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# Unmet Support Needs of Informal Caregivers of Older Adults

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This is to certify that the doctoral dissertation by

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Abstract

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# Abstract

Due to projected growth of the 65-and-older population and concerns of an impending care gap, reliance on informal caregivers is expected to increase. Improving support for informal caregivers is viewed as a national priority, yet research related to the unmet support needs of informal caregivers is limited. The purpose of this cross-sectional correlational study was to examine predictive relationships between contextual factors (caregiving relationship and type of illness) and environmental factors (rurality) and the unmet support needs (classes, service access, support groups, counseling, and respite) of informal caregivers of older adults. The theoretical framework was Bronfenbrenner's ecological systems theory. Archival data were drawn from the 2015 Behavioral Risk Factor Surveillance System optional caregiver module dataset provided by the Centers for Disease Control and Prevention. Findings from multiple logistic regression analysis revealed that spousal caregivers had 42.7% lower odds than adult child caregivers of reporting unmet support needs related to service access. Dementia caregivers had 2.05 times higher odds of reporting unmet support needs of counseling, 1.31 times higher odds of reporting unmet support needs related to service access, and 1.91 times higher odds of reporting unmet support needs for respite care, relative to other caregivers. Caregivers residing in a suburban county had 28.7% lower odds and caregivers not residing in a metropolitan statistical area (MSA) had 30.5% lower odds of reporting unmet support needs related to service access, relative to caregivers residing in the center city of an MSA. Health care leaders and policymakers may use the findings to distribute resources and tailor interventions to better meet the needs of informal caregivers of older adults.

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# Dedication

This dissertation is dedicated to all the informal caregivers that work tirelessly and give so generously of their time to care for loved ones, and often do so with little recognition or support. This is also dedicated to my loved ones who I had the privilege of caring for.

# Acknowledgments

I would like to express my deepest appreciation to my committee chair, Dr. Michael Furukawa. I had the pleasure of meeting Dr. Mike at my very first residency and from that point on he guided me on my dissertation journey. His guidance and support were instrumental in my success, and I cannot thank him enough for responding to my countless emails and for his encouragement to “keep pushing ahead.” I would also like to thank my committee member, Dr. Eboni Green, who shares a passion for supporting informal caregivers. I appreciated her support, guidance, and words of encouragement. I am grateful to have had such a wonderful committee that helped me to achieve my goals.

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Lastly, I would like to thank my mom who is also my best friend. She is my role model and the strongest woman I know. She has always been my biggest cheerleader throughout my entire life and I am so blessed to call her mom.

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# Chapter 1: Introduction to the Study

Informal caregivers, who are most often unpaid family or friends, play a substantial role in the healthcare delivery system in the United States. The number of informal caregivers far exceed the number of paid direct-care workers, and it is estimated that 8.2 million older adults currently depend on assistance and support from informal caregivers (Freedman & Spillman, 2014; National Alliance for Caregiving [NAC] & AARP, 2015). Tasks of informal caregiving can range from grocery shopping and household chores to complex medical and nursing tasks that were previously provided in hospitals or nursing homes (Diduk-Smith, 2017; NAC & AARP, 2015; Reinhard, Given, Petlick, & Bemis, 2008). As the long-term services and support (LTSS) system has shifted away from institutional care to home-based services in recent years, the demands and responsibilities of informal caregivers have become more complex (Moorman & Macdonald, 2013; Schulz & Eden, 2016). Despite the complexities, as many as 42% of informal caregivers surveyed in a national caregiver study reported they were providing support to a care recipient but with no prior training (NAC & AARP, 2015).

Research has indicated that most informal caregivers feel they need more support than they are currently receiving, and it has been suggested that better supporting informal caregivers should be viewed as a national priority (Black et al., 2013; McCabe, You, & Tatangelo, 2016; NAC & AARP, 2015). Even with recognition of the need to better support informal caregivers, research related to the unmet support needs of those in caregiving roles has not kept pace with the changing healthcare landscape and the shift to more home-based services (Jenkins, 2016; Wall, 2018).

Research that advances the understanding of the needs of informal caregivers in today's modern society is needed (Jenkins, 2016; Reid, 2015; Shaji & Reddy, 2012). The types of supports needed by informal caregivers can vary based on individual circumstances; however, how differences impact the unmet support needs of informal caregivers is not well understood (Gitlin, Marx, Stanley, & Hodgson, 2015; Tatangelo, McCabe, Macleod, & You, 2018; Montgomery, Kwak, & Kosloski, 2016; Reinhard et al., 2008; Tatangelo et al., 2018). Limited studies exist that examine the relationship between contextual and environmental factors and the unmet support needs of informal caregivers, especially from the perspective of the informal caregiver (Bangerter, Griffin, Zarit, & Hayver, 2017; Crouch, Probst, & Bennett, 2017; Hobfoll, 1989; McCabe et al., 2016). A better understanding of how factors are associated with the unmet support needs of informal caregivers would enable interventions to be modified to meet the unique needs and demands of those in caregiving roles (Diduk Smith, 2017, Gitlin et al., 2015; Hong, 2010).

More research is needed to determine how factors such as the caregiver relationship, type of illness, and rurality influence the unmet support needs of caregivers Studies have shown increased emotional strain and burden for informal caregivers based on the caregiving relationship and type of illness, but few studies have explored if these factors are associated with the unmet support needs of informal caregivers of older adults (Brazil, Kaasalainen, Williams, & Dumont, 2013; Reinhard et al., 2008). Rural caregivers face unique geographic barriers related to accessing support services, but few studies have examined the extent of rurality as a predictor of unmet support needs. The purpose of this quantitative study was to help fill this knowledge gap. Using data from the 2015 BRFSS optional caregiver module, I examined the association of the caregiver relationship, type of illness, and rurality with the unmet support needs (classes, service access, support groups, counseling, respite care) of informal caregivers of older adults. In conducting this study, I hoped that the results would provide health care leaders and policymakers with greater insight into the needs of today's informal caregivers.

In this chapter, I explain the background of the study along with the problem statement and purpose of the study. I introduce the research questions, hypotheses, and variables. In addition, I briefly discuss the theory selected for the study along with definitions of key terms, study assumptions, delimitations, and limitations. I also explain the significance of the study and potential social change implications.

## Background

The reliance on informal caregivers to provide needed LTSS is expected to increase as the nation faces what has been termed a *silver tsunami* where the 65 and older population is expected to nearly double by the year 2050 (U.S. Census Bureau, 2014). The number of older adults with multiple chronic conditions is also expected to rise as seniors are now often living into their 80s and 90s (U.S. Department of Health and Human Services, 2013). With the shift away from institutionalization, along with many older adults choosing to age in place, the role informal caregivers play in the LTSS system will likely increase in importance. Informal caregivers will be relied on to provide support and assistance to loved ones often for months and years at a time (Family Caregiver Alliance, 2009). There is a predicted corollary drop in the supply of informal caregivers in the coming years thus causing concern of an impending care gap for older adults with chronic conditions (Eldercare Workforce Alliance, 2018).

As the LTSS faces an impending care gap, a better understanding of how to support informal caregivers will be needed to ensure caregivers remain healthy, improve their caregiver skills, and remain in their caregiving roles (NAC & AARP, 2015; Freedman & Spillman, 2014). Research has shown a relationship between the level of support an informal caregiver receives and their ability to provide effective care (Lilly, Robinson, Holtzman, & Bottorff, 2012) yet research looking at the unmet support needs of informal caregivers is limited (Bangerter et al., 2017; Brazil et al., 2013; Tatangelo et al., 2018). Previous studies have instead often focused on burden of care or on the support needs of the care recipient (Shaji & Reddy, 2012).

Informal caregivers are a diverse group, and the types of challenges they face can vary depending on individual circumstances. Past caregiver research has shown that differing factors such as the caregiver relationship and type of illness can increase caregiver burden and may also impact the overall caregiving experience (Chappell, Dujela, & Smith, 2014; Gitlin et al., 2015; Montgomery et al., 2016; Reinhard et al., 2008). Informal caregivers in rural areas face unique geographic challenges that may also contribute to differing support needs (Crouch et al., 2017; National Rural Health Alliance, 2010). It has even been suggested that there is a greater reliance on informal caregivers in rural areas (Bouldin, Shaull, Andresen, Edwards, & McGuire, 2017). While it is recognized that the support needs of informal caregivers may differ based on contextual and environmental factors such as the caregiving relationship, type of illness, and rurality, it is not clear how these factors influence the unmet support needs of informal caregivers. It is hoped that expanded knowledge in this area will lead to more effective caregiver interventions that will maximize caregiver success while reducing burden (Gitlin et al., 2015; Hong, 2010; Tatangelo et al., 2018; Trivedi et al., 2017).

## Problem Statement

The population of older adults is one of the fastest growing segments in the United States (U.S. Census Bureau, 2014). Between now and 2030, approximately 10,000 baby boomers will turn 65 every day and by 2030, 20% of the population will fall into the category of an older adult (U.S. Census Bureau, 2014). As older adults age, they often combat chronic conditions requiring some level of care. Approximately 50% of aging adults have one or more chronic conditions and as many as 11 million aging adults have five or more conditions (National Council on Aging, 2018). As the population of aging adults rises, the number of older adults with multiple chronic conditions is expected to also rise, thus placing increased demand on informal caregivers.

Currently, most older adults with chronic health conditions rely on support from informal caregivers to remain living in the community (Freedman & Spillman, 2014; NAC & AARP, 2015). Research has shown that supporting someone with a chronic condition at home is stressful and can lead to negative consequences such as a decline in physical and mental health, and a reduced quality of life for the caregiver (Pearlin, Mullan, Semple, & Skaff, 1990). As the United States faces a rapidly aging population, the need to better support informal caregivers has perhaps never been so important.

Despite the recognition of the importance of informal caregivers, past research has often focused on the needs of the care recipient rather than the caregiver. Caregiver research has often focused on burden of care issues or has considered caregiver needs from the perspective of a third party rather than the caregivers themselves (Bangerter et al., 2017; McCabe et al. 2016). Researchers have suggested that caregiver research needs to move beyond looking at psychological dimensions and issues related to burden of care (Shaji & Reddy, 2012).

Caregiver research often lists several types of illnesses as the reason for needing care and notes multiple caregiver relationships, yet very few studies have considered the impact of these factors (Grossman & Webb, 2016). Studies have shown that contextual factors such as these can be predictive variables in the level of burden experienced by informal caregivers (Pearlin et al., 1990), but limited research exists evaluating if these same predictors impact the types of supports needed (Chappell et al., 2014; Gitlin et al., 2015; Montgomery et al., 2016; Reinhard et al., 2008).

The two most common caregiving relationships for older adults with chronic conditions are spouses and adult children (NAC & AARP, 2015). Research looking at these two caregiver groups has shown significant differences in the overall caregiving experience. Studies have shown adult child caregivers to be at an elevated risk for strain and burden due to multiple role demands (Jayani & Hurria, 2012). However, other studies have shown that spousal caregivers experience the most extensive caregiving challenges, which has been attributed to residing with the care recipient full-time and often providing care with almost no outside assistance or support (Ornstein, Kelley, Bollens-Lund &

Wolff, 2017). Past studies have shown that the caregiving relationship is considered a predictive variable when evaluating levels of burden (NAC & AARP, 2015). What is not clear is how the caregiver relationship impacts the unmet support needs of informal caregivers, as studies in this area of study are sparse (Chappell et al., 2014).

The level of caregiver burden has also been associated with the type and progression of the care recipient's illness. Studies have shown increased emotional and physical strain, and as the hours of needed care increase, so does the level of burden (NAC & AARP, 2015). A study evaluating lung cancer patients and their primary caregivers indicated a high level of unmet support needs for informal caregivers, but no predictor variables were found to be statistically significant (Sklenarova et al., 2015). A quantitative study looking at the use and nonuse of support services by informal caregivers also found few statistically significant predictive relationships; however, the study did indicate a positive relationship between the care recipient's health condition and the nonuse of support services (Potter, 2018). This outcome suggests that increased intensity in caregiving may impede the caregiver's ability to access support services. Research evaluating the association between the type of illness and the unmet support needs of informal caregivers is limited. Researchers such as Potter (2018) have suggested that more research is needed so that funding and interventions can be targeted to the needs of specific caregiver groups.

There is recognition that there are likely differences in the resources provided and resources needed between rural caregivers and their urban counterparts, yet few studies have looked at caregiver needs based on residence (Bangerter et al., 2017). The few studies that have been conducted have typically been limited to small sample sizes or specific regions (Goins, Spencer, & Byrd, 2009; Trivedi et al., 2017). Crouch et al. (2017) claimed to have conducted one of the first national examinations looking at urban and rural differences of informal caregivers, but the study did not focus on unmet support needs. It is not clear how the factor of rurality impacts the unmet support needs of informal caregivers and more research is needed to help fill this gap in knowledge (Brazil et al., 2013; Reinhard et al., 2008; Trivedi et al., 2017).

Additional information is needed to evaluate the unmet support needs of informal caregivers based on determinants such as the caregiving relationship, type of illness, and geographic challenges (Gitlin et al., 2015; Mansfield et al., 2016; Montgomery et al., 2016; Reinhard et al., 2008; Tatangelo et al., 2018). The findings from the current study helped to fill a gap in the literature and provided insights from the perspective of the informal caregiver. I hope that a greater understanding of how contextual and environmental factors influence the unmet needs of informal caregivers will assist health care providers and policymakers to better target strategies and interventions for those in caregiving roles.

## Purpose of the Study

The purpose of this quantitative study was to examine the association of the caregiving relationship, type of illness, and rurality with the unmet support needs (classes, service access, support groups, counseling, respite care) of informal caregivers of older adults. Studies on caregiver interventions have lagged behind those for care recipients, and much of the previous research on informal caregivers has focused on burden of care or perceived needs from the perspective of health care professionals (McCabe et al., 2016). To date, few peer-reviewed studies have been conducted using the newly revised 2015 BRFSS optional caregiver module (Howells, 2015). The findings from the current study provided insights into the unmet support needs of informal caregivers of older adults and reflected the viewpoints of those providing the care.

## Research Questions and Hypotheses

RQ1: What is the association between the caregiver relationship (spousal, adult child) and the reported unmet support needs of informal caregivers of older adults?

$H_0$1: There is no statistically significant association between caregiver relationship and the reported unmet support needs of informal caregivers of older adults.

$H_a$1: There is a statistically significant association between caregiver relationship and the reported unmet support needs of informal caregivers of older adults.

RQ2: What is the association between the type of illness of the care recipient (dementia, COPD, other) and the reported unmet support needs of informal caregivers of older adults?

$H_0$2: There is no statistically significant association between type of illness and the reported unmet support needs of informal caregivers of older adults.

$H_a$2: There is a statistically significant association between type of illness and the reported unmet support needs of informal caregivers of older adults.

RQ3: What is the association between rurality and the reported unmet support needs of informal caregivers of older adults?

$H_0$3: There is no statistically significant association between rurality and the reported unmet support needs of informal caregivers of older adults.

$H_a$3: There is a statistically significant association between rurality and the reported unmet support needs of informal caregivers of older adults.

## Theoretical Framework

Bronfenbrenner’s ecological systems theory (EST), first presented in the 1970s, provided the theoretical framework for this research. The theory blends ecological principles with systems theory (Bronfenbrenner & Ceci, 1994). Bronfenbrenner postulated that individual choices are impacted by both social and environmental factors. The theory asserts that performance improves when individuals are actively engaged in a supportive environment (Cho, Ory & Stevens, 2015; Wilder, 2010).

It has been suggested that future caregiver research would benefit from the application of the EST model (Wilder, 2010). Wilder noted the need to better understand the interrelationships between an individual and the various environmental systems. The EST model as described by Bronfenbrenner and Ceci (1994) includes the microsystem (roles, activities, and relationships), mesosystem (interactions between microsystems), exosystem (external factors that affect the individual), and macrosystem (culture, beliefs, and ideologies).

Intrapersonal, interpersonal, and organizational factors are three common contextual factors in the socioecological framework and aligned well with the determinants considered in this study. I this study I examined the association of the caregiver relationship to the care recipient, type of illness, and rurality with the unmet support needs of informal caregivers of older adults. The caregiver relationship and type of illness fell into Bronfenbrenner's micro and mesosystems. The social ecology of the caregiver relationship can be shaped by the illness, and multiple environmental systems may be impacted by the chronic condition (Brown, 2002; Kazak, 1997). The factor of rurality was captured in the meso, exo, and macrosystems of the EST model. EST provides a helpful framework for evaluating barriers and access issues that often accompany living in rural areas. It is important to understand how these factors may contribute to service availability and access issues for informal caregivers (Keefe & Curtin, 2012).

## Nature of the Study

The overall purpose of this study was to evaluate if contextual and environmental factors of caregiver relationship, type of illness, and rurality were associated with the reported unmet support needs of informal caregivers of older adults.

This study used a quantitative, nonexperimental, evaluation design with correlational analysis of a publicly available secondary dataset. Data were evaluated from questions drawn from the 2015 BRFSS optional caregiver module. The data had already been collected and publicly released by the Centers for Disease Control and Prevention (CDC). In 2015, 24 states participated in the optional caregiver module with over 20,000 study participants self-identifying as caregivers (CDC, 2016).

The quantitative analysis assisted in identifying which variables had the strongest predictive relationship with unmet support needs of informal caregivers. I used SPSS (version 24), which is a statistical software program, to conduct the data analysis. I performed a series of multiple logistic regression tests to evaluate associations between the independent variables (caregiver relationship, type of illness, rurality), covariates (gender, education level, hours of weekly care provided, duration of care), and each of the support service types (classes, service access, support groups, counseling, respite). I analyzed data both controlling for and not controlling for the covariates, so that it could be determined if the confounding variables had any influence on the dependent variables. I interpreted the adjusted odds ratios using a significance or $p$-value $< .05$ with a confidence interval of 95%. I used the Wald-Chi Square statistic to evaluate the significance ($p < .05$) of the explanatory variables. To determine if the model fit the data, I assessed goodness of fit using Hosmer-Lemeshow chi-square analysis with a nonsignificant $p$-value ( $p > .05$) desired. The data analysis provided an improved understanding of the factors associated with the unmet support needs of informal caregivers of older adults.

## Definitions

The following terms are defined for clarity, as they are common terms used throughout this study.

*Activities of daily living:* Routine self-care activities that are necessary for normal daily living such as eating, bathing, getting dressed, toileting, transferring, and continence (CDC, 2009)

*Burden of care:* The physical, emotional, social, and financial toll experienced by informal caregivers because of providing support to a care recipient (Kim, Chang, Rose, Kim, 2012).

*Caregiver relationship:* The relationship of the informal caregiver to the care recipient (CDC, 2015).

*Duration of care:* The number of years an informal caregiver has provided care to a care recipient (CDC, 2015).

*Educational level:* The highest grade of school completed by the survey respondent (CDC, 2015).

*Gender:* The reported sex of the survey respondent, male or female (CDC, 2015).

*Instrumental activities of daily living:* Activities necessary to live independently in the community that are not fundamental to self-care such as activities of daily living. Activities might include managing money, cooking, managing medications, housekeeping, and shopping (CDC, 2009).

*Informal caregiver:* An unpaid relative, friend, or neighbor who provides assistance with activities of daily living, instrumental activities of daily living, or complex medical tasks to a community-dwelling older adult with a chronic or disabling condition, and who may or may not reside with the care recipient (Family Caregiver Alliance, 2014).

*Metropolitan statistical area (MSA):* A geographic region that consists of at least one urbanized area of 50,000 or more inhabitants (CDC, 2015).

*Older adult:* An aging adult who is 65 years of age or older (Ortman, Velkoff, & Hogan, 2014).

*Rurality:* A term used to describe remoteness from major centers of population (Haynes & Bentham, 1982). Rural communities are typically defined as an area consisting of fewer than 10,000 people and have not been classified as urban by the U.S. Census Bureau (Thompson, 2012).

*Type of illness:* The main health problem, long-term illness, or disability of the care recipient selected by the survey respondent, which may include illnesses such as cancer, COPD, dementia, and heart disease (CDC, 2015)

*Unmet support needs:* A broad term addressing the adequacy of support services received versus the support services needed. Informal caregiver services can include features such as classes, access to information, counseling, support groups, assistive technologies, and respite (Kelly, Gibson, & Feinberg, 2013).

*Weekly hours of care:* The average number of hours of weekly care or assistance the informal caregiver provides to the care recipient (CDC, 2015).

## Assumptions

The study was based on the following assumptions. Participation in the BRFSS was voluntary and volunteers could withdraw or refuse to participate in the survey without ramifications. Participants were assured anonymity and that all responses would be kept confidential. It was assumed that the questions in the 2015 BRFSS caregiver module were asked consistently as written in all participating states and that survey responses provided by the study participants were answered truthfully, without bias, and to the best of the participant's ability. It was assumed there were no language barriers and that the proper version of the survey was used based on the primary language spoken by the participant. It was also assumed that the archival data used for this study were coded accurately. A final assumption of the study was that not all informal caregivers have the same support needs, and that needs likely vary based on individual circumstances.

## Scope and Delimitations

The scope of this study was defined by the 2015 BRFSS, which is a publicly available secondary dataset provided by the CDC. Study participants included adults over the age of 18 with a landline or cellular telephone. All 50 U.S. states, the District of Columbia, Puerto Rico, and Guam participated in the 2015 BRFSS. However, the caregiver module dataset used for this study was optional. Each state determines which of the optional modules, if any, they want to include in the survey process. In 2015, 24 states participated in the optional caregiver module, which was the largest number of participating states up to that point (CDC, 2017). The following states elected to complete the module: Alabama, Florida, Hawaii, Idaho, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maine, Maryland, Mississippi, Nebraska, New Jersey, New York, Oregon, Pennsylvania, South Carolina, Tennessee, Utah, Virginia, West Virginia, Wisconsin, and Wyoming.

A delimitation of this study was my choice to focus on a specific subgroup of informal caregivers of older adults. The BRFSS dataset does not delineate the age of care recipients, so the types of illness used in this study were limited to conditions that were prevalent among seniors. The types of illness selected for this study are among the most common chronic health conditions and leading causes of death for adults aged 65 and older (Xu, Kochanek, Murphy, & Arias, 2014). Other illnesses identified in the study such as asthma, HIV, mental illness, and substance abuse were excluded from this study since they are not chronic conditions that are necessarily associated with aging.

Another delimitation of this study included my decision to focus on the two most common informal caregiver groups of spouse and adult child. According to a study completed by NAC and AARP (2015), spousal and adult child caregivers are the two most common caregiving relationships for older adults. It has also been noted in previous research that there are significant differences in the caregiving experience for spousal versus adult child caregivers, yet how those differences impact the needs of caregivers is not well understood (Chappell et al., 2014; Gitlin et al., 2015; Howells, 2015; McCabe et al., 2016; Tatangelo et al., 2018).

An additional delimitation of this study was my decision to focus on the impact of rurality on the unmet support needs of caregivers. As a result, data from all participating states were used provided the dataset included MSA codes, thus allowing urban versus rural status to be determined.

## Limitations

The study had the following limitations. The study evaluated BRFSS data collected during the calendar year of 2015. The dataset provided information from one year and provided a snapshot that was dependent on conditions during that specific time. The caregiver module was redesigned in 2015, and questions were both eliminated and added to the module. The CDC (2015) cautions that data cannot be compared to previous years due to the survey revisions.

Other limitations included that the data compiled was based on self-reports and there was no way to validate responses from participants. Participation in BRFSS is limited to community-dwelling adults over the age of 18 with either a landline or cellular telephone. It is possible that telephone coverage may differ by geographic regions or by subpopulations. The CDC (2009) noted that coverage can be lower among low-income adults, persons with less than a high school diploma, persons with poor health, and African Americans in some of the southern states.

The use of archival data limited the choice of variables to be studied. A limitation of the caregiver module is that no information is provided regarding the stage or progression of the stated illness. For example, a care recipient may be in the early stages versus late stages of dementia or be near the end of life due to a cancer diagnosis, but the survey does not provide that level of detail. It would be anticipated that the stage of illness could impact the unmet support needs of informal caregivers.

## Significance

Despite the recognition that informal caregivers provide most of the care for community-dwelling older adults, there is a lack of research looking at the unmet support needs of informal caregivers, especially from the perspective of those in caregiving roles (Bangerter et al., 2017; McCabe et al., 2016). The Healthy People 2020 initiative identified a goal to reduce the proportion of informal caregivers who reported an unmet need for caregiver support services, but the goal was archived due to a lack of viable data

(Office of Disease Prevention and Health Promotion, 2018). To help fill this gap, a question was added to the 2015 BRFSS caregiver module asking informal caregivers what support service they most needed but were not currently receiving. This study provided insights into the types of support services needed from the viewpoint of informal caregivers.

This study was important because the reliance on informal caregivers is expected to rise, as the 65 and older population nearly doubles over the next three decades (United States Census Bureau, 2014). The results of this study helped fill the current gap in literature related to the influence of contextual and environmental factors on the unmet support needs of informal caregivers. Studies have shown that factors such as caregiver relationship, type of illness, and rurality can be a predictive factor related to caregiver burden, but how these factors were associated with the unmet support needs of informal caregivers was less clear (Gitlin et al., 2015; Mansfield et al., 2016; Montgomery et al., 2016; Reinhard et al., 2008; Tatangelo et al., 2018). More research continues to be needed to determine if predictive factors related to caregiver burden are also associated with the unmet support needs of informal caregivers.

Despite the commonalities among caregivers, it is recognized that the challenges they face are often unique and dependent on their individual circumstances. However, past caregiver research has often broadly categorized caregivers thus clouding contextual and environmental differences of the caregiving experience (Dwyer & Coward, 1992). It has been acknowledged that there are differences in the caregiving trajectory based on the caregiving relationship and type of illness yet little is known about how support needs differ based on these factors (Montgomery et al., 2016; McCabe et al., 2018; Reinhard, et al., 2008; Tatangelo et al., 2018; Gitlin et al., 2015). It was hoped that this study would add to the current body of knowledge in these areas.

For this study, the caregiving relationship of spouse and adult child caregivers was evaluated, which are the two most common caregiving relationships for older adults (NAC & AARP, 2015). Past research has shown increased emotional strain and burden for caregivers taking care of a close relative thus illustrating the importance of supporting this group of important caregivers. It is hoped that a better understanding of how the caregiving relationship is associated with the need for services will ultimately result in better care for both the caregiver and care recipient (Jayani & Hurria, 2012).

This study examined how the type of illness is associated with the unmet support needs of informal caregivers of older adults. For this study, cancer, COPD, dementia, and heart disease were studied, which are among the most common chronic health conditions and leading causes of death for adults aged 65 and older (Xu et al., 2014). To fully comprehend the complete burden associated with a care recipient's type of illness, the effect of the illness on family members must also be considered (Wittenberg, Saada, & Prosser, 2014). Previous research evaluating the impact of predictor variables on the support needs of informal caregivers is limited and more research is needed to determine if certain predictor variables impact the unmet support needs of informal caregivers (Potter, 2018).

This study evaluated if there was an association between rurality and the unmet support needs of informal caregivers. It has been acknowledged that a disproportionate number of older adults reside in rural communities yet there is limited research on the specific challenges of rural caregivers (Henning-Smith & Lahr, 2018). Previous studies have demonstrated that rural communities face geographic challenges that can create barriers and access issues to needed support services, but few studies have looked at caregiver differences based on rurality (Brazil et al., 2013; Reinhard et al., 2008; Trivedi et al., 2017). Understanding there are likely differences in the resources provided and resources needed between rural and urban caregivers, it is important to understand how these differences impact the unmet support needs of informal caregivers (Bangerter et al. 2017).

Understanding the implications of factors such as the caregiving relationship, type of illness, and rurality on the unmet support needs of informal caregivers could enable caregiver interventions to be adapted to meet the needs of this highly diverse group. Additional research in this area may also shed light on whether certain sub-groups of informal caregivers are in greater need of assistance than their counterparts. Understanding how these contextual and environmental factors impact the support needs of informal caregivers may enable resources to be better utilized. For example, support programs and funding could be targeted to specific caregiver groups and geographic locations (Potter, 2018).

The social change implications of this study could be far reaching as failure to meet the support needs of informal caregivers is likely to exacerbate the anticipated care gap for community-dwelling older adults in need of care. The impending care gap has increased the sense of urgency around the need to improve strategies and interventions for informal caregivers of older adults (Colby & Ortman, 2014; Eldercare Workforce Alliance, 2018; Frey, 2014; Mather, Jacobsen, & Pollard, 2015; NRC, 2012; Schulz & Eden, 2016; Wall, 2018). Informal caregivers with unmet support needs may not be able to continue in their caregiving role thus creating quality of care issues and unmet needs for care recipients (Brazil et al., 2013). During a time of diminishing resources, additional information related to the unmet support needs of informal caregivers may help health care leaders and policymakers to determine how to better utilize resources and target interventions to improve support for those in caregiving roles.

## Summary

Projections suggest that by 2050 the United States will experience the largest number of older adults over the age of 65 in the country's history with numbers estimated to exceed 89 million (U.S. Census Bureau, 2014). As the aging population grows, the number of people living with chronic conditions is also expected to grow thus resulting in the need for more home and community-based support. It is already estimated that 44 million Americans are providing informal care to persons with chronic conditions (NAC & AARP, 2015; Wilborn, 2015). With the aging population expected to double over the next couple of decades, the reliance on informal caregivers is only expected to increase.

Current economic and workforce challenges are forcing the health care delivery model to change (Khan, Hussein, & Deane, 2017; Schulz & Eden, 2016; Wall, 2018). New policies and new models of care will be necessary to meet the supply and demand issues the United States will face in the coming years. Better supporting informal caregivers is viewed by many as one of the most cost-effective investments that can be made in the current health care delivery model (Family Caregiver Alliance, 2009; Wall, 2018). Health care providers must recognize that they are no longer just serving the care recipient but also the caregiver (Wall, 2018). Informal caregivers are a critical component of the health care delivery model yet there is a lack of research looking at contextual and environmental factors that may impact the unmet support needs of informal caregivers.

This quantitative analysis enhanced the knowledge related to the unmet support needs of specific caregiver groups and helped to identify what types of support services informal caregivers most need and want. Using data from the 2015 BRFSS optional caregiver module, a series of multiple logistic regression tests were performed to evaluate predictive relationships between the independent variables (caregiver relationship, type of illness, rurality), covariates (gender, education, weekly hours of care, duration of care), and the dependent variables (classes, service access, support groups, counseling, respite). To date, few peer-reviewed studies have been conducted using the newly revised caregiver module. The dependent variables for this study were drawn from one of the newly added questions asking respondents “Of the following support services, which one do you most need, that you are not currently getting?” The BRFSS survey results also reflect the perspective of the informal caregiver, which has been lacking in previous caregiver studies (McCabe et al., 2016; Tatangelo et al., 2018).

There is recognition that the needs of informal caregivers are complex and can vary based on individual circumstances yet there is a lack of research differentiating between the needs of informal caregivers and their unique caregiving situations (Tatangelo et al., 2018; Gitlin et al., 2015). More efforts are needed to understand the influences of predictors such as the caregiving relationship, type of illness, and rurality on the unmet support needs of informal caregivers, so that intervention strategies can be matched to specific sub-groups of informal caregivers (Gitlin et al., 2015). The information gained from this quantitative study may assist health care providers and policymakers to better address the unmet support needs of informal caregivers, and in turn aid in the nation’s ability to meet the health care needs of the rapidly rising number of older adults

In chapter 2, I discuss peer-reviewed literature on the unmet support needs of informal caregivers, along with the theoretical foundation of EST and its application to the study.

# Chapter 2: Literature Review

## Introduction

Informal caregivers, who are most often unpaid family or friends, play a vital role in providing home-based health care for older adults with chronic conditions. As a large segment of the population in the United States ages, and as the health care industry faces workforce challenges, the importance of informal caregivers will increase in the coming years (Eldercare Workforce Alliance, 2018; Tatangelo et al., 2018). There is concern about an impending care gap as the need for care of older adults with chronic conditions is quickly rising while the supply of informal caregivers is declining (Eldercare Workforce Alliance, 2018; Wall, 2018) Despite the increasing importance of informal caregivers, this group is still often referred to as *hidden victims* or *invisible second patients* (Russell, 2013; Thies & Bleiler, 2013). Informal caregivers play an integral role in the health care delivery system; however, the extra caregiving demands often lead to increased stress and burden for those in informal caregiving roles (Pearlin et al., 1990)

According to Jenkins (2015), “Public and private sector policies regarding informal caregivers have not kept pace with the changing family dynamic of the nation.” Many researchers believe supporting informal caregivers should be viewed as a national priority, and a failure to address the unmet support needs of informal caregivers will have negative implications for individuals, families, and society (NAC & AARP, 2015; Reinhard, Feinberg, Choula, & Houser, 2015; Shaji & Reddy, 2012). It is essential that more effective policy strategies are put in place to reduce the unmet support needs of older adults and those who care for them (NAC & AARP, 2015; Freedman & Spillman, 2014).

The types of supports needed by informal caregivers can vary based on individual circumstances; however, how factors such as the caregiving relationship, type of illness, and rurality impact the unmet support needs of informal caregivers is not well understood (Gitlin et al., 2015; McCabe et al., 2018; Montgomery et al., 2016; Reinhard et al., 2008; Tatangelo et al., 2018). For example, persons living in rural areas may find themselves with fewer resources and longer distances to access needed services, limited or no public transit, and fewer young people residing in their communities (Bangerter et al., 2017; Brazil et al., 2013; Charlton, Schlichting, Chioreso, Webb, & Vikas, 2015; Jackson, Coultas, Suzuki, Singh, & Bae, 2013; Tatangelo et al., 2018). Thus, with over a quarter of adults above the age of 65 living in rural areas (U.S. Census Bureau, 2010), it is important to understand how these rural-specific challenges impact the support needs of informal caregivers.

According to a study funded by NAC & AARP (2015), several factors can increase caregiver burden including the caregiver relationship and type of illness. Previous research has also indicated significant differences in the overall caregiving experience based on these factors, but data on how these differences may influence the unmet support needs of informal caregivers is lacking (Chappell et al., 2014). It is important to understand how contextual factors such as this are associated with the unmet support needs of informal caregivers so that interventions can be tailored to meet the unique needs and demands of those in caregiving roles (Gitlin et al., 2015; Tatangelo et al., 2018).

A theme noted in a literature review of caregiver studies also showed there was a lack of research looking at unmet support needs from the perspective of the informal caregiver (Bangerter et al., 2017). Researchers McCabe et al. (2016) found comparable results in their literature review looking at support needs for dementia caregivers. The results of both literature reviews showed that much of the previous research related to caregiver support needs has been from the perspective of third parties, often health care professionals.

Previous research has often focused on the support needs of the care recipient or on caregiver burden, but little research exists that provides insight into the unmet support needs of today’s informal caregiver (Reid, 2015). There is a paucity of research related to the unmet support needs of informal caregivers with few studies evaluating caregiver needs based on the individual circumstances of the caregiving role (Bangerter et al., 2017; Brazil et al., 2013; Tatangelo et al., 2018). This study was designed to help fill this knowledge gap. I investigated whether contextual (caregiving relationship, type of illness) and environmental (rurality) factors were associated with the reported unmet support needs (classes, service access, support groups, counseling, respite) of informal caregivers of older adults. The current study used the 2015 BRFSS optional caregiver module in which self-identified caregivers were asked what support service they most needed but were not currently receiving. The findings of this study reflected the perspectives of the actual caregiver unlike much of the previous caregiver research that has looked at unmet support needs from the perspective of a third party.

The social change implications of this study could be far reaching as failure to meet the support needs of informal caregivers may exacerbate the anticipated care gap for community-dwelling older adults in need of care. During a time of diminishing resources, additional information related to the unmet support needs of caregivers may help health care leaders and policymakers to determine how to best use resources and target interventions to ensure the growing number of older adults have access to needed home-based health care services in the years to come.

This chapter includes a focus on the literature related to the unmet support needs of informal caregivers of older adults and the importance of addressing this issue. The chapter is broken up into major sections and subsections highlighting the relevant literature related to the area of study. The sections include an introduction to the problem followed by a section describing the literature search strategy, which includes databases and search terms utilized, along with the current and seminal literature included in the review. The next section provides an extensive literature review of the theoretical framework selected for the study including a rationale for the use of the theory and how it was applied to the study. A section on the nature and extent of informal caregiving provides foundational information for the study and is followed by a section on the demographic changes occurring in the United States that are causing concerns of an impending care gap. A section on the unmet support needs of informal caregivers of older adults provides an evaluation of the literature based on the research questions and key variables of the study. The closing section includes a summary of the literature in relation to the research questions and the gap in the literature, along with a preview of the content covered in Chapter 3.

## Literature Search Strategy

Databases utilized included CINAHL, EBSCO Host, Medline with Full Text, ProQuest, PsychINFO, PubMed, Sage Premier, ScienceDirect, and SocINDEX. I selected these databases based on relevancy to the topic area and needs of the study, along with the desire to acquire peer-reviewed information. Search terms that I used included: *BRFSS and caregivers, carers, caregiver cliff, caregiver gap, caregivers and support services, caregiver relationship, COPD caregivers, coping ethnology, dementia caregivers, ecological systems theory, family caregivers, informal caregivers, older adult caregivers, spousal caregivers, unmet needs of caregivers,* and *urban and rural caregivers.*

The literature review included both current literature and seminal literature due to the needs of the study. I gathered current literature from the years of 2012-2018. Information related to the 2010 U.S. Census was needed for this study. I also viewed seminal research as important due to some landmark caregiver studies published in the late 1990s and early 2000s. The studies, while dated, provided important background information and foundational knowledge for the area of study.

## Theoretical Foundation

Bangerter et al. (2017) conducted an extensive review of the literature looking at how caregiver needs were assessed in the literature. Findings suggested that the level of validity and rigor was questionable for some studies and that caregiver research using conceptual and theoretical frameworks was relatively uncommon. While uncommon, there are theories that have been credited for making contributions to understanding the experiences of informal caregivers. In this section, I discuss some of the theoretical frameworks that have been applied to past caregiver studies, along with criticisms of the theories. I also discuss the proposed benefits to applying a socioecological model to future caregiver research. The section concludes with the theoretical framework selected and how it was applied to the study.

## Theoretical Frameworks Applied to Caregiver Research

Two theories that have been used when examining caregiver well-being and experiences are Goode’s (1960) scarcity hypothesis of role theory and Pearlin et al.’s (1990) stress and coping model. Goode’s theory asserts there will be role strain if resources are lacking and individuals do not feel they have adequate support. Informal caregivers must balance multiple roles, and Goode suggested that having multiple role commitments and inadequate support often results in role strain, role demand overload, and role conflict.

Pearlin et al.’s (1990) stress and coping model postulates that stressors can affect the well-being of informal caregivers and that the availability of resources is necessary to offset adverse effects or burden. Pearlin et al.’s model focuses on interrelationships between variables such as the caregiving context, primary and secondary stressors, mediators, and how they impact caregiver well-being. While Pearlin et al.’s theory has been used extensively in gerontological research, few studies have directly applied the stress and coping model to the actual usage of caregiver support services (Bengtson, Settersten, Kennedy, Morrow-Howell, & Smith, 2016; Dal Santo, Scharlach, Nielsen, & Fox, 2007; Schulz, Gallagher-Thompson, Haley, & Czaja, 2000).

The theories of Goode (1960) and Pearlin et al. (1990) have been credited for making significant contributions to understanding the caregiver experience and the development of caregiver interventions (Bengtson, et al., 2016). A criticism of both theories is that they do not adequately capture social and contextual influences. Health care intervention strategies that do not fully consider social and contextual influences lack long-term success (Talmadge, 2009). It has been proposed that socioecological models may provide a more comprehensive approach to examining the various determinants that can affect those in caregiving roles and that future studies would benefit from applying this type of framework (Cho et al., 2015; Fleury & Lee 2006; McLeroy, Bibeau, Steckler, & Glanz, 1988).

Another theory that has been applied to research related to access and use of support services by informal caregivers is Andersen's health services utilization model (Andersen, 1995). Andersen's model focuses on how predisposing, enabling, and need factors impact the use of services (Andersen, 1995). The model initially focused on the family as a unit and has also been used extensively to evaluate the attitudes and beliefs of individuals as they relate to the utilization of services (Andersen, 1995). The model has gone through several iterations over the years. The most current version emphasizes a public health perspective and the belief that personal health practices are a driving force in achieving successful health outcomes (Andersen & Newman, 2005).

Despite the various iterations of Anderson's health services utilization model, criticisms include the lack of attention paid to socioecological and cultural perspectives (Evans & Stoddart, 1990). Some researchers think the model is too narrowly focused and does not fully capture the interdependence of factors (Aday & Awe, 1997; Gochman, 1997). It can also be difficult to classify certain factors as either predisposing or enabling (Potter, 2018).

It has been suggested in modern society that there is a need to look at informal caregiver research from an ecological perspective (Wilder, 2010). The EST, first presented by Bronfenbrenner in the 1970s, captures environmental fit and the interrelationships between the individual and various environmental systems (Bronfenbrenner & Ceci, 1994). When applied to caregiver research, EST provides a framework for understanding the interconnectedness of factors associated with the unmet support needs of informal caregivers. For this reason, I used EST as the theoretical base for this study.

## Ecological Systems Theory

The EST is a human development theory that combines ecological assumptions with systems theory (Bronfenbrenner & Ceci, 1994). Bronfenbrenner's work initially focused on child development but expanded over the years to capture the development of individuals, families, and communities throughout the life course (Smedley & Syme, 2000). According to Bronfenbrenner & Ceci, the ecological systems perspective "considers environmental fit based on the assumption that patterns of health and well-being are affected by an interplay among biologic, behavioral, and environmental factors."

By Bronfenbrenner's own admission, the theory has been in an almost constant state of refinement (Bronfenbrenner, 1989). Bronfenbrenner critiqued his own work and in later years self-criticized the theory for placing too much emphasis on context and for discounting the role the individual plays in the development process throughout the lifespan. Regardless of his criticisms and alterations to the theory, EST has remained focused on person-context interconnectedness (Tudge, Gray & Hogan, 1997).

Ecological as defined by Merriam-Webster (2018) is a branch of science concerned with the interrelationship of organisms and their environments. In the context of a socioecological framework, this often refers to how individuals function in their existing environments (Dale, Smith, Nolan, & Chess, 2009). Systems theory is rooted in the belief that individuals are continuously interacting with their environment. Bronfenbrenner (1994) contends that the behavior of individuals is influenced by the different environments they encounter throughout their lifespan.

Bronfenbrenner's original work surrounding the EST suggests that human development across the lifespan is influenced by distinct types of environmental systems, which consist of the microsystem, mesosystem, exosystem, and macrosystem. This figure illustrates the interrelationship between the individual and the various systems. Bronfenbrenner (1999) pointed out the importance of the person, process, and environment within the framework.

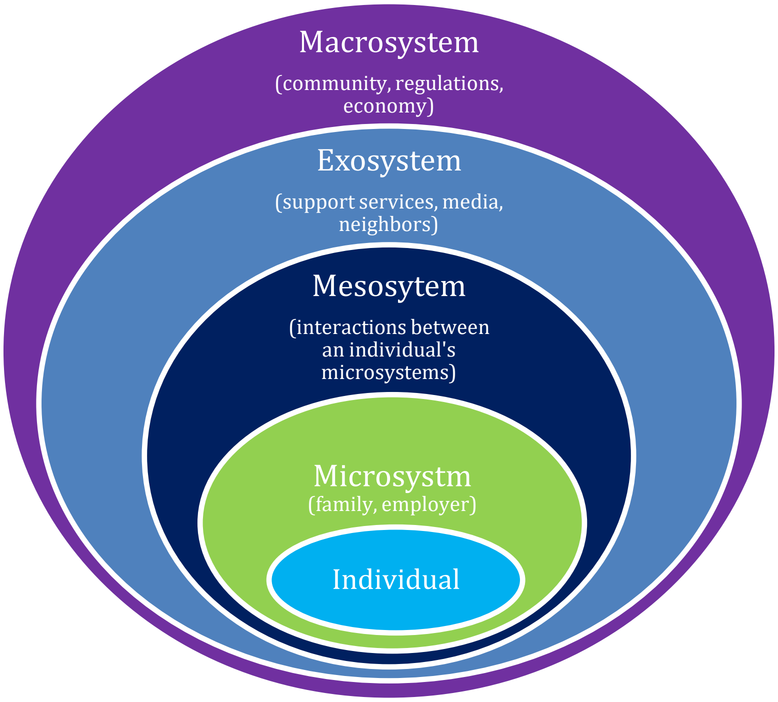

*Figure 1.* A diagram showing the types of environmental systems as outlined in Bronfenbrenner's ecological systems theory.

The EST can be used to evaluate how a person functions within their environment (Forte, 2007). EST asserts that performance improves when individuals are actively engaged in a supportive environment (Cho et al., 2015; Wilder, 2010). According to EST, factors ranging from familial relations to political structures influence the individual and can create demands and supply resources to meet needs. Forte suggests there is an ideal sub-environment that provides the supports needed to help an individual succeed. EST provides a framework for identifying the resources that are available to meet the needs of an individual (Wise, Sneed, & Berry, 2011).

## Application of Ecological Systems Theory to Study

Intrapersonal, interpersonal, and organizational factors are three common contextual factors in a socioecological framework aligned well with the determinants considered in this study. The current study examined the association of caregiver relationship, type of illness, and rurality with the unmet support needs of informal caregivers of older adults. EST includes both physical and structural settings, which for this study included support services needed by informal caregivers that they were not currently receiving. EST addresses processes and connections between individuals and their communities. An understanding of these processes and connections can help detect sources of strain within an individual's ecosystem and ultimately assist practitioners with connecting individuals to needed resources (Forte, 2007; Ungar, 2002).

In this study, the determinants of the caregiver relationship and type of illness were tied to Bronfenbrenner's micro and mesosystems. EST has been used in past research to understand the impact of chronic health conditions on both the care recipient and family caregivers (Carcone, 2010). The social ecology of the caregiver relationship can be shaped by the illness and multiple environmental systems may be impacted by the chronic condition (Brown, 2002; Kazak, 1997). The type of illness ultimately affects caregiver demands and the daily routine of the caregiver. Adequate resources are needed within each of Bronfenbrenner's environmental levels from family support to available support services to maintain optimal health and well-being for the individual (Bivens, 2016). This contributes to the overarching tenet of the EST that asserts the whole is greater than the sum of its parts. According to Ungar (2002), “the well-being of individual systems contributes to the well-being of the entire system.”

The unmet support needs of informal caregivers related to rurality were captured in Bronfenbrenner’s meso, exo, and macrosystems. The EST framework can be especially useful when examining caregiver issues within a rural context due to barriers that often accompany living in rural areas such as limited availability of health care services, limited transportation options, and fewer young people residing in rural communities. These environmental factors not only influence the care-mix available for older adults but can also impact the services available to meet the needs of those in caregiving roles (Halverson, Friedell, Cantrell, & Behringer, 2012; Keefe & Curtin, 2012).

EST asserts that functioning improves if individuals are well connected and are engaged in a supportive environment (Cho et al., 2015; Wilder, 2010). A study completed by Ali and Bokharey (2015) evaluated the lived experiences of dementia caregivers using the EST to evaluate the inconsistencies between role demands and access to resources. Ali and Bokharey noted that there tends to be a correlation between the quality of life for the caregiver and care recipient and the ability for informal caregivers to balance demands with access to resources. Their research findings indicated that study participants perceived stressors as being at crisis level and caregiver demands were incompatible with available resources. Their study results also helped confirm their belief that informal caregivers who contribute time and energy often do so at the peril of their own well-being.

The application of the EST related to informal caregiving provided a useful framework for evaluating the numerous factors that can impact the support needs of informal caregivers (Wilder, 2010). Wilder (2010) suggested that a central focus of EST is to improve functioning for individuals through increased access to resources. The theory looks at the environmental fit and supports needed versus supports available and considers the interconnectedness of factors associated with caregiving.

## Nature and Extent of Informal Caregiving

### Population of Informal Caregivers

Informal caregivers, who are most often unpaid family or friends, provide most of the long-term care in the United States, and it is estimated that as many as 87% of Americans needing long-term care rely on informal caregivers (NAC & AARP, 2015). The most recent caregiver research report completed by the NAC and AARP (2015) found that over 34 million people in the United States had provided care to an adult over the age of 50 in the previous twelve-month period. While informal caregivers are unpaid, the economic value of the care provided was estimated at $470 billion dollars in 2013, which exceeds federal and state government spending that same year for medical and long-term care services (Reinhard et al., 2013).

The level of support provided by informal caregivers varies based on the needs of the care recipient, but research has shown that millions of informal caregivers are providing extensive to substantial care and support (NAC & AARP, 2015). A national study using data from the 2011 National Health and Aging Trends survey showed that as many as 6.5 million informal caregivers reported providing extensive health care assistance to a care recipient, 4.4 million provided some assistance, and 3.8 million provided no assistance with health care related tasks (Wolff, Spillman, Freedman, & Kasper, 2016). This same study showed that 8.5 million informal caregivers provided care for someone with substantial care needs, which is defined as a person having dementia or needing assistance with two or more self-care activities. The 2015 Caregiving in the U.S. report shows that informal caregivers spend an average of 24.4 hours a week providing support to care recipients and the average duration of care is four years. This same study looked at level of caregiver burden with 40% of informal caregivers reported as being in high burden situations. For informal caregivers providing more than twenty-one hours of care each week, the level of burden went up to 92%.

The characteristics of informal caregivers vary but demographic data shows some common trends for those in caregiving roles. The 2015 Caregiving in the U.S. report showed that six in ten caregivers are female, and the average age is 49.2 years old (NAC & AARP, 2015). Similar caregiver characteristics related to age and gender were found in a national caregiver study using data from the 2009 and 2010 caregiver module included in the BRFSS (Trivedi et al., 2017). The study was comprised of 111,156 informal caregivers and showed the average caregiver age to be 55 years old. Most caregivers were female (56.7%), were of Caucasian or Hispanic origin, and most reported having at least some college education. As compared to noncaregivers, more caregivers reported being out of work for more than a year. Trivedi et al. (2017) reported that while many demographic differences were statistically significant between caregivers and noncaregivers, differences overall were small. When compared to noncaregivers, those in caregiving roles were more likely to report poorer mental health, fewer social connections, and insufficient sleep. Trivedi et al. suggested that the study findings demonstrated an inherent risk for future health problems because of caregiving responsibilities.

Demographic data also shows that approximately 20% of older adults aged 65 and older reside in nonmetropolitan areas and research has shown a greater prevalence of caregiving takes place in rural areas (Bouldin et al., 2017). Resources can be scarce for informal caregivers in rural areas due to services being spread out over larger distances and transportation at times being cost prohibitive (Monohan, 2013). Family members often live further away from the care recipient, which can create an added burden for informal caregivers due to time away from their home and work (Monohan).

Research has indicated that despite the heavy demands often placed on informal caregivers only a small percentage use support services (Hong, 2010). A study completed by Hong and Harrington (2016) looking at patterns of service utilization, suggested that informal caregivers only use an average of 1.7 services during their caregiving experience. A quantitative study of 1,739 paid and unpaid caregivers using the 2011 National Health and Aging Trends dataset showed comparable results and found as little as 25% of caregivers ever reported having used support services (Wolff, Spillman, Freedman, & Kasper, 2016). The reasons for the underutilization of support services are not well understood. Informal caregivers have been called the "*single most important allies*" in health care and researchers have suggested that more studies are needed to understand the caregiver experience so support services can be tailored to maximize caregiver success while reducing burden (Trivedi et al., 2017).

## Responsibilities of Informal Caregivers

As the LTSS system has shifted away from institutional care to home-based services in recent years, the demands and responsibilities of informal caregivers have become more complex. Caregiving tasks range from grocery shopping and household chores to complex medical and nursing tasks that were previously provided in hospitals or nursing homes (Diduk-Smith, 2017; NAC & AARP, 2015; Redfoot, Feinberg, & Houser, 2013; Reinhard et al., 2008). Shorter hospital stays have also contributed to the changing tasks of informal caregivers, and recent research has shown six in ten informal caregivers are now performing medical and nursing related tasks (NAC & AARP, 2015). Tasks can include assisting with surgical dressings, wound care, administering injections, tube feedings, catheter and colostomy care, or assisting with the use of complex medical equipment (Emanuel, Fairclough, Slutsman, & Emanuel, 2000; Keith, 2009; Redfoot et al.,2013; Wilburn-Lee, 2015).

Caregiving today is more costly, stressful, and demanding than ever before and informal caregivers are often ill-equipped for the expanded roles and duties they now must take on (NAC & AARP, 2015; Reinhard, Levine, & Samis, 2012). Recent research has indicated that 42% of informal caregivers reported completing complex medical and nursing tasks without any preparation or training (NAC & AARP, 2015). A mixed methods study provided comparable results indicating that most informal caregivers reported wanting more assistance than they were currently receiving (Stirling, Andrews, Croft, Vickers, Turner, & Robinson, 2010). As the reliance on informal caregivers continues to grow, levels of burden and unmet support needs for those in caregiving roles will likely increase (Redfoot et al., 2013).

## Aging Population and Increasing Burden of Care

### Demographic Changes in the United States

The population distribution of the United States is shifting quickly in both the number and proportion of older adults 65 and over. It is well recognized that the changing demographics will impact the nation's health, social, and economic institutions (Khan et al., 2017; Schulz & Eden, 2016). Life expectancy has increased over the years and as older adult's age, they often combat chronic conditions requiring some level of care. Approximately 50% of aging adults have one or more chronic condition and as many as 11 million aging adults have five or more (National Council on Aging, 2018). Research has shown that supporting someone with a chronic condition at home is stressful and can lead to negative consequences such as worsening physical and mental health, and reduced quality of life for the caregiver (Pearlin et al., 1990). As the population of aging adults rises, the number of older adults with multiple chronic conditions is expected also to rise thus placing increased demand on informal caregivers.

Several factors have changed the caregiving landscape in the United States including low fertility rates leading to less offspring to help care for aging adults (Khan et al., 2017). Khan et al. (2017) suggested that increased de-population trends in rural areas, and increased migration of adult children due to occupational opportunities, are also issues contributing to the uncertainty of family members being available to provide needed care for community-dwelling older adults. Past studies have suggested these changes can decrease quality of care and adversely affect overall quality of life (Bernstein, 2002; Hussein & Khan, 2012; Khan, 2014). The changing family dynamic only adds to the concerns of an impending care gap and reinforces the need to ensure informal caregivers receive the support needed to remain in their caregiving roles.

Economic institutions and health care providers are also feeling the mounting pressures of the rapidly aging population. LTSS providers are already facing workforce shortages that are only predicted to worsen in the coming years (Elder Workforce Alliance, 2018; Molvig, 2016; Wall, 2018). These same providers are functioning in a do more with less environment and have watched funding sources such as Medicare and Medicaid tighten. Without the support provided by informal caregivers, Medicare expenses would be significantly higher yet changes in health policy to address how to better meet the needs of informal caregivers has been slow (Jenkins, 2016; Reid, 2015).

## Caregiver Gap: Supply and Demand Issues

Informal caregivers provide the majority of LTSSs for older adults in the United States, and the future demand for services is expected to outpace the supply of informal caregivers (Redfoot et al., 2013; Schulz & Eden, 2016). With a shrinking economic base and the rapidly aging population facing the United States, health care leaders are struggling to find ways to continue delivering services while at the same time maintaining quality of care (Eldercare Workforce Alliance, 2018; Hussein & Khan, 2012; Khan, 2014; Wall, 2018). The workforce shortage facing health care providers is one of the industry’s greatest challenges (Elder Workforce Alliance, 2018;

Molvig, 2016). A recent survey of 700 long-term care communities for older adults showed that one in seven paid caregiver positions went unfilled in the previous twelve months and nearly half of the providers reported they had no applicants for vacant positions. The study's findings are considered common across the country (Molvig, 2016).

The workforce shortage coupled with the rising number of older Americans has led to concerns of an impending care gap or what some call a *caregiving cliff* (NAC & AARP, 2015; Wall, 2018). Health care leaders acknowledge that any reductions in paid or unpaid caregiver support will have negative implications that can lead to quality of care issues for both the caregiver and care recipient (Litzelman, Kent, Mollica, & Rowland, 2016; Shaji & Reddy, 2012; Wall, 2018). Failure to address the unmet support needs of informal caregivers is likely to exacerbate the care gap leading to the inability to provide needed home and community-based health care for older adults with chronic conditions (Brazil et al., 2013; Levine, Halper, Peist, & Gould, 2010; Schulz & Eden, 2016).

The changing demographics and current economic conditions are forcing a change in the current health care delivery model. Informal caregivers are a critical component of the health care delivery system yet in a recent study only 16% of caregivers reported ever having a health care provider inquire about what supports and services the caregiver would benefit from (NAC & AARP, 2015). A study of 188 dyads of patients diagnosed with lung, urological, or gastrointestinal cancer, and their primary caregivers, showed that only 14.4% of the participants reported having no unmet support needs while 43.6% of the study participants reported at least ten unmet support needs, which included access to services, informational needs, and the need for emotional support (Sklenarova et al., 2015). It is essential for health care providers to recognize that they are no longer just serving the care recipient but also the caregiver (Wall, 2018). Caregiver research must move beyond looking at psychological dimensions and issues related to burden of care and must start incorporating research related to the long-term care system and caregiver interventions (Shaji & Reddy, 2012).

## Caregiver Support Ratio

According to a recent study completed by the AARP Public Policy Institute (2013), the number of available caregivers will drop by as much as 50% by the year 2030. This significant drop in caregivers is sometimes referred to as the *“2030 problem”* (Redfoot et al., 2013; Wall, 2018). AARP illustrates the impending care gap with a caregiver support ratio and uses the calculation as one means for evaluating the availability of future caregivers. The caregiver support ratio is measured by using the number of potential informal caregivers aged 45-64, which is the most common caregiving age range, divided by the number of people aged 80 and older.

Looking at twenty-year periods, the caregiver support ratio reflected seven potential informal caregivers for every person aged 80 and older in 2010. That number is forecasted to plummet in the next few decades as baby boomers transition into old age. By 2030, the caregiver support ratio is expected to drop abruptly from a 7 to 1 to 4 to 1 ratio, and by the year 2050, it is expected to drop even further to less than 3 to 1. Between

2010-2030, this reflects a one percent increase in the population of persons aged 45-64 while the population of those 80 years and older will grow by 79% (Redfoot et al., 2013).

While many in the industry speak of the approaching “*2030 problem*,” some in the industry believe the caregiver crisis is already here, especially in certain geographic regions (Shaji & Reddy 2015; Wall, 2018). New policies and new models of care will be required to meet the caregiver supply and demand issues facing the United States. Executing strategies and interventions to meet the unmet support needs of informal caregivers is considered by many to be one of the most cost-effective investments that can be made in the current health care delivery model (Family Caregiver Alliance, 2009; Wall, 2018).

## Implications of Unmet Support Needs for Informal Caregivers

Researchers Shaji and Reddy (2012) believe the contributions of informal caregivers often go unnoticed and that policymakers and the long-term care system largely disregard informal caregivers. They point out that informal caregivers should be viewed as irreplaceable because no society could afford to replace all of them with paid workers. Several researchers believe the caregiving issues facing the country both now and, in the future, must be a shared responsibility among individuals, family, and the government (Levine et al. , 2010; Reid, 2015; Shaji & Reddy, 2012; Wall, 2018). However, Levine et al. (2010) believes that informal caregivers have been neglected by policymakers due to their reluctance to begin paying for something that has typically been free.

Government funded programs such as Medicare and Medicaid spend billions of dollars on care related expenses for older adults with chronic conditions each year (Centers for Medicare & Medicaid Services, 2015). As an example, it is estimated that one in every five Medicare dollars already goes towards supporting those with Alzheimer’s and other dementia-related disorders. That number is projected to climb to one in every three dollars by the year 2050, and there is concern that Alzheimer’s could ultimately bankrupt the Medicare system if policies and interventions are not put in place to combat the disease (AARP Public Policy Institute, 2015; Alzheimer’s Association, 2017).

The Medicaid program spends approximately $80.6 billion a year on home and community-based services (HCBS) (Centers for Medicaid & Medicare, 2015). According to the Kaiser Family Foundation (2018), Medicaid is the primary source of funding for LTSS for older adults needing support with self-care needs and household activities. Over a quarter of HCBS enrollment is for home health services, but three-quarters of all states report long waiting lists for funding (Kaiser). Kaiser reported that in 2016, 656,195 individuals were on a waiting list for services with an average wait time of 23 months. This only adds to the reliance on informal caregivers. While HCBS is a cost-effective approach to LTSS, needed funding has not kept pace with inflation and demand due to the growing number of seniors.

Health policy efforts will be needed to adequately address the growing number of seniors and how to better support informal caregivers. Reid (2015) completed a qualitative study aimed at discovering how health policy could improve the caregiving experience for under-supported dementia caregivers. The study looked at the caregiving experience for both paid and unpaid caregivers. Study findings indicated an overall lack of support for caregivers resulting in many unmet support needs for those in caregiving roles. Specifically, Reid's study found that both formal and informal caregivers experience difficulty, an overall frustration with a lack of support services such as respite, and lack of information about the care recipient's condition. Reid suggested that more caregiver research is needed that will provide policymakers with the acumen to establish policies that increase needed services and supports for caregivers. The implications of Reid's study aligned with the recommendations of researchers Shaji and Reddy (2012) who believe caregiver research needs to begin addressing various caregiving issues including the efficacy of caregiving interventions.

It is evident that the services and care provided by informal caregivers are vital and results in tremendous costs savings to the government. A shortage of paid caregivers coupled with the concern that informal caregivers will burn out and institutionalize care recipients should give policymakers cause for great concern (Levine et al., 2010; Reid, 2015). With the rapidly rising number of seniors in the United States, policies and funding will be needed to address the unmet support needs of informal caregivers more fully.

## Unmet Support Needs of Informal Caregivers

Many older adults with chronic conditions rely heavily on family and friends to provide needed care. Jayani and Hurria (2012) completed a literature review looking at the key aspects of informal caregiving of older adults with cancer and found as much as

63% of care to cancer patients is provided at home. This same review showed that informal caregivers, especially spousal, are often at an even higher risk for depression and burden than the cancer patient. Other studies also confirmed the negative impact informal caregiving can have on the quality of life and overall welfare of informal caregivers, and that unmet needs for a caregiver can result in unmet needs for the care recipient (Brazil et al., 2013; Hazzan et al., 2016; Litzelman et al., 2016; Pearlin et al., 1990).

Previous research has indicated that most informal caregivers want more or better support than they are currently receiving with one study indicating that over 85% of informal caregivers have unmet needs (Black et al., 2013; NAC & AARP, 2015; McCabe et al., 2016). A quantitative study looking at how caregiver stress was interpreted by the caregiver showed that informal caregivers who do not feel they are receiving adequate supports had been found to experience feelings of helplessness and anger (Cheng et al 2012). Another study found that dementia caregivers felt forgotten and abandoned when having difficulty accessing sufficient and appropriate services (Lilly et al., 2012).

## Service Utilization

A quantitative study by Hong and Harrington (2016) looked at the impact of service utilization on the perceived health of caregivers. The study looked at 1,838 informal caregivers of older adults using a secondary dataset from the 2004 National Long-Term Care Survey. The study looked at various caregiver support services including the use of home health services, meal delivery, support groups, housekeeping, and transportation services. The study found that there was a positive relationship between a lower use of resources and higher burden and poorer perceived health by informal caregivers. Hong and Harrington also suggested that as the health of the care recipient worsens, and caregiver tasks increase, there is the perception that resources and social support diminish.

Using the same secondary dataset, Hong (2010) also looked at patterns of service utilization by informal caregivers of older adults, along with determinants associated with the patterns. Services evaluated in the study included financial information, support groups, respite, adult day care, personal and nursing services, housework, meal delivery, transportation, home modifications, and assistive devices. Study findings showed that informal caregivers use 1.7 services on average with assistive devices, home modifications, and personal and nursing services being the most widely used services. According to the study, respite, day care, and support groups were rarely used.

The Hong (2010) study showed that determinants impacting service utilization patterns were access to Medicaid or private insurance to pay for support services, the need level of the care recipient, and race. According to Hong, even when support services are available, many informal caregivers do not take advantage of the services or they wait until very late in the caregiving process to access needed supports. Hong suggested that efforts to create a more effective system of supports for informal caregivers are needed, along with more research looking at the impact of determinants on service utilization. Hong believes further research in this area would provide beneficial information that could help shape policy and practice aimed at better supporting informal caregivers of older adults.

More research is needed to expand the understanding of unmet support needs for informal caregivers. Bangerter et al. (2017) conducted an extensive review of the literature looking at how caregiver needs are currently assessed in the literature. The search covered a twenty-six-year span from 1990-2016 and identified only twenty-six relevant articles. As a part of the literature review, a seminal study completed by Patrick and Peach (1989) was noted for placing caregiver needs into categories of unmet (needs that are not satisfied) and undermet (needs that are partially satisfied). Bangerter et al. (2017) suggested that future caregiver research would benefit from considering these two categories, as it would help drive services that need to be improved versus caregiver services that need to be developed. A theme noted in the literature review was that previous studies looking at caregiver needs often reflected the view of the health care professional or clinician rather than the caregiver. This view is consistent with the findings of McCabe et al. (2016) who have done extensive research on dementia caregivers. According to McCabe et al., few studies have looked at factors impacting unmet support needs from the perspective of the informal caregiver.

As suggested in the EST framework, both contextual and environmental factors come into play in the caregiving process. Talley and Crews (2007) proposed a triadic model that includes three partners in the long-term care process, the care recipient, caregiver, and health care provider. According to Talley and Crews, only when the three partners work together does the caregiving process function effectively. Health care providers must recognize informal caregivers as partners and must view them as vital to the caregiving process (Roth, Fredman, & Haley, 2015). Health care providers need to play an active role in ensuring that resources are provided for informal caregivers including providing them with helpful tools and information to assist them with their caregiving duties (Roth et al., 2015; Wolff et al., 2014).

## Caregiver Support Needs

Maintaining the physical and mental health of informal caregivers is a crucial factor in their ability to continue in their caregiving role. When the well-being of informal caregivers decreases to a point where they are no longer able to sustain care and perhaps need to seek care themselves, this is referred to as the "*double boomerang*" effect (van Exel, de Graaf, & Brouwer, 2008). This then results in two people seeking formal health care services, which might have been avoided if more had been done to meet the needs of the caregiver.

Over the years, some of the common caregiver interventions have included services such as classes, respite, support groups, individual counseling, and information and referral services (Diduk-Smith, 2017). Despite these offerings, the NAC (2015) continues to speak of a "*needs gap*" related to services provided versus services needed for older adults and those that care for them. According to a pilot study of 37 survey participants looking at the unmet needs of caregivers, caregiver interventions have not always produced desired results and even when available at times are underutilized (Diduk-Smith, 2017). Research overall related to underutilization of services has been inconclusive. Previous studies have shown that informal caregivers, especially in rural settings, have had difficulty accessing care due to a shortage of health care workers, along with transportation challenges (Wilson, Justice, Sheps, Thomas, Reid, & Leibovici, 2006). A literature review by Monahan (2013) looking at the demographics of informal caregivers of older adults in rural areas also showed transportation challenges as a major barrier to service access. This same review noted that access to resources such as respite may also be limited due to the dispersion of services over large geographic areas. However, a cross-sectional telephone survey looking at 140 informal caregivers showed no statistically significant difference in access issues between urban and rural caregivers (Brazil et al., 2013). While these studies report conflicting results, small sample sizes may have played a role.

Respite services are often said to be one of the most commonly requested services by informal caregivers, and it is believed that respite services are positively associated with the ability for caregivers to keep care recipients at home for longer periods of time (Phillipson, Jones, & Magee, 2014). However, Phillipson et al. (2014) conducted an extensive literature review to better understand the use of respite services by informal caregivers of people with dementia and found that respite services are often underutilized and do not seem to match the needs of those in caregiving roles. Due to this inconsistency, Phillipson et al. believed more needs to be done to understand the needs of caregiver subgroups so that support services can be tailored to meet the needs of the various caregiver groups.

Another study involving 884 informal caregivers in Alabama also found respite services to be underutilized. Study results showed that 50% of the survey participants had difficulty accessing respite services and 25% of the participants reported not even knowing how to request respite support (Geiger & O’Neal, 2014). Respite services have been found to be beneficial, but it is unclear why respite services are underutilized. A better understanding of the unmet support needs of informal caregivers may lead to interventions such as respite being better utilized.

Informal caregivers also report needing other types of support services and previous studies have confirmed a gap in services provided versus services needed. A quantitative study of 83 informal caregivers providing support to care recipients with lung cancer showed that distressed caregivers are often not receiving the support services they need or desire (Mosher et al., 2013). The study showed that 67% of those surveyed reported needing emotional support, and 61% reported needing more informational support with 74% desiring written materials and 2% desiring to attend classes. Comparable results were noted in a study looking at the unmet support needs of 166 informal caregivers, which found the top two unmet support needs to be access to health care professionals and services followed by the need for more information (Chen et al., 2016). This same study reported other unmet support needs for caregivers ranging from legal and financial support to psychosocial and emotional support that might be provided in support groups or through individual counseling. According to Monahan (2011), the need for more emotional support helps explain the increased popularity of caregiver support groups in recent years.

Much of the previous caregiver research has been limited to small sample sizes or a specific disease type. Also, limited peer-reviewed studies exist using the newly revised 2015 BRFSS caregiver module, which added a question asking what services informal caregivers most need. More research is needed using larger sample sizes to determine how contextual and environmental factors such as the caregiver relationship, type of illness, and rurality influence the unmet support needs of informal caregivers (Brazil et al., 2013; Reinhard et al., 2008; Trivedi et al., 2017). This additional knowledge will provide insight into the needs of today's informal caregiver.

## Contextual and Environmental Factors

The needs of informal caregivers are complex and unique yet there is a lack of research differentiating between the needs of caregivers and their individual circumstances (Bangerter et al., 2017; Brazil et al., 2013; Bryant, 2016; Diduk-Smith, 2017; Gitlin et al., 2015; Grossman & Webb, 2016; Mansfield et al., 2016; Tatangelo et al., 2018). Researchers have recommended further caregiver research looking at contextual and environmental factors so that interventions can be tailored to meet the unique needs of those in caregiving roles. For this study, contextual and environmental factors including the caregiver relationship, type of illness and rurality were evaluated to determine if the factors were associated with unmet support needs (classes, assistance with access, support groups, counseling, respite care) of informal caregivers of older adults.

## Unmet Support Needs and the Caregiver Relationship

For this study, the caregiving relationship of spouse and adult child were studied to determine if there was an association related to the caregiver relationship and the unmet support needs of informal caregivers. This contextual factor was captured in Bronfenbrenner's micro and mesosystems. Based on a caregiver study funded by the NAC and AARP (2015), several factors can increase caregiver burden including the caregiver relationship. According to the caregiver study, 85% of informal caregivers are taking care of a relative. The study showed spousal and adult child caregivers are the two most common caregiving relationships for older adults. This same study indicated increased emotional strain and burden for caregivers taking care of a close relative, such as a spouse or parent, as compared to those taking care of a distant or nonrelative.

A qualitative study examining the health needs of spousal and adult child caregivers found that significant unmet needs exist for these two types of caregivers, and their needs are often complex and multi-dimensional (Tatangelo et al., 2018). Tatangelo et al. (2018) noted the needs of spousal and adult child caregivers can be very different and suggested assorted reasons for the differences. Spousal caregivers of older adults tend to be older and are more likely to reside with the care recipient resulting in a full-time caregiving role. Adult child caregivers often must juggle multiple roles as many are employed and still supporting their own families. The study's findings were consistent with previous research showing that adult child caregivers often must make significant changes to their daily routines and often express difficulty with having to fulfill multiple roles due to their caregiving responsibilities (Chappell et al., 2014).

While studies have confirmed differences in the caregiving role for these two groups, studies looking at strain and burden for spousal and adult child caregivers have shown contradictory results. A literature review completed by Jayani and Hurria (2012) looking at the differences between spousal and adult child caregivers of cancer patients, found that adult child caregivers were at elevated risk for strain and psychological effects related to their caregiving role. Jayani and Hurria speculated that the higher risk for strain and psychological effects were due to taking on caregiving duties in addition to work and family responsibilities. These results contrast with a 2011 study that compiled a national profile of end of life informal caregivers using two secondary datasets, the National Health and Aging Trends Study and the National Study of Caregiving (Ornstein et al., 2017). Study results showed that spousal caregivers experience the most extensive caregiving challenges including increased depression and more exhaustion. The researchers noted this could be due to residing with the care recipient and providing assistance alone. The study showed that 2/3 of spousal caregivers reported no outside assistance from family or friends.

Previous research indicates significant differences in the caregiving experience for spousal versus adult child caregivers yet how the differences impact the unmet support needs of informal caregivers is not well understood (Chappell et al., 2014; Gitlin et al., 2015; Howells, 2015; McCabe et al., 2016; Tatangelo et al., 2018). Much of the previous research has focused on specific disease types and the overall caregiving experience as it relates to burden, but few studies have looked at the differences in unmet support needs of these two groups of caregivers. A better understanding of how the caregiving relationship is associated with the need for services could result in better care for both the caregiver and care recipient (Jayani & Hurria, 2012).

## Unmet Support Needs and Type of Illness

The level of support provided by informal caregivers can vary based on the type of illness of the care recipient or the progression of the chronic condition. The 2015 Caregiving in the United States  report indicated that 42% of informal caregivers perform complex medical and nursing tasks and often with little or no training or support (NAC & AARP, 2015). A literature review looking at informal caregivers of cancer patients found that most medical care was provided at home and that caregivers of cancer patients are often providing services like that of health care professionals (Ullgren, Tsitsi, Papastavrou, & Charalambous, 2018). The level of support needed can also increase as the care recipient nears the end of life thus creating a greater need to support the informal caregiver (Ornstein et al., 2017). Despite the heavy demands often placed on informal caregivers, a quantitative study evaluating 1,739 paid and unpaid caregivers using the 2011 National Health and Aging Trends dataset found that only a quarter of survey participants reported ever having used support services (Wolff et al., 2016).

To fully comprehend the complete burden associated with a care recipient's type of illness, the effect of the illness on family members must also be considered (Wittenberg et al., 2014). Wittenberg et al. (2014) completed a qualitative study looking at the spillover effects of illness on the lives of informal caregivers. The caregivers interviewed included parents, adult children, and spouses and the types of illnesses included arthritis, cancer, Alzheimer's disease, cerebral palsy, and depression. Study results showed the type of illness had substantial effects on the lives of caregivers and could adversely impact the quality of life and well-being of those in caregiving roles. The type of illness can also increase the emotional and physical strain of caregivers, especially when caring for a chronically or terminally ill family member (Empeño, Raming, Irwin, Nelesen, & Lloyd, 2013). Howells' (2015) research looking at differences in the health characteristics of dementia caregivers as compared to those caregiving for persons with other chronic conditions further confirmed these findings.

Previous research evaluating the impact of predictor variables on the support needs of informal caregivers has been inconsistent. A quantitative study looking at 188 dyads of lung cancer patients, and their primary caregivers, showed a high level of unmet support needs for caregivers but showed few predictive variables (Sklenarova et al., 2015). The factors of age, gender, employment, relationship, and social class did not show a statistically significant association between the variables and the unmet needs of patients or informal caregivers. Limitations noted for this study, however, were a strong gender and spouse imbalance of the participants. A study completed by Potter (2018) using data compiled from a 2011 national caregiver survey looked at factors associated with the use and nonuse of services sought by informal caregivers. Study participants included 1,973 informal caregivers and the results also showed that few demographic factors were associated with services used or unused. However, Potter's study did note a statistically significant relationship between the health of the care recipient and services used and unused. Potter expressed concern with the association of hours of caregiving with unused services because of the fear that caregiving intensity perhaps interferes with the ability to use services. Potter recommended the need for additional research to further understand the types of support services most needed by informal caregivers, so funding can be targeted to specific caregiver groups and geographic locations.

More research is needed to determine if certain predictor variables impact the unmet support needs of informal caregivers. Grossman and Webb (2016) completed an extensive literature review looking at the caregiver experience for informal caregivers of older adults. The researchers found much of the literature addressed the tasks performed by caregivers, along with the negative aspects associated with caregiving. Grossman and Webb (2016) noted that research studies addressing caregiver support needs were lacking. They also noted that within the research several types of illness were listed as reasons for needing care, and multiple caregiver relationships were noted, yet very few studies evaluated the impact of these factors. Based on their review, Grossman and Webb suggested that future studies using comparative data would provide valuable information that would help in creating programs targeted at meeting the needs of informal caregiver subgroups.

## Unmet Support Needs and Rurality

EST addresses processes and connections between individuals and other entities within a community. The challenges associated with living in rural areas are captured in Bronfenbrenner's meso, exo, and macrosystems. It is recognized that persons living in rural areas often experience geographic challenges. Rural residents frequently face a shortage of health care providers, limited public transportation options, longer distances to access services, and fewer young people living in their communities due to de-population trends (Bangerter et al., 2017; Brazil et al., 2013; Jackson et al., 2013; Tatangelo et al., 2018). Previous studies have also shown that rural caregivers tend to have lower incomes, and experience geographic challenges related to accessing support services (Bouldin et al., 2017; Crouch et al., 2017).

Aging issues are prominent in rural areas because a disproportionate number of older adults reside in rural communities. According to the United States Census Bureau (2010), a quarter of older adults 65 and over live in rural areas. With a higher proportion of older adults residing in rural communities, there is a higher demand for health care services for those with chronic conditions (Jackson et al., 2013) thus increasing the reliance on informal caregivers. A quantitative study evaluating data from the 2012 BRFSS caregiver module confirmed the higher demand and showed a greater prevalence of caregiving taking place in rural areas (Bouldin et al., 2017).

It is recognized that residents residing in rural areas face geographic challenges that are unique from their urban counterparts, but studies evaluating these differences are limited and study results have been contradictory. Brazil et al., (2013) completed a quantitative study looking at the differences between 70 urban and 70 rural caregivers providing palliative care. The study found that both urban and rural caregivers reported having unmet support needs, but rural caregivers experienced greater unmet needs in the category of tangible support, which included things such as assistance with errands, adequate time to rest, getting help with transportation, and obtaining financial assistance. Another study also found disparities in a study examining rural and urban differences in quality of life for persons with COPD (Jackson et al., 2013) The study confirmed disparities between those residing in urban and rural areas and determined that residing in rural areas was associated with diminished health status and greater utilization of health care services.

A quantitative study completed by Li (2006) also noted urban and rural disparities in the use of unmet support needs of the care recipient, but some of the study results contradicted the findings of other studies evaluating support needs based on residence. The study found unmet needs differed based on residence, and 1/3 of the 17,633 caregivers that participated in the survey reported that one or more services received by the care recipient did not meet their needs. A unique finding of Li's study was that urban care recipients experienced greater unmet needs than those residing in rural areas. These study results are contradictory to many of the other studies looking at residence, but it is important to note that the survey focused on the unmet needs of the care recipient instead of the caregiver, and the study is also quite dated. The study used survey data from 1999. While insights can be gained from the study, both issues make it difficult to generalize the survey results to the needs of today's informal caregiver.

A more recent quantitative study completed by Crouch et al. (2017) provided some insights into the needs of today's caregiver. The study evaluated data using the 2015 Caregiving in the US survey, which evaluated urban and rural differences of 1,392 informal caregivers. The study largely focused on differences in factors of physical and financial strain, emotional stress, and overall caregiver health, but also considered factors related to the caregiver relationship and the use of respite services. The study findings indicated no statistically significant differences related to the caregiver relationship or the use of respite services based on residence, however, the researchers noted a couple of significant study limitations that may have impacted the findings. The study was heavily weighted with female participants and only 205 of the 1,392 participants were classified as living in a rural locale. Crouch et al. noted that their study was one of the first national examinations to look at informal caregivers based on residence and that more studies are needed that consider the characteristics of informal caregivers and urban and rural differences.

Previous studies have demonstrated that rural communities face unique geographic challenges that can create barriers and access issues to needed support services. However, few studies have looked at caregiver differences based on residence and it is not clear how the factor of rurality impacts the unmet support needs of informal caregivers (Brazil et al., 2013; Reinhard et al., 2008; Trivedi et al., 2017). Hobfoll (1989) noted that past caregiver research has neglected to look at the environmental effects on resources. Understanding there are likely differences in the resources provided and resources needed between rural and urban caregivers, it is important to understand how these differences impact the unmet support needs of informal caregivers (Bangerter et al. 2017).

## Summary and Conclusion

The current health care delivery model is designed to serve the care recipient with little attention often paid to the informal caregiver (Gillick, 2013; Wall, 2018). Studies have demonstrated the emotional and physical toll informal caregivers often endure, as well as the importance of their role, yet they often remain invisible to practitioners and policymakers (Russell, 2013; Shaji & Reddy, 2012; Thies & Bleiler, 2013). Providing informal caregivers with adequate interventions and resources to meet their needs is an essential element in reducing stress and burden and improving their quality of life

(Pearlin et al., 1990). Researchers Schulz and Eden (2016) suggested that meeting the needs of informal caregivers is one of the most significant and overlooked challenges facing the United States. As noted earlier in this chapter, several researchers believe the caregiving issues facing the country must be viewed as a national priority and will require shared responsibility among individuals, family, and the government (Levine et al., 2010; Shaji & Reddy, 2012; Reid, 2015; Wall, 2018).

Past caregiver research has shown that despite the availability of caregiver support services, the use of services remains low (Diduk-Smith, 2017). The reasons for low utilization are not well understood and more research is needed to understand the types of support services informal caregivers both need and want. Diduk-Smith suggested that future caregiver research would benefit from narrowing the focus to more closely evaluate the influencing factors associated with caregiver support needs, especially related to disease type. Howell (2015) noted that little peer-reviewed research exists in this area of study, and recommended a need for additional research that explores caregiver differences such as the caregiving relationship.

The impact of rurality on the unmet support needs of informal caregivers is lacking and more research is needed to advance the understanding of how residence impacts the needs of those in caregiving roles (Crouch et al., 2017). A seminal study by Li (2006) noted differences in the utilization of support services based on residence, but the study was focused on unmet support needs of the care recipient rather than the caregiver. As noted earlier in the chapter, a more recent study completed by Crouch et al. (2017) looked at urban and rural differences of informal caregivers, but the study primarily focused on differences in factors related to financial and physical strain, emotional stress, and overall caregiver health. Research needs to consider other aspects of caregiving including the efficacy of caregiving interventions (Shaji & Reddy, 2012). Both health care leaders and policy analysts point out that an improved understanding of formal and informal support systems is necessary to determine if additional caregiver resources are needed, especially in rural areas where more than a quarter of informal caregiving takes place (Crouch et al., 2017).

With the expected reliance on informal caregivers expected to increase in the coming years, a better understanding of how to support informal caregivers is needed. Previous research has often focused on the support needs of the care recipient or on caregiver burden, but little research exists that provides insight into the unmet support needs of today's caregiver (Reid, 2015). Previous caregiver studies that have been conducted have often focused on a specific disease type, small sample sizes, or have been focused on a specific region (Goins et al., 2009). Also, few caregiver studies have looked at factors related to the unmet support needs from the perspective of the informal caregiver (Bangerter et al., 2017; McCabe et al., 2016).

More research is needed to determine how contextual and environmental factors such as the caregiver relationship, type of illness, and rurality influence the unmet support needs of informal caregivers (Brazil et al., 2013; Reinhard et al., 2008; Trivedi et al., 2017). It has been suggested that to adequately meet caregiver needs more needs to be done to match intervention strategies to specific sub-groups of caregivers (Gitlin et al., 2015). The purpose of this quantitative study was to help fill these gaps and to examine the association of the caregiver relationship, type of illness, and rurality with the unmet support needs (classes, assistance with access, support groups, counseling, respite care) of informal caregivers of older adults. This study also evaluated the unmet support needs of informal caregivers from the perspective of the actual caregiver.

The current study used the newly revised BRFSS optional caregiver module launched in 2015. To date, few peer-reviewed studies have been done using data from the BRFSS caregiver module (Howells, 2015). The newly revised module added a question that asks informal caregivers what support service they most need but are not currently receiving. This question was added to address a lack of viable data related to the unmet support needs of caregivers (Office of Disease Prevention and Health Promotion, 2018). As LTSS faces an impending care gap, a better understanding of how to support informal caregivers will be needed to ensure caregivers remain healthy, improve their caregiver skills, and remain in their caregiving roles (AARP, 2015; Freedman & Spillman, 2014).

The current study adds to the body of knowledge related to caregiver research using the EST model. It had been suggested that future caregiver research would benefit from applying socioecological models, as it may provide a more complete view of the factors that can impact unmet support needs of informal caregivers (Cho et al., 2015; Fleury & Lee 2006; McLeroy et al., 1988). Wilder (2010) suggested that in modern society there is a need to look at family caregiver research from an ecological perspective that takes into consideration environmental fit and the interrelationships between the individual and the various environmental systems.

In Chapter 3, information on the secondary dataset used for the study is shared. The methodology I utilized in the study is also discussed, including a comprehensive explanation of the research questions and variables. I will define the statistical methods used to evaluate the association of the selected variables, along with levels of significance. In addition, threats to study validity and ethical considerations are also discussed.

# Chapter 3: Research Method

## Introduction

The overall purpose of this study was to evaluate if the contextual and environmental factors of caregiver relationship, type of illness, and rurality were associated with the reported unmet support needs of informal caregivers of older adults. The quantitative study examined information from the 2015 BRFSS optional caregiver module, which is a publicly available secondary dataset. The 2015 BRFSS caregiver module was revised, and a question was added to the module asking informal caregivers what support service they most needed but were not currently getting (CDC, 2016). This question served as the dependent variable for this study.

The following chapter outlines the research methods that I used for this study. Sections include information on the study's variables, research design and rationale, methodology, validity threats, and ethical considerations. Historical and background information on the BRFSS survey process is also provided.

## Research Design and Rationale

This study examined three hypotheses querying the association between contextual and environmental factors related to the unmet support needs of informal caregivers of older adults. The variables for this study were drawn from questions included in the publicly available 2015 BRFSS optional caregiver module dataset (CDC, 2016). According to the CDC (2016), the caregiver module is designed to help states better understand the needs of informal caregivers. The 2015 revised caregiver module was reduced from ten questions down to eight, and three new survey questions were added (CDC, 2016). The caregiver module questions utilized in this study can be found in Appendix A.

The research approach for this study was a quantitative study with a nonexperimental design and correlational analysis using a secondary dataset of CDC’s 2015 archived BFRSS database. I used cross-sectional data to examine associations between the independent variables, covariates, and the dependent variables. This type of research design is frequently used to evaluate associations between variables that are drawn from a secondary dataset (Frankfort-Nachmias & Nachmias, 2015). The data analysis provided an improved understanding of contextual and environmental factors associated with the unmet support needs of informal caregivers of older adults.

I used archival data from a population-level data source in the United States. The benefits of using archived data is the ability to access nationwide data promptly and at no cost. A potential disadvantage to using the BRFSS dataset is the complexity of the survey design. This can be mediated by the researcher becoming acquainted with the contents of the dataset, including a review of codebooks, manuals, and methods utilized in the original survey (Aponte, 2010).

## Methodology

To determine if associations existed between the factors of caregiver relationship, type of illness, and rurality and the reported unmet support needs of informal caregivers of older adults, I performed a quantitative correlational research study using an archival database from the CDC. I conducted a series of multiple logistic regression tests to test the hypotheses. I used multiple logistic regression analysis to evaluate relationships between various predictor variables and a dichotomous dependent variable. The growth in popularity of multiple logistic regression analysis is attributed to researchers having easy access to sophisticated statistical software (Peng, Lee, & Ingersoll, 2002).

The foundation of multiple logistic regression is the natural logarithm of an odds ratio referred to as the logit (Peng et al., 2002). This type of study can be useful for predicting outcomes or explaining relationships (Constantine, 2012). I chose this research design based on the research questions and the desire to determine if the independent variables were associated with the dependent variables.

## Target Population

The number of BRFSS interviews conducted in 2015 was 441,456, with 24 states completing the optional caregiver module, which was the dataset used for this study (CDC, 2016). Of those interviewed for the caregiver module, 24,034 people self-identified as caregivers. Caregiver status was determined by answering yes or no to the following question, “During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?” (CDC, 2015).

The target population for this study was a subset of the individuals who identified as informal caregivers within the optional caregiver module. The subset of persons was determined based on how individuals self-identified for questions related to caregiver relationship, type of illness, residence, and unmet support needs. I used a total sample of 6,447 respondents for the final analysis.

## Sampling Procedures

The BRFSS uses two different sampling methods determined by the type of phone used to conduct the interview, landline versus cellular (CDC, 2016). For landline phones, disproportionate stratified sampling is used, which is a type of sampling that does not require the sample size of each stratum to be proportionate to the population size of the stratum (Frankfort-Nachmias, &  Nachmias, 2017). Using a disproportionate stratified sampling method is viewed as being more efficient than random sampling (CDC, 2016). The disproportionate stratified sampling draws telephone numbers from two strata, high or medium density, with a 1:1.5 sampling ratio of high to medium density. It is assumed that landlines are often shared phone lines, so the BRFSS uses household sampling for questionnaires conducted via a landline. After determining how many eligible adults live at the residence, random sampling is then used to determine the respondent for the survey. More strata groups can be determined, but the BRFSS only uses two groups.

The annual goal is for each state to complete around 4,000 interviews with approximately 20% of the interviews completed with respondents using a cellular telephone. A cellular telephone number is recognized as a single adult household, and random sampling is applied providing equal probability of selection for adult individuals with cellular telephones. For the 2015 BRFSS, cellular telephone numbers were generated from a sampling frame of confirmed cellular area codes and prefix combinations using the Telcordia database of telephone exchanges and 1,000 banks (CDC, 2016).

## Sample Size and Power Analysis

When considering the sample size needed for a study, it is important to use a large enough sample to represent the population group so that inferences can be generalized and to reduce the margin of error (Kadem & Bahlerao, 2010). The available sample for this study was determined by the survey data reported in the 2015 BRFSS caregiver module. In 2015, 24 states completed the optional caregiver module providing a large sample size. Approximately, 24.034 survey participants self-identified as a caregiver for the 2015 survey.

When considering sample size, a procedure referred to as a power analysis is used to determine if the study contains enough power to make a reasonable conclusion (Lau & Kuk, 2011). Power is the probability of rejecting the null hypothesis when it is false. Power calculations assist researchers in understanding how many participants are needed for a quantitative study to avoid a type I or a type II error (Burkholder, 2015). According to Burkholder, 80% is typically considered an acceptable power and was used for this study. Power set at .80 (80%) means that a possible difference will only be missed 20% of the time. The alpha level, which is the probability of rejecting a true null hypothesis, was set at .05, which is the most common level used for psychological research (Burkholder, 2015).

For multiple logistic regression models, a rule of thumb has been suggested that for each predictor variable there should be at least ten events (Ranganathan, Pramesh, & Aggarwal, 2017). For example, if the population sample is 70, then a maximum of seven predictor variables should be utilized. This rule has been questioned, and an alternative suggestion of five to nine events for each independent variable has been said to be reliable (Vittinghoff & McCulloch, 2007).

I computed a priori power analysis using G*power 3.0 to identify the required sample size for this study (Faul, Erdfelder, Buchner, & Lang, 2009). I conducted the analysis for multiple logistic regression with a binary dependent variable and more than one independent variable using a medium effect size ( $f2 = 0.15$), ($\alpha$ error = 0.05) and confidence level ($1- \beta = 0.95$). With seven predictor variables, the required output sample size was 153. As predictor variables increase, the sample size increases slightly. For example, with 16 predictor variables, the required sample rose to 204. For the current study, I used a national sample with thousands of participants, so the sample size and events per variable far exceeded the minimum numbers suggested.

## Behavioral Risk Factor Surveillance System Process and Procedure for Recruitment

The BRFSS originated in 1984 with 15 states participating in the survey. Today, all states participate. The BRFSS is hailed as the nation’s premier system of health-related telephone surveys for collecting state-specific data on health practices and behaviors associated with conditions such as chronic disease, injuries, and preventable infectious diseases (CDC, 2017). According to the CDC website (2017), it is the largest continuously conducted health survey in the world with more than 400,000 adult interviews completed each year. In 2015, 441,456 interviews were included in the overall study (CDC, 2016).

The BRFSS questionnaire contains a core set of questions that must be asked without modification. There are also several optional modules available, and each state can determine if they want to utilize any or all modules. If a state decides to include an optional module, the module questions must be asked as written. In 2015, there were 24 optional modules available for use, including the caregiver module utilized for this study (CDC, 2017). States may also add state specific questions and are encouraged to do so based on their specific health priorities.

Historically, the BRFSS survey has been conducted via landlines, but starting in 2011, approximately 20% of surveys began to be conducted via cellular phones (CDC, 2016). The goal is to conduct approximately 4,000 surveys annually in each state resulting in responses from over 400,000 participants (CDC, 2016). The 2015 BRFSS caregiver module was the primary data source for this survey and provided access to caregiver data on a national landscape with over 20,000 informal caregivers participating in the 2015 module. The data is made available to the public free of charge on the CDC website and can be accessed at any time with no permission or consent process needed.

## Behavioral Risk Factor Surveillance System Data Confidentiality

The CDC makes public health data available to the public via their website but works diligently to ensure the privacy and security of protected health information. Data posted in the publicly available dataset has been aggregated and scrubbed of any individually identifying information such as zip codes or telephone numbers. Disclosure of data not included in the publicly available dataset requires a formal data usage agreement that adheres to HIPAA privacy rules. For the current study, the data needed was included in the publicly available dataset, and a formal data usage agreement was not required. The variables considered for the study contained no personal identifiers. The current study was also approved by Walden's University Institutional Review Board.

## Instrumentation and Operationalization

### Instrumentation

I used the 2015 BRFSS caregiver module dataset for this study. The BRFSS data is available to the public free of charge and can be accessed at any time via the CDC website. The dataset provides access to a large population sample including over 400,000 adult interviews annually (CDC, 2016). The 2015 caregiver module was completed by 24 states and included over 20,000 participants who self-identified as caregivers, providing a large sample for this study.

Numerous studies have been completed evaluating the reliability and validity of the BRFSS instrument (CDC, 2017). An extensive bibliography list can be accessed on the CDC website noting several publications that illustrate the instrument is a valid and reliable data source for health-related information. One study compared three national health surveys (BRFSS, National Health and Nutrition Examination Survey, National Health Interview Survey) and found consistency in prevalence estimates across key health indicators for all three surveys (Li, Balluz, Ford, Okoro, Zhao, & Pierannunzi, 2012).

### Operationalization

A cross-sectional study design was used to evaluate the association between three independent categorical variables of caregiver relationship, type of illness, and rurality and the dependent variable of unmet support needs. The independent and dependent variables were drawn from four questions included in the 2015 BRFSS caregiver module, which can be found in Appendix A.

**Dependent variable**. The dependent variable of unmet support needs was drawn from a question asking respondents “Of the following support services, which one do you most need, that you are not currently getting?” The BRFSS provided variable name is CRGVMST2. The dependent variable was a nominal variable with the following categories of support services (a) Classes about giving care, (b) Help in getting access to services, (c) Support groups, (d) Individual counseling to help cope with giving care, (e) Respite Care. For this study, each support service was analyzed separately as a binary variable coded as “1” for yes indicating unmet support need for the service and “0” for no unmet support need for the service. Responses of don’t know, not sure, or refused were coded as missing variables.

**Independent variables**. The independent variable of caregiver relationship was drawn from a question asking, “What is his/her relationship to you?” The BRFSS provided variable name is CRGVREL1. Caregiver relationship was a categorical variable, and the categories of spouse (husband/wife) and adult child (mother/father) were used for this study. The variable was dummy coded with adult child being the reference category.

The second independent variable was drawn from a question asking, “What is the main health problem, long-term illness, or disability that the person you care for has?” The BRFSS provided variable name is CRGVPRB1. Type of illness was also a categorical variable and included (a) all others, (b) cancer, (c) chronic respiratory conditions such as emphysema or COPD, (d) dementia and other cognitive impairment disorders, and (e) heart disease. These conditions were selected because they are among the most common chronic health conditions and leading causes of death for adults aged 65 and older (Xu, Kochanek, Murphy, & Arias, 2014). This variable was dummy coded with all others serving as the reference category.

The third independent variable being studied was rurality, which is defined by the BRFSS under the weighting variable of Metropolitan Status Code. The following values were identified in the survey (a) In the center city of a Metropolitan Service Area (MSA), (b) Outside the center city of an MSA but inside the county containing the center city, (c) Inside a suburban county of the MSA, and (d) Not in an MSA. The variable was dummy coded with inside the center city of an MSA serving as the reference category.

**Potential confounding variables.** Failing to control for potential confounding variables may result in study results showing false correlations. Gender and educational status of the caregiver, along with hours of weekly care provided, and duration of care, are common confounding variables that have been considered in past caregiver research (Li, 2006; NAC & AARP, 2015; Potter, 2018). For this study, all of these were evaluated as potential confounding variables. The confounding variables were dummy coded as listed in Table 1.

Table 1 includes the measures used for each of the independent variables, covariates, and dependent variables, along with the type of variable and coding for each variable. The independent variables selected were contextual and environmental factors that have been associated with increased caregiver burden in previous studies (Brazil et al., 2013; NAC & AARP, 2015). This study evaluated if these factors were associated with the reported unmet support needs of informal caregivers of older adults.

Table 1

*Coding of Variables*

| Variable | Type of variable | Coding |
|---|---|---|
| Dependent variables | Binary | (1=yes/0=no) |
| Unmet support need - Classes | | |
| Unmet support need - Access to services | | |
| Unmet support need - Support groups | | |
| Unmet support need - Individual counseling | | |
| Unmet support need - Respite | | |
| Independent variables | | |
| Caregiver relationship | Categorical | (1=yes/0=no) |
| Adult child (reference) | | |
| Spouse | | |
| Type of illness | Categorical | (1=yes/0=no) |
| All others (reference) | | |
| Cancer | | |
| COPD | | |
| Dementia | | |
| Heart disease | | |
| Rurality | Categorical | (1=yes/0=no) |
| In center city of MSA (reference) | | |
| Outside center city of MSA | | |
| Inside suburban county of MSA | | |
| Not in MSA | | |
| Covariates | | |
| Gender | Categorical | `(1=yes/0=no) |
| Male (reference) | | |
| Female | | |
| Education level | Categorical | (1=yes/0=no) |
| Less than HS (reference) | | |
| High school | | |
| Some college | | |
| College graduate | | |
| Hours of care per week | Categorical | (1-yes/0=no) |
| Up to 8 hours (reference) | | |
| 9 to 19 hours | | |
| 20 to 39 hours | | |
| 40 hours or more | | |
| Duration of care | Categorical | (1=yes/0=no) |
| Less than 2 years (reference) | | |
| 2 years to less than 5 | | |
| More than 5 years | | |

# Data Analysis Plan

## Analysis Software and Cleaning

The data analysis plan included exporting the data from the publicly available 2015 caregiver module dataset on the CDC website. I imported the data into SPSS (version 24) software for analysis and then reviewed the data for any significant outliers or discrepancies. The data was cleaned, and any unacceptable or missing fields were removed. Data was reviewed to ensure MSA codes were provided for each of the 24 states that participated in the module.

## Research Questions and Hypotheses

This study was conducted to address the following research questions. The questions were created to determine if associations existed between contextual and environmental factors and the reported unmet support needs of informal caregivers of older adults.

RQ1: What is the association between the caregiver relationship (spousal, adult child) and the reported unmet support needs of informal caregivers of older adults?

$H_0$1: There is no statistically significant association between caregiver relationship and the reported unmet support needs of informal caregivers of older adults.

$H_a$1: There is a statistically significant association between caregiver relationship and the reported unmet support needs of informal caregivers of older adults.

RQ2: What is the association between the type of illness of the care recipient (cancer, COPD, dementia, heart disease) and the reported unmet support needs of informal caregivers of older adults?

$H_0$2: There is no statistically significant association between type of illness and the reported unmet support needs of informal caregivers of older adults.

$H_a$2: There is a statistically significant association between type of illness and the reported unmet support needs of informal caregivers of older adults.

RQ3: What is the association between rurality and the reported unmet support needs of informal caregivers of older adults?

$H_0$3: There is no statistically significant association between rurality and the reported unmet support needs of informal caregivers of older adults.

$H_a$3: There is a statistically significant association between rurality and the reported unmet support needs of informal caregivers of older adults.

## Statistical Testing

The data analysis plan was to conduct multiple logistic regression tests, which enables researchers to evaluate relationships between various predictor variables and a dichotomous dependent variable (Field, 2013). The independent variables, covariates, and dependent variables were coded as reflected in Table 1. For RQ1, the independent variable of caregiver relationship was evaluated. For RQ2, the independent variable was the type of illness, and for the final research question, the independent variable was rurality. For all three research questions, the dependent variables remained the same with each support service type coded as a binary variable with “1” indicating yes, it was the service most needed and “0” indicating no it was not the service most needed. For all three research questions, descriptive statistics were first performed to determine frequencies for each of the predictor variables in relation to the outcome variable. To evaluate associations between the independent variables, covariates, and each of the support service types, a series of multiple logistic regression tests were performed using a significance level of $p < .05$ and a confidence interval of 95%. Data was analyzed both controlling for and not controlling for covariates (gender, educational level, hours of care per week, duration of care) to determine if the confounding variables had any influence on the dependent variables. To determine the precision of the adjusted odds ratio, data was interpreted using a significance of $p < .05$ with a confidence interval of 95%. The Wald-Chi Square statistic was used to evaluate the significance ($p < .05$) of the explanatory variables. To determine if the model was a good fit for the data, goodness of fit was assessed using Hosmer-Lemeshow chi-square analysis with a nonsignificant p-value ( $p > .05$) desired.

## Threats to Validity

Threats to validity must be considered when preparing to conduct a study. This study used a secondary dataset thus limiting any direct bias of the researcher. A strength of using the BRFSS dataset is that it has been widely tested to ensure the reliability and validity of the instrument. Extensive comparative studies have been completed and a bibliography listing numerous publications is provided on the CDC website. As noted in a previous section, comparative studies with other national surveys have illustrated consistency in prevalence estimates across various indicators (Li et al., 2012).

External validity refers to the degree the results of a study can be generalized to the larger population. Achieving representativeness of the sample is said to be one of the primary issues with external validity (Frankfort-Nachmias & Nachmias, 2017). The BRFSS dataset is credited as being the largest continuous health indicator survey in the world and provided access to national caregiver data from 24 states (CDC, 2017). In 2015, over 20,000 survey participants self-identified as caregivers providing a large sample size enabling the results of this study to be generalized.

Data weighting is a process that attempts to remove bias in the sample (Burkholder, 2015) and is utilized in the BRFSS dataset to account for the complex sampling design. Since 2011, the BRFSS has used a statistical method referred to as raking, which helps to ensure data are representative of the population including demographic characteristics and the type of telephone utilized by respondents. Several data weighting variables were included in the BRFSS data set for probability sampling including the number of persons aged 18 and older living in a household and the number of phones in a household, both landlines and cellular telephones. To account for nonresponse and noncoverage households, post stratification adjustments were also applied.

The CDC provides BRFSS datasets in a variety of formats for analysis purposes. The datasets are publicly available for downloading with no permission needed to access. One of the formats provided is for SPSS statistical software, which is the software that was used for this study.

## Ethical Considerations

This study used the 2015 publicly available BRFSS dataset provided on the CDC website. The dataset is made available to the public free of charge and can be accessed at any time. Data posted in the publicly available dataset has been aggregated and scrubbed for anonymity purposes. All data was stored on my laptop, which requires biometric facial recognition authentication. When home, my laptop is stored in a locked closet in my home office. When traveling, a keyed cable lock is used to ensure security. Data will be retained for the required five years from the completion of my doctoral studies at Walden University. This study did not include any high-risk areas, but to ensure academic integrity, IRB approval was sought from Walden University's Institutional Review Board before data analysis. The study was approved with the following approval number provided 10-09-8-0727222.

## Summary

The overall purpose and intent of this study was to evaluate if the contextual and environmental factors of caregiver relationship, type of illness, and rurality were associated with the reported unmet support needs of informal caregivers of older adults. A series of multiple logistic regression tests were completed to evaluate associations between the independent variables (caregiver relationship, type of illness, rurality), covariates (gender, educational levels, hours of care per week, duration of care), and each of the support service types (classes, access to services, support groups, counseling, respite) coded as a dichotomous dependent variable. The adjusted odds ratios were interpreted using a significance or $p$ - value < .05 with a confidence interval of 95%.

As the nation faces concern of an impending care gap for older adults with chronic conditions, there is recognition of the need to better support informal caregivers who provide most of the care for community-dwelling older adults (Eldercare Workforce Alliance, 2018). Despite this recognition, studies on caregiver interventions have lagged behind those for care recipients and limited studies have looked at factors associated with unmet support needs from the perspective of the informal caregiver (McCabe et al., 2016). It is hoped that further knowledge in this area of study will assist health care providers and policymakers to better target strategies and interventions to address the unmet support needs of informal caregivers.

In Chapter 3, I provided an overview of the research methods that were utilized for this study. Following Walden's IRB approval for the study, data analysis occurred. In Chapter 4, I discuss the results of the study.

# Chapter 4: Results

## Introduction

The purpose of this study was to evaluate the association of contextual and environmental factors on the unmet support needs of informal caregivers of older adults. Using data from the 2015 BRFSS optional caregiver module, the study was designed to evaluate the predictive relationship between three independent variables (caregiver relationship, type of illness, rurality) and a dependent variable (classes, service access, support groups, counseling, respite). For this study, each support service was analyzed separately as a binary variable coded as “1” for yes, the support service was most needed, and “0” for no, the support service was not needed. The control variables selected for the study included gender, educational status, weekly hours of care, and duration of care. During the multiple logistic regression analysis, I analyzed data both controlling for and not controlling for the covariates.

I constructed the following research questions and hypotheses to evaluate if the factors of caregiving relationship, type of illness, and rurality were predictive indicators of the reported unmet support needs of informal caregivers of older adults.

> RQ1: What is the association between the caregiver relationship (spousal, adult child) and the reported unmet support needs of informal caregivers of older adults?
>
> > $H_0 1$: There is no statistically significant association between caregiver relationship and the reported unmet support needs of informal caregivers of older adults.

$H_a1$: There is a statistically significant association between caregiver relationship and the reported unmet support needs of informal caregivers of older adults.

RQ2: What is the association between the type of illness of the care recipient (all others, cancer, COPD, dementia, heart disease) and the reported unmet support needs of informal caregivers of older adults?

$H_02$: There is no statistically significant association between type of illness and the reported unmet support needs of informal caregivers of older adults.

$H_a2$: There is a statistically significant association between type of illness and the reported unmet support needs of informal caregivers of older adults.

RQ3: What is the association between rurality and the reported unmet support needs of informal caregivers of older adults?

$H_03$: There is no statistically significant association between rurality and the reported unmet support needs of informal caregivers of older adults.

$H_a3$: There is a statistically significant association between rurality and the reported unmet support needs of informal caregivers of older adults.

This chapter includes an explanation of the secondary dataset utilized for the study, dates the data was collected, descriptive statistics (frequency percentages) for the variables analyzed, and the study results of the multiple logistic regression tests performed.

## Data Collection

The data for this study were drawn from the revised 2015 BRFSS optional caregiver module, which is a publicly available secondary dataset provided by the CDC. Data was collected from January 1, 2015 to December 31, 2015. In 2015, 24 states participated in the optional caregiver module with 24,034 survey participants self-identifying as informal caregivers. The target population for this study included a subset of the individuals who identified as informal caregivers within the module. The subset of individuals was determined based on how individuals self-identified for questions related to caregiver relationship, type of illness, residence, and unmet support needs.

For caregiver relationship, the variable was recoded and caregiver groups that were not spouse (husband/wife) or parent (mother/father) were excluded. For type of illness, the variable was recoded to include cancer, COPD, dementia, and heart disease with all other types of illness lumped together into an all others category. The rurality variable was coded as reflected in the 2015 BRFSS Codebook and included the categories of in an MSA, outside the center city of an MSA, inside a suburban county of MSA, and not in MSA. As noted previously for the dependent variable, each support service (classes, service access, support groups, counseling, respite) was analyzed separately as a binary coded variable with “1” for yes, if the support service was noted as the most needed, and “0” for all other categories indicating no, the support service was not the most needed.

Data was exported from the CDC website and imported into SPSS (version 24) software for analysis. The data was reviewed for outliers and discrepancies, and observations containing missing data were eliminated from the dataset. The 2015 BRFSS caregiver module only contained a small number of missing variables, generally totaling less than 1% of total responses (CDC, 2016). SPSS removes missing cases by default using listwise deletion, and if a case is missing for any of the variables, it is dropped from the model (Field, 2013). Descriptive statistics were run, and data was crosschecked for accuracy with the 2015 BRFSS Codebook Report (CDC, 2016). A total sample of 6,447 respondents was used for the final analysis.

## Demographic Characteristics

Baseline demographic characteristics are shown in Table 2. The data showed significantly more female respondents, with females composing 67% of the study sample ($N$ = 6,447). The highest frequency demographic characteristics for the other variables included college graduates (35.9%), less than 8 hours of weekly care (49.7%), and less than 2 years for duration of care (42.3%).

Table 2

*Baseline Demographic Characteristics*

| Variable | Level | Frequency percentage |
|---|---|---|
| Gender | Male | 33.43 |
| | Female | 66.57 |
| Educational level | Less than HS | 5.07 |
| | High School | 29.19 |
| | Some College | 29.87 |
| | College | 35.86 |
| Weekly hours of care | Up to 8 hours | 49.71 |
| | 9 to 19 hours | 14.04 |
| | 20 to 39 hours | 12.04 |
| | 40 hours or more | 24.21 |
| Duration of Care | Less than 2 years | 42.31 |
| | 2 years to less than 5 | 24.94 |
| | More than 5 years | 32.74 |

*Note*. *N* = 6,447.

## Descriptive Statistics for Independent and Dependent Variables

As shown in Table 3, I ran descriptive statistics for the independent and dependent variables. The data showed more adult child caregivers (59.9%) than spouse caregivers (40.1%). For type of illness, the all others category was the largest category (66.1%). Dementia was the most frequently reported demographic for chronic conditions of older adults (12.80%), and inside the center city of an MSA was most frequently reported for the rurality variable (41.0%). When looking at reported unmet support needs, service access had the highest frequency percentage (48.9%), followed by respite (17.1%), support groups (15.0%), counseling (12.1%), and classes (6.9%).

Table 3

*Descriptive Statistics*

| Variable | Level | Frequency percentage |
|---|---|---|
| Independent variables: | | |
| Caregiver relationship | Adult child | 59.94 |
| | Spouse | 40.06 |
| Type of illness | All others | 66.11 |
| | Cancer | 7.55 |
| | COPD | 4.65 |
| | Dementia | 12.80 |
| | Heart disease | 8.89 |
| Rurality | | |
| | In a center city of an MSA | 41.00 |
| | Outside of a center city of MSA | 14.95 |
| | Inside a suburban county of MSA | 8.95 |
| | Not in MSA | 35.10 |
| Dependent variables: | | |
| Unmet support need- Classes | Yes, most needed | 6.90 |
| | No, not most needed | 93.10 |
| Unmet support need- Service access | Yes, most needed | 48.92 |
| | No, not most needed | 51.08 |
| Unmet support need- Support groups | Yes, most needed | 14.97 |
| | No, not most needed | 85.03 |
| Unmet support need- Counseling | Yes, most needed | 12.14 |
| | No, not most needed | 87.86 |
| Unmet support need- Respite | Yes, most needed | 17.05 |
| | No, not most needed | 82.95 |

*Note*. *N* = 6,447.

## Research Question 1

In the first research question, I evaluated the predictive relationship between adult children and spousal caregivers and the reported unmet support needs of informal caregivers of older adults. The first research question reads: What is the association between caregiver relationship (adult child, spousal) and the reported unmet support needs (classes, service access, support groups, counseling, respite) of informal caregivers of older adults? The null hypothesis stated there was no statistically significant association between caregiver relationship and the reported unmet support needs of informal caregivers of older adults. The alternative hypothesis stated there is a statistically significant association between caregiver relationship and the reported unmet support needs of informal caregivers of older adults.

The hypothesis for research question one was tested using a multiple logistic regression model. The first round of testing analyzed the three independent variables and each of the five binary dependent variables. The second round of testing analyzed the three independent variables and four control variables with the five binary dependent variables. The results for RQ1 are explained below and the study findings are presented in Tables 4 through 13.

**Classes**. The findings showed there was no statistically significant association between caregiver relationship and the unmet support need of classes, Wald $X^2 = .492$, $df = 1$, $p = .483$, as shown in Table 4. The Hosmer Lemeshow Test, $p = .687$, indicated the model was a good fit for the data. The model explained 1.4% to 3.5% of the variance in the need for classes and correctly predicted 98.7% of the participants.

Table 4

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality and Unmet Support Need for Classes*

| | | | | 95% Confidence for Exp(B) | |
|---|---|---|---|---|---|
| | *B* | *p*-value | Exp(B) | Lower | Upper |
| Caregiver relationship | | | | | |
| Spouse | -.163 | .483 | .850 | .540 | 1.339 |
| Type of illness | | | | | |
| Cancer | .228 | .588 | 1.247 | .561 | 2.769 |
| COPD | .688 | .092 | 1.990 | .894 | 4.430 |
| Dementia | .199 | .542 | 1.220 | .644 | 2.310 |
| Heart Disease | .030 | .942 | 1.030 | .464 | 2.285 |
| Rurality | | | | | |
| Outside center city MSA | .061 | .858 | 1.063 | .544 | 2.080 |
| Inside suburban co. MSA | .160 | .690 | 1.173 | .536 | 2.568 |
| Not in MSA | .189 | .456 | 1.209 | .734 | 1.989 |
| Constant | -4.462 | .000 | .012 | | |

*Note*. *N* = 6,447. Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA.

The inclusion of control variables with the multiple logistic regression model for caregiver relationship and the unmet support need of classes did not improve the predictive power of the model and no statistically significant association was noted, Wald $X^2 = .896$, *df* = 1, *p* = .344, as shown in Table 5. The Hosmer Lemeshow Test, *p* = .955, indicated the model was a good fit for the data. The model explained 3.2% to 8.0% of the variance in the need for classes and continued to correctly predict 98.7% of the participants.

Table 5

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality, and Unmet Support Need for Classes with Control Variables*

| | | | | 95% Confidence for Exp(B) | |
|---|---|---|---|---|---|
| | *B* | *p*-value | Exp(B) | Lower | Upper |
| Caregiver relationship | | | | | |
| Spouse | -.227 | .344 | .797 | .498 | 1.275 |
| Type of illness | | | | | |
| Cancer | .205 | .617 | 1.227 | .550 | 2.741 |
| COPD | .726 | .077 | 2.066 | .923 | 4.623 |
| Dementia | .162 | .624 | 1.175 | .616 | 2.244 |
| Heart Disease | .061 | .881 | 1.063 | .478 | 2.364 |
| Rurality | | | | | |
| Outside center city MSA | .057 | .868 | 1.059 | .540 | 2.074 |
| Inside suburban co. MSA | .144 | .720 | 1.154 | .526 | 2.534 |
| Not in MSA | .211 | .410 | 1.235 | .747 | 2.043 |
| Covariates | | | | | |
| Gender-Female | -.415 | .069 | .660 | .422 | 1.032 |
| Education-High school | .872 | .239 | 2.391 | .561 | 10.190 |
| Education-Some college | .874 | .238 | 2.396 | .561 | 10.242 |
| Education-College graduate | .948 | .199 | 2.580 | .607 | 10.978 |
| Hours/week-9 to 19 | .627 | .039 | 1.872 | 1.032 | 3.394 |
| Hours/week-20 to 39 | .379 | .286 | 1.461 | .728 | 2.929 |
| Hours/week-40 or more | .442 | .129 | 1.555 | .879 | 2.751 |
| Duration-2 yrs. to less than 5 | -.273 | .351 | .761 | .429 | 1.350 |
| Duration-More than 5 years | -.069 | .790 | .934 | .563 | 1.548 |
| Constant | -5.231 | .000 | .005 | | |

*Note*. *N* = 6,647. Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA. Gender is for females as compared to males, education level is compared to less than high school, weekly hours of care is compared to the category of up to 8 hours, and duration of care is compared to the category of less than 2 years.

**Service access.** The findings showed there was a statistically significant association between caregiver relationship and the unmet support need of service access, Wald $X^2 = 27.131$, $df = 1$, $p = .000$, as shown in Table 6. The Hosmer Lemeshow Test, $p = .828$, indicated the model was a good fit for the data. The model explained 1.0% to 2.1% of the variance in the need for service access and correctly predicted 90.9% of the participants. The odds ratio for caregiver relationship (ExpB = .608, CI [.505, .733]) indicated spousal caregivers had 39.2% lower odds of reporting unmet support needs related to service access, relative to adult children.

Table 6

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality and Unmet Support Need for Service Access*

|  |  |  |  | 95% Confidence for Exp(B) |  |
|---|---|---|---|---|---|
|  | *B* | *p*-value | Exp(B) | Lower | Upper |
| Caregiver relationship |  |  |  |  |  |
| Spouse | -.497 | .000 | .608 | .505 | .733 |
| Type of illness |  |  |  |  |  |
| Cancer | -.123 | .496 | .885 | .621 | 1.259 |
| COPD | .086 | .677 | 1.090 | .727 | 1.634 |
| Dementia | .364 | .002 | 1.439 | 1.141 | 1.813 |
| Heart disease | -.113 | .497 | .893 | .644 | 1.238 |
| Rurality |  |  |  |  |  |
| Outside center city MSA | -.206 | .110 | .814 | .632 | 1.048 |
| Inside suburban co. MSA | -.363 | .031 | .696 | .501 | .967 |
| Not in MSA | -.386 | .000 | .680 | .557 | .830 |
| Constant | -1.981 | .000 | .138 |  |  |

*Note*. *N* = 6,447. Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA.

The inclusion of control variables with the multiple logistic regression model for caregiver relationship and the unmet support need of service access did not improve the predictive power of the model for caregiver relationship. The caregiver relationship variable continued to show a statistically significant association with the unmet support need of service access, Wald $X^2 = 31.725$, *df* = 1, *p* = .000, as shown in Table 7. The Hosmer Lemeshow Test, *p* = .514, indicated the model was a good fit for the data. The model explained 1.4% to 3.1% of the variance in the need for service access and continued to correctly predict 90.9% of the participants. The odds ratio for caregiver relationship (ExpB = .573, CI [.472, .695]) indicated that spousal caregivers had 42.7% lower odds of reporting unmet support needs related to service access, relative to adult children.

Table 7

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality and Unmet Support Need for Service Access with Control Variables*

| | *B* | *p*-value | Exp(B) | 95% Confidence for Exp(B) | |
|---|---|---|---|---|---|
| | | | | Lower | Upper |
| Caregiver relationship | | | | | |
| Spouse | -.557 | .000 | .573 | .472 | .695 |
| Type of illness | | | | | |
| Cancer | -.139 | .444 | .870 | .610 | 1.242 |
| COPD | .056 | .788 | 1.057 | .704 | 1.589 |
| Dementia | .271 | .024 | 1.311 | 1.037 | 1.659 |
| Heart disease | -.129 | .441 | .879 | .633 | 1.220 |
| Rurality | | | | | |
| Outside center city MSA | -.201 | .122 | .818 | .634 | 1.055 |
| Inside suburban co. MSA | -.338 | .045 | .713 | .512 | .993 |
| Not in MSA | -.363 | .000 | .695 | .568 | .851 |
| Covariates | | | | | |
| Gender-Female | .043 | .653 | 1.044 | .855 | 1.257 |
| Education-High school | -331 | .118 | .718 | .474 | 1.087 |
| Education-Some college | -.049 | .815 | .953 | .634 | 1.431 |
| Education-College graduate | .040 | .847 | 1.041 | .695 | 1.559 |
| Hours/week-9 to 19 | .197 | .134 | 1.217 | .941 | 1.574 |
| Hours/week-20 to 39 | .238 | .092 | 1.268 | .962 | 1.672 |
| Hours/week-40 or more | .456 | .000 | 1.578 | 1.269 | 1.962 |
| Duration-2 yrs. to less than 5 | .163 | .132 | 1.178 | .952 | 1.672 |
| Duration-More than 5 years | .016 | .876 | 1.017 | .826 | 1.251 |
| Constant | -2.120 | .000 | .120 | | |

*Note*. *N* = 6,447. Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA. Gender is for females as compared to males, education level is compared to less than high school, weekly hours of care is compared to the category of up to 8 hours, and duration of care is compared to the category of less than 2 years.

**Support groups.** The findings showed there was no statistically significant association between caregiver relationship and the unmet support need of support groups, Wald $X^2 = 2.919$, $df = 1$, $p = .088$, as shown in Table 8. The Hosmer Lemeshow Test, $p = .993$, indicated the model was a good fit for the data. The model explained .2 % to .8% of the variance in the need for support groups and correctly predicted 97.2% of the participants.

Table 8

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality and Unmet Support Need for Support Groups*

| | | | | 95% Confidence for Exp(B) | |
|---|---|---|---|---|---|
| | *B* | *p*-value | Exp(B) | Lower | Upper |
| Caregiver relationship | | | | | |
| Spouse | .262 | .088 | 1.300 | .962 | 1.757 |
| Type of Illness | | | | | |
| Cancer | .355 | .172 | 1.426 | .857 | 2.372 |
| COPD | -.185 | .600 | 1.293 | .603 | 2.400 |
| Dementia | .489 | .020 | 1.616 | 1.077 | 2.424 |
| Heart disease | -.108 | .717 | .898 | .501 | 1.608 |
| Rurality | | | | | |
| Outside center city MSA | -.414 | .101 | .661 | .403 | 1.084 |
| Inside suburban co. MSA | -.180 | .527 | .835 | .478 | 1.460 |
| Not in MSA | -.130 | .446 | ,878 | .628 | 1.227 |
| Constant | -3.651 | .000 | .026 | | |

*Note*. *N*= 6,447. Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA.

The inclusion of control variables with the multiple logistic regression model for caregiver relationship and the unmet support need of support groups did not improve the predictive power of the model and no statistically significant association was noted, Wald $X^2 = 1.071$, $df = 1$, $p = .301$, as shown in Table 9. The Hosmer Lemeshow Test, $p = .703$, indicated the model was a good fit for the data. The model explained 1.0% to 4.4% of the variance in the need for support groups and continued to correctly predict 97.2% of the participants.

Table 9

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality and Unmet Support Need for Support Groups with Control Variables*

| | | | | 95% Confidence for Exp(B) | |
|---|---|---|---|---|---|
| | *B* | *p*-value | Exp(B) | Lower | Upper |
| Caregiver relationship | | | | | |
| Spouse | .166 | .301 | 1.180 | .862 | 1.616 |
| Type of illness | | | | | |
| Cancer | .403 | .127 | 1.496 | .892 | 2.509 |
| COPD | .187 | .598 | 1.206 | .601 | 2.421 |
| Dementia | .300 | .156 | 1.349 | .892 | 2.040 |
| Heart disease | -.156 | .602 | .856 | .476 | 1.538 |
| Rurality | | | | | |
| Outside center city MSA | -.366 | .149 | .694 | .422 | 1.141 |
| Inside suburban co. MSA | -.115 | .689 | .892 | .508 | 1.564 |
| Not in MSA | -.055 | .751 | .947 | .674 | 1.329 |
| Covariates | | | | | |
| Gender-Female | .340 | .051 | 1.405 | .998 | 1.980 |
| Education-High school | .176 | .696 | 1.192 | .493 | 2.879 |
| Education-Some college | .735 | .093 | 2.085 | .885 | 4.914 |
| Education-College graduate | 1.010 | .020 | 2.746 | 1.170 | 6.447 |
| Hours/week-9 to 19 | -.189 | .684 | .828 | .334 | 2.053 |
| Hours/week-20 to 39 | .098 | .703 | 1.103 | .667 | 1.822 |
| Hours/week-40 or more | .400 | .105 | 1.491 | .920 | 2.417 |
| Duration-2 yrs. to less than 5 | .254 | .219 | 1.289 | .860 | 1.930 |
| Duration-More than 5 years | .560 | .002 | 1.752 | 1.225 | 2.505 |
| Constant | -5.135 | .000 | .006 | | |

*Note*. *N* = 6,447. Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA. Gender is for females as compared to males, education level is compared to less than high school, weekly hours of care is compared to the category of up to 8 hours, and duration of care is compared to the category of less than 2 years.

**Counseling.** The findings showed there was no statistically significant association between caregiver relationship and the unmet support need of counseling, Wald X² = .001, *df* = 1, *p* = .976, as shown in Table 10. The Hosmer Lemeshow Test, *p* = .858, indicated the model was a good fit for the data. The model explained .3% to 1.3% of the variance in the need for counseling and correctly predicted 97.7% of the participants.

Table 10

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality and Unmet Support Need for Counseling*

| | | | | 95% Confidence for Exp(B) | |
|---|---|---|---|---|---|
| | *B* | *p*-value | Exp(B) | Lower | Upper |
| Caregiver relationship | | | | | |
| Spouse | -.005 | .976 | .995 | .707 | 1.400 |
| Type of illness | | | | | |
| Cancer | .341 | .261 | 1.406 | .776 | 2.548 |
| COPD | -.133 | .775 | .876 | .352 | 2.178 |
| Dementia | .829 | .000 | 2.292 | 1.525 | 3.446 |
| Heart disease | .091 | .772 | 1.095 | .593 | 2.022 |
| Rurality | | | | | |
| Outside center city MSA | -.083 | 751 | .920 | .551 | 1.536 |
| Inside suburban co. MSA | -.252 | .464 | .777 | .395 | 1.528 |
| Not in MSA | .112 | .551 | 1.119 | .773 | 1.620 |
| Constant | -3.950 | .000 | .019 | | |

*Note*. *N = 6,447.* Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA.

The inclusion of control variables with the multiple logistic regression model for caregiver relationship and the unmet support need of counseling did not improve the predictive power of the model and no statistically significant association was noted, Wald X² = 054, *df* = 1, *p* = .817, as shown in Table 11. The Hosmer Lemeshow Test, *p* = .293, indicated the model was a good fit for the data. The model explained .6% to 3.2% of the variance in the need for counseling and continued to correctly predict 97.7% of the participants.

Table 11

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality and Unmet Support Need for Counseling with Control Variables*

| | | | | 95% Confidence for Exp(B) | |
|---|---|---|---|---|---|
| | *B* | *p*-value | Exp(B) | Lower | Upper |
| Caregiver relationship | | | | | |
| Spouse | -.042 | .817 | .959` | .673 | 1.367 |
| Type of illness | | | | | |
| Cancer | .322 | .292 | 1.381 | .758 | 2.515 |
| COPD | -.157 | .737 | .855 | .343 | 2.133 |
| Dementia | .720 | .001 | 2.054 | 1.356 | 3.112 |
| Heart disease | .035 | .910 | 1.036 | .560 | 1.917 |
| Rurality | | | | | |
| Outside center city MSA | -.059 | .821 | .942 | .563 | 1.577 |
| Inside suburban co. MSA | -.238 | .493 | .788 | .400 | 1.555 |
| Not in MSA | .133 | 485 | 1.142 | .786 | 1.660 |
| Covariates | | | | | |
| Gender-Female | .370 | .060 | 1.447 | .985 | 2.128 |
| Education – High school | .553 | .298 | 1.739 | .613 | 4.932 |
| Education – Some college | .784 | .141 | 2.178 | .773 | 6.136 |
| Education – College | .778 | .141 | 2.178 | .773 | 6.136 |
| Hours/week-9 to 19 | .398 | .126 | 1.489 | .894 | 2.483 |
| Hours/week-20 to 39 | .2882 | .000 | 2.415 | 1.513 | 3.854 |
| Hours/week-40 or more | .559 | .011 | 1.749 | 1.136 | 2.692 |
| Duration-2 yrs. to less than 5 | -.067 | .760 | .935 | .607 | 1.440 |
| Duration-More than 5 years | .559 | .548 | 1.126 | .765 | 1.656 |
| Constant | -5.248 | .000 | .005 | | |

*Note*. *N* = 6,447. Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA. Gender is for females as compared to males, weekly hours of care is compared to the category of up to 8 hours, and duration of care is compared to the category of less than 2 years.

**Respite.** The findings showed there was no statistically significant association between caregiver relationship and the unmet support need of respite, Wald $X^2 = 2.458$, *df*= 1, *p* =.117, as shown in Table 12. The Hosmer Lemeshow Test, *p* = .384, indicated the model was a good fit for the data. The model explained .5% to 2.2% of the variance in the need for respite and correctly predicted 96.8% of the participants.

Table 12

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality and Unmet Support Need for Respite*

| | | | | 95% Confidence for Exp(B) | |
|---|---|---|---|---|---|
| | *B* | *p*-value | Exp(B) | Lower | Upper |
| Caregiver relationship | | | | | |
| Spouse | .229 | .117 | 1.257 | .944 | 1.673 |
| Type of illness | | | | | |
| Cancer | .047 | .871 | 1.048 | .596 | 1.841 |
| COPD | -.312 | .460 | .732 | .319 | 1.677 |
| Dementia | .973 | .000 | 2.647 | 1.896 | 3.696 |
| Heart disease | -.109 | .703 | .896 | .511 | 1.573 |
| Rurality | | | | | |
| Outside center city MSA | .188 | .357 | 1.207 | .809 | 1.800 |
| Inside suburban co. MSA | .078 | .763 | 1.082 | .650 | 1.799 |
| Not in MSA | -.029 | .863 | .971 | .700 | 1.349 |
| Constant | -3.706 | .000 | .025 | | |

*Note*. *N* = 6,447. Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA.

The inclusion of control variables with the multiple logistic regression model for caregiver relationship and the unmet support need of respite did not improve the predictive power of the model, and no statistically significant association was noted, Wald $X^2 = .009$, *df* = 1, *p* = .926, as shown in Table 13. The Hosmer Lemeshow Test, *p* =

.786, indicated the model was a good fit for the data. The model explained 2.8% to 11.4% of the variance in the need for service access and continued to correctly predict 96.8% of the participants.

Table 13

*Logistic Regression Predicting Caregiver Relationship, Type of Illness, Rurality and Unmet Support Need for Respite with Control Variables*

| | | | | 95% Confidence for Exp(B) | |
|---|---|---|---|---|---|
| | *B* | *p*-value | Exp(B) | Lower | Upper |
| Caregiver relationship | | | | | |
| Spouse | .014 | .926 | 1.014 | .750 | 1.372 |
| Type of illness | | | | | |
| Cancer | -.017 | .953 | .983 | .552 | 1.749 |
| COPD | -.403 | .347 | .669 | .289 | 1.547 |
| Dementia | .649 | .000 | 1.913 | 1.354 | 2.702 |
| Heart disease | -.184 | .527 | .832 | .471 | 1.470 |
| Rurality | | | | | |
| Outside center city MSA | .236 | .257 | 1.266 | .842 | 1.903 |
| Inside suburban co. MSA | .170 | .521 | 1.185 | .705 | 1.991 |
| Not in MSA | .056 | .745 | 1.057 | .756 | 1.479 |
| Covariates | | | | | |
| Gender-Female | .494 | .004 | 1.639 | 1.167 | 2.302 |
| Education-High school | -.011 | .978 | .989 | .451 | 2.167 |
| Education-Some college | .448 | .249 | 1.565 | .731 | 3.353 |
| Education-College graduate | 1.122 | .003 | 3.072 | 1.455 | 6.486 |
| Hours/week-9 to 19 | .821 | .001 | 2.273 | 1.384 | 3.371 |
| Hours/week-20 to 39 | 1.012 | .000 | 2.751 | 1.660 | 4.558 |
| Hours/week-40 or more | 1.832 | .000 | 6.247 | 4.263 | 9.155 |
| Duration-2 yrs. to less than 5 | .362 | .052 | 1.436 | .997 | 2.068 |
| Duration-More than 5 years | .301 | .093 | 1.351 | .951 | 1.919 |
| Constant | -5.710 | .000 | 003 | | |

*Note*. *N = 6,447.* Caregiver relationship is compared to adult child caregivers, type of illness is compared to all others, and rurality is compared to in center city of MSA. Gender is for females as compared to males, education level is compared to less than high school, weekly hours of care is compared to the category of up to 8 hours, and duration of care is compared to the category of less than 2 years.

## Research Question 1: Summary of Findings

Based on the findings, no statistically significant relationships were found between caregiver relationship and the unmet support needs of classes, support groups, counseling, or respite. However, a statistically significant association was found between caregiver relationship and the unmet support needs of service access ($p$ = .000); therefore, for research question one the null hypothesis is rejected and the alternative hypothesis is accepted.

## Research Question 2

In the second research question, I evaluated the predictive relationship between the care recipient's type of illness and the reported unmet support needs of informal caregivers of older adults. The second research question reads: What is the association between the type of illness (all others, cancer, COPD, dementia, heart disease) and the reported unmet support needs (classes, service access, support groups, counseling, respite) of informal caregivers of older adults? The null hypothesis stated there was no statistically significant association between the type of illness and the reported unmet support needs of informal caregivers of older adults. The alternative hypothesis stated there is a statistically significant association between the type of illness caregiver and the reported unmet support needs of informal caregivers of older adults.

The hypothesis for research question two was tested using a multiple logistic regression model. The first round of testing analyzed the three independent variables and each of the five binary dependent variables. The second round of testing analyzed the three independent variables with the addition of the four control variables and each of the five binary dependent variables. The results for research question two are explained below and the study findings are presented in Tables 4 through 13.

**Classes**. As shown previously in Table 4, the findings showed no statistically significant association between the type of illness and the unmet support need of classes, Wald $X^2 = 3.100$, $df = 4$, $p = .541$. The Hosmer Lemeshow Test, $p = .687$, indicated the model was a good fit for the data. The model explained 1.4% to 3.6% of the variance in the need for classes and correctly predicted 98.7% of the participants.

The inclusion of control variables with the multiple logistic regression model for type of illness and the support need of classes (Table 5) did not improve the predictive power of the model and no statistically significant association was noted, Wald $X^2 = 3.252$, $df = 4$, $p = .517$. The Hosmer Lemeshow Test, $p = .955$, indicated the model was a good fit for the data. The model explained 3.2% to 8.0% of the variance in the need for classes and continued to correctly predict 98.7% of the participants.

**Service access.** As previously shown in Table 6, there was a statistically significant association between type of illness and the unmet support need of service access, Wald $X^2 = 11.899$, $df = 4$, $p = .018$. The Hosmer Lemeshow Test, $p = .828$, indicated the model was a good fit for the data. The model explained 1.0% to 2.1% of the variance in the need for service access and correctly predicted 90.9% of the participants. The odds ratio for type of illness (ExpB = 1.439, CI [1.141, 1.813]) indicated that dementia caregivers had 1.44 times higher odds of reporting unmet support needs related to service access, relative to caregivers in the all others category.

The inclusion of control variables with the multiple logistic regression model for type of illness and the unmet support need of service access (Table 7) did not result in an increase in the predictive power of the model and continued to show a statistically significant association, Wald $X^2 = 7.368$, *df* = 4, *p* = .024. The Hosmer Lemeshow Test, *p* = .514, indicated the model was a good fit for the data. The model explained 1.4% to 3.1% of the variance in the need for service access and continued to correctly predict 90.9% of the participants. The odds ratio for type of illness (ExpB = 1.311, CI [1.037, 1.659]) indicated that dementia caregivers had 1.31 times higher odds of reporting unmet support needs related to service access, relative to caregivers in the all others category.

**Support Groups.** As shown previously in Table 8, there was no statistically significant association between type of illness and the unmet support need of support groups, Wald $X^2 = 7.074$, *df* = 4, *p* = .132. The Hosmer Lemeshow Test, *p* = .993, indicated the model was a good fit for the data. The model explained .2% to .8% of the variance in the need for support groups and correctly predicted 97.2% of the participants.

The inclusion of control variables with the multiple logistic regression model for type of illness and the unmet support need of support groups (Table 9) did not improve the predictive power of the model and no statistically significant association was noted, Wald $X^2 = 4.577$, *df* = 4, *p* =.334. The Hosmer Lemeshow Test, *p* = .703, indicated the model was a good fit for the data. The model explained 1.0% to 4.4% of the variance in the need for support groups and continued to correctly predict 97.2% of the participants.

**Counseling.** As shown previously in Table 10, there was a statistically significant association between type of illness and the unmet support need of counseling, Wald $X^2$ =

16.693, *df* = 4, *p* = .002. The Hosmer Lemeshow Test, *p* = .858, indicated the model was a good fit for the data. The model explained .3% to 1.3% of the variance in the need for counseling and correctly predicted 97.7% of the participants. The odds ratio for type of illness (ExpB = 2.292, CI [1.525, 3.446]) indicated that dementia caregivers had 2.29 times higher odds of reporting unmet support needs of counseling, relative to caregivers in the all others category.

The inclusion of control variables with the multiple logistic regression model for type of illness and the unmet support need of counseling (Table 11) did not improve the predictive power of the model and continued to show a statistically significant association, Wald $X^2$ = 12.674, *df* = 4, *p* =.013. The Hosmer Lemeshow Test, *p* = .293, indicated the model was a good fit for the data. The model explained .6% to 3.2% of the variance in the need for counseling and continued to correctly predict 97.7% of the participants. The odds ratio for type of illness (ExpB = 2.054, CI [1.356, 3.112]) indicated that dementia caregivers had 2.05 times higher odds of reporting unmet support needs of counseling, relative to caregivers in the all others category.

**Respite.** As shown previously in Table 12, there was a statistically significant association between type of illness and the unmet support need of respite, Wald $X^2$ = 37.061, *df* = 4, *p* = .000. The Hosmer Lemeshow Test, *p* = .384, indicated the model was a good fit for the data. The model explained .5% to 2.2% of the variance in the need for respite and correctly predicted 96.8% of the participants. The odds ratio for type of illness (ExpB= 2.647, CI [1.896, 3.696]) indicated that dementia caregivers had 2.65 times higher odds of reporting unmet support needs of respite, relative to caregivers in the all others category.

The inclusion of control variables with the multiple logistic regression model for type of illness and the unmet support need of respite (Table 13) did not result in an increase in the predictive power of the model and continued to show a statistically significant association, Wald $X^2 = 17.352$, *df* = 4, *p* =.002. The Hosmer Lemeshow Test, *p* = .786, indicated the model was a good fit for the data. The model explained 2.8% to 11.4% of the variance in the need for respite and continued to correctly predict 96.8% of the participants. The odds ratio for type of illness (ExpB = 1.913, CI [1.354, 2.702]) indicated that dementia caregivers had 1.91 times higher odds of reporting unmet support needs of respite, relative to caregivers in the all others category.

## Research Question 2: Summary of Findings

Based on the findings, no statistically significant associations were found between the type of illness and the reported unmet support needs of classes and support groups. However, a statistically significant association was found between type of illness and the unmet support needs of counseling (*p* = .001), service access (*p* = .024), and respite (*p* = .000); therefore, for research question two the null hypothesis is rejected and the alternative hypothesis is accepted.

## Research Question 3

In the third research question, I evaluated the predictive relationship between rurality and the reported unmet support needs of informal caregivers of older adults. The third research question reads: What is the association between rurality and the reported unmet support needs (classes, service access, support groups, counseling, respite) of informal caregivers of older adults? The null hypothesis stated there was no statistically significant association between rurality and the reported unmet support needs of informal caregivers of older adults. The alternative hypothesis stated there is a statistically significant association between rurality and the reported unmet support needs of informal caregivers of older adults.

The hypothesis for research question three was tested using a multiple logistic regression model. The first round of testing analyzed the three independent variables and each of the five binary dependent variables. The second round of testing analyzed the three independent variables and four control variables with each of the five binary dependent variables. The results for research question three are explained below and the study findings are presented in Tables 4 through 13.

**Classes**. As shown previously in Table 4, there was no statistically significant association between rurality and the unmet support need of classes, Wald $X^2 = .601$, $df = 3$, $p = .896$,. The Hosmer Lemeshow Test, $p = .687$, indicated the model was a good fit for the data. The model explained 1.4% to 3.5% of the variance in the need for classes and correctly predicted 98.7% of the participants.

The inclusion of control variables with the multiple logistic regression model for rurality and the unmet support need of classes (Table 5) did not improve the predictive power of the model and no statistically significant association was noted, Wald $X^2 = .715$, $df = 3$, $p = .870$. The Hosmer Lemeshow Test, $p = .955$, indicated the model was a good fit for the data. The model explained 3.2% to 8.0% of the variance in the need for classes and continued to correctly predict 98.7% of the participants.

**Service access.** As shown previously in Table 6, there was a statistically significant association between rurality and the unmet support need of service access, Wald $X^2$ = 16.159, *df* = 3, *p* = .001. The Hosmer Lemeshow Test, *p* = .828, indicated the model was a good fit for the data. The model explained 1.0% to 2.1% of the variance in the need for service access and correctly predicted 90.9% of the participants. The odds ratio for rurality inside a suburban county MSA (ExpB = .696, CI [.501, .967]) and not in an MSA (ExpB = .680, CI [.557, .830] indicated that caregivers residing in a suburban county had 30.4% lower odds of reporting unmet support needs related to service access, relative to caregivers residing in the center city of an MSA. The findings also indicated that caregivers not residing in an MSA had 32% lower odds of reporting unmet support needs related to service access, relative to caregivers residing in the center city of an MSA.

The inclusion of control variables with the multiple logistic regression model for rurality and the unmet support need of service access (Table 7) did not result in an increase in the predictive power of the model and continued to show a statistically significant association, Wald $X^2$ = 14.014, *df* = 3, *p* = .003. The Hosmer Lemeshow Test, *p* = .514, indicated the model was a good fit for the data. The model explained 1.4% to 3.1% of the variance in the need for service access and continued to correctly predict 90.9% of the participants. The odds ratio for rurality - inside a suburban county MSA (ExpB = .713, CI [.512, .993]) and not in an MSA (ExpB = .695, CI [.568, .851] indicated that caregivers residing in a suburban county had 28.7% lower odds of reporting unmet support needs related to service access, relative to caregivers residing in the center city of an MSA. The findings also indicated that caregivers not residing in an MSA had 30.5% lower odds of reporting unmet support needs related to service access, relative to caregivers residing in the center city of an MSA.

**Support groups.** As shown previously in Table 8, there was no statistically significant association between rurality and the unmet support need of support groups, Wald $X^2 = 2.871$, $df = 3$, $p = .412$. The Hosmer Lemeshow Test, $p = .993$, indicated the model was a good fit for the data. The model explained .2% to .8% of the variance in the need for support groups and correctly predicted 97.2% of the participants.

The inclusion of control variables with the multiple logistic regression model for rurality and the unmet support need of support groups (Table 9) did not improve the predictive power of the model and no statistically significant association was noted, Wald $X^2 = 2.121$, $df = 3$, $p = .548$. The Hosmer Lemeshow Test, $p = .703$, indicated the model was a good fit for the data. The model explained 1.0% to 4.4% of the variance in the need for support groups and continued to correctly predict 97.2% of the participants.

**Counseling.** As shown previously in Table 10, there was no statistically significant association between rurality and the unmet support need of counseling, Wald $X^2 = 1.418$, $df = 3$, $p = .701$. The Hosmer Lemeshow Test, $p = .858$, indicated the model was a good fit for the data. The model explained .3% to 1.3% of the variance in the need for counseling and correctly predicted 97.7% of the participants.

The inclusion of control variables with the multiple logistic regression model for rurality and the unmet support need of counseling (Table 11) did not improve the predictive power of the model and no statistically significant association was noted, Wald $X^2 = 1.476$, $df = 3$, $p = .688$. The Hosmer Lemeshow Test, $p = .858$, indicated the model was a good fit for the data. The model explained .6% to 3.2% of the variance in the need for counseling and continued to correctly predict 97.7% of the participants.

**Respite:** As shown previously in Table 12, there was no statistically significant association between rurality and the unmet support need of respite, Wald $X^2 = 1.198$, $df = 3$, $p = .754$. The Hosmer Lemeshow Test, $p = .384$, indicated the model was a good fit for the data. The model explained .5% to 2.2% of the variance in the need for respite and correctly predicted 96.8% of the participants.

The inclusion of control variables with the multiple logistic regression model for rurality and the unmet support need of respite (Table 13) did not result in an increase in the predictive power of the model and continued to show no statistically significant association, Wald $X^2 = .788$, $df = 3$, $p = .852$. The Hosmer Lemeshow Test, $p = .116$, indicated the model was a good fit for the data. The model explained 8.6% to 13.9% of the variance in the need for service access and correctly predicted 96.8% of the participants.

### Research Question 3: Summary of Findings

Based on the findings, no statistically significant associations were found between rurality and the reported unmet support needs of classes, support groups, counseling, and respite. However, a statistically significant association was found between rurality and the unmet support needs of service access; therefore, for research question three the null hypothesis is rejected and the alternative hypothesis is accepted.

## Summary

In this quantitative study, a total sample of 6.447 respondents were drawn from the 2015 BRFSS optional caregiver module. Three research questions were constructed to analyze the unmet support needs of informal caregivers of older adults. Multiple logistic regression analysis was performed to determine predictive relationships between three independent variables (caregiver relationship, type of illness, rurality) and five binary dependent variables (classes, service access, support groups, counseling, respite). Multiple logistic regression tests were performed using a significance level of $p < .05$ and a confidence interval of 95%. Data was analyzed both controlling for and not controlling for covariates (gender, education levels, weekly hours of care, duration of care). The Wald test was used to determine statistical significance and goodness of fit was assessed using the Hosmer-Lemeshow chi-square analysis with a nonsignificant *p*-value ($p > .05$) desired.

The first research question evaluated the association between the caregiver relationship and the reported unmet support needs of informal caregivers of older adults. According to the multiple logistic regression analysis, no statistically significant relationships were found between caregiver relationship and the unmet support needs of classes, support groups, counseling, or respite. However, a statistically significant association was found between caregiver relationship and the unmet support needs of service access. Based on the findings for research question one, the null hypothesis was rejected, and the alternative hypothesis was accepted.

The second research question evaluated the association between the type of illness of the care recipient and the unmet support needs of informal caregivers of older adults. According to the multiple logistic regression analysis, no statistically significant associations were found between the type of illness and the unmet support needs of classes, and support groups. However, a statistically significant association was found between the type of illness and the unmet support needs of counseling, service access, and respite. Based on the findings for research question two, the null hypothesis was rejected, and the alternative hypothesis was accepted.

The third research question evaluated the association between rurality and the reported unmet support needs of informal caregivers of older adults. According to the multiple logistic regression analysis, no statistically significant relationships were found between rurality and the unmet support needs of classes, support groups, counseling, or respite. However, a statistically significant association was found between rurality and the unmet support needs of service access. Based on the findings for research question three, the null hypothesis was rejected, and the alternative hypothesis was accepted.

In Chapter 5, I provide an interpterion of the key findings collected from the multiple logistic regression models, limitations of the study, recommendations, and implications for positive social change.

# Chapter 5: Discussion, Conclusions, and Recommendations

## Introduction

The purpose of this study was to evaluate the association of contextual and environmental factors and the unmet support needs of informal caregivers of older adults. Using secondary data from the 2015 BRFSS optional caregiver module, the quantitative, nonexperimental design allowed for the analysis of predictive relationships between three independent variables (caregiver relationship, type of illness, rurality) and a dependent variable of support services (classes, service access, support groups, counseling, respite). For this study, I analyzed each support service separately as a binary coded variable.

The research questions that framed the study were:

RQ1: What is the association between the caregiver relationship (spousal, adult child) and the reported unmet support needs of informal caregivers of older adults?

RQ2: What is the association between the type of illness of the care recipient (all others, cancer, COPD, dementia, heart disease) and the reported unmet support needs of informal caregivers of older adults?

RQ3: What is the association between rurality and the reported unmet support needs of informal caregivers of older adults?

For the 2015 BRFSS optional caregiver module, 24,034 survey participants self-identified as informal caregivers. The target population for this study included a subset of the informal caregivers based on how individuals self-identified for questions related to caregiver relationship, type of illness, residence, and unmet support needs. A total sample of 6,447 respondents was used for the final analysis. A series of multiple logistic regression tests were performed to evaluate associations between the independent variables (caregiver relationship, type of illness, rurality), covariates (gender, education level, hours of weekly care provided, duration of care), and each of the support service types (classes, service access, support groups, counseling, respite). I analyzed data both controlling for and not controlling for covariates.

Based on the results of the current study, there was some evidence that all three independent variables significantly predicted unmet support needs of informal caregivers of older adults. According to the first regression analysis, caregiver relationship was a statistically significant predictor of the unmet support need of service access ($p$ = .000). The second analysis found that type of illness was a statistically significant predictor of the unmet support need of counseling ($p$ = .013), service access (.024), and respite ($p$ = .002), and the third analysis found that rurality was a statistically significant predictor of the unmet support need of service access ($p$ = .003). Based on the findings, the null hypotheses were rejected, and the alternative hypotheses were accepted for all three research questions.

## Interpretation of the Findings

### Ecological Systems Theory

Bronfenbrenner’s EST provided the theoretical framework for this research. The theory asserts that when a person is well connected and engaged in a supportive environment that functioning should improve (Cho et al., 2015; Wilder, 2010). The EST model as described by Bronfenbrenner and Ceci (1994) includes the microsystem (roles, activities, and relationships), mesosystem (interactions between microsystems), exosystem (external factors that affect the individual), and macrosystem (culture, beliefs, and ideologies). Researchers have suggested that important insights could be gained from applying EST to future caregiver studies (Wilder, 2016).

The EST model provided a helpful framework for examining the associations of the caregiver relationship, type of illness, and rurality with the reported unmet support needs of informal caregivers of older adults. The contextual factors of the caregiver relationship and type of illness fell into Bronfenbrenner’s micro and mesosystems, and the environmental factor of rurality was captured in the meso, exo, and macrosystems of the EST model (Bronfenbrenner & Ceci, 1994). EST includes both physical and structural settings, and for this study, the focus was on the types of support services most needed by informal caregivers of older adults that they were not currently receiving. Researchers Forte (2007) and Ungar (2002) suggested that expanded knowledge in this area could help detect strain within an individual’s ecosystem and, ultimately, assist practitioners with connecting individuals to needed resources.

The results of the study showed that contextual (caregiver relationship, type of illness) and environmental (rurality) factors were associated with the unmet support needs of informal caregivers of older adults. The EST model suggests that adequate resources are needed within each of Bronfenbrenner’s environmental systems from family support to available support services to maintain optimal health and well-being for the individual (Bivens, 2016). The study findings align with the foundational principle of

EST, which asserts that the whole is greater than the sum of its parts, and the well-being of individual systems contribute to the well-being of the entire system (Ungar, 2002).

## Insignificant Findings for Support Services

The current study revealed mixed results and showed no statistically significant relationships between the independent variables and some of the support service types. Classes and support groups were not found to be statistically significant in any of the tests performed, and respite care was only found to be significant for the type of illness variable. Previous studies have shown comparable results for the support service types that were found to be insignificant in the current study. For example, a quantitative study by Hong (2010) looked at patterns of service utilization for informal caregivers and found that respite and support groups were two support services that were rarely used, but the reason for low utilization was unclear. Another quantitative study that evaluated community-dwelling older adults with chronic conditions found that less than 5% of informal caregivers reported using support groups or respite care (Wolff, Dy, Frick, & Kasper, 2007). Respite care, as addressed later in this chapter, has also been shown in other studies to be underutilized despite being one of the most commonly requested service types by informal caregivers (Phillipson et al., 2014).

Another quantitative study that looked at informal caregivers of cancer patients found a high level of unmet support needs overall, but a very low desire for classes as a support service (Mosher et al., 2013). The Mosher et al. (2013) study showed 61% of the survey participants reported needing more informational support with 74% desiring written materials, but only 2% desiring to attend classes. Attending classes can be difficult for informal caregivers that are already juggling multiple tasks. Attending classes may also require informal caregivers to arrange for someone to stay with the care recipient while away. It is understandable with access to the internet that informal caregivers may desire more written materials versus having to attend a traditional face to face class. Mosher et al. also suggested that the majority of informal caregivers do not desire to use traditional mental health services with the results of their study showing that 79% of study participants expressed a desire to participate in counseling services via the telephone.

## Caregiver Relationship

The current study revealed mixed results and indicated no statistically significant relationships between caregiver relationship and the unmet support needs of classes, support groups, counseling and respite. However, caregiver relationship was a statistically significant predictor of unmet support needs related to service access: therefore, the null hypothesis was rejected, and the alternative hypothesis was accepted. The study results indicated that adult child caregivers were more likely than spousal caregivers to report unmet support needs related to service access.

For the significant findings related to caregiver relationship and service access, the current study aligned with a previous qualitative study indicating the needs of spousal and adult child caregivers are complex and can vary based on the type of relationship (Tatangelo et al., 2018). Tatangelo et al. suggested assorted reasons for the differences including spousal caregivers of older adults tend to be older and are more likely to reside with the care recipient whereas adult child caregivers often must juggle multiple roles as many are employed and still supporting their own families. Tatangelo el al. also noted that adult child caregivers reported a general lack of knowledge of support options, which may be indicative of concerns related to service access.

Two additional quantitative studies looking at predictive factors and service utilization demonstrated potential concerns with service access for adult child caregivers. A quantitative study by Hong (2010) revealed that spousal caregivers were 1.33 times more likely to use multiple services as compared to adult child caregivers. A recent study by Potter (2018) looking at factors associated with the use and nonuse of services sought by informal caregivers also aligned with the results of the current study. Potter's study revealed that adult child caregivers were 3.25 times more likely than other caregivers to report unused services.

A study by Jayani and Hurria (2012) further confirmed differences in strain and burden for spousal and adult child caregivers. Following an extensive literature review evaluating the differences between spousal and adult child caregivers of cancer patients, they found that adult child caregivers were at an elevated risk for strain and psychological effects related to their caregiving role. While much of the past caregiver research has focused on differences in the caregiver relationship and emotional strain and burden, the findings of the current study suggest that the caregiver relationship also influences the types of support services needed by these two distinct caregiver groups.

## Type of Illness

The current study revealed mixed results and indicated no statistically significant relationships between the type of illness and the unmet support needs of classes and support groups. However, the type of illness was a statistically significant predictor of unmet support needs for counseling, service access, and respite services; therefore, the null hypothesis was rejected, and the alternative hypothesis was accepted. The study results indicated that dementia caregivers were 2.05 times more likely to report unmet support needs related to counseling, 1.31 times more likely to report unmet support needs related to service access, and 1.91 times more likely to report unmet support needs related to respite than caregivers in the all others category.

**Counseling.** Previous research examining the relationship between type of illness and the unmet support needs of informal caregivers is limited, but existing studies have shown some comparable results. Research has indicated that type of illness can increase the emotional and physical strain of caregivers, especially when caring for a chronically or terminally ill family member (Empeño et al., 2013). This was further confirmed in a qualitative study of dementia caregivers, which revealed that adult child caregivers often reported their mental health needs were not being met nor did they know what psychosocial service options were available (Tatangelo et al., 2018). These results align with findings from the current study indicating a need for counseling services by dementia caregivers.

Another study looking at cancer patients provided further findings that suggest a predictive relationship between the type of illness and the need for counseling services. Study results indicated a high level of unmet support needs for informal caregivers, with emotional and psychosocial needs being especially prevalent (Sklenarova et al., 2015). Sklenarova et al. (2015) noted that participants expressed fears related to disease progression and anxiety related to ultimately losing the care recipient. Dementia caregivers must also deal with disease progression and the eventual loss of the care recipient, which explains why a need for counseling services may be present.

**Respite care.** Respite care is one of the most commonly requested services by informal caregivers, yet it is a service that is often underutilized by dementia caregivers (Phillipson et al., 2014). Phillipson et al. (2014) conducted an extensive literature review to better understand the use of respite services by dementia caregivers and suggested that services do not match the needs of those in caregiving roles. Another quantitative study involving informal caregivers in Alabama also found respite services to be underutilized. Study results showed that 50% of the survey participants had difficulty accessing respite services, and 25% of the participants reported not knowing how to even request respite support (Geiger & O'Neal, 2014). While it is unclear why respite services are so underutilized, it is not surprising based on previous research findings to see respite care listed by dementia caregivers as a service they feel they need but are not currently receiving.

**Service access.** The current study does not address why service access may be an issue for dementia caregivers. However, a qualitative study by Reid (2015) suggested that dementia caregivers may experience increased or unique challenges due to the slow progressivity and higher care needs associated with dementia related illnesses. The need for extensive care in the later stages of the disease may impede the ability of informal caregivers to access needed support services.

A recent study by Potter (2018) looking at factors associated with the use and nonuse of services sought by informal caregivers further illustrates challenges for dementia caregivers related to service utilization. Potter’s study found a statistically significant relationship between the health of the care recipient and use of support services. Specifically, Potter’s study found that dementia was a predictor for unused services, which was defined as a person that sought information about services but never used the services. Potter’s study revealed that dementia caregivers were 2.19 times more likely to report unused services. Potter’s study looked at unique categories based on unused services versus no services sought, all services used versus no services sought, and all services used versus any unused services thus making it difficult to do a direct comparison of survey results. However, Potter’s study, along with the current study, confirmed a positive relationship with the predictive factor of the health of the care recipient and service utilization. The current study results further expand on the limited knowledge available in this specific area of study.

## Rurality

The current study revealed mixed results and indicated no statistically significant relationships between rurality and the unmet support needs of classes, support groups, counseling and respite. However, rurality was a statistically significant predictor of unmet support needs related to service access: therefore, the null hypothesis was rejected, and the alternative hypothesis was accepted. Previous studies have demonstrated that rural communities face unique geographic challenges that can create barriers and access issues to needed services, but few studies have looked at caregiver differences based on residence (Brazil et al., 2013; Reinhard et al., 2008; Trivedi et al., 2017). Previous studies have also often lumped caregivers in to two broad categories of urban versus rural. The current study looked at the association of the various levels of rurality and found that caregivers residing in a suburban county had 30% lower odds, and caregivers not residing in an MSA had 32% lower odds, of reporting unmet support needs related to service access, relative to caregivers residing in the center city of an MSA.

There is a paucity of research related to the association of rurality and the unmet support needs of informal caregivers of older adults. Previous research looking at urban and rural differences has often focused on differences in emotional stress, caregiver characteristics, perceived health status, or differences in financial health. Crouch et al. (2017) believed their study was one of the first national studies to evaluate caregiver differences based on residence. Their study largely focused on differences in factors of physical and financial strain, emotional stress, and overall caregiver health, but also considered factors related to the use of respite services. They found no statistically significant difference in the use of respite services based on residence, which aligns with the results of the current study.

Previous study results looking at urban and rural differences have also been inconsistent. Researchers Brazil et al. (2013) completed a quantitative study looking at the differences between urban and rural caregivers providing palliative care. Their study findings revealed that both urban and rural caregivers reported having unmet support needs. However, rural caregivers were shown to have experienced greater unmet needs in the category of tangible support, which included things such as assistance with errands, adequate time to rest, getting help with transportation, and obtaining financial assistance. Another study confirmed disparities between urban and rural caregivers of persons with COPD and determined that rural residence was associated with higher utilization of health related support services (Jackson et al., 2013).

Other researchers have found contradictory results and have suggested that urban caregivers experience greater unmet support needs, as was indicated in the current study. A cross-sectional telephone survey looking at 140 informal caregivers showed no statistically significant difference in service access between urban and rural caregivers (Brazil et al., 2013). An additional study looking at caregiving difficulties among urban and rural caregivers was also consistent with the results of the current study. The quantitative study looked at 7,436 caregivers and indicated that rural caregivers were less likely to report caregiving related difficulties (Bouldin et al., 2017). The study results showed that urban caregivers were 1.11 times more likely than their rural counterparts to report difficulties with caregiving responsibilities. However, a noted limitation of the study was the use of a course measure of rurality in which caregivers were categorized simply as urban versus rural.

A study by Li (2006) further confirmed the results of the current study and revealed that care recipients residing in urban areas experienced greater unmet support needs than those residing in rural areas. Specifically, Li’s study reported that rural caregivers reported lower odds than urban caregivers related to the use of personal care services (42%), homemaker services (55%), and the use of assistive devices (38%). However, Li’s study lumped caregivers into two broad categories of urban versus rural and was also focused on the unmet needs of the care recipient. The current study remains unique in its contribution, as there are few studies that have looked at the differing levels of rurality and the association with unmet support needs of informal caregivers of older adults.

## Limitations of the Study

The primary limitation of the current study was associated with the secondary data source used and the limited data available. The study used BRFSS data collected during the calendar year of 2015, which provided a snapshot that is dependent on conditions during that specific time-period. Since the caregiver module was re-designed in 2015 and questions were both eliminated and added to the module, it was not possible to combine data periods or to do any type of comparative analysis between reporting periods.

Other limitations included that data was compiled based on self-reports and there was no way to validate responses from participants. Certain demographics may have also been underrepresented, as participation in BRFSS is limited to community-dwelling adults over the age of 18 with either a landline or cellular telephone. Telephone coverage may have differed by geographic regions or by sub-populations. The CDC (2009) notes that coverage can be lower among low-income adults, persons with less than a high school diploma, persons with poor health, and African Americans in some of the southern states.

The use of archival data limited the choice of variables studied, and as a result, there may have been important predictors or confounding variables not accounted for.

For example, a limitation of the BRFSS caregiver module is that no information is provided regarding the stage or progression of the stated illness. For example, a care recipient may be in the early stages versus late stages of dementia or be near the end of life due to a cancer diagnosis, but the survey does not provide that level of detail. It would be anticipated that the stage of illness could influence the unmet support needs of informal caregivers.

## Recommendations for Further Research

The types of supports needed by informal caregivers can vary based on individual circumstances. However, studies examining the relationship between contextual and environmental factors and the unmet support needs of informal caregivers are limited and have produced inconsistent results. Prior research has also typically been limited to small sample sizes and narrow geographic regions (Goins et al., 2009). Further studies, both qualitative and quantitative, could improve the understanding of how various determinants impact the support services desired by informal caregivers. Expanded knowledge in this area could provide valuable insights thus enabling health care leaders and policymakers to direct funding and tailor interventions to better meet the needs of informal caregivers of older adults.

The BRFSS optional caregiver module was revised in 2015 thus limiting the ability to combine data with prior years or the ability to do any comparative analysis between reporting periods. Following compilation of additional data using the newly revised module, future researchers may consider evaluating multiple years of data providing a larger sample size for analysis. As more BRFSS data is compiled, researchers may want to compare data by geographic regions of the United States  providing further insights into the impact of residence on the unmet support needs of caregivers.

The BRFSS caregiver module provides a limited list of support service types, and many survey participants did not select one of the listed services as an unmet support need. It is unclear if they had no unmet support needs or if they needed support services that were not listed. Additional research is needed considering a broader list of support services. For example, there was no mention of key services such as transportation, assistive devices, or homemaker services. The 2015 module also listed access to services as a service type when access to services is often not thought of as a specific support service, but rather a barrier to services. Additional research looking at a broader range of service types could provide an improved understanding of the needs of informal caregivers.

A longitudinal study comparing the needs of informal caregivers may be beneficial and would help capture how support needs may change throughout disease progression. Research looking at additional covariates such as the state of disease progression may also provide valuable insights into the needs of those in caregiving roles. Further research looking at the differing levels of rurality may also shed further light on the influence of residence as a predictor variable.

Due to the paucity of research related to the unmet support needs of informal caregivers of older adults, along with the inconsistency in findings, more studies are needed. Hong (2010) suggested that to create a more effective support system for caregivers more evidence is needed that evaluates predictors for service utilization.

Additionally, studies that explore the reasons why informal caregivers are experiencing service access issues are needed, along with studies related to understanding the reasons for the general underutilization of services. Expanded knowledge in these areas may provide health care practitioners with the ability to improve resource availability and to help caregivers navigate access to resources.

## Implications and Social Impact

The study findings have the potential to result in positive social change and to contribute to expanded caregiver research using the EST model. It is recognized that the needs of informal caregivers often vary depending on individual circumstances yet past caregiver research, as well as the types of support services offered, often treat caregivers as a homogenous group. According to Dwyer & Coward (1992), this has resulted in a clouding of the influence of contextual and environmental factors in past caregiver research. The study findings may produce positive social change benefits by contributing to the field and helping to fill the gap in knowledge related to the influence of contextual (caregiver relationship, type of illness) and environmental (rurality) factors on the unmet support needs of informal caregivers of older adults. It is hoped that increasing awareness of how these factors are associated with the need for services will ultimately result in better care for both the caregiver and care recipient (Jayani & Hurria, 2012).

The current study identified the support service most needed by informal caregivers that they were not currently receiving. While the study does not address the reasons for difficulty in accessing services, the study results provide insight into the unmet support needs of informal caregivers of older adults. This type of information can assist those working in health care to understand some of the current gaps in services. Based on the study results, health care leaders may consider how to better connect dementia caregivers to respite services or increase offerings of phone-based counseling services. The area of service access was a consistent unmet support need across all variables indicating that health care practitioners may need to do more to ensure informal caregivers understand how to access the services that are available.

Health care providers are often a first line of defense when it comes to supporting both the care recipient and caregiver. It is essential that they recognize that they are no longer just serving the patient, but also the caregiver (Wall, 2018). In addition, it is important for health care practitioners to understand that a one size fits all approach may not work for those in caregiving roles. As illustrated by the current study, adult child caregivers are reporting greater unmet needs related to service access than spousal caregivers, dementia caregivers are more likely than other caregivers to report unmet support needs related to counseling, service access, and respite, and caregivers residing in the center city of an MSA are reporting greater needs tied to service access than those residing in a suburban county or outside of an MSA. These findings reinforce that caregivers are a diverse group and this type of information can help health care practitioners connect specific caregiver groups to needed resources, along with helping them to navigate access.

The current study also expands caregiver research using the EST and presents a unique theoretical perspective for addressing contextual and environmental factors relevant to the unmet support needs of informal caregivers of older adults. The research findings indicate that when looking through the lens of the EST model, the factors of caregiver relationship, type of illness, and rurality are significant factors related to how caregivers function within their existing environments.

Informal caregivers with unmet support needs may not be able to continue in their caregiving role thus creating quality of care issues and unmet needs for care recipients (Brazil et al., 2013). With the reliance on informal caregivers expected to increase in the coming years, improving support for informal caregivers is viewed as a national priority (Black et al., 2013; McCabe et al., 2016; NAC & AARP, 2015). The study findings were mixed but statistically significant relationships were found between all three independent variables of caregiving relationship, type of illness, and rurality and the unmet support needs of informal caregivers. It is hoped that this information may fuel further research. With many competing priorities for funding, a greater understanding of how contextual and environmental factors impact the support needs of informal caregivers may enable resources to be targeted to specific caregiver groups and geographic locations (Potter, 2018).

## Conclusion

Informal caregivers play a substantial role in the health care delivery system in the United States, and far exceed the number of paid direct-care workers providing care to older adults (Freedman & Spillman, 2014; NAC & AARP, 2015). As the United States faces a rapidly aging population in the coming years, the reliance on informal caregivers will increase and the need to better support informal caregivers has perhaps never been so important (Eldercare Workforce Alliance, 2018). Past research has indicated that most informal caregivers feel they need more support than they are currently receiving, yet there is a lack of research looking at how to improve services for those in caregiving roles (Bangerter et al., 2017; McCabe et al., 2016).

According to the Office of Disease Prevention and Health Promotion (2018), viable data related to the unmet support needs of caregivers is currently lacking. Previous research has often focused on the support needs of the care recipient or on caregiver burden, but little research exists that provides insight into the unmet support needs of today’s caregiver (Reid, 2015). The current study is one of the first peer-reviewed studies using the revised 2015 caregiver module to examine the predictive relationships between caregiving relationship, type of illness, and rurality and the reported unmet support needs of informal caregivers. The findings of this study also reflect the perspectives of the actual caregiver unlike much of the previous caregiver research that has solicited input from third parties, often health care professionals (Bangerter et al., 2017; McCabe et al., 2016). The purpose of this quantitative study was to address the existing gap in literature and to provide a greater understanding of the association between contextual and environmental factors and the reported unmet support needs of informal caregivers of older adults.

A series of multiple logistic regression tests were performed to test the hypotheses. The results of the current study were mixed and found no statistically significant relationships existed for the service types of classes and support groups. However, despite mixed results, the findings indicated that the caregiving relationship, type of illness, and rurality were significant predictors for unmet support needs of informal caregivers of older adults. The results showed that spousal caregivers had 42.7% lower odds of reporting unmet support needs related to service access, relative to adult children. The odds ratio for type of illness indicated that dementia caregivers had 2.05 times higher odds of reporting unmet support needs of counseling, 1.31 times higher odds of reporting unmet support needs related to service access, and 1.91 times higher odds of reporting unmet support needs of respite, relative to caregivers in the all others category. The findings also indicated that caregivers residing in a suburban county had 30.4% lower odds of reporting unmet support needs related to service access, and caregivers not residing in an MSA also had 32% lower odds of reporting unmet support needs related to service access, relative to caregivers residing in the center city of an MSA.

The results of the current study demonstrate the influence of contextual and environmental factors on the reported unmet support needs of informal caregivers of older adults. Based on the findings, it appears classes and support groups are not viewed as support services that are most needed by those in caregiving roles. However, problems related to service access were noted across all three independent variables. The results of the current study also indicate that dementia caregivers have more unmet support needs relative to other caregivers. As noted previously, these findings further reinforce that informal caregivers should not be treated as a homogenous group. Instead, efforts are needed to create intervention strategies that are targeted to meet the needs of specific caregiver groups. Health care practitioners play a critical role in maintaining the health and wellness of informal caregivers and can use this type of information to connect informal caregivers to needed resources based on their unique and diverse needs.

Limited studies exist that examine the relationship between contextual and environmental factors and the unmet support needs of informal caregivers. As the nation faces a rapidly aging population and an impending care gap, a better understanding of how to support informal caregivers is needed to ensure caregivers remain healthy, improve their caregiver skills, and remain in their caregiving roles (AARP, 2015; Freedman & Spillman, 2014). It is hoped that the results of this study will contribute to the field and help fill the current gap in literature related to the influence of contextual and environmental factors on the unmet support needs of informal caregivers. Health care leaders and policymakers may use the findings to distribute resources and tailor interventions to better meet the needs of informal caregivers of older adults.

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# Appendix A: 2015 Behavioral Risk Factor Surveillance System Caregiver Module Questions

## BRFSS Caregiver Module
## 2015

**People may provide regular care or assistance to a friend or family member who has a health problem or disability.**

**1. During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?**

1. Yes
2. No **[Go to Question 9]**

7 Don't know/Not sure
9 Refused

**IF NEEDED: If caregiving recipient has died in the past 30 days, say "I'm so sorry to hear of your loss." and skip to the next module.**

**2. What is his or her relationship to you? For example is he or she your (mother or daughter or father or son)?**

**[DO NOT READ; CODE RESPONSE USING THESE CATEGORIES]**
1 Mother
2 Father
3 Mother-in-law
4 Father-in-law
5 Child
6 Husband
7 Wife
8 Same-sex partner
9 Brother or brother-in-law
10 Sister or sister-in-law
11 Grandmother
12 Grandfather
13 Grandchild
14 Other relative
15 Non-relative/Family friend

77 Don’t know/Not sure

99 Refused

**3. For how long have you provided care for that person? Would you say…**

1 Less than 30 days
2 1 month to less than 6 months
3 6 months to less than 2 years
4 2 years to less than 5 years
5 More than 5 years
7 Don’t Know/ Not Sure
9 Refused

**4. In an average week, how many hours do you provide care or assistance? Would you say…**

1 Up to 8 hours per week
2 9 to 19 hours per week
3 20 to 39 hours per week
4 40 hours or more
7 Don’t Know/Not Sure
9 Refused

**5. What is the main health problem, long-term illness, or disability that the person you care for has?**

**IF NECESSARY: Please tell me which one of these conditions would you say is the major problem?**

**[DO NOT READ: RECORD ONE RESPONSE]**
1 Arthritis/Rheumatism
2 Asthma
3 Cancer
4 Chronic respiratory conditions such as Emphysema or COPD
5 Dementia and other Cognitive Impairment Disorders
6 Developmental Disabilities such as Autism, Down’s Syndrome, and Spina Bifida
7 Diabetes
8 Heart Disease, Hypertension
9 Human Immunodeficiency Virus Infection (HIV)
10 Mental Illnesses, such as Anxiety, Depression, or Schizophrenia
11 Other organ failure or diseases such as kidney or liver problems
12 Substance Abuse or Addiction Disorders
13 Other

77 Don’t know/Not Sure
99 Refused

**6. In the past 30 days, did you provide care for this person by…**

**a. …Managing personal care such as giving medications, feeding, dressing, or bathing?**

1 Yes
2 No
7 Don’t Know /Not Sure
9 Refused

**7. In the past 30 days, did you provide care for this person by…**

**b. …Managing household tasks such as cleaning, managing money, or preparing meals?**

1 Yes
2 No
7 Don’t Know /Not Sure
9 Refused

**8. Of the following support services, which one do you MOST need, that you are not currently getting?**

**[INTERVIEWER NOTE: IF RESPONDENT ASKS WHAT RESPITE CARE IS]:**

**Respite care means short-term or long-term breaks for people who provide care.**

**[READ OPTIONS 1 – 6]**
1 Classes about giving care, such as giving medications
2 Help in getting access to services
3 Support groups
4 Individual counseling to help cope with giving care
5 Respite care
6 You don’t need any of these support services
**[DO NOT READ]**
7 Don’t Know /Not Sure
9 Refused

**[If Q1 = YES, GO TO NEXT MODULE]**

9. **In the next 2 years, do you expect to provide care or assistance to a friend or family member who has a health problem or disability?**

1 Yes
2 No
7 Don’t know/Not sure
9 Refused