No	55 64.7	110 77.5
Yes	30 35.3	32 22.5
Marriage		
No	64 83.1	121 89.6
Yes	13 16.9	14; 10.4
Marriage separation or divorce		
No	70 92.1	127 94.1
Yes	6 7.9	8 5.9

Table 4.3 (cont'd)

Change	Caregiver	Non-caregiver
Spouse major illness		101
No	57	121
	62.0	86.4
Yes	35	19
	38.0	13.6
Diagnosis of a severe disease of a loved one		
No	45	102
	53.6	65.0
Yes	39	55
	46.4	35.0
Legal issue of a network member		
No	61	124
	81.3	89.9
Yes	14	14
100	18 7	10.1
	10.7	10.1

Note. Statistics presented in the table are numbers and percentages.

*Content social networks*. In this study, health behavior, service use, and information channel were measured to examine the content of social networks of the sample. Descriptive data analyses indicated that, except for one caregiver and two non-caregivers, all respondents had health insurance. A lower percentage of caregivers (27.4%) reported to have four health behaviors—namely, nutrition intake, physical exercise, absence of alcohol misuse, and absence of smoking—than non-caregivers (34.4%). Of caregivers who had health condition(s), 26.5% did not undergo treatment. In comparison, this number was 31.0% in the non-caregiver group. Table 4.4 presents more details about this comparison.

### Table 4.4

Variable	Caregiver	Non-caregiver
Health behavior	(M=2.81)	(M=2.99)
4	37 27.4	75 34.4
2–3	86 63 7	132
0–1	12	11
Treatment use	8.9 (M=.73)	5.0 (M=.69)
No	35	66
Yes	26.5 97	31.0 147
	73.5	69.0

### Frequency of Health Behavior and Treatment Use

Note. Statistics presented in the table are numbers, percentages, and means.

In addition, 20 caregivers (14.8%) used human and health services for family caregivers in the past year. The other 115 caregivers either did not use family caregiving services (85.2%) or did not answer the question about family caregiving service utilization (20.7%). Fifteen caregivers (11.0%) never knew family caregiving services were available. Of caregivers who used family caregiving services, 39.9% reported that they had obtained information about family caregiving services through both professionals and social network members; 32.3% of caregivers reported that they had obtained information exclusively from social network members; and 37.8% had obtained information exclusively from professionals. Table 4.4 reports means of health behavior and service use between caregivers and noncaregivers. Caregivers reported an average of 2.81 health behaviors, in comparison to 2.99 reported by non-caregivers. In contrast, caregivers appeared to have a slightly higher service use rate (0.73) than non-caregivers (0.69) when treatments for their health conditions were considered.

#### Table 4.5

Number of Co-residents	Caregiver	Non-caregiver
0	41 (32.0)	80 (39.2)
1	67 (52.3)	107 (52.5)
2	15 (11.7)	14 (6.9)
3–5	4 (3.9)	3 (1.3)

*Co-residency by Caregiving Status* (n = 358)

Note. Statistics presented in the table are numbers and percentages.

*Functional social networks*. A revised Berkman-Syme Social Network Index (BSNI) was used to investigate functional social networks. Table 4.5 presents numbers of co-residents among caregivers and non-caregivers. Caregivers were less likely than non-caregivers to live alone and more likely to live with two and more people than non-caregivers. Figure 4.4 breaks down the BSNI scores into four levels. It suggests that non-caregivers presented higher percentages at both the most functional level (31.67%) and the least functional level (6.79%) than caregivers (30.37% and 5.19%, respectively). It also showed that although caregivers presented a lower risk of being least functioning, 29.63% of them were at the medium low functional level, indicating marginal risk of social dysfunction.

### Figure 4.4

Functional Social Networks by Caregiving Status (n = 356)



Note. Statistics presented in the table are percentage.

Results from social network analyses answer research question one: "What are social network characteristics of older family caregivers, compared to other older adults who do not provide family caregiving?" Using ecomap, figure 4.5 summarizes key social network characteristics of family caregivers in this study. It indicates that a typical family caregiver in the sample had a range of 9–12 members in his or her social networks, consisting of relatives, friends, and neighbors, with medium high social functioning. More than a quarter of caregivers practiced health behaviors, and the majority of them used treatments when they had health conditions. They obtained treatment information from both network members and professionals, with a preference for professionals.

### Figure 4.5



Ecomap of Social Networks of Family Caregivers in Later Life (n = 136)

## Health status

Table 4.6 reports results from descriptive statistics. It reveals that the majority of family caregivers reported excellent or good health, high physical function, and good mental health.

Almost one in five family caregivers rated their global health as excellent, more than half of caregivers identified their health as good, 75.4% reported high daily function, and 76.9% reported being mentally healthy. Results, however, also suggest that higher percentages of caregivers were at risk for problems associated with physical function, diseases, and depression; for example, 15% of caregivers reported their health as poor or very poor, which was higher than non-caregivers (8.3%). Results from other health indicators confirm this finding. In comparison to non-caregivers, higher percentages of caregivers were found to have some degree of dependency and total dependency. Similarly, data analysis found that 84.6% of caregivers reported that they had two or more chronic conditions, 10.4% higher than non-caregivers. It also found that 17.2% of caregivers had GDS scores of 6–10, and 5.9% had scored greater than 10. Both were higher than non-caregivers (10.7% and 3.8%, respectively).

An Analysis of Variance (ANOVA) was conducted to further examine whether there were significant health differences between family caregivers and non-caregivers. Table 4.7 provides the results of ANOVA. It indicates significant health differences between two comparison groups, especially in terms of physical function and absence of chronic diseases (p<.001).

In summary, results from caregivers' demographics, social network characteristics, and health outcomes provide rich information about social networks, health, and family caregiving in later life. Family caregivers presented strengths in all three dimensions of social networks. Compared to non-caregivers, family caregivers showed a higher level of social function, stronger and reciprocal relationships with family, neighbors and friends, and a higher rate of service use.

### Table 4.6

Health	Caregiver	Non-caregiver	Total
Self-rated health			
Excellent	26	41	67
	(19.5)	(19.0)	(19.2)
Good	74	133	207
	(55.7)	(61.5)	(59.3)
Neutral	13	33	40
	(9.8)	(15.3)	(13.2)
Poor or very poor	20	9	29
	(15.0)	(4.2)	(8.3)
IADLs-R			
≥6	101	202	303
	(75.4)	(93.1)	(86.3)
2-5	27	10	37
	(22.1)	(4.6)	(10.6)
≤1	6	5	11
	(4.5)	(2.3)	(3.1)
Number of chronic conditions			
≤1	22	56	78
	(16.4)	(25.8)	(22.2)
≥2	112	161	273
	(84.6)	(74.2)	(77.8)

# Descriptive Statistics of Health Variables by Caregiving Status

Table 4.6 (cont'd)

Health	Caregiver	Non-caregiver	Total	
GDS				
<5	103	183	286	
	(76.9)	(85.5)	(82.2)	
6-10	23	23	46	
	(17.2)	(10.7)	(13.2)	
>10	8	8	16	
	(5.9)	(3.8)	(4.6)	

Note. Statistics presented in the table are numbers and percentages.

### Table 4.7

# Analysis of Variance for Health between Family Caregivers and Non-caregivers

	Mean			
Health Outcomes	$d\!f$	Square	F	р
	Between	groups		
Self-rated health	1	2.73	3.85	.05
Physical function	1	34.41	19.25	.000
Absence of chronic diseases	1	107.13	22.39	.000
Mental health	1	105.48	10.11	.002
	Within	groups		
Self-rated health	347	246.21		
Physical function	349	623.95		
Absence of chronic diseases	349	1669.95		
Mental health	346	3608.51		

Comparisons also suggest that higher percentages of family caregivers were at risk of social isolation, absence of health behaviors, and least social function. Descriptive statistics and preliminary analyses demonstrate the differences in demographic characteristics and health status between family caregivers and non-caregivers.

### **Results from mixed methods**

Quantitative and qualitative data were obtained through use of a standardized instrument, BCOS, in family caregiving and two open-ended questions to address research question two in the study: "How do older family caregivers perceive family caregiving in later life?" A total of 99 participants rated the BCOS scale to indicate changes they had experienced since serving in the family caregiving role. A total of 56 participants answered two open-ended questions. Responses from open-ended questions triangulated results from quantitative analysis of BCOS scores to ensure validity and reliability of data. The results of mixed methods presented below include either quantitative or qualitative analysis or a combination of both data analyses. *Results from quantitative analysis* 

Table 4.8 details results from mean tests of the total BCOS scores. The total BCOS scores ranged from -23 to 30, with an overall mean BCOS score of 4.47. It compares BCOS scores to examine whether or not family caregiving experience in later life was different for different geographic residences. Urban caregivers reported the biggest range of caregiving experience, from -23 to 30, representing a broad range of experience, from very negative change to most positive change, as result of caregiving. Rural caregivers reported no change or positive changes due to family caregiving. Suburban caregivers reported changes ranging from -8 to 29, a narrower range, leaning more toward positive changes.

An ANOVA test indicates that changes in family caregiving experience between three types of residence were not statistically different, with F=2.67 at p=.08. Overall change and changes in three resident areas were positive, with mean scores of the sample and three sub-samples above 0, ranging from 2.95 in the urban area to 13.60 in the rural area. When specific BCOS items were examined, the only negative item was "My time for family activities" in the urban area. *Results from qualitative analysis* 

To triangulate results from quantitative analyses, the qualitative data were analyzed using content analysis techniques. The raw data were obtained from narrative responses to the two open-ended questions. Open coding was used to conceptualize the raw data. The raw data were documented in a Word file for a line-to-line coding. 21 codes were identified, for they repeatedly occurred across lines and cases. A code was identified when it occurred equal to or more than two times across cases. Axial coding was then performed to review the initial codes from open coding. 12 themes emerged in the axial coding. Three categories were detected from themes. Figure 4.6 shows the coding process and coding paradigm.

*Caregiving*. In responding to two open-ended questions "How does caregiving make you feel?" and "In general, how has your life changed as a result of family caregiving?" caregivers described their caregiving background, especially care relations, care demand, care activities, and care receiver's health condition. Caregivers reported the distance to their care receivers. They explained the years of caregiving and weekly care hours. Some mentioned caregiving activities related to IADLs and ADLs. One wife listed care activities as lifting her husband and bowel excrement cleaning. One reported that "I manage finances for my mother-in-law who lives in a nursing home."

Care activities and health conditions of the care receiver were often talked about simultaneously. It was noted that among six respondents who discussed care activities, two articulated the importance of emotional care. One emphasized, "I care for my life partner emotionally." One husband saw himself as "more of an emotional supporter than caregiver. I try to keep my wife's mood high." It is because he identifies "(...) memory loss and emotional stress are the biggest (concern) of the carer so far."

Qualitative data reveal that in the majority of cases family caregivers were solo caregivers or permanent caregivers of care receivers. In some cases they were partners of formal health care providers. A wife caregiver took care of her husband before he went to a nursing home, and between nursing home stays: "He was kicked out (of) the last one because he is an extremely difficult patient."

Caregivers recognized the importance of family caregiving for community living in later life. A daughter caregiver articulated this best: "She is 94 and living independently with support from us. She wants to stay in her home, and we are happy to help her realize this." She went on to say "Life is wonderful! I have the time and enjoy (thank God!) doing all that I want and have to do." A long-term caregiver signified the meaning of caregiving in his life: "Magnificent part of life, I care for my life partner emotionally. Huge part of my and our life together." He went on to criticize society for overlooking caregiving: "I realize how much one benefits from caregiving, and how truly little society cares about such things in an emotionally, meaningful way."

### Table 4.8

# *Mean Scores of Changes in Family Caregiving Experience in Later Life* (n = 99)

Variable	Urban	Suburban	Rural	Total
Caregiving outcome score	2.95	5.46	13.60	4.47
	(10.33)	(10.25)	(13.58)	(10.63)
Caregiver well-being				
My self-esteem	.56	.71	1.20	.65
	(1.28)	(1.09)	(1.10)	(1.20)
My physical health	.14	.31	1.00	.25
	(1.53)	(1.38)	(1.41)	(1.46)
My emotional well-being	.38	.62	1.40	.52
	(1.51)	(1.35)	(1.52)	(1.46)
My ability to cope with stress	.25	.26	1.40	.32
	(1.60)	(1.14)	(1.52)	(1.44)
My future outlook	.12	.67	1.40	.40
	(1.49)	(1.45)	(1.52)	(1.51)
Family relations				
My relationship with family	.90	.86	2.00	.95
	(1.56)	(1.59)	(1.41)	(1.57)
My relationship with care recipient(s)	.81	1.23	2.40	1.07
	(1.65)	(1.67)	(1.34)	(1.68)
My time for family activities	20	.25	.80	.02
	(1.63)	(1.24)	(1.92)	(1.53)
Relations with friends				
My relationship with friends	.29	.75	1.40	.53
	(1.37)	(1.16)	(1.34)	(1.31)
My time for social activities with friends	.00	.53	.60	.24
	(1.65)	(1.44)	(1.95)	(1.59)

Note. Standard deviations are in parentheses.

### Figure 4.6

Coding Paradigm of Perceived Family Caregiving Experience in Later Life



It was important to discover what caregivers articulated as the reason why they engaged in family caregiving in later life. The top three rationales were obligation, giving, and reciprocity. Among 12 respondents who rationalized caregiving as *obligation*, three respondents used "duty," two used "family obligation," and another two used "responsible" to state the reason for caring for a family member. Similar phrases used include "I have to" and "It is the right things [thing] to do for those you love." A long-term caregiver described his spousal caregiving experience as, "Complete, I feel like I have a reason for being alive." Thirteen respondents rationalized their caregiving as giving. A long-distance caregiver said: "I do like to help or give." Many indicated that they felt good to help. Six caregivers explained caregiving in later life as *reciprocity*. A male caregiver for his ill parent declared, "It is time to return the love and care that was given to me!" An 84-year-old husband stated the rationale for his caregiving was to "repay my wife." A longterm caregiver described her caregiving as "-helping my husband who helps me." A solo family caregiver explained the reason she has cared for her mother and step-father: "I feel they raised me and I have to take care of them." A retired math teacher who cared for her mother with the help of siblings said: "She has always been there for her children, and now it is our turn!" It was noticed that the reciprocity theme did not emerge exclusively from spousal caregiving and adult child caregiving. A care receiver articulated reciprocity in family caregiving: "My support network and I exchange giving/receiving help from each other." An 86-year-old, life-long caregiver described giving and receiving in her life: "Makes me happy to help others! Appreciation for help I received after a knee replacement."

*Social networks*. Two open-ended questions did not specifically mention social networks of caregivers, but social networks were described by respondents when their family caregiving experience was presented. An 86-year-old wife caregiver mentioned her parents and parents-in-

law, neighbors who lived alone or needed assistance, and others. The retired teacher mentioned her mother, siblings, and grandchildren in her social networks. A newly widowed woman described her grief related to a smaller network size due to the loss of her mother and husband. One explanation for this phenomenon is that social networks were essential in family caregiving and that caregivers recognized their significance from both positive and negative approaches.

Four respondents repeatedly described care networks a total of six times. An urban woman constructed a care network of five siblings, with one sister living in town, one sister living outside of the town, one sister living out of state, and two working brothers. She detailed how she and her sister in town shared the care hours, how her sisters out of town provided long-distance care to their mother, and how her brothers and other sisters provided respite care to her and the sister in town on weekends. Although conflicts in care networks were only mentioned twice, conflicted relationships stood out for the strong emotion they carried. A veteran discussed stress caused by network conflicts: "Stress (one of three siblings has own agenda—will not listen to others.)" A woman was angry that "no family members lifted a finger to help me."

*Changes.* It was evident that caregivers indicated many changes as a result of family caregiving. A widow who had cared for a friend for over five years said, "I had changed my life very, very much." Changes in social life, emotional experience, and positive effects were reported. The theme of changes in social life emerged from two codes—*changed social life* and *better relationships.* Qualitative data suggest that caregivers' social lives changed in two directions. Three family caregivers stressed that their social lives were limited due to caregiving. A daughter caregiver for her older parents cried out she was "tired and alone!" A female caregiver for her co-resident parent reported "Social life has suffered—don't get any time away." A 66-year-old grandmother caring for three school-age grandsons also mentioned that "social

activities (are) limited." Others suggested caregiving led to greater connectedness with a greater society. An older mother of two adult daughters with intellectual disabilities reported her high involvement in disability advocacy because she made caregiving her cause. She exclaimed, "We are very active in disability ministry, in disability advocacy, and disability housing. We seek to raise awareness of the value of persons with disabilities, especially intellectual disabilities." A 71-year-old volunteer legal guardian and caregiver also made caregiving a social cause.

More respondents reported better relationships with the care receiver and their family. A 75year-old man who has been caring for his ill parent and disabled adult child mentioned caregiving made him "closer to family members!" A husband caregiver said that caregiving made him have "more time with my spouse." A 90-year-old husband was thankful "to appreciate more and love more the person-spouse... share so much time together." A sibling caregiver also expressed: "I love my brother even more."

Strong emotions were expressed by caregivers. Anger and guilt were displayed in narratives, but they were not repeated across cases or within cases. Four emotions repeatedly occurred: *exhaustion, stress, lack of sense of control,* and *loss and grief.* Eight respondents used "tired," "overwhelmed," "lack of sleep," or "physically taxing." Two said they "sometimes" experienced tiredness. Others did not specify the frequency of exhaustion. Stress was another emotion frequently described by respondents. "Stress," "frustrated," "worried," and "concerned" were used to express caregivers' feelings. Lack of sense of control was described four times in qualitative data. A son caregiver described how his life had changed as a result of caregiving: "There is not as much personal time." A daughter caregiver expressed: "My life is no longer my own." Caregivers also described their loss and grief over death and sickness. An 86-year-old woman expressed that she was "concerned for person's suffering." A bereaved woman who had

lost her mother and husband shared her grief: "Sad @ [at] times when I knew death was closer each day." A mother described that she was "distressed (because) my 2 (two) daughters are very sick."

Despite strong emotional experiences, respondents overwhelmingly articulated the positive effects family caregiving had on their lives. Caregivers described related positive feelings and personal growth related to caregiving: 21 respondents used words like "happy," "feel good," "great," satisfied," "positive," "better," and others 31 times. Night caregivers detailed their growth. An 81-year-old caregiver reported that caregiving resulted in him "being more responsible, being more on schedule." A great-grandmother said that co-caregiving for her two great-grandchildren "keeps me active and unselfish with my money, living space, and time." Similarly, a son caregiver expressed that caregiving made him understand life and love more. He spoke of the "Chance to discover how fragile we are! Show and practice more love!" A female caregiver successfully managed to "serve as a volunteer legal guardian and caregiver for family members and friends" while she underwent chemo therapy, which facilitated her growth. *Triangulation* 

Results of qualitative and quantitative data point to the same conclusion: Older caregivers have made positive changes as a result of family caregiving experience. BCOS scores indicated the highest gained items were the relationship with the care recipient, the relationship with family, self-esteem, the relationship with friends, and emotional well-being. From the qualitative data analysis, the codes with the highest frequencies (13–31 responses) were positive feelings, giving, obligation, better relationships, and growth. As Jick (1979) argued, triangulation of multiple methods was largely a vehicle for cross validation. The convergence of the results from
BCOS scores and two open-ended questions provided a more valid conclusion about changes in caregivers' well-being and relationships.

While BCOS scores yield comparable data with existing family caregiving studies (Bakas & Champion, 1999), qualitative data collected by two open-ended questions added rich and authentic details to the study. Codes and themes provided insights as to how caregivers interpreted the meanings of caregiving, which explained changes in caregivers' well-being and relationships. This shed light on altruism, obligation, and reciprocity and the positive feelings they brought to the caregiving experience. Qualitative data not only reached the same conclusions about changes in caregivers as quantitative data indicated, but also added a deep understanding of these changes in caregivers' own words. First, negative emotions like anger, guilt, and distress were rare but powerful. Gerontological social work must cautiously address their harmful effects. Secondly, active social engagement with family and society co-existed with lack of sense of control. The mother of adult daughters with severe intellectual disabilities exemplified the best of caregivers, who take control over health conditions and contributed to a greater cause.

### **Effect modeling**

For the purpose of testing the effect model, table 4.9 displays results from bivariate correlation analyses among the variables included in the effect model, including covariance variables, age, gender, race, and SES. The table reveals that there were significant correlations between family caregiving and three of four health measures, structural social networks and two health measures, content social networks and two health measures, and functional social networks and three health measures. Specifically, family caregiving was negatively associated with physical function, absence of chronic diseases, and mental health, with p<. 001. All three

dimensions of social networks were positively and significantly associated with self-rated health (p<.001). Structural social networks were positively associated with mental health (p<.05). Content social networks were positively associated with absence of chronic diseases (p<.05). Functional social networks were positively associated with physical function and mental health (p<.001).

Table 4.9 also indicates that SES was the most significant factor for health of older adults in the sample. It was positively associated with social networks and self-rated health, and was negatively associated with physical function and lack of chronic diseases. Age was negatively associated with self-rated health and positively associated with physical function and absence of chronic diseases. Gender was negatively associated with functional social networks and positively associated with absence of chronic diseases. Race was not significantly associated with any health indicator. The model then answered: "Are there significant mean differences in the combined health, as measured by self-rated health, physical function, absence of chronic diseases, and mental health, for different levels of social networks between family caregivers and non-family caregivers, before and after removing the effects of age, gender, race, and SES?"

To test null hypotheses in multivariate analysis, a preliminary MANOVA found that the Box's Test was significant (p<.001). The Pillai's Trace then was used for MANCOVA results. The preliminary MANOVA observed that social networks and family caregiving interaction was not significant (p=.31), indicating the main effect of social networks and family caregiving could be interpreted accurately by examining the *F* ratio, *p* values, and effect sizes for the associated test statistic.

Results from multivariate analysis are reported in table 4.10. Overall, the table reveals that both social networks (p<.001) and family caregiving (p<.001 or .05) in later life significantly

affected health of the older adults in the study. The significance of health effects of social networks did not change after controlling for age, gender, race, and SES independently or combined, while the significant level of effect of family caregiving was reduced from p<.001 to p<.05 when age of family caregivers was controlled or when the effects of the combined age, gender, race, and SES were removed.

Table 4.10 further indicates that the effect model in MANOVA has a Partial  $\eta^2$  of .68, p<.001. When controlling for age, gender, race, and SES, the effect models in MANCOVA have a Partial  $\eta^2$  ranging from .14 to.67, p<.001. According to Cohen (1988), the benchmark for a small effect size is the effect-size measure  $\eta^2 = .0099$  or Partial  $\eta^2 = .01$ , a medium effect size of  $\eta^2 = .0588$  or Partial  $\eta^2 = .09$ , a large-effect size of  $\eta^2 = .1379$  or Partial  $\eta^2 = .25$ . A Partial  $\eta^2$ ranging from .14 to .67, p<.001 suggests that social networks and family caregiving had significant effects on health of family caregivers in later life, independently of age, gender, race, and SES.

Table 10 also reveals that the demographic factors of age, gender, race, and SES both individually and collectively reduced effects of social networks and family caregiving on health of older adults in the study, but they only reduced the effect sizes from a large one to a medium one. Table 4.10 suggests the effect of social networks and family caregiving gender reduced Partial  $\eta^2$  from .68 to .14 when removing combined effects of age, gender, race, and SES.

To determine whether there were significant mean differences for each of the four measures of health among different levels of social networks after removing the effects of age, gender, race and SES, results from descriptive statistics and tests of Between-Subjects effects of MANCOVA and Post Hoc tests are displayed in table 4.11.

# Table 4.9

# Correlation Matrix for Major Variables of Interest

	1	2	3	4	5	6	7	8	9	10	11	12
1	_											
2	02	_										
3	.05	.11*										
4	.02	.71**	.08	_								
5	11	.18**	.18**	.23**								
6	23**	.12*	.09	.20**	.38**	_						
7	25**	.06	.12*	.08	.53**	40**						
8	17**	.13*	.02	.20**	.36**	31**	31**					
9	.02	07	.03	13*	12*	.24**	.13*	.10				
10	.05	07	.01	13*	10	.09	.10*	.07	.10			
11	03	12*	06	14**	06	01	.02	.06	10	.10	—	
12	08	.16**	.13*	.25**	.23**	19**	14**	08	20**	32**	04	—

Note. Twelve variables above represent as 1. Caregiving status; 2. LSNS; 3. Health behavior; 4. BSNI; 5. Self-rated health; 6. IADLs—R; 7. Absence of chronic diseases; 8. GDS—R; 9. Age; 10. Gender; 11. Race; and 12. SES. \*\*p<. 001 (2-tailed). \* p<.05 (2-tailed).

# Table 4.10

# Multivariate Statistics for Social Networks and Family Caregiving on Health

Model	F	р	Partial $\eta^2$
MANOVA***	176.93	.000	.68
Social networks (high function vs. non-high function)	3.41	.000	.04
Family caregiving (caregiving vs. non-caregiving)	6.71	.000	.07
Social networks • family caregiving	1.12	.31	.01
MANCOVA with age***	28.75	.000	.27
Age (<65 vs. 65–74 vs. ≥75)	3.75	.005	.05
Social networks	3.46	.000	.04
Family caregiving	5.02	.001	.06
Social networks • family caregiving	0.90	.54	.01
MANCOVA with gender**	18.99	.000	.19
Gender (male or female)	1.21	.31	.02
Social networks	3.23	.000	.04
Family caregiving	6.19	.000	.07
Social networks • family caregiving	0.04	.36	.01
MANCOVA with race***	165.82	.000	.67
Race (white or non-white)	0.97	.42	.01
Social networks	3.53	.000	.04
Family caregiving	5.69	.000	.07
Social networks • family caregiving	0.04	.40	.01
MANCOVA with SES***	65.31	.000	.45
SES (Covariate) (Low vs. middle vs. high)	2.42	.048	.03
Social networks	3.01	.000	04
Family caregiving	5.89	.000	.07
Social networks • family caregiving	1.10	.36	.01

Table 4.10 (cont'd)

Model	F	р	Partial $\eta^2$
MANCOVA with age, gender, race, and SES***	12.31	.000	.14
Age	4.69	.001	.06
Gender	0.76	.55	.01
Race	0.32	.87	.00
SES	1.16	.33	.02
Social networks	2.95	.000	.04
Family caregiving	4.89	.001	.06
Social networks • family caregiving	0.86	.59	.01

Note. The Pillai's Trace was used because the Box's Test is significant.\*\*\* A large effect size. Data in table 4.11 suggest that there were significant mean differences in self-rated health and physical function, absence of chronic disease, and mental health for social networks and family caregiving by SES category. Specifically, the table reveals that there were significant mean differences in self-rated health and physical function but not for absence of chronic disease and mental health among different levels of social networks after removing the effect of SES.

Table 12 presents results from Sheffe's tests of Post Hoc multiple comparisons of mean differences in health by social networks. It indicates that self-rated health specified that the least function level significantly differed from the medium high function level and the most function levels; that the medium low level differed from the most function level (p<.05); that the medium high function significantly differed from the least function level (p<.05); and that the most function (p<.05). Post Hoc tests on mean differences of physical function observed that the most function level significantly differed from the least function level and the most function (p<.05).

## Table 4.11

# Adjusted and Unadjusted Mean Differences for Health by Social Networks and Family

	0.16 / 1			
	Self-rated Health	Physical	Absence of Chronic Disease	Mental Health
	Health	Function	Chiome Disease	Healui
Social Networks				
Least function	.55	.40	.86	.34
	.53	.35	.82	.35
Medium low	.31	.19	.79	.21
	.30	.17	.79	.20
	10	16	02	1.4
Medium high	.19	.16	.82	.14
	.19	.14	.80	.14
Most function	.09	.07	.73	.15
1.10501.011011	.09	.06	.72	.14
Family Caregiving				
Caregiver	.24	.09	.73	.19
5	.19	.07	.74	.14
NT '	22	20		02
Non-caregiver	.55	.32	.86	.23
	.08	.24	.83	.21

Caregiving Category

Note. Statistics presented in the table are adjusted *M* and unadjusted *M*. The covariate in the model is evaluated at the following values: What is the level of SES? = 2.22

Table 4.12 also provides results from ANOVA tests on mean differences of health between family caregivers and non-caregivers. It suggests that there were significant mean differences on physical function (p<.001) and mental health (p<.05) but not on self-rated health and absence of chronic disease between family caregivers and non-caregivers.

This study found that family caregivers and non-caregivers presented significantly different health outcomes in levels of physical function and mental health and that social network significantly affected health of family caregivers in later life. Although the combined effect of social networks and family caregiving was not significant in health of older adults in the sample, significant mean differences were observed in the combined health for social networks and family caregiving independently.

# Table 4.12

Health Measure	Social Networks		Family Caregiving		
	Group		р	Between groups	р
Self-rated health	1	2	.393		.237
		3	.047		
		4	.003		
	2	1	.393		
		3	.232		
		4	.002		
	3	1	.047		
		2	.232		
		4	.438		
Physical function	1	2	.475		.040
-		3	.226		
		4	.023		
	2	1	.475		
		3	.812		
		4	.040		
	3	1	.226		
		2	.812		
		4	.350		

### Multiple Comparison of Health by Social Networks and Family Caregiving

### Table 4.12 (cont'd)

Health Measure		Social N	letworks	Family Caregiving		
	Group		р	Between groups	р	
Absence of chronic disease	1	2	.475			
		3 4	.226 .023		.237	
	2	1	.953			
	_	3	.988			
		4	.617			
	3	1	.987			
		2	.988			
		4	.446			
Mental health	1	2	.468		.040	
		3	.122			
		4	.116			
	2	1	.468			
		3	.493			
		4	.463			
	3	1	.112			
		2	.463			
		4	1.000			

Note. The mean difference is significant at the 0.05 level.

MANCOVA tests revealed that different levels of social networks caused different self-rated health and physical function after controlling for the effect of demographic factors. Specifically, not only older adults with the least function social networks were significantly lower in self-rated health than those with the medium high function social networks and the most function social networks, but also older adults with the medium low function social networks had a significantly lower self-rated health than those with the most function social networks, and the medium high function social networks predicted a significant higher self-rated health comparison to the least function social networks.

In summary, this study drew a probability sample of 358 older adults aged 64 and above from a regional representative population. It provided a comprehensive picture of health effects of social networks between older family caregivers and non-caregivers. Results of the study are methodologically reliable and significant because the study's unique design included an effect model using multivariate techniques and mixed methods, which integrated a relatively large sample size, a rigorous quantitative analysis, and in-depth understanding of the phenomenon under investigation.

### **CHAPTER FIVE: SUMMARY AND DISCUSSION**

This chapter provides a summary of the study, an interpretation of the data, and limitations. Implications and recommendations are also explored for future gerontological social work research, education, practice, and policy related to family caregiving in later life. Finally, conclusions are drawn about family caregiving in later life, social networks, and healthy aging. **Summary of the study** 

# The purpose of this study was to better understand the social value of family caregiving in later life by examining the effects of social networks and family caregiving in later life on the health of older adults aged 65 and over. In this study, *family caregiving in later life* was conceptualized as a social event in which community-dwelling older social network members contribute to unpaid, informal caregiving of a kin or a non-kin person with chronic illness, disability, or other dependent characteristics on a regular basis within the last 30 days. *Social networks* were defined as older-adult-centered multidimensional social relationships that cut across traditional kinship, residential, and class groups. Specifically, structure, function, and content of social relations were integrated into three-dimensional social networks. *Health* was defined as high self-rated health, a high level of physical function, absence of chronic diseases, and a high level of mental health.

# Theoretical framework

The significance of this study first comes from its positive gerontology framework, based on critical gerontology and positive psychology (Minkler & Estes, 1999; Seligman & Csikszentmihalyi, 2000). Built on prior studies and theory, this study attempted to highlight the positive effects of social networks and family caregiving on healthy aging among family caregivers in later life. It expected to find that family caregivers with stronger social networks

would be more likely to have higher levels of self-rated health and physical function, lower risk of disease, and higher levels of mental health after controlling for age, gender, race, and SES. *Methodology* 

This was a cross-sectional, explanatory study. Data were collected from a population-based self-administered mail survey during July–September 2011. Stratified random sampling was used to compile a mailing list of 1,000 older adults aged 64 and above in three distinct Midwest communities. A multiple contact was employed and resulted in a response rate of 36.6% and a final sample of 358 community-dwelling older adults.

The questionnaire was developed specifically for this study. It had five components. The first was comprised of LSNS-18 and a subscale of civic engagement of revised BSNI. The second was comprised of IADLs, chronic diseases and related treatments, and GDS-15. The third was related to health insurance coverage, nutrition intake, alcohol drinking, smoking, and exercise. The fourth was comprised of self-identified family caregiving status, caregiving activities, service use, BCOS, and two open-ended questions about family caregiving experience. The fifth was comprised of demographics. The questionnaire presented 58 quantitative questions and two-open-ended, qualitative questions investigating: (1) age, gender, race, and SES structures of older family caregivers; (2) structural social networks; (3) changes in structural social networks; (4) functional social networks; (5) content of social networks; (6) care networks of family caregiving in later life; (7) perceived family caregiving experience in later life; (8) self-rated health; (9) physical function; (10) chronic diseases; and (11) mental health of the sample.

An operational model of Health Effects of Social Networks and Family Caregiving in Later Life was adapted from previous works on family caregiving and social networks in gerontology by Carpentier and Ducharme (2003) and Berkman et al. (2000). Multivariate models and mixed methods were employed to gain a comprehensive and accurate picture of social values of family caregiving in later life by examining the observed effects of social networks and family caregiving in later life on the health of older adults. Quantitative and qualitative data were collected to gain in-depth understanding of social values of family caregiving in later life reported by older family caregivers. Efforts were made to assess independent variables of social networks and family caregiving in later life and dependent variables of health through multiple indicators. Multivariate analysis allowed the study to inquire into separated and combined effects of social networks and family caregiving in later life on the health of older adults after controlling for four key demographic factors.

### Research questions

Three research questions were answered in this study. The overarching hypothesis and research question was to compare the similarities and differences in health due to different levels of social networks and different family caregiving statuses. The null hypotheses were that there would be no observed differences among different levels of social networks and between different family caregiving status on the combined health, as measured by levels of self-rated health, levels of physical function, levels of absence of chronic diseases, and levels of mental health. MANOVA and MANCOVA were used to determine whether there were significant differences in the health of older adults for levels of social networks and different family caregiving statuses before and after controlling for age, gender, race, and SES. Qualitative analysis was conducted based on data from two open-ended questions to examine family caregiving in later life using caregivers' own words.

The first research question sought demographics, social network characteristics, and health status of family caregivers and non-caregiving older adults aged 64 and above. Frequency tests,

ecomap, and one-way ANOVA were performed to compare similarities and differences of all independent variables, dependent variables, and covariates between family caregivers and non-caregivers. The second question sought perceptions of family caregivers on family caregiving in later life through the standardized scale BCOS and two open-ended qualitative questions about changes in family caregiving. The third question examined the causal relationships that social networks and family caregiving independently had on the health of older adults through bivariate correlation analysis and a series of multivariate analyses.

### Results

Results of the investigation indicated that both social networks and family caregiving in later life independently and significantly affected the combined health, as measured by levels of selfrated health, levels of physical function, levels of absence of chronic diseases, and levels of mental health, after controlling for demographic factors. High levels of social networks significantly predicted better self-rated health and higher physical function. Being family caregivers in later life significantly predicted lower levels of physical function and mental health. More detailed results are presented below for each of the research questions.

Question one was stated as: "What are demographics, social network characteristics, and health status of older family caregivers, compared to other older adults who do not provide family caregiving?" The final sample of the study consisted of 358 community-dwelling older adults aged 64 and above, involving 136 family caregivers and 222 non-caregivers. A total of 114 respondents identified themselves as family caregivers. Another 22 respondents performed family caregiving activities but did not identify themselves as family caregivers. Among caregivers, 87 cared for older adults; 34 for adult children with disabilities; and 15 for grandchildren/great grandchildren.

*Demographics.* Data in this study found that caregivers were slightly older than noncaregivers. The majority of older adults in both groups were between 65 and 79 years of age, and 24.8% of caregivers were among the oldest old. Frequency tests indicated that 45.7% of caregivers were male, and the gender ratio was higher for caregivers than non-caregivers. The percentages of non-white older adults with low household income were higher in caregivers than non-caregivers. Caregivers were less educated than non-caregivers, with a higher rate of high school education or less and a lower rate of higher education.

Social networks. Surprisingly, data in this study found that among three dimensions of social networks, the functional social network presented as the most important dimension in social networks for the combined health of the sample. Results from descriptive statistics uncovered no significant difference in structural social networks between caregivers and non-caregivers, who had LSNS scores of 46.90 and 47.44, respectively. An estimated one-third of both groups had LSNS scores greater than 54, an indicator of socially high connectedness. However, more caregivers than non-caregivers had average LSNS scores lower than 36, an indicator of risk for social isolation. Social network structural statistics found that caregivers and non-caregivers each had a network size of 9–12, consisting of relatives, friends, and neighbors. Caregivers and noncaregivers had a similar number of relatives, friends, and neighbors in their social networks. Descriptive statistics from SF-LES found that caregivers generally experienced more radical changes in structural social networks than non-caregivers. Data found that in the two years prior to the study survey, 42.2% of caregivers and 32.5% of non-caregivers had lost an immediate family member, and 62.6% of caregivers and 51.2% of non-caregivers lost one or more close friends. At the same time, more caregivers than non-caregivers had gained new family members as well as started school, training, or other learning.

Results from bivariate correlation analyses suggest that family caregiving in later life was significantly and positively associated with levels of physical function, absence of chronic diseases, and mental health, with p<. 001. All three dimensions of social networks were positively and significantly associated with self-rated health (p<.001). Structural social networks were negatively associated with mental health (p<.05). Content social networks were significantly and negatively associated with absence of chronic diseases. Functional social networks were significantly and negatively associated with physical function and mental health (p<.001).

Data found a lower percentage of caregivers (27.4%) reported to have four health behaviors—namely, nutrition intake, physical exercise, absence of alcohol misuse, and absence of smoking—than non-caregivers (34.4%). Caregivers reported an average of 2.81 health behaviors, in comparison to 2.99 reported by non-caregivers. By contrast, caregivers appeared to have a slightly higher service use rate (0.73) than non-caregivers (0.69) when treatments for their health conditions were considered. A noticeable finding about service use was that only 20 caregivers (14.7%) had used health and human services for family caregivers within the past year. The other 116 caregivers either did not use family caregiving services (64.0%) or did not answer the question about family caregiving service utilization (20.6%). Fifteen caregivers (11.0%) never knew family caregiving services were available. Of caregivers who used family caregiving services, 39.9% reported that they obtained information about family caregiving services through both professionals and social network members, 32.3% of caregivers reported that they obtained information exclusively from social network members, and 37.8% exclusively from professionals.

Descriptive statistics of revised BSNI scores uncovered that caregivers had a moderately higher BSNI score (6.28) than non-caregivers (6.13), indicating a relatively higher degree of overall social function. Higher percentages of non-caregivers had engaged in organizations, groups, and volunteering than caregivers, while on average both had exactly the same degree of religious participation. Caregivers were less likely than non-caregivers to live alone and more likely to live with two and more people than non-caregivers. Non-caregivers presented higher percentages at both the most functional level (31.67%) and the least functional level (6.79%) than caregivers (30.37% and 5.19%, respectively). It was also noted that although caregivers presented a lower risk of being least functioning, 29.63% of them were at the medium low functional level, indicating marginal risk of social dysfunction.

Results from social network analysis indicated that a typical family caregiver in the sample had a range from 13–20 members in his or her social networks, consisting of relatives, friends, and neighbors, with medium high social functioning. More than a quarter of them practiced health behaviors, and the majority of them used treatments when they had health conditions. They obtained treatment information from both network members and professionals, with a preference for professionals.

*Health.* Results from descriptive statistics revealed that the majority of family caregivers reported excellent or good health, high physical function, and good mental health. Almost one in five family caregivers rated their global health as excellent, more than half of caregivers identified their health as good; 75.4% reported high daily function; and 76.9% were mentally healthy. Results, however, also suggested that higher percentages of caregivers were at risk for problems associated with physical function, diseases, and depression. Of all caregivers, 15% reported their health as poor or very poor, which was higher than non-caregivers (8.3%). Of all

caregivers, 84.6% reported that they had two or more chronic conditions, 10.4% higher than noncaregivers. Data also found that 17.2% of caregivers had GDS scores of 6–10, and 5.9% had GDS scores greater than 10; both were higher than non-caregivers (10.7% and 3.8%, respectively). Results of ANOVA analysis indicated significant health differences between caregivers and non-caregivers, especially in terms of physical function and absence of chronic diseases (p<.001).

Question two was stated as: "How do older family caregivers perceive family caregiving in later life?" Frequency tests of BCOS scores found that 52.5% of caregivers reported positive changes since assuming the caregiver role. An ANOVA test revealed that positive changes existed among three different geographic residence types. Qualitative data triangulated results from quantitative analysis of BCOS scores. Among 21 codes, more codes denoted positive changes than negative ones, and more respondents repeated positive codes than negative ones.

Question three was stated as: "Are there significant mean differences in health for different levels of social networks and for different family caregiving status after controlling for demographic factors?" Multivariate analysis found that the effect model in MANOVA has a Partial  $\eta^2$  of .68, *p*<.001 and that social networks and family caregiving interaction was not significant (*p*=.31). This result indicated that social networks and family caregiving in later life independently and significantly predicted the health of older adults, and that the health of the sample was not caused by the combined effect of social networks and family caregiving in later life. When controlling for age, gender, race, and SES, the effect models in MANCOVA had a Partial  $\eta^2$  ranging from .14 to.45, *p*<.001, suggesting that social networks and family caregiving independently had significant effects on the combined health of family caregivers in later life, independently had significant effects on the combined health of family caregivers of age, gender, race, and SES—both individually and collectively—reduced effects of social networks and family caregiving on health of older adults in the study, but they only reduced the effect sizes from a very large one to a medium one. More specifically, family caregivers and noncaregivers presented significantly different health outcomes in levels of physical function and mental health. Older adults with the least social function were significantly lower in self-rated health than those with the medium high social function and the most function social networks. Older adults with the medium low social function had a significantly lower self-rated health than those with the most social function, and the medium high social function predicted a significantly higher self-rated health comparison to the least function social networks.

### **Interpretation of the results**

This study found significant effects of social networks and family caregiving in later life on the health of older adults in the study. Population-based studies on health effects of social networks among older family caregivers have been sparse, which made it difficult to compare results of this study to those from prior studies. Nevertheless, this study added new knowledge to the family caregiving literature by presenting new empirical evidence on the social realities of family caregivers and their health outcomes. Within a positive gerontology framework, results from this study highlighted the positive aspects of social networks of family caregivers in later life. They can be expressed as: (1) family caregiving as a valuable event in later life, (2) strengths and resilience of caregivers, and (3) relational aging.

### Family caregiving as a valuable event in later life

Previous literature has suggested that the reasons why people were called for family caregiving were that they were young, healthy, and/or available (Szinovacz & Davey, 2006). This study provided empirical evidence that family caregiving is a daily event of older adults, no

matter whether they are young or old, healthy or not healthy, working or retired, or living close or living far. It is important to note that inclusion of all informal caregivers other than primary family caregivers made it possible for this study to capture the meaning of family caregiving in later life. More importantly, older caregivers interpreted caring for people around them as a meaningful part of their life, aging, or responsibility, which was undervalued by society from their perspective. The fact that there were 22 family caregivers in the final sample who did not identify themselves as family caregivers was further evidence that family caregiving was undervalued by society.

Re-evaluation of family caregiving challenges ageism by reconstructing the realities of aging and family caregiving in later life. Data in this study revealed that 38% of older adults in the sample provided unpaid care to family members, friends, and relatives, a higher percentage than AARP's estimates (Armo et al., 1999; Houser & Gibson, 2008). Their care recipients were across the life span, including older adults, adult children, and grandchildren or great grandchildren. Older adults at all age groups have had an almost equal chance to become family caregivers. Of the oldest old in the sample, 37.2% were caring for a family member, friend, or neighbor within the last 30 days prior to the study. Data on employment and civic engagement other than informal caregiving further supported the notion of productive aging. Employment data revealed that 25.28% of older adults in the sample were employed, ranging from full-time to being a student. In comparison to non-caregivers, the retired rate in the caregiver group was only 2.5% higher than the non-caregiver group; the full-time employment rate was 5.2% lower; and the part-time employment rate was 1.1% higher.

Strength and resilience of family caregivers

The reason that over half of caregivers reported positive changes since assuming the caregiver role partially rested on the meaning of family caregiving in later life as conveyed in the study, and partially was the result of caregivers' personal growth throughout the caregiving journey. Data in this study provided strong evidence to support positive gerontology, particularly through the strengths and resilience presented by family caregivers in the study. One caregiver wrote at the end of the survey: "A lot of water has gone under the bridge—Life goes on." It constructed family caregivers' way of life as well as aging. Although loss and grief were devastating and care responsibility was demanding, dignity remained, and the best within the individual caregiver and institutions emerged. Among 136 family caregivers: 35.4% cared for two or more family members, friends, and neighbors; 43.8% cared for co-residents; 52.3% provided care to non-co-resident family members, friends, and neighbors; 3.9% were longdistance family caregivers; 50.0% were solo family caregivers; 39.8% were long-term caregivers; and 26.6% provided more than 20 hours of informal care per week. The resilience of family caregivers also showed in their general health and positive self-assessed health. Although caregivers might present significantly low levels of physical function and a high number of chronic diseases, they were socially connected and adjusted. The majority of family caregivers reported excellent or good health, high physical function, and good mental health. Almost one in five family caregivers rated their global health as excellent, more than half of caregivers identified their health as good, and over three of four reported high daily function and high mental health.

From a historical perspective, the study further documented the continuity of family protection in contemporary American society, where greater public protection and sophisticated institutional intervention have been evident. Findings of the study about the high prevalence of

family caregiving in later life supported the argument that the family system continues to be critical to the well-being of its members. One possible explanation for this might be the high quality of care provided by social network members. Previous literature has identified the following qualities in family caregiving: care provision, better care outcomes, respect, low cost, and accessibility (Dooley, Shaffer, Lance, & Williamson, 2007; Raphael & Cornwell, 2008; Harrow et al., 2004). This study observed that family caregivers provided extensive care for family members, friends, and neighbors. Among older family caregivers in the sample, 34.4% provided care for two or more spouses, parents, adult children, or grandchildren. More than 26% of older family caregivers spent more than 20 hours a week providing unpaid care within 30 days prior to the study. Nearly 40% had been family caregivers for five or more years, and about 21% of them for 10 or more years. Furthermore, findings indicated that family caregiving had respected and met care recipients' needs for kinship care and community living. Consequently, older adults and adults with chronic illness or disabilities often either delayed use or simply did not use institutionalized long-term care.

### Relational aging

Convenience samples and small sample sizes in literature have contributed to inconsistency about the social consequences of family caregiving in prior literature. Drawing conclusions from a medium-large-size probability sample and well-thought study design and data analysis strategies, this study has added compelling evidence that family caregivers in later life do not present significantly different patterns in all three dimensions of social networks when compared with non-caregiving older adults.

*Structural social networks*. Family caregivers presented similar patterns of structural social networks as non-caregivers. Average network size of 9–12 reported in this study is consistent

with Greenberg et al. (1993) and Haley et al. (2010), and is much larger than most social networks studies on family caregivers (Penrod et al., 1995; Tolkacheva et al., 2011). Similarly, caregivers, as non-caregivers, often saw and heard from relatives, friends, and neighbors with whom they had the most contact. Considering changes in social network structures over the past two years prior to the study, including higher rates of loss of family members and friends, network size, and frequency of contact with network members among caregivers, on average, led to conclusions that caregivers generally presented a similar level of social connectedness as noncaregivers. However, the fact that 23.1% of family caregivers were at risk of social isolation, 2.7% higher than non-caregivers, should be an alarm sign for policy makers and gerontological social workers. On the other hand, the study confirmed the results from caregiving networks literature that caregiving networks are smaller than social networks of family caregivers (Fast et al., 2004; Keating & Dosman, 2009; Keating et al, 2003). Among the 9–12 network members of caregivers in the sample, only 6–9 were caregiving network members. This explains why caregivers perceived their network members and confidants "sometimes" or "often" reachable when the caregiver had an important decision to make. Frequencies of reachability and reciprocity were reported as "sometimes," while frequency of network contacts was "often." The distinction between social networks and caregiving networks has important implications for social work practice and policy.

In terms of diversity of social network compositions, conclusions drawn in this study confirmed that family members, particularly immediate family members, are the core of caregiving networks in most cases and that, while friends count for the second most important support for family caregiving in later life, friends are not always reachable in caregiving networks (Carpentier & Ducharme, 2005; Keating & Dosman, 2009). Data also discovered that

neighbors are more reachable in care networks than the literature has tended to recognize. In comparison to non-caregivers, caregivers rely more on neighbors for help.

One contribution that the current study has made to social networks of family caregiving research is to demonstrate that caregivers present higher scores of network strength and reciprocity than non-caregivers, but slightly lower scores of network size, frequency, help, and reachability. Caregivers had six or more confidants with whom they could talk about private matters and 6–9 network members they could call on for help. One explanation of these minor differences, which arise from mixed methods, is that caregivers had experienced more intensive relationship development with family members and the care recipient than friends. Caregivers reported better relationships as the result of caregiving.

*Functional social networks*. Previous literature on social networks of family caregivers has overwhelmingly addressed the importance of structural social networks for the health of family caregivers. This study has provided new evidence: Functional social networks presented as the most influential dimension in social networks to explain health effects of social networks. Results in this study indicated that caregivers had a relatively higher degree of overall social function. Civic engagement data suggested that nearly half of caregivers had participated in organizations, groups and volunteering. Caregivers had lower scores of organization participation, group membership, and volunteering than non-caregivers, but the differences were not significant. Although there was no correlation between levels of functional social networks and different family caregiving status, data nevertheless revealed that caregivers presented a lower risk of being least functioning than non-caregivers. One explanation of the results about those functional social networks is the significance of co-residency in health of older adults, in general, and of family caregivers in later life, in particular. Data suggested that caregivers were

less likely than non-caregivers to live alone and more likely to live with two and more people than non-caregivers.

Two additional findings are worth noticing about functional social networks among family caregivers. While caregivers presented low risk of social dysfunction with a higher percentage of having a co-resident presence, more than a quarter of them were at marginal risk of social dysfunction. Care demands and family conflicts might have been two factors contributing to caregivers being subject to marginal risk. Qualitative data indicated network conflict was rare but harmful for relationships and health of caregivers. Quantitative data from SF-LES uncovered that 18.63% of caregivers, verses 10.1% of non-caregivers, reportedly had legal issues with a social network member during the two years prior to the study. Family conflicts manifested in more informal forms in caregiving families. Anger and guilt were two topics identified by family caregivers in the sample. Although they did not emerge as codes due to their infrequency, they added new evidence to recent literature on prevention of elder abuse in regard to family caregivers' harmful behavior (Beach et al., 2005, Cooper, Selwood, Blanchard, Walker, Blizard, & Livingston, 2009).

*Content social networks*. Social networks influenced information and behavior shared by network members. Data revealed that more than a quarter of family caregivers reported having healthy nutrition intake, regular exercise, and absence of alcohol misuse and smoking. Although family caregivers used more treatments and services available than non-caregivers, only a very small percentage of family caregivers used human and health services for family caregivers in the two years prior to the study. Family caregivers used social networks and professionals to seek information regarding treatments and human services. Nearly one-third of caregivers solely relied on their information channel of network members, while a little more than one-third solely

relied on professionals. Ability and skills to seek access to services and treatment were particularly important for the health of family caregivers, since they were more likely than noncaregivers to have had two or more chronic conditions, to have suffered depressive symptoms or depression, and to have experienced more radical changes in social network structures.

Evidence about older family caregivers' strength and capacity to live a loving, productive, social functional, and civic engaged life leads to a better understanding of how sustainable and quality family caregiving can be possible in the United States at the grassroots level. One of the stunning results in this study was the small number of family caregivers who had known the availability of and used human and social services for family caregivers, while family caregivers trusted professionals for information and access to treatment and services. Although this result was consistent with previous findings, it has sounded an alarm about the severe disconnection between service needs and service delivery. Anger, resentment, and other negative emotions existing among family caregivers were signs that our family caregiving system is overburdened and overly exploited. It is an ethical issue for social work that a sustainable caregiving system cannot solely rely on family and community institutions.

### Limitations

Although this study was valuable for the investigation of social network factors affecting healthy aging of older family caregivers, this study had a number of limitations. First, the notion of positive gerontology suggested that healthy aging among older family caregivers is an outcome of innate strength and resource. This study has provided important empirical evidence regarding positive features of family caregiving in later life and positive health outcomes of high levels of social networks in a final sample of 358 older adults. Threats to external and internal validity were identified in this study. Key threats included a relatively small sample size, a

relatively low response rate, a cross-sectional study, a regional representative sample, and measurement development.

### Sample size and response rate

A probability sample size of 358 drawn from a population of 6,514 older adults in three research sites could have tolerated an estimated ±.5% margin of error and met data requirements for multivariate analysis, but it was not qualified for a desirable large sample size for a population-based study. In the same line of data evaluation, efforts were made to produce results representative of the general population using stratification by random sampling strategies, but the mailed survey only achieved a response rate of 36.6%, which created concerns about the representativeness of the sample respondents and response bias. It is possible that caregivers who had extremely high or low levels of social networks that provided information on extremely positive or negative health conditions did not participate in the study. In terms of data collection methods, the multiple contact strategy certainly increased the response rate. On the other hand, a 12-page-long questionnaire with a 14-point font size was a harmful approach for a higher response rate. For many respondents as well as potential respondents it could have taken longer than 15 minutes to complete the questionnaire. It could even have taken longer for those caregivers who wrote long responses to two open-ended questions.

### *Cross-sectional study*

The cross-sectional study allowed an examination of how properties of social networks were related to the health of the individual respondent at one point in time. Although efforts had been made to include non-caregivers as a comparison, results drawn from the study could not lead to a confident claim about the causal relationships between social networks and health of respondents as it could have been drawn from longitudinal data. Specifically, this was limiting for at least

three reasons. First, it did not allow for tracing social network changes over time among older family caregivers. An effort was made to investigate changes in the size and composition of social networks over the last two years using SF-LES. Since SF-LES was not a caregivingspecific measurement, it was limited to linking social network changes with family caregiving. Second, no data on baseline health status was available to record changes in health over time or control for previous health status. Third, there were no follow-up data collections that would have allowed for in-depth explanations regarding health effect questions identified in this study.

Other limitations of the survey study included problems with the sample frame. The mailing list for stratified random sampling contained 4.2% of incorrect or outdated addresses. Wrong addresses, death, age, and institutionalized older adults contributed to the low response rate. Because the sample frame used 64 or 66 as the cut-off age, the study used a sample of 358 older adults aged 64 and over, which contained 16 participants who were 64 years old. A final sample that excluded 16 participants under 65 would create a more comparable sample in gerontology literature. Additionally, the mailing list had a lower percentage access to rural areas than urban and suburban areas. Even after oversampling rural population, only 15 rural respondents were included in the study, which was too small to establish enough power for a meaningful comparison between urban, suburban, and rural residences. It is also important to point out that subjectivity of data tends to limit reliability of data as well as generalization of the results. Information collected in the study was retrospective and self-reported by nature. Socially desirable answers and other subjective biases could have distorted the accuracy of the information collected in this study. Two open-ended questions gave voice to family caregivers about their caregiving experience in later life. This method added a new data source and viewpoint but failed to bring objectivity of measures or accuracy of data to the study.

### Regional representative sample

Results reported and interpreted in this study were based on data drawn from a Midwest sample where economic downturn has affected demographics dramatically, including population decline over the last ten years. It was possible that changes in social network size, composition, and availability were caused by demographic declines, family financial crisis, or unemployment. This regional representative sample was limited in terms of population diversity. Even though efforts had been made to integrate more diverse populations into the sample through carefully selected research sites and oversampling rural older adults, the percentages of minority, rural older adults, and people living in poverty were lower than national averages. The results cannot be generalized in other parts of the country since they do not reflect regional differences.

# Measurement errors

Two types of measurement errors might have contributed to threats to internal validity in my investigation. First, there were measures and items included in the questionnaire that did not closely tie to research questions and the effect model. For instance, questions related to frequency of civil engagement, insurance coverage, exercise categories, reason for retirement, and immigration should have been excluded from the questionnaire. Secondly, there were measures and items not included in the survey that might have increased internal validity and consistency between research questions and data collected in the study. For example, the data only captured the dyad relationships between the participants and their social network members. It did not provide for an explanation in the relationships between and among social network members. Therefore, the study only revealed a partial picture of the social location of the caregivers within their complex social networks. Additionally, previous studies and qualitative data in this study suggested the importance of emotional support in family caregiving, but the

measure for caregiving activities in the questionnaire did not include emotional support. It was possible that issues in conceptualization and measurement development might have missed alternative explanations for the relationships between social networks and health of family caregivers in later life. Most importantly, the study design failed to accurately measure the content dimension of social networks for caregivers and non-caregivers. Thus, the notion of three-dimensional social networks could not be fully carried out in the study.

### **Triangulation**

Methodological efforts have been made to enhance validity of the results by using multiple data collection and data analysis methods, namely, between-methods triangulation and withinmethods triangulation (Jick, 1979). Open-ended questions were used in the survey design for cross validation about changes of family caregivers' well-being and relationships. Multiple scales were used to cross-check for international reliability of the social network construct. However, the use of mixed methods in the study was not systematic. Between-methods triangulation was only reflected in research question two about family caregiving perceptions. Only quantitative approaches were used as a single reference point to health efforts of social networks among older family caregivers. In short, triangulation was not integrated in the overarching research question on health effects of social networks among older family caregivers.

Although it is debatable as to whether mixed methods is more than method, an integrative mixed methods research can provide multiple reference points and greater accuracy of research findings about social networks among older family caregivers (Johnson, Onwuegbuzie, & Turner, 2007; Harrits, 2011). For instance, face-to-face interviews of family caregivers and their

network members might collect different kinds of data bearing on health effects of social networks of family caregivers in later life.

### **Implications and recommendations**

As President Barack Obama recognized in the Presidential Proclamation National Family Caregivers Month of 2011, family caregivers "sustain American men, women, and children at their most vulnerable moments, and through their devoted acts, they exemplify the best of the American spirit" (Obama, 2011). Findings of the study highlighted the perseverance of caregivers. The findings suggested that social support networks play a vital role in sustaining older family caregivers in their daily activities as well as in their overall well-being. Empirical evidence that helps us to recognize and better understand the contributions of these networks is important for gerontological social work in both community settings and long-term care facilities. Below, I have identified a number of implications for theory, research, practice, and policy.

### Implications for research

Although a systematic discussion about the roles of older adults was beyond the scope of this study, findings of the study emphasized the intersections of older adults with retirement, employment, care work, and civic engagement. The study raised a series of questions about what roles older adults are playing in the private and public spheres. Of 358 older adults in the sample, 73% were retired, 24% were working or in school, 38% provided informal caregiving, and 56% volunteered in civic society (m=.56; SD=.50). An engaging and productive old age challenges the stereotype that older adults are exhausting fiscal and social capital as dependent and burdensome to the family system and the society. In light of critical gerontology, this study calls for a commitment to change the social construct of old age in social work research by

promoting a positive gerontological perspective of roles of older adults (Holstein & Minkler, 2007; Minkler & Estes, 1999; Brothers & de Jong Gierveld, 2011).

One specific example would be the roles of older family caregivers in the caregiving system. The study found that there were older adults who were both care recipients and care providers. It confirmed previous findings that the culture of aging becomes increasingly complicated in terms of definitions of family, aging, relationships, and growth (Edwards, 2003; Cohen, 2006; Dunne, Wrosch, & Miller, 2011). Prior literature has found that families exchange all kinds of support and services in all types of forms throughout the life course (Fingerman, Miller, & Seidel, 2009; Moen, 2011). Social work research has yet to answer practical questions such as: What is the meaning of "family"? How can we professionals make a difference in older adults' lives? How do we change caregiving systems to support these individuals? What best-practices are available to provide quality and sustainable care for care recipients as well as their social network members? Negative health outcomes of family caregiving in later life indicate the urgency and significance of these unanswered questions. Gerontological social work researchers have a professional obligation to find evidence-based practice to better support older adults and their families to create, navigate, and utilize health care systems and caregiving systems.

This study provided useful findings for future studies regarding family systems, social networks, and health of older adults. It provided new empirical evidence about positive features of family caregiving in later life and positive effects of social networks on self-rated health and physical function of family caregivers in later life. Since the nature of a cross-sectional study prevented the results of this study from being generalized to older adults from other states or other countries, retesting the conceptual model and research design might contribute to better

understanding of the variations that result in more positive experience for some older family caregivers but more negative experience for others.

Limitations of this study suggest that future research in quantitative and qualitative methods or their combination is needed to continue exploration of the health effects of social networks among older family caregivers. Specifically, a larger and national representative sample of family caregivers in later life could contribute to validation of the significant differences found in their social networks and health. Further research is needed to identify whether the findings of this study are relevant to older family caregivers in other states. Future research could lead to identifying whether the network effects may vary in relation to the prior health status or the length of caregiving. Longitudinal studies would be a more suitable methodological strategy.

Social networks are complicated phenomena to conceptualize and measure. More research on social networks in gerontology, including care networks, would be critical to better understand the differences in family caregiving experience in later life. This study proposed a threedimensional social network concept and only assessed three dimensions separately. Knowledge would be enhanced by continuing to combine those social network dimensions into a more integrated concept, by collecting new data regarding social networks of older family caregivers, and by applying more social network analysis technology. For example, the revised BSNI used in this study made significant changes from the original BSNI, although it maintained a total of 12 points and was divided into four functional levels. It weighted marriage status as 0 (no) or 2 (yes) but did not weight as much as BSNI, 0 (no) or 4 (yes). It scored three relationship items as 0 (no relative or friend), 1 (3–4 relatives and/or friends), or 2 (5 and more relatives and/or friends). I scored three dichotomous items to assess organizational memberships as 0 (no) or 1 (yes). Since reliability of the revised BSNI ( $\alpha$ =.66) did not reach the level of high internal

reliability ( $\alpha$ =.70), retests must be conducted before any confident claims for the revised BSNI can be made.

Negative emotions and relationship conflicts among network members experienced by older family caregivers affect the health of caregivers as well as sustainability and quality of family caregiving. Further research efforts regarding issues related to anger, resentment, or other understudied emotional aspects within social networks of family caregivers could be useful to not only better understand social networks and care networks, but also prevent negative relations and network changes and further facilitate positive changes in caregiving networks. Furthermore, more research about the downside of social capital in older adults will advance not only our knowledge of the culture of aging, but our practice toward the well-being of older adults and their network members (Portes & Landolt, 1996; Carr & Hendricks, 2011)

This multivariate study measured health outcomes of social networks and family caregiving that included self-rated health, physical function, absence of chronic disease, and mental health. It observed the inconsistent health effects of family caregiving in later life from quantitative and qualitative data analyses. One might view this inconsistency as being a result of available health constructs. In line with previous studies on health constructs, this view emphasizes the unanswered question about conceptualization and measurement of "health" (Pinquart, 2001). Attempts have been made to propose new frameworks of health, such as subject well-being (Cheng et al., 2009; Moor, Zimprich, Schmitt, & Kliegel, 2006), quality of life (Shiovitz-Ezra, Leitsch, Graber, & Karraker, 2009), or a resource for everyday life (Williamson & Carr, 2009) and beyond (Raehurn & Rootmen, 2007). However, we still have limited tools to fully observe the health of older adults as well as their experience and understanding of health. For instance, this study failed to capture cognitive health of older adults through a self-administered

questionnaire. Future geriatric research can further evaluate existing health constructs as well as explore and develop new health constructs that measure a holistic state of physical, functional, mental, cognitive, social, and subjective well-being of older adults (WHO, 1946; Pinquart, 2001; Lee et al., 2010). It also can use multiple data collection models to better measure health of older adults. This advancement in health measures is expected to contribute to the health of older adults and to policy and practice that promote the health of older adults (Moor et al., 2006; Rochat, et al., 2010).

### Implications for practice

Social networks of family caregivers in later life and their health effects are geriatric issues that have several implications for social work practice, with special reference to life course oriented social work practice, from gerontological social work to the child welfare system. Evidence regarding family caregiving in later life urges social workers and related professionals to reappraise the role of family and state in the health care system. Since the turn of the 21st century, many debates and thoughts have occurred about a new partnership between informal family caregiving and formal service provision (Zarit et al., 1992; Sundström, Johansson, & Hassing, 2002; Bonsang, 2009). Litwin and Attias-Donfut (2009) found a shared, complementary relationship between formal and informal care in France and Israel. The fact that older family caregivers in the current study articulated their needs for family support and professional services justifies the need for both formal and informal care. It is crucial to note that need for formal services includes a greater governmental understanding and support of informal caregiving.

On the other hand, findings about low utilization of family caregiving services should urge gerontological social workers to reexamine current family caregiving programs and program
delivery systems. New information and educational programs are needed to disseminate related policy and programs. It was evident in this study that every older adult has the chance to become a family caregiver. Social workers have professional responsibilities to prepare the public, both older adults and their families, about family caregiving, including informal caregiving and its economic and social value.

Social workers may also want to pay closer attention to the effects of social networks for family caregiving in later life as well as health behaviors and service utilization among older family caregivers. For those caregivers with small available networks, information about the health effects of supportive social networks can raise awareness of the importance of social capital in aging. As regards caregivers with homogeneous networks, referral to informal and formal supportive family caregiving programs could expand their perspective on network resources. Harmfulness of network conflict in family caregiving expressed in this study also calls for social workers to provide preventive intervention designed for family relations in caregiving situations. Special attention needs to be paid to interventions that protect the social network members from negative peer pressure and other downsides of social capital.

This study has indicated the significant effects of demographic characteristics—especially age, gender, race, and SES—on the health of family caregivers in later life. Gerontological social workers need to develop culturally sensitive family caregiving interventions to assist sustainable and quality of family caregiving in diverse family and community groups. It is particularly crucial to understand in the social and professional environment that family caregiving is tied to there have been so many stigmas and stereotypes that it can be difficult to discuss family caregiving beyond narrow interest areas, for instance, care burden or dementia care. Gerontological social workers have special knowledge about family caregiving in later life. They

may help the public and other professionals realize the significance and value of family caregiving. The fact that older family caregivers have so much faith in professional knowledge might require social work and other professions to reach a whole new level of professional practice.

#### Implications for policy

Community-based caregiving has been the center of American health care for decades. By definition, family caregiving involves unpaid, community-dwelling, non-professionals, and ranges from primary family caregivers to any network member providing certain care to a family member, friend, or neighbor. This study confirmed that older adults have taken caregiving responsibility to an extensive degree, no matter the proportion of older adults involving in unpaid caregiving, the scope of their caregiving, or the length of caregiving. This study suggests the need to use family caregiving in later life as a public policy analysis tool in future public policy considerations. For example, legal status of family caregivers has not been changed in the American public policy arena even though the importance of family caregiving has been evident (Heller et al., 2007; Murray, 2008). As the data confirmed in this study, some family caregivers did not identify themselves as caregivers as a result of this policy culture. Legal rights of family caregivers involve many policy issues, including family leave, housing policies, and various eligibility issues.

Recent policy changes have addressed issues related to grandparents raising grandchildren. For example, the *Fostering Connections to Success and Increasing Adoption Act of 2008* supports relative caregivers of children in foster care and improves incentives for adoption (P. L. 110—351). Obviously, this amendment focuses on grandparents raising grandchildren or other relative caregivers of children. Additional people who provide care or who are able to provide

care are continuously excluded from policy design and service delivery. For example, siblings have the longest-lasting relationship among older adults, and they often assume caregiving roles without being recognized by society and/or their family. The focus of current federally funded family caregiving support is limited to older adults and their parents and excludes sister and brother caregivers. Future family caregiving policy should involve siblings more in policy development, programmatic planning, services, supports, care planning, and discussion of rights and supports of individuals with disability. More generally, social workers, including gerontological social workers, should partner with family caregivers to re-conceptualize care work in later life in public policy to advocate for and promote policy change (Daly, 2001; Hinrichsen, 2010).

#### Conclusion

This study employed the positive gerontological framework to investigate the social value of family caregivers in later life. A positive psychological framework was used to highlight meaning and values of late family caregiving beyond caregiving burden and stress, with special emphasis on strengths and capacities of older family caregivers and their social networks. By defining family caregiving as unpaid, community-based, intergenerational caregiving for any kin or non-kin person, this study departed from family caregiving literature that separated older family caregivers by the informal care recipient's disease, disability, or problem (Baker et al., 2010; Dillenburger & McKerr, 2009; Standing et al., 2007). This study recognized family caregivers' commonalities in their contributions to both the care recipient and society, no matter whether they were spousal caregivers of patients with Alzheimer's disease, parental caregivers of adult children with physical or mental disabilities, or grandparents raising grandchildren. Although the scope of this study was limited to a certain level of analysis to examine the health

effects of social networks among older family caregivers, results indicated that positive gerontology added new evidence to the study of family caregiving in later life.

Methodologically, the study investigated the health effects of social networks among older family caregivers through a multi-site probability survey study with quantitative and qualitative components. The study will contribute to geriatric social work research in two ways. First, a multi-site community-based survey has allowed the research to reach older family caregivers who have not previously utilized services. Three research sites maximized the comparisons of diversity in family caregiving in later life in terms of race, ethnicity, and locale. Secondly, social networks analysis is an emerging arena in family caregiving studies. The notion of "family caregiving network" deconstructed the presumption that caregiving was an isolated and lonely act. It suggested that family caregiving involved a web of social relations in which interactions among different network members are sources of support and conflict, and strengths and vulnerability. A social network analysis of family caregiving in later life paid direct attention to caregiving relationships in social contexts. It was through such relationships that social networks were transformed to influence the health and well-being of older family caregivers. The results of this study recognized that the functional dimension rather than structural dimension was the most determinative factor in social networks analysis of health aging among older family caregivers.

APPENDICES

## APPENDIX A

## INITIAL IRB APPLICATION APPROVAL

Michigan State University

Initial IRB Application Approval

July 7, 2010

To: DeBrenna Agbényiga

254 Baker Hall

School of Social Work

Re: IRB# 10-528 Category: EXPEDITED 2-7

Approval Date: July 6, 2010

Expiration Date: July 5, 2011

Title: Effects of social networks on health of family caregivers in later life

The Institutional Review Board has completed their review of your project. I am pleased to advise you that **your project has been approved**.

The committee has found that your research project is appropriate in design, protects the rights and welfare of human subjects, and meets the requirements of MSU's Federal Wide Assurance and the Federal Guidelines (45 CFR 46 and 21 CFR Part 50). The protection of human subjects in research is a partnership between the IRB and the investigators. We look forward to working with you as we both fulfill our responsibilities.

**Renewals**: IRB approval is valid until the expiration date listed above. If you are continuing your project, you must submit an *Application for Renewal* application at least one month before expiration. If the project is completed, please submit an *Application for Permanent Closure*.

**Revisions**: The IRB must review any changes in the project, prior to initiation of the change. Please submit an *Application for Revision* to have your changes reviewed. If changes are made at the time of renewal, please include an *Application for Revision* with the renewal application. **Problems**: If issues should arise during the conduct of the research, such as unanticipated problems, adverse events, or any problem that may increase the risk to the human subjects, notify the IRB office promptly. Forms are available to report these issues.

Please use the IRB number listed above on any forms submitted which relate to this project, or on any correspondence with the IRB office.

Good luck in your research. If we can be of further assistance, please contact us at 517-355-2180 or via email at IRB@msu.edu. Thank you for your cooperation.

Sincerely,

Gail M. Dummer, Ph.D.

SIRB Chair

c: Lihua Huang

## **APPENDIX B**

## **INVITATION LETTER**

July 12, 2010

#### Dear Mr. Smith,

We are writing to ask for your help for a study "Family caregiving and social networks." We are asking people like you to reflect on your experience as caregivers for your family member. Your responses to this survey are very important and will help in advancing human services and research in family caregivers and social networks.

Your participation is entirely voluntary and all of your responses will be kept confidential. No personal identifiable information will be associated with your responses in any reports of this data.

The survey will involve approximately one hour of your time. You may choose not to participate, or choose not to answer a particular question. You may withdraw your participation at any time. You are encouraged to ask the researchers any questions you may have. If you decide to participate, we will be asking you to fill out the survey. There is no right or wrong answers to the questions to be asked. The important thing is for you to share your experience and opinions.

If you have any questions about this study, please contact Dr. DeBrenna Agbényiga, the Responsible Project Investigator, School of Social Work, MSU, 104 Baker Hall, East Lansing, MI 48824, USA, at 1-517-432-4459, fax: 1-517-353-3038, or email: agbenyi1@msu.edu. You may also contact the director of MSU's Human Research Protection Programs, Judy McMillan, at 1-517-432-4502, Fax: 1-517-432-4503, or email mcmill12@ora.msu.edu, or regular mail at 202 Olds Hall, East Lansing, MI 48824.

We appreciate your time and consideration in completing the survey. Thank you for participating in this study! It is only through the help of grandparents like you that we can provide information to help human services and policy making related to health and well-being of grandparent caregivers in Michigan.

Many thanks.

Lihua Huang

Study Coordinator

School of Social Work, Michigan State University

## APPENDIX C

## **INFORMED CONSENT**

#### A Research Study of Family Caregiving and Social Networks Survey

#### **Consent Form**

Hi, we are researchers from Michigan State University. We are conducting a study that involves research about family caregiving and social networks. The study involves completing survey and interviewing. You are invited to complete in this survey because you belong to one of three groups: primary and secondary family caregivers (mostly family caregivers), care recipients of family caregiving, and non-family caregivers. 3–5 of you may be selected for a follow-up study that involves interviewing. No matter whether you have direct experience with family caregiving or not, your response to this survey will help in advance in human services for family caregivers in Michigan.

The survey will take about 15 minutes to complete. Your participation is entirely voluntary. You may choose complete or not complete this survey. Refusal to participate will involve no penalty or loss of benefits to which the subjects is otherwise entitled. You may choose not to answer any question(s), and you may end your participation at any time. There is no penalty if you decide that you do not want to complete some or all of the survey.

#### How will the information you provide be protected?

All of your responses will be kept confidential and your confidentiality will be protected to the maximum extent allowable by law. Do not write your name on this form or anywhere on your survey. We will keep all of the surveys in a locked cabinet at 104 Baker Hall, Michigan State University for at least 3 years after the project closed. Only the two Principal Investigators and authorized organization, including the MSU Institutional Review Boards, will have access to the surveys.

When the results of the research are published or discussed at conferences, no information will be included that would reveal your identity.

#### What are the risk and benefits of participation?

There are no known physical, social, legal or economic risks to you if you choose to participate. Some of the questions may cause you some emotional discomfort if they remind you of situations or people. Remember, your participation is voluntary and you may choose not to participate at all, or you may skip questions or end your participation at any time. We will ensure that no one else knows what you have responded in your survey.

You will not directly benefit from your participation in this study. However, your participation in this study may contribute to the understanding of family caregiving and social networks.

#### Who should you contact if you have questions or concerns?

If you have concerns or questions about this study, such as scientific issues, how to do any part of it, or to report an injury, please contact the Responsible Project Investigator: Dr. DeBrenna Agbényiga at Michigan State University. Phone: 517-432-4459. Address: 104 Baker Hall, East Lansing, MI 48824.

If you questions regarding your role and rights as a study participant, or would like to register a complaint about this research study, or report a research-related injury (i.e. physical, psychological, social, financial, or otherwise), you may contact, anonymously, if you wish the Human Research Protection Program, at 517-355-2180, Fax 517-432-4503, or email irb@msu.edu, or regular mail at HRPP, 207 Olds Hall, MSU, East Lansing, MI 48824. You indicate your voluntary agreement to participate by completing and returning this survey.

#### THANK YOU FOR YOUR TIME AND HELP!

This consent form was approved by the Social Science/Behavioral/Education Institutional Review Board (SIRB) at Michigan State University. Approved 07/06/10 – valid through

07/05/11. This version supersedes all previous versions. IRB # 10-528.

## **APPENDIX D**

## QUESTIONNAIRE

## Family Caregiving and Social Networks

## A Research Study to Understand Family Caregiving and Social Network in Michigan

To be completed by the adult age 64 and over in your household

School of Social Work

Michigan State University

East Lansing, MI 48442

#### Instructions for completing the survey

On this survey, you are asked to answer questions to help us understand your social networks, health, and family caregiving. There are five sections. Please take the time to read and answer each question carefully by filling in the blank or checking the box that best represents your response. Please remember, *your answers will not be shared with anyone. Your name or identification will not be on this form at all.* 

\_\_\_\_\_

#### SECTION ONE: SOCIAL NETWORKS

#### 1. How many relatives/neighbors/friends do you see or hear from at least once a month?

	0	1	2	3–4	5–9	9 and more
Relatives	[]	[]	[]	[]	[]	[]
Neighbors	[]	[]	[]	[]	[]	[]
Friends	[]	[]	[]	[]	[]	[]

#### 2. How often do you see or hear from them with whom you have the most contact?

	Never	Seldom	Sometimes	Often	Very Often	Always
Relatives	[]	[]	[]	[]	[]	[]
Neighbors	[]	[]	[]	[]	[]	[]
Friends	[]	[]	[]	[]	[]	[]

#### 3. How many do you feel at ease with that you can talk about private matters?

	0	1	2	3–4	5–9	9 and more
Relatives	[]	[]	[]	[]	[]	[]
Neighbors	[]	[]	[]	[]	[]	[ ]
Friends	[]	[]	[]	[]	[]	[]

1. How many relatives/neighbors/friends do you feel close to such that you could call on them for help?

	0	1	2	3–4	5–9	9 and more
Relatives	[]	[]	[]	[]	[]	[]
Neighbors	[]	[]	[]	[]	[]	[]
Friends	[]	[]	[]	[]	[]	[ ]

## 5. When one of your relatives/neighbors/friends has an important decision to make, how

#### often do they talk to you about it?

	Never	Seldom	Sometimes	Often	Very Often	Always
Relatives	[]	[]	[]	[]	[]	[]
Neighbors	[]	[]	[ ]	[]	[]	[]
Friends	[]	[]	[]	[]	[]	[]

#### 6. How often is one of your relatives/neighbors/friends available for you to talk to when

#### you have an important decision to make?

	Never	Seldom	Sometimes	Often	Very Often	Always
Relatives	[]	[]	[]	[]	[]	[]
Neighbors	[]	[]	[]	[]	[]	[]
Friends	[]	[]	[]	[]	[ ]	[]

#### 7. Do you attend religious services?

|--|

## If yes, about how often have you attended services in the last four weeks? **\***

- [] More than once a week [] Once a week [] Twice [] Once [] None
- 8. Not including attendance at religious services, do you belong to national or local community organizations?

[] No. Go to Question 9.	[] Yes		
If yes, how many times did you	u participate in activiti	es during the past year? $*$	
[] More than once a month	[] Once a month [	] 2 or 3 times a year	
[] About once a year	[] Less than once a ye	ar	
9. Do you belong to groups or	clubs?		
[] No. Go to Question 10.	[] Yes		
If yes, how many times did yo	u participate in activiti	es during the past year? 🕇	
[] More than once a month	[] Once a month	[] 2 or 3 times a year	
[] About once a year	[] Less than once a y	ear	
10. Have you spent any time in	n the past 12 months do	ing volunteering work for	religious,
educational, health-related	or other charitable or	ganizations?	
[]Yes			
11. Please check the life events	that have occurred du	ring the past two years. 0=	never, 1=
<ul><li>11. Please check the life events</li><li>once, 2= twice, and so on and so</li></ul>	that have occurred du	ring the past two years. 0=	never, 1=
<ul> <li>11. Please check the life events</li> <li>once, 2= twice, and so on and so</li> <li>1) Marriage</li> </ul>	that have occurred du	ring the past two years. 0=	never, 1=
<ul> <li>11. Please check the life events</li> <li>once, 2= twice, and so on and so</li> <li>1) Marriage</li> <li>2) Marriage separation/dive</li> </ul>	that have occurred du so for.	ring the past two years. 0=	never, 1=
<ul> <li>11. Please check the life events</li> <li>once, 2= twice, and so on and so</li> <li>1) Marriage</li> <li>2) Marriage separation/diversional solution</li> <li>3) Major illness of spouse</li> </ul>	that have occurred du so for.	ring the past two years. 0=	never, 1=
<ul> <li>11. Please check the life events</li> <li>once, 2= twice, and so on and so</li> <li>1) Marriage</li> <li>2) Marriage separation/diversional separational separation/diversional separational separational separational separational separational separational separational separational separatio</li></ul>	that have occurred du so for.	ring the past two years. 0=	never, 1=
<ul> <li>11. Please check the life events</li> <li>once, 2= twice, and so on and so</li> <li>1) Marriage</li> <li>2) Marriage separation/dive</li> <li>3) Major illness of spouse</li> <li>4) Death of spouse</li> <li>5) Death of immediate fam</li> </ul>	that have occurred du so for.	ring the past two years. 0=	never, 1=
<ul> <li>11. Please check the life events</li> <li>once, 2= twice, and so on and so on</li></ul>	s that have occurred du so for.	ring the past two years. 0=	never, 1=
<ul> <li>11. Please check the life events</li> <li>once, 2= twice, and so on and so on</li></ul>	s that have occurred du so for.	ring the past two years. 0=	never, 1=
<ul> <li>11. Please check the life events</li> <li>once, 2= twice, and so on and so on</li></ul>	s that have occurred du so for. orce	ring the past two years. 0=	never, 1=
<ul> <li>11. Please check the life events</li> <li>once, 2= twice, and so on and so on</li></ul>	ily member	ring the past two years. 0=	never, 1=

11) Change in social activities	
12) Change in number of family get-togethers	
13) Diagnosis of a severe disease of a loved one	
14) Legal issue of a social network member	
15) Beginning school, training, or other learning	
SECTION TWO: HEALTH	
1. In general, would you say your health is:	
[] Excellent [] Good [] Neutral [] Poor [] Very Poor	
2. Are you able to drive?	
[] Yes [] No	
[] Never drove	
If yes, do you limit your driving to hearby places, or do yo	u also drive on
longer trips?	
[] Limit to nearby [] Drive long trips	
3. About how tall are you?Feet Inches	
4. About how much do you weigh? (lb)	
5. Do you have any difficulty with these activities?	
	No Yes
Shopping for groceries	[][]
Preparing a hot meal	[][]
Making phone calls	[][]
Taking medications if you needed to do so	[][]

	No	Yes
Housework	[]	[]
Handling your money-e.g. paying bills and keeping tracking of expenses	[]	[]
6. Do you take prescription drugs daily?		
[] No. Go to Question 7. [] Yes		
If yes, how many prescription drugs you take daily?		
(Write the number of drugs in the box.)		
7. Has a doctor ever told you that you have any of the following condition	ns?	
	No	Yes
High blood pressure or hypertension	[]	[]
Diabetes or high blood sugar	[]	[]
Cancer	[]	[]
Chronic lung disease such as asthma, chronic bronchitis or emphysema	[]	[]
Congestive heart failure	[]	[]
Stroke	[]	[]
Arthritis or rheumatism	[]	[]
Heart attack, coronary heart disease, congestive heart failure or other heart		
problems	[]	[]
8. Have you fallen down in past five years?		
[] No. [] Yes	7	
If yes, how many times have you fallen in past five years?		
9. Are you taking any medication or treatment to control my condition?		
	No	Yes
High blood pressure or hypertension	[]	[]
Diabetes or high blood sugar	[]	[]

	No	Yes
Cancer	[]	[]
Chronic lung disease such as asthma, chronic bronchitis or emphysema	[]	[]
Congestive heart failure	[]	[]
Stroke	[]	[]
Arthritis or rheumatism	[]	[]
Heart attack, coronary heart disease, congestive heart failure or other heart		
problems	[]	[]

## 10. Have you ever

## No Yes

[]
[]
[]

11. How have you felt over the past week? Choose the best answer.

#### Yes No

Am I basically satisfied with my life?	[]	[]
Have I dropped many of my activities and interests?	[]	[]
Do I often get bored?	[]	[]
Am I in good spirits most of the time?	[]	[]
Am I afraid that something bad is going to happen to me?	[]	[]
Do I feel happy most of the time?	[]	[]
Do I often feel helpless?	[]	[]
Do I prefer to stay at home, rather than going out and doing new things?	[]	[]

Yes No

	res	INO
Do I feel I have more problems with memory than most?	[]	[]
Do I think it is wonderful to be alive now?	[]	[]
Do I feel pretty worthless the way I am now?	[]	[]
Do I feel full of energy?	[]	[]
Do I feel that my situation is hopeless?	[]	[]
Do I think that most people are better off than I am?	[]	[]
SECTION THREE: HEALTH CARE		
1. Do you have health insurance?		
[ ] No		
[]Yes		
If yes, what kind of health insurance coverage? Choose applicable	le	
[] Private insurance		
[] Employment-based private insurance		
[ ] Direct purchased private insurance		
[] Medicaid		
[] Medicare		
[ ] Other government insurance		
Are you currently covered by the following Medicare plans? Choo	ose app	plicable.
[] Yes, Part A of Medicare		

- [ ] Yes, Part B of Medicare
- [ ] Yes, Part D of Medicare
- [] Don't know

## What is the Medicaid plan you are covered?

(Write the name of the plan)

2. Are you receiving benefits from the Social Security Disability program?

[]No []Yes If yes, when did you start to receive? (MM/YYYY) 3. Are you receiving benefits from the Supplemental Security Income program? []No []Yes \_\_\_\_ If yes, when did you start to receive? (MM/YYYY) 4. How many full meals do you eat daily? [] One [] Two [] Three [] Other\_\_\_\_ 5. Do you eat or drink the following: No Yes At least one serving of dairy products (milk, cheese, yogurt) per day [] [] Two or more servings of beans or eggs per week ..... [] [] Meat, fish, or poultry per day ..... [] [] 6. Do you ever drink alcoholic beverages such as beer, wine, or liquor? []No [] Yes \_\_\_\_\_ If yes, in the last four weeks, on average, how many days per week have you had any alcohol to drink? (1-7)

#### In the last four weeks, on the days you drink, about how many drinks do

you have?



(Write the number in the box.)

7. Have you ever smoked cigarettes? (By smoking we mean more than 100 cigarettes in your

lifetime. Do not include pipes or cigars.)

[ ] No

[] Yes \_\_\_\_\_

If yes, do you smoke cigarettes now?

[]Yes []No

#### 10. Do you exercise regularly?

- [ ] No
- []Yes \_\_\_\_\_

If yes, how many times do you do aerobic exercise each week? Examples of aerobic

exercises are walking, running, and biking.

[] Hardly once a week [] Once a week [] Two-three times a week

[] More than three times a week [] Other\_\_\_\_\_

How many times do you do strengthening and toning exercise each week? Examples

of strengthening and toning exercises are lifting and weights.

[] Hardly once a week [] Once a week [] Two-three times a week

[] More than three times a week [] Other\_\_\_\_\_

#### How many times do you do stretching and flexibility exercise each week? Examples

for stretching and flexibility exercises are lifting and weights.

- [] Hardly once a week [] Once a week [] Two-three times a week
- [] More than three times a week [] Other\_\_\_\_\_

#### SECTION FOUR: FAMILY CAREGIVING

# 1. Do you consider yourself a caregiver for or a care receiver from a loved one (a family member, relative, friend, neighbor or other)?

[] Both [] Caregiver [] Care receiver [] Neither. Go to Page 11.

2. Over the past 30 days, have you regularly helped a loved one or been helped by a loved one with following activities? Check all that apply.

	No	Yes
Getting in and out of beds and chairs	[]	[]
Getting dressed	[]	[]
Getting to and from the toilet	[]	[]
Bathing or showering	[]	[]
Dealing with incontinence or diapers	[]	[]
Feeding	[]	[]
Managing medicines, pills, injections	[]	[]

3. Over the past 30 days, have you regularly helped a loved one or been helped by a loved one with following activities? Check all that apply.

	No	Yes
Managing finances	[]	[]
Grocery shopping	[]	[]
Housework	[]	[ ]
Preparing meals	[]	[]
Transportation	[]	[ ]
Arranging or supervising services	[]	[]

## 4. Who are you currently caring for or cared by? Choose all applicable. Writing down 2 after

"sibling" if you care for two siblings, for example.

Grandparent/Parent/step paren	it Spo	use/ Partner	
Sibling/step sibling	Adu	lt child/step child	
Grandchild/Great grandchild	In-la	aw	
Friend	Neig	hbor	
5. How long have you been carin	g for or cared by	the loved one? Choose the	e longest time if
you care for more than one.			
<ul><li>[ ] Less than 6 month</li><li>[ ] 3 or 4 years</li></ul>	[ ] 6–11 months [ ] 5–9 years	[ ] 1 or 2 years [ ] 10 years or more]	
[ ] Other, specify			
6. What brought him/her or you	into the care? Ch	oose all applicable.	
[] Absence or unavailability of	of birth parents of 1	ny grandchild	
[ ] Chronic ill, specify	[ ] Disabil	ity, specify	
7. How many hours did you care	for him/her or w	ere you cared last week?	
[] Less than 9 hours	[]	9–20 hours	
[] 21–40 hours [] Over 40 hours			
8. Except professionals, are you the only person caring for him/her or are you cared by			
only one family member/relative	/friend/neighbor		
[ ] Yes. Go to Question 9.			
[] No.			
If no, who are the other people providing cares? Choose all applicable			
[] Parent/step parent [	] Spouse/ Partner	[ ] Sibling/step sibling	
[] Adult child/step child [	] In-law	[] Friend	
[] Grandchild/Great grandcl	hild	[] Neighbor	

## 9. Where does the loved one live currently? Choose all applicable.

- [] Live in the same household with me
- [] Live less than 20 minutes away [] Live between 20 to 60 minutes away
- [] Live between 1 to 2 hours away [] Live more than 2 hours away

## 10. Have you used human and health services for family caregivers in the past year? If your

are not a caregiver, skip Question 10-14, and go to Page 11.

- [] No. Go to Question 11.
- [] Yes

## If yes, what services have you used? How many times have you used them in the last year?

## Are you satisfied with them?

	Service Use	Times Used	Satisfaction
	No=0 Yes=1	Last Year	No=0 Yes=1
Personal care	[]	[ ]	[]
Home making	[]	[ ]	[]
Home delivered meals	[]	[ ]	[]
Adult day care	[]	[ ]	[]
Case management	[]	[ ]	[]
Congregate meal	[]	[ ]	[]
Nutrition counseling	[]	[ ]	[]
Psychosocial services	[]	[ ]	[]
Transportation	[]	[ ]	[]
Legal assistance	[]	[ ]	[]
Nutrition education	[]	[ ]	[]
Information & assistance .	[]	[ ]	[]

	Service Use	Times Used	Satisfaction
	No=0 Yes=1	Last Year	No=0 Yes=1
Home environmental skill			
building	[]	[ ]	[]
Outreach	[]	[ ]	[]
Support group	[]	[ ]	[]
Recreation/social center	[]	[ ]	[]
Medical education program	[]	[ ]	[]
Other	[]	[ ]	[]

#### 11. Have you ever received services through the internet?

[]No []Yes

If Yes, have you received help from relatives, friends, neighbors or professionals to use internet services? Choose applicable.

[] Relatives [] Friends [] Neighbors [] Professionals

#### 12. How did you know of these services?

- [] From friends [] From neighbors [] From relatives
- [] From physicians/nurses [] From social workers [] From media

[] From other professionals [] I never know them available

#### 13. Rank these changes you have experienced since serving in the family caregiving role,

#### using a scale of -3 to 3 with -3 = changed for the worst and 3 = changed for the best.

-3 -2 -1 0 1 2 3

Changed for the worst No change Changed for the best

[ ] My self-esteem

- [ ] My physical health
- [ ] My time for family activities
- [ ] My ability to cope with stress
- [ ] My relationship with friends
- [ ] My future outlook
- [ ] My emotional well-being
- [ ] My time for social activities friends
- [ ] My relationships with family
- [ ] My relationship with the loved one I care for

14. Your answers to the following two questions are very important for understanding what family caregiving brings to you and your family.

## 1) How does caregiving make you feel?

2) In general, how has your life changed as a result of family caregiving?

## SECTION FIVE: DEMOGRAPHICS

1. What is your gender?	[] Male	[] Female	
2. What is your race?			
[] Caucasian/White, non-Hispanic			
[ ] Black/African American			
[] American Indian and Alaska Nati	ive		
[] Asian (Asian Indian, Chinese, Fil	lipina, Japanese, Kor	ean, Vietnamese, etc.)	
[] Native Hawaiian and other Pacifi	c Islander		
[] Multiracial			
3. What is your date of birth?	_/ /(D	D/MM/YYYY)	
4. Were you born in the United Stat	t <b>es?</b> [] No	[] Yes	
5. Are you Hispanic or Latino?	[] Yes	[ ] No	
6. What is your current marital stat	tus?		
[] Single, Never married	[] Married/live	with a partner	
[] Separated	[] Divorced		
[] Widowed			
How many years and mont	ths have you been w	vidow/widower?	
(Year & month)			
8. What is the highest education you have completed?			
[] None	[] Less than Hig	gh School Diploma	
[ ] A High School Diploma/GED	[] Some Colleg	e, no Degree	
[] Associate degree	[] Bachelor's D	legree	
[] Master's Degree	[] Post Master'	S	

9. What is your employment status? Choose all applicable.

[] Retired	[] P	art-time employed
[] Full-time employed	d []U	nemployed and looking for work
[ ] On disability	[]T	emporarily laid off
[ ] On sick leave	[]H	lomemaker
[] Student	[]0	ther
Did you retire because	of an ongoing health p	roblem, impairment or disability?
[ ] No	[ ]	Yes
10. Where do you live?		
[] House	[] Mobile home	[] Apartment

## 11. What is your total household income (Including all earners and benefits in your

household)?

[] Condo

[] Less than \$25,000	[ ] \$25,000-\$49,999
[ ] \$50,000-\$74,999	[ ] \$75,000–\$99,999

[] Farm/Ranch

[] \$100,000 and more

#### 12. Not including you, how many people currently live in the residence?

(Write down the total number of people living in the household with you.)

If one or more, who are they? Check all applicable.

Spouse/partner	Parent	
Child/step child	Grandchild	
Sibling	In-law	
Other		

## 13. Do you and your family speak a language other than English at home?

- [] Yes
- [] No. The end of the Section.

If yes, what language is it?

Thank you for taking the time to complete our survey. Your contribution is greatly appreciated.

## Please use the pre-stamped envelope to return your survey.

Thank You!

## **APPENDIX E**

## DEMOGRAPHIC COMPARISON OF RESEARCH SITES

## Table A1

## Demographic Comparison of Research Sites

	48197	49506	19871
Zip Code Tabulation Areas	YT	GR	PV
Residence	Metropolitan	Suburban	Rural
Region	Southeast	Southwest	Upper Peninsula
County	Washtenaw	Kent	Menominee
Total 64 and over	3,684	2,715	115
Aging (%)	6.1	13.3	27.5
Race (Non-white, %)	.347	.254	.020

Source: U.S. Census 2000.
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