

USING TECHNOLOGY TO ENHANCE THE WELL-BEING OF CAREGIVERS OF
PERSONS WITH DEMENTIA: IMPLICATIONS FOR SOCIAL WORK PRACTICE
AND POLICY

Eun-Hye Yi

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Doctoral Committee

Margaret E. Adamek, PhD, Chair

Michin Hong, PhD

August 17, 2020

David Wilkerson, PhD

Yvonne Lu, PhD

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Eun-Hye Yi

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Eun-Hye Yi

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Difficulties caring for people living with dementia (PWD) contribute to their family caregivers' diverse unmet needs and adverse outcomes in health and well-being. This dissertation research explored the influence of macro systems on individual caregivers' well-being reflecting on the prevalence of online use among caregivers.

Caregivers have migrated to online platforms to seek support. However, there is limited understanding of how online social support [OnSS] compares to offline support [OffSS] in terms of caregivers' well-being. The first study examined the associations of OnSS and OffSS with the psychological well-being [MH] of caregivers. A subsample of the *Health Information National Trends Survey* (HINTS) from 2017 to 2018 (n=264) was analyzed. The data indicate that OnSS supplemented rather than replaced OffSS. Emotional support delivered offline had a positive direct association with MH, while OnSS did not. OffSS interacted with caregiving stressors while OnSS interacted with life stressors. Caregivers who are in less favorable situations, such as working part-time while caring for a PWD, living with economic hardship, and being unhealthy, tended to be significantly affected by OnSS. The results suggest that practitioners need to incorporate caregivers' OffSS into OnSS to maximize the available support resources, specifically for those who are in less favorable conditions.

There is limited understanding of caregivers' experiences within the complex health care system, especially after the significant policy changes brought about by the

Affordable Care Act (ACA). The second study analyzed caregivers' perceptions of and experiences with the ACA using national online forum data posted in 2011-2017 (n=514 posts). Text-mining thematic analysis method was used to analyze the posts. Three overall themes emerged: (a) concern about cost implications of placement decisions for care recipients, (b) skepticism about government and healthcare system support of their caregiving roles, and (c) caregivers' own well-being and concerns about health insurance. Efforts are needed to enhance clear and effective communication among policymakers and health professionals serving service users, including caregivers of PWD.

The present dissertation provides preliminary evidence to increase understanding of the complex contexts that affect the overall well-being of caregivers. Implications and suggestions for practitioners, policymakers, and researchers are discussed.

Margaret E. Adamek, PhD, Chair

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LIST OF ABBREVIATIONS

ACA	The Patient Protection and Affordable Care Act
ADRD	Alzheimer's Disease and Related Dementia
FMLA	The Family and Medical Leave Act
NFCSP	National Family Caregiver Support Program
PWD	Person living with dementia
MH	Psychological Well-being

CHAPTER ONE

INTRODUCTION

Alzheimer's disease and related dementias (ADRD) is a syndrome presenting difficulties in cognitive function such as language, memory, and problem-solving that lead to dysfunction in everyday activities (Alzheimer's Association, 2020). Due to the enormous impairments in daily activities, people living with dementia (PWD) need intensive assistance for handling complex issues as the disease progresses. According to the World Alzheimer Report, in 2019 there were more than 50 million people worldwide with ADRD, and this number is expected to increase to 152 million by 2050 (Alzheimer's Disease International, 2019). As the size of the population of Americans age 65 and older continues to increase, it is expected that the number of Americans with ADRD will also rapidly grow (Alzheimer's Association, 2020). In 2020, out of almost 6 million Americans who have dementia across all age groups, 5.3 million were age 65 and older, which represents 10 percent of the overall older adult population (Alzheimer's Association, 2020). The number of Americans living with ADRD is projected to increase to 88 million by 2050 (Alzheimer's Association, 2020). Dementia symptoms initiate many years earlier than the onset of the disease (Alzheimer's Association, 2020). Accordingly, we may expect more PWD in the near future given that nearly half of dementia patients are not diagnosed (Zaleta, Carpenter, Porensky, Xiong & Morris, 2012).

Family caregiver is defined as a family member who provides a broad range of assistance without payment to someone with a chronic or disabling condition. In 2015, 15 million family caregivers were providing care to their older family members with

dementia (Alzheimer's Association, 2017). Because of the long duration of the illness and high dependency of those with dementia (Alzheimer's Association, 2017), caregivers may themselves suffer from physical, mental, social, and economic difficulties as a result of their caregiving roles (Alzheimer's Association, 2017; Kasper, Freedman & Spillman, 2014; National Academies of Sciences, Engineering, and Medicine, 2016; Wennberg, Dye, Streetman-Loy, & Hiep Pham, 2015). For example, caregivers of people with dementia reported emotional, financial and physical difficulties that were twice as high as for non-dementia caregivers (Kasper, Freedman & Spillman, 2014). Dementia caregivers have more changes in employment such as retirement, turning down a promotion, and cutting back working hours compared with caregivers of those with non-dementia patients (Alzheimer's Association, 2017). The total costs as well as out-of-pocket costs for caregivers of dementia patients were almost twice that of caregivers of non-dementia patients (Delavande, Hurd, Martorell & Langa, 2013; Geldmacher et al., 2013). Thus, a large number of family caregivers are assisting their loved ones with dementia in the community, resulting in their own various hardships.

Many strategies and interventions have been developed to support dementia caregivers in the United States. Over 200 RCT-based face-to-face interventions have been developed to help family caregivers improve their caregiving efficacy and quality of life (Gitlin, Marx, Stanley & Hodgson, 2015). Scholars have classified the various types of interventions. For example, Feinberg (1997) classified such programs into four types: (a) direct services, (b) consumer-directed approaches, (c) employment-based programs, and (d) financial support through incentives and compensation. Sørensen, Duberstein, Gill, and Pinquart (2006) categorized caregiver interventions into eight categories:

consultation/case management, psychotherapy, psychoeducation, support groups, respite, training, pharmacotherapy, and multicomponent interventions. A series of systematic review studies evaluated the effects of various interventions on dementia caregivers (Brodaty & Arasaratnam, 2012; Selwood, Johnston, Katona, Lyketsos & Livingston, 2007; Sørensen et al., 2006; Van't Leven et al., 2013; Wennberg et al., 2015). Most studies report short or long-term benefits of psychoeducational interventions (e.g., Sørensen et al., 2006). Though caregivers reported subjective positive effects of such interventions, more rigorous evidence is needed to be confident of the effects of support (Elmore & Talley, 2009).

Policymakers have realized the significance of caregivers, especially for those with dementia. Caregiving issues have moved to the center of American policy discussions along with the idea of 'aging in a community' (Qualls & Zarit, 2009). The National Family Caregivers Support Program (NFCSP) and Family and Medical Leave Act (FMLA) are major federal programs that assist family caregivers. The NFCSP is the first federal government policy that targets family caregivers. Funded by Title III-E based on the Older Americans Act in 2000, the NFCSP aims to comprehensively address the needs of family caregivers of Americans aged 65 and older with disabilities as well as caregivers who are older Americans and care for family members with disabilities regardless of age (Doty & Spillman, 2015). However, unsatisfactory resources to match the needs of all caregivers, fragmented programs across states, and restricted integration with health care providers remain limitations (Riggs, 2003). The Family and Medical Leave Act (FMLA) is an employment-based caregiver assistance policy. Under FMLA, full-time employees working at a company with more than 50 employees are allowed

twelve weeks of unpaid leave annually for taking care of a family member with an illness (Public Law 103-3). One study reported that most employees covered by FMLA used the leave for a brief period, typically below ten days (42 percent) and for their own illness (55 percent) (Klerman, Daley & Pozniak, 2012). Despite governmental efforts to support family caregivers, the approach of the current policies remains limited for family caregivers of a person with dementia.

During recent decades, caregiver support programs have increasingly incorporated technology. Web-based technology enables service providers to overcome the barrier of face-to-face interventions in helping caregivers who may be unable to reach out to their programs and services due to long distances or less-flexible schedules. Web-based services usually focus on providing information, educational videos, support groups, and consulting (Dam, de Vugt, Klinkenberg, Verhey & van Boxtel, 2016; Glueckauf, Ketterson, Loomis & Dages, 2004). Dementia-related nonprofit organizations such as the Alzheimer's Association, Family Caregiver Alliance, and National Council on Aging (NCOA) also offer web pages that contain dementia information, current research, and social support. Most preexisting technology-based approaches to help older adults and their caregivers focus on five domains: physical/mental health, mobility, social connectedness, safety, daily activities, and leisure (Schulz, Wahl, Matthews, Dabbs, Beach & Czaja, 2014). There have been many efforts to expand such services on the web. However, some caregiver needs are not adequately addressed. For example, financial stability, which is a fundamental life issue in later life, and caregivers' overall psychological well-being, which may be directly associated with

the quality of care for PWD, are rarely addressed. More studies are needed to determine how such interventions can benefit caregivers in various contexts.

This dissertation is composed of two studies with one key theme: the use of online resources to support the well-being of caregivers of PWD. Each study has its own focus. The first paper examined the roles of online and offline social support in relation to caregiver stress and psychological well-being. The second paper examined dementia caregivers' experience with and perception of the Patient Protection and Affordable Care Act (ACA), using online social media data. This dissertation study aimed to identify preexisting solutions for helping caregivers of dementia patients and recommend ways to improve technological supports for family caregivers.

CHAPTER TWO

BACKGROUND KNOWLEDGE

This chapter explores background knowledge related to family caregivers in the U.S. First, in order to understand the current situations of the caregiving population, their prevalent unmet needs and use of online resources is described. Second, foundational theories underlying the research inquiries are reviewed. The ecological perspective, life course theory, and social network/support theories are interpreted with the lens of the caregiving context. Third, social and health policies in the United States, including the National Family Caregiver Support Program (NFCSP), the Family and Medical Leave Act (FMLA), the Patient Protection and Affordable Care Act (ACA), are reviewed in relation to caregivers' needs and contexts. These theories and policies will be used as undergirding frameworks to deduce research questions and provide suggestions.

Unmet Needs and Internet Use of Caregivers

Demographics of Dementia Caregivers

Along with the prevalence of dementia patients, the social needs of family caregivers have increased. Statistics show that 30 percent of older adults having dementia live in the community and rely on three and more caregivers (Kasper, Freedman, Spillman & Wolff, 2015). In 2017, the number of dementia patients who are 65 and older was 5.3 million, which comprised 96 percent of all dementia patients in the U.S. (Alzheimer's Association, 2017). There were an estimated over 15 million dementia caregivers in 2015, which comprised nearly half of all caregivers (Alzheimer's Association, 2017).

Demographic characteristics of the dominant dementia caregivers were: non-Hispanic white (nearly 67 percent), 65 years old or older (34 percent), married (nearly 67 percent), female (nearly 67 percent); having college and higher degree (40 percent) and having a job while providing care (60 percent); and taking care of their parents (over 50 percent), for four or more years (57 percent), and living with their care recipients in the same community (66 percent) (Alzheimer's Association, 2017; Bouldin & Andresen, 2014; Langa et al., 2005). However, current statistics show that the characteristics have been getting more diverse regarding race/ethnicity, gender, sexual orientation, and relationship with care recipients, though the portion of diverse caregivers is still small (Alzheimer's Association, 2017).

Dementia caregivers' roles with their loved ones include assisting with activities of daily living (ADLs) (including bathing, dressing, transferring, walking, eating, grooming, climbing stairs, toileting, and mouth care) and instrumental activities of daily living (IADLs) (including shopping, cooking, managing medications and finances, doing housework and laundry, driving, and using a phone) (Alzheimer's Association, 2017; Coleman & Williams, 2007). Compared with caregivers of other older adults, caregivers of dementia patients provide more assistance with ADLs and IADLs (Alzheimer's Association, 2017). Moreover, due to the complexity of the disease of their care recipients, dementia caregivers take more responsibility for handling care challenges. Caregivers of PWD pay more attention to monitoring their care recipients to adhere to medical directions and recommendations for both dementia and comorbid diseases, arranging care-related appointments, services, and paperwork, searching for support services and networks, advocating for one's care recipients, and providing emotional

support (Alzheimer's Association, 2017; Coleman & Williams, 2007). Dementia caregivers reported more hours of care for their care recipients compared to non-dementia caregivers: 92 hours per month for dementia caregivers vs. 65 hours per month for non-dementia caregivers (Kasper, Freedman & Spillman, 2014).

Researchers have estimated the value of caregivers' non-paid labor. Using the Cache County Dementia Progression Study, which contains longitudinal data on community-residing dementia patients and their caregivers in Utah from 1998 to 2007, Rattinger and colleagues (2015) estimated the value of informal dementia care by family caregivers by calculating the hours of each caregiving activity and adjusted for the median wage of the region in 2010. The value of informal care increased as the care recipient's condition worsened (i.e., from an average of \$13.63 a day in the very mild stages to an average of \$101.23 a day in the severe stage), and it increased 18 percent over time from the onset of the disease (Rattinger et al., 2015).

From the perspective of overall society, informal caregivers' economic contribution is huge. By assisting dementia patients at home, family caregivers enabled 80 percent of elderly cognitive disorder patients to reside in the community and maximize their well-being (Alzheimer's Association, 2017). The total estimated hours served by caregivers of dementia patients were 18.2 billion hours in 2016, and the estimated value of their work was \$230.13 billion in the same year, with the care valued at \$12.65 per hour (Alzheimer's Association, 2017). Studies also reported that family caregiving for dementia patients delays their care recipients' entry into the long-term care system (Alzheimer's Association, 2017; Mittelman, Ferris, Shulman, Steinberg & Levin, 1996). Consequently, informal caregiving reduces overall long-term care costs in society.

Despite caregivers bringing tremendous benefits to society, their caring labor has often been undervalued resulting in significant unmet needs in economic well-being and overall health.

Economic and Health Challenges of Dementia Caregivers

Studies indicate that dementia caregivers suffer from stress and caregiving burdens because of their care recipient's memory loss, behavioral disturbances, and waning physical and psychiatric functioning. Diverse evidence-based interventions aimed at reducing caregiving burdens and stress have been developed and examined for decades. However, many studies reported that many caregivers of patients with cognitive disorders continue to suffer from unmet needs. Caregivers have problems with high caregiving burdens (Vitaliano, Zhang, & Scanlan, 2003; Wennberg et al., 2015), mental, emotional, and cognitive problems (Joling et al., 2010; O'Brien, 2006), lack of social support (Bateman et al., 2017), physical weakness (Fonareva & Oken, 2014; Norton et al., 2010), and chronic disease that may lead to higher mortality (Schulz & Beach, 1999; Lavretsky, 2005). Moreover, as the dementia progresses, caregivers usually experience more difficulties in health and finances (Alzheimer's Association, 2017). Nevertheless, there are relatively limited studies and supports focused on caregivers' financial issues and health problems. This chapter reviews previous studies that examined dementia caregivers' economic and their health problems.

Economic Challenges

Economic security is a significant determinant of one's health and overall wellness. In this sense, it is imperative to pay attention to unpaid family caregivers' financial well-being. Dementia caregivers' economic hardships seem to come from two

factors: (a) loss of a job or taking adverse working conditions and (b) increasing costs for their care recipients' health care. Current statistics of caregivers indicate that approximately half of all caregivers have a paid job (Alzheimer's Association, 2017). However, unlike different types of family caregivers, a significant number of dementia caregivers seem more likely to experience disruptions in their employment to maintain their caregiving role.

According to the Alzheimer's Association survey in 2016, family caregivers of dementia patients and people who share responsibility for care reported that in order to support their family member with dementia, they had to reduce their work hours (27 percent), resign from or lose a job (16 percent), retired earlier than the age limit (13 percent), or take a different job (11 percent). Such changes in employment led to household income loss for 35 percent of the family caregivers and care contributors by an average of \$15,194, compared with their income the year before (Alzheimer's Association, 2016). Dementia caregiving families also reported that they had to increase work hours (14 percent), postpone their retirement (13 percent), return to the job (11 percent), or take an additional job (9 percent) (Alzheimer's Association, 2016). In sum, the primary caregivers of dementia patients tended to leave work to take the caring role entirely while other family members tend to increase their work hours or extend their years in the labor market to have sufficient income to support the care recipient.

Medical and living expenditures of dementia caregivers also comprise a huge portion of their financial burden. The main reason for such high burdens for the care of dementia patients is that Medicare does not cover the high price of prescription drugs and long-term care (Riggs, 2003) unless they pay the extra monthly premium to purchase

Medicare Part D or private longterm care insurance. Studies have examined the medical expenditures of caregivers for the health care of dementia patients including Medicare, Medicaid, out-of-pocket spending, private insurance, and other types of expenses (Alzheimer's Association, 2016; Delavande et al., 2013; Geldmacher et al., 2013; Kelley, McGarry, Gorges, & Skinner, 2015; Lin, Zhong, Fillit, Chen & Neumann, 2016). A group of studies examined longitudinal administrative data from Medicare or Medicaid claims files (Geldmacher et al., 2013; Lin et al., 2016). By comparing changes in medical spending before and after the diagnosis of dementia with the cost gaps of the non-dementia patients, these studies reported significantly higher expenses for dementia patients. Expenses were approximately 40 percent higher for Medicare (Lin et al., 2016) and 1.6 times greater for Medicaid (Geldmacher et al., 2013). Prescription drug spending and health care such as home care and day care services for dementia patients was also significantly higher for dementia caregivers (Geldmacher et al., 2013; Lin et al., 2016).

Another group of studies examined the total expenditures for dementia care. These studies reported at least 1.5 times higher spending than for those without dementia (Delavande et al., 2013; Geldmacher et al., 2013). Using the imputed Health and Retirement Study (HRS) data, a nationally representative data set of older adults in the U.S., Hurd and colleagues (2013) found that, in 2010, the expense of caring for a dementia patient was between \$41,689 and \$56,290 per person on average, depending on the estimation method, indicating the highest out-of-pocket expense for dementia patients compared to those with other diseases. Kelley et al. (2015) analyzed 5-years of HRS data and found the total cost of caring for dementia patients until their death including Medicare, Medicaid, private insurance, out-of-pocket spending, and informal care was

\$287, 038 per person which is approximately 1.5 times higher than the cost for other types of patients (Kelley et al., 2015).

A series of studies identified the substantially high out-of-pocket spending for dementia care. Using the Aging, Demographics, and Memory Study (ADAMS) based on a nationally representative dataset of older adults in the U. S., Delavande et al. (2013) found that dementia patients spent \$8,126 per person on average, which is three times higher out-of-pocket spending compared to those with normal cognition, who spent \$2,570 on average. Kelley et al., (2015) also identified 81 percent higher out-of-pocket spending for dementia patient care (\$61,522) than non-dementia groups (\$34,068) between 2005 and 2010, which represents 32 percent of their household assets on average during the five years before they passed away. Based on the Medicare Current Beneficiary Survey, the Alzheimer's Association (2016) reported four times higher out-of-pocket expenditures for dementia patients (approximately \$10,500 a year per person on average for a dementia patient vs. \$2,500 for those without dementia). Due to such high out-of-pocket expenses for providing help for their family member with dementia, family caregivers or their relatives paid an average of \$5,155 of their own money annually by reducing spending (48 percent) or saving (43 percent) for themselves, and even selling their assets (30 percent) or taking out money from a retirement savings (20 percent). These findings present the serious financial burdens for caring for a person with dementia not only for individual primary caregivers but also for their family members or relatives which threatens their financial security.

Health Challenges

The high expenses of caring for a person with dementia as well as caregiving burdens negatively affect the health of family caregivers. Using their own resources to assist their loved ones with dementia may leave a very limited family budget to care for themselves. The Alzheimer's Association (2016) reported that caregivers and their family members experienced limiting the time to see a doctor (20 percent out of the sample) or to buy medications (11 percent out of the sample) for themselves, and even worse, some reported they had difficulties buying the proper amount and quality of food due to the expense of caregiving. Family members of the primary caregiver are often forced to cut back their household budget that was intended to maintain their own health and well-being while they work more or take an additional job to afford the care costs.

Additionally, dementia caregivers' emotional and psychological difficulties compound the health risks for caregivers (Alzheimer's Association, 2017; Atteih, Mellon, Hall, Brewer, Horgan, Williams, et al., 2015; Dassel, Carr & Vitaliano, 2015; Epstein-Lubow et al., 2012; Kasper, Freedman & Spillman, 2014). Caregivers are under tremendous emotional stress as they watch the progressive decline of their loved one's cognitive and physical abilities and confront the unexpected behavioral disturbances that often occur with dementia. Many caregivers are at high risk of depression and mental issues and experience different symptoms such as fatigue, anxiety, insomnia, headaches, or dysphoria particularly as the care recipient's cognitive ability worsens (Atteih et al., 2015; Gallagher-Thompson & Coon, 2007; Sallim, Sayampanathan, Cuttilan & Ho, 2015; Dassel, Carr & Vitaliano, 2015).

According to a group of studies that examined physiologically adverse changes due to chronic stress among dementia caregivers, the physical consequences of caregiving include decreased immune system functioning (Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996; Schleifer, Keller, & Stein, 1985), higher levels of stress hormones (Von Känel, Dimsdale, Mills, Ancoli-Israel, Patterson, Mausbach, et al., 2006), slow wound repair (Kiecolt-Glaser, Marucha, Mercado, Malarkey & Glaser, 1995), higher chances of cardiovascular disease and kidney problems (Gouin, Glaser, Malarkey, Beversdorf & Kiecolt-Glaser, 2012; Mausbach et al, 2010; Von Känel et al., 2012), and increased hazard of hypertensive blood pressure (Shaw et all, 1999). Sleep disturbance is also caused by the common problem behaviors of dementia patients and negatively affects caregivers' health (Peng & Chang, 2013; von Känel et al., 2014). Fonareva and Oken (2014) concluded that the long-term stress endured by dementia caregivers increases their physical susceptibility to disease and, consequently, they have a greater chance of developing health problems. For all of these reasons, caregivers are often called the invisible secondary patients. Summing up, previous literature suggests family caregivers and other family members who assist in the care process of a family member with dementia face severe emotional and financial burdens for an extended period. This set of burdens may lead to income and asset depletion and may also threaten their health.

Internet Use and Online-mediated Interventions

Evidence showed significant and positive impacts of caregiving support programs that include psychoeducational support for helping with stress management, effective family communications, and organizations, and asking for and accessing help;

information about disease and resources; skills training, peer support group, counseling, and other supportive services (e.g., Brodaty & Arasaratnam, 2012; Olazarán et al., 2010; Selwood et al., 2007; Sörensen et al., 2006; Van't Leven et al., 2013; Wennberg et al., 2015). Despite the importance and necessity of these supports for caregivers, online supports have often been ignored in health care and long-term services and support delivery systems though caregivers heavily rely on online resources (Feinberg, 2017). Although such programs are provided through local AAAs agencies, many caregivers are still not aware of the programs (Giunta & Scharlach, 2009). Even when caregivers have information about relevant services, many are not able to take advantage of the support due to time conflicts with caregiving responsibilities, limited time for a fixed schedule at work, and long distance from the agencies that offer such programs. Given that appropriate and timely support is pivotal for helping family caregivers provide care for someone with dementia (Feinberg, 2017), such limitations are significant pitfalls.

Openness, ubiquitousness, and cost-efficiency would be the biggest benefits of using contemporary online technology for caregiver interventions. Technological advances can make it easier for family caregivers to search and contact available services anytime and anywhere they can access the Internet. This aspect may be particularly helpful for those living in rural areas and of lower-incomes who have limited access to in-person resources. Caregivers can adjust the schedule, time, and frequency of accessing services based on their individual situation. Already developed programs and services can also be modified based on the individual caregiver's needs. Already developed educational videos, programs, and modules are easy to modify and are reusable. Highly

advanced computer-based technology that has widely penetrated into our daily lives enable us to overcome limitations that were found in earlier models of intervention.

Current gerontology scholars and practitioners have briskly developed and tested technology-based interventions for dementia caregivers with the tremendous evidence from off-line based interventions that emphasize the importance of intervention and support for dementia caregivers. Diverse technical tools have been developed as an alternative for interventions, including web pages, videophones, multimedia, support groups via social media, online community forums, and smartphone applications. One group of intervention trials reported positive impacts on caregivers' psychological and emotional well-being, including reduced caregiver depression (Beauchamp, Irvine, Seeley, & Johnson, 2005), caregiving burdens (Glueckauf, Ketterson, Loomis, & Dages, 2004), stress (Beauchamp et al., 2005), and sense of isolation (Kelly, 2004) and increased social support (Bateman et al., 2016; Beauchamp et al., 2005).

Another group of studies that tested the effects of technology on caregiving skills and knowledge reported positive results such as: caregiving competency and self-efficacy (Beauchamp et al., 2005; van der Roest, Meiland, Jonker, & Droes, 2010), confidence in decision-making processes (Brennan, Moore, & Smyth, 1995), ability to accomplish preexisting goals (Ducharme et al., 2011), knowledge about the dementia disease process and caregiving skills (Lai, Wong, Liu, Chan, & Yap, 2013), coping skills (Kelly, 2004; Lai et al., 2013), and having a good relationship with care recipients (McKechnie, Barker & Stott, 2014). The main goals of previous online-based interventions focused on lessening caregiving distress and improving skills at the individual level. Beyond this framework, the impact of technology interventions on more fundamental and structural

issues that family caregivers experience that cause unequal health and economic consequences need to be addressed.

Theoretical Background

Ecological Perspective.

Bronfenbrenner (1979) defined the ecological approach as a “scientific study of the progressive, mutual accommodation, throughout the life course between an active, growing human being and his or her environment” (p.188). One of the critical assumptions of this perspective is the reciprocal nature of the relationship between organisms and their environments rather than to highlight one single factor (Bronfenbrenner, 1994; Greene, 2008; Stokols, 1992). Transaction is a unique and important concept of the ecological perspective. Transaction implies not only a mutual effect between person and environment but also an interaction between a system of the individual and environment as a unit (Fay, 1996). Humans and their environment cannot be considered separately, and both constitute a unitary system by interacting and shaping each other (Greene, 2008).

Following is a summary of the main propositions of the ecological perspective. First, human development appears in the process of complex back and forth interactions between a person’s immediate environment and other systems fairly regularly and over time (Bronfenbrenner, 1994; Hayden, 2013). Second, the effects of interactions vary contingent on the characteristics of the person and of the environment (Bronfenbrenner, 1994; Hayden, 2013). Third, the environment is a set of concentric systems which starts the relationships from those closest to the person to the most distant (Bronfenbrenner, 1994; Hayden, 2013) and the environment is a

critical component of human behavior (Hayden, 2013). From an ecological perspective, an individual's behavior is understood as resulting from the interactions within systems over time.

Because ecological models are considered as a perspective rather than a full-fledged theory, it does not have detailed constructs per se (Sallis, Owen, & Fisher, 2008). However, Bronfenbrenner (1979) and other scholars who investigated ecological system theory provided various types of images to explain relationships and interactions among systems. Figure 1 is one of ecosystem models provided by McLeroy and colleagues (McLeroy, Steckler, & Bibeau, 1988). Each circle represents a system. The intrapersonal system located in the most central area affects individuals' behaviors directly. The interpersonal level refers to formal and informal social network and social support systems such as family, friends, intimate partners and peers. Institutional system refers to social institutions and organization characteristics, and formal and informal rules and regulations for operations. Community system is where social relationships happen among organization and institutions. The societal system does not affect individuals directly but influences by encouraging or discouraging certain behaviors through policies and social/cultural norms.

For the social work discipline, the ecological model is one of core concepts represented as a 'person-in-environment (PIE)' framework (Fay, 1996). Since the ecological framework makes it possible to explain problematic behaviors as a result of dynamic interactions among risk factors residing in different levels of the system, it opens a possibility of change in human behaviors through the interactions with others in their environment (Greene, 2008). By framing PIE as a unit (Greene, 2008), the

ecological perspective can provide a useful framework to identify problems and stratify intervention strategies for at-risk populations. Moreover, the ecological framework sees interactions among the various systems influence one another and values all interactions with different systems to be equal with interactions within a single system (Spence & Lee, 2003). Thus, it can be possible that an intervention in one system can make changes to all (Spence & Lee, 2003). In other words, in order to promote health and the quality of life of older adults and their families, efforts to change the social and physical environment can affect individuals' behavior and health outcomes.

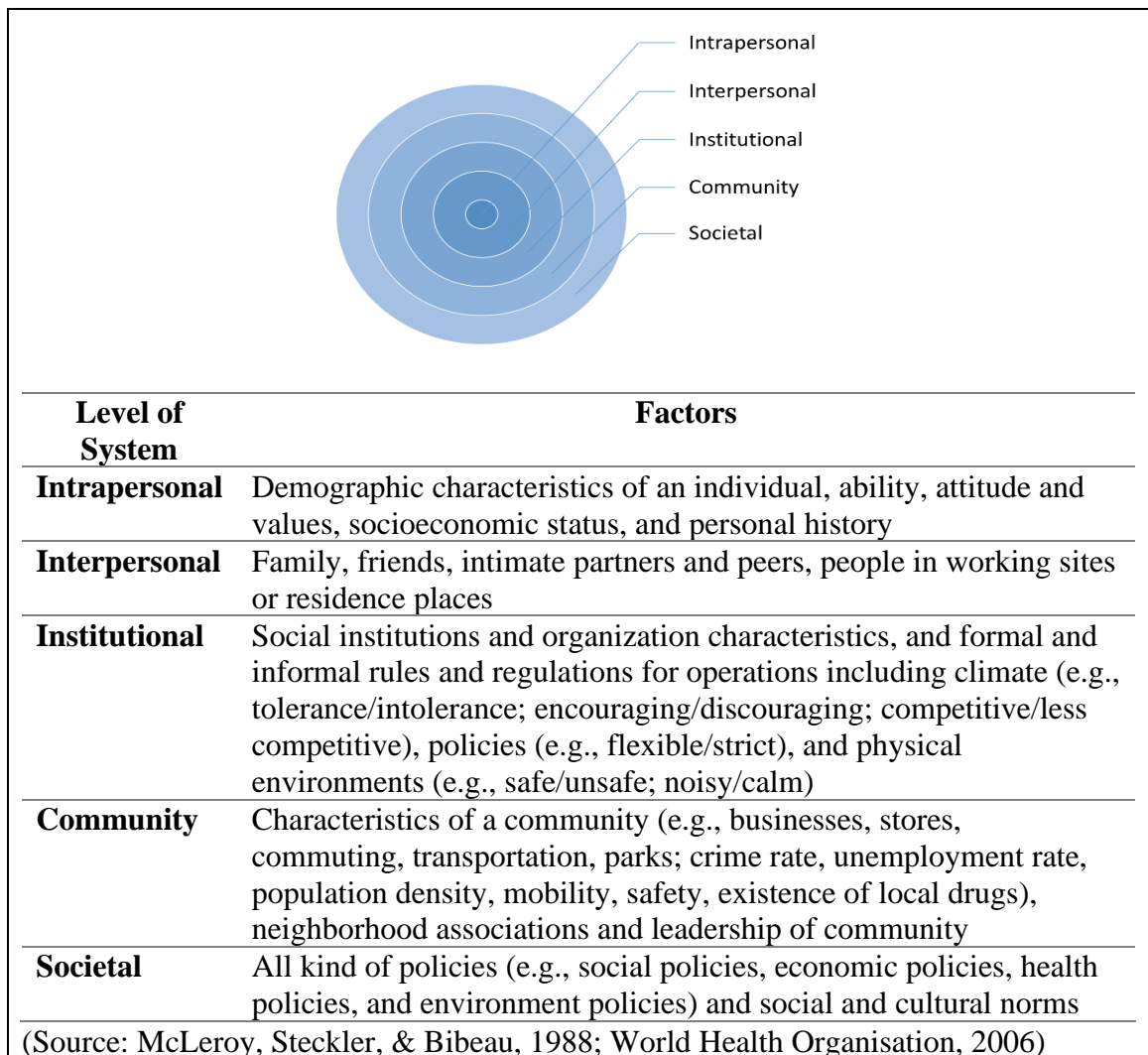


Figure 1. Ecological perspective approach

Life Course Theory

Overview of the Life Course Theory

The life course perspective is defined as a “view of human development that focuses on changes with age and life experiences in the larger social, historical, and political context” (Hutchison, 2011, p. 334). According to the life course theory, people constantly develop and adapt to different aspects of their environment through reciprocal exchanges (Payne, 2005). The life course perspective emphasizes socially defined events and roles that the individual enacts over time. This perspective also explores the patterns that historical time, social location, and culture interact with the individual experience in each life stage (Giele & Elder, 1998; Hutchison, 2011). These points are the difference from other relevant concepts such as lifespan which simply means the duration of life which is closely related to age (George, 2007) or developmental psychology which aims at universal, predictable events and pathways (Hutchison, 2011).

Five basic concepts are incorporated into the life course perspective: cohorts, life events, transitions, trajectories, and turning points (Elder, 1985; Hutchison, 2011). A cohort is defined as a group of persons who were born during the same time period (Newman & Newman, 2017). Individuals in the same cohort are assumed to share the same historical and social experience, especially social changes, within a given culture at approximately the same age (Newman & Newman, 2017). Life events refer to an occurrence itself that leads to significant changes that may cause long-lasting effects (Settersten, 2003). Transitions and trajectories are key themes in life-course research (Elder, 1985; George, 2007). Transitions refer to changes in status and roles that are

discrete from previous roles and statuses (Andrew & Ruel, 2010; Elder, 1985; George, 2007). Trajectories refer to long-term patterns of change and stability that can be distinctive from alternate patterns (Alwin, 2012; Clipp, Pavalko, & Elder, 1992). Multiple transitions in the life course are embedded in a trajectory that shows a certain pattern of one's life course (Alwin, 2012). Thus, they are inevitably interrelated. Finally, turning points refers to a specific time point when a major life change happened in the life course trajectory (Hutchison, 2011). Three types of life events emerged as turning points: life events that (a) open or close opportunities, (2) cause a long-term change in an individual's environment, and (3) cause changes in an individual's self-concept, beliefs, or expectations (Rutter, 1996).

Glen Elder Jr. (1998), one of the pioneers who identified the life course perspective, also identified four dominant principles in the life course approach which include: (a) interplay of human lives and historical time, (b) timing in lives, (c) linked or interdependent lives, and (d) human agency to make choices. Elder (1998) and Shanahan (2000) added two additional principles: (e) variability in life course trajectories and (f) developmental risk and protection.

Based on the understanding that human development and aging is a life course process, these principles imply that individuals' life experience is influenced by life events and roles in their early life stages which were embedded in social, historical, institutional, and cultural contexts. Moreover, human lives are reciprocally connected at various levels so that people share and transmit their experiences by forming or controlling others' values, attitudes, and behaviors. However, each person is an active agent who is not passively affected by circumstances but uses power to lead and shape

one's life trajectory. The life course perspective considers the intersection of social and historical factors with personal biography and development (Elder 1985; Hareven 1996) to help understand the multidirectional, interactive, and nonlinear processes of life as well as structured influences within a particular social and historical context (Hooyman, 2011).

A Life Course Perspective and Caregiving

The life course perspective can be a critical analysis tool to help understand caregiving-related issues. Given that human life expectancy is getting longer and many older adults with chronic diseases are likely to reside in a community, providing care for frail family members becomes a long-term life task. A person enters and exits consecutive roles several times during adulthood particularly for women who are historically assumed to take on caring role throughout the life course (Campbell, Abolafia, & Maddox, 1985; Dentinger & Clarkberg, 2000; Marks & Lambert, 1997).

Three key principles, which can be rephrased as 'process, context, and timing' can be used to understand caregiving issues (Moen, Dempster-McClain, & Williams, 1992). First, a framework that allows us to see a series of role transitions as a process helps us pay attention to the role trajectories of caregivers as well as the interrelation of other roles with the caregiving role (Dentinger & Clarkberg, 2000; Marks & Lambert, 1997). We can examine how caregiving roles across the life course affect a caregiver's well-being and how caregivers interpret their caregiving experience (Blieszner, 2009). Based on the process frame, we can guess that if a caregiver has a guideline or has time to prepare in advance to take on the caring roles, the transition would be easier than if it abruptly occurs without preparation (Qualls & Zarit, 2009).

Second, the life course perspective highlights the importance of context, which means personal as well as social and historical circumstances that a caregiver has responded to and interacted with and that affects a caregivers' life in their later years (Moen, 1992). Development of dementia differs by person. Based on each family's culture and situations, their reactions, decisions, and approaches to managing their caregiving roles vary. Having a framework that considers the context of caregiving is important for gerontological social workers who support caregiving families of PWD. That framework can expand understanding of various life transitions of each family, not only based on social and historical context but also individual family members' life changes.

Social roles that a person is expected to assume or voluntarily takes also reflects the social context (Vincent, Phillipson & Downs, 2006). For example, from a feminist perspective, women have been excluded from the mainstream of society throughout history for the purpose of meeting primary family obligations (Hooyman, 1995). Aged female caregivers who complete their caring roles are more likely to be susceptible to social isolation because they missed many opportunities to build their career, they are too old to get a new job, and mostly they are alone without the support of a spouse. Female caregivers' social integration and isolation and their health and well-being across the life course can be explained through this perspective (Moen, 1992). Furthermore, given the demographic changes among caregivers in the United States, paying attention to the context helps us to understand caregivers from different backgrounds including race/ethnicity and gender/sexual orientation.

Third, timing is about the duration, frequency, and sequence of roles throughout the life course (Elder, 1985). When and how long and often a caregiver has taken on caring roles for family members are important to determine a caregiver's needs for support as well as their quality of later life. Thus, for social work researchers, practitioners, and policymakers who provide supports for caregivers, it is important to recognize the significance of timing because caregivers' needs may vary based on the stage of caregiving. Smith, Folan, and Haaland (2002) suggested four stages of caregiving—early, moderate, late and bereavement. Caregivers in the early stage may have positive and rewarding experiences, but those in middle and late stages tend to be overwhelmed and exhausted due to the caregiving burdens and emotional, physical, and financial difficulties (Smith et al., 2002). When a caregiver gets to the bereavement stage, they are more likely to have mixed feelings such as a sense of relief while having deep grief simultaneously (Smith et al., 2002). From a social work perspective, timing is critical. For example, caregiving beginners may have strong needs for education about disease and medications whereas experienced caregivers may primarily need social support and respite services to allow them to take care of themselves.

Adding to timing as an element for identifying proper interventions, it is also important to know the developmental timing of transitions while caregivers carry out their caregiving roles. Many caregiving families experience difficulties in deciding the timing of transition to and from different caregiving roles, adjusting to competing roles, and managing the timing and other relevant issues depending on the life events in the family. Timing within a life course framework makes room for gerontological researchers

to consider the intersections of other roles along with the caregiving role and its patterns in diverse groups and cohorts (Dentinger & Clarkberg, 2000; Marks & Lambert, 1997).

Social Support and Social Network Theories

In general, social support is an aid, which is either tangible or intangible, purposively offered by other people who are in one's social relations to contribute to a person's well-being. The concept of social support is rooted in various relevant theories and perspectives, especially with social network theory (Glanz, Rimer, & Viswanath, 2008). Since social support occurs within one's social network, it is a prerequisite to participate in at least one significant social network to receive social support (Knack, Waldrip, & Jessen-Campbell, 2007). Thus, it is helpful to have background knowledge of related theories to develop a more comprehensive understanding of the context and mechanisms through which social support is generated, delivered, and appreciated.

Overview of Social Network Theory

Social network is a theoretical construct that refers to a cluster made up of social actors and their relations, which is represented by dyadic ties. Burgeoning in the sociology discipline since Emile Durkheim's work on suicide and social factors, social network studies have been widely conducted in different areas, such as politics, public health, and other social science disciplines. Most recently, this theory has been actively tested in computer informatics as online social networking becomes a normal part of life for the last few decades. The social network framework views relationships of people who are in a bounded group as a structure (Berkman, Glass, Brissette, & Seeman, 2000). Instead of individual actors in the network, network analysis tends to focus on the characteristics and patterns of ties that connect individual actors in a system (Berkman et

al, 2000). Social network serves as a bridge that connects the macro system (i.e., culture, political environment, and socioeconomic factors) and micro system (i.e., individuals' psychosocial mechanisms) enabling the factors in the macro system to cascade into the micro level (Berkman et al., 2000). In this process, social network provides pathways to exchange support with each other.

Social ties can be strong or weak. Strong ties represent a connection with very close relationships based on trusts, such as family, friends, or members in a particular group having cohesive membership, who can more frequently contact to discuss important matters and seek help from one another (Granovetter, 1983). This type of social tie is characterized by emotional intimacy and frequent contact, which is readily available to be transformed into social capital. On the other hand, weak ties represent a connection with relatively distant ties (Granovetter, 1983). With those in weak ties, such as colleagues, people discuss less significant matters with less frequent contacts, moderate emotional interactions, and are less apt to seek help. Although being less extensive than strong ties, weak ties can become necessary when people access their network to get help or advice or new perspectives (Granovetter, 1983).

Overview of Social Support Theory

Along with social network research, social support theory and research became prominent in the early 1970s (Lincoln, 2007), especially among scholars in a discipline that supports a social cognitive perspective, like psychology (Glanz, Rimer, & Viswanath, 2008). Caplan (1974), Cassel (1974), and Cobb (1976) laid foundational concepts of social support, and Cohen and Will (1985) reviewed extended literature on social support. Caplan (1974) and Cassel (1974) defined social support as feedback

provided by significant others that reduces the adverse effects of stress while facilitating coping with difficult situations. Similarly, Albrecht and Adelman (1987) defined social support as verbal or nonverbal communicative behavior that helps individuals in coping with difficult circumstances by increasing one's perception of control in a situation. Definitions of social support tend to emphasize the perception of being supported by individuals who are supposed to receive assistance regardless of actual availability. Accordingly, most consequent studies tended to examine the association of perceived social support, especially emotional support with outcomes of health or well-being (Lakey & Cohen, 2000; Lincoln, 2007). Most of the studies concluded that, compared with actual support, perceived support might be more critical in improving health and well-being (Knack, Waldrip, & Jessen-Campbell, 2007).

Cohen and Wills' (1985) conceptualized relevant concepts and evaluated models in social support research. After Cohen and Wills (1985) study, there seem to have been no substantial variations thus far. Social support consists of four functions: (a) emotional support, (b) informational support, (c) social companionship, and (d) instrumental support (Cohen & Wills, 1985; Uchino et al., 1996). Emotional and informational supports tend to be responsive to a wide range of stressful situations, while social companionship and instrumental support tend to work effectively when the supports are closely related to the specific needs that are elicited by a stressful event (Cohen & Wills, 1985).

Two pathways of social support that affect human health and well-being were tested: one is the direct effect, and the other is a moderating effect. The direct model assumes that social resources, which include emotional, informational, and instrumental

support that is embedded in the social network, have a beneficial effect on others' well-being. Since social support itself has a positive impact, having a stressful event is not a pre-condition to have a positive impact on social support. On the other hand, the moderation model hypothesizes that social support plays a function in reducing the adverse effects of stress on health and well-being. Thus, in the moderation model, stressors are prerequisites.

In empirical research, a relatively small number of studies tested the direct effect model. These studies found that social support, which is delivered via communication and actual provision of coping assistance, helps to maintain regulation of response systems in the human body while preventing extreme responses associated with dysfunction, which affects mental health (Lahey & Cohen, 2000). Also, social support influences health behaviors directly, such as sleep, medical regimens, or exercise (Lahey & Cohen, 2000). The moderation effect was more likely to be tested. Hypothesizing that social support is related to well-being primarily for persons under stress, a stream of studies identified strong and appropriate social support could buffer against physical or social pain due to stress while promoting health (e.g., Cohen & Wills, 1985; Ownsworth, Henderson, & Chambers, 2010). On the other hand, the lack of social support was associated with increased adverse physical and mental health outcomes, such as anxiety, depression, and cardiovascular problems (e.g., Uchino, Cacioppo, & Kiecolt-Glaser, 1996).

A caveat of social support is the possible negative aspects embedded in social networks (Knack, Waldrip, & Jessen-Campbell, 2007). For example, an individual who is a source of social support can also cause conflict or stress. Gaps in desired support and

actually received support may increase psychological distress, discontinuity of support from support providers may happen due to physical or psychological drain when supporting needs long duration. Additionally, support providers may have adverse effects on their well-being as well.

Social Support for Caregivers

Caregivers are under a stressful condition due to the caring role as well as other life stressors. Being a caregiver of a family member is a single factor that cause stress due to restriction in work and social roles, personal and recreational time, and privacy (Given, Given, Sherwood, & DeVoss, 2012). Care-related factors, including multiple caring roles, the severity of care recipients' symptoms, stage of the disease, level of involvement in caring, types of care provided, complex medical procedures, duration of illness, staying with the care recipient, and restrictions in daily life (e.g., Given et al., 2012; Stommel & Kingry, 1991) contribute to yielding caregiving stress and detrimental health outcomes. Strain from care tasks trigger caregivers' distress, and these conditions are strongly associated with adverse health outcomes, such as depression, anxiety, a sense of helplessness, and fear (Nijboer, Tempelaar, Triemstra, van den Bos, & Sanderman, 2001). Stressors embedded in daily life, such as socioeconomic conditions, including care expenses, reduced income and financial resources; and changed employment status, are also significant factors (e.g., Aneschensel et al., 1995; Clipp & George, 1990). Additionally, social and healthcare policies, which are system-level factors, also make care conditions more complex while caregivers access information and services that are available and needed (Given, Stommel, Given, Osuch, Kurtz, & Kurt, 1993; Given et al., 2012).

Given that caregivers undergo complicated and stressful situations, the importance of social support for this population has been emphasized and studied for decades. Studies found that social support is a crucial factor in enhancing caregivers' physical and psychological well-being (e.g., Cohen & Wills, 1985; Kelley, Lewis, and Southwell, 2017; Pearlin, Mullan, Semple, & Skaff, 1990). Reviewing empirical studies on caregiving stress and social support, Cohen and Wills (1985) concluded that social support might provide a solution to the problems which cause stress by canceling out the negative impacts of stressful events. A series of subsequent studies found direct and indirect effects of social support on caregivers' physical, emotional, and mental health (e.g., Kelley, Lewis, & Southwell, 2017; Ownsworth, Henderson, & Chambers, 2010; Kelley, Lewis, & Southwell, 2017; Poulin, Brown, Ubel, Smith, Jankovic, & Langa, 2010). Adequate social support improves physical health in the immune system, cardiovascular functioning, and health maintenance (e.g., Helgeson & Cohen, 1996; Uchino, 2006) and psychological well-being by reducing stress and a sense of depression (Cohen & Wills, 1985; Thoits, 1995). Using two years of nationally representative datasets, a recent study also found that engagement in a close social network was positively associated with higher caregiving confidence and predicted better health outcomes (Kelley, Lewis, & Southwell, 2017). Studies concluded that social support may help caregivers maintain a decent quality of life during and after the period of caregiving (e.g., Pearlin, Mullan, Semple, & Skaff, 1990; Wilks & Croom, 2008).

Social Support for Alzheimer's Caregivers

Exceptionally stressful situations of caregivers of PWD and its consequences on health and overall well-being were identified by researchers and practitioners. More than

forty years of studies examined the roles of social network and social support in a natural setting for caregivers of people living with Alzheimer's and related dementia (PWD) and tested social support programs and services designed to mitigate caregiving stress and increase health and psychological well-being (e.g., Pearlin, Mullan, Semple, & Skaff, 1990; Zarit & Talley, 2012). Many empirical studies highlighted the needs and importance of social support as a moderator in the stress-coping model (e.g., Cohen & Wills, 1985; Zarit & Talley, 2012). However, an increasing number of studies found the adverse role of social networks as a detriment to the well-being of caregivers as well (Chiriboga, 2006).

Interestingly, despite the hypothetical importance of social support and positive results from other types of caregivers, multiple systematic review studies found no significant or little benefits of social support for the caregivers of Alzheimer's and dementia patients (Acton & Kang, 2001; Pinquart & Sorensen, 2006; Parker, Mills, & Abbey, 2008; Dam, de Vugt, Klinkenberg, Verhey, & van Boxtel, 2016). Through the meta-analysis of 24 intervention studies published in 1982-1999, Acton and Kang (2001) reported non-significant effects of support intervention on caregiving burden. After reviewing 127 intervention studies published from 1982 to 2005, Pinquart and Sorensen (2006) also found that support intervention did have a small effect on caregiving burden, depression, caregiving knowledge and skills, and care recipients' symptoms. Parker and colleagues (2008) reviewed published intervention studies from 2000 to 2005 (N=40) and found that only two out of seven interventions showed small but significant improvement in caregiving burden. The most recent systematic review study evaluated 39 social support intervention studies published in 1988-2015 (Dam, de Vugt, Klinkenberg,

Verhey, & van Boxtel, 2016) and reported that most interventions provided a low level of evidence, and the results were inconsistent. Summing up, social support interventions for caregivers of PWD based on different definitions, measures, and models have been tested since the late 1980s, but studies demonstrated relatively small effectiveness of the interventions for improving physical and mental health and overall well-being. Studies recommended providing individualized services or programs that include multiple components, encouraging caregivers' active participation, and providing specific and updated information that helps caregivers solve their daily caregiving issues (Parker et al., 2008). Simple design, such as providing a peer support group only or self-help materials only did not bring significant benefit to caregivers' well-being (Parker et al., 2008).

Online Social Network and Human Well-being

Along with groundbreaking development of communication technology over the last few decades, the realm of social networks where people make connections with others is exponentially expanded to a virtual world, and its boundary with the physical world becomes a blur. Direct person-to-person contact or direct online communication enables people to enhance frequent communication with those in their close ties. Contrarily, building a social network through online social media or social network sites provides a tool to widen their weak social ties. Online social media can help people overcome barriers embedded in traditional social networks by offering asynchronous services along with cost efficiency to reach out to a wider social network (Nikzad-Terhune, Anderson, & Bey, 2015). There is a potential to transform the strengths of the weak ties online to get diverse support and to supplement the strong ties (Chan, 2015).

This aspect of online communication can be helpful for those who are informationally underserved people, like caregivers who frequently face challenges to access proper information.

There have been long debates on the effects of internet-based social media and social networks on human well-being. A group of studies identified adverse effects of the Internet and social media, which include social isolation and deficient psychological well-being (Kraut, Patterson, Lundmark, Kiesler, Mukophadhyay, & Scherlis, 1998), depressive feelings (Bessièrè, Kiesler, Kraut & Boneva, 2008), reduced offline social networking (Nie, 2001), cyberbullying (Whittaker & Kowalski, 2015), diminished life satisfaction (Krasnova, Wenninger, Widjaja, & Buxmann, 2013), addiction (Griffiths, Kuss, & Demetrovics, 2014), suicidal thought (Luxton, June, & Fairall, 2012), and misuse of private information (Leist, 2013). Underscoring that online social support does not operate like offline social support, Shaw and Grant (2002) claimed that negative feelings, such as jealousy and anxiety, could arise when social media users watch posts of others. Flores (2014) pointed out that there is an increase in dopamine, a hormone in the brain that gives instant reward but also brings anxiety right after if there is no following stimulation, which is often associated with addictive social media use. Staying on social media for a prolonged time may result in greater anxiety, depressive feelings, and lower self-esteem. In order to avoid such painful feelings, users may choose passive ways by avoiding adding or deleting those who trigger such negative feelings in their contacts or hiding posts; however, these methods would yield missing information or support that may be helpful for users (Krasnova et al., 2013). More seriously, social media users tend

to choose a self-promotion strategy by overstating one's accomplishment or feelings (Krasnova et al., 2013), which may bring a distorted self-identity in a virtual world.

On the other hand, other studies advocate for the positive roles of social media on cognitive and psychological outcomes. Social media, including online chatting, forum discussion, a specific social media channel (e.g., Facebook), and online support groups, mitigated depressive symptoms (Mazzoni et al., 2016) and loneliness (Shaw & Gant, 2002) while increasing emotional and social support (Eastin & LaRose, 2005; Shaw & Gant, 2002) and psychological well-being (Kim & Lee, 2011). Positive impacts of social media use in marginalized populations, such as older people or patients, were also reported. Studies reported that older people felt less loneliness due to online communication (e.g., Cotton, Anderson, & McCullough, 2013; Morris et al. 2014; Sum, Mathews, Hughes, & Campbell, 2008) and increased cognitive function through learning and using a social network site (Myhre, Mehl, & Glisky, 2017). For example, using a nationally representative dataset of Medicare beneficiaries aged 65 and older in 2013-14 (n=3,401), Ang and Chen (2019) found that visiting online social network sites moderated the association between physical pain and depression of older people who have limited offline social participation. Challands, Lacherez, and Obst (2017) surveyed 108 older people who ceased driving and found that online communications with family and friends and social participation (e.g., reading news, banking) moderate the negative effects of driving cessation.

Online Social Support for Caregivers

Paralleling the trends of increased online use among caregivers, online-based support programs for caregivers of PWD have been developed and tested (e.g., Bateman

et al., 2017). A systematic review that evaluated existing online-based social support interventions in 1990-2018 found that informational support and peer support were the most valuable components of internet-based interventions benefiting caregivers of PWD (Hopwood et al., 2018). However, results are inconsistent; many interventions mixed both offline and online components, and there was limited evidence from high-quality research. For these reasons, uncertainty remains whether online-based support enhances the psychological well-being of caregivers (Hopwood et al., 2018). Moreover, these studies intentionally designed social network platforms with specific goals and expected outcomes for the caregivers or their care recipients. There is limited knowledge currently available regarding the relationship between caregivers' well-being and online social support within general social network sites in a natural setting instead of intentionally designed platforms.

In recent decades, caregivers have been actively using social media as a tool to access social support (AARP, 2016). A majority of caregivers and patients used online discussion forums (66.6%) and blogs (14.1%) (Hamm et al., 2013). Both platforms may be less intimate than direct communication, such as direct messages, online chatting, or video conferences. Still, they may be valuable to increase the size of networks and diversity of social support (Burke, Kraut, & Marlow, 2011). An online forum is a large and democratic community that allows all participants to hold discussions and communications on particular subjects in an open format. For example, the Alzheimer's Association, the largest non-profit association in the United States that supports Alzheimer's patients and their caregiving families as well as funds Alzheimer's disease research, provides a caregivers' discussion board on their website. Also, there are many

public and private groups on Facebook for peer caregivers. A blog is an informal and conversational-style webpage that is run and updated by an individual or small group that usually contains online journals, reflections, comments, or resources of interest to the blog owner ('blogger'). The 'US Against Alzheimer's blog' and 'Dealing with Dementia' run by Ms. Kay Bransford are examples of blog type online social support. Bloggers and visitors of a blog express their emotions, thoughts, and knowledge and receive feedback from those who have a substantial understanding of or commonalities with the blogger's concerns.

There is little literature on the benefits and disadvantages of using online forums and blogs, especially for underserved people like patients and their caregivers. Tanis and colleagues (2011) explored online forum use of caregivers in the context of caregiving strain and caregivers' well-being. Rodgers and Chen (2005) analyzed longitudinal qualitative data from online bulletin board posts written by female breast cancer patients. Both studies identified a positive association between active participation (e.g., number of postings, duration of participation in the board) and psychological well-being, such as lowered caregiving stress (Tanis, Das, & Fortgens-Sillmann, 2011) and improved mood (Rodgers & Chen, 2005). These studies pointed out the therapeutic effects that study participants might experience while participating in an online community when the social media platform provides a secure and empathetic environment. The therapeutic effect of online writing is supported by Flores (2014) as well. Flores (2014) explains that when a person writes about themselves or receives positive feedback online, oxytocin is secreted in the central reward system in the human brain, which makes people feel reduced stress responses and anxiety. Also, social media makes people feel that they are being

understood and have connections with others, although the level of compassion and affection that can be delivered online is limited (Flores, 2014).

Writing in online space targeting unanimous others is less rich in relationship-maintaining as compared with direct communication with specific individuals, such as email or direct messaging, which contributes to strong relationships (Burke et al., 2011). Blogging and writing on online forums and community can be categorized as a weak tie, which is considered less intimate and relationship-maintaining social behavior. Thus, there is potential for online social media mediated social support to be beneficial. However, these activities may not bring a similar outcome as offline social support, which is based on an already established strong relationship. More research in these areas is needed.

Policies That Support Caregivers of People Living with Dementia

The quality and fiscal sustainability of the U.S. health care and long-term care system has been a growing concern to policymakers, healthcare providers, and all citizens. As the life expectancy of older adults who desire to reside in the community has rapidly increased and health care costs have also grown, numerous programs and interventions that provide services to family caregivers have been developed and tested during the recent decades. During the 1990s, federal policymakers developed a couple of federal policies specifically aimed at supporting persons who care for their family members. This chapter will review two major policies that address caregivers' overall well-being and employment: the National Family Caregiver Support Program (NFCSP) and the Family and Medical Leave Act (FMLA). The Affordable Care Act will also be

reviewed because this reformed health care policy may affect family caregivers' and their care recipients' health and medical expenditures.

There are other federal and state programs that support family caregivers' financial needs. For example, Cash & Counseling Programs pay family caregivers of frail older Medicaid beneficiaries as a program participant (Auxier, 2009; Elmore & Talley, 2009). Currently, 49 states have their own names for Cash & Counseling programs (Paying for Senior Care, 2017). Family caregivers also can receive tax reductions if their total income is below a certain level (e.g., \$3,950 a year in 2014) and the caregiver provides more than 50 percent of their care recipients' support (Hasson, 2015). Once caregivers meet certain criteria, they can receive a \$3,900 tax exemption for each care recipient (Hasson, 2015). In addition, there are other sources to support family caregivers in non-profit or profit sectors such as company paid sick leave. Due to the limited number of reliable resources including current evaluation research or reports on these programs, however, the author will focus on three major federal policies.

National Family Caregiver Support Program (NFCSP)

Overview of the National Family Caregiver Support Program (NFCSP)

By authorization of the Older Americans Act of 2000, the NFCSP was created to provide services focusing on family caregivers. The NFCSP requires all State Units of Aging (SUAs) and area agencies on aging (AAAs) to concentrate on meeting the needs of the family caregiver as well as older adults (Administration on Aging, 2004). In specific, two population groups, family caregivers and a grandparent or older relative caregivers of children, are to be served by the program (Older Americans Act, Title III, Part E, Section 372). Family caregiver is defined as "an adult family member or another individual, who

is an informal provider of in-home and community care to an older individual,” and a grandparent or older individual who is a relative caregiver is “a grandparent or step-grandparent of a child, or a relative of a child by blood or marriage, who is 60 years of age or older and lives with the child” (Older Americans Act, Title III, Part E, Section 372.). The NFCSP is intended to provide multifaceted, comprehensive supports, which include: information to caregivers about available services, access assistance to help caregivers gain access to services, counseling/caregiver training, respite care, and supplemental services (Administration on Aging, 2004). The goals of this program are: supporting caregivers dealing with emotional, physical, and financial burdens; reducing caregiver stress, depression, and anxiety to enable caregivers to continue providing care longer, thereby delaying the need for costly institutional care (Administration on Aging, 2004).

Service Delivery System

Although it is a federally designed program, a huge variance exists in the content and quality of services state by state. SUAs and AAA are given the discretion to use the NFCSP grants however they choose. Thus, once the AoA provides formula grants to SUAs, each SUA and AAA provide the services through the local AAAs and contract service providers based on the needs of the community (Administration on Aging, 2004). The federal government spends approximately \$150 million per year on grants for the NFCSP program and approximately \$2.5 million a year to support states to develop more accessible respite systems, based on the Lifespan Respite Care Act of 2006 (Lipson, 2015). Prior to the enactment of the NFCSP, some states already funded family caregiver support programs, thus these states connected the NFCSP funds and resources to the

established service infrastructure (Administration on Aging, 2004; National Association of State Units on Aging, 2003). States also give priority to individuals with greater social or economic needs due to the limited resources; whereas, the NFCSP was originally designed to provide services to a caregiver regardless of other conditions like income level or region (Giunta & Scharlach, 2009). In addition, each state expanded the program connecting to Medicaid Home and Community-Based Services (HCBS)-waiver and state-funded programs as an effort to overcome the limitation of resources and to meet caregivers' diverse needs (Kelly, Wolfe, Gibson, & Feinberg, 2013). Consequently, such efforts by states increased flexibility to meet the various needs and preferences of caregivers and helped to maximize the effectiveness of the NFCSP (Administration on Aging, 2004; National Association of State Units on Aging, 2003). At the same time, allowing autonomy to each state-run grants and programs also increased the variance of the service quality across and within states (Administration on Aging, 2004).

Limitations

The NFCSP is the first federal policy that addresses caregivers' needs directly and comprehensively. Moreover, throughout the enactment of the program since 2000, this federal effort made it possible to systemically help family caregivers (The Lewin Group, 2016). Nevertheless, there are some critiques about the quality and adequacy of the program, which include limited assistance and services that serve only a relatively small number of selected caregivers (Doty & Spillman, 2015); low accessibility to the services due to the eligibility criteria; lack of knowledge about the services available for health care and service providers as well as caregivers; lack of self-identification of caregivers

and cultural barriers such as language, cost, and lack of transportation (Feinberg, 2017; Scharlach, Kellam, Ong, Baskin, Goldstein & Fox, 2006).

The program also has been critiqued for the mismatch between caregivers' needs and delivered services. According to the most recent NFCSP evaluation report conducted by the Lewin Group (2016) which surveyed SUS, AAA, and local agencies in 2015, an overwhelming number of caregivers requested respite care services (74.7 percent) and federal and state financial assistance (26.5 percent). However, most direct services provided by AAAs were information (84.8 percent), access assistance (74.9 percent), and training/education (59.6 percent). Respite services heavily relied on local service providers (79.1 %). Though not discussed in this evaluation report, it should be noted that a substantial number of family caregivers requested financial assistance from the federal and state government due to their economic deficiencies. In the report, SUAs showed their biggest concerns in a few recent years, which include increasing demand from a growing caregiving population and decreasing funding, and limited provider availability (The Lewin Group, 2016). It is urgent for caregiver policy makers and service providers to make an effort to fill the service gaps.

The Family and Medical Leave Act (FMLA)

Description

The Family Medical Leave Act (FMLA), established in 1993, is an employment-based family caregiver support program. The law requires employers of 50 or more to provide at least 12 weeks of unpaid leave per year to their full-time employees who care for children, elderly persons, other family members, or the employee themselves for family and medical reasons. They also have to secure an employee's job until the end of

the leave with the same health benefits (Public Law 103-3). Qualified reasons for the protections of the FMLA include (a) caring for serious health condition of self, spouse, parent, or child; (b) having a new child (birth, adoption, foster); and (c) deploying the employee's parent, spouse or child to covered active duty as a member of the regular Armed Forces or reserves (Klerman, Daley & Pozniak, 2012). Specifically, to be eligible for the FMLA, an employee must: work for a firm with 50 employees within 75 miles of the employee's worksite; have 12 months of tenure with this firm; and have worked 1,250 hours of service in the past year, which means approximately 24 hours per week (Klerman et al., 2012). Once an employee meets the criteria, she or he can schedule a total of 12 weeks of unpaid leave in a 12-month work period (Public Law 103-3). Due to the flexibility of the time regulation, caregivers can manage transitional or critical situations of their care recipient with relatively fewer worries about their job security (Doty & Spillman, 2015) or can make a regular time to visit health professionals for their care recipient's medical purposes.

Limitations

An insufficient number of employees are covered by the FMLA. According to survey data by the U. S. Department of Labor in 2012, companies with more than 50 employees are only 17 percent of the employers and only 59 percent of employees reported they meet all eligibility criteria (Klerman et al., 2012). Adding to the criteria, employers can deny the request of the FMLA leave if an employee is salaried in the highest 10% of the company's payroll and the absence of the person presumably can cause financial risk to the company (Wisensale, 2003). Thus, due to such complicated conditions for the employees and the fact that a very limited number of work sites are

regulated by the law make it difficult for caregivers who may desperately need leave to care for their loved ones in a given period.

The provision of the unpaid leave also underestimates the severity of economic hardship of family caregivers who are in financial need (Wisensale, 2009). Given that dementia caregivers have to spend more on medical expenditures for their care recipient as the disease develops, most are placed in a no-win situation to choose between either making more money or having more time to care for their loved ones.

Moreover, from a feminist perspective, the FLMA has been critiqued for promoting unequal structures of the society based on gender, race/ethnicity, class, and marital and occupational status. By tying in with familyism, the FMLA imposes the caring role to an individual family member rather than sharing the caring burden with society. The law does not give an opportunity for leave to people who are employed in small businesses, have an insecure job, and have to choose to earn money to care for all family members. Typically, White, married women with higher education levels are more aware of and more likely to use the provisions of FMLA than are their male or minority coworkers (Wisensale, 2003). Currently, California, New Jersey, New York, Rhode Island, and Washington, D.C. have enacted paid family leave statutes, and twelve states and Washington D.C., (e.g., Connecticut, California, Connecticut, Massachusetts, Oregon, and Vermont) have paid sick leave laws that require private-sector employers to allow workers a reasonable number of earned sick days to care for an ill family member (including some older adults) (National Academies of Sciences, Engineering, and Medicine, 2016; National Conference of State Legislatures, 2017, 2020). More research is needed to review the effects of the paid leave in these states.

The Patient Protection and Affordable Care Act (ACA)

A brief History of U.S. Health Insurance

Unlike most developed countries that adopt either the Bismarck or Beveridge health care models which let all or nearly all of the population have health insurance coverage that is provided by either the government or an employer, the U.S. has established their own system of health insurance. During World War II in 1943, the US Congress initiated the blueprint for the modern system of employer-sponsored insurance (Lyke, 2008). Despite widespread public support for national insurance, universal health insurance was not accomplished. Instead, a limited health insurance proposal for older adults was passed. Later, during the Great Society era in the 1960s, Medicare and Medicaid were enacted. Employer-based health insurance, Medicare, and Medicaid have formed a patchwork health system, and most Americans searched for insurance coverage through one of these three programs (Bhattacharya, Hyde & Tu, 2013).

Most health care provisions are private, thus supply and demand in the healthcare workforce as well as price for treatments are determined in the market (Bhattacharya, Hyde & Tu, 2013). People who are considered able to work seek insurance in the private health insurance market, which is centered around employer-based health insurance pools. Medicare and Medicaid, government health insurance programs, only cover older adults, people with disabilities or those living in the poverty. Most Americans are insured under the private and government-run health care systems. However, a sizeable number of people were still not insured. In 2013, more than 44 million people, which comprised 16.6 percent of the nonelderly population, lacked health coverage (The Henry J. Kaiser Family Foundation, 2017). According to the Centers for Disease Control and Prevention

(2011), 67 percent of unpaid American caregivers rarely go to the doctor because they put family needs first. To address the uninsurance problem, the Patient Protection and Affordable Care Act (PPACA), which is commonly called the Affordable Care Act (ACA), was passed in March 2010 and implemented in 2014.

Overview of the Affordable Care Act

The Patient Protection and Affordable Care Act (ACA) is a groundbreaking federal policy that aims at providing quality, affordable health care for all Americans. The law includes health-related provisions that help all legal residents of the U.S. have minimum health coverage. Among thousands of separate provisions, two key parts of the provisions include expanding Medicaid and mandating that citizens have health insurance. First, the ACA expands Medicaid eligibility for people making up to 133% of the federal poverty line (FPL) and prohibits insurers from establishing annual spending caps. This provision enables all Americans who are under a certain income level (for example, up to \$15,000 household income in 2014) can access Medicaid, which is funded by both the federal and state governments (Bhattacharya et al., 2013).

Moreover, the law mandates that all American citizens purchase individual health insurance to enhance the coverage rate. As a method to cover all citizens, the ACA requires all 50 states and D.C. to build and operate a private health insurance marketplace, called Insurance Exchange, which aims to provide adequate health insurance plans and promote transparency and accountability of insurance providers through competition (Blumberg & Pollitz, 2009). The law provides federal funds for establishing and operating the exchanges in each state by request up to 2015 (Blumberg & Pollitz, 2009). However, each state has the discretion to moderate policy and standards

regarding eligibility of the enrollees and coverage level and plans provided by insurers to meet each state's particular needs (Sodergren, 2013). Thus, if a state has a higher rate of people with a certain disease like dementia or diabetes, the state can select insurers that offer special programs to address the disease. Under an exchange, enrollees with a wide range of health conditions are pooled together, so that the insurers can spread risk and administrative costs, thereby they can provide plans at a low cost (Sodergren, 2013). Moreover, the law provides substantial subsidies to individuals and families adjusted for household income level when they purchase insurance on the exchange (Holtz-Eakin & Smith, 2010). The law subsidizes insurance premiums for individuals and families making up to 400% of federal poverty level (FPL) and caps expenses from 2% to 9.8% of annual income, so even middle-income families can afford generous insurance (Bhattacharya et al., 2013). Adding to these provisions, the law tactically regulates individuals and private insurance companies. On the one hand, it charges a penalty for the uninsured when filing one's tax returns. For example, the penalty for 2016 was 2.5 % of yearly household adjusted gross income or \$695 per adult. On the other hand, the policy requires all insurance companies to comply with consumer protection provisions in the ACA. Accordingly, all insurers are prevented from charging people higher premiums or denying claims due to pre-existing conditions or other predictors that increase health expenditures (Bhattacharya et al., 2013).

Evaluation of the ACA

The fundamental goal of the ACA is to increase health equity by having all U.S. citizens have their own health insurance. Many studies that examined whether the government achieved the goal reported that the ACA has successfully increased the

coverage rate across the U.S. at a certain point (e.g., Barnett & Vornovitsky, 2016; Blumenthal & Collins, 2014; Schoen, Doty, Robertson & Collins, 2011; Sykes, 2017). According to data from the Centers for Disease Control and Prevention (CDC) that shows the trends of the uninsured by years based on the National Health Interview surveys, it was around 15 percent (above 40 million) between 1997 and 2013, but after that it decreased to 9.0 percent (28.6 million) in 2016 (Clarke, Norris, & Schiller, 2017). There was an estimated 70 percent drop in the uninsured among adults ages 19-64 (Schoen et al., 2011). Other studies found that the ACA's increased health care insurance coverage in general by approximately 20 million people (Gallagher, Gopalan, & Grinstein-Weiss, 2019; Sykes, 2017). Out of 20 million, 11.1 million were covered through the ACA's Marketplace, and 85 percent received subsidies (Gallagher et al., 2019). For the middle-aged population between ages 55 and 64, more than 2 million purchased health insurance (Sykes, 2017). Despite the large scale of actions across the states with large government funds, many Americans remain uninsured. Nearly four million who are in poverty are not insured (Garfield, Damico, Stephens & Rouhani, 2014). One of the reasons for the low coverage rate is that, unlike the previous plan of the federal government, many states conditionally expanded their Medicaid programs, so people who were expected to be eligible did not get the benefit of health care reform (Garfield et al., 2014).

The Affordable Care Act and Family Caregivers

The ACA provides potential support to family caregivers who are situated in an economically vulnerable situation. Most caregivers are middle-aged females without a permanent job (Alzheimer's Association, 2017). Among caregivers who are employed, many experience a change in their work hours or give up promotion opportunities due to

their caregiving roles (National Academies of Sciences, Engineering, and Medicine, 2016). Adversely, some of them experience job-lock to maintain their health care benefits and income to support their care recipient's medical expenditures (Doty & Spillman, 2015). American health insurance policy is designed on the assumption that adults are supposed to be provided employer-based insurance. Thereby, family caregivers who do not have a job, along with people who have jobs that do not provide health insurance are easily caught in the policy gap. According to the NHATS/NSOC data, 14% of family caregivers in 2011 reported that they did not have health insurance coverage (Spillman, Wolff, Freedman & Kasper, 2014). Family caregivers who are not eligible for federal health care programs such as Medicaid and Medicare, but do not have private health insurance from their employer fall between two major public programs without proper coverage. In this sense, the ACA can help caregivers who are not supported by employment-based insurance.

Moreover, the ACA can provide benefits for caregiving families with low-incomes. Since the ACA aims at health equality among all Americans, the law enables individuals and families who are below a certain level, which usually includes middle class individuals, access to more health services. Since the law was enacted in 2014, there is still limited research that examined the effects on underserved populations. One study that examined the ACA effects for people living in the near-poor condition reported positive effects (Gallagher, Gopalan & Grinstein-Weiss, 2019). Using administrative data from an online tax-preparation software and survey following the tax-filing process, Gallagher et al. (2019) found that people who are in 100% federal poverty level (FPL) and received subsidization through the enrollment in insurance marketplace have 11

percent point increased coverage. Compared to uninsured households with similar financial condition, they are 41 percent less likely to experience foreclosure and evictions (Gallagher et al., 2019).

Prohibiting insurers from denying enrollees for their pre-existing medical conditions would help family caregivers, especially those who care for people with dementia. As many studies reported, family caregivers who provide care to elderly dementia patients suffer from severe physical and mental health conditions. Compared to other groups including non-caregivers and non-dementia caregivers, dementia family caregivers are at higher risk for stress-related illnesses and depression (13.2 percent) (O'Brien, 2006); have poorer health habits such as smoking and alcohol use, and limited leisure time (National Academies of Sciences, Engineering, and Medicine, 2016). Indeed, medical expenditures for dementia patients is higher than for those who are without such disease (Delavande et al., 2013). Out-of-pocket spending for dementia patients was almost three times Medicare spending and 19 times Medicaid spending (National Academies of Sciences, Engineering, and Medicine, 2016). Due to the limited living budget, many caregivers put a priority on their care recipients' health and well-being, and neglect their own health. Given that early preventive care will reduce the likelihood of later medical costs for treatment of chronic illness or disorders and possible disease, it is important to intervene in dementia caregivers' unmet needs at an early stage. If not, accumulated needs for health care of family caregivers may return as a bigger fiscal burden to the society to pay more for institutional care for both cognitively impaired patients and their caregivers.

CHAPTER THREE

The Impact of Social Support on Dementia Caregivers' Mental Health: Is Online Comparable to Offline?

Background

In 2020, an estimated 16 million family members are caring for nearly 6 million Americans who are living with Alzheimers' and related dementias, and that number is projected to grow to 88 million by 2050 (Alzheimer's Association, 2020). Family caregivers of people living with Alzheimer's or related dementia (PWD) are at risk of being isolated from others due to their heavy caring duties and possible stigma. They are also in great need of assistance to master their care responsibilities and maintain their own physical and mental health (Alzheimer's Association, 2020).

Given that having meaningful social relationships with others is pivotal to attaining a decent quality of life for all human beings, it is critical for family caregivers to have a robust social network with supportive people who can help them acquire adequate resources, solve challenging situations, and make important decisions. As internet-based communication technologies have exponentially developed in recent decades, many caregivers have been moving to online platforms to access information, resources, and emotional supports (Pew Research Institute, 2006). The Internet and online social media may expand the opportunities for caregivers to enhance their contacts, which can provide needed support and information. However, studies have also warned of potential adverse outcomes of social media use on human well-being (e.g., Krasnova, Wenninger, Widjaja, & Buxmann, 2013). Despite the increase of social media use among caregivers of PWD

(AARP, 2016), the dynamics of online social support to family members facing the stress and burden of caregiving is understudied.

Caregivers' Online Social Media Use and Social Support

Caregivers are increasingly turning to the Internet and online social media to seek information and support. An estimated 70 to 95% of American family caregivers have used online resources to seek help and information related to their caregiving roles (AARP, 2016; Fox & Brenner, 2012). Being a caregiver is significantly associated with a higher level of accessing online health information (Fox & Brenner, 2012). Around 60 percent of Alzheimer's caregivers seek health-related information online, according to the national survey conducted by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) in 2009 (N=450) (Kim, 2015). A scoping review that examined studies focused on social media use by caregivers and patients found that discussion forums and online support groups were the most dominant platforms (67%) and the primary purpose of using online tools was to facilitate self-care (77.1%) (Hamm et al., 2013). It is reasonable to think that caregivers move online for seeking help and information for their care recipients and themselves because of the unique benefits of online over offline services.

Social Support for Caregivers

In general, social support is an aid purposively provided to contribute to a person's well-being. From a social psychological perspective, social support is defined as verbal or nonverbal communication that helps individuals cope with stressful situations (Nikzad-Terhune, Anderson, & Bey, 2015). Social support occurs within one's social network. Thus, it is a prerequisite to participate in at least one significant social network

to receive social support (Knack, Waldrip, & Jessen-Campbell, 2007). Two types of hypotheses regarding the influence of social support -- main effect and moderation effect - have been tested and verified by numerous studies (e.g., Cohen & Wills, 1985; Wilks & Croom, 2008). Main effect hypothesis assumes direct association of social support with physical and mental health regardless of the existence of stressors. Thus, main effects of social support on Alzheimer's caregivers' health and well-being was rarely investigated (Cohen, Underwoods, & Gottlieb, 2000) considering their common stressful life conditions that tend to affect caregivers' overall well-being. Instead, most studies proposed and tested the moderation effect of social support, hypothesizing that social support mitigates the negative association between stressors and caregivers' health and well-being (e.g., Liang, Aranda, & Lloyd, 2020; Wilks & Croom, 2008).

Social Media and Human Well-Being

Social media are the online platforms that allow all users to create, modify, and exchange content and information (Nikzad-Terhune et al., 2015). Individuals are separately but actively connected in the online world via social media to seek appropriate resources (Pew Research Center, 2006), and increase the depth and width of their social networks. According to social network theory, strong ties indicate links with those who are in the existing close social network. In contrast, weak ties imply relatively many yet loose links with those who would not have connection earlier or narrow (Granovetter, 1973). Strong ties tend to be beneficial for obtaining emotional support, while weak ties are helpful to access appropriate information or new perspectives (Granovetter, 1973). Various functions of online social network sites can allow users to create and accumulate

two types of ties, and later, they can leverage their social network established online to get proper social support.

There have been long debates on the effects of the Internet and online social media use on human well-being. A group of studies identified adverse effects of the Internet and social media, such as social isolation and deficient psychological well-being (Kraut, Patterson, Lundmark, Kiesler, Mukopadhyay, & Scherlis, 1998), depressive feelings (Bessière, Kiesler, Kraut & Boneva, 2008), jealousy and diminished life satisfaction (Kranova et al., 2013), suicidal thoughts (Luxton, June, & Fairall, 2012), and misuse of private information (Leist, 2013). On the other hand, another group of studies advocates for the positive roles of social media on cognitive and psychological outcomes. Studies reported that social media, including online chatting, forum discussions, a specific social media channel (e.g., Facebook) and online support groups, mitigated depressive symptoms (Mazzoni et al., 2016) and loneliness (Shaw & Gant, 2002) while increasing emotional and social support (Shaw & Gant, 2002) and psychological well-being (Kim & Lee, 2011).

Social Media as a Tool of Social Support for Caregivers

Online forums and blogs are examples of online social media platform that enables users to communicate and exchange information and thoughts reciprocally with fewer restrictions. Caregivers have increasingly been using social media as a tool to access social support (AARP, 2016). Through a scoping review, Hamm and colleagues (2013) found that a majority of caregivers and patients used online discussion forums (66.6%) and fewer used blogs (14.1%). Both platforms may be less intimate than direct communication (e.g., direct message or chatting), but may still be valuable to increase the

size of networks and diversity of social support (Burke, Kraut, & Marlow, 2011). An online forum (e.g., caregivers' discussion board in the Alzheimer's Association website, private groups on Facebook for peer caregivers) is a large and democratic community that allows all participants to hold discussions on particular subjects in an open board. A blog (e.g., 'Dealing with Dementia' run by Ms. Kay Bransford and the 'US Against Alzheimer's blog') is an informal and conversational-style webpage that is run and updated by an individual or small group that usually contains online journals, reflections, comments, or resources posted by the blog owner ('blogger'). A blogger and the visitors of the blog express their emotions, thoughts, and knowledge and receive feedback from those who have a substantial understanding of or commonalities with the blogger.

Despite the prevalence of social media use among caregivers, studies on the use of online and offline social support within the context of caregivers' stressors and well-being are still underdeveloped. Two studies investigated caregivers' use of the Internet, and found that caregivers who are younger, more highly educated, and who report more caregiving stress are more likely to use the Internet to access online resources (Kim, 2015; Li, 2015). However, in terms of financial stability, Kim (2015) reported more Internet use was associated with economic hardship, while Li (2015) found an association with a higher income of caregivers. Caregivers who had a part-time job were more likely to use online-mediated services over the traditional format of services (Meyer, Gassoumis, Kelly & Benton, 2019). Tanis and colleagues (2011) found that active participation in an online forum (e.g., posting) benefited caregivers with higher caregiving strain while less active participation (e.g., lurking) significantly reduced the well-being of caregivers when they experienced higher caregiving stress. They concluded

that caregivers might experience therapeutic effects while participating in an online community if the social media platform provides a secure and empathetic environment (Tanis, Das, & Fortgens-Sillmann, 2011). Despite the intriguing findings, this work lacks statistical reliability due to the small sample size and possible self-selection bias for the online survey with only 66 voluntary participants.

Study Purpose and Research Questions

In order to fill the research gaps, this study had three aims. First, we tested if there is a difference in the level of mental health of dementia caregivers using offline and online social supports, respectively. Next, we examined the effects of offline and online social supports, assuming that online social support plays a similar role as offline social support (Main effects). Finally, we tested if offline and online social supports moderate the relationship between stressors and mental health of caregivers (Moderation effects). We hypothesized the following:

Hypothesis 1.1: Offline social support increases the mental health of caregivers of PWD (Main effect).

Hypothesis 1.2.: Online social support through social media increases the mental health of caregivers of PWD (Main effect).

Hypothesis 2.1.: Offline social support ameliorates the adverse effects of caregiving burden and life stressors on the mental health of caregivers of PWD by offsetting or moderating the main effect (Moderation effect).

Hypothesis 2.2.: Online social support through social media ameliorates the adverse effects of caregiving burden and life stressors on the mental health of caregivers of PWD by offsetting or moderating the main effect (Moderation effect).

Method

Data and Sample

This study used a subsample of the *Health Information National Trends Survey* (HINTS) from 2017 to 2018 ($N_{2017}= 3,285$, $N_{2018}= 3,504$). The HINTS is a cross-sectional survey of a nationally representative sample of adults whose age 18 and older in the United States. HINTS includes data about cancer-related knowledge, attitudes, and health behaviors. To our knowledge, the HINTS is the only publicly accessible and nationally representative dataset that contains information on social media use and caregiving. With the stratified sampling method, racial and ethnic minority groups were oversampled in order to increase the reliability and precision of the estimate of health status indicators. Data were collected through mailed questionnaires, and the response rates for both years were 25.0% and 24.2%, respectively. More details about the HINTS dataset is available elsewhere (WeStat, 2019).

For the current analysis, study participants who indicated that they were currently providing the most care for an individual with Alzheimer's, confusion, dementia, or forgetfulness were extracted from the merged two-year dataset ($n=264$; 4.6% of the study sample). Although there is no accurate estimate of the prevalence of informal caregivers of PWD, combining statistics from the U. S. Census Bureau (2011) and the National Survey of Caregiving in 2011 (Kasper, Freedman, & Spillman, 2016), it is assumed that around 3.3 % are informal caregivers (i.e., an estimate of caregivers of PWD: nearly 8.5 million; an estimate of the population age 18 years and older: nearly 256.2 million). Thus, the study sample is considered to be representative of the caregivers of PWD in the United States.

Measures

Mental Health

Mental health was measured with the Patient Health Questionnaire (PHQ-4) which contains four items that asked respondents to indicate to what extent they experienced the following conditions in the previous two weeks: (a) Little interest or pleasure in doing things, (b) Feeling down, depressed or hopeless, (c) Feeling nervous, anxious or on edge, and (d) Not being able to stop or control worrying (4-point Likert scale, 1=nearly every day: 4=not at all) (Kroenke, Spitzer, Williams, & Löwe, 2009). This measure was developed for quick yet accurate screening for anxiety and depression (Kroenke et al., 2009). The HINTS data provide the PHQ-4 scores in the original data, summing up the rescored and reversed variables (0= not at all: 3= nearly every day), which range from 0 to 12 with higher scores indicating a more negative emotional status. The reliability of the scale with the study data was high (Cronbach's alpha = 0.937), and the principal component analysis with one factor explained by the four items provided an acceptable level of fit (Component 1 Eigenvalue=2.94, KMO=.79) (Appendix A). The authors of the PHQ-4 suggested using the score as a categorical indicator for practitioners with the following designations for the scores: normal (0-2), mild (3-5), moderate (6-8), and severe (9 and higher) (Kroenke et al., 2009). For the descriptive statistics, PHQ-4 scores that were provided with the original data were used. For convenience of interpretation, we recoded PHQ-4 scores and used the categorized PHQ-4 values, indicating that higher rank refers to better psychological well-being (i.e., reversed PHQ-4: 0=severe: 12=not at all; reversed categorical PHQ-4: 1=severe: 4=normal) in the analyses.

Risk Factors: Stressors

Stressors were composed of two indicators: caregiving burden and life stress. Caregiving burden was indicated by: (a) caregiving hours per week and (b) the number of care recipients being cared for. The choice of these two indicators was based on studies showing that more caregiving stressors, including caregiving hours and caring roles, tend to cause more negative effects on caregivers' well-being (e.g., Thunyadee, Sitthimongkol, Sangon, Chai-Aroon, & Hegadoren, 2015). For this study, caregiving hours were coded as a binary (1=caregiving less than 20 hours per week). Having multiple care recipients were also coded as binary (0=one care recipient; 1= two or more).

A significant association between life factors, such as health and socioeconomic status, and mental health were reported in previous studies (e.g., Thunyadee et al., 2015). In this study, life stressors were measured with the level of family income and health status. The subjective level of the overall health of the respondent that was originally measured as a 5-point Likert scale (1 excellent: 5 poor) was recoded as binary (1=good or higher health). Income is one of the most challenging variables to measure accurately. In the original data, household annual income level was measured as nine categories (e.g., \$0 to \$9,999, \$10K to \$14,999, \$15K-19,999). The researcher picked the median of each category and divided the amount with the number of households to get a proxy per capita income; then, made quantiles with the following amounts: 1=25%, 2=50%, 3=75%, 4=100%.

Preventive Factors: Offline and Online Social Support

Offline social support, which was defined as help from others in the real world in this study, was measured with three types: (a) emotional support, (b) friend who can talk about a health concern, and (c) tangible help for chores. Survey questions asked (a) is there anyone the respondent can count on to provide emotional support when it is needed, (b) if the respondent has friends or family members to talk about their health, and (c) if the respondent has someone who helps with daily chores when he/she is sick. In the original data, social support variables were measured as binary in 2017 (1=yes) while they were measured using a 5-point Likert in 2018 (1=never, 5=always). For analysis, the researcher dichotomized the variable in the 2018 dataset, transmitting ‘sometimes,’ ‘often,’ and ‘always’ into ‘1=yes’ and ‘never’ or ‘rare’ into ‘0=no’.

Online social support was defined in the HINTS survey as “use the Internet to connect with other people online through social networks like Facebook or Twitter”. Three items asked if a respondent had used social media in the past 12 months (d) to share health information social networking sites, (e) to write in an online diary or blog, and (f) to participate in an online forum or support group for people with a similar health or medical issue (binary, 1=yes).

Characteristics of six variables [(a)~(f)] were included in the descriptive statistics. In the regression analysis models, however, (a) emotional support and (b) friends who can talk about health concerns for the offline social support and (e) blogging and (f) online forum for the online social support were included to increase the explanatory power of the analysis models.

Covariates: Socio-Demographics

Demographic variables were controlled in the statistical analyses. Age, initially measured as continuous (mean: 59.43, SD: 16.36, range: 18-101), was transformed into a categorical variable: young adults aged 18-54, middle-aged adults aged 55-64, and older adults aged 65 or older. Gender was coded as binary: 1=male. Marital status was also coded as binary: 1=married or living together. Ethnicity was coded as binary: 0=non-Hispanic White, 1=being an ethnic or racial minority. Education level was also coded as binary: 1=Bachelor's degree or higher.

Analytical Strategy

First, we present the descriptive statistics of caregivers along with summary statistics from non-caregivers as a comparison. Descriptive statistics are provided based on unweighted data. To test the research hypotheses, t-test and ordered logistic regression analyses were applied with jackknife estimation. Analyses were performed using Stata 15.1SE.

Results

Sample Characteristics

Table 1 present the characteristics of the caregivers of PWD (n=264) as compared with non-caregivers (n=5,517). Non-caregivers were those who marked 'No' for the question that asks if the person is currently caring for or making health care decisions for someone with a medical, behavioral, disability, or other condition. The mean age of caregivers in the sample was 61.03, which was significantly higher than for non-caregivers (56.79). Nearly 45% of caregivers were between 50 and 64 years. The dominant portion of caregivers was female (70.83%) who were married or living as

married (61.36%) with bachelors or higher degrees (48.86%). The mean score of the mental health [MH] of caregivers of PWD was 2.05, which was marginally higher than for non-caregivers (mean: 1.76). In the four sub-items, the mean scores of worrying (mean: .53) and nervousness (mean: .57) of caregivers were statistically higher than those of non-caregivers. The categorical form of MH shows that the majority of both caregivers (68.94%) and non-caregivers (74.51%) were in the normal range for MH.

Over one-third of caregivers spent 5-14 hours per week caring for their loved ones, and nearly 25% spent 35 or more hours per week with care duties. Almost 90 percent of caregivers cared for single care recipients. About half of each group reported good or higher health status with no significant difference between caregivers and non-caregivers. The distribution of income per capita was also relatively even in both groups. Cases with per capita income included in the fourth quartile were the highest, over 27 percent for both. Over 70% of both groups had offline social support, while less than 17% of both groups relied only on online social support. As compared with non-caregivers, caregivers had significantly less emotional (85.26% vs. 89.62%, $p < .10$) and tangible (73.95% vs. 80.25%, $p < .05$) supports. However, more caregivers than non-caregivers used social media for sharing information (16.99% vs. 12.06%, $p < .05$) and were more likely to participate in online forums and groups (10.81% vs. 4.98%, $p < .001$).

Table 1. Profile of caregivers vs. Non-caregivers

Variables		Alz Caregiver (n=264) Freq (%)/ Mean (SD)	Non-caregiver (n=5,517) Freq (%)/ Mean (SD)	sig
<u>Mental Health</u>				
PHQ-4 total score (0:12) ^{a)}		2.05 (2.90)	1.76 (2.71)	+
Little Interest (0:3)		.49 (.84)	.49 (.85)	
Hopeless (0:3)		.46 (.82)	.39 (.75)	
Nervous (0:3)		.57 (.83)	.47 (.78)	+
Worrying (0:3)		.53 (.88)	.42 (.79)	*
<i>PHQ-4 category</i>				
Normal		182 (68.94)	3,993 (74.51)	
Mild		44 (16.67)	849 (15.84)	
Moderate		20 (7.58)	286 (5.34)	
Severe		13 (4.92)	231 (4.31)	
<u>Risk Factors</u>				
<i>Caregiving burden</i>				
Caring hours/wk	Less than 5 hrs	63 (25.10)	NA	
	5-14 hrs	78 (31.08)		
	15-20 hrs	34 (13.55)		
	21-34 hrs	14 (5.58)		
	35 or more hrs	62 (24.70)		
Caring for multiple family members	No, only 1 care recipient	233 (89.27)	NA	
	Yes, 2 or more	28 (10.73)		
<i>Life factors</i>				
Health status	Good or higher	132 (50.00)	2,668 (48.36)	
Income	1 st Quartile (Below 25%)	67 (26.38)	1,375 (25.94)	
	2 nd (25-50%)	57 (22.44)	1,257 (23.72)	
	3 rd (50~75%)	59 (23.23)	1,211 (21.85)	
	4 th (75-100%)	71 (27.95)	1,457 (27.49)	
<u>Preventive Factors</u>				
<i>Offline Social Support</i>				
Having emotional support	Yes	226 (85.26)	4,889 (89.62)	+
Having close people to talk about health	Yes	232 (88.55)	4,896 (89.70)	
Having someone who helps for daily chores	Yes	193 (73.95)	4,373 (80.25)	*

<i>Online Social Support</i>				
Sharing information on social network sites	Yes	44 (16.99)	656 (12.06)	*
Writing an online blog	Yes	8 (3.11)	181 (3.34)	***
Participating in online forum/group	Yes	28 (10.81)	271 (4.98)	***
<u>Demographics</u>				
Age		61.03 (12.74)	56.79 (16.73)	***
	Below 50	41 (15.53)	1,686 (30.56)	
	50-64	120 (45.45)	1,734 (31.43)	
	65+	97 (36.74)	1,939 (35.15)	
Gender	Male	75 (28.41)	2,327 (42.18)	***
	Female	187 (70.83)	3,116 (56.48)	
Marital Status	Married	162 (61.36)	2,769 (50.19)	***
	Living alone	95 (35.98)	2,633 (47.73)	
Race/Ethnicity	White	156 (59.09)	3,193 (57.86)	
	Black	40 (15.15)	676 (12.25)	
	Hispanic	31 (11.74)	727 (13.18)	
	Asian	7 (2.65)	221 (4.01)	
	Others	9 (3.41)	184 (3.34)	
Education	BA or higher	129 (48.86)	2,387 (43.25)	+

Note: ^aScores provided by the original data; *** $p > .001$, ** $p < .01$, * $p < .05$, + $p < .10$

Missing Patterns and Treatment

The majority (79%) of the sample completed the items selected for this analysis (Appendix B). Each variable included in the analysis had missingness ranging from 0.76% to 8.9%. Ethnicity had the highest missingness ($n=21$, 8.9%) followed by caregiving hours ($n=13$, 4.92%) and income ($n=10$, 3.79%). Except for the control variable of ethnicity, the key research variables had less than 5 percent missing. Also, the correlation between data with and without missingness was not significant ($p > .10$). Thus, it is reasonable to judge that, at least, the missing data mechanism was random. Also, given the sample size and the number of study variables included in the analysis models,

the statistical power at an alpha level .5 with moderate effect size ($f^2=.15$) is higher than .95 based on the calculation using G*Power 3.1. Thus, considering the small portion of missingness and random patterns of missingness as well as sufficient power, it was judged that listwise deletion would be appropriate for the analysis.

Differences in mental health status by online and offline social support

The order of overall means of mental health [MH] of caregivers in relation to offline social support [OffSS] or online social support [OnSS] was the following: Having OffSS > Not having OnSS > Having OnSS > Not having OffSS [Table 2]. Thus, caregivers with OffSS had better MH than those who did not have OffSS. In particular, emotional support and having someone to talk with about their health concern (hereafter 'close others') was associated with a statistically significant increase in MH of caregivers. MH of caregivers with emotional support was 10.06~10.31, which is considered normal in a categorical form while the scores of their counterparts were 7.47~7.85, which was considered a lower level of MH. Likewise, caregivers who had 'close others' showed better MH than their counterparts (9.92~10.08, a normal stage of former vs. 8.75~9.17, close to the mild stage of the latter). Unlike OffSS, OnSS was associated with lower MH of caregivers in general. The level of MH of those who did not write blogs or participate in online forums showed normal status in MH (means of blogging: 9.86~9.97; means of forum participation: 10.04~10.11) while those who used blogs or online forum were considered to have mild issues: means of blogging: 7.88~8.91; means of forum participation: 9.86~9.97).

Table 2. Differences in PHQ4 scores in relation to offline and online social support

	Yes			No			Sig.
	n	Mean (SE) ^{a)}	Mean (SE) Weighted ^{b)}	n	Mean (SE) ^{a)}	Mean (SE) Weighted ^{b)}	
<u>Offline SS</u>							
Emotional support	226	10.31 (.16)	10.06 (.32)	36	7.47 (.72)	7.85 (.95)	***
Close Others	232	10.08 (.18)	9.92 (.37)	30	8.75 (.66)	9.17 (.70)	*
Help for chores	193	10.10 (.20)	9.89 (.36)	68	9.49 (.40)	9.61 (.49)	
Mean		10.16	9.96		8.57	8.88	
<u>Online SS</u>							
Sharing posts	44	9.21 (.45)	9.33 (.54)	215	10.06 (.20)	9.95 (.33)	+
Writing blogs	8	7.88 (1.33)	8.91 (4.66)	249	9.97 (.18)	9.86 (.29)	*
Participating forums	28	8.89 (.69)	8.32 (1.56)	231	10.04 (.19)	10.11 (.24)	*
Mean		8.66	8.85		10.02	9.97	

Note: ^{a)} Outcomes without weighting. ^{b)} Data were replicated 100 times weighted with the Jackknife estimate method, whose estimated population size was 18E6.

***p<.001, *p<.05, +p<.10

Hypotheses Test 1: Main Effects

For the regression analysis, four indicators (i.e., emotional support and having a friend to talk about health from OffSS and writing a blog and participating online forum from OnSS) were selected. Variables included in the analysis models showed moderate or low correlations ($r \leq .69$, $p < .05$) (Appendix C). Table 3 presents the results of the ordered logistic regression models using jackknife estimation methods. In the simple stress model [Model 1], caregivers who cared for 21 to 34 hours per week (equivalent to a part-time job) had significantly lower MH as compared with those who cared for their loved ones less than 5 hours per week (OR: .13, 95% CI: .03, .48). As compared with those whose per capita income level was in the first quantile, those who were in the second quantile were likely to have 3.66 times higher MH (OR:3.66, 95% CI: 1.18, 11.35). Good or very good health status was also associated with better MH (OR: 3.88, 95% CI: 1.82, 7.90). Also, proportional odds, one of the important assumptions for the ordered logistic regression, were tested using `omodel` command in Stata. The

proportional distribution of the outcome variables was confirmed in Appendix D, which presents the matrix of chi-square and p-values by models.

In the OffSS models [Model 2], having emotional support tends to increase the odds of having better MH [OR: 11.27, 95%CI: 1.59, 79.69]. Caregiving burden and life stressors still showed a direct association with MH. Caring for 20-35 hours was associated with lower MH [OR: .11, 95% CI: .03, .42], and good health was associated with higher MH [OR: 3.57, 95% CI: 1.64, 7.79]. The OnSS model [Model 3] showed that blogging and forum participation was negatively associated with MH, but the associations were not statistically significant. Finally, Model 4 including both OnSS and OffSS indicated a significant positive impact of emotional support on MH of caregivers [OR: 12.48, 95% CI: 1.64, 94.78] while OnSS did not have a significant association with the MH. Across all models, older age was positively associated with greater MH.

Table 3. Stress Models: Ordered logistics regression models predicting mental health (PHQ4-cat) controlling for demographics using Jackknife estimation methods

	Odds ratio [95% CI]			
	[1] Base model	[2] Offline SS	[3] Online SS	[4] Total SS
Risk Factors				
<u>CG Burden</u>				
Caregiving hour (ref: <5hrs/wk)				
5-14 hrs	.74 [.27, 1.99]	.81 [.29, 2.26]	.69 [.24, 2.00]	.75 [.25, 2.27]
15-20 hrs	.90 [.25, 3.28]	.94 [.26, 3.42]	.92 [.24, 3.54]	.74 [.24, 3.74]
21-34 hrs	.13* [.03, .48]	.11** [.03, .42]	.14** [.03, .54]	.11** [.03, .47]
35 or more hrs	.53 [.18, 1.62]	.52 [.17, 1.61]	.56 [.17, 1.81]	.53 [.16, 1.79]
Multiple care recipients (1=yes)	.96 [.20, 4.62]	1.23 [.25, 6.13]	1.05 [.21, 5.32]	1.36 [.27, 6.74]
<u>Life Stressors</u>				
Income (ref:1st quartile)				
2 nd	3.66* [1.18, 11.35]	2.72 [.81, 9.16]	3.24+ [.95, 10.99]	2.28 [.58, 8.90]
3 rd	2.55 [.88, 7.39]	2.42 [.74, 7.93]	2.41 [.78, 7.45]	2.22 [.61, 8.00]

4 th	2.13 [.75, 6.08]	1.78 [.51, 6.18]	2.06 [.68, 6.24]	1.64 [.41, 6.42]
Good health	3.80*** [1.82, 7.90]	3.57** [1.64, 7.79]	3.94** [1.74, 8.94]	3.75** [1.54, 9.13]
Preventive Factors				
<u>Offline SS</u>				
Emotional SS		11.27* [1.59, 79.69]		12.48* [1.64, 94.78]
Close Others		.14 ⁺ [.02, 1.23]		.13 ⁺ [.01, 1.18]
<u>Online SS</u>				
Writing blogs			.60 [.06, 6.09]	.47 [.04, 5.13]
Participating forums			.49 [.15, 1.58]	.44 [.13, 1.55]
<u>Demographics</u>				
Male	1.15 [.54, 2.44]	1.05 [.45, 2.44]	1.07 [.49, 2.35]	.95 [.40, 2.27]
Age (ref: below 50)				
50-64	3.30* [1.23, 8.79]	4.44** [1.61, 12.22]	3.36* [1.22, 9.30]	4.72** [1.61, 13.84]
65+	3.45* [1.21, 9.80]	4.72** [1.61, 13.88]	3.18* [1.11, 9.11]	4.40** [1.48, 13.08]
College or higher	.71 [.31, 1.64]	.80 [.34, 1.90]	.74 [.30, 1.82]	.86 [.33, 2.22]
Married	1.14 [.52, 2.48]	1.21 [.53, 2.77]	1.19 [.54, 2.62]	1.30 [.56, 3.03]
Ethnic minority	1.41 [.63, 3.12]	1.54 [1.59, 79.69]	1.33 [.60, 2.97]	1.43 [.58, 3.53]
<i>DF</i> , n-1	15, 214	17,214	17, 208	19, 208
F	2.80***	3.11***	2.35***	2.61***
Pseudo R2	.133	.166	.141	.175

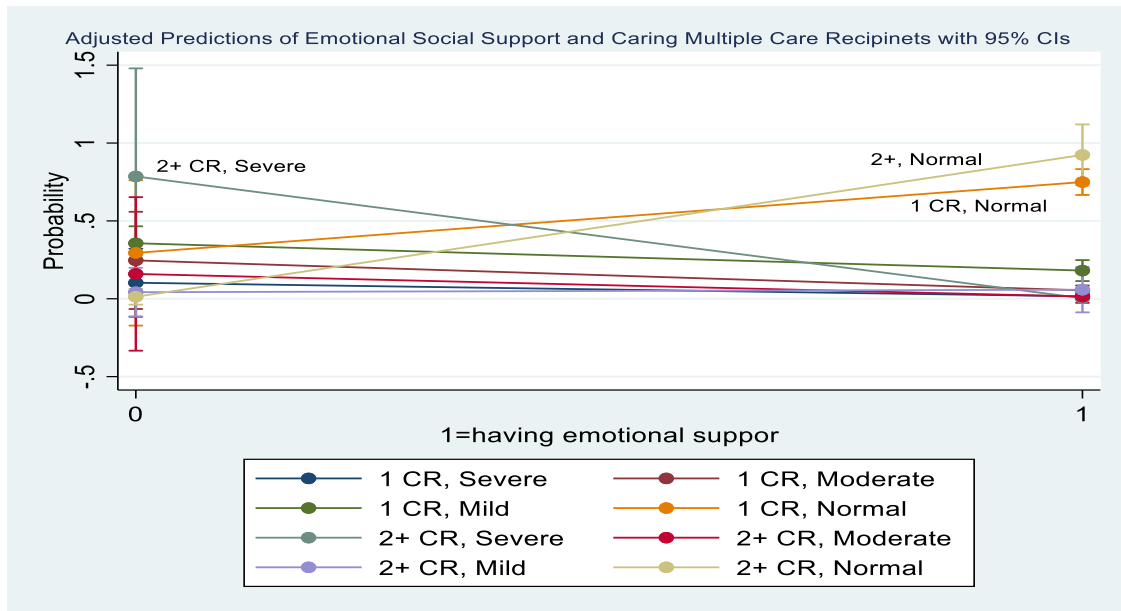
***p>.001, ** p<.01, *p<.05, +p<.10

Hypotheses Test2: Moderation Effects

Overall, the analysis of moderation effects of off- and online social support and stressors on caregivers' psychological well-being was inconclusive. Although the estimates of interaction terms were statistically significant, the odds ratios and standard errors were too large, which would lead to low precision of the estimates. Due to the limitations of the data, it was inevitable to take these potential risks. Thus, we wanted to consider the findings in this section as preliminary and in need of further investigation with larger, generalizable datasets.

The moderation models examined the interactions between OffSS and the components of caregiving burden (Appendix E). For the practical interpretation of the interaction terms, results of the interactions were presented as an adjusted prediction of

being in ‘normal’ range in MH depending on Off- or OnSS and stressors, considering that all of the other variables in the sample were at the mean. When it comes to the interaction between OffSS and stressors, emotional support positively moderated the relationships between having multiple care recipients and caregivers’ MH. As Figure 2 depicts, the moderation effect of emotional support was dramatic for those having multiple care recipients. Without emotional support, the probability of being ‘normal’ in MH for caregivers with multiple care recipients was only 1.28%; however, it reached 92.37% [91.09 percent point (hereafter ‘%p’) increase] when they had emotional support.



Note: CR indicates a care recipient.

Figure 2. Interactions between having multiple care recipients and offline social support on the probability of being psychologically normal in the PHQ4 measure

Unlike hypothesis 2.2., having ‘close others’ negatively interacted with caregiving stress on MH (Figure 3). In all caregiving hour categories, caregivers having ‘close others’ showed lower probability of being in the normal range of MH than those who did not have ‘close others’, given that all other conditions were at means in the sample.

Notably, the chance to be in normal range of MH of caregivers who provided care for between 21-35 hours per week was the lowest (72.46% vs. over 90% among those who did not have ‘close others’; 27.77% vs. over 64% among those who had ‘close others’) regardless of having ‘close others’. However, having ‘close others’ dramatically reduced the prediction of being in the normal range of MH of caregivers who cared for 21-34 hours, showing 44.69%p decreases (72.46%-27.77%) while the gaps in other categories were in 16.73%p~28.24%p.

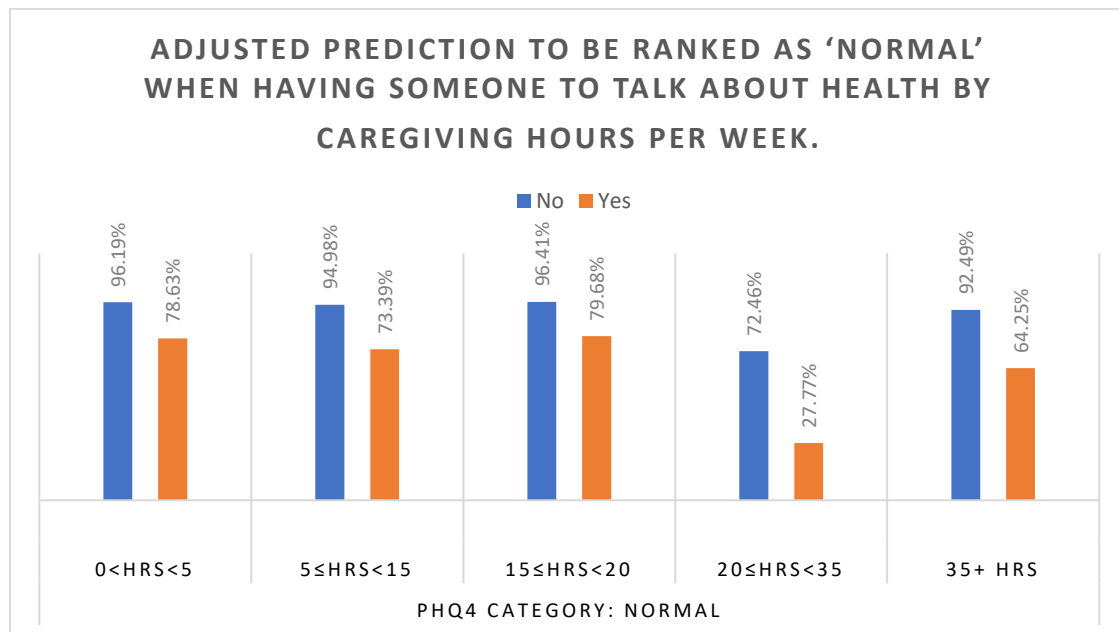
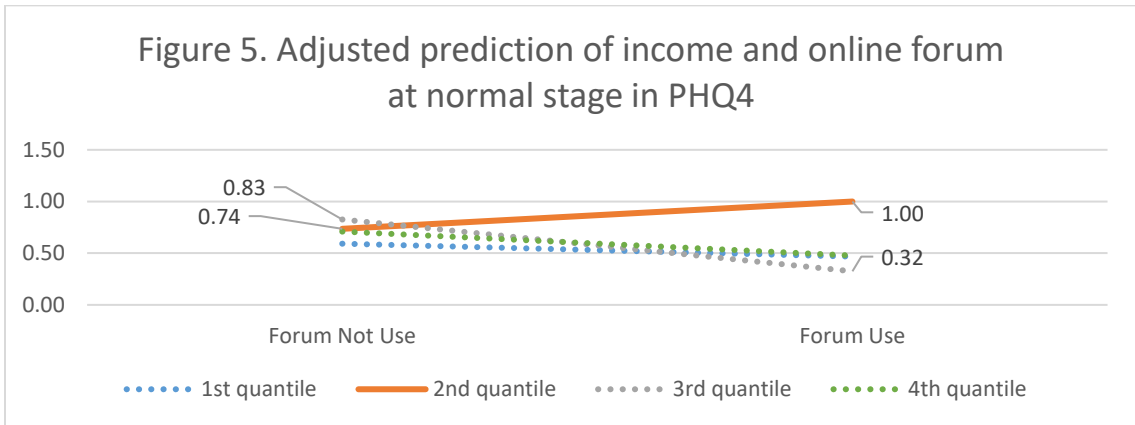
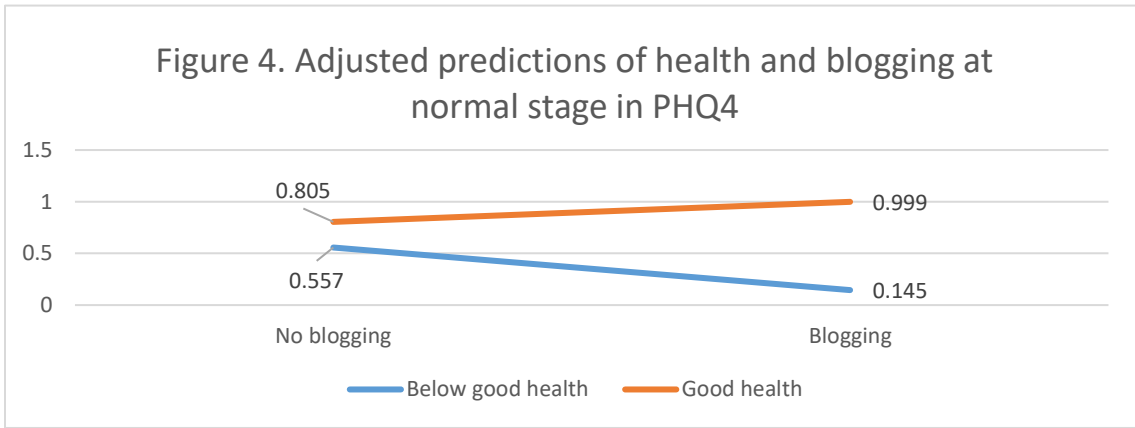


Figure 3. Interactions between caregiving burden (i.e., caregiving hours) and offline social support on the probability of being psychologically normal in the PHQ4 measure

Online social support showed positive and significant interactions with life stressors (Appendix F). Graphs 3 and 4 show the adjusted predictions of online social support and life stressors at the ‘normal’ MH range. Assuming all other conditions are at the mean, writing on an online blog slightly increased the chance to be in a normal range of MH for those with good health status from 80.5% to 99.9%. However, for those who

had a lower health status, blogging decreased the probability of being ‘normal’ dramatically from 55.7% to 14.5% (Figure 4). In the same condition, participating in the online forum increased the chance to be in a normal range of MH only for those whose per capita income falls in the second quantile, indicating 74% to almost 100% while the probabilities of other income categories decreased (Figure 5).



Discussion

This study inquired how offline- [OffSS] and online social support [OnSS] interplay with one another in relationship with mental health [MH] of caregivers of a person with dementia. Three major sets of findings were identified. First, this study found that caregivers who had offline social support were better off in terms of their MH

than those without online support. However, it was better for caregivers' MH to have online support than not having in-person support. Second, OffSS, specifically emotional social support, had a positive and direct association with MH. However, OnSS had a negative but insignificant association with MH. Finally, OffSS interacted with caregiving burden while OnSS interacted with life stressors, and the directions of interactions differed.

Supplemental Roles of Online Social Support

Among caregivers of PWD, networking online supplemented, rather than replaced, OffSS networks. This finding supports findings from previous studies showing that people tend to use social media to communicate with strong ties (e.g., families, close friends) primarily, and their online social support was considered as supplements rather than replacements of OffSS (e.g., Chan, 2015; Kraut & Burke, 2015). These studies concluded that online communication with people considered as weak ties, including colleagues, acquaintance, and strangers, is unlikely to bring the same psychological benefits as OffSS (Chan, 2015; Kraut & Burke, 2015). Likewise, for caregivers of PWD, Meyer and colleagues (2019) reported that online-based service from a social service agency was used as a supplement to offline service.

Direct Effects of Social Support

As hypothesized, emotional support was a significant factor that directly helped caregivers to have better MH. Social support delivered through online social media, however, had a negative yet insignificant association with MH. Given a series of studies that are primarily from computer informatics and communication disciplines reported a positive role of OnSS for mental health (e.g., Cole, Nick, Zelkowitz, Roeder, & Spinelli,

2017), this finding is somewhat surprising. Why is the finding of this study incongruent with the majority of previous studies? One possible reason could be the difference in the study population and target outcomes. Most previous studies targeted college students or youths focusing on different aspects of psychological well-being, such as bullying, victimization, self-esteem, or depressive thoughts (e.g., Bessière et al., 2008). Adding to life stressors, it is well known that caregivers have caring-related stress, which is more likely associated with exacerbated physical, mental, and psychological well-being (e.g., Cohen & Wills, 1985). The level of available social support is was also lower for caregivers than non-caregivers, as Table 1 showed.

The question remains why did OnSS in this study, which was represented as a blog and online forum, not have a significant association with MH of caregivers? The benefits of online communication can be achieved when users communicate with people with whom they are also communicating offline (Ellison, Steinfield, & Lampe, 2011; Pew Research Institute, 2006). Writing online to non-unanimous others is less powerful to maintain relationships as compared with direct online communication, such as email and direct messaging, which is considered as a strong relationship-maintaining behavior (Burke et al., 2011). Blogging and writing in online forums are considered as networking with anonymous others rather than with those who have a connection offline, which is considered less intimate relationship-maintaining social behavior. There would be substantial chances of miscommunication without enough understanding of the person, giving and receiving unexpected – often negative-- feedback from unknown others. Thus, these activities would not bring a similar outcome of OffSS, which is based on an already established strong relationship.

Moderation Effects of Social Support

Although generalizing this study's results should be done with caution due to the limitations of the sample, we found impressive results that OffSS and OnSS interacted with caregiving and life stressors, respectively. More importantly, caregivers who are in the less favorable condition, such as having multiple care recipients, working part-time while caring for a family member with cognitive disease, being unhealthy, and living with economic hardship, tended to be significantly affected by OnSS. Unfortunately, there are sparse theories and evidence that clearly explain why OffSS interacts with caregiving stress while OnSS interacted with life stress in terms of MH. Some scholars who support buffering effects of social support believe that a good match between the content of support and the needs of a support recipient is key to increasing the effectiveness of social support (Knack, Waldrup, & Jesen-Campbell, 2007). Based on this view, a possible explanation is that caregiving stress tends to require micro but practical solutions along with emotional support, which can be provided within close ties, like assisting with caregiving duties. On the other hand, health or income is a more fundamental or systematic stressor, which is not curable at once and, oftentimes, needs massive efforts, information, knowledge, time, and resources to move to a better status. As social network theory suggested (Coleman, 1988), resources gathered through weak ties embedded in the online social network would benefit the specific needs in order to get more opportunities or information.

Confirming previous findings of buffering effects of social support (e.g., Cohen & Wills, 1985; Cole et al., 2017), emotional support made a dramatic change in the MH of caregivers when they have multiple care recipients. Unlike the hypothesis, however,

having close informal informants who can discuss health concerns ('close others') was negatively associated with the probability of being in a normal range of MH, especially among those who provide care for 25-35 hours per week. Why did the caregivers in this band show a significant reduction in the chance to be in the normal range in their MH? A possible explanation is the following. In the sample, over two-thirds of caregivers are below 65 years old, and it is likely that many have other roles, such as jobs or caring for other family members—we can call them 'working caregivers.' These working caregivers would help their care recipient as a primary caregiver while they also manage another major role. Young adult caregivers tend to feel more stress than older ones because of concerns about losing opportunities at work and in their career, sacrificing time for social activities and leisure, and taking on the economic burden for the medical costs for their loved ones (Buehler & Lee, 1992). Consequently, managing dual roles contributes to role conflicts, and would increase psychological distress and lower their quality of life. As our results show, being a 'working caregiver' itself lowers MH. Also, working caregivers may have less time to devote to seeking support online. Thus, due to the serious unmet needs, they would be more likely to seek help in their close network, such as 'close others,' but the inputs from online support, which is more likely to be informal support groups in this study context, would not be adequate enough to fulfill the ample unmet needs of working caregivers.

Likewise, writing a blog has a negative interaction with bad or worse health status to enhance MH, whereas it positively interacted with good or higher health status. Cassel (1976) argued that absence or confusion in feedback from one's social networks would lead to negative physical outcomes. Applying Cassel (1976)'s perspective, it is

conceivable that caregivers having significant needs for health information for taking care of their own health as well might have higher stress and worse psychological well-being than those in better health. They would be more likely to actively seek help and health information online. However, if the quality, accuracy, or consistency of the feedback and information they receive from these online social networks did not help to solve their concerns, they may be left in the lower MH status.

Caregivers in the second income quantile (25-50%), who were considered as living in near poverty and low socioeconomic condition, benefitted from online forums to have better MH. This finding corresponds to Cole and colleagues' (2017) findings that people without enough offline social support tend to benefit more from online social support while it is redundant for those who already have sufficient offline social support. In general, online forums provide a democratic environment for all users. Thus, it is likely that these caregivers who may have less chance to discuss or sometimes argue with others or to access information with less restriction in the real-world would experience a release of stress by anonymously sharing their concerns, sense of being understood by others without bias, or feeling of freedom in a magnanimous online world. Thus, although online social support, especially forum participation, would not bring the tangible solutions to solve economic concerns of caregivers at financial risk, the online community may provide a safe place to release stress and enhance MH.

Implications

Practitioners working with family caregivers of PWD can consider incorporating the Internet and social media component into their practice to assist this population enhancing their well-being as well as achieving mastery in caregiving. For example, in

the caregiver training or peer support group, a series of sessions can be offered that deal with enhancing online communication skills and attitudes for giving and receiving proper and positive feedback including ways to prevent receiving offensive feedback, self-checking about the level of reliance of social media, ability to appraise the quality of information provided through social networking websites, and skills for using devices, social media platforms, and software to be in virtual contact with their support groups, including family members, friends, neighbors, healthcare providers, and service agencies. Also, it should be highlighted that online support is supplemental to face-to-face support. Intentional efforts are needed to incorporate caregivers' OffSS into OnSS to maximize the potential of all social support resources available to a caregiver.

Given caregivers who are in less favorable conditions have more benefits of the online community, social workers need to consider strategies for developing and designing online services and programs which can be more accessible to this population. Most of all, caregivers with health issues and those with low income should be helped to access appropriate and continuous online resources and support. Providing this segment of caregivers with proper technological devices, encouraging them to use the devices strategically, and developing user-friendly online platforms, which is characterized as easily accessible and intuitive design, would be helpful. Cassel (1976) highlighted the importance of consistent communication and feedback, along with practical support. Thus, along with careful moderation in the online community, practitioners need to provide continuous updates of evidence-based information that would be helpful as well.

Limitations

Although the original HINTS data used a rigorous sampling method, the subsample of caregivers of PWD may have some drawbacks. The small sample size with a substantial portion of missingness in study variables would yield inaccurate and less efficient estimation which could increase bias in the interaction terms. We applied jackknife estimation, one of the resampling methods, to minimize sampling error that aims to estimate from the sample close to it from the population (Cameron & Trivedi, 2005; 2010). Nevertheless, there remains a possible bias due to the relatively small sample. Thus, the results needed to be interpreted cautiously. The findings of this study should be tested with a larger sample to confirm the generalizability of the results.

Since we used secondary data that was designed and collected for different research purposes, the conceptual drawbacks of social support remain. The HINTS dataset does not include in-depth information regarding online and offline social support and online support behaviors (e.g., to whom and how often a participant contacted others using which social media methods) based on theories. More comprehensive models with theory-driven measures are needed that include promising influences on caregivers' well-being and accurate and compatible measurements of online and face-to-face social support.

Despite these limitations, the findings of this study can contribute to the knowledge base of social support by adding evidence of complicated mechanisms of the association of online and offline social support, which were positive or negative according to the types of stress.

Conclusion

The current study presents evidence of the effects of online and offline social support mediating the association of stressors and psychological well-being of caregivers of PWD. Despite some positive emotional rewards, caregiving is stressful work. Along with the elongated life expectancy of people in the recent era, caregiving has become an imputable and natural stage that most families experience in their middle and late life aged developmental stages. Thus, practitioners working with caregiving families, policymakers, and researchers need to assist family members in the caregiving stage to make the period meaningful, lessen the challenges, and help caregivers reenter their normal life after completing the caregiving process. It is no doubt that technology has made breakthroughs to help those affected by Alzheimer's and related dementia and their family caregivers. This study suggests developing a practical approach of using an online social network to address the emotional well-being of caregivers of PWD harmonizing with caregivers' existing social support.

CHAPTER FOUR

Alzheimer's Caregivers' Experience with and Perceptions of the *Affordable Care Act*:

Thematic Analysis of Online Discussion Forums

In 2018 an estimated 5.6 million older adults in the United States lived with Alzheimer's disease or other types of dementia (Alzheimer's Association, 2019). The absolute number of people with dementia (PWD) has continuously increased over time and is expected to double by 2060 (Matthews et al., 2018). These estimations include only people in the late stages of dementia who have a clinical diagnosis. If those in the preclinical and mild cognitive impairment (MCI) stages were included, the number increases exponentially (Alzheimer's Association, 2019). Nearly 80 percent of PWD are cared for in the community by family members. More than 16 million Americans provide care for their family members living with dementia (Alzheimer's Association, 2019). By delaying transfer of their family members with dementia to assisted living or long-term care facilities, family caregivers contribute an estimated \$233.9 billion (Alzheimer's Association, 2019) to \$470 billion (Reinhard, Feinberg, Choula, & Houser, 2015) annually to society, ultimately shielding government budgets from astronomical long-term care expenses.

Background

Health and Financial Challenges of Caregivers of Persons with Dementia

Studies have consistently identified significant and diverse unmet needs relating to caregivers' health and financial well-being (e.g., Gilhooly et al., 2016). Many caregivers are at risk of depression and mental health issues and experience symptoms such as fatigue, anxiety, insomnia, or dysphoria--particularly as the care recipient's

cognitive ability worsens (e.g., Dassel, Carr & Vitaliano, 2015). Physiologically adverse changes due to chronic stress among caregivers bring about various physical consequences, such as decreased immune system functioning (e.g., Kiecolt-Glaser, Glaser, Gravenstein, Malarkey, & Sheridan, 1996), higher chances of cardiovascular disease and kidney problems (e.g., Gouin, Glaser, Malarkey, Beversdorf & Kiecolt-Glaser, 2012; Mausbach et al., 2010), and increased hypertensive blood pressure (Shaw et al, 1999). Fonareva and Oken (2014) concluded that the long-term stress endured by caregivers of PWD increases their susceptibility to disease increasing their health problems.

Economic hardships of caregivers of PWD include the loss of a job or cutbacks in work hours as well as increasing out-of-pocket expenses for their family members' health care. According to a national Alzheimer's Association survey, caregiving families of PWD reported that due to their caregiving responsibilities, they had to reduce their work hours (27 percent), resign from or lose a job (16 percent), retire early (13 percent), or take a different job (11 percent) (Alzheimer's Association, 2016). According to a 2014 national survey, approximately 41% of caregivers of PWD have annual incomes below the U.S. median household income (i.e., \$50,000 vs. \$53,657). Decreased employment led to household income loss for 35 percent of family caregivers of PWD, which may leave them in or near poverty (Alzheimer's Association, 2019).

Along with reduced family income, medical expenditure for PWD comprises a considerable portion of caregivers' financial burden. Medicare does not cover the high price of prescription drugs and long-term care (Riggs, 2003) unless recipients pay an extra monthly premium to purchase Medicare Part D or private long-term care insurance.

A series of studies reported higher medical costs of caregivers for the health care of PWD compared with other types of caregivers or non-caregivers (e.g., Geldmacher et al., 2013; Lin, Zhong, Fillit, Chen & Neumann, 2016). For example, using nationally representative retrospective cohort data from 2005 to 2010, a study estimated total medical costs for PWD, including Medicare, Medicaid, private health insurance, and out-of-pocket costs (Kelley, McGarry, Gorges, & Skinner, 2015). This study found that the average costs for caring for PWD, nearly \$290,000, was about 1.7 times higher than the costs for those with other diseases (Kelley et al., 2015). Analyses of medical spending before and after the diagnosis of dementia and in comparison to non-dementia patients revealed that the costs for PWD were nearly 1.4 times higher for Medicare (Lin et al., 2016) and 1.6 times greater for Medicaid (Geldmacher et al., 2013).

ACA as a Potential Solution to Relieve Caregivers' Health and Financial Burdens

Provisions and Regulations of the ACA

The Patient Protection and Affordable Care Act (ACA) is a groundbreaking federal policy that aims to provide quality and affordable health care for all U.S. citizens. At the federal level, the ACA expanded Medicaid eligibility to citizens below age 65 and those with adjusted gross incomes below 138 percent of the federal poverty level (FPL). Establishing an online Marketplace, the ACA provides premium tax credits for the purchase of private health insurance through the marketplace for families with incomes up to 400% of the FPL. It also regulated the preexisting condition exclusions and established annual limits on out-of-pocket costs for the purchase of insurance plans from the Marketplace. In addition, Medicare enrollees were enabled to access preventive

services through zero-cost sharing that was suggested by the ACA aiming to close the “Donut Hole” in Medicare Part D (Prindiville, 2019).

Cooperating with state governments, the ACA streamlined the application process to relevant programs such as Medicaid and Children’s Health Insurance Program (CHIP) by requiring one application form. States that accepted the Medicaid expansion option improved at-home services through the Community First Choice Options program that provides services to assist with daily activities of older adults and people living with disabilities (Prindiville, 2019).

The ACA has the potential to assist with the unmet health and financial needs of family caregivers through those provisions and regulations. Adding to the economic hardship that was discussed above, a majority of caregivers of PWD are middle or older aged family members caring for parents or a spouse, and are at high risk of physical and mental health problems yet seldom see a doctor (Alzheimer’s Association, 2019).

Considering such social and demographic characteristics of caregivers, the policies of the ACA through Medicaid, Medicare, and the Marketplace are a significant avenue for caregivers to access proper health services and save on medical costs of both their family member with dementia and their caregivers.

Accomplishments of the ACA

Since the ACA was passed in 2011, the number of uninsured persons across the states significantly decreased from 46.5 million in 2010 (17.8%) to 26.7 million in 2016 (10.0%) (Kaiser Family Foundation, 2017). Since then, it was estimated that nearly 20 million people were covered by the ACA across the nation, nearly 11.1 million purchased health insurance plans through Marketplaces, and 85 percent received subsidies (e.g.,

Gallagher, Gopalan & Grinstein-Weiss, 2019). States that expanded Medicaid eligibility showed an increase in coverage rates of health insurance (e.g., Barnett & Berchick, 2017; Decker, Lipton & Sommers, 2017). People enrolled in Medicaid in those states used more health care services (e.g., Cole, Wright, Wilson, Galárraga & Trivedi, 2018; U.S. Government Accountability Office, 2018) and prescription drugs (e.g., Ghosh, Simon & Sommers, 2017) than those in the states that did not opt-in to the Medicaid expansion option. Also, low-income people living in Medicaid expansion states were less likely to have out-of-pocket expenses than those in non-expansion states (Blavin, Karpman, Kenney & Sommers, 2018) and were more likely to save (Gallagher, 2018). However, despite the large-scale actions across the states, nearly four million individuals with poverty-level incomes remain uninsured (Garfield, Damico, Stephens & Rouhani, 2014). One of the reasons for the limited coverage rate is the state-to-state variations in eligibility and coverage. Some states opt out of the program or conditionally expanded their Medicaid programs, so many people who were expected to be eligible did not realize the benefit of health care reform (Garfield et al., 2014).

Barriers to Understanding Caregivers' Policy-related Experiences

Since health care reform was implemented, family caregivers of PWD are one group that could potentially benefit from the ACA. However, limited studies have focused on caregivers' experiences in relation to the ACA. Many studies reported challenges in recruiting family caregivers to learn about their opinions (e.g., Szabo, Whitlatch, Orsulic-Jeras & Johnson, 2018). Barriers may include the weak identity of being a caregiver (Levitsky, 2014; Lloyd & Stirling, 2011), lack of time due to multiple caregiving demands, or unwillingness to share their difficulties publicly (e.g.,

Shatenstein, Kergoat, & Reid, 2008; Szabo, et al., 2018). The process of becoming a caregiver is transitional, so having a caregiver identity from a previous role (e.g., spouse, son, or daughter) to a caregiver may not happen at once (Talley & Montgomery, 2012). Thus, caregivers may not be easily distinguished from the general public. Even though they view themselves as a caregiver, many caregivers cannot spare the time due to their intense and complex caring duties, which includes managing different health conditions of their loved ones and managing daily activities and behavior issues (Reinhard et al., 2019). Although they may encounter challenges with the health care system and policies, caregivers may not put their priority on discussing and actively solving policy-related issues over other at-hand daily caring tasks related to the PWD's health and wellness. Moreover, at the state level, reluctance to collect and analyze data from caregivers to uncover the unmet needs of this population (Meyer, Rath, Gassoumis, Kaiser & Wilber, 2019) serves as a barrier to understanding caregivers' opinions and experiences. Existing support programs tend to focus on education and training of caregivers to enhance caregiving skills and manage psychological stress. Thus, there have been limited opportunities for family caregivers to share their voices about their experience with health care systems and policies.

A small group of studies documents the difficulties family caregivers face in accessing larger systems, such as social services or health care systems (e.g., Neville, Beattie, Fielding, & MacAndrew, 2015; Phillipson, Jones & Magee, 2014). Based on narratives shared by family members of persons with chronic brain issues, Fins (2013) documented the ongoing struggles caregivers face in navigating health care systems and reimbursement schemes designed for acute care patients. To explain the underutilization

of social services developed for caregivers, Levitsky (2014) conducted qualitative research with caregivers as well as social service providers and identified socially structured beliefs among caregivers regarding providing care for their loved ones as their primary responsibility. Levitsky (2014) argues that this belief was shaped by laws and policies and prevents caregivers from seeking institutional assistance.

Benefits of Using Online-based Communication Data

Social media is increasingly used in social science research as a powerful platform for understanding emerging societal trends (Szabo, Polatkan, Boykin, & Chalkiopoulos, 2018). Likewise, caregivers have been increasingly turning to online social media to meet their need for information and emotional support (Nikzad-Terhune, Anderson & Bey, 2015). An online discussion forum is one of the most popular platforms through which caregivers can interact with each other. Nationally, about 80 percent of caregivers have used online resources, with the majority seeking health information (Fox & Brenner, 2012). Among caregivers of PWD, around 59% were identified as health-related Internet users, according to a 2009 study by the National Alliance for Caregiving and the American Association of Retired Persons (Kim, 2015).

Communication is a critical tool to support caregivers' advocacy for care recipients. Caregivers may seek out health information from health care professionals and service providers as well as peer caregivers. They also communicate with their care recipient and other family members to provide a more therapeutic environment for care recipients (Wittenberg-Lyles, Goldsmith & Shaunfield, 2015). Online social media provides a venue for caregivers to communicate in an open, secure, and empathetic environment while helping them maintain anonymity and flexibility in time and place

(Tanis, Das & Fortgens-Sillmann, 2011). With such advantages provided by online social media, caregivers can expand the routes to communicate with professionals and peers for seeking help not only for their care recipients but also for themselves. Caregivers are more likely than non-caregivers to read others' posts on social media to access information about health management and caregiving (Fox & Brenner, 2012). A randomized control experiment found that greater participation in online communication is associated with reduced stress of caregivers of PWD with an initially high level of stress (Bass, McClendon, Brennan & McCarthy, 1998). Another qualitative study found that online communication fills the gaps in traditional modes of communication between caregivers, health service providers, and other family members (Piraino, Byrne, Heckman & Stolee, 2017). Considering that online social media use among caregivers of PWD is increasing, analyzing online communication data could be a useful way to identify the unmet needs of this population. Analyzing social media can provide a rich and contextualized understanding of the meaning and experiences that are socially constructed and individually perceived.

Research Questions

It is essential for health care providers and health policymakers who are responsible for planning efficient service delivery systems to know how service users perceive and use the services. However, there is limited understanding about caregivers' experiences within the complex health care system, especially after the significant policy changes brought about by the ACA. Although the ACA has significant potential to improve family caregivers' health and well-being, to our knowledge, no study has explored caregivers' experiences with and perceptions of the ACA. With the growing

popularity of online social media among caregivers of PWD, this rich yet unstructured source of data is a practical alternative for gaining insight into caregivers' views during the period of ACA implementation. In response to the research gap, this study explored caregivers' perceptions of and experiences with the ACA using online forum discussions from a nationally representative Alzheimer's online community. The guiding research questions were: (1) How do caregivers view the ACA as revealed by the content and tone of their online posts? and (2) How do caregivers experience the ACA in various caregiving contexts? This study aimed to provide insights into future research by illuminating family caregivers' experience with health care programs and to offer actionable information for policy development relating to family caregivers of PWD.

Research Design and Methods

Data Collection and Preparation

Data for this study was downloaded from ALZConnected®, a publicly open online community for people living with Alzheimer's disease and their families. We obtained permission from the Alzheimer's Association and from the Indiana University Institutional Review Board to use this online forum as a data source. Participants in this forum were self-identified family caregivers of those living with Alzheimer's or other dementia. Participants, most of whom use pseudonyms, voluntarily contributed by posting and reacting to previous posts (i.e., threads), which can be publicly seen. The "main post" refers to the initial post that leads a discussion, and "thread" refers to a reply following the main post and any accompanying threads (Figure 6). Since we were interested in caregivers' perceptions about the ACA, we strategically filtered data using the keywords: Affordable Care Act, ACA, Obama Care, Obamacare, and health policy.

The main posts and threads containing any of these words were included in the sample. The posts and threads we identified were generated by family caregivers from 2011 to 2017. The sample was collected in November 2017.

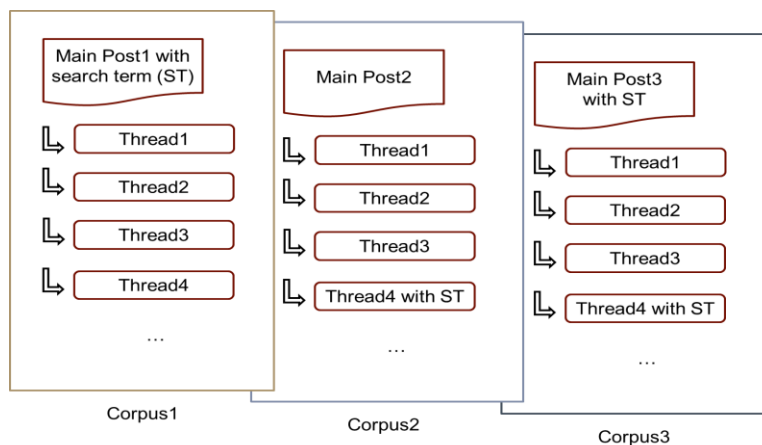


Figure 6. Structure of analyzed data

A search tool embedded in the forum webpage was used for the initial filtering, and selected data were saved as text-format. Since the analysis unit was an individual post rather than a participant, the research team imposed a unique identification number on each post and thread. The IDs presented in this paper are a combination of the search term, year posted, and ID# of a leading post (e.g., ACA-2015-001). A combination of data management and analysis tools, including Dedoose, an online platform for mixed methods research; NVivo12, a qualitative research software; and Excel spreadsheets were used to structure and analyze the data in both numerical and text formats and then to identify patterns and narrative themes.

Data Analysis Strategy

A mixed-method approach was used for analysis. First, descriptive statistics were used to identify the characteristics and tones of the posts and attitudes of caregivers

toward the ACA. Next, text-mining thematic analysis was used to uncover the emerging themes and to navigate the patterns of the links between the themes. Text mining is a computer-oriented analysis method used to structure a significant amount of narrative or unstructured data to identify patterns or themes (Wiedemann & Wiedemann, 2016).

Thematic analysis (TA) is a qualitative analysis method aimed at identifying patterns of text data and interpreting the aspects of research topics without specific theory or epistemology (Braun & Clarke, 2006).

Using computer-assisted coding and analysis, we created a text tree and word cloud to identify the initial patterns from the explicitly appearing meanings (i.e., analysis at the semantic level) (Braun & Clarke, 2006). Next, we identified themes and labeled the underlying connections following the six stages suggested by Braun and Clarke (2006): (a) familiarizing oneself with the data, (b) generating initial codes, (c) searching for themes, (d) reviewing themes, (e) defining themes, and (f) producing the report. Initially, we read the overall posts and threads (thereafter ‘posts’) repeatedly and actively to understand the context of each discussion, and then focused on posts that contained the search terms to identify how the key terms were mentioned in which contexts. Next, one researcher manually coded each quote in the posts to organize the data into meaningful groups and categories, and then extracted codes and tagged names to generate data-driven initial themes. The second researcher reviewed the codes and schemes developed by the first researcher. Using an iterative coding and recoding process between stages (c) and (e), we extracted the emerging key themes and sub-themes and the relationships among them across the data. Additionally, we manually developed thematic maps with refined

labels which visually represented the relationships among the themes. Each theme is illustrated with excerpts of caregiver posts.

The primary tone and purpose of each post were identified based on the judgment of the researchers. Posts that were primarily encouragement or consolation or that expressed positive emotions or experiences were coded as positive; those that contained caregiving information, tips, and resources were coded as neutral; and those that expressed concerns, complaints, critiques, and challenging a certain topic in a heated manner, or shared adverse experiences were coded as negative. For the posts that contained multiple tones and/or purposes, the authors re-reviewed them to seek the most dominant purpose and tone of the post. Using the same criteria, attitudes toward the ACA were coded separately. Discrepancies in the coding were discussed until an agreement was reached.

Data Description

Of the initial 739 posts identified, 225 were duplicates, which referred to the posts or threads that appeared multiple times (e.g., when a post includes ‘ACA’ and ‘Obama Care’ together, it was captured twice.)[Table 4]. In this case, we eliminated one of them. After omitting duplicates, 514 posts/threads that were posted by 209 forum participants were included in the analysis sample. Fifty posts included the exact search terms.

Table 4. Sample posts characteristics

	Post/threads with duplicates (n)	Posts/threads without duplicates (n)	Discussants (n)	Posts/threads containing search terms (n)
Affordable Care Act	176	101	65	11
ACA	132	132	37	11
Obama Care	95	95	30	10
Obamacare	253	138	58	14
Health policy	83	48	19	4
Total	739	514	209	50

Characteristics of the analysis sample are depicted in Table 5. In addition to the total sample (TS, n=514), we generated a subsample by selecting posts and threads that contained the exact search terms ('ACA sample'(AS), n=50). The TS helps us to understand the background or context in which the ACA appeared in the discussions, while the AS enables us to identify caregivers' specific attitudes toward the ACA. In the TS, 209 caregivers generated 514 posts with an average of 2.65 posts per participant (SD=3.74). In the AS, 20 caregivers posted 50 posts with an average of 4.15 posts per participant (SD=5.02). Around half of the discussions in TS were concentrated in 2012 (n=122, 23.8%) and 2015 (n=128, 25%) while the AS posts tended to be posted in 2012 (n=10, 20%) and 2017 (n=14, 28%). In both samples, most posts shared some aspect of caregiving experiences (TS: n=243, 47.3%; AS: n=19, 38.0%), expressed concerns or complaints (TS: n=77, 15.0%; AS: n=13, 26.0%), or provided information or caregiving tips (TS: n=69, 13.40%; AS: n=7, 14.0%). Most caregivers reported the PWD was a parent (TS: n=81, 68.1%; AS: n=7, 43.8%). A subgroup of caregivers reported that they cared for two or more family members who need significant assistance comprising 11% (n=13) in TS and 25% (n=4) in AS.

Table 5. Sample posts and participants' demographic characteristics

	Total sample (n ^a =514)		ACA sample (n ^a =50)	
	Freq.	%	Freq.	%
<u>Year</u>				
2012	122	(23.8)	10	(20.0)
2013	76	(14.8)	8	(16.0)
2014	5	(1.0)	1	(2.0)
2015	128	(25.0)	9	(18.0)
2016	87	(17.0)	8	(16.0)
2017	95	(18.5)	14	(28.0)
<u>Primary purpose of posting</u>				
Reply/Sharing experience	243	(47.3)	19	(38.0)
Concern/Complain	77	(15.0)	13	(26.0)
Information	69	(13.4)	7	(14.0)
Encouraging/Comforting	44	(8.6)	-	-
Argument	40	(7.8)	6	(12.0)
Asking for help/Asking questions	37	(7.2)	5	(10.0)
Others	4	(0.8)	-	-
	(n ^b =209)		(n ^b =20)	
	Mean/Freq	SD/%	Mean/Freq	SD/%
Posts per participant	2.65	(3.74)	4.15	(5.02)
Participants that identified the relationship with PWD	119	(56.9)	16	(80.0)
Participants that did NOT identify the relationship with PWD	90	(43.1)	4	(20.0)
<u>Relation with Caregiver</u>				
Parent	81	(68.1)	7	(43.8)
Mother	59	(49.6)	6	(37.5)
Father	13	(10.9)	-	-
Mother-in-law	7	(5.9)	1	(6.3)
Father-in-law	2	(1.7)	-	-
Spouse	18	(15.1)	4	(25.0)
Wife	7	(5.9)	2	(12.5)
Husband	11	(9.2)	2	(12.5)
Grandparent	4	(3.4)	1	(6.3)
Grandmother	2	(1.7)	-	-
Grandfather	1	(0.8)	-	-
Grandmother-in-law	1	(0.8)	1	(6.3)
Self	2	(1.7)	-	-
Sibling	1	(0.8)	-	-
Multiple Care Recipients	13	(10.9)	4	(25.0)
Both parents	9	(7.6)	3	(18.8)
Others ^c	4	(2.0)	1	(6.3)

Note: ^a number of posts and threads; ^b number of participants; ^c Others include: (a) father + husband, (b) grandmother + mother, and (c) mother-in-law + husband

Results

Tones of the ACA Posts and Health Care System Discussions

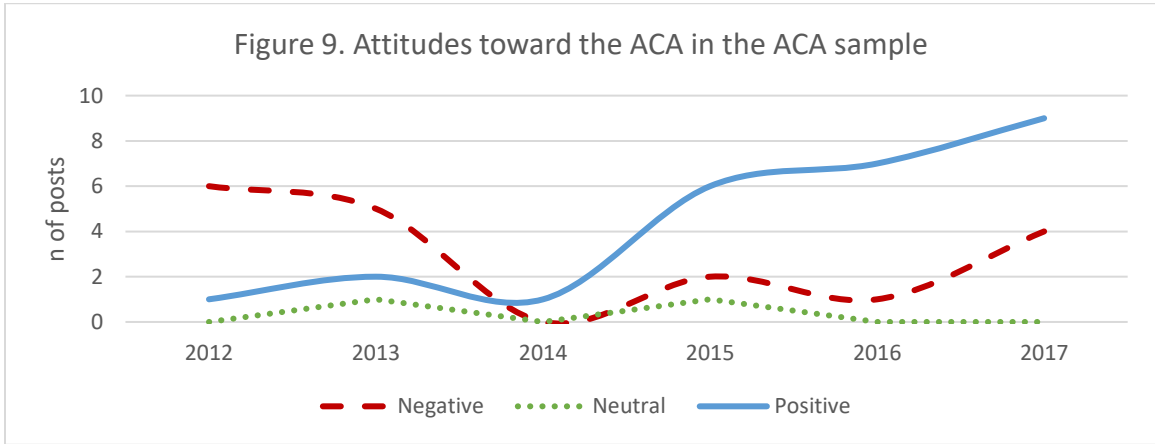
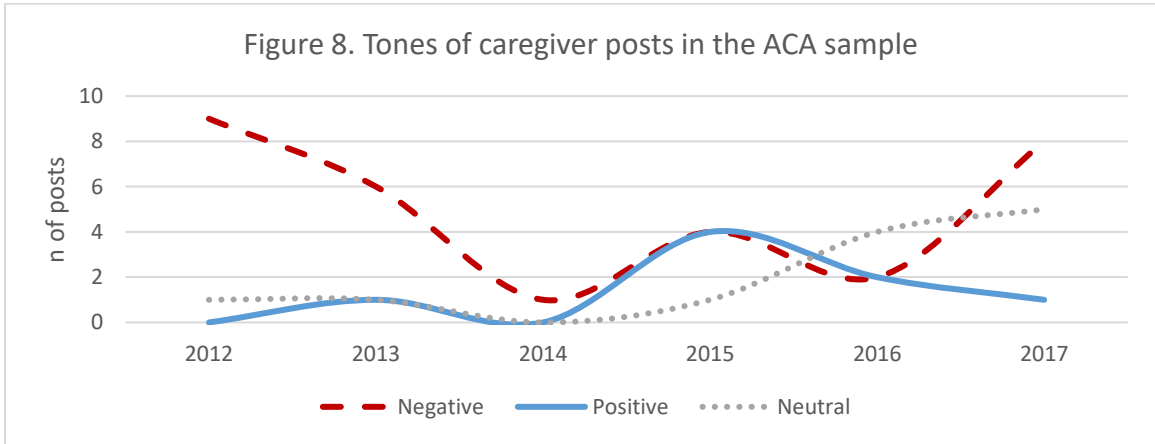
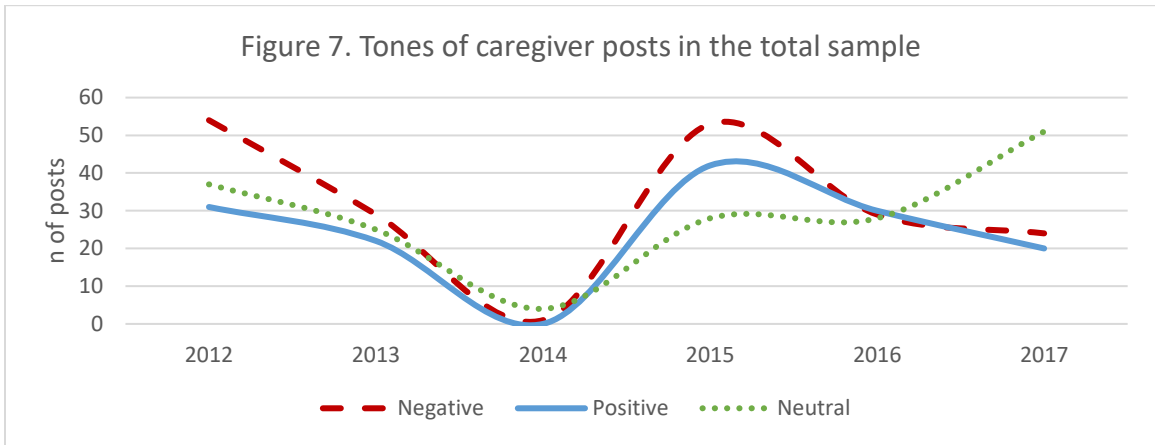
Table 6 presents the type and frequency of each tone in posts mentioning the ACA. The three tones were relatively evenly distributed in the total sample (TS), although the proportion of negatively slanted posts (n=190, 37.2%) was slightly higher. In the ACA sample (AS), the proportion of posts with a negative tone was 60% while only 16% had had a positive tone. Over half of posts revealing caregivers' attitudes toward the ACA had a positive tone (n=26, 52.0%).

Table 6. Tones of caregiver posts revealing attitudes toward the ACA

	Overall Tones of the posts				Attitudes toward the ACA	
	Total sample (n=514)		ACA sample (n=50)		ACA sample (n=50)	
	Freq.	%	Freq.	%	Freq.	%
Positive	145	(28.4)	8	(16.0)	26	(52.0)
Neutral	176	(34.4)	12	(24.0)	2	(4.0)
Negative	190	(37.2)	30	(60.0)	18	(36.0)

Figures 7-9 show changes over time in tones of the posts and attitudes toward the ACA. In the TS, a negative tone that implies concerns, complaints, or critiques was dominant in 2012-2013 and 2015, while posts with a neutral tone that purported to deliver factual information, resources, or tips for caregiving continuously increased since 2014 (Figure 7). Although the increasing pattern of neutral posts was observed in the AS as well, the direction of the negative tone in 2017 was different (Figure 8). After 2016, the presidential election year, negative posts sharply increased. Similarly, negative attitudes toward the ACA were predominant in 2012-2013, largely decreased from 2013 after the federal government and some states launched exchanges, but suddenly increased in 2017

(Figure 9). Positive attitudes toward the ACA continuously increased throughout the timeframe of the study.



Context, Perception of, and Experience with the ACA and the Health Care System

Theme 1: Concern about placement decisions and care expenses for PWD

Caregivers face insurmountable expenses related to the cost of long-term care facilities especially in the transition phase. This financial concern commonly appeared in relation to gaining eligibility for Medicaid to cover the expense of a long-term care facility or hospice. Caregivers noted the lack of coverage offered through Medicare, which was linked to various criticisms of the nursing home industry and insurance companies [excerpts (a) and (b)]:

(a) ... the nursing home was so greedy. They didn't tell me that my dad qualified for hospice and that I could nurse him at home. (ACA-2013-050)

(b) ... Medi-Gap insurance does NOT pay either as they will only pay a portion of what Medicare does. No Medicare coverage; no Medi-Gap coverage. (ACA-2016-120)

The ACA was discussed along with in-home care services and Medicaid as both a barrier and a benefit. Initially, caregivers tended to perceive the ACA as an unpromising policy that prevented their PWD from getting Medicaid benefits, which was crucial for covering long term care expenses—whether in-home or in a facility. Specifically, caregivers living in particular states that added restrictions to Medicaid eligibility or launched new programs due to the ACA often had adverse experiences with the complicated qualification criteria and evaluation process to gain eligibility, as illustrated by the following excerpts (c) and (d).

(c) We were told that there are changes currently being made nationwide that will make it even harder to get qualified for home health care, too. (ACA-2013-018)

(d) We've spoken with every agency available and this is our new normal because of the changes in health care and Medicaid. ...Her doctor feels she should be in a facility but Medicaid, ...will not pay for nursing home care until she is bedbound. (ACA-2013-021)

On the other hand, a group of caregivers that posted well into the implementation of the policy was favorable about the ACA for covering the expense of in-home care for their PWD, like excerpts (e) and (f).

(e) ... the Affordable Care Act has worked to expand home and community options through Medicaid. (Affordable Care Act-2015-055)

(f) I can give my mother much pleasanter surroundings and quality of life things for a fraction of a cost of an institution. Her disease has progressed very slowly here with us from what I can observe. (Affordable Care Act-2015-005)

Figure 10 depicts a conceptual map of the themes that represent the context for making a decision about care transitions for the PWD. The ACA appeared as both a complaint and a solution in the context that caregivers felt challenged with both the caring and cost for placement among different placement options ranging from home care to nursing home placement. Caregivers' posts about their experiences and thoughts about relevant systems were summarized as a concern about the financial burden of caring for their family member living with dementia.

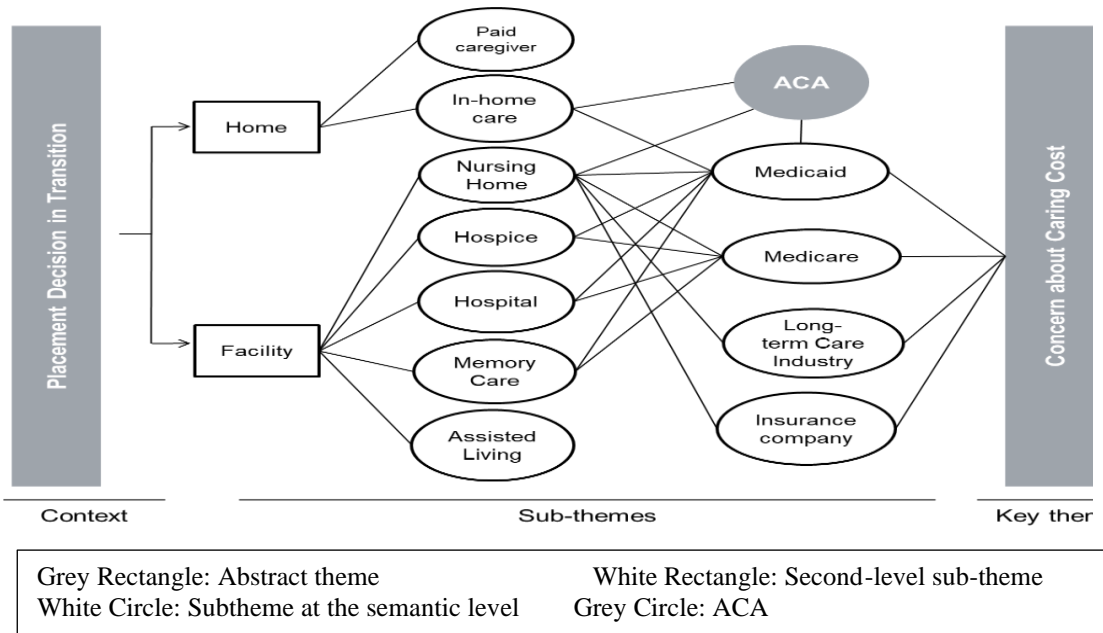


Figure 10 Thematic web: Decision-making for placement of PWD and cost concerns

Theme 2. Skepticism about a government-supported health care system

Skepticism about a government-supported health care system emerged as a second theme in the context of handling various caregiving roles, including advocacy in the medical, financial, and legal areas. Caregivers faced multifaceted struggles in relation to navigating the intricate health care system and government payment programs. ACA-related posts frequently appeared with health care advocacy themes, specifically relating to Medicare and Medicaid. When caregivers worked with health care providers and staff from government agencies on behalf of their PWD, they encountered multiple adverse interactions such as inaccurate or unreliable guidance, erroneous advice from untrained staff, inefficient administrative processes, overwhelming paperwork demands, and unprofessional attitudes of staff, specifically during the early years of the implementation of the ACA [see posts (g) and (h)].

(g) My own doctor didn't know about these changes. It was swift and silent when it was passed into law. Most in health care [providers] in my state aren't aware yet unless they are directly affiliated with a nursing home or Medicaid. (ACA-2013-022)

(h) Everyone can call all day long and get different responses from different people you talk to. ... Just what you're being advised by someone on the phone who may or may not be aware of all the details themselves. (ACA-2013-034)

Caregivers experienced the ACA in both positive and negative ways, especially in the medical advocacy context. As a supportive program, the ACA was mentioned along with the needs of early diagnosis and evaluation/examination, and timely treatment and medication for PWD. Interestingly, the ACA was used as an inducement to have a PWD see a doctor when they refused to, as illustrated in excerpt (i).

(i) If you can convince your mom's new doctor to tell her that the referral or neuropsych testing is now a mandatory part of Obamacare ... [anything] that helps her believe that it is necessary in order to keep benefits could be useful. (Obamacare-2016-118)

On the other hand, caregivers noted obfuscated procedures and altered eligibility brought on by the ACA [see excerpt (j)].

(j) We were told that due to the new ACA and changes our state made in light of it, we weren't allowed to just have her admitted [to the nursing home] by the doctor like the old days. ... we had to be evaluated to see her condition. Then we had to earn points to get accepted into the nursing home. (ACA-2013-018)

Numerous concerns and experiences of caregivers working with public agencies were encapsulated as caregiving roles in three categories: medical, legal, and financial advocate (Figure 11). The ACA was frequently mentioned in connection with Medicaid. Negative experiences working with government agencies and healthcare systems were summarized as complicated and long processes, overwhelming yet inaccurate information, and concerns about unfriendly staff and inappropriate referrals. Finally, skepticism about the health care system and government-led programs was extracted as an underlying theme.

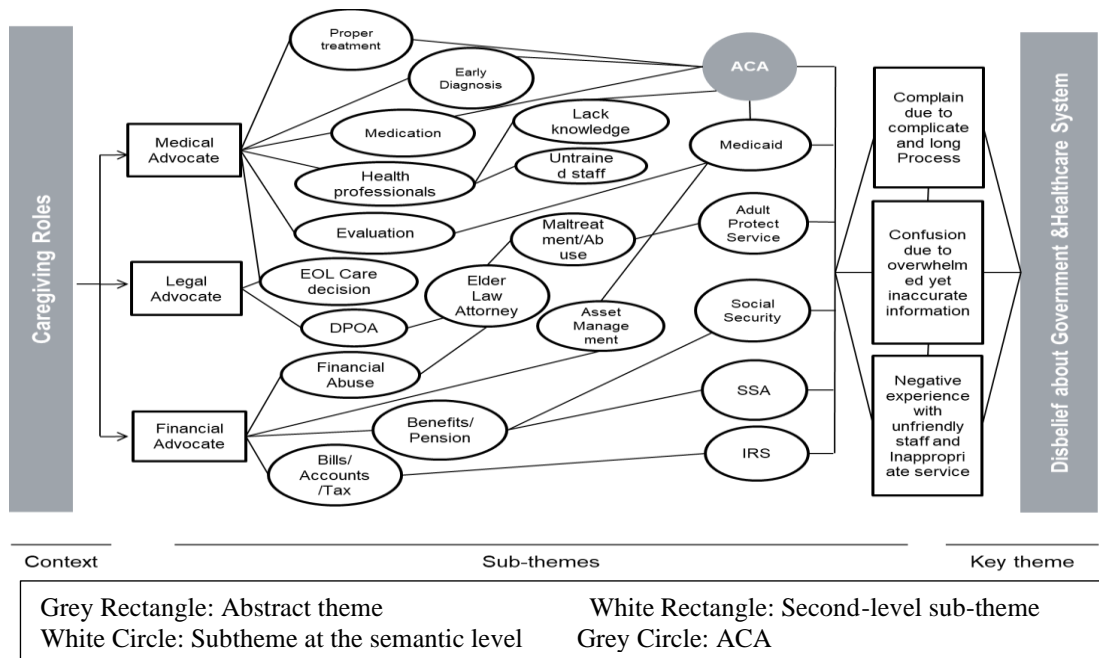


Figure 11 Thematic web: Overwhelming caregiving role and stress connected with government programs and the health care system

Theme 3. Caregivers' well-being and concerns about health insurance

Caregiver's well-being regarding financial security and their own health emerged as a third theme (Figure 12). Quitting a job and changing one's employment status in order to take on caring roles for the PWD often led to concerns and difficulties with finances and health insurance due to reduced income and the loss of resources covered by an employer [excerpt (k)]. In relation to caregivers' own health and well-being, the ACA was positively viewed by caregivers. Some caregivers shared about the benefits of the ACA and their concerns about repealing of the ACA, as illustrated by excerpts (l) and (m).

(k) We are lucky to be able to pay our bills, eat what we want ... (But), we don't go anywhere anymore together except to doctor and dentist appointments. (Affordable Care Act-2017-046)

(l) I also have my own health concerns that I am trying to manage. ... I was finally able to use the ACA to get insurance and so manage some things that I had been letting stagnate or get worse due to financial limits. (ACA-2015-003).

(m) What am I supposed to do when they kill the ACA, work full-time AND do live-in care 24/7? That is physically impossible... (ACA-2017-053).

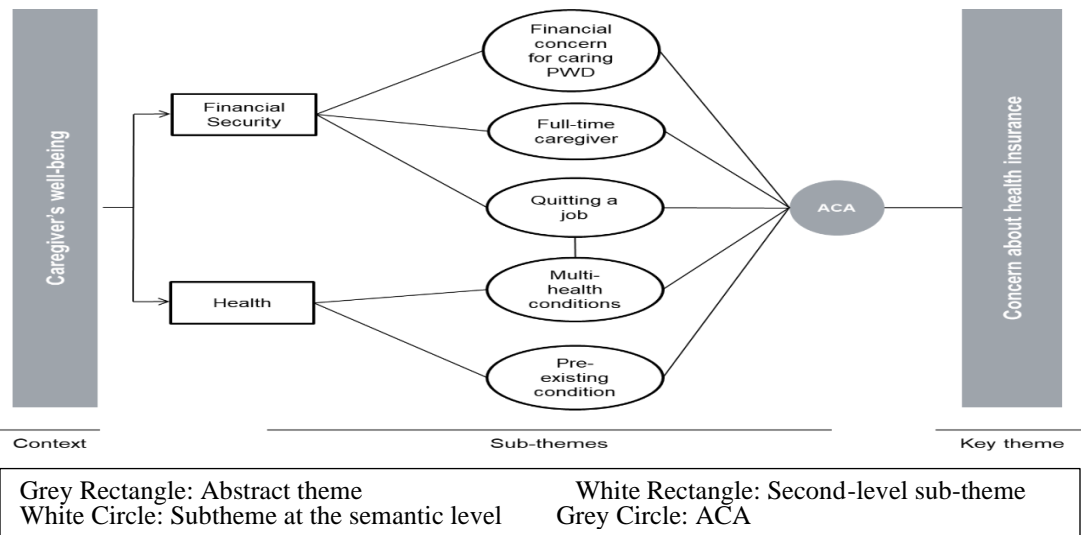


Figure 12 Thematic Web: Caregivers' concerns about their own health and financial security

Discussion and Implications

To date, little attention has been given to understanding experiences with the ACA among family caregivers of PWD. The current study analyzed online forum discussions reflecting caregivers' experiences and perceptions during the health policy reform period. Findings demonstrated that caregivers' views about the ACA became increasingly positive over time, whereas their views of the health and social care system, in general, were more likely expressed in negative terms. Three key themes emerged from caregivers' posts which reflected caregivers' experiences with and attitudes toward the ACA under the complex health care systems in the United States: (1) concerns about placement decisions and the expense of caring for PWD, (2) skepticism about government and health care systems being supportive of caregiving roles, and (3) concerns about caregivers' own well-being and health coverage.

Trends in Attitudes toward the ACA

Trends in attitudes toward the ACA among caregivers were similar to those of the general public with mostly negative opinions in the beginning years transitioning to more positive views later on (e.g., Kaiser Family Foundation, 2017). National surveys in 2010 and 2012 showed that over 50% of Americans did not understand the health care reform though most people favored most elements of the ACA (Gross et al., 2012). Likewise, caregivers in the current study expressed much confusion with the overwhelming amount of information about changes in health care brought about by the ACA, some of which was inaccurate, as well as with the complex and inconsistent services. Given health care reform was an abrupt change in the American health care system, it is understandable that there was tremendous resistance and confusion among the public, especially in the early

years of implementation. Nevertheless, there are lessons to be learned by reviewing the process of policy implementation.

The current study found that caregivers experienced a lack of understanding of the underlying health care system that was compounded by the ACA changes, which led caregivers to be confused and skeptical about government-led programs for family caregivers. The federal administration that pursued the ACA made extensive efforts to expand health insurance coverage, including: developing an online Marketplace where eligible consumers can purchase insurance plans; streamlining the application process with relevant programs such as Medicaid and CHIP in one application; and educating the public through diverse mass media (e.g., Ho, 2015).

Ironically, the efforts and goals of the policy were often misunderstood by potential consumers, especially in the beginning years. One possible reason for the discrepancy between the intended goals of the policy and perceptions among caregivers is an ineffective method of communication. Conflicting information from different media did not help caregivers to understand and use the programs. Indeed, the federal government allowed each state to choose to opt-in or opt-out of the Medicaid expansion option, and thus, each state had authority to adjust the eligibility criteria and the content of the services and programs. Thus, the ACA has been applied differently in each state. Because of the between-state variance in implementing the ACA, confusion and misunderstandings among potential users, including caregivers, were exacerbated.

Theme 1: Concerns about Placement Decisions and the Expense of Caring for PWD

The current study found that caregivers considered the ACA when they faced challenges in placement decisions for their care recipients, especially related to the

concern about expenses related to care options. Transitions between care settings are very common for PWD (Callahan et al., 2015; Hirschman & Hodgson, 2017). Using nationally representative data from 1999 to 2008, Callahan et al. (2015) found that nearly 60 percent of PWD who stayed in a nursing facility transitioned to a hospital and about 34 percent transitioned from a hospital to a nursing facility. Moreover, over 52 percent of the study population returned home from the hospital without home care services and 25 percent transferred from a nursing facility (Callahan et al., 2015). Such fragmented care in transitions are associated with poor outcomes for PWD and their caregivers, including extra health care expenditures (Phelan, Borson, Grothaus, Balach, & Larson, 2012). Moreover, since placement decisions often occur during unplanned situations, it is stressful for caregivers and care recipients to experience difficulties in communication with care professionals due to lack of accurate information and support and ineffective coordination by care professionals (e.g., Kable, Chenoweth, Pond & Hullick, 2015). Focusing on transitional care that centers on the person and family in the care process, a systematic review analyzed 130 papers and highlighted several effective approaches in care transitions, such as involving caregivers and care recipients at the goal establishment stage, educating and communicating with family caregivers, and creating effective inter-professional care teams (Hirschman & Hodgson, 2018). Likewise, our results emphasize the importance of policy-competency of care professionals in order to provide comprehensive support for caregivers and PWD.

Theme 2: Skepticism about Government-led Health and Social Services

Skepticism about government-led health and social programs was one of the critical themes uncovered in this study. Besides the ACA, caregivers often have

difficulties encountering complex health and social service systems in their usual caregiving life (Broda et al., 2017; Peel & Harding, 2014). Thus, the key for helping caregivers to be better informed about new policies and to get into the health and social service systems would be proper guidance that helps them to trust and feel confident within the systems. What, then, is the most effective approach to communicate with and inform caregivers? A current study found that caregivers tend to trust the information provided by health care providers (Meyer, Gassoumis, Kelly, & Benton, 2019). Thus, a strategic approach for federal and state government policymakers is to first enhance policy knowledge among health care professionals. In order to do that, aggressive training and continuing education of professionals and students, specifically, those who are working in the health care settings should be pursued. Also, family-centered communication in health and social care settings would be desirable to assist caregivers in a professional manner. In addition to educating service providers, efforts are needed to improve caregivers' health system literacy, so they are empowered to make well-informed decisions for their care recipients as well as for themselves. Our findings reinforce the call to enhance family caregivers' literacy about the health care system to ensure that the burden that caregivers face is not intensified by their experiences accessing health care for themselves or their care recipients (e.g., Fields, Rodakowski, James, & Beach, 2018).

Theme 3: Concerns about Health Care Expenses

More importantly, concerns about health and long-term care expenses for PWD, especially in care transitions, as well as for caregivers themselves were key topics discussed among caregivers in a national online forum. In the current political climate

with efforts to repeal the ACA by the current administration, greater awareness of the impact of changes to national health care policy is needed along with proactive action to advocate for the ACA. Following a lawsuit by twenty states, an effort to repeal the ACA, especially to invalidate the protections for pre-existing conditions section was supported by the Department of Justice (Linberg, 2018). If the ACA were to be repealed, the consequence would be higher premiums for health insurance among people in vulnerable situations, including family caregivers, many of whom must leave their jobs to take on caring roles while experiencing health and mental health problems themselves (Alzheimer's Association, 2019). Such massive changes in health care programs would intensify confusion and stress among dementia-affected families and other types of caregivers who rely on government-supported health programs.

Some methods were suggested to reduce care cost, such as including caregivers in care transition programs and educating caregivers to enhance their capacity to identify risk signs of care recipients, which can prevent unnecessary hospital visits (e.g., Coleman, Parry, Chalmers, & Min, 2006). These suggestions, however, seem to remain in the traditional hegemony that emphasizes the family's responsibility of care that would push caregivers to fit into existing systems. According to nationally representative survey research conducted by AARP in 2012 with over 2,000 family caregivers, most caregivers were worried and stressed due to increasing and complex care demands (Reinhard et al., 2019). Moving forward, efforts are needed to make fundamental changes in health and social care systems.

Our findings highlight the importance of proactive online advocacy for caregiving families. Using cultural hegemony theory, Levitsky (2014) explained the underutilization

of established public services for caregivers. The prevalent belief among family caregivers that caregiving is a family's responsibility, which is constructed by government's hegemony in the United States, restricts them from seeking help outside of the family. The current study, however, identified that at least a segment of caregivers did seek help and interact with various government agencies and health care systems to advocate for their care recipients. In sum, some caregivers are aware of the help and seek assistance while there remains a gap in the actual use of available services.

In this sense, adding to Levitsky's (2014) cultural hegemony hypothesis, our findings suggest another explanation at a psychological level. Practically, it is imperative for family caregivers to seek help outside of the family due to the extended caregiving period and the increase in health care costs. However, while working with various staff to get an answer or proper assistance, caregivers often face repetitive challenges within the health care and social service systems. Such challenges may lead to 'learned helplessness' and even giving up on seeking help. Considering that family responsibility is a strong belief among caregivers, they tend to handle the undesirable experiences and difficulties working with health care systems privately or even internalize their failure as their own fault.

Social isolation is a critical barrier that compounds the challenges in accessing information and services to assist with caregiving activities (Reinhard et al., 2019). An online community would be an ideal venue for advocacy by linking caregivers and gathering their voices to make them heard. Thus, proactive online advocacy could be a powerful platform, which includes encouraging discourses about their experiences

working with larger systems, raising awareness of the problems, assisting them to recognize their influence to change the policies, and claiming their rights.

Limitations

The findings of this study should be interpreted in light of the possibility of sample bias. Although the Alzheimer's Association caregiver forum is nationwide, sampling from one site could cause selection bias considering that there are many more online peer support groups for caregivers of PWD. The inability to control the quality of the sample (e.g., self-selection, limited eligibility criteria, and different participation rate) may decrease the generalizability of the study findings. On the other hand, the caregiver posts from social media can be considered as authentic data since they were unsolicited for the purposes of research, which reduces social desirability effects from research participants that traditional forms of research commonly bring about (Ignatow & Mihalcea, 2017). Another limitation is a paucity of demographic information about the participants, which would be helpful for a better understanding of caregivers' experiences. The literature reports significant associations among demographic characteristics, including age, education, and income level with Internet use among middle age and older people (e.g., Kim, 2015). Thus, our findings may have less generalizability to represent older people with lower socioeconomic status, whose lack of access is likely to affect the amount of care received. For future health care policy studies, empirical data is needed to accurately estimate how many and which caregivers experience difficulties and benefits of health care policies and services. Despite the limitations, through examining the rich and detailed data that represent the experiences

that were not able to be captured through traditional forms of data, the current study contributes to making caregivers' voices heard.

Conclusion

Family caregivers are a critical component of the health care continuum for individuals with chronic illnesses such as dementia, and thus, their perspectives are essential to enhancing the operation of that continuum. Policymakers, as well as health and social care professionals working with Alzheimer's patients and their families, should be empowered to develop and support a family-centered service system. Meeting the needs of Alzheimer's patients means meeting the needs of their primary caregivers. Continuing education of care professionals is vital to ensure that caregivers receive unbiased, accurate, and updated guidance. Protecting the ACA and developing a universal long-term care system is essential not only for supporting the growing number of individuals with dementia but as importantly, their family caregivers.

CHAPTER FIVE

CONCLUSIONS

Summary of the Research Inquiries

Along with the rapid increase of people living with Alzheimer's disease and related dementias (PWD) across the world, their family caregivers also receive attention from policymakers, health and social service practitioners, and researchers for their stress and their diverse unmet needs. Due to the adverse outcomes in health and socio-psychological well-being after taking over the caring role, caregivers are often called invisible second patients. Reflecting on the prevalence of online social media use among caregivers of PWD, the current study explored the relations of individual caregivers' well-being with mezzo and macro systems.

With the social support theory framework, the first study examined the association of offline-and online-based social support on caregivers' psychological well-being. One research question and two sets of research hypotheses were set. First, we tested if there is a difference in the level of psychological well-being of dementia caregivers with offline and online social supports, respectively. Second, we examined the main effects of offline and online social supports, assuming that online social support plays a similar role as offline social support. Finally, we tested if offline and online social supports moderate the relationship between stressors and the psychological well-being of caregivers. Using the caregivers' subsample of the *Health Information National Trends Survey* (HINTS) from 2017 to 2018 (n=264), this study found the following. First, online social support supplemented rather than replaced offline social support. Second, emotional support delivered offline had a positive direct association with MH, while

online social support did not have a significant direct association. Third, offline social support interacted with caregiving burden while online social support interacted with life stressors. Caregivers who are in less favorable situations, such as working part-time while caring for a PWD, living with economic hardship, and being unhealthy, tended to be significantly affected by online social support.

The second study analyzed Alzheimer's caregivers' perceptions of and experiences with the *Affordable Care Act (ACA)* using unsolicited posts on a national online forum that were posted in 2011-2017. The guiding research questions were: (1) How do caregivers view the ACA as revealed by the content and tone of their online posts? And (2) How do caregivers experience the ACA in various caregiving contexts? Text-mining thematic analysis was used to code and analyze posts. Our analysis found that perceptions with the ACA became more positive over time, although many caregiver posts about the ACA had a negative tone. Three themes emerged: (a) concern about cost implications of placement decisions for care recipients, (b) skepticism about government and healthcare system support of their caregiving roles, and (c) caregivers' own well-being and concerns about health insurance.

Implications

Implications for Social Work

The social work profession teaches and applies the person-in-environment perspective as a guiding principle, which emphasizes the importance of reciprocal interactions between an individual and multi-layers of social environments to understand a specific agent's behaviors and lives. Gerontological or geriatric social work, i.e., social workers who work for older adults and their families, has been concerned with improving

the health and well-being of these populations, not only focusing on individuals at a specific life stage but also taking account of their social relations and macro systems. Findings from these two studies call for more active participation of social work practitioners to expand their skills and practice areas into online and social and health policies.

Currently, many social or health service organizations started to provide online services for caregivers, such an online community, chatting, or video conference with peers or professional service providers or other types of communication tools via online. Adding to the provider-leading websites, caregivers also develop online self-help communities on social network platforms to share information and experiences and to exchange opinions and concerns. Such an approach may not only help caregivers who are primarily in vulnerable conditions to learn not only health information, caregiving knowledge, communication with peers, and health professionals but also release their life and caregiving stresses. Given more caregivers and patients rely on online sources for accessing information and support, social workers need to monitor and moderate the activities of online participants more carefully. Practitioners and researchers can benefit from understanding the exact and complicated issues surrounding caregivers' life and psychosocial needs and develop more validated services based on the needs of caregiving families.

At the stage of designing online support platforms, social work practitioners need to collaborate with web developers when developing strategies to reduce the negative feelings associated with social media use. Jealousy, lack of attention from others, feelings of loneliness, and time lost on using social media are factors that feed the frustration of

users (Krasnova et al., 2013). In general, social media users either behave in a passive way (e.g., hiding posts that trigger negative feelings) or, in contrast, overstate one's feelings or accomplishment to promote oneself to avoid painful feelings (Krasnova et al., 2013). These adverse strategies of individual users would cause separation of one's identity as well as uneasiness with using the online community. Positive self-presentation in social media is directly associated with better psychological well-being. Honest self-presentation could have a significant relationship with positive well-being through social support (Kim & Lee, 2011). Thus, when it comes to developing an online self-support community, practitioners need to pay attention to cultivate a democratic and safe environment by welcoming and supporting all users. Also, it would be helpful to encourage passive users to participate actively in communication to help them enjoy the benefits of a widened online social network.

Finally, online social support is still to be considered as a supplement of offline social support. Thus, social workers and health practitioners in a geriatric setting can encourage individual caregivers and caregiving families to incorporate their online and offline social networks to arrange their possible resources and help to maintain their well-being while caring for PWD. Also, as helping professionals who appraise human behaviors and social phenomenon with the person-in-environment perspective, social workers need to be prepared to assist caregivers in accessing reliable and updated knowledge about relevant policies and proper services in a macro system. Helping caregivers improve health, finance, and legal literacy is much needed to help them make well-informed decisions for their care recipients as well as themselves. Continuing

education of social work practitioners and care professionals is vital to ensure that caregivers receive updated and accurate guidance.

Implications for Policy

Findings of the two research papers call for policy practitioners to enhance multidimensional social support systems in the United States. The first manuscript identified that working caregivers are in a more vulnerable condition that negatively affects their MH. The culture of the labor market in the United States has not been favorable in this respect. Historically, caring work was underestimated and considered to be women's work. This study suggests providing proper compensation to the caregivers, such as paid leave, flexible leave, and an easy return to work. As the life expectancy of older people continues to lengthen, it is expected that more people will become involved in caregiving and for longer periods. A family-friendly labor market policy is urgent. Paid family leave is a small step to move forward. California implemented the Paid Family Leave Program (CA-PEL) in 2004. The initial evaluation report presented that the program was effective in assisting caregivers in keeping their jobs, especially those who are in their middle-age and having a job or those who are near-poor (Kang et al., 2019). More progressive programs, such as stimulus checks, universal basic income, and payments for caregiving labor, have recently been discussed (Stokes & Patterson, 2020). These programs will be helpful for family caregivers, especially those who are in vulnerable situations, to relieve their material hardship and psychological distress.

The second paper that explored Alzheimer's caregivers' perception of the *Affordable Care Act* highlighted the significance of consumer-friendly healthcare systems. Regarding the ACA, higher sensitivity toward people in vulnerable situations

should be considered by policymakers in designing long term care policies and services. The ACA aimed at assisting citizens who were not available to purchase private health insurance plans, most of whom are low-income or have preexisting health conditions. Though the overall uninsured rate has increased (Clarke, Norris, & Schiller, 2017), an uncovered gray area remains. More importantly, in the current political climate that shows severe movement to repeal the ACA and replace it with a new program, association health plans (AHPs), more awareness of the significance of this situation and proactive action among healthcare professionals to advocate for the ACA are needed. An effort to repeal the ACA, especially to invalidate the protections for preexisting conditions section, has been given support by the Department of Justice (Linberg, 2018). The consequences of repealing the ACA include higher premiums for health insurance for people in vulnerable situations, including family caregivers who leave their job to take caring roles while experiencing health and mental health problems themselves (Alzheimer's Association, 2019). Policymakers and administrators who build and implement a policy targeting vulnerable populations must consider reducing disadvantages and providing fair conditions for caregivers of PWD.

Suggestions for Future Research

Further work to improve the reliability and generalizability of the exploratory or preliminary findings is suggested. First, more reliable and theory-based scales that measure the study variables are needed. For example, compatible measures of online and offline social support need to be developed given incompatible measures would bring about confounding during comparisons (Trepte et al., 2012). Although some measurements of social supports exist (Glanz, Rimer & Viswanath, 2008), as of our

knowledge, there are limited reliable scales that measure online social support of caregivers, which can be compatible with online social support scales. In this study, we tried to adjust the number of online and offline social support variables. Thus, for more accurate inference, future research may need to consider developing compatible measures of social support in both domains- online and offline. Future research might also address the density, homogeneity, and direction of online social support that a caregiver gave and received.

In addition, future research should take care of diversity in the caregiving population. Around 30 % of family caregivers are self-identified racial/ethnic minorities, and their proportion is expected to increase (National Academics and Sciences, Engineering, and Medicine, 2016). The unmet needs of caregivers differ by ethnic groups based on the different cultures, beliefs, and living environments (Rote, Angel, Moon, & Markides, 2019). Also, the subjective experience of racial or ethnic minority caregivers within the support systems would be different. Unfortunately, due to the limited information about race/ethnicity in data used for both studies, this dissertation research suffers from limited implications for the racially/ethnically diverse populations. Future research needs, therefore, to consider this limitation.

Finally, researchers need to pay careful attention to recruiting caregivers to enhance the validity of the studies. Caregivers tend to be reluctant to participate in a research study in general due to the limited time and stress (Szabo, Whitlatch, Orsulic-Jeras & Johnson, 2018). Thus, there is a higher chance that this type of national survey may lose substantial size or certain types of caregiving populations, such as primary caregivers, those who do not identify themselves as caregivers, or those who are from

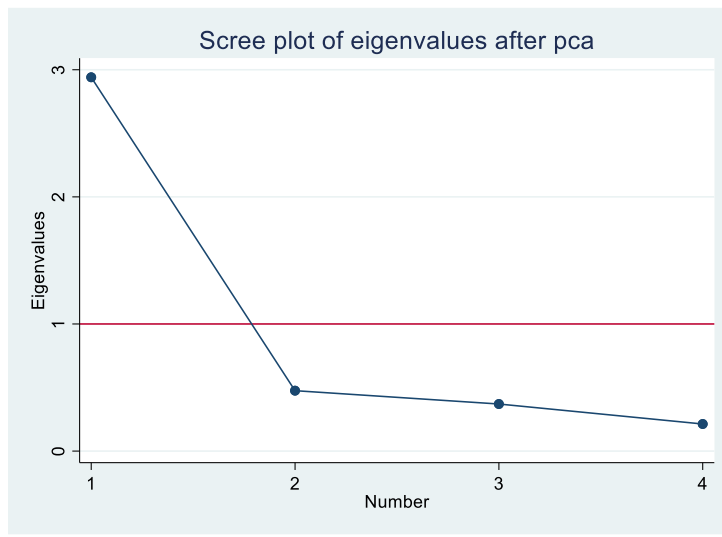
ethnic minority groups. Likewise, big data from the national-wide online community also suffers from possible risks to include populations with specific characteristics. Self-selection bias is possible with these samples. Due to these data limitations, the two studies in this dissertation research are not conclusive to draw definitive causal relationships and dynamics. Although it is true that large-scale observational studies may also confront these challenges, analysis with a larger longitudinal caregiver-representative sample would be helpful to obtain more accurate and reliable findings.

Conclusion

This dissertation research examined the association of social support and health policy with the well-being of caregivers of persons living with Alzheimer's disease and related dementias in relation to online social media. Findings of both studies contribute to the knowledge base about social support mechanisms in contemporary online contexts and illuminate experiences with the *Affordable Care Act* from caregivers' perspectives. The findings of the study highlight the influence of mezzo (i.e., social network, online and offline) and macro systems (i.e., health and social policies and programs) on individual caregivers' psychological health and well-being, specifically among those in vulnerable conditions. The present dissertation is an incremental step to enhancing our understanding of the complex contexts of Alzheimer's caregivers, which affect their overall well-being. Further study is needed to uncover the detailed dynamics among both offline and online social networks and larger support systems.

Appendix A. Results of Principle Factor Analysis

	Factor loading	Uniqueness
Little Interest	.874	.236
Hopeless	.884	.218
Nervous	.843	.289
Worrying	.827	.315
Eigenvalue	2.941	
% of total variance	0.735	



Appendix B. Missing Pattern

Missing-value patterns
(1 means complete)

Percent	Pattern															
	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
79%	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
5	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
4	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
2	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	1
1	1	1	1	1	1	1	0	0	0	0	1	1	1	1	0	1
<1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1
<1	1	1	1	1	1	1	1	1	1	1	1	0	1	0	1	1
<1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1
<1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0
<1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0
<1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0
<1	0	0	0	0	1	1	1	1	1	1	1	1	0	1	1	0
<1	0	0	1	0	1	0	1	1	1	1	1	0	0	0	1	0
<1	1	1	0	1	1	1	1	1	1	1	0	0	0	0	1	0
<1	1	1	1	0	1	1	1	1	1	1	1	1	1	1	1	1
<1	1	1	1	1	0	0	1	1	1	1	1	1	1	1	1	1
<1	1	1	1	1	0	1	1	1	1	1	1	1	0	1	1	0
<1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	1	1
<1	1	1	1	1	1	1	0	0	0	0	1	1	1	1	0	1
<1	1	1	1	1	1	1	1	1	0	0	1	1	1	1	0	1
<1	1	1	1	1	1	1	1	1	1	1	1	0	0	0	1	0
<1	1	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1
<1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1
<1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1	1
<1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1	1
<1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0
100%	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1

Variables are
 Row 1: (1) ssemo (2) ssfrnd (3) male (4) sschore (5) cgmulc (6) goodhlth
 (7) smvis (8) smyrb (9) smfrm (10) smshr (11) phq4c (12) BAggrad
 (13) agegr3 (14) mar (15) smblg (16) qinc
 Row 2: (1) cghr20 (2) ethminor

Appendix C. Correlation Matrix

	phq4n	cghr20	cgmuld	qinc	goodhlth	ssemo	ssfrnd
phq4n	1.0000						
cghr20	-0.1669*	1.0000					
cgmuld	0.1959*	0.0247	1.0000				
qinc	-0.2132*	0.2219*	-0.0895	1.0000			
goodhlth	-0.3279*	0.0843	-0.1078	0.2143*	1.0000		
ssemo	-0.3318*	0.1005	-0.1170	0.1627*	0.1288*	1.0000	
ssfrnd	-0.1428*	0.1841*	-0.0735	0.1532*	0.0283	0.6921*	1.0000
smblg	0.1257*	0.0213	0.0980	-0.0278	-0.0473	-0.0562	-0.0739
smfrm	0.1238*	-0.0628	0.0777	-0.0363	-0.0041	0.0332	0.0104
male	-0.0126	-0.0005	-0.0304	0.1740*	0.0382	-0.0689	-0.0398
age1	-0.1942*	-0.0362	-0.1663*	-0.0201	-0.0010	-0.0423	-0.0021
BAGrad	-0.0501	0.1880*	0.0237	0.4051*	0.1921*	0.0015	0.0137
mar	-0.1004	0.0406	0.0765	0.1616*	0.0854	0.0839	0.1113
ethminor	0.0030	-0.1257	0.1283*	-0.0969	-0.1330*	-0.1038	-0.0948

	smblg	smfrm	male	age1	BAGrad	mar	ethminor
smblg	1.0000						
smfrm	0.1578*	1.0000					
male	-0.0159	-0.1421*	1.0000				
age1	-0.1221	-0.1380*	0.0413	1.0000			
BAGrad	0.0432	0.0210	0.0585	-0.1890*	1.0000		
mar	-0.0011	0.0611	0.1701*	0.0652	0.0303	1.0000	
ethminor	0.0569	-0.0166	-0.1003	-0.1484*	-0.0720	-0.1100	1.0000

end of do-file

Appendix D. Proportional Odds Assumption Test

Models	Chi-square	Prob>chi2 ^{a)}
[1] Base model	35.49	.10
[2] Offline SS	23.89	.35
[3] Online SS	22.60	.43
[4] Total SS	35.49	.10
Interaction models		
[5] Caregiving hours * Close Others SS	35.06	.17
[6] Multiple caregiving * Emotional SS	40.51	.05
[7] Income * Blog	38.30	.09
[8] Income * Online forum	34.03	.20
[9] Health * Blog	35.09	.11

^{a)} This method tests the approximate likelihood ratios from multiple iteration analyses to see if there is a difference in the coefficients between models, assuming no difference (H0). Thus, a non-significant result (i.e., $p > .05$) is desirable.

**Appendix E. Interaction Models of caregiving burden and offline social support:
Ordered logistic regression models predicting psychological well-being (PHQ4-cat)
controlling for demographics using Jackknife estimation.**

	Odds ratio [95% CI]	
	[5]	[6]
<u>Interactions</u>		
Caregiving hours x Close Others		Multiple CR x emotional SS
5-14 hrs x No	2.49e-07*** [1.53e-10, .00]	Yes x Yes 129.33* [1.15, 14595.44]
21-34 hrs x No	9.09e-07** [3.33e-10, .00]	
35+ hrs x No	2.18e-06** [8.28e-10, .01]	
<u>CG Burden</u>		
Caregiving hour (ref: <5hrs/wk)		
5< ≤15	1.02 [.36, 2.91]	.75 [.27, 2.07]
15< ≤20	1.22 [.31, 4.86]	1.06 [.27, 4.19]
20< ≤35	.13* [.02, .69]	.10** [.02, .45]
35<	.53 [.16, 1.71]	.49 [.15, 1.55]
Multiple CR (1=yes)	1.23 [.23, 6.59]	1.23 [.25, 6.13]
<u>Life Stressors</u>		
Income (ref: 1 st quartile)		
25-49.99%	2.68 [.75, 9.51]	2.50 [.74, 8.44]
50-74.99%	2.24 [.63, 7.94]	2.42 [.74, 7.93]
75% and higher	1.83 [.46, 7.33]	1.78 [.51, 6.18]
Good health	3.83** [1.66, 8.84]	3.52** [1.57, 7.89]
<u>Offline SS</u>		
Emotional	13.63 [1.85, 100.31]	7.17+ [.74, 69.11]
Close Others	1.37e-07 [1.08e-10, .00]	.15 [.01, 1.56]
<u>Online SS</u>		
Writing blogs Participating forums		
<u>Demographics</u>		
Male	.97 [.39, 2.41]	1.18 [.49, 2.85]

Age (ref: below 50)		
50-64	4.55* [1.55, 13.39]	4.70** [1.78, 12.41]
65+	5.43* [1.73, 17.04]	4.85** [1.66, 14.14]
College or higher	.82 [.33, 2.05]	.72 [.30, 1.74]
Married	1.15 [.48, 2.78]	1.14 [.49, 2.66]
Ethnic minority	1.48 [.57, 3.87]	1.61 [.65, 4.02]
<i>DF</i> , n-1	21, 214	18,213
F	3.16***	2.78**
Pseudo R2	.180	.189

Appendix F. Interaction Models of life stressors and online social support: Ordered logistic regression models predicting psychological well-being (PHQ4-cat) controlling for demographics using Jackknife estimation.

	Odds ratio [95% CI]	
	[7]	[8]
<u>Interactions</u>		
Income x Forum		Good health x Blogging
2 nd quantile x Yes	3246253* [6.65, 1.58e+12]	Yes x Yes 6194411* [13.09, 2.93e+12]
3 rd quantile x Yes	.17 [.01, 3.14]	
4 th quantile x Yes	.62 [.02, 19.18]	
<u>CG Burden</u>		
Caregiving hour (ref: <5hrs/wk)		
5< ≤15	.74 [.23, 2.35]	80 [.27, 2.43]
15< ≤20	.90 [.21, 3.82]	.78 [.20, 3.13]
20< ≤35	.08** [.02, .37]	.11** [.03, .48]
35<	.45 [.13, 1.56]	.57 [.16, 2.00]
Multiple CR (1=yes)	1.70 [.34, 8.49]	1.54 [..31, 7.60]
<u>Life Stressors</u>		
Income (ref:1 st quartile)		
25-49.99%	1.92 [.49, 7.42]	2.23 [.56, 8.89]
50-74.99%	3.28 [.72, 15.01]	2.25 [.63, 8.06]
75% and higher	1.68 [.37, 7.71]	1.62 [.39, 6.76]
Good health	3.81** [1.53, 9.49]	3.29** [1.37, 7.90]
<u>Offline SS</u>		
Emotional	15.91* [1.92, 131.72]	13.29* [1.68, 105.23]
Close Others	.10+ [.01, 1.05]	.18+ [.01, 1.05]
<u>Online SS</u>		
Writing blogs	.47 [.04 5.48]	.14 [.00, 9.98]
Participating forums	.60 [.08 4.42]	.43 [.11, 1.63]
<u>Demographics</u>		
Male	.96 [.39, 2.41]	.87 [.35, 2.11]
Age (ref: below 50)		

50-64	5.11** [1.72, 15.19]	4.93** [1.71, 14.19]
65+	4.51* [1.39, 14.70]	4.40** [1.51, 12.85]
College or higher	.88 [.32, 2.41]	.87 [.33, 2.30]
Married	1.26 [.52, 3.08]	1.28 [.54, 3.02]
Ethnic minority	1.56 [.62, 3.97]	1.29 [.52, 3.23]
<i>DF</i> , n-1	22,208	20, 209
F	2.62**	2.79***
Pseudo R2	.199	.186

^{a)} Terms automatically omitted in the analysis process due to multicollinearity.

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of C-reactive protein and other biomarkers relevant to cardiovascular disease risk: A longitudinal study. *Gerontology*, 58(4), 354-365.
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- Wilks, S. E., & Croom, B. (2008). Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. *Aging and Mental Health*, 12(3), 357-365. <https://doi.org/10.1080/13607860801933323>.
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- Zarit, S. H., & Talley, R. C. (Eds.). (2012). *Caregiving for Alzheimer's disease and related disorders*. NY: Springer.

Curriculum Vitae

Eun-Hye Yi

Education

- PhD. December 2020
Indiana University School of Social Work, Indianapolis, IN, US
Minor: Economics
Dissertation Title: *“Using Technology to Enhance the Well-Being of Caregivers of Person Living with Dementia: Implications for Social Work Practice and Policy”*
- MSW August 2009
Soongsil University School of Social Welfare, Seoul, Korea (accredited by the Council on Social Work Education)
Concentration: Social Welfare Policy
Thesis Title: *“A Study on the Decomposition of Poverty Differences between Female-headed Households and Male-headed Households in Korea: Based on Urban Working Families from 1982 to 2008”*
- BA. February 2002
Soongsil University School of Social Work, Seoul, Korea

Academic Employment

- 2020-current Adjunct professor. California State University Fullerton
Department of Social Work, Fullerton, CA
- 2015, 2018-current Adjunct Professor. IUSSW, Indianapolis, IN
- 2016-17 Project Coordinator. Regenstrief Institute, Indiana University, Indianapolis, IN

Awards and Honors

National Level

- 2019 Graduate Student Research Award, American Society on Aging
- 2019 TJ McCallum Memorial Award, Gerontological Society of America
- 2017-18 Social Work HEALS Doctoral Fellowship, National Association of Social Workers Foundation/Council on Social Work Education

University Level

- 2019 Jerry Powers Esprit Award. IUSSW, Indianapolis, IN
- 2015-19 Travel Grants (Eight times). IUSSW, Indianapolis, IN
- 2015-19 Graduate-Professional Educational Grants (Four times), Indiana University-Purdue University (IUPUI) Indianapolis, IN
- 2012-19 University Fellowship, Indiana University, Indianapolis, IN

- 2018 Travel Fellowship, IUPUI Graduate School, Indianapolis, IN
- 2009 Distinguished Thesis Award, Soongsil University (SSU) School of Social Welfare, Seoul, Korea
- 2008 Academic Excellence Scholarship, SSU Graduate School, Seoul, Korea
- 2007-08 Administrative Scholarship (Two times), SSU Graduate School, Seoul, Korea
- 2001 Excellent Research Award, SSU College of Social Science, Seoul, Korea
Title: "A Study on the Living Conditions of the Homeless with Mental Illness in Seoul, Korea: Ethnographic Qualitative Approach."
- 1999 Church Scholarship (Two times), SSU, Seoul, Korea
- 1998-99 General Scholarship (Four times), SSU, Seoul, Korea
- 1998 Mandolin Orchestra Leaders Scholarship (Two times), SSU, Seoul, Korea

Grants

- 2019 CO-PI. "Reducing child fatalities and recurring child injuries caused by crime victimization." Agency: U.S. Department of Justice Office for Victims of Crime. PI: Susana Mariscal, PhD. Total costs \$750,000. (Participated in grant proposal writing.)
- 2017-18 Dissertation Grant (PI). "Using technology to enhance well-being of dementia caregivers: Implications for social work practice and policy." Agency: New York Community Trust through the NASW/CSWE Social Work HEALS Doctoral Fellowship. Total costs \$17,900.
- 2016-17 CO-Investigator. "Increasing Alzheimer's caregiver's self-management through social microvolunteering." Agency: Regenstrief Institute. PI: Daniel Bateman, PhD.

Publications

Manuscripts Published in the Peer-Reviewed Journals

- Yi, E.** & Adamek, M. (2020). Perspectives of Alzheimer's caregivers on the Affordable Care Act: A thematic analysis of social media data from discussion forums. *Journal of Applied Gerontology*.
<https://doi.org/10.1177/0733464820964088>.
- Yi, E.** (2019). Does acculturation matter? End-of-life care planning and preferences among foreign-born older immigrants in the U. S. *Innovation in Aging*, 3(2), 1-14. DOI: 10.1093/geroni/igz012.
- Kim, J., **Yi, E.**, Pierce, B. & Hall, J. (2019). Effective workload management in child welfare: Understanding the relationship between caseload and workload. *Social Policy & Administration*, 1-13. <https://doi.org/10.1111/spol.12499>.
- Wilkerson, D., Brady, E., **Yi, E.**, & Bateman, D. (2018). Friendsourcing peer support for Alzheimer's caregiver using Facebook social media. *Journal of Technology in Human Services*. DOI: 10.1080/15228835.2018.1449709.

- Hong, M., **Yi, E.**, Johnson, K., & Adamek, M. (2018). Facilitators and barriers for advance care planning among ethnic minorities in the U.S.: A systematic review. *Journal of Immigrant and Minority Health, 20*(5), 1277-1287. DOI: 10.1007/s10903-017-0670-9.
- Bateman, D., Brady, E., Wilkerson, D., **Yi, E.**, Karanam, Y. & Callahan, C. (2017). Comparing crowdsourcing and friendsourcing: A social media-based feasibility study to support Alzheimer's disease caregivers. *JMIR Research Protocols, 6*(4), e56. DOI: 10.2196/resprot.6904.
- Gentle-Genitty, C., Kim, J., **Yi, E.**, Slater, D. Reynolds, B. & Bragg, N. (2017). School-community assessment of youth on youth violence in five Caribbean countries: Gender and age as criminal justice considerations. *Journal of Human Behavior in the Social Environment, 27*(7), 745-759. DOI: <http://dx.doi.org/10.1080/10911359.2016.1273811>.
- Hong, M., Hong, S., Kim, M. H., & **Yi, E.** (2016). Intention to use long-term care facilities between the Korean pre-elderly and the Korean baby-boomers. *Journal of Cross-Cultural Gerontology, 31*(4), 357-368. DOI:10.1007/s10823-016-9300-6.
- Lee, S. & **Yi, E.** (2013). National endowments and welfare preference. *Korean Journal of Social Welfare Studies, 44*(4), 149-176. Accessible at <http://www.papersearch.net/thesis/article.asp?KEY=3191998>. [in Korean].
- Lee, S., **Yi, E.** & Jung, C. (2011). Trend and decomposition of asset poverty in Korea. *Health and Social Welfare Review, 31*(3), 3-37. Accessible at <http://repository.kihasa.re.kr:8080/handle/201002/7423>. [in Korean].
- Yi, E.** & Lee, S. (2009). A decomposition of gender differences on the poverty among the urban working households in Korea. *Korean Journal of Social Welfare, 61*(4), 333-354. Accessible at <http://www.dbpia.co.kr/Journal/ArticleDetail/NODE01292590>. [in Korean].

Presentations

National/International Refereed Conferences

- Yi, E.** & Adamek, M. (2020, March). *Perspectives of Alzheimer's caregivers on the Affordable Care Act: A thematic analysis of social media discussions*. Poster presentation at the 2020 American Society on Aging (ASA)'s Aging in America Conference, Atlanta, GA. [accepted]
- Yi, E.** & Jang, Y. (2020, January). *The use of complementary and alternative medicine and unmet healthcare needs in Asian Americans*. Poster presentation at the Society for Social Work and Research (SSWR) 24th Annual Conference, Washington, DC.
- Yi, E.** & Adamek, M. (2019, November). *Internet use, mental health, social support, and care burden of informal caregivers*. Poster presented at the Gerontological Society of America (GSA)'s 71st Annual Scientific Meeting, Austin, TX.
- Yi, E.** (2019, January). *Differences in the advance care planning activities and end-of-life treatment preference among immigrant older adults in the U. S.: Moderation effects of race/ethnicity and acculturation*. Poster presented at the Society for Social Work and Research (SSWR) 23rd Annual Conference, San Francisco, CA.

- Yi, E.,** Kim, J., & Hall, J. (2018, November). *Satisfaction with child welfare services: Comparing three types of caregivers*. Poster presented at the Council on Social Work Education (CSWE) 2018 Annual Program Meeting, Orlando, FL.
- Yi, E.,** Bateman, D., Wilkerson, D. & Brady, E. (2018, March). *Increasing Alzheimer's caregiver's informational/emotional support through online support group*. Poster presented at the 2018 American Society on Aging (ASA)'s Aging in America Conference, San Francisco, CA.
- Yi, E.** & Adamek, M. (2018, January). *Perspectives of Alzheimer's caregivers on the Affordable Care Act: A thematic analysis of social media discussions*. Paper presented at the Society for Social Work and Research (SSWR) 22nd Annual Conference, Washington, D.C.
- Yi, E.,** Kim, J., Jagers, J., Pierce, B. & Hall, J. (2017, October). *Evaluation of service quality in the Title IV-E Waiver Demonstration Program in Indiana*. Paper presented at the Council on Social Work Education (CSWE) 2017 Annual Program Meeting, Dallas, TX.
- Yi, E.,** Bateman, D., Wilkerson, D. & Brady, E. (2017, July). *Increasing Alzheimer's caregivers' informational and emotional support through online peer group and social microvolunteering*. Poster presented at the 2017 National Hartford Center of Gerontological Nursing Excellence (NHCGNE) Leadership Conference, San Francisco, CA. [accepted].
- Hong, M., **Yi, E.,** Johnson, K., & Adamek, M. (2017, July). *Facilitators and barriers for advance care planning among ethnic minorities: A systematic review*. Poster presented at the 21st IAGG World Congress of Gerontology and Geriatrics, San Francisco, CA.
- Hutcherson, A., **Yi, E.,** Kim, J. & Kim, H. (2017, January). *College social capital and educational completion: A moderation effect of first-generation college status*. Poster presented at the Society for Social Work and Research (SSWR) 21st Annual Conference, New Orleans, LA.
- Yi, E.** & Hong, M. (2016, November). *Gender differences in death attitudes among baby boomers*. Poster presented at the Gerontological Society of America (GSA)'s 69th Annual Scientific Meeting, New Orleans, LA.
- Johnson, K., **Yi, E.** & Johns, E. (2016, November). *Through the lens of time: Childhood visual difficulty and midlife productive activities*. Poster presented at the Gerontological Society of America (GSA)'s 69th Annual Scientific Meeting, New Orleans, LA.
- Yi, E.,** Adamek, M., & Gentle-Genitty, C. (2016, April). *Students' perspectives on diverse teaching approaches*. Paper presented at the 17th Annual Midwest Conference on the Scholarship of Teaching and Learning, South Bend, IN.
- Hong, M., Cassado, B. L., & **Yi, E.** (2016, January). *Supporting caregivers of older adults with cognitive impairment: Moderating effects of support resources*. Paper presented at the Society for Social Work and Research (SSWR) 20th Annual Conference, Washington, DC.
- Hong, M., **Yi, E.,** Johnson, K., & Adamek, M. (2016, January). *Toward culturally competent care at the end-of-life: A systematic review of end-of-life care studies with ethnic minority groups*. Poster presented at the Society for Social Work and Research (SSWR) 20th Annual Conference, Washington, DC.

- Yi, E.** (2015, November). *Medical marijuana use among older adults: A systematic review*. Poster presented at the Gerontological Society of America (GSA)'s 68th Annual Scientific Meeting, Orlando, FL.
- Kim, J., **Yi, E.**, & Jagers, J. (2015, October). *Dynamic interactions among subethnicity, class, and gender in Asian/Pacific Islander Americans' discrimination*. Poster presented at the Council on Social Work Education (CSWE) 2015 Annual Program Meeting, Denver, CO.
- Gentle-Genitty, C., Kim, J., & **Yi, E.** (2015, October). *School community partnership: Exploration of risk, protective, threat, and social bonding factors in 5 Caribbean Countries*. Paper presented at the International Truancy and Dropout Prevention 103rd Conference, Memphis, TN.
- Yi, E.** & Carlin, P. (2015, January). *Marriage premium effects on wage among male workers in Korea*. Paper presented at the Society for Social Work and Research (SSWR) 19th Annual Conference, New Orleans, LA.

Invited Presentations

- Yi, E.** (2019, April). *Does acculturation matter? End-of-life care planning and preferences among foreign-born older immigrants in the U. S.* Invited presentation at the 2019 American Society on Aging (ASA)'s Aging in America Conference, New Orleans, LA.
- Yi, E.** & Adamek, M. (2018, June). *Perspectives and experience of Alzheimer's caregivers on the Affordable Care Act and healthcare system: A thematic analysis of social media discussions*. Invited presentation at the 2018 National Association of Social Workers (NASW) Annual Conference, Washington, D.C.

Teaching

Indiana University School of Social Work

<u>Year</u>	<u>Course Title</u>	<u>Roles</u>	<u>Level/Format</u>
2020F	Introductory Statistics in Social Science	Computer Lab Facilitator	PhD/Online
2020F	Integrated Practice and Policy Seminar- Aging	Instructor	BSW/Online
2019F	Research I	Instructor	MSW/Online
2019SM	Practice with Individuals, Families & Communities in Healthcare Settings	Co-instructor	MSW/In-class
2018F	Social Policy and Services	Instructor	MSW/Online
2017S	Practice Research Integrative Seminar	Guest Lecturer	MSW/In-class
2016F, 2017F	Integrative Seminar I	Guest Speaker	PhD/In-class
2015F	Integrated Practice and Policy Seminar- Aging	Instructor	BSW/In-class

2014F	Integrated Practice and Policy Seminar- Aging	Teaching Assistant	BSW/In-class
<i>California State University Fullerton Department of Social Work</i>			
<u>Year</u>	<u>Course Title</u>	<u>Roles</u>	<u>Level/Format</u>
2020F	Master's Project (Master's thesis)	Instructor	MSW/Online

Research Experience

- 2019 Research Consultant. IUSSW, Indianapolis, IN.
- A transnational project with Alzheimer's organization in Ireland to use Facebook group as a media to support caregivers. PI: David Wilkerson, PhD in Social Work.
- 2016-17 Project Coordinator. Indiana University Center for Aging Research & Regenstrief Institute, Indianapolis, IN.
- An interdisciplinary project developing a Facebook application supporting Alzheimer's caregivers. PI: Daniel Bateman, MD.
- 2015-16 Researcher. IUSSW, Indianapolis, IN.
- Scholarship of Teaching and Learning (SOTL) project of using technologies as a pedagogical tool on teaching a seminar under the supervision of Margaret Adamek and Carolyn Gentle-Genitty, PhDs in Social Work.
- 2013-16 Research Assistant. IUSSW, Indianapolis, IN.
- Sight disability in childhood on the midlife employment status. PI: Kimberly Johnson, PhD in Gerontology. 2015-16.
 - End-of-Life care among ethnic minority older adults. PI: Michin Hong, PhD in Social Work. 2014-16.
 - The implicit curriculum assessment of social work education and social work education electronic services. PI: Cathy Pike, PhD in Social Work. 2013-14.
- 2014 Research Intern. Indiana University, Bloomington, IN.
- Legalization of recreational marijuana in Colorado and Washington. PIs: Maureen Pirog and Haeil Jung, PhDs in Public Policy. School of Public Environment and Affairs.
 - Immigration effects on the native citizens' wages in the U.S. PI: Lynn Dugan, PhD in Economics. Department of Labor Studies.
- 2013 Research Intern. Indiana University Department of Economics, Indianapolis, IN.
- Male marriage premium among Korean male workers under the supervision of Paul Carlin, Ph.D. in Economics.

Professional Career Development

Methodological Training

- 2020 *Harnessing Big Data for Social Science and Health Research*. Research Method Workshop at Society for Social Work and Research (SSWR), Washington, DC. January 2020.
- 2019 *Health Disparities in Alzheimer's Research: Methodological Considerations*. Educational Workshop at the Alzheimer's Association International Conference (AAIC), Los Angeles, CA. July 2019.
- 2017 *Statistical Big Data Analysis using R* (Certificate). Statistics Summer Camp in Research Institute of Applied Statistics, Sungkyunkwan University, Seoul, Korea. August 2017.
- 2016 *Grounded Theory*. Workshop at the Indiana University School of Nursing, Indianapolis, IN. June 2016.
- 2015 *Mixed Methods Research Studies*. Workshop at the Center for Teaching and Learning at Indiana University-Purdue University, Indianapolis, IN. October 2015.
Systematic Review and Meta-Analysis (Certificate). Johns Hopkins University offered through Coursera. July 2015.

Teaching Training

- 2019 *Diversity and Inclusion Seminar*, Multicultural Center at Indiana University-Purdue University, Indianapolis, IN. August 2019.
Faculty Mentoring Training, Graduate Mentoring Center at Indiana University-Purdue University, Indianapolis, IN. May 2019.
- 2017 *Preparing Future Faculty Program* (Certificate), Indiana University Graduate School, Indianapolis, IN. November 2017.

Grant Writing Training

- 2016 & 13 *Write Winning Grant Proposals Workshops*, Indiana University School of Medicine, Indianapolis, IN. August 2016 & June 2013.

Professional Development

- 2018 *Domestic Violence Education* (Certificate), funded by Department of Justice California, Korean American Family Services, Los Angeles, CA. March-April 2018.
- 2015-16 *Clinical, Ethical, and Policy Challenges of Optimal Care for Frail Elders* (Certificate), Indiana University Health.

Professional Experience

Professional Employment

- 2016-18 Title IV-E Program Evaluator. *Post-MSW, Part-time employed*. Indiana University Department of Pediatrics Adolescent Medicine & School of Social Work, IN.

- 2011-12 Policy/Data Analyst. *Post-MSW, Full-time employed.* Korea Research Institute for Vocational Education and Training, Seoul, Korea.
- 2006 Policy Analyst. *Post-BSW, Part-time employed.* Hope in Education, Seoul, Korea.
- 2003-04 Social Worker. *Post-BSW, Full-time employed.* Seocho Community Welfare Center, Seoul, Korea.
- 2005-06 & 2002-03 Social Worker. *Post-BSW, Full-time employed.* Student Counseling Center, Soongsil University, Seoul, Korea.

Practicum/Internship/Volunteer

- 2018-2020 Community Educator. *Volunteer.* Alzheimer's Greater Los Angeles, Los Angeles, CA.
- 2008 Social Work Research Intern. *Practicum.* Korea Institute for Health and Social Affairs, Seoul, Korea.
- 2001 Social Work Practicum. Sadang Community Welfare Center, Seoul, Korea.
- 2001 Outreach Counselor. *Volunteer.* Homeless Support Center, Seoul, Korea.
- 2000 Social Work Practicum. Homeless Support Center, Seoul, Korea.
- 1999 Social Work Practicum. Karam Mental Health Clinic, Seoul, Korea.
- 1998-2000 Group Therapy Facilitator. *Volunteer.* Dr. Oh's Neuropsychiatric Clinic, Seoul, Korea.

Service And Leadership

Professional

- 2019-current *Ad hoc reviewer.* Advance in Social Work.
- 2019 *Abstract reviewer.* Alzheimer's Association International Conference.
- 2018- current *Ad hoc reviewer.* Journal of Medical Internet Research.
- 2018 *Abstract reviewer.* Gerontological Society of America.

University

- 2018-current *Leader.* Gerontology-focused Doctoral Students' Research and Writing Group, IUSSW, Indianapolis, IN.
- 2016 *Invited Speaker.* Presented 'What is Democracy: Democracy as a Way of Life' at the Korean Student Association, IUPUI, Indianapolis, IN.
- 2015-16 *Co-leader/Board member.* Underrepresented Professional and Graduate Student Organization, Indiana University Graduate School, IN.
- 2014-16 *Mentor.* Office of International Affairs, Indiana University-Purdue University, Indianapolis, IN.
- 2013 *Program Evaluator.* Assessed student learning outcomes for the accreditation standards of the CSWE. IUSSW, Indianapolis, IN.