

**HOW DOES SOCIAL SUPPORT AND HEALTH CARE POLICY
INFLUENCE THE OVERALL WELL-BEING OF A FAMILY CAREGIVER
FOR PERSONS WITH CHRONIC ILLNESSES AND THE ELDERLY?**

by

Roberto Jose Muniz

A thesis submitted to the Faculty of the University of Delaware in partial fulfillment of the requirements for the degree of Master of Science in Human Development and Family Studies

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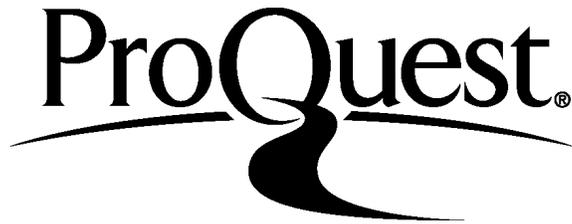
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ABSTRACT

The rapid increase in the 65 and older population, coupled with the decline in the working age population, has caused concern for the elderly and policymakers, ushering health care policy, long-term services and supports, community-based services, and the welfare of family caregivers to the forefront of the policy agenda. The increasingly popular desire to age-in-place and the shift to community- and home-based health services have added emphasis to the extensive role of the family caregiver, thus highlighting the importance of caregiver well-being. For this study, a secondary data analysis was conducted using a data set from *Chronic Illness and Caregiving; 2000*. Based on a sample of 320 caregivers, this study examines the influence of social support on caregiver well-being for sole caregivers and co-caregivers, how the perception of social support relates to caregiver well-being, and whether access to resources influences caregiver well-being. Attitudes surrounding policy change and tax initiatives targeting caregivers and the care recipients are examined to identify whether differences exist between those who can and cannot provide the care that is needed. Results show that sole caregivers and co-caregivers do not differ in well-being ($p=1.50$), there is a clinically significant relationship between perceived social support and well-being ($p=0.55$), and that a strong relationship exists between well-being and the accessibility of resources via community groups/organizations ($p= 0.034$). Results show that the willingness to support various tax breaks and policy changes does not differ for those who can and cannot provide care without the need for assistance. This study has limitations due to the small sample of caregivers. Further research should control for gender and race and examine the differences between well-being for caregivers and non-caregivers.

Chapter 1

INTRODUCTION

The problem is clear: with the shift in U.S. demographics and the rapid increase of the elderly population, we, as citizens of the United States, need to be prepared to provide support for our aging population and its caregivers. This goal can be accomplished through policy and supportive services for caregivers and care recipients, intrinsically delaying the need for formal care. Addressing the needs of the elderly population and its caregivers by spreading awareness and increasing public support programs and caregiver supportive services focusing on caregiver well-being should be a focal point for policymakers and health care and human services professionals. The population of Americans ages 65 and older is expected to double over the next 25 years due to the increased life expectancy of the baby boomers. To prevent further issues, long-term care policy and support programs must be amended to adequately address the needs generated by the increase in the elderly population (CDC, 2013). The projected growth rate of the 16-64 population shows that the ratio of people ages 16-24, compared to those age 65 and over, is projected to decline from 5.1% in 2000 to 2.9% in 2050 (Wiener & Tilly, 2002). This decline in the working age population has implications for the financial stability of the United States, the elderly, and their caregivers. It will mean that there will be relatively fewer people to pay the taxes that support programs for the older population, and there will be fewer people to provide the services that older people need (Wiener & Tilly, 2002). Sustaining quality informal care will help in maintaining the greatest levels

of quality of life and help delay the inevitable loss of independence in old age. Yet, this outcome can only occur by increasing caregiver supportive services and forming policy initiatives to support the aging population and its caregivers.

Chronic disease is the leading cause of death and disability in the United States and a leading cause of decreased quality of life (CDC, 2011). The number of citizens ages 65 and older varies state to state, causing state legislators to only understand the severity of the aging trends specific to their state. Reviewing past and present policies targeting the aging population, especially those who are chronically ill, and their caregivers is essential to addressing the current gaps in the health care system and to creating future policy to aid the caregiving process.

Policymakers have recognized the importance of the family caregiver as the backbone of the long-term care system. Efforts to support family caregivers partially stem from a shortage of paid workers and fear that the elderly will end up in nursing homes at the public's expenses if family caregivers experience burnout and diminished well-being (Levine, Halper, Peist, & Gould, 2010). Due to the fragmented geriatric health care system and the desire of the elderly to age-in-place, in-home and community-based services have become increasingly popular. The assistance made available through community programs and public services targeting the aging population can greatly improve the lives of the elderly and their caregivers, yet those in need can only benefit from such services if they know they exist. The availability of resources for family caregivers has progressively become an important topic in caregiver research, especially with two-thirds of all non-institutionalized persons needing assistance with activities of daily living depending solely on family and friends (Whittier, Scharlach, Dal Santos,

2005). Policymakers recognize that enhancing caregiver involvement, training, and support will reduce the frequency of hospitalization and institutionalization and improve patient outcomes. That being said, further progress is needed. To help shape future policy and practice for training, financial reform, and program development, the contributions and experiences of family caregivers should be considered (Levine et al., 2010).

The topic of aging in the United States has gained increasing popularity and deserves immediate attention to address the issues in health care and family policy, the flawed health care system, and the importance of informal family caregivers. The extant literature on caregivers does not explore the effects of social support on well-being and their experiences, yet special attention must be given to the resources and resilience factors that help maintain caregiver well-being. This study offers an analysis of social support and its benefits through a stress-buffering framework.

Statement of the Problem

A growing number of family caregivers provide support and care for older, frail, and chronically ill family members who are no longer able to care for themselves. Despite empirical evidence signifying the important of social support, insufficient attention has been given to examining the effect of the perceived adequacy of social support and the impact it may have on caregivers' well-being, particularly the extent to which public policy impacts caregiving. In comparison to formal care, informal care is often preferred by the elderly and can delay the need for formal, institutionalized care (Van Houtven & Norton, 2004).

The drastic increase of the aging population and its need for care calls for health care and family policy to address the needs of the elderly and their caregivers. Policies are in place to promote informal care, yet adjustments must be made to better serve this aging population and its caregivers. Attitudes toward support for policy changes and tax initiatives targeting caregivers and the aging population must be evaluated to adequately support caregivers. To better evaluate and formulate a long-term care and supports policy, we need to understand how formal and informal care can affect the caregiving process and the types of assistance that would be appropriate to provide the care that is needed.

The two guiding research questions for this study are as follow:

1. Does access to social support relate to caregiver well-being?

2. Are there differences between those who can and cannot provide care in their support for tax and policy initiatives?

Chapter 2

LITERATURE REVIEW

What is Caregiving?

Caregiving comes in many forms and provides several types of assistance and support for those who are ill or otherwise in need of care. According to the *Blackwell Encyclopedia of Sociology*, “Caregiving is the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological, or developmental needs. Caring for others generally takes three forms: Instrumental, emotional, and informational caring” (Drentea, 2007, p. 1). Caregiving rarely refers to the daily care that parents provide for their children; however, caring for a disabled adult son or daughter is considered caregiving because it is outside of the norm of expectations (Drentea, 2007, p. 1). Caregiving is often used to describe the assistance or support given to elderly persons with chronic illnesses. Caring for the elderly population can take many forms, including institutionalized skilled care, assisted living facilities, privately paid and Medicare/Medicaid funded care, and care provided by family members. Studies have shown that the majority of older adults prefer to age in place (i.e., at home) and receive long-term care services in their homes rather than being placed in an institutional setting (Marek, Popejoy, Petroski, Mehr, Rantz, & Lin, 2005). This preference holds true despite empirical evidence that links home hazards to negative physical health risk for care recipients, for example, objects or obstacles that may result in falls (Oswald, Jopp, Rott & Wahl, 2010; Tang & Pickard, 2008). Caregiving duties vary from situation to situation. If

the person in need of assistance is married, his or her spouse often assumes a significant portion of the caregiving duties. As Stoller (1983) points out, “Older couples can maintain considerable independence in the face of infirmities by nursing one another or relocating housekeeping chores” (p. 851). When a spouse is not present or the amount of assistance is insufficient, other family members— particularly adult daughters—step in to provide help (Stoller, 1983). Family care has been identified as the most preferred and trusted source of assistance across all ethnic groups, which could help explain the increase in family caregiving (Hooyman & Kiyak, 2010).

Family Caregivers

The definition of “family” may differ from one person to another. According to Feinberg (2014), the term ‘family caregiver’ refers to the ‘traditional’ definition of family members, but also any relative, partner, friend, or neighbor who may be considered ‘like family,’ who has a significant relationship with and provides a broad range of assistance for an older adult or adult with chronic or disabling conditions.” (p. 65)

About two thirds of all older people with disabilities who received long-term services and supports (LTSS) at home receive all of their care from family members: about 26% receive a combination of family care and paid help, and only 9% receive paid help alone (Feinberg, 2014). In 2009, approximately 42.1 million family caregivers in the United States provided unpaid care to an adult with limitations in daily activities (Feinberg, 2014). Research conducted by the National Alliance for Caregiving (2009) and The Scan Foundation (2012) shows that the majority of family caregivers, 66%, are

co-caregivers, meaning they have at least one other unpaid caregiver to help their care recipient. The portion of caregiving adults who are co-caregivers has increased from 59% in 2004 to 66% in 2009 (National Alliance for Caregiving, 2009). In 1999, the portion of sole caregivers was 52.8%, with the portion of sole caregivers in 2009 being 44%, a decrease of about 9% (Wolff & Kasper, 2006). Compared to younger caregivers, caregivers who are age 65 and older are more likely to be sole caregivers without the support of another unpaid caregiver (The Scan Foundation, 2012). Family caregivers and co-caregivers provide a wide range of assistance, including emotional, financial, decisions making, and medical help, an estimated value of \$450 billion in 2009 (Feinberg, 2014).

In addition to being the preferred source of assistance for the elderly, family caregiving has become a popular option for a number of other reasons, including the care recipients' desire to age in place, the resources available for the care recipient, the perception of social support, and the accessibility of resources and social support for the caregiver and the care recipient. Aging in place refers to the ability for individuals to grow old in their own homes with modifications to support their needs (Ball, Perkins, Whittington, Connell, Hollingsworth, King, Elrod, & Combs, 2004). This assistance can come from formal support, informal support, publically funded services, or private resources. The distinction between informal and formal social support is important to note. Informal support can be in the form of assistance, information sharing, guidance, and material aid from family and friends, while formal support refers to paid professional assistance, organizations, and support groups (Kaufman, Kosberg, Leeper, & Tang, 2010). It is also important to note that formal arrangements can be made with informal

caregivers, that is, payments can be made to nonprofessionals in exchange for providing assistance with mealtimes, housekeeping, and household chores. Family caregiving is often just a temporary arrangement. More than two thirds of caregivers sustain their commitment for more than one year to delay the need for institutionalization in a long-term care facility (Brodaty & Donkin, 2009). Family caregiving can be taxing on the caregiver and, when involved, other family members. The common distinction between formal and informal care does not accurately reflect the reality of what family caregivers do. Informal care is defined as care provided outside of institutions by untrained and unpaid providers. Family caregivers assume a wide variety of responsibilities, some of which go unnoticed.

Role of the Caregiver

The family caregiver plays a role in many areas of care. To measure the full range of family caregivers' involvement, a more holistic analysis is needed to explore their personal care, medical care, and interactions with the health care system and policy (Bookman & Harrington, 2007). Family caregivers have been described by some experts as an "invisible, isolated army" due to the complicated tasks, frustrations, and challenges they face when providing care with little to no recognition, support, or training and at their own personal expense (Feinberg, 2014, p. 66). Caregivers' responsibilities go far beyond personal care for the elderly: they often have significant involvement in medically related tasks. Due to the increasing complexity of family caregiving, the role of the caregiver has expanded significantly, both at home and in institutional settings. They often provide difficult nursing tasks such as wound care, administering injections, and operating specialized medical equipment. These tasks, which were once only provided in

hospitals, nursing homes, and by home care professionals, are being performed by family members with little formal preparation, training, or support, along with the responsibilities of arranging and providing long-term services and supports (Feinberg, 2014). These situations highlight the need for supportive services, programs, and policies necessary to better equip family caregivers and facilitate the caregiving process. Family caregivers may also partake in caregiving in institutional settings when their family member is in need of paid care. Yamamoto-Mitani, Aneshensel, and Levy-Storms (2002) provide evidence that family involvement inside institutional settings seems to benefit the quality of life and psychological functioning of elderly persons, along with assuring the quality of institutional care being provided. Due to the diversity of care provided by family caregivers, and their interaction with the healthcare system, it is essential to capture the full range of work done by family caregivers and their dependence on the geriatric health care system (Bookman & Harrington, 2007).

Despite the lack of formal training and monetary compensation, caregivers frequently operate as a part of the geriatric health care workforce and as navigators of health care policy. Their range of work often includes attending doctor's appointments, coordinating hospital and rehabilitation stays, and distributing medications, in addition to assisting with activities of daily living (ADLs) (Bookman & Harrington, 2007). Within the health care system, family caregivers and the elderly encounter different systems of organization and communication between institutions when receiving care (Bookman & Harrington, 2007). Family caregivers also play an essential role in communication between the patient and his or her doctors, health care providers, and community services. Those who care for elders with memory loss, or other difficulties related to

illness, serve to describe the trajectory of the patient's conditions and provide detailed information about the patient's medical history, some of which is not listed on the patient's charts or medical records (Bookman & Harrington, 2007).

Coordinating services is another aspect of caregiving that family caregivers encounter, especially with in-home care and reliance on community services, all while being employed. Each service must be set up and monitored, often resulting in caregivers having to call multiple providers to schedule each service. Caregivers often encounter problems when seeking and coordinating care, especially with the eligibility criteria under the current policy. Insurance issues may arise when the elderly need certain services and procedures that may only be covered by supplemental Medicare policies, which are sold by private companies to help pay some of the health care costs that Medicare does not cover (Bookman & Harrington, 2007). These issues often occur when the services of a specialist are needed for a common chronic disease or conditions such as heart disease, cancer, arthritis, and dementia. These specialist visits may not be covered, and access to patient medical records may be difficult to obtain (Bookman & Harrington, 2007). This issue may be partially affected by the Health Insurance Portability and Accountability Act (HIPAA, P.L. 104-191), which includes a privacy rule that provides federal protection for personal health information and rules to ensure and protect confidentiality (Thomas & McDaniels, 2014). Nonetheless, the diverse roles of a family caregiver are essential to the care recipient. Changes in policy and the health care system must be made to help caregivers provide the care that is needed, without neglecting their own needs. A more coordinated system utilizing the role of the family caregiver in the health care system could be used to amend and create policies that simultaneously benefit

families and health care providers, community-based service organizations, and public-sector agencies.

Consequences of Caregiving

Although caregiving for a family member has been shown to be beneficial for the care recipient, the caregiver is often exposed to a number of caregiving consequences. The caregiving role can impact the caregiver in both negative and positive ways, across all domains of development. Research shows that family caregivers reported a higher level of stress and poorer health than the general population, often diminishing the well-being of the caregiver, which can adversely affect the quality of the care provided (Kaufman et al., 2010). In addition, family caregivers often experience difficulties with their emotional and physical health, social networks, careers, and retirement security (Feinberg, 2014). A majority of family caregivers surveyed in the *Stress in America* survey felt overwhelmed by the amount of care their family member needed (American Psychological Association, 2012). Inadequate economic resources can cause additional stress, just as caregivers' physical and mental health can decline or be neglected while caring for their family member. Caregiving has also been associated with a significant reduction in employment and hours of work. Informal caregiving often leads to absenteeism, lack of concentration at work, and irregular attendance, further jeopardizing their ability to provide care (Colombo, 2011). Coordinating support programs and resources could help caregiver's better cope with stress.

Family caregivers often experience extreme fatigue and are at risk of jeopardizing their own well-being, which can compromise their ability to provide care (Bookman & Harrington, 2007). Due to the demands of caregiving, time for social and leisure activities

and work performance can be negatively impacted. This long-term burden often leaves caregivers feeling drained and unavailable to engage in social activities. Caregivers may find it difficult to do anything besides caregiving, highlighting the need for support. The type of care and hours of care provided also impact the amount of social support needed. Research has shown that when family caregivers received the appropriate support, there can be better outcomes for the caregiver and the care recipient (Feinberg & Houser, 2012). Stress can induce a negative self-evaluation, resulting in negative feelings about themselves. This finding suggests that people who believe their competence is insufficient, when faced with the inability to control important outcomes, will have a decreased sense of self-esteem (Cohen & McKay, 1984). Depression is the most commonly observed consequence of caregiving, and studies have found that family caregivers experience social strain when frustrated by a lack of perceived support (Lai & Thomson, 2011). Research has also found that those who lack a close confidant have an increased risk of depression; conversely, the effects of caregiving can be buffered when support ties are available (Clipp & George, 1990; Lai, 2010). Caregivers who have a strong social network, or the perception of one, can experience less severe caregiver burden, especially when they have the support of a spouse or other household member (Maulik, Eaton, & Bradshaw, 2011).

Social Support and Caregiver Needs

Though there is a general consensus regarding the importance of social support, conflicting ideas of how it ameliorates the experience of caregiving still exist. A distinction between social networks and social support is necessary to conceptualize social support. A caregiver's social network describes his or her social relationships in

structural properties, such as composition, the degree of social integration, and isolation experienced with family members, relatives, and friends (Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993). Support refers to the functional aspects of positive and potentially stress-reducing relationships. Emotional caring, concern from somebody within a close relationship, instrumental assistance, and information that others can offer are examples of support. It is important to note that not all relationships provide similar kinds of support. Thompson et al. (1993) identify 5 types of social support: informational support, tangible assistance, emotional support, esteem support, and social integration. Informational support refers to guidance and advice received from others. Tangible assistance includes the goods and instrumental behavior that aid the caregiver's caregiving responsibilities. Emotional care and support given to caregivers refers to the behavior of others, which promotes a sense of comfort, ease, and security for the caregiver (Thompson et al., 1993). Esteem support refers to the positive feedback provided to enhance the caregiver's self-efficacy and sense of competence, while social integration refers to a sense of belonging derived from engaging in social and recreational activities with others outside of caregiving.

An alternative definition of social support views the conceptualization as psychological and material resources available to individuals through interpersonal relationships (Rodriguez & Cohen, 1998). These resources can be accessed through structural or functional supports. The structural characteristics of social networks and the resources that networks provide, respectively, are the basic distinguishing measures. Structural supports include the extent and interconnectedness of one's social relationships, while functional supports include the availability of psychological and

material resources from an individual. Three primary types of support are identified: instrumental, that is, the provision of material aid; informational, or the provision of relevant information intended to help the coping process; and emotional, which involves expressing empathy, caring, and reassurance (Cohen & McKay, 1984; Swickert, Hittner, & Foster, 2010).

Tangible support is a common form of support offered to caregivers. Tangible support refers to material resources such as money, care, or other types of assistance, and is only beneficial if it seems adequate to the recipient. Material aid provided to the caregiver may not be an accurate measure of support; indeed, the perception of support has been identified as a more accurate protective factor, often activating the benefits of the stress-buffering effect (Swickert, Hittner, & Foster, 2010). Emotional support, conceptualized in cognitive terms, provides the caregiver the perception that she or he is being cared for and is loved. This perception acts as a protective factor from stress and causes the caregiver to feel an increased sense of self-esteem, reducing the feeling of being overwhelmed (Wethington & Kessler, 1986). This result occurs regardless of whether the perception is accurate or not.

Support, as defined by Cohen and McKay (1984), can be “information leading one to believe any of the following: that he or she is cared for or loved, esteemed and valued, and/or belongs to a network of communication and mutual obligation” (p. 259). Emotional support may be more beneficial than material, or tangible, aid. Support boosting one’s self-esteem might encourage a person to cope with a situation, in turn increasing one’s feeling of self-efficacy, resulting in more positive performance. Conversely, social support can negatively affect well-being, particularly if the

relationship induces more stress. Although the extant literature is limited, Cohen and Wills (1985) indicate that social networks can also be sources of stress and conflict, negatively affecting an individual in the relationship. In accordance with Cohen and Wills (1985), Swickert et al. (2010) propose that those who are prone to anger or hostility may be viewed by members of his or her social network as more difficult with which to interact. Network conflicts and negative social exchanges have been related to poorer health and negative effects on psychological well-being (Charles & Carstensen, 2010). Furthermore, an overwhelming majority of literature primarily focuses on the health benefits of social support. There is a distinction between social networks and social support. In general, one does not exist without the other, with the exception of a situation in which the provider of social support is particularly isolated or when an individual's social network is toxic (Charles & Carstensen, 2010). A link between social support and well-being has been identified. Despite the lack of consensus within the scientific community of the exact definition of social support, the following definition is the most appropriate for this study: "The process by which individuals manage the psychological and material resources available through their social networks to enhance their coping with stressful events, meet their social needs, and achieve their goals" (Rodriguez & Cohen, 1998, p. 536).

Research has validated the importance of social support for the caregiver's individual well-being, identifying social support as a valuable resource in tangible and intangible forms of assistance received from family and friends. Social support can provide caregivers with feelings of affection, opportunities to relate meaningfully to others, or a source for assistance in a time of need, often giving the caregiver a sense of

comfort and belief that stressful situations are manageable (Cohen & McKay, 1984; Wittenberg-Lyles, Washington, Demiris, Oliver & Shaunfield, 2014). The impact from these forms of assistance helps buffer the harmful effects of stress. In some cases, knowing that support is available is enough to provide substantial relief (Lai & Thomson, 2011).

The notion of perceived support and actual support received is relevant when analyzing the literature on social support. Perceived social support is the amount of social support an individual believes he or she could get, whereas actual support received is the actual amount of support the individual receives (Wethington & Kessler, 1986). Perceived support is more often associated with improved emotional adjustment than is received support (Wethington & Kessler, 1986). Perception is a subjective concept. This ambiguity adds to the complexity of the link between social support, health, and well-being. Chappell and Reid (2002) claim that although perceived social support is strongly related to well-being, there is no relationship between social support and caregiving burden. In contrast, Lai and Thomson (2011) found that a higher level of perceived adequacy of social support was significantly related to a lower level of caregiving burden. Using measures of perceived and actual social support received, Lai and Thomson (2011) found that caregivers, in general, experience a higher level of burden when they have lower levels of support.

Social support has been shown to act as a buffer against the negative consequences associated with family caregiving. In conjunction with Lai and Thomson (2011), other studies have indicated that perceived social support is a better predictor of caregiver burden than actual support received (Cohen & McKay, 1984; Lai & Thomson,

2011; Wethington & Kessler, 1986). It is important to note that the type or amount of social support a caregiver receives may not be perceived as sufficient or adequate (Lai & Thomson, 2011). This point highlights the importance of the quality of support received or perceived, rather than the amount, as well as the centrality of the goodness of fit between desired and perceived support. Caregivers recognize that more support and training are needed to be as helpful as possible. Indeed, a lack of knowledge about training and available resources often impedes the caregiver's ability to provide care. Therefore, caregivers' needs and social support are important aspects to consider when evaluating caregivers' well-being and the level of care they are able to provide. Having defined the role of the family caregiver and numerous perceived needs and supports for family caregivers, an understanding of the interplay between caregivers' level of well-being and the geriatric health care system is appropriate.

Geriatric Health Care System and Policy

The often fragmented geriatric health care system and health care policies create yet another threat to caregiver well-being and therefore to the care recipient as well. The lack of communication between hospitals, doctors, nurses and other health care providers makes caregiving more difficult. The lack of cross-institutional communication places an enormous burden on the caregiver and may inhibit him or her from engaging in care provision. Transitions are being made by the federal government to help manage communication issues and the increase in the elderly population. Recent attempts to transition from paper-based records to electronic systems could improve cross-institutional communication (Bookman & Harrington, 2007). Hospitals are also addressing the needs and preferences of the elderly by creating family-centered geriatric

care units, as well as specialized geriatric emergency rooms (Bookman & Harrington, 2007).

There has been an increase in in-home visits by physicians and visiting nurses, which addresses the desire to age in place (Adler-Milstein & Jha, 2012). The desire to age in place is a driving point for community-based home care. Aging in place is conceptualized as the ability for individuals to grow old in their homes or assisted living facilities—with emphasis on modifications of home environments to compensate for limitations and disabilities (Ball et al., 2004). Some state agencies offer community-based services such as aging service access points (ASAP) and area agencies on aging (AAA), which are private, non-profit agencies that provide coordinated home-care and community services to individuals with disabilities, seniors, their families, and caregiver, taking some of the burden off of the caregiver and making it easier to provide care (The Massachusetts Network of Information Providers for People with Disabilities, 2014). Although case management is available through public agencies, it is only available at the time of discharge. Outside of discharge scenarios, these services are only available to families with very low annual household incomes or to those who can afford privately paid services (Bookman & Harrington, 2007). The underlying problem with utilizing such community-based agencies is that many caregivers do not know these agencies exist, what services they offer, or where to find one near their home (Bookman & Harrington, 2007). This existing knowledge about the fragmented and disorganized geriatric health care system calls for policies that compensate for family care and policies that increase the funding and availability of services to assist caregivers in adequately addressing the needs of the elderly.

Health Care Policy

Amendments to family and health care policies could be useful to better promote and inform the elderly and their caregivers of potential resources, including how to access resources, eligibility and insurance coverage, and the potential risks and benefits of using those resources. Recent policy and service initiatives have aimed to address the desire to age in place for as long as possible by improving local infrastructures to expand home- and community-based services, yet further improvement is necessary. Policies and initiatives aimed at helping the elderly can aid caregivers in providing care while keeping costs at a minimum. Analyzing past and current policy could be useful for shaping future policy to address the needs of the elderly.

The Older Americans Act of 1965, P.L. 89-73 (OAA) created the Administration on Aging (AOA). It was intended to address and promote the social services needed by the aging population and supportive services for their family caregivers. OAA's mission was to "help older people maintain maximum independence in their homes, communities and to promote a continuum of care for the vulnerable elderly" (O'Shaughnessy, 2012, p. 1). The Act's objectives were to improve the lives of all people 60 and older, including adequate income in retirement, the best possible physical and mental health, opportunity for employment, and comprehensive long-term services and supports. Many programs were set to target these objectives; in particular, the AOA created the National Eldercare Locator Service, which provided a nationwide informational toll-free number that could be called to identify community resources. This law focused on long-term services and supports, authorizing funds for supportive and nutritional services, disease prevention, and health promotion services. It also focused on providing family caregiver support,

along with funding available for Senior Community Service employment programs and programs to prevent elderly abuse, neglect, and exploitation. In 2006, The Older American Act was reauthorized through fiscal year 2011. The extension expanded the role of the AOA and authorized funds for competitive grants to states to promote comprehensive elder justice systems and systems for mental health screening and treatment services. The OAA was still authorized through appropriations for fiscal year 2014. The federal government appropriated \$1.88 billion for 2014, and states are required to provide a non-federal match, 25% for family caregiver support and 15% for supportive services (Fox-Grage & Ujvari, 2014). Compared to Medicaid, which spent roughly \$136 billion on long-term services and supports in 2011, the \$1.88 billion appropriated seems miniscule. Despite the growth of the aging population, the OAA funding for 2014 (\$1.88 billion) has changed very little compared to 2004 (\$1.8 billion), in fact, when adjusted for inflation, it has declined in terms of real dollar value. The decrease in funding value is a potential flaw that might be adjusted in future policy. Although the services provided under the OAA play a key role in delaying or preventing costly institutionalization and autonomy, the budget has not kept up with the growth of the aging population.

Congressman John Larson (D-CT-1) recently introduced a proposal to expand the benefits of Social Security and secure it into the next century (Carey, 2014). Larson's Social Security 2100 Act (H.R. 1391) called for tax cuts for Social Security recipients by raising the threshold on taxation of benefits, providing a benefit bump for current and future beneficiaries, protecting low-income workers by raising the minimum benefit from below the poverty line to 25% above, and offering long-term protection against inflation for cost of living adjustments (U.S. House of Representatives, 2015). Progress has been

made with such policies, yet there is still a greater need for sustainable policies that support care for the elderly and their caregivers.

The Affordable Care Act (P.L. 111-148) was amended and signed into law in 2010. This amendment aimed to expand access to insurance, increase consumer protections, emphasize prevention and wellness, improve quality and system performance, expand the health workforce, and curb rising health care costs. The Affordable Care Act impacts the elderly and their health care providers by protecting Medicare coverage and offering additional preventative services to the patient at a lower cost. Preventative measures and services can help delay the need for formal long-term services and supports. These measures include programs and services aimed toward promoting community and clinical partnerships and elderly communities where housekeeping, laundry, and handy-man services are available. The elderly will have access to brand name drugs at a discounted rate, while at the same time providing added support for doctors. Medicare wants to ensure that all doctors have the resources and information to coordinate consistent care. Health care providers and doctors will work together to give patients the right care at the right time in the appropriate setting (Medicare.Gov, n.d.).

The Community Living Assistance Services and Supports Act (P.L. 111-148), or CLASS Act, was a federally administered voluntary insurance program to help adults 18 or older with disabilities pay for long-term services and supports. It was unique in the realm of long-term services and supports in that these benefits would have been financed entirely by individuals' age-adjusted premiums. Those eligible would receive cash payments to help pay for services in order to live in communities, or institutional settings.

Eligibility was determined based on three principles: An individual must have voluntarily enrolled and be an active enrollee, paid premiums for five years, and had the minimum earnings sufficient to be credited for one quarter of Social Security coverage in at least three of the first five years (O’Shaughnessy, 2011). A level of functional limitations also had to be met, the individual must meet least one of the following criteria: “Was unable to perform at least the minimum number of activities of daily living without substantial assistance from another individuals,” “required substantial supervision to protect him or her from threats to health and safety due to substantial cognitive impairment,” or “had a level of functional limitation similar to the level of functional limitations specified above” (O’Shaughnessy, 2011, p. 2-3). Eligibility would be granted when an individual was assessed and identified as having a functional limitation expected to last for a continuous period of 90 days or more. Once an individual was deemed eligible, each beneficiary would have been provided with a cash benefit, advocacy services, and advice and assistance counseling.

The CLASS Act differed from similar LTSS programs because beneficiaries would receive cash benefits to purchase services rather than receiving the services authorized, provided, and/or paid for by an agency, as is the case with other LTSS programs. The idea of self-determination signifies the control of decision-making and other activities by an individual, allowing the individual to hire and manage the people who provide his or her services (Individual Outcomes, 2010). An important aspect of the CLASS Act was the ability for participants to remain eligible for other federal benefit programs, such as Social Security, Supplemental Security Income, Medicare, Medicaid, the Children’s Health Insurance Program, Veterans Administration programs, low-

income housing assistance programs, or the Food and Nutrition Act Supplemental Nutrition Assistance Program (O'Shaughnessy, 2011). Annual age-adjusted premiums would have been established, and once an individual was enrolled, and remained enrolled, premiums would not increase. The Department of Human Services conducted an analysis of the CLASS act. In 2003, after 19 months of analysis, Congress repealed the Act, stating that the Department "had not identified a way to make CLASS sustainable, legal, and attractive to potential buyers" (O'Shaughnessy, 2011, p. 1). It was repealed because of the voluntary, self-selective nature of the program. Due to the voluntary nature of this program, a review of other voluntary actions, such as private long-term care insurance, is appropriate.

Private Long-term care insurance encompasses a wide range of services for people who require assistance on a regular basis. Long-term care insurance is a contract that agrees to provide covered benefits in exchange for regular premium payments. Policies are based on average daily benefits. In 2002, the average daily benefit was about \$100 (Johnson & Uccello, 2005). By 2030, adjusting for inflation, \$100 will not be sufficient for a daily benefit amount, it is suggested that benefits must increase at least 5% annually (Longtermcare.gov, 2014). This type of insurance helps take some of the financial burden off of the care recipient and his or her family.

Private insurance tends to be costly, and fewer than 10% of Americans had private long-term care insurance coverage in 2014 (Cohen, 2014; Robert Wood Johnson Foundation, 2014). Medicare provides coverage for skilled home health services for older Americans, but patients must meet eligibility requirements. For eligibility for Medicare coverage for home health services, the following conditions must be met: 1) The

applicant must be under the care of a doctor and receiving established services under a regularly reviewed plan of care, 2) have his or her doctor certify the need for either intermittent skilled nursing care or occupational, speech-language, or physical therapy, 3) the home health agency providing care must be approved by Medicare, and 4) a doctor must certify that the applicant is homebound (Medicare and Home Health Care, 2010). Those whose wealth is too high to qualify initially for Medicaid are forced to spend down, exhausting their resources, including inheritances, before being eligible for Medicaid. Eligibility for Medicaid requires an income below the federal poverty line (\$29,700 for a family of 4), and individuals need to satisfy federal and state requirements regarding residency, immigration status, and documentation of U.S citizenship (Medicaid.gov, 2014). Medicare eligibility requires individuals to be 65 or older, under 65 with certain disabilities, or a person with end-stage renal disease, that is, permanent kidney failure that requires kidney transplant or dialysis (LongTermCare.gov, 2014).

Medicare does not pay for long-term care services or personal care, but it will help pay for home health care if the individual meet certain conditions. Conditions include having a prior hospital stay of at least three days, being admitted to a Medicare-certified nursing facility within 30 days of that prior hospital stay, or the need for skilled care such as skilled nursing services or therapy (LongTermCare.gov, 2014). If these conditions are met, some costs will be paid for up to 100 days. Medicare will pay for 100% of costs for the first 20 days, and for days 21-100, the individual must pay for expenses up to \$140 per day and Medicare will pay the balance (LongTermCare.gov, 2014). A Medicare supplement insurance policy (Medigap) will cover the cost of home health services from certain agencies if the Medicare benefits through a Medicare health

plan does not cover them (Home Health Plan of Care, n.d.). Home and other care services, part-time skilled nursing care, therapy, and medical equipment will be covered by Medicare for a limited time when the patient's doctor deems it medically necessary to treat an illness or injury (LongTermCare.gov, 2014). Hospice care is covered for those with a terminal illness and not expected to live more than six months. Coverage for long-term care services other than skilled home health services and hospice is limited with Medicare, and much of the financial burden falls on the care recipient and their family. That being said, it is important to note that some employee health care plans, such as Blue Cross Blue Shield, fully and partially cover some of services while others providers do not (Blue Cross Blue Shield, 2015). The policies mentioned above are directed at the care recipient, potentially affecting the caregiver indirectly. A review of policies aimed to support family caregivers could provide a greater understanding of the impact policy has on the caregiver and what could be done to improve existing policy.

Support for Family Caregivers

In an effort to continue to find ways to support and maintain the supply of family caregivers, policies targeted at family caregivers have focused on five supportive areas, with special attention to caregiver well-being and financial recognition for caregivers. The five support service areas that have been identified are 1) information for caregivers about available services and tax breaks, 2) assistance to caregivers in gaining access to these services, 3) individual counseling, 4) organization of support groups, and 5) caregiver training to assist caregivers in making decisions and solving problems related to their caregiving roles, to enable caregivers to be temporarily relieved from their caregiving responsibilities, and supplemental services, on a limited bases, to complement

the care provided by caregivers (Whittier et al., 2005). Whittier et al. (2005) examine the scope and range of existing resources from the perspective of the Area Agencies on Aging (AAA) in California. In examining the extent and adequacy of resources available, California was chosen because of its rich history of state-funded caregiving support activities and its well-established array of potential resources for caregivers. The federal funds are awarded to state units on aging, who work in partnership with AAAs to develop plans for meeting the needs of local caregivers. An important component of AAA planning responsibilities for this program on local levels is the examination of existing resources, which includes the availability, appropriateness, accessibility, and adequacy of the existing services (Whittier et al., 2005). Working on the local level will allow the AAA to develop plans and allocate resources to respond better to local caregiver needs in the most efficient and effective manner. This study highlights the lack of large scale attention given to caregivers and service gaps among caregiver services, most commonly consisting of culturally-appropriate services, transportation, and care in rural areas (Whittier et al., 2005).

Policy aimed at support for family caregivers in the United States do exist, yet they lag in some respects when compared to other developed countries. Although policies directly and indirectly targeting family caregivers through respite care and compensation exist, some caregivers still struggle to balance their caregiving role with work and often suffer from mental and physical health problems. In the United States, financial and support systems such as an allowance for the person being cared for, tax credit, unpaid leave, flexible work arrangements, training/education, respite care, and counseling are available, but the majority are provided at the state level, and not at the federal level

(Colombo, 2011). According to Whittier et al. (2005), state caregiver supportive services can positively impact caregivers' well-being, especially through respite care. Policies that help reduce the combined pressure from work and caregiving could potentially increase the amount of family caregivers.

To help support family caregivers, Congress established the National Family Caregiver Support Program (P.L. 106-365; NFCSP) in 2000, along with other programs offering support services (Hayslip & Kaminski, 2005). This program is the first of its type in that it aims to meet the needs and desired services of family caregivers through a federally-based program administered by the state by providing the critical support needed for caregivers. Supportive measures, such as family leave and tax benefits, have also been a focal point for policymakers striving to support caregivers and facilitate the caregiving process.

The Family and Medical Leave Act of 1993 (P.L. 103-3) allows eligible employees to take unpaid, job-protected leave for specific family and medical reasons (U.S. Department of Labor, n.d.). Unpaid leave in the United States is available for employees who work in private companies with 50 or more employees. They are granted up to 12 weeks of unpaid leave per year, either intermittently or through a reduced work schedule. Eligible employees are entitled to the 12-workweek leave to care for a spouse, child, or parent with a serious illness, a serious health condition of their own, the birth of a child, and certain adoption situations (U.S. Department of Labor, n.d.). This unpaid leave may help alleviate work stress, yet the combination of respite care and family leave may act as a buffer for caregiving stress as a whole.

Respite care is a common form of support that can alleviate caregiver burden and stress. Respite care refers to different types of interventions that temporarily provide ease from the burden of care (Columbo, 2011). These temporary breaks work towards increasing and restoring the caregiver's morale and his or her ability to handle the caregiving responsibilities. Respite care differs depending on the length of respite. The most common forms of respite care are day-care services, in-home respite, and institutional respite (Columbo, 2011). These types of care can provide caregivers with a break from their caregiving duties, allowing for temporary stress relief. Caregivers could face serious health and social risks if respite care is not available.

In 2006, the Lifespan Respite Care Act (P.L. 109-442), which aimed to establish a program to assist family caregivers in accessing affordable respite care, was signed into law. Though the programs vary from state to state, it authorized programs at state and local levels, planned respite care for family caregivers, provided assistance for caregivers in gaining access to such care, and offered training for respite care workers (National Respite Coalition, 2007).

In New Jersey, the Statewide Respite Care Program was created in 1987 specifically to provide support and relief to family caregivers. It was designed to give short-term, intermittent relief to caregivers (Department of Human Services, 2015). The cost of respite care varies greatly depending on the services offered by the facility and the skill level of the caregivers. Adult day care services cost roughly the same amount as in-home respite services, the difference being that the cost of adult day service is less for the care recipient and his or her family due to federal and state funding. Federal and state programs may help pay for respite care, along with some long-term care insurance

policies and supplemental security income (SSI) (Michon, 2015). Unpaid family leave and respite care services could help suppress some of the caregiving burden, but they do not help with the financial aspect of caregiving. Therefore, tax benefits and tax breaks have been set in place.

Tax benefits are available through Medical Expenses Tax Deduction. If the tax payer— either the caregiver or care recipient—has a medical expense that exceeds 7.5% of his or her adjusted gross income, medical expenses are deductible, contingent on the expenses being itemized (Alzheimer’s Association, 2015; Colombo, 2011). Claiming a dependent offers some tax relief, yet there are stipulations. In 2015, relatives are eligible to become a dependent on a caregiver’s tax return if their total income, excluding nontaxable Social Security and disability payments, is less than \$3,950 a year and if the caregiver provided more than 50% of the relative’s care (Hasson, 2015). The policies and programs noted above could be beneficial and potentially increase caregiver well-being. That being said, these resources are potentially nullified if those in need are unaware of such programs or policies. The awareness and availability of these resources is as important as their existence. Without the proper knowledge of available resources, utilization is almost impossible.

Availability and Awareness of Resources

The availability and awareness of services, resources, and programs for both caregivers and the chronically ill has a significant role in the use of such resources. Tang and Pickard (2008) examined the awareness of community-based long-term care services among the elderly population and found that most elderly people express the desire to age in place, or at least in their community, as long as possible. Early use of in-home and

community-based services for the elderly with dementia has been shown to delay institutionalization and reverse mental and physical deterioration (Tang & Pickard, 2008). Knowledge of these services has been found to be one predictor of service use, and a lack of knowledge of about these services was a major barrier to their utilization, yet it was not the only predictor (Tang & Pickard, 2008). Perceived awareness of availability of community services, for example, home repair, housekeeping, and adult day services, and out-of-home services such as therapeutic activities, health monitoring, socialization, medical care, and transportation, were associated with the likelihood of aging in place (Gaugler & Zarit, 2001).

Spreading awareness of programs and resources for family caregivers and the care recipients, with a focus on preserving independence and autonomy, can help reduce healthcare costs, improve caregiver well-being, and delay the need for institutionalized care (Zhu & Sano, 2006). Improving channels of communication can spread this awareness, more effectively promoting healthy lifestyles and producing quality services that can help maintain maximum levels of function.

Attitudes Toward Policy Change and Tax Initiatives

Over the past several decades, social and demographic changes in the United States have brought family policy to the forefront of government policymakers. These changes have sparked discussion on the public's attitudes toward policy initiatives and changes to increase support for family caregivers and the elderly population as a whole. The changes in family composition and the aging trend in the United States have drawn added attention to the need for caregiving, thus demanding attention from policymakers to consider policy changes that will help this vulnerable population.

The underlying question is as follows: How much support will policymakers receive from the U.S. citizens for policies supporting the elderly and their caregivers, especially from those who do not provide care. Attitudes toward policies that support the activities of informal caregivers and the care recipients, such as tax credits to partially offset caregiving expenses, a tax break for people who purchase private long-term insurance, public long-term insurance, and compensation through direct payment to caregivers, will be the focus of this discussion.

Silverstein and Parrott (2001) show that non-caregivers are less likely to support policies to pay caregivers than are caregivers. This trend may be due to the fact that non-caregivers do not have firsthand experience of the caregiver burden. The same holds true for the level of support for tax credits in that current caregivers had the greatest levels of support for this policy (Silverstein & Parrott, 2001). Yet people with caregiving experience had higher levels of support than those with none. For those who supported this type of policy but have never provided care, African Americans, the elderly, and those who have a dependent child in the household offered the greatest levels of support (Silverstein & Parrott, 2001). Findings show that those who are married offer support for tax credits more than those who are not (Silverstein & Parrott, 2001).

Thamer, Hwang, and Anderson (2002) compare public support for initiatives that would add a Medicare prescription drug benefit, create public long-term care insurance, and offer a tax break for unpaid caregivers and for those who purchase private long-term care insurance. According to the survey responses collected, Americans strongly supported or somewhat supported all four initiatives (Thamer et al., 2002). Of the 1663 adults surveyed, 72% strongly supported a drug benefit for Medicare beneficiaries, 68%

strongly support government-funded long-term care insurance, 63% strongly supported a tax break for persons who provide unpaid care, and 50% strongly supported a tax break for persons who purchase long-term care insurance (Thamer et al., 2002). It is important to note the characteristics of those who support such tax initiatives. In general, the strongest supporters of all four initiatives were women, African Americans, and caregivers, and those ages 45-64 were the strongest supporters of a tax break for persons who purchase private long-term care insurance (Thamer et al., 2002).

This data, although outdated, show that women have been in the caregiving role and African Americans have had higher levels of approval for policies that help caregivers and the care recipients. This information is important in tracking changes in attitudes toward caregiving policy and in comparing older data with current data.

Through a review of existing services that support and assist informal caregivers, gaps in service and areas in need of improvement identified by caregivers and care recipients can shed light on the attitudes of those who currently receive help or have received help in the past. The findings collected by the New York State Office for the Aging (NYSOFA) (2009) highlight some types of formal services available to caregivers and care recipients provided by paid care providers and volunteers. Local area agencies of aging and NYSOFA provide information about available programs and services, respite care to temporarily relieve caregivers from their responsibilities, supplemental services to complement the care provided by the caregiver, and training to assist caregivers in the areas of health, financial literacy, and problem-solving skills (NYSOFA, 2009).

This survey shows that caregivers provide care to older adults with significant health needs, the most prevalent health condition being Alzheimer's or other forms of dementia. Other prevalent conditions include vision problems, depression, heart disease, and arthritis. Survey responses show that information and assistance, respite care, and caregiver training or education were the top three services utilized through this initiative (NYSOFA, 2009). Respondents were also asked what additional services or help would be valuable to them, and the top two desired services were tax credits or tax breaks and respite care. Caregivers identified tax credits or tax breaks as areas in which they need assistance to help the financial aspect of caregiving. This result shows that caregiver policy has not changed enough in the past decade, as caregivers still offer the highest levels of support for such tax and policy initiatives (Silverstein & Parrott, 2001). Caregivers also reported financial assistance to pay for services and adult day services as desirable, which does not differ from the findings from surveys conducted in the early 2000s, implying that the needs for these services have not been met (NYSOFA, 2009; Silverstein & Parrott, 2001; Thamer et al., 2002). Viewing social support, and the influence it has on caregivers dealing with health care policy, caregiving responsibility, and caregiver burden through a theoretical framework may further highlight the importance of social support for caregivers.

Chapter 3

THEORETICAL FRAMEWORK

To further expand on informal social support and its impact on caregivers' well-being, it is beneficial to explore the stress-buffer hypothesis, which states that social support acts to protect people from the potentially harmful effects of stressful life events (Kaufman et al., 2010). This framework suggests that stress occurs when one appraises a situation, or change, as threatening and does not have the resources or skills to appropriately respond. In recent years, there has been a continued expansion in the amount of interest in the role of social support and interpersonal relationships acting as a protective factor from pathogenic effects of stress and caregiver burden and its impact on the care recipients' physical health (Jaremka, Lingren, & Kiecolt-Glaser, 2003; Kelly, 2010; Strozier, 2012; Wittenberg-Lyles et al., 2014). Possible protective effects of social support, in the face of psychosocial stress, have been identified as having a buffering effect.

The buffering hypothesis states that social support can lessen or eliminate the harmful effects of stress on the health and well-being of those with stronger support systems, and analysis shows that perceived support is, in general, more important than received support (Lakey & Cohen, 2000; Wethington & Kessler, 1986). Conversely, those with little or no support are more likely to experience harmful effects. Multiple definitions of stress are needed to understand the broad range of effects it may have.

Cohen and McKay (1984) state that the manifestation of stress occurs when “one is called to respond to a situation for which one has no adequate response and the consequences of failure to respond effectively are important” (p. 254). Stress can also be defined as the brain’s response to any demand. Change is a major trigger of stress (National Institute of Mental Health, n.d.). Change can be viewed, or perceived, as positive or negative. The individual’s perception of the change can intensify or decrease the level of stress; the former could potentially lead to traumatic stress reactions (National Institute of Mental Health, n.d.). There are at least three different types of stress: routine stress, which is related to family, work, and other responsibilities; stress incurred by sudden change; and traumatic stress, which is triggered by a life threatening or potentially dangerous life event such as war or natural disaster (National Institution of Mental Health). Although the body responds to each type of stress similarly, different individuals may react to the same type of stress in different ways. Rodriguez and Cohen (1998) suggest that support is related to well-being only when people are dealing with stressful life events, and that it only buffers or protects individuals when they are exposed to stress. Their research has shown that in the absence of stress, the beneficial effects of social support has no effect on health and well-being (Rodriguez & Cohen, 1998). Perceived support may help enhance an individual’s ability to cope with the stressful event or help the individual perceive an event as less potentially harmful (Rodriguez & Cohen, 1998). The support may help the individual appraise the situation as less dangerous, or act as a buffer/protective factor. This framework can be applied to support the notion that social support for family caregivers of the chronically ill can positively influence caregivers’ well-being.

Chapter 4

METHODOLOGY

This section delineates the methodological approaches taken in this research. To recap, the goals of this study are to identify 1) if access to social support is associated with caregiver well-being and 2) any differences between those who can and cannot provide care in their support for tax and policy initiatives. Given the primary objectives of the research and the large amount of existing research on social support and caregiver well-being, a secondary analysis of an existing data, *Chronic Illness and Caregiving, 2000*, obtained from Harris Interactive, Inc. on behalf of the Robert Wood Johnson Foundation, Johns Hopkins University, and Partnership for Solutions, was used. The contribution to existing research on this topic will be presented through an analysis of the willingness to support policy changes addressing health care issues for caregivers and their ability to provide care. To further contribute to the extant knowledge on this topic, an analysis will examine whether caregivers' well-being differs if they are the sole provider of care or if the care recipient receives unpaid caregiving from two or more unpaid caregivers. The most appropriate data set for the proposed questions and analyses was collected in 2000. Changes in technology, national demographics, policy, and the health care system have occurred since this information was collected; however, this dataset most closely matches the aims of the study. Furthermore, with the use of past and up-to-date research and journal articles, these data obtained in the 2000 study can be validated and may provide critical insights into the most important issues regarding

family caregiving, social support, and policy interfaces, some of which may remain unaddressed.

Background

In 2000, Harris Interactive, Inc. conducted *Chronic Illness and Caregiving*, based on telephone interviews of individuals from the general public, including chronically ill persons, informal caregivers, and non-caregiver or chronically ill persons. Participants were interviewed to survey health issues regarding how people in the United States make decisions about health care, how they feel about the health care available to them, and the level of support offered for chronic care policy initiatives. Telephone numbers were randomly generated, and a \$15 honorarium was offered to those adults 18 or older who qualify for and complete the 15-to-25- minute survey. The objectives of this survey were threefold: 1) to assess public awareness of chronic care issues and the level of support for chronic care policy initiatives, 2) to examine experiences and needs of chronically ill Americans concerning health care and other assistance, and 3) to evaluate the experiences and needs of informal caregivers. This study included a national cross-section of persons with chronic illnesses. Adults who provided informal caregiving services were oversampled. In all, 1,663 interviews were conducted, of which 680 were neither ill nor caregivers, 189 were caregivers but not chronically ill, 559 were chronically ill but not caregivers, and 235 were chronically ill caregivers. The data collection process was driven by a qualitative method of inquiry consisting of semi-structured interviews. Data were then quantified, or organized, coded, and presented in frequencies. Questions to all participants addressed awareness of the availability of supportive and housing services for the chronically ill, knowledge about coverage for long-term care, support for policy

initiatives such as tax credits for the chronically ill and their caregivers, and policy concerning pharmaceutical coverage in Medicare. Those who identified as chronically ill responded to questions about access to and their experience with chronic care and other health care services, service coordination, and the need for social supports and interventions. Informal caregivers responded to questions regarding their experience with caregiving, how many hours they devoted to caregiving per week, caregiving/life balance, and the availability of social supports for caregivers.

The Sample

A national cross-section of adults was selected, and persons with chronic illnesses and adults who provided informal caregiving services were oversampled. In all, 1,663 subjects were interviewed. Of those 235 respondents who were both chronically ill and caregivers, 131 were coded as caregivers in addition to the 189 who responded as caregivers but not chronically ill, equaling a total of 320 caregivers. Each participant responded to “core” questions regarding their perception of chronic illnesses, personal worries and expectations, policy issues, health care coverage, and knowledge of chronic care and volunteer organization. In addition, all who participated were asked about their willingness to support various tax breaks for people who purchase private long-term care insurance and people who provide unpaid care to family members or friends who are old, frail, or disabled. They were also asked how willing they would be to support policies that provide government funded long-term care insurance, adding prescription drug benefits to Medicare, funding for volunteer organizations helping the elderly and disabled, and passing legislation to help the uninsured get health insurance. Following the “core” questions, participants responded to semi-structured interview questions focusing

on their classification as a caregiver or as chronically ill. Demographic information was collected and resulted in a nationally representative sample. Data collected from the combined cross section and oversample of non-ill caregivers and chronically ill caregivers show that the age of those classified as caregivers ranged from 18 to 65+ years old ($M=44.2$, $SEM = .8$), the majority of which were female (62%). Sixty-nine percent identified as Caucasian, 14% as Black/African American, and 59% were married or living with a partner. Among the caregivers, 65% were employed, and 16% were retired. Responses from those who identified as caregivers indicated that 68% were the primary caregivers for a relative, including spouses, parents, children, grandparents, aunts, uncles, and mothers/fathers-in-law and 17% provided care for nonrelatives. Additional inquiry provides data identifying 21% (61 participants) of caregivers acting as the sole provider of care and 76% (259 participants) acting as part of a caregiving team (weighted base $M=4.5$, $SEM= 0.6$).

Measures

The frequencies used for this study were generated from the interview responses from the *Chronic Illness and Caregiving, 2000*, study with the objective of discovering whether access to social support, as well as the accessibility of resources, influences the well-being of family caregivers, and how the ability to provide care impacts the willingness to support policy changes and tax initiatives. The caregiver group, 320 participants, includes those who were caregivers but not chronically ill (189) and the 131 caregivers of the 235 who reported being chronically ill. A linear regression was conducted to examine the research questions. Linear regressions permit an examination

of the relationship between the independent and dependent variables after accounting for other factors.

To address the first research question, the analysis investigated whether or not perceived social support, being a sole caregiver, or accessibility of resources when needed, positively or negatively influences well-being. Caregiver well-being was an ordinal measure and measured by overall life satisfaction using a 4-point Likert scale that rates each response as very satisfied, somewhat satisfied, not very satisfied, and not satisfied at all. The first variable, Sole Caregivers vs. Co-Caregivers, was taken from Q1545: “How many other people like yourself, for example friends or family, provide/provided unpaid help?” A dichotomous measure from 0 to 5+, those caregivers who responded 0 were coded as 1, and all other answers were coded as 0. The next independent variable was perceived social support, which is also a dichotomous measure. Caregivers responded to Q1805 “Do you feel you receive or received all the support you need when you feel stressed or overwhelmed or would you like to receive more support?” Response options were “Yes, received all the support I need” or “No, would like more support.” Those who responded “Yes, received all the support I needed” were categorized as perceiving social support to be adequate. The third and final independent variable for research question 1, accessibility of resources when needed via community support, is a dichotomous measure. Caregivers responded to Q1825, “Did you receive the type of help you needed (when contacting local group/organization),” with either “Yes, received” or “No, did not receive.”

The second research question measured willingness to support tax initiatives and policy changes as the dependent variable. This question included six specific items, using

a continuous measure. Q800 asks, “For each statement, indicate if you would strongly support it, somewhat support it, somewhat oppose it, or strongly oppose it.” The six specific items were 1) a tax break for people who purchase private long-term insurance, 2) a tax break for people who provide unpaid care to family members or friends who are old, frail, or disabled, 3) government funded long-term insurance for the elderly, disabled, and others who need ongoing care, 4) adding a new prescription drug benefit to Medicare, which provides health insurance to adults ages 65 and older and some disabled people, 5) government funding for volunteer organizations helping the elderly, disabled, and others needing ongoing care, and 6) legislation to help the uninsured acquire health insurance. The independent or predictor variable was the ability to provide the care needed without the need for assistance, and was measured through responses to Q1570: “Was there a time in the past year when you needed paid care or help for the person being cared for, but did not get it, or not?” This was a dichotomous measure, and response options were “Yes, needed but did not get” or “No.”

For the first analysis, a linear regression was appropriate because the research sought to explore the extent of a relation between the predictor variables and the outcome variable, and because the primary dependent variable was continuous. In this case, the predictor variables were perceived social support, being a sole-caregiver, and accessibility of resources when needed via the community, and the outcome variable was the caregivers’ well-being. In regard to the second research question, an analysis will identify if there are any differences between those who can and cannot provide care in their support for tax and policy initiatives. The outcome variable is the willingness to support tax initiatives and policy change, and the predictor variable is the ability to

provide the care needed without the need for assistance. A series of T-tests addressed the six elements that comprise the willingness to support tax initiatives and policy changes. Independent sample t-tests are used to compare the willingness to support policy changes and tax initiatives for two separate unrelated groups.

Prior to conducting my analyses, the following three hypotheses were formed based on the research questions and literature review:

- Those caregivers who perceive social support to be adequate will report higher well-being;
- Sole caregivers will report lower levels of well-being than those who are part of a caregiving group; and
- Those who can provide care without the need for assistance will be less likely to support tax initiatives and policy change.

Results

Caregiver Well-being and Access to Social Support

In the review of 320 caregivers, including both non-chronically ill caregivers and the 131 of 235 chronically ill participants who identified as also being caregivers, the analyses of whether access to social support influences caregiver well-being in relation to being a sole-caregiver, perceived social support, and accessibility of resources when needed via community groups/organizations shows no relationship between sole caregivers and social support, borderline significance for perceived social support, and a statistically significant relationship for accessibility of resources when needed.

The overall model was significant ($F(3,92) = 5.402, p > .002$), with an adjusted r^2 of .122 (Table 1). After determining that the overall model was significant, each individual variable was examined. Analysis shows that there is no statistically significant relationship between being the sole provider or a co-provider for caregiver well-being ($p = 1.50$), using an alpha level of .05.

Results for perceived social support on caregiver well-being show borderline significance, approaching significance, $r = .20, p = 0.055$. Finally, respondents with increased access to resources, compared to those without access, reported higher levels of well-being. Increased well-being was associated with increased accessibility of resources when needed via community groups/organizations, $r = .219, p = 0.034$. This result suggests a positive relationship between accessibility of resources and caregiver well-being.

Table 1 Access to Social Support and Well-being

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.387 ^a	.150	.122	.62046

a. Predictors: (Constant), Q1825 Q1545, Q1805

ANOVA

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	6.239	3	2.080	5.402	.002 ^b
	Residual	35.417	92	.385		
	Total	41.656	95			

a. Dependent Variable: Q220 All things considered, how satisfied are you with your life

b. Predictors: (Constant), Q1825 Q1545, Q1805

For survey questions- Q220, Q1825, Q1545, and Q1805, See Appendix A-D

Coefficients^a

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	.853	.235		3.628	.000
	q1545	-.001	.000	-.141	-1.450	.150
	Q1805 Do you feel you receive all the su...	.262	.135	.199	1.945	.055
	Q1825 Did you receive the type of help y...	.329	.153	.219	2.154	.034

a. Dependent Variable: Q220

Willingness to Support Tax Initiatives and Policy Changes

An analysis of a series of independent t-tests shows that two of the six models were statistically significant (Table 2 and Table 3). A tax break for people who purchase private long-term insurance and a tax break for people who provide unpaid care to family members or friends who are old, frail, or disabled were both statistically significant. There was a significant difference in the average scores for those who were willing to support a tax break for people who purchase private long-term insurance (M= 1.4474, SD= 0.737) and those not willing to support it ((M=1.723, SD= 1.01) conditions; $t(313)=-2.202$, $p= 0.028$).

There was also a significant difference in average scores for those who supported a tax break for people who provide unpaid care to family members or friends who are old, frail, or disabled (M=1.23, SD= .56) and those who did not (M= 1.49, SD= .82); $t(313)= -2.52$, $p= 0.012$.

For those willing to support government funded long-term insurance for the elderly, disabled, and others who need ongoing care, there is no relationship. There was no significant difference in average scores for those willing to support government-funded long-term insurance for the elderly, disabled, and others who need ongoing care (M= 1.38, SD= .87) and those who did not ((M= 1.422, SD= .0784) conditions; $t(313)= -.386$, $p= 0.070$).

Results show that for those who were willing to support adding a new prescription drug benefit to Medicare, which provides health insurance to adults aged 65 and older and some disabled people, there is no significant difference. There is no significant difference in scores for those who were willing to support adding a new prescription drug

benefit to Medicare (M=1.23, SD= .763) and those who did not ((M= 1.37, SD= 0.860), t(313)= -1.26, p= 0.206).

A separate analysis provides results for those who were willing to support government funding for volunteer organizations helping the elderly, disabled, and others who need ongoing care. There is no significant difference in scores for those who were willing to support government funding for volunteer organizations helping the elderly, disabled, and others who need ongoing care (M= 1.32, SD= 0.619) and those who did not ((M= 1.41, SD= 0.72), t(313)= -0.933, p= 0.352).

The final t-test results show the scores for those willing to support legislation to help the uninsured get health insurance. There is no significant difference in the scores for those who are willing to support legislation to help the uninsured get health insurance (M=1.31, SD= 0.615) and those who do not ((M= 1.42, SD= .846), t(313)= -1.05, p=0.291). These values were shown using two-tailed significance.

Table 2 Willingness to Support Tax initiatives and Policy Changes

Group Statistics					
	Q1570	N	Mean	Std. Deviation	Std. Error Mean
Q800a	Yes, needed but did	76	1.4474	.73747	.08459
	No	239	1.7238	1.01206	.06546
Q800b	Yes, needed but did	76	1.2368	.56258	.06453
	No	239	1.4937	.82945	.05365
Q800c	Yes, needed but did	76	1.3816	.87889	.10082
	No	239	1.4226	.78408	.05072
Q800d	Yes, needed but did	76	1.2368	.76365	.08760
	No	239	1.3766	.86021	.05564
Q800e	Yes, needed but did	76	1.3289	.61942	.07105
	No	239	1.4142	.71594	.04631
Q800f	Yes, needed but did	76	1.3158	.61559	.07061
	No	239	1.4268	.84632	.05474

For survey question Q1570, see Appendix E
 For survey questions Q800a-f, see Appendix F

Table 3 T-tests. Willingness to Support Tax Initiatives and Policy Changes

Independent Samples Test											
	Levene's Test for Equality of Variances		t	df	Sig. (2-tailed)	Mean Difference	Std. Error Difference	95% Confidence Interval of the Difference			
	F	Sig.						Lower	Upper		
Q800 For each statement, indicate if you	5.314	.022	-2.202	313	.028	-.27648	.12556	-.52354	-.02942		
Equal variances assumed											
Equal variances not assumed											
Q800 For each statement, indicate if you	14.903	.000	-2.520	313	.012	-.25688	.10192	-.45741	-.05635		
Equal variances assumed											
Equal variances not assumed											
Q800 For each statement, indicate if you	.015	.902	-.386	313	.700	-.04102	.10638	-.25033	.16830		
Equal variances assumed											
Equal variances not assumed											
Q800 For each statement, indicate if you	3.116	.079	-1.266	313	.206	-.13973	.11037	-.35688	.07743		
Equal variances assumed											
Equal variances not assumed											
Q800 For each statement, indicate if you	2.265	.133	-.933	313	.352	-.08528	.09140	-.26511	.09455		
Equal variances assumed											
Equal variances not assumed											
Q800 For each statement, indicate if you	3.212	.074	-1.057	313	.291	-.11099	.10497	-.31753	.09556		
Equal variances assumed											
Equal variances not assumed											

For survey questions, Q800a-f, see Appendix F

Chapter 5

DISCUSSION

Results for the analysis of social support, caregiver well-being, attitudes toward tax initiatives and policy changes, and the ability to provide unassisted care were somewhat consistent with similar studies and contrary to two of the three hypotheses. Analyzing caregiver well-being with three different predictor variables shows that caregiver well-being does not differ between sole caregivers and co-caregivers. Perceived social support, however, does show clinical significance in relation to caregiver well-being. Additionally, a positive relationship exists between caregiver well-being and the accessibility of resources from the community. The overall model was significant, showing a p-value of .002, with an adjusted r^2 of .122. The 12% r^2 signifies that this model explains 12% of the variability of the response data around its mean. Once the overall model was determined to be significant, each individual variable was examined. The findings show that caregiver well-being could be enhanced when certain supports are available. In other words, social support from community groups/organizations and the perception of social support could act as a buffer against caregiving burden and stress.

Results from the above analysis show that sole caregivers and co-caregivers' well-being do not differ, contradicting the first hypothesis, which states that sole caregivers would report lower levels of well-being, leading me to reject the null hypothesis. Thus, I oppose the idea that the decrease in the number of sole caregivers in the past decades is due to poor caregiver well-being. That being said, this result does not

indicate how well a caregiver performs caregiving responsibilities or how satisfied the care recipient is with the care he or she receives. The results from this sample indicate that sole caregivers and co-caregivers could have the same level of well-being, despite assuming full or shared caregiving responsibilities. The lack of literature on sole caregiver vs. co-caregiver well-being inhibited any comparison to other findings, and this finding may initiate further inquiries. Future research should focus on aspects of the caregiving role to examine why assuming all caregiving responsibilities is not negatively associated with caregiver well-being. In considering why there was no observed effect, I hypothesize that sharing responsibilities may cause additional stress, worry, conflict between caregivers, or control issues for the caregiver. This suggestion may indicate that the social support sole caregivers receive is adequate to cope with the stress. If this study were to be duplicated, sole caregiver social supports would be an element to conceptualize, operationalize, and measure.

Consistent with literature surrounding perceived social support (Chappell & Reid 2002; Cohen & McKay, 1984; Lai & Thomson 2011; Wethington & Kessler, 1986), these results show that caregivers who perceived social support to be adequate reported higher levels of well-being. Results were clinically significant, approaching a significance of $p=0.55$, suggesting that if one perceived his or her social support to be adequate enough to cope with caregiving stress, his or her well-being will be higher than those who do not. With a p-value of 0.55, the current conceptualization and measurement of the variables did not yield results that reached significance at the .05 level. However, the robustness of the relationship between the measured variables may be a fruitful area to explore in the future. This finding suggests that a relationship may exist. However, this study focused

solely on perceived support. This analysis does not take into account the amount of support actually received, but as the literature states, the perception that support exists may be more impactful than actually receiving the support (Lai & Thomson, 2011). These findings also give strength to the idea that perceived support is a better predictor of caregiver well-being, in relation to caregiver burden, than measures of actual support received. In future research, a comparison of support received and perceived support may shed light on a more holistic view of well-being and the ability to cope with caregiving responsibilities; however, this area is beyond the scope of this study.

Social support has been identified as a buffer against caregiving burden and stress. The findings show that access to social support buffers against the stress and burden of caregiving, positively impacting caregiver burden.

Results from the above analysis show the influence of the accessibility of resources when needed via the community on well-being showed a strong level of significance, $p=0.034$. This finding shows that increased well-being was associated with increased accessibility of resources via the community. A positive relationship exists, meaning that if the caregiver has access to resources in a time of need, his or her well-being is higher than those who do not have access to such resources. This trend is consistent with research supporting the notion that social support can buffer against the harmful effects of caregiving. These results are consistent with the notion that accessibility to resources can lessen or eliminate the harmful effects of stress on well-being. However, the scope of this study did not allow for an examination of any potential effects of socio-economic status or environmental factors on the accessibility of resources. Although this sample was nationally representative, future research may

benefit from a focus on the factors that make these supports available to the caregiver or how the caregiver's environment may affect his or her knowledge of supportive resources.

Access to public resources may influence the well-being of caregivers and care recipients. Yet, those who purchase private long-term care insurance may not need public resources as much as those who do not have private long-term care insurance. Private long-term care insurance has its caveats, as it is usually only purchased by those with significantly high income. Private long-term insurance tends to be very costly, meaning that only those with a significant income can afford the high premiums. This reality leads me to believe that if one were to place the cost of regular premium payments into an account, when the need for care arises, the funds in the account would be sufficient to pay for the care needed. Those who already have private insurance may be less willing to support tax initiatives and policies that help those who do not purchase this insurance. Investigation of the attitudes of those who purchase long-term care insurance toward supporting tax initiatives for those who do not purchase private long-term care insurance may be an interesting topic for future research.

A series of t-tests were conducted to examine of differences between those who can and cannot provide care in their support for tax and policy initiatives. Results show that the hypothesis that those who can provide care without the need for assistance will be less likely to support tax initiatives and policy changes was partially supported. Of the six models tested in the independent t-tests, two were statistically significant (two-tailed significance, .05). There was a statistical difference in the average scores for those who were and were not willing to support a tax break for people who purchase private long-

term care insurance, and for those who were and were not willing to support a tax break for people who provide unpaid care to family members or friends who are old, frail, or disabled. Those who were willing to support a tax break for people who purchase private long-term care insurance had a mean score of 1.44, $SD = .73$, and those who did not support it had a mean score of 1.734, $SD = 1.01$. Those who were willing to support a tax break for people who provide unpaid care to family members or friends who are old, frail, or disabled had mean score of 1.23, $SD = .56$, and those who were not willing to support that tax break had a mean score of 1.49, $SD = .82$. The results from the t-tests indicate that there is a difference between those who supported these two initiatives and those who did not, supporting hypothesis number three. The results show the difference between the two groups (those who were willing to support and those who were not willing to support) is unlikely to have occurred because the sample is atypical, supporting the notion that those who could not provide care would be more willing to support these two initiatives.

The positive impact of social support has been widely documented in the literature, yet the results from this study add policy and tax initiatives into the equation. Policies directed at the chronically ill have the potential to be identified as social support for the caregiver. When policies and tax initiatives are aimed toward supporting the chronically ill, their caregivers are indirectly affected. Although policies are not generally identified as social support for family caregivers, these findings confirm the notion that policies could potentially offer similar types of support and assurance in comparison to social support from family and friends. The support offered through policy could positively impact the emotional adjustment, self-efficacy, and self-esteem of the

caregiver, enhancing their ability to cope with the emotional and financial consequences associated with caregiving.

These findings align with my personal observations of caregiving for the elderly. Because the caregiving experience is complex and impacts caregivers' financial, social, physical, and mental health, those who voluntarily purchase long-term care insurance to protect themselves, and simultaneously lessen the burden on the public, should be compensated. Also, those who have experienced caregiving understand the consequences and the sacrifices associated with being a primary caregiver. This perspective validates the findings that those who cannot provide the care needed would be more supportive of tax breaks for those who are caregivers. Further analysis on support of tax breaks for people who provide unpaid care should expand the sample to caregivers and non-caregivers. Caregivers were the focus of this study, but it would be interesting to see how much variation in level of support for tax breaks and policy changes exists between caregivers and non-caregivers.

The remaining models looking for differences between those who and were not willing to support government funded long-term insurance for the elderly, disabled, and others who need ongoing care— adding a new prescription drug benefit to Medicare; government funding for volunteer organizations helping the elderly, disabled, and others who need ongoing care; and legislation to help the uninsured to acquire health insurance—yielded different results. Analysis of these data showed that there is no relationship between the ability to provide care without the need for assistance and support for these initiatives. This information was somewhat surprising. Hypothesis number three was driven by the thought that caregivers who could provide care without

the need for assistance would be less likely to support tax initiatives and policy changes. This response was not the case, as these data show that caregivers who could and could not provide care without the need for assistance show the same willingness to support these policy initiatives, leading me to fail to reject the null hypotheses. These data were collected over a decade ago, yet as noted above, attitudes toward policy changes have not changed much. Policies and supportive services have changed since these data were collected, but current research shows that caregivers still support further policy changes. This finding is an indication that although we are moving into the right direction in supporting caregivers, further change may still be needed.

Viewing private and public policies through the stress-buffering framework may help clarify policy's impact on caregiving. Private and public policies impact various domains in the lives of the care recipients, as well as the caregivers. Although indirect, when resources are made available to the care recipient through programs and policies, the caregiver could potentially benefit from the utilization of those resources. Community groups, religious organizations, volunteer groups, and public agencies that offer supportive services to the elderly in their own community could act as protective factors, buffering or helping to lessen the caregiving burden for the caregiver. On the other hand, the lack of such resources could act as risk factors, negatively impacting the care recipient, causing increased burden or stress for the caregiver. The presence of risk factors or protective factors could cause cascades across domains, simply meaning that positive or negative outcomes in one domain of life could spillover or cascade into another domain(s). This notion highlights the potential impact of public and private

policies on the caregiver, demonstrating the extent that policy intersects with the well-being of caregivers.

The analyses conducted were far from exhaustive, yet these findings contribute to the existing pool of knowledge surrounding caregivers, their well-being, and their attitudes toward policy changes. There were several notable limitations to this study. Focusing solely on the responses of the 320 caregivers, 131 who were chronically ill caregivers, provides useful data for well-being and their attitudes toward policy change, yet, such a focus does not yield any implications for the attitudes toward policy change of the millions of non-caregivers in the United States. Also, because this study only focused on caregiver well-being, there was no comparison of well-being between caregivers and non-caregivers. Finally, the analyses show that well-being does not differ for sole caregivers and co-caregivers, but the difference in level of policy support was not measured. Initially, a comparison of healthy versus chronically ill caregivers was intended; however, the power analyses of the available samples precluded making this important comparison. Therefore, though it is an important construct to explore in the future, the current dataset and sample did not allow me to appropriately make those comparisons.

To further expand our knowledge of willingness to support policy change in the future, research studies should consider the difference in attitudes between sole caregivers and co-caregivers and data collected through qualitative inquiry. Qualitative inquiry, for example, data collected through in-depth unstructured interviews, may contribute to fruitful topics for developing quantitative items for new research. This approach may identify reasons for support, things learned through past experiences, and

additional variables that could influence the willingness to support policy and tax initiatives. An examination of the difference in support for tax breaks and initiatives among caregiving and non-caregiving men could offer interesting possibilities for future research.

Inquiries of gender differences are an additional possibility or variation to this study that could be conducted in the future. Thamer et al. (2002) offer evidence suggesting that female caregivers are more likely to support caregiver policies than men, yet there is scant evidence as to why. Research directed at why women are more likely to support policies may be useful for policymakers in an effort to gain additional support. Changes in family composition, the increase of women in the workplace, and the increasing number of women as the primary wage earner results in greater role-sharing households, including blurred gender roles in caregiving. These changes call for an examination of men acting as the caregiver and how traditional gender roles affect caregiving. Meanings of manhood and masculinity may impact adaptive and coping strategies for male caregivers, identifying a need for further exploration (Russell, 2007). Further research may identify differences in social support and a different set of caregiver stress between men and women. Identifying different stressors and protective factors for men may help researchers discover how men cope with the consequences of caregiving. Such an exploration could be used to amend current policy and shape future policy to meet the needs of all caregivers, male and female alike.

The age of the caregiver may also be an area of interest in identifying reasons for support or lack of support. Perhaps younger caregivers have more access to supportive services or have larger social networks than their older counterparts, suggesting that

supportive policies are not as much of a necessity for younger cohorts. These are all areas of study for future research in gaining the public's support for caregiver policies.

Although these analyses addressed the desired scope and guiding research questions, work on this topic is not done. A multitude of different studies could be performed to further our understanding of well-being and social support and caregivers' willingness to support tax initiatives and policy changes.

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Appendix A

Q220

Job#: J11298 "Chronic Illness And Caregiving"
Harris Interactive Inc.

Q220 All things considered, how satisfied are you with your life these days -- very satisfied, somewhat satisfied, not very satisfied, or not satisfied at all?

Base: All Respondents

	COMBINED CROSS SECTION/OVERSAMPLE							CROSS SECTION				OVERSAMPLE			
	All Chro- nica- lly Total Ill	All Care- giver	Nei- ther CI/ Care- giver	Chro- nica- lly Ill Only	Care- giver Only	Both CI & Care- giver	Both CI & Care- giver	Chro- nica- lly Ill Only	Care- giver Only	Both CI & Care- giver	Nei- ther CI/ Care- giver	Chro- nica- lly Ill Only	Care- giver Only	Both CI & Care- giver	
Unweighted Base	1663	794	424	680	559	189	235	1490	470	161	179	680	89	28	56
Weighted Base	1663	631	376	837	450	195	181	1516	381	159	139	837	69	36	42
Satisfied (Net)	1532	567	347	784	401	181	166	1410	346	152	129	784	56	29	37
	92%	90%	92%	94%	89%	93%	92%	93%	91%	96%	93%	94%	80%	80%	88%
Very satisfied	922	321	197	491	234	110	87	855	205	91	68	491	29	19	20
	55%	51%	53%	59%	52%	56%	48%	56%	54%	57%	49%	59%	42%	52%	48%
Somewhat satisfied	610	246	149	293	167	71	78	556	141	61	62	293	27	10	17
	37%	39%	40%	35%	37%	36%	43%	37%	37%	38%	44%	35%	39%	28%	40%
Not Satisfied (Net)	99	53	27	33	38	12	15	74	26	5	10	33	13	7	5
	6%	8%	7%	4%	9%	6%	8%	5%	7%	3%	7%	4%	18%	20%	12%
Not very satisfied	71	36	20	25	25	9	11	52	19	2	6	25	6	7	5
	4%	6%	5%	3%	6%	5%	6%	3%	5%	1%	4%	3%	9%	20%	12%
Not satisfied at all	28	17	7	8	13	3	4	22	7	3	4	8	6	-	-
	2%	3%	2%	1%	3%	2%	2%	1%	2%	2%	3%	1%	9%	-	-
Not sure	7	3	2	3	2	1	*	7	2	1	*	3	1	-	-
	* 2%	* 1%	* *	* 2%	1% 2%	1% *	* -	* 2%	* 2%	* *	1% -	* 2%	* 1%	-	-
Decline to answer	25	8	*	17	8	*	-	25	7	*	-	17	*	-	-
	2% 100%	1% 100%	* 100%	2% 100%	2% 100%	* 100%	- 100%	2% 100%	2% 100%	* 100%	- 100%	2% 100%	1% 100%	- 100%	- 100%
Sigma	1663	631	376	837	450	195	181	1516	381	159	139	837	69	36	42
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Q1545 How many other people like yourself, for example friends or family, (provide/provided) unpaid help?

Base: Caregivers

	COMBINED CROSS SECTION/OVERSAMPLE				CROSS SECTION				OVERSAMPLE				
	All Chro- nica- lly Total	Nei- ther CI/ Care- Ill Only	Chro- nica- lly Total	Both Care- CI & giver Total	Chro- nica- lly Total	Both Care- CI & giver Total	Nei- ther CI/ Care- Ill Only	Chro- nica- lly Total	Both Care- CI & giver Total	Nei- ther CI/ Care- Ill Only	Chro- nica- lly Total	Both Care- CI & giver Total	
Unweighted Base	320	131	320	-	109	131	268	-	161	107	-	28	24
Weighted Base	286	92	286	-	195	92	231	-	159	73	-	36	19
1	61	25	61	-	36	25	51	-	30	21	-	6	4
	21%	27%	21%	-	18%	27%	22%	-	19%	29%	-	15%	21%
2	49	24	49	-	26	24	36	-	18	18	-	8	6
	17%	26%	17%	-	13%	26%	15%	-	11%	25%	-	22%	29%
3	39	15	39	-	24	15	29	-	19	10	-	5	5
	14%	16%	14%	-	12%	16%	12%	-	12%	13%	-	13%	27%
4	36	12	36	-	23	12	29	-	20	9	-	3	3
	12%	13%	12%	-	12%	13%	13%	-	13%	13%	-	10%	15%
5	29	5	29	-	24	5	29	-	24	4	-	*	*
	10%	5%	10%	-	12%	5%	12%	-	15%	6%	-	-	2%
6	19	3	19	-	16	3	13	-	10	3	-	6	-
	7%	4%	7%	-	8%	4%	6%	-	6%	5%	-	17%	-
more than 5 people	45	7	45	-	39	7	38	-	32	6	-	6	*
	16%	7%	16%	-	20%	7%	17%	-	20%	8%	-	18%	2%
not sure	8	2	8	-	6	2	6	-	4	1	-	2	1
	3%	2%	3%	-	3%	2%	2%	-	3%	2%	-	5%	3%
decline to answer	1	-	1	-	1	-	1	-	1	-	-	-	-
	*	-	*	-	*	-	*	-	*	-	-	-	-
sigma	286	92	286	-	195	92	231	-	159	73	-	36	19
	100%	100%	100%	-	100%	100%	100%	-	100%	100%	-	100%	100%

Appendix B

Q1545

Appendix C

Q1805

Job#: J11298 "Chronic Illness And Caregiving"
Harris Interactive Inc.

Q1805 Do you feel you receive all the support you need when you feel stressed or overwhelmed or would you like to receive more support?

Base: Caregivers

	COMBINED CROSS SECTION/OVERSAMPLE						CROSS SECTION			OVERSAMPLE					
	All Chro- nica- lly Total	All Care- giver Ill	Nei- ther Care- giver Ill	Chro- nica- lly Only	Both Care- giver Only	Both Care- giver Only	Chro- nica- lly Total	Both Care- giver Only	Nei- ther Care- giver Only	Chro- nica- lly Total	Both Care- giver Only	Both Care- giver Only			
Unweighted Base	320	131	320	-	-	189	131	268	-	161	107	-	-	28	24
Weighted Base	286	92	286	-	-	195	92	231	-	159	73	-	-	36	19
Yes, receive all the support I need	188 66%	61 67%	188 66%	-	-	127 65%	61 67%	153 66%	-	103 65%	49 68%	-	-	24 65%	12 62%
No, would like more support	90 32%	29 32%	90 32%	-	-	61 32%	29 32%	70 30%	-	49 31%	22 30%	-	-	13 35%	7 38%
Not sure	6 2%	2 2%	6 2%	-	-	4 2%	2 2%	6 3%	-	4 3%	2 2%	-	-	-	-
Decline to answer	2 1%	-	2 1%	-	-	2 1%	-	2 1%	-	2 1%	-	-	-	-	-
Sigma	286 100%	92 100%	286 100%	-	-	195 100%	92 100%	231 100%	-	159 100%	73 100%	-	-	36 100%	19 100%

Q1825 Did you receive the type of help you needed?

Base: Caregivers And Contacted Local Group/Organization

Sex	Age				Education				Income				Race			
	18-29	30-39	40-49	50-64	65+	HS Grad	Col- lege	Some Col- lege	Post Grad	Less than \$15K	\$15K- \$25K	\$25K- \$50K		More than \$50K	White	Black

Q1825

Unweighted Base	96	24	72	5	25	34	25	7	24	26	33	13	12	10	13	12	9	25	71	11	5	0	
Weighted Base	84	18	66	12	25	28	14	5	33	27	18	7	21	12	12	7	7	17	50	15	0	9	
Yes, received	65	14	52	12	23	16	13	2	28	16	16	6	14	10	9	5	7	14	39	12	0	6	
No, did not receive	208	248	208	118	398	78	538	158	368	138	88	358	108	198	298	78	168	228	238	238	308	308	
Not sure	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	
Decline to answer	28	28	28	28	28	28	28	28	28	28	28	28	28	28	28	28	28	28	28	28	28	28	
Sigma	84	18	66	12	25	28	14	5	33	27	18	7	21	12	12	7	7	17	50	15	0	9	
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Q1570 Was there a time in the past year when you needed paid care or help for the person being cared for, but did not get it, or not?

Base: Caregivers

Q1570

	Sex		Age					Education				Income				Race							
	Pe-	r-	Age					Education				Income				Race							
			18-29	30-39	40-49	50-64	65+	HS Grad	Col.- lege	Some Col.- lege	Post Grad	Less than \$15K	\$15K- \$25K	\$25K- \$35K	\$35K- \$50K	More than \$50K	White	Black	Hisp	Other			
Total Male	182	182	53	59	79	64	32	136	83	52	15	62	44	57	38	49	47	61	239	35	23	20	
Unweighted Base	320	121	199	32	62	96	82	48	109	89	89	33	44	57	38	49	47	61	239	35	23	20	
Weighted Base	286	104	182	53	59	79	64	32	136	83	52	15	62	44	42	36	40	42	188	38	34	23	
Yes, needed but did not get	69	23	47	8	11	26	16	8	29	27	12	1	15	14	7	10	8	12	44	18	2	5	
No	208	81	126	45	48	51	40	24	101	53	40	14	41	30	35	26	27	31	139	19	30	18	
Not sure	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	5	
Decline to answer	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	4	
Sigma	286	104	182	53	59	79	64	32	136	83	52	15	62	44	42	36	40	42	188	38	34	23	
	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%	100%

Appendix F

Q800

Job#: J11288 "Chronic Illness And Caregiving"
 Harris Interactive Inc.

Absolutes/col percents

Q800 For each statement, indicate if you would strongly support it, somewhat support it, somewhat oppose it, or strongly oppose it?
 Summary Table With 'Strongly Support'

Base: All Respondents

	COMBINED CROSS SECTION/OVERSAMPLE				CROSS SECTION				OVERSAMPLE						
	All Chro- nica- lly Total	Nei- ther CI/ Care- giver Only	Chro- nica- lly Care- giver Only	Both CI & Care- giver Total	Chro- nica- lly Care- giver Only	Both CI & Care- giver Only	Nei- ther CI/ Care- giver Only	Chro- nica- lly Care- giver Only	Both CI & Care- giver Only						
Unweighted Base	1663	794	424	680	559	109	235	1490	470	161	179	680	89	28	56
Weighted Base	1663	631	376	837	450	195	181	1516	381	159	139	837	69	36	42
A tax break for people who purchase private long-term care insurance	833	328	221	395	218	110	111	752	188	85	84	395	30	25	26
	50%	52%	59%	47%	48%	57%	61%	50%	49%	54%	61%	47%	43%	68%	63%
A tax break for people who provide unpaid care to family members or friends who are old, frail, or disabled	1051	400	252	519	280	131	120	943	234	102	87	519	45	30	33
	63%	63%	67%	62%	62%	67%	66%	62%	62%	64%	63%	62%	65%	81%	79%
Government funded long-term care insurance for the elderly, disabled, and others who need ongoing care	1137	434	278	559	299	144	135	1031	257	114	100	559	42	30	34
	68%	69%	74%	67%	66%	74%	74%	68%	68%	72%	72%	67%	60%	81%	82%
Adding a new prescription drug benefit to Medicare (which provides health insurance to adults aged 65 and older and some disabled people)	1205	476	292	584	328	145	147	1091	276	118	113	584	53	27	34
	72%	75%	78%	70%	73%	74%	81%	72%	72%	74%	81%	70%	76%	74%	82%
Government funding for volunteer organizations helping the elderly, disabled, and others who need ongoing care	1126	408	270	582	274	136	134	1019	230	106	101	582	44	30	33
	68%	65%	72%	68%	61%	70%	74%	67%	60%	67%	73%	69%	63%	83%	79%

Appendix G

IRB EXEMPTION LETTER



RESEARCH OFFICE

210 Hollibaugh Hall
University of Delaware
Newark, Delaware 19716-1551
Ph: 302/831-2136
Fax: 302/831-2828

DATE: August 6, 2015

TO: Roberto Muniz, B.S
FROM: University of Delaware IRB

STUDY TITLE: [758120-1] How does Social Support and Health Care Policy Influence the Overall Well-Being of a Family Caregiver for Persons with Chronic Illnesses and the Elderly?

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS
DECISION DATE: August 6, 2015

REVIEW CATEGORY: Exemption category # (4)

Thank you for your submission of New Project materials for this research study. The University of Delaware IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will put a copy of this correspondence on file in our office. Please remember to notify us if you make any substantial changes to the project.

If you have any questions, please contact Nicole Farnese-McFarlane at (302) 831-1119 or nicolefm@udel.edu. Please include your study title and reference number in all correspondence with this office.