TRANSPORTATION, SOCIAL SUPPORT, FAMILY VISITATION, AND DEPRESSION OF
RESIDENTS IN NURSING HOMES: A MIXED-METHODS STUDY

by

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DISSERTATION

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Abstract

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The purpose of this study was to explore transportation between family members in the community to visit their loved ones residing in long-term care nursing homes. This study is presented across three articles. First, a systematic review of the literature investigating barriers to family members visiting their loved ones in nursing homes identified seven barriers to visitation, including transportation access and travel time. These findings laid the foundation for articles two and three, which report results from a larger two-phase mixed-methodological study. The second article, guided by the Social Determinants of Mental Health, is an analysis examining the effect of transportation on depression symptoms of residents in nursing homes, mediated by social support and. This study took place in North Central Texas across 11 nursing homes and included a total sample of 86 participant-dyads ($N = 86$). Thirdly, phase-two of the mixed-methods study uncovered seven primary themes to family members' visitation of residents in nursing homes through the lived experiences of 11 family members ($N = 11$). Findings taken from this overall study have significant implications for future research, policy, and practice. These implications are discussed at length in the conclusion section.

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Chapter 1: Introduction

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Residents in nursing homes (NHs) are a growing sub-set of older adults who are at an increased risk for mental illness (e.g., depression, anxiety) due to a number of reasons. Research suggests that key factors impacting the mental health of nursing home (NH) residents are social connections and social support through familial relationships, which may include spouse, siblings, and children (Bern-Klug & Forbes-Thompson, 2008). These relationships support resident's psychosocial well-being, socioemotional care, and the provision of personalized care (Gaugler, 2005). Family visitation often offers nursing home residents the opportunity to find comfort, maintain a sense of belonging, and quality of life (Roberts & Bowers, 2014). However, research suggests that one of the primary barriers to maintaining familial relationships and visitation of residents in NHs is transportation (Port et al., 2001; Port, 2004). As such, the purpose of this proposed study is to examine the relationship between family members' transportation, family visitation, social support, and resident depression within the context of the social determinants of mental health framework. This is achieved through the following four chapters. Chapter 2 identifies transportation access and travel time as a barrier to family visitation of residents in nursing homes. Chapter 3 and Chapter 4 are two-phases of an exploratory, sequential mixed-methodological study (Creswell & Plano Clark, 2018) that investigates transportation of family members to visit the resident in long-term care nursing home, and the effect of family members' transportation on the depression symptoms of residents.

Review of the Literature

Aging populations are a worldwide phenomenon. Globally, there are currently 617 million persons aged 65 years and older (National Institutes of Health [NIH], 2016). The latest statistics report that the world's population of older adults is expected to grow to 1.6 billion by

the year 2060 (He et al., 2016). Similarly, on a national scale, the number of older Americans is

expected to increase dramatically. Presently there are over 46 million Americans over the age of

65 years old and this number is projected to reach 98 million by 2060 (HealthyPeople2020, n.d.).

As this population grows, the structure of the overall population will dramatically shift over the

next 40 years (Ortman, Velkoff, & Hogan, 2014). Estimates indicate that as soon as 2050, 20.9

percent of the total population will be 65 years and older, and 4.5 percent will be the oldest-old at

85 years of age and above (Ortman, Velkoff, & Hogan, 2014).

In addition to this shift in the population structure in the coming years, the older adult

population is becoming increasingly diverse (Ortman, Velkoff, & Hogan, 2014). America is

expected to become a "majority-minority" nation with non-Hispanic older adults making up a

majority of the population by the year 2045 (United States Census Bureau, 2015). By 2050, the

percent of older adults identifying as non-Hispanic whites is expected to drop from a current 78.3

percent to 54.6 percent (Mather, n.d.). Racial and ethnic minorities will comprise nearly one-

third of the total older adult population in America as soon as the year 2030 (Pandya, 2005).

Hispanic elders will triple to nearly 20 percent of the total population of older Americans and the

proportion of African-American elders will grow from 8.3 to 11.2 percent by 2050 (Centers for

Disease Control and Prevention [CDC], 2013). Moreover, the percentage of Asian-Americans

over 65 years old will grow from 3.3 percent to 8.5 percent (CDC, 2013).

Living Arrangements Among Older Adults

The landscape of older adults' living arrangements will evolve as the population surges.

Older adults generally have a variety of living arrangements, such as living alone, with a spouse,

unmarried and living with children, unmarried and living alone or with other family or non-

family or living in a long-term care facility such as a nursing home (Stepler, 2016). According to

Pew Research Center, living arrangements are determined in part by social lives and relationships, financial status, and overall lifestyle (Stepler, 2016). Most older adults with decreased functional ability and increased care needs due to challenges with health or cognition opt for remaining at home in the community (National Academies of Science, Engineering, and Medicine [NASEM], 2016). Nearly all in-home support is provided through help and informal caregiving services of family and friends (Anderson, Dabelko-Schoeny, & Fields, 2018; NASEM, 2016). Although most often older adults prefer to remain at home in the community, long-term nursing home care may be the only option for some older adults if staying in the community exceeds and/or threatens "the ability of caregivers to provide adequate care or to survive the exhausting process of caregiving" (Pitkin, 2009, p. 2).

Recent statistics report there are a total of 1.4 million older adults living in nursing homes across America (CDC, 2014). These nursing home residents are most often 65 years or older and 41.6 percent of them are identified as oldest-old (age 85+; Centers for Medicare and Medicaid Services [CMS], 2015). A growing population of nursing home residents are adults between the age of 55 and 65 years old, which, according to many existing studies, is still senior age (Petry, 2002; The Society for Post-Acute Long-term Care Medicine, n.d.). The majority of all nursing home residents identify as non-Hispanic white, though 14 percent identify as African-American, and just over five percent are Hispanic/Latino older adults (CMS, 2015). Roughly half of one percent of nursing home residents identify as American Indian/Alaskan Native (CMS, 2015).

Research published by the Centers for Medicare and Medicaid Services found that nursing home utilization rates declined between the late-1990s and 2007, mainly due to an increase in utilization of Home and Community Based Service (HCBS) funded by Medicaid-waivers (Weiner, Anderson, & Brown, 2009). However, given recent policy changes resulting in

cuts to Medicaid funding for HCBS and the recent changes in penalties for Medicare- certifiable programs that scales back Medicare's program penalties (e.g., nursing homes), and the growing population of older adults suggests an increase in nursing home utilization will occur in coming years (Rau, 2017; Solomon, 2017).

Nursing home care is intended to address the increased physical and/or cognitive care needs of older adults. That is, older adults who have decreased physical and/or cognitive functioning and who can no longer live in the community typically move to a NH in order to have their needs met by the level of care provided in a NH setting. Generally, this level of care provides older adults with nursing and custodial care. Nursing care includes attending to medically-related health needs of residents such as changing sterile dressings and giving medicine while custodial care is non-skilled care that helps the resident with the activities of daily living (e.g., dressing, eating, bathing, getting in and out of bed, and using the bathroom; Medicare.gov, n.d.). Custodial care has long been associated with the loss of identity and ability to choose for oneself (Ryvicker, 2006), thus the transition from living in the community to a NH may result in a challenging adjustment for residents. Research suggests that moving from the community into a NH can be a traumatic event that may negatively impact both the NH resident and his or her family members, resulting in significant psychosocial distress (Oosterveld-Vlug et al., 2013; Pitkin, 2009; Ryan & McKenna, 2014).

Depression in Nursing Homes

Depression is not a normal aspect of aging (CDC, 2017). However, depression is the most common mental illness experienced NH residents (Kramer et al., 2009). Roughly twenty percent of NH residents are diagnosed with major depressive disorder (Rosen, 2014). Residents of NHs often experience an acute loss of control, which may exacerbate any already existing

symptoms and signs of depression (Hansen, 2016). Given the detrimental consequences this mental illness has in late-life (Fiske, Wetherell, & Gatz, 2009), more research is needed to examine the factors that may contribute to depressive symptoms among NH residents in an effort to address this growing problem.

Furthermore, nursing home residents may experience isolation and may lack strong social connectivity, which in turn may lead to feelings of loneliness (Steptoe, Deaton, & Stone, 2015; Price, 2015). Loneliness is defined as the unmet needs of one needing to belong, addressed in the seminal work by Baumeister and Leary (1995). Loneliness is a particularly salient issue for NH residents (Routasalo & Pitkala, 2003). Human beings fundamentally need to belong (Heinrich & Gullone, 2006) and a lack of belonging can result in poor mental health outcomes and increase depression in an already at-risk population (Baumeister & Leary, 1995).

Theoretical Framework

Research on the physical health and mental well-being of older adults is of growing importance across public health, medical professions, social work, and allied fields. This research is particularly important as the aging population increases nationally and internationally. The mental health of older adults and persons across the lifespan are shaped by the social, economic, and physical environments in which people live (World Health Organization & Calouste Gulbenkian Foundation [WHO & CGF], 2014). These "social determinants of mental health" (SDMH) are defined as unfavorable social, economic, and environmental circumstances, which place certain subpopulations at an increased risk for mental illness (Compton & Shim, 2015; WHO & CGF, 2014), and are built on the long-standing health research of the Social Determinants of Health (Marmot, 2011).

The Social Determinants of Health (SDH) have been at the forefront of health research for over fifty years (Irwin & Scali, 2010; Ratcliff, 2017). The SDH address conditions in life as a result of the way society is built, which ultimately impacts health (Ratcliff, 2017). These conditions in life include how people live (e.g., socioeconomic status, quality of housing, amount of pollutants in an environment), how people travel and its impact on the built environment (e.g., access and use of cars, lack of walkable space), working conditions (e.g., safety, availability, stress-levels), and nutrition (e.g., access to and affordability of healthy foods and clean water) (Ratcliff, 2017). This view addresses life conditions globally rather than on the micro-perspective at the biological level. These conditions, which are often referred to as driving factors, lead to poor quality of health and well-being (Marmot & Allen, 2014; Ratcliff, 2017). Taken from the foundational SDH, the Social Determinants of Mental Health (Compton & Shim, 2015) include these challenges that persistently face individuals in their ability to achieve overall mental health and well-being (Irwin & Scali, 2010; Shim & Compton, 2018).

Conceptually, the SDMH postulates that poor mental health and mental illness is driven by these same factors. Socioenvironmental factors, public policies, and social norms perpetuate inequality and unequal opportunities among vulnerable populations (Compton & Shim, 2015). The SDMH framework, on the micro-/individual- level, describes that mental health and mental illness is shaped by poor access and poor quality of health care, low education, poverty and low income, poor neighborhoods/built environment, social exclusion and poor social connection, under/un-employment, and housing instability (Compton & Shim, 2015). Such individual- level factors are driven by the short-term, mezzo- level factors such as the shifting economic environment in the United States.

The political and economic context, on the mezzo- level, significantly influences the distribution of wealth within the nation, in turn impacting individual- level mental health outcomes (Compton & Shim, 2015). Moreover, these political- and economic- determinants are driven by long-standing historical and socio-cultural contexts, macro- level factors (Compton & Shim, 2015). Ongoing prejudice, racial exclusion, and cultural norms within the United States places historically marginalized populations at an increased risk for mental illness. These determinants are "upstream" (Compton & Shim, 2015, p. 422), in that these risk factors would exist regardless if closer risk factor, or micro- level (e.g., nutrition, educational status, age, etc.) factors, were addressed. However, modifications to closer, individual- level, risk factors can improve mental health and well-being. Closer risk factors, for instance inadequate health care, unemployment, and lack of social support can cause greater issues, thus perpetuating these social injustices that lead to mental illness (Compton & Shim, 2015).

This SDMH framework has been applied to examine mental health outcomes in persons across the life course. For instance, the SDMH when applied to children articulates that neglect, physical abuse, psychological abuse, and children in low socioeconomic groups are predisposed to mental disorders (WHO & CGF, 2014). Buffers to lessen or mitigate mental health concerns among children include building strong communities, increasing social support, and widening families (WHO & CGF, 2014). Across the lifespan, physical and mental health differs most among older adults because this population is at an increased risk for changing life events, which may trigger depression (WHO & CGF, 2014). At the micro- level, mental health in older adulthood is found to be related to socioeconomic status, gender, ethnicity, age, health care, and levels of social support. Between genders, older men most often experience mental illness as a result of chronic physical illness, whereas older women most often report differences in mental

health due to social factors, which includes contact with family, belonging to community groups, and levels of social isolation (WHO & CGF, 2014). At the macro- level as a public health issue, older adults are prone to multiple risk factors. Social support programming, housing support, financial policies, community programming, and the economy all contribute to the mental health and well-being among older adults (Healthy People 2020, n.d.; WHO, 2017). One example is evident in the socioeconomic status of aging Americans. Older adults most often experience a decline in their socioeconomic status upon retirement years. For most older adults, social security benefits are a reduced income compared to a steady paycheck, thus lowering one's standard of living (Social Security, n.d.). Research suggests that socioeconomic status in later life is linked to poorer mental health outcomes such as depression (WHO & CGF, 2014). Figure 1 visually conveys the SDMH driving factors at the individual-, mezzo-, and macro- level.

Figure 1. *Social Determinants of Mental Health framework (adapted) (Compton & Shim, 2015; WHO & CGF, 2014; Silva, Loureiro, & Cardoso, 2016).*
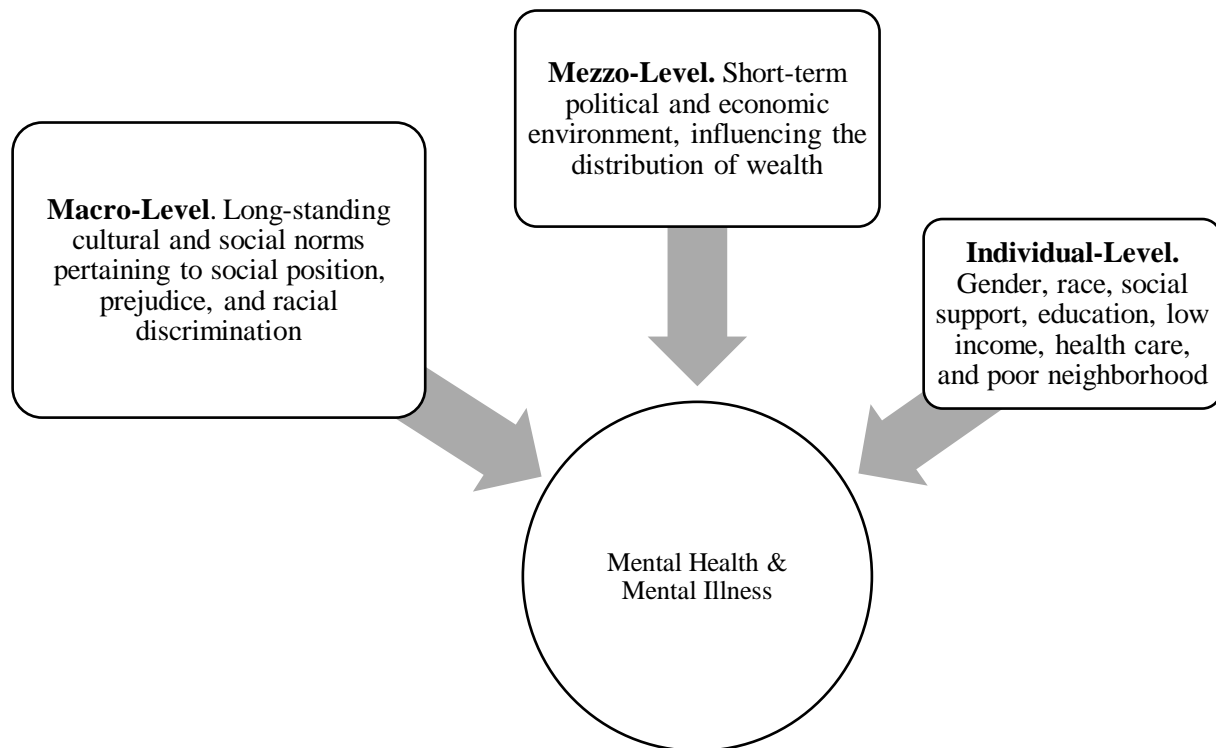
Application of SDMH to Residents in Nursing Homes

Although research has not yet applied this framework to study mental health outcomes within the context of older adults residing in nursing homes, previous studies support the application of this theory to such a population (Greenfield & Russell, 2011; Wu, Schimmele, & Chappell, 2011). At the individual- level, studies have applied this framework to articulate loneliness among older adults' in later life (Greenfield & Russell, 2011), as well as depression in late-life (Wu, Schimmele, & Chappell, 2011). Equally so, residents are faced with another set of risk factors at the mezzo-level, which can impact mental health outcomes. Namely, the quality of the nursing home based on the five-star quality-rating, identified across extant literature, and the social support programs provided within the nursing facility. In 1998, the Centers for Medicare and Medicaid Services (CMS) developed a five-star rating system on a scale of one- to five-stars, with five being the best at much above average ratings and one being the lowest at quality much below average. This rating system is primarily used by consumers and community members to indicate Medicare- and Medicaid- certified facilities that provide less than average quality care, compared to high above average quality care. Initially, this rating system provided just basic characteristics between facilities, and has since expanded to include an array of information based on health inspections, staffing, and quality measures (Williams et al., 2016). Extant literature highlights that these deficiency ratings are associated with quality of life, wherein facilities with lower star ratings are found to be homes to residents with lower quality of life, including increased issues with staffing and heightened risks of mental illness (Campbell et al., 2016; Degenholtz et al., 2014; Wunderlich et al., 1996).

Research continues to emphasize the importance that individualized social and group psychosocial activities have on resident well-being and everyday functioning. However, despite

this research, nursing facilities vary on their levels and opportunities for social support programming (Lorenz et al., 2012). Nursing facilities are tasked with providing residents individualized social activities and programming. Nursing homes provide residents with activities and opportunities for social support programming, oftentimes through facility employees and/or community partnerships (Tak et al., 2015). Moreover, the social opportunities and social supports provided by the nursing home may be especially important for residents who do not have family members, or for residents who do not have family actively involved in care and are unable to visit due to various reasons.

The proposed study is guided by the SDMH at the individual- level. Individual- level factors that will be included in this study are gender, race, education, poverty, health care, neighborhood location, transportation access, and social support. Most individual- level factors within this study include understanding of nursing home activities and participation in these activities. Primarily, this research proposes to examine depressive symptoms of residents in nursing homes as they are impacted by transportation, mediated by family social support and family visitation. Furthermore, this study will examine the lived experiences of family members' access, opportunities, and challenges with transportation that may contribute to visitation of residents in nursing homes.

Significance: Importance of the Problem

Research suggests that maintaining social engagements, relationships, and social connections within the community can be accomplished mainly through access to transportation and transportation opportunities (Currie, 2010). Extant research links transportation disadvantage, those who are "unable to provide their own transportation or even use public transportation" (U.S. GAO, 2003), to poorer social and psychological well-being outcomes

(Adorno et al. 2018;; Currie et al., 2010; Currie, 2010; Delbosc & Currie, 2011; Delbosc & Currie, 2011b; Fields et al., 2019). A study connecting transportation to an individual needing medical services also noted that transportation to visit loved ones, for instance an older adult visiting a patient at a hospital who may not be safe to drive themselves, can greatly improve quality of life (NASEM et al., 2016).

Transportation challenges impact life in a variety of ways. Transportation issues are notably one of the primary reasons people miss medical appointments (Kim, Myers, & Allen, 2017). Additionally, transportation directly increases the scale and scope of social interactions (Rodrigue, n.d.). Thus, challenges in transportation, or transportation disadvantage, may impact family members' ability and desire to visit their loved one within a nursing facility and maintain social connection and social support, which in turn may affect the mental health (e.g., depression) of residents in nursing homes.

Innovation Statement

Transformative changes are being made to address and meet the needs of the growth of older adults in America. To this end, attention towards building communities and areas that promote healthy aging (Goldman, 2016) and mental well-being in older adulthood (National Council on Aging, 2018) are on the rise, however we know much less about the impact transportation has on mental health in older adulthood, particularly within the context of this proposed study. Thus, to make this link between transportation access and opportunities and depressive symptoms among residents of nursing homes is warranted.

Furthermore, this study is interdisciplinary in nature, bridging the professions of social work and civil engineering. Interdisciplinary work, and interdisciplinary research, has been a long-standing central focus of the social work field. Social workers are often tasked, for instance

in a nursing home setting, with responsibilities and duties as lead of an interdisciplinary team consisting of doctors, therapists (i.e., Physical Therapy, Speech Therapy, Occupational Therapy), and nurses. While such interdisciplinary work within the profession, and within research of social work, has traditionally been with health care (e.g., Bronstein et al., 2010; Gilbert, 2014), interdisciplinary work has fallen short between the fields of social work and civil engineering (Miller, et al., in press). This study aims to advance the field by bridging the gap between civil engineering and social work to examine the concept of transportation access and opportunities on community members and the mental health (e.g., depression) of older adults living in institutionalized nursing homes.

Aims of Study

Based on the review of the literature, studies suggest that residents of nursing homes without the social supports and visitation of family members are at an increased risk for depression, and that these visitations are driven by access to and opportunities to transportation, however empirical research has not yet studied this connection. Therefore, this study will examine the relationship between transportation, social support, family visitation, and depression, guided by the SDMH framework. Results of this study are presented in the following three articles that includes: (1) A systematic review of the literature investigating barriers to family members visiting residents in nursing homes, (2) The effect of family member's transportation on depression symptoms of residents in nursing homes: A mediation analysis of social support and family visitation, and (3) The experiences of family member's transportation to visit their resident in a nursing home: A qualitative follow-up study.

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Chapter 2: Investigating Barriers to Family Visitation of Nursing Home Residents: A

Systematic Review

*Permission from the publisher to use this paper in the dissertation has been granted (see Appendix A)

Abstract

Families are integral in helping nursing home residents maintain feelings of social inclusion and an overall sense of belonging, thus reducing consequences of social exclusion. Preliminary research, particularly of the culture change movement in long-term care, shows there are barriers to family engagement and visitation of residents. The objective of this study was to: (1) identify and summarize the barriers most reported to family visitation, and (2) synthesize the findings to determine which barriers are most often reported in literature, and which may pose the greatest challenges to family involvement. Using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, a final sample of 15 articles across 11 databases report seven barriers to visitation: psychological, health, staff to family member relationship, employment/finances, travel time, access to transportation, and other. Findings suggest barriers to family visitation and point toward a need for further research as relationships between resident and family member is complex and warrants attention across professions. Interprofessional efforts between social work, allied professionals, and transportation planners are necessary to address this pressing concern experienced by residents in nursing homes, with the ultimate goal of lessening such barriers.

Investigating barriers to family visitation of nursing home residents: A systematic review

Introduction

Residents of nursing homes may miss face-to-face connection with loved ones. At times, older adult residents transition from living at home in the community with family, to residing in long-term nursing home care, where they are often faced with isolation and may lack strong social connectivity, which in turn can lead to feelings of loneliness (Price, 2015; Steptoe, Deaton, & Stone, 2015). Loneliness can be defined as the unmet needs of one needing to belong and is addressed in the seminal work by Baumeister and Leary (1995). Human beings fundamentally need to belong (Heinrich & Gullone, 2006) and a lack of belongingness can result in anxiety, depression, and poor health (Baumeister & Leary, 1995). This is especially important to be aware of in older adult nursing home (NH) residents, who most often experience decreased functional ability and physical dependence (Valenzuela, 2012), increased rates of depression (Stewart, 2013), high levels of cognitive impairment (Schussler & Lohrmann, 2017), and other acute health problems (i.e., incontinence, vascular disease, and musculoskeletal disorders) (Van Rensbergen & Nawrot, 2010). NH residents do have frequent contact and communication with NH staff, but this communication often focuses on care tasks, which includes assessing functional status and technical care (Lee, Lee, & Armour, 2014) and may do little to alleviate loneliness.

Family members help maintain social connection through visitation and the provision of personalized care (Gaugler, 2005; Yamamoto-Mitani et al., 2002). Positive social interactions and social connection between residents and family members have been found to reduce loneliness (DeWall, 2013). Even more so, these positive connections are found to counteract the consequences of social exclusion (DeWall, 2013). Many family members take on the role as

resident advocate by monitoring the quality of care provided and help staff in detecting changes in resident health status (Gaugler, 2005; Powell et al., 2017). While many family members aim to remain socially connected with their loved one in a NH, there are many challenges and barriers to doing so including the health of caregivers, commitments to work, and financial constraints (Strain & Maxwell, 2015; Yamamoto-Mitani et al., 2002). Additionally, travel time, which, at times, may be referred to as proximity, and access to transportation are significant barriers to family members' visitation and this leads to social isolation and exclusion of residents (Parmenter, Cruickshank, & Hussain, 2012; Port, 2004).

This involvement in care of family members to residents of nursing homes (NHs) is found to be critical to the well-being and quality of life of older adults, and is key to person-centered care (Koren, 2010). Person-centered care, a feature of the culture change movement across nursing homes and long-term care, aims to improve the overall quality of life of residents (Grabowski et al., 2014). This culture change movement focuses on both family visitation, involvement, and engagement, as well as staff developing relationships with residents that goes beyond just the basic care tasks (Corazzini, Twersky, White, Buhr, McConnell, Weiner, & Colon-Emeric, 2015). A better understanding of the connections between family members' access and involvement to visitation of residents is a fundamental component to overall improve these opportunities.

Given the negative consequences the lack of family visitation has on residents, as well as the growth of the older population, the number of older Americans requiring NH care may increase 75 percent, from 1.3 million in 2010 to 2.3 million by 2030 (Population Reference Bureau, n.d.), it is an especially important time to best understand these barriers that inhibit the connections between family members and residents. No systematic review identifying the

barriers to family visitation of NH residents has been done before. Therefore, this research aims

to address the following objectives: (1) identify and summarize barriers to family visitation

between loved ones of nursing home residents, and (2) synthesize the findings to determine

which barriers are most often reported in literature, and which may pose the greatest challenges

to family involvement. The article concludes with implications for future research and practice.

Method

This review was conducted using the Preferred Reporting Items for Systematic Reviews

and Meta-Analyses (PRISMA) (Moher et al., 2009) guidelines. The PRISMA guidelines are an

evidence-based methodology to investigate, systematically, a body of literature on a particular

topic or concept (Liberati et al., 2009). This methodology provides a transparent, accurate

approach to reporting articles, and has been used widely in literature across professions, such as

healthcare (Liberati et al., 2009), psychiatry (Rivero, Nunez, Pires, & Bueno, 2015), and social

work (Smith-Osborne & Felderhoff, 2014).

Data Collection – Search Strategy

The databases searched include Academic Search Complete, AgeLine, AltHealthWatch,

CINAHL Complete, Health Source – Consumer Edition, Health Source: Nursing/Academic

Edition, MEDLINE, PsycARTICLES, Psychology and Behavioral Sciences Collection,

PsycINFO, and Social Work Abstracts for articles published in English between January 1, 1997

and November 9, 2017. The key terms and phrases for the search were: "long-term care or

nursing home," "barriers or obstacles or challenges," "social exclusion or socially excluded or

social isolation," "isolation," "visit*," "contact," and "family or families or relatives or parents

or siblings." There was an asterisk placed at the end of the stem search term "visit" to capture

articles that used variations of this term, for instance "visitation". A similar search was done

using Google Scholar, though no additional articles were found. To be included in the review,

articles had to meet the following criteria: (a) be published in a peer-reviewed, scholarly journal;

(b) identify a barrier to family and/or caregiver visitation to residents in U.S. nursing homes; and,

(c) explicitly include residents aged 65 years old and above. Articles were excluded from the

final sample if they were not written in English, were book reviews, editorials or policy briefs,

and did not report a barrier to family visitation of residents in nursing homes.

Article Selection

These searches identified 1,928 articles, some of which were duplicates yielding a total of

1,109 separate articles. The full process for article inclusion is shown in Figure 1.

Figure 1. *Flowchart of Study Selection Protocol Guided by the PRISMA (Moher, 2009) Guidelines*
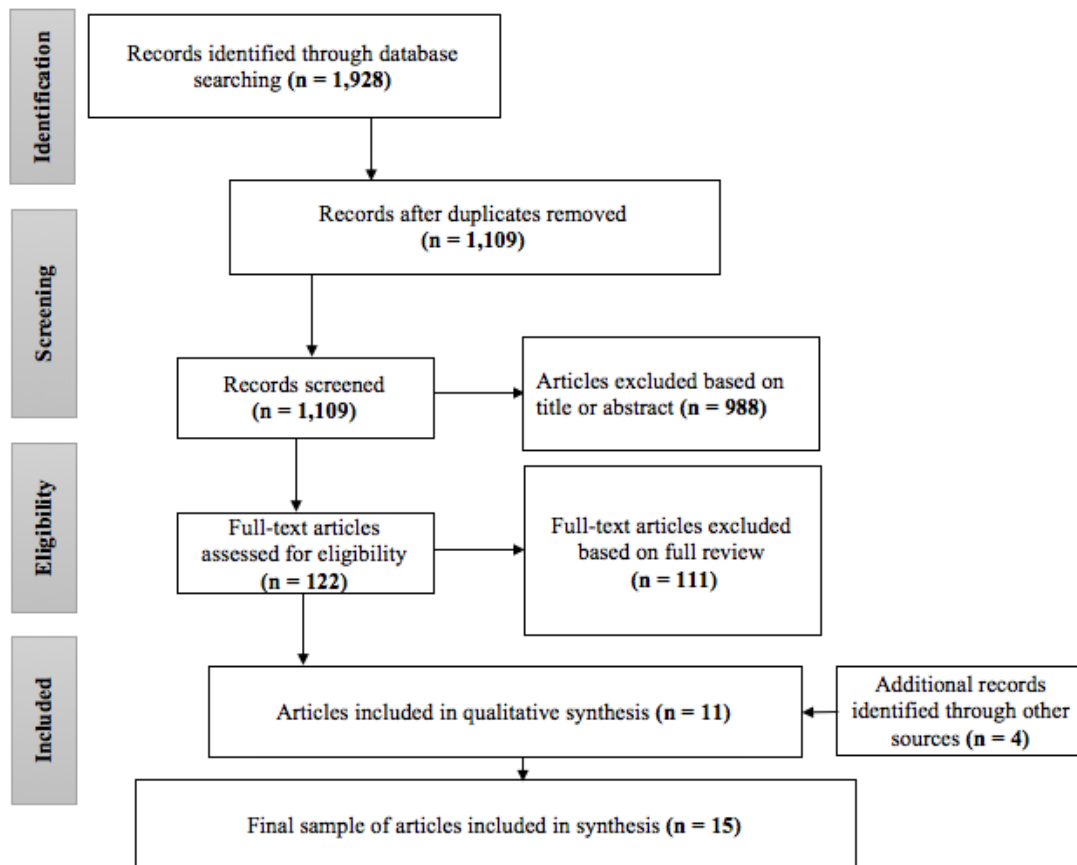
Table 1. *Exclusion of Articles*

Exclusion	Title & Abstract	Full-Text
Not English	41	0
Not United States	363	27
Not Nursing Home	254	21
Not Older Adults	142	0
Not reporting barriers to visitation	158	56
Other (e.g., book review, editorial, policy brief)	30	7
	988	111

The criteria for excluding articles are shown in Table 1. Nine hundred and eight articles were excluded because inclusion criteria were not met in title and abstract. One hundred and eleven articles of those remaining were excluded because inclusion criteria were not met in the full-text of the article. Four ($n=4$) additional articles were identified after a hand-checked review of references in the original 11 articles. The final fifteen articles ($n=15$) of the data set are listed in Table 2.

Authors	Date of Publication	Title of Article	Journal	Volume/Issue	Page Numbers
Bern-Klug, M.	2008	The emotional context facing nursing home residents' families: a call for role reinforcement strategies from nursing homes and the community	*Journal of the American Medical Directors Association*	*9*	36-44
Calne, S.M.	2003	The psychosocial impact of late-stage Parkinson's disease	*Journal of Neuroscience Nursing*	*35*(6)	306-313
Choi, N.G. et al.	2008	Depression in older nursing home residents: The influence of nursing home environmental stressors, coping, and acceptance of group and individual therapy	*Aging & Mental Health*	*12*(5)	536-547
Flinders, S.L.	2003	The internal struggles of aging	*Journal for the Psychoanalysis of Culture & Society*	*8*(2)	258-262
Friedemann et al.	1999	Family involvement in the nursing home	*Western Journal of Nursing Research*	*21*(4)	549-567
Gaugler, J.E. et al.	2000	Caregiver involvement following institutionalization	*Research on Aging*	*22*(4)	337-359
Gwyther, L.P.	2001	Family caregivers and long-term care: caring together	*Alzheimer's Care Quarterly*	*2*(1)	64-72
Janzen, W.	2001	Long-term care for older adults: the role of the family	*Journal of Gerontological Nursing*	*27*(2)	36-43
Levine, C. & Kuerbis, A.	2002	Building alliances between social workers and family caregivers	*Journal of Social Work in Long-Term Care*	*1*(4)	3-17
Mickus, M.A. & Luz, C.C.	2002	Televisits: sustaining long distance family relationships among institutionalized elders through technology	*Aging & Mental Health*	*6*(4)	387-396
Parker Oliver, D. et al.	2006	A promising technology to reduce social isolation of nursing home residents	*Journal of Nursing Care Quality*	*21*(4)	302-305
Port, C.L. et al.	2001	Resident contact with family and friends following nursing home admission	*The Gerontologist*	*41*(5)	589-596
Port, C.L.	2004	Identifying changeable barriers to family involvement in the nursing home for cognitively impaired residents	*The Gerontologist*	*44*(6)	770-778
Webster et al.	2016	Mental health concerns of older adults living in long-term care facilities: an area of expansion for MFTs	*The American Journal of Family Therapy*	*44*(5)	272-284
Yamamoto-Mitani et al.	2002	Patterns of family visiting with institutionalized elders: the case of dementia	*Journal of Gerontology: SOCIAL SCIENCES*	*57B*(4)	S234-S246

Table 2. *Articles Included in the Final Dataset*

Seven barriers to the visitation by family members of residents in nursing homes, which can be classified as internal and external barriers, are described in the 15 articles. These barriers, listed in Table 3, are: (1) psychological, (2) health, (3) staff-to-family-member relationship, (4) employment/finances, (5) travel time, (6) access to transportation, and (7) other.

Table 3. *Barriers Described in Article Dataset and Number of Articles Describing Each Barrier*

	Barrier	Number of Articles
1	Psychological	9
2	Health	10
3	Employment/Finances	3
4	Proximity	8
5	Transportation	4
6	Staff/Family Relationships	9
7	Other	4

Data extraction

Two independent reviewers screened the final sample of articles and extracted data from the final articles. In cases which were unclear, consensus was reached by discussion between the reviewers. Quantitative articles were assessed based on: sample size, internal validity, analytical methods, and explicit versus implicit examination of barriers (e.g., empirically studying barriers to visitation). Qualitative articles were assessed based on: analytical methods and explicitly studying barriers to visitation. No articles included in the final sample employed mixed-methodological study designs. Seven articles of the total sample were review articles. Table 4 includes the final sample of articles, as well as the study methodology, sample size, and design of each study.

Table 4. *Results of Data Extraction*

	Author(s)	Title and Date	Sample Size	Design
Survey and secondary data analysis designs	Bern-Klug, M.	The emotional context facing nursing home residents' families (2008)	44 family members	Qualitative ethnographic data
Quantitative	Gaugler, J.E., Leitsch, S.A., Zarit, S.H., & Pearlin, L.I.	Caregiving involvement following institutionalization (2000)	185 primary caregivers	Multivariate regression
	Mickus, M.A. & Luz, C.C.	Televisits: sustaining long distance family relationships (2002)	20 residents and family members	Brief surveys pre- and post-on effect
	Port, C.	Identifying changeable barriers to family involvement in nursing homes (2004)	98 family and resident pairs	Regression modeling
	Friedemann, M-L., Montgomery, R.J., Rice, C., & Farrell, L.	Family involvement in the nursing home (1999)	216 family members	Regression analyses
	Port, C.L., Gruber-Baldini, A.L., Burton, L., Baumgarten, M., et al.	Resident contact with family and friends following nursing home admission	1,441 significant others of residents	Pearsons correlation
	Yamamoto-Mitani, N., Aneshensel, C.S., & Levy-Storms, L.	Patterns of family visiting with institutionalized elders: The case of dementia	210 caregivers	Semiparametric, group-based method using a latent class mixture model
Qualitative	Choi, N.G., Ransom, S., & Wyllie, R.J.	Depression in older nursing home residents: (2008)	65 nursing home residents	In-depth interviews
Review Articles	Calne, S.M.	The psychosocial impact of late-stage Parkinson's disease (2003)		Review article
	Flinders, S.L.	The internal struggles of aging (2003)		Review article
	Gwyther, L.P.	Family caregivers and long-term care: caring together (2001)		Review article
	Levine, C. & Kuerbis, A.	Building alliances between social workers and family caregivers (2002)		Review article
	Parker Oliver, D., Demiris, G., & Hensel, B.	A promising technology to reduce social isolation of nursing home residents (2006)		Review article
	Webster, T.N., Yorgason, J.B., Maag-Winter, A., Clifford, C., et al.	Mental health concerns of older adults living in long-term care facilities: (2016)		Review article
	Janzen, W.	Long-term care for older adults, the role of the family (2001)		Review article

Results

Description of the Barriers

Internal Barriers

Psychological

Psychological barriers to NH visitation include guilt, depression, and feelings of being emotionally overwhelmed, heartbroken, and uncomfortable when visiting the nursing home. These barriers are the most complex to describe and one of the most widely reported. Nine of the 15 papers report psychological factors as barriers to family members visiting their loved ones. This barrier most often posed challenges for the family members (Bern-Klug, 2008; Flinders, 2003; Gaugler et al., 2000; Gwyther, 2001; Janzen, 2001; Mickus & Luz, 2002; Port et al., 2001; Webster et al., 2016; Yamamoto-Mitani et al., 2002).

Flinders (2003) reported "Family members may feel upset about their loved one living outside of the family unit and struggle with the changes associated with aging and nursing home placement" (p. 258). It was also reported that feelings of dislocation, in addition to other psychological factors, such as depression, can cause families to rarely visit the NH. Gwyther (2001) reported family members may have an emotionally difficult time visiting a loved one because of cognitive decline of the resident. For some, it may be emotionally overwhelming and heartbreaking to witness a loved one's personality changes associated with dementia, which in turn may cause a decrease in the number of or even a lack of visits.

Health

The Health barrier refers to the health of family members outside the nursing home and health of the resident in the nursing home. Ten of the 15 articles report that people have trouble visiting nursing homes when they or other family members have health needs of their own

(Bern-Klug, 2008; Calne, 2003; Choi et al., 2008; Friedemann et al., 1999; Gaugler et al., 2000; Gwyther, 2001; Janzen, 2001; Levine & Kuerbis, 2002; Mickus & Luz, 2002; Parker Oliver et al., 2006). Calne (2003) suggested that the health decline of family members/caregivers was the strongest precursor to nursing home placement. In other words, decline of the caregiver's health eventually became the deciding factor for nursing home placement. After placement of the loved one in the nursing home, the caregiver or family member may become acutely sick leaving the nursing home resident without support (Calne, 2003). Similarly, two studies (Gwyther, 2001; Levine & Kuerbis, 2002) identified that family members (former caregivers) can be overwhelmed with their own health concerns, such as fatigue associated with cancer treatment, which leaves them less able to focus on the needs of the loved one in the nursing home.

Staff-to-Family-Member-Relationship

The relationship between the nursing home staff and the family member is listed as a barrier because in nine articles the relationships between facility staff and family members were found to influence family member involvement in care (Calne, 2003; Gaugler, 2000; Gwyther, 2001; Janzen, 2001; Levine & Kuerbis, 2002; Parker Oliver et al., 2006; Port et al., 2001; Port, 2004; Yamamoto-Mitani et al., 2002). Janzen (2001) reports that the positive staff to family relationships could encourage and promote involvement. Conversely, disagreements and misunderstandings between family and staff may discourage family involvement and engagement in care (Janzen, 2001). For family members who are apprehensive and unsure about their new role after placing a loved one in the nursing home, staff should help with this transition (Gwyther, 2001). Similarly, Levine and Kuerbis (2002) highlight that the relationship between staff and family member is crucial. Family members should feel confident and assured of the staff of the facility when they place their loved ones in the nursing home. The resident's care is

one of the most important considerations of family members, and a "family caregiver should feel confident that if illness, weather, or another event precludes visiting, the resident" (Levine & Kuerbis, 2002, p. 14) the NH resident would still be cared for.

External Barriers

Employment/Finances

The Employment/Finances barrier includes ability of family members to take time off of work and their means to pay for the visits. Three of the 15 articles either state Employment/Finances were a predictive factor related to reduced visitation or links this factor to other contributing factors (Bern-Klug, 2008; Friedemann et al., 1999; Port et al., 2001). Bern-Klug (2008) found financial worries and concerns with paid employment affect family members ability to visit their loved one in the nursing home. A similar study (Port et al., 2001) found that more financial resources may facilitate contact in several ways because higher socioeconomic status results in fewer practical barriers to visitation and phone calls and reduces the risk of losing a job when taking off work for visits. That study showed those who have more financial freedom may have the ability to visit their nursing home resident more frequently and consistently. Gaugler et al. (2000), on the other hand, found those with higher education (e.g., high school, some college, college or more) and more financial flexibility may actually visit nursing home residents less frequently and theorized that those who have more financial resources can place loved ones in facilities that are a better match for residents' care needs, which can give family members a sense that the care is good, and they do not need to be as involved.

Travel Time

The Travel Time barrier is related to time travel from family member's house or work to the nursing home, e.g., mileage, driving time, and proximity. Visiting the nursing home resident can be a challenge, especially when family members have to travel, what is perceived to be, a long distance to the nursing home facility. A short commute to the nursing home is associated with more frequent visits, as reported in the study conducted by Yamamoto-Mitani (2002). Eight studies (Bern-Klug, 2008; Gaugler et al., 2000; Janzen, 2001; Mickus & Luz, 2002; Parker Oliver et al., 2006; Port et al., 2001; Port, 2004; Yamamoto-Mitani et al., 2002) reported travel time (or travel distance) to the nursing home was negatively associated with family visits. In some of the articles, travel time, coupled with the relative's duration of residency, impacted frequency of visits to the nursing home.

Access to Transportation

The Access to Transportation barrier is related to a means of transportation to the nursing home, including access to an automobile. One study by Port et al. (2001) using interviews conducted with the significant others of 1,441 nursing home residents in Maryland, found that the variable of transportation was most predictive of difficulty to frequency of visits when considered in the context of transportation. People who have a transportation disadvantage are those, "unable to provide their own transportation or even use public transportation" (United States General Accounting Office, 2003, p. 1). This was a barrier identified in four of the 15 studies (Bern-Klug, 2008; Choi et al., 2008; Port et al., 2001; Port, 2004).

Other

Other factors that have been found associated with lower visitation of family to residents in nursing homes visits include race, gender, weather conditions, and other relationship, which have been reported in six articles (Friedemann et al., 1999; Janzen, 2001; Levine & Kuerbis,

2002; Port et al., 2001; Port, 2004; Yamamoto-Mitani et al., 2002). Janzen (2001) found that when family members are involved in the care of their loved one once placed in the nursing home it is the gender of the family member that dictates the level of involvement. While Janzen (2001) pinpointed gender-specifics in that women visit more frequently than men, Friedemann et al. (1999) found that it is the eldest daughter of a nursing home resident who tends to assume the role as first contact and primary caregiver to their resident.

Port et al. (2001) found that African-American residents had fewer visits following admission, "due to an increase in the other identified barriers (e.g., socioeconomic status, greater work obligations impeding the ability to visit, paying for transportation, and other practical barriers)" (p. 594). Another barrier to visitation, noted by Levine and Kuerbis (2002), is weather. Weather may deter family members from visiting for a number of reasons including safety and issues in driving. Finally, spousal partnerships and parenting is noted to impact frequency of visitation (Yamamoto-Mitani et al., 2002). NH residents who are widowed, single, and those who do not have children may have extremely low levels of visitation (Yamamoto-Mitani et al., 2002).

Discussion

The systematic review done here provides evidence of barriers that family members/caregivers face to visiting loved ones in NHs. While comprehensive and rigorous, the study shows that this complex topic needs more research, as it has been limited research on this topic over the past 20 years. The barriers described in the fifteen articles can be classified as internal and external barriers to NH visitation and participation in the NH resident's care. The internal barriers describe individual behaviors and include psychological factors and health

issues of both the family member and NH resident, as well as staff-to-family-member relationships.

Psychological factors, health concerns, and staff-to-family-member relationships are all notable barriers, which are in line with findings most often taking place in the traditional, medical-model of nursing home care. This care, within such a structured framework, provides older adults with little autonomy or sense of independence, cut seniors off from the larger society, and are modeled as health care institutions (Cornelison, 2016). Culture changes to these institutionalized models of nursing home care have become a movement across nursing homes, which promotes person-centered care, most specifically focusing on the improvement of staff-to-family-member and staff-to-resident relationships (Corazzini, Twersky, White, Buhr, McConnell, Weiner, & Colon-Emeric, 2015). This family involvement is also a primary focus in alternative long-term care models, such as the Green House Project (The Green House Project, 2018). Additionally, addressing the psychosocial needs and health choices of residents in nursing homes is part of this ongoing transformation to promote and change the culture and principles of long-term care (Social Work Policy Institute, 2010).

External barriers to visitation most notably include employment/finances, travel time (proximity) to nursing home, and transportation. These external barriers are also referred to as "changeable barriers" by Port (2004) and are less frequently reported by the literature. Employment/finances is described as an external barrier to NH visitation and is also linked with low socioeconomic status. Family members with low socioeconomic status and the associated economic instability are more likely to experience several internal barriers to NH visitation. Family members with low income are more likely to have poor health and mental health outcomes, which affect the internal factors to visitation (WHO & CGF, 2014). People in this

socioeconomic category often experience heightened family problems at an increased frequency that can impact the relationship with their nursing home resident including their ability to visit (University of Minnesota, n.d.).

Travel time has been noted as the number one consideration for nursing home placement in order for family to remain involved and provide care (Konetzka & Perraillon, 2016). Resident family members and caregivers may utilize web-based information sources, such as Nursing Home Compare, to make informed decisions regarding placement (Nursing Home Compare, n.d.). Nursing Home Compare allows users to locate a facility close to home or work, however the most convenient facilities may not always have the highest ratings across quality of care, cleanliness, staffing, or other notable features (Konetzka & Perraillon, 2016). Moreover, travel time and location of the facility may not be congruent with access to transportation, which is discussed next.

Articles found in the present study identified transportation access as a problem but did not describe how it was a problem. For example, they did not address whether family members had access to transportation due to socioeconomic status or health concerns and did not study travel-time for commuting (public transit or personal vehicle) between home and work or between home and the nursing home. Access to transportation, together with travel time, driven by socioeconomic status has been found to narrow the options for resident placement (Konetzka & Perraillon, 2016). Public transportation, public transit stops, and geographic location of the nursing facility impact the ability to visit nursing home residents, particularly those relying on Medicaid (Konetzka & Perraillon, 2016).

Of these identified barriers, access to transportation and travel time warrant greater attention. Evidence of this challenge can be seen through the role that social workers and allied

health care professionals take on as they are tasked with assessing and meeting the needs of marginalized, vulnerable populations. Nursing home social workers are tasked with assisting in residents to adjust to the nursing home environment and promoting the relationships with residents to family and staff. In this role, they may assist in advocating for adding assessments to include identifying whether or not transportation is a barrier to family members' visitation. This information may also be obtained during Care Plan meetings with family, residents, and staff. From these assessments and Care Plans, social workers may be best positioned to help family or caregivers connect with community resources that offer transportation services to persons in need, such as organizations that provide discounted bus passes. Additionally, social workers, as advocates for residents, may work within their own facility with administrators to create solutions to help families find subsidies for other means of transportation, such as ride-share programs.

Transportation planners and engineers most often focus on individuals getting to work, whereby underserved members of the community may need assistance in traveling to opportunities for social connectivity, engagement opportunities, and their socially isolated older adult residents of nursing homes, which is a primary feature of becoming an "age-friendly" community (Plouffe & Kalache, 2010). Together, transportation planners and social workers can work towards providing community members with equitable transportation access and opportunities, including the opportunity to travel to nursing homes. Given the growing impact social workers, nursing home health care professionals, and transportation planners have on older adult residents in nursing homes suggests that these interprofessional collaborative efforts may serve as a foundation for best caring for such an at-risk population.

Critique of publications reviewed

The studies included within this article have both strengths and limitations. The studies that reviewed present qualitative and quantitative findings that help to establish an understanding of barriers to family visitation in nursing homes, through multiple professional areas, including health care and transportation planning. Of the 15 articles in this study, over half are review articles or practical application articles (*n*=7), which have been initially written with the family members or nursing home staff as a target audience. These articles may be especially useful for community members, practitioners, and family members of residents, despite these articles not using robust methodologies or sophisticated statistical analyses (Calne, 2003; Flinders, 2003; Gwyther, 2001; Janzen, 2001; Levine & Kuerbis, 2002; Parker Oliver et al., 2006; Webster et al., 2016). Two studies used qualitative research methods (*n*=2), including a secondary-data analysis of qualitative ethnographic data of 44 family members of residents (Bern-Klug, 2008), and a qualitative methodological design using in-depth interviews of 65 residents in nursing homes (Choi et al., 2008). Six studies (*n*=6) applied quantitative data collection methods. Across the quantitative research articles, three (*n=3)* articles used regression analyses with sample sizes including 98 family-resident dyads (Port, 2004), 185 primary caregivers (Gaugler et al., 2000), and 216 family members of residents (Friedeman et al., 1999). The smallest sample size (*n=20*) across these studies used a pre- and post- brief survey to test the effect of Televisits in long distance family relationships (Mickus & Luz, 2001). Finally, Pearsons correlation was used in a study with 1,441 significant others of residents (Port et al., 2001), and a semiparametric, latent class mixture model was used in a study of the patterns of family visitation, in a sample of 210 caregivers (Yamamoto-Mitani et al., 2002). Few articles controlled for many other demographic variables, such as race or gender.

Limitations of this Study

Several limitations of this study should be noted. First, this study focused solely on nursing homes within the United States. Adding studies that have been conducted in other locations, such as United Kingdom and Europe, may confirm the barriers found within this study and provide insight into additional barriers. Moreover, adding more studies may have strengthened the review due to the rather scarce sample of articles using rigorous statistical analyses. Also, this study did not examine differences between organizational characteristics of the nursing homes such as not-for-profit versus for-profit status, or Medicare-only versus Medicare and Medicaid-eligible facilities. Considering the profit status and primary funding source of nursing homes may uncover an area of nursing home care that focuses on socioeconomic status and financial barriers to both care and visitation. Studying these underlying causes could help address new issues and barriers to visitation. Finally, quantitative and qualitative research studies that were included in this review suggest a more complicated picture than family involvement to residents in nursing homes simply leading to a positive outcome.

Implications for Practice and Research

The role of relationships between resident and family member is an identified domain of importance in the culture-change movement in nursing homes and long-term care, aimed at improving resident's well-being and quality of life (Burack, Weiner, & Reinhardt, 2012; Jablonski, Reed, & Maas, 2005; Shier et al., 2013). An underlying assumption of the present work may suggest that having family members visit and participate in the care of NH residents is important for the health and care of the NH resident. Over fifty percent of nursing home residents have Alzheimer's-type dementia or other cognitive impairment (CDC, 2016). Ongoing and continual visits by family members to NH residents with dementia may be especially important since family are often the best partners in care (Graneheim, 2013). Family caregivers

have a unique understanding of resident preferences, so they are best suited to contribute to the care plan process and also monitor quality in care (Graneheim, 2013). Caregivers may benefit from gathering information from community resources, such as the Alzheimer's Association, to better understand caregiving techniques and the disease process.

Many studies that address issues of NH quality-of-care propose a person-centered care model to improve quality of life of the NH resident. Person-centered care, defined as a holistic approach to achieve and maintain well-being and quality of life for residents and a feature of the culture change movement in long-term care, includes maintaining an ongoing working relationship between the individual, staff, and family members (Corazzini, Twersky, White, Buhr, McConnell, Weiner, & Colon-Emeric, 2015; National Nursing Home Quality Improvement Campaign, 2017). Maintaining connections between the NH resident and a wider social group is an important part of person-centered care. Staff members may encourage family members to increase the frequency, duration, and quality of their visits as well as encourage additional friends and family members to be involved with care and visitation, should immediate family be unavailable to visit due to work obligations or other barriers. Finally, this care model may encourage a home-like nursing home environment. An increased frequency of family visitation coupled with a home-like environment may provide residents with comfort and improve psychological well-being.

Future research examining the various roles and involvement of staff members (e.g., nursing home social worker) may provide insight into which staff to family relationships are strongest. The social worker may be best suited to ensure delivery of adequate and consistent mental health and psychosocial care in nursing homes (Social Work Policy Institute, 2010). Social work, tasked with educating facility staff, may provide nursing assistants and nurses with

an understanding of the importance of family member involvement in care. Building the working relationship and trust between nursing assistants, nurses, and family members may increase rapport for family members/caregivers, which may improve interest to family members visiting in nursing homes. This confirms findings that facilities that welcome and encourage family member involvement send a clear message that they, too, are welcomed and valued (Port, 2004).

Lastly, future research incorporating interdisciplinary studies that include transportation planners and professionals in the community who explore first/last mile issues, such as travel time and access to transportation, will strengthen the evidence-base of knowledge to improve services to those underserved in the community who are experiencing a gap in desired activities. Community revitalization and planning can ensure that older adults in the community are considered, which includes seniors aging in the community who desire to visit loved ones who require higher levels of care residing in nursing homes (Grantmakers in Aging & the Pfizer Foundation, 2013).

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Chapter 3: Family Member's Transportation and Depression Symptoms of Residents in

Nursing Homes: The Mediating Effect of Social Support and Visitation

Family Member's Transportation and Depression Symptoms of Residents in Nursing Homes:

The Mediating Effect of Social Support and Visitation

Introduction

The involvement in care of family members to residents of nursing homes (NHs) is found to be critical to the well-being and quality of life of older adults and is key to person-centered care (Koren, 2010). Person-centered care, a culture change movement in long-term care, aims to improve the overall quality of life of residents (Grabowski et al., 2014). Person-centered care is typically defined as the resident directing their own care; Nursing home practices and structures are detracting from the medical model of care to provide residents with a homelike environment, as well as foster supportive relationships across all residents and staff (Abbott, Heid, Kleban, Rovine, & Van Haitsma, 2018; Koren, 2010). This concept of person-centered care is a critical feature of the latest 2016 Centers for Medicare and Medicaid (CMS) Quality Strategy, specifically, "as noted in Goal 2: Strengthen person and family engagement as partners in their care" (Fazio, Pace, Flinner, & Kallmyer, 2017, p. S13). Thus, the visitation and social support of family members to resident in nursing homes should be encouraged as it may offer promising outcomes for both resident engagement and provision of care service delivery.

The visitation and engagement of family members to residents in nursing homes varies between families, and these changes take place immediately following admission to a nursing facility (Port, Gruber-Baldini, Burton, Baugmgarten, Hebel, Zimmerman, & Magaziner, 2001; Reid & Chappell, 2015). Cognitive status, race, support network proximity, and non-use of Medicaid were all found to be positively related to visitation of residents (Port et al., 2001). Preliminary research shows that transportation plays a critical role in this visitation among family members to older adults in long-term nursing home care. Previous studies on

transportation of family members to NHs have focused primarily on loved ones' difficulties visiting the residents, including access to transportation, ability to pay for transportation, and travel time to the nursing facility (Miller, 2018). The challenges in transportation access may limit the social opportunities and connections between family members and residents in NHs, leading to a decreased ability to participate in resident care planning, provide social support, and monitor resident health, which are integral features of person-centered care and overall quality of life indicators (McCreedy, Loomer, Palmer, Mitchell, Volandes, & Mor, 2018). Research also suggests that transportation disadvantage, defined as the experience of transportation challenges of persons of low socioeconomic status, older adults, persons with physical and mobility issues (Shay, Combs, Findley, Kolosna, Madeley, & Salvesen, 2016), may result in barriers to the social connectivity of older adults and their family members (Fields et al., 2019). Furthermore, visitation by family members has also been linked to the provision of social support, as family members help residents maintain an overall sense of belonging and inclusion (Dewall, 2013).

This lack of visitation and social support of family members to residents in nursing homes places residents at an increased risk for social isolation, loneliness, and depression due in part to other aspects of aging (e.g., loss of loved ones, chronic medical problems, diseases; NIMH, n.d.). It may be through these positive social interactions and social connections between community and their family members residing in long-term care that residents may have a reduction in loneliness (DeWall, 2013) and decreased symptoms of depression (National Institute on Aging, n.d.). Extant literature (Gaugler, 2005) has focused on the importance of familial visitation and social support to residents in nursing homes, however despite these findings focused on individual- systems level of care, no attention to date has been given to relationships between resident depression, family visitation, social support, and transportation access and

opportunities. To this end, this research examines the relationship between transportation, family visitation, social support, and depression symptoms of residents in long-term care nursing homes.

Review of the Literature

Aging populations are a phenomenon worldwide. Presently there are 46 million Americans over the age of 65 years old (Population Reference Bureau, 2016). This number is projected to increase drastically and will reach 98 million by 2060 (HealthyPeople2020, n.d.). Older adults experience a range of mental health concerns and physical health problems. Over 20 percent of this population experiences mental illness or neurological disorder (World Health Organization [WHO], 2017). Moreover, this population is at an increased risk for social isolation, loneliness, and depression due to other aspects of aging, such as the loss of loved ones, chronic medical problems, or diseases (NIMH, n.d.). Mental and physical health are inextricably linked; Mental health has an impact on physical health as well as conversely, physical health having a grave impact on mental illness.

While the majority of older adults live at home in the community aging in place, a number of older adults can no longer live independently or at home with a caregiver, due to increased health care needs (National Institutes on Aging, 2017). Older adults with complex health needs, including those with mild- to severe- cognitive impairment, chronic health conditions, or physical disabilities, may require around the clock, 24-hour care (Medicare.gov, n.d.). Recent statistics report 1.4 million older adults live long-term in nursing homes across America (CDC, 2014). Although this totals just under 5 percent of the total population of Americans over the age of 65 years old, projections estimate that the number of older Americans

requiring nursing home care may rise to 2.3 million by 2030 (Population Reference Bureau, n.d.).

Depression among Residents in Nursing Homes

Residents' of nursing homes are at a compounded risk for mental health concerns (e.g., depression) compared to older adults aging in place, as a result of a number of factors including their increased isolation and loneliness (Choi, Ransom, & Wyllie, 2008). Depression, in particular, is an epidemic among residents in nursing homes. Research suggests that roughly 22 to 40 percent of residents have a diagnosis of depression (Crespy, Van Haitsma, Kleban, & Hann, 2016). Another study found that as many as 78 percent of residents in nursing homes have depression (Gaboda, Lucas, Siegel, Kalay, & Crystal, 2011). Overall, research indicates that depression places residents at, "at higher risk for disability, medical morbidity, and mortality" (In Crespy, Van Haitsma, Kleban, & Hann, 2016, p. e76).

Social Support and Visitation of Family to Residents in Nursing Homes

The involvement of family members with residents of nursing homes has been found to help these residents maintain an overall sense of connection and belonging, thus reducing the consequences of isolation and loneliness (Dewall, 2013; Gaugler, 2005; Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). Additionally, family visitation to nursing homes may help to promote ongoing, working relationships between staff members and residents, which may provide residents with comfort and improved psychological well-being (Gaugler, 2005; Miller, 2018). A systematic review of the literature (Miller, 2018) identified seven barriers to family members visiting residents in nursing homes and found that these connections are mainly driven by the transportation access and mobility of the family members, which is also a key feature of

the Social Determinants of Mental Health (Allen, Balfour, Bell, & Marmot, 2014; Sederer, 2015).

Transportation impacts life in a variety of ways. Transportation systems shape how community-members and individuals operate on a daily basis. Moreover, transportation is vital to livable communities (AARP, n.d.). Transportation mobility, defined as the options of moving people from one place to another (Johnson, 2003), is connected to quality of life and well-being, especially for older adults (World Health Organization [WHO], n.d.). Access to transportation directly increases the scale and scope of social interactions (Rodrigue, 2017), which is also true for residents in nursing homes. A recent study by Konetzka & Perraillon (2016) found that transportation access, stops (public transit), and geographical location of the nursing home facility impact family members' abilities to visit residents and especially those relying on Medicaid. These findings suggest that diminished visitation, and in turn social support, may have negative consequences for residents such as increased risk for mental health problems (e.g., depression) of individuals living in these settings.

Social Determinants of Mental Health

The overarching theoretical framework guiding this study is the Social Determinants of Mental Health (SDMH; Allen, Balfour, Bell, & Marmot, 2014; Compton & Shim, 2015; Shim & Compton, 2018). Adapted from the Social Determinants of Health (Marmot & Wilkinson, 2006), the SDMH postulates that mental health is influenced by conditions, experiences, and contexts (Allen, Balfour, Bell, & Marmot, 2014; Compton & Shim, 2015; Shim & Compton, 2018). Across the lifespan, inequalities across socio-economic status, education status, gender, physical health, cultural factors, and social isolation are all factors that contribute to mental health and mental well-being (Compton & Shim, 2015; Shim & Compton, 2018). In addition to these

personal, individual-level factors, features of the built and natural environment (e.g., geography and transportation systems) impact mental health and functioning, especially for older adults (Allen et al., 2014). In total, 90 percent of these determinants of health, which includes mental health, are derived "…from our lifetime social and physical environment" (Sederer, 2015, p. 234). Sederer writes that it is through understanding and responding to these SDMH that better mental health can be achieved. Thus, the SDMH framework were used in this study to examine the role of transportation, social support, and visitation on depression symptoms of residents in nursing homes.

Current Study

Extant literature suggests that transportation, broadly, impacts family visitation and social support of NH residents, however, less attention is given to the actual impact these challenges have on these individuals. It is hypothesized that transportation of family members has an effect on depressive symptoms of residents, as transportation is the vehicle which facilitates family visits to nursing facilities, mediated by social support and visitation (see Figure 1 below). However, no literature to date explores these associations. Findings from this study offer implications across professions including transportation planning, social work, and nursing.

The main hypotheses in this study include: (1) Transportation of family has an effect on depression symptoms of residents in nursing homes, mediated by visitation; and (2) Transportation of family has an effect on depression symptoms of residents in nursing homes, mediated by social support.

Figure 1. *The Effect of Transportation on Depression Symptoms of Nursing Home Residents*
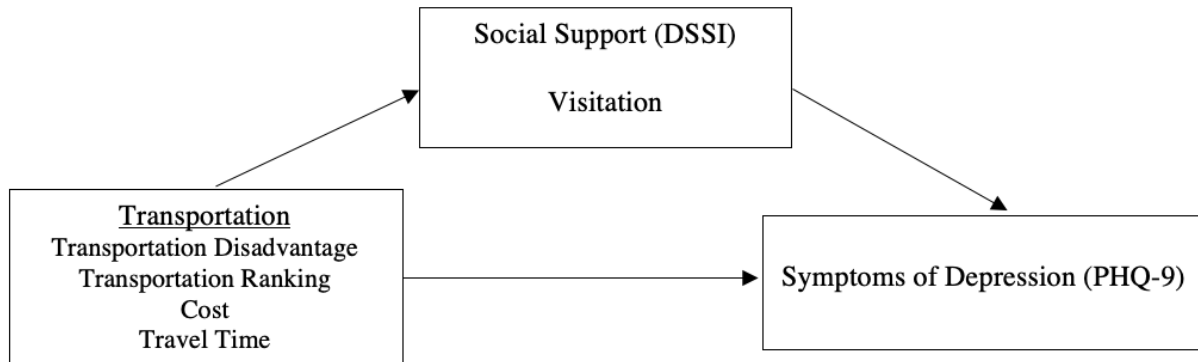
Methods

Design

This study is the first of two phases in a larger explanatory sequential mixed-methodological design, which is the most straightforward of the mixed-methods design (Creswell & Plano Clark, 2018). The core component of this study design is the quantitative portion that consisted of surveys with residents in nursing homes and their family members (i.e., resident-family dyad). A total of 11 nursing homes across North Central Texas were selected for this study using the *Nursing Home Compare* rating system to ensure sampling of Medicare- and Medicaid- certifiable facilities for consistency in regulatory practices and care delivery (Centers for Medicare and Medicaid Services, n.d.).

Nursing home star ratings. Nursing facilities were sampled to include a range of facilities with the highest star rating and those with the lowest star rating based on the Quality Measure (QM) ratings on *Nursing Home Compare*. Quality Measures ratings provide users with information regarding how well nursing homes are caring for residents' physical and clinical needs. This rating includes information on the use of antipsychotic medicine, specialized dementia care, in addition to over 12 million ancillary assessments of resident and nursing home

condition (CMS, 2017). These ratings include differences in levels of care to ensure each resident has their needs met (CMS, 2017).

Nursing home locations. The nursing homes in this study included 3-facilities in Weatherford, TX, 3-facilities in Arlington, TX, and 5-facilities in Fort Worth, TX.

Weatherford. Weatherford, Texas, is a rural community located in Parker County. Weatherford does not have public transit. The latest population estimates report 29,969 people living in Weatherford (U.S. Census Bureau, 2016). The latest census reports 15.2 percent of the total population over the age of 65 years old (U.S. Census Bureau, 2016).

Arlington. Arlington, Texas, located in Tarrant County, is a high-density suburban community located between Fort Worth and Dallas, Texas. This community lacks a comprehensive public transit system. The latest population estimates report 392,772 people living in Arlington (U.S. Census Bureau, 2016). A reported 8.1 percent of the population are over the age of 65 years old (U.S. Census Bureau, 2016).

Fort Worth. Fort Worth, Texas is a low-density urban community located in Tarrant County. Fort Worth, Texas operates public transit in a variety of ways, including buses, rails, and paratransit services. The latest population estimates report 854,113 people living in Fort Worth (U.S. Census Bureau, 2016). The 2010 census reports 8.2 percent of the Fort Worth population over the age of 65 years old (U.S. Census Bureau, 2016).

Data Collection

First, residents of nursing homes were interviewed face-to-face with the Abbreviated Duke Social Support Index (Koenig et al., 1993), indicators of visitation, and the Patient Health Questsionaire-9 (PHQ-9; Kroenke & Spitzer, 2002). Second, family members were interviewed face-to-face or via telephone with questions related to travel time, cost in fuel, the adapted

Transportation Disadvantage Assessment Tool (TDAT; Delbosc & Currie, 2011), and indicators

of visitation. Demographic information was also collected from each participant in study.

Quantitative data examined the relationship between transportation on depressive

symptoms (PHQ-9) of residents in nursing homes, mediated by social support (DSSI) and family

visitation. Once the quantitative components were analyzed, this explanatory design used

significant or non-significant results, and surprising findings, to guide the purposive sampling for

the qualitative follow-up phase (Creswell & Plano Clark, 2018; Morgan, 2014; Morse, 1991).

Sampling Strategy

Eligible participants were purposively sampled to participate in this study. To be eligible

for participation and to meet inclusion criteria, residents were: aged 55 years and above;

cognitively alert and oriented to person, place and time (A&Ox3); did not intend to return home

to the community; and, had a family member who visited. To ensure that residents were eligible

for participation, each volunteer was screened for cognitive orientation using the Mini Mental

State Examination (MMSE), with the scores ranging from 24 to 30 points to be in the study

(Folstein, Folstein, & McHugh, 1975). For family members of residents to be included in this

study they were: over the age of 18 years old and visited the nursing home from time to time,

according to the resident.

The University of Texas at Arlington Institutional Review Board approved this study

(*UTA IRB#: 2018-0486*). Data were collected between May 2018 and January 2019. An a priori

power analysis using the statistical power analysis program G*Power indicates that 89 total

subjects were needed to have 90% power for detecting a medium effect size ($f=0.25$) when

employing the traditional .05 criterion of statistical significance for conducting regression with

12 variables as control variables. The final sample included a total of 86 resident-family member

dyads (*N=86*), which was appropriate as just one variable was controlled for in the final study.

Quantitative data. Face-to-face interviews were conducted with each resident in their

own room or at another location within the nursing home of their choosing. Data were collected

by the principal investigator and one hired Master of Social Work (MSW)-level student support

staff. The MSW underwent extensive training by the principal investigator related to nursing

home procedures and protocols, study protocol, consent protocol, and interview schedules for

each participant population (i.e., residents and family members). Prior to interviewing residents,

the researcher explained confidentiality, study purpose, procedures, benefits, and risks. Residents

of the nursing home had a right to decline participating. Interviewers ensured each resident had

full understanding of the study and understood all questions. Informed consent was obtained

through written- documentation or verbal- consent, as necessary, due to many participants having

issues in dexterity due to partial paralysis from health effects (e.g., stroke).

Similarly, face-to-face interviews were conducted with resident family members in

resident's room or another in-facility location that was appropriate. For family members who

were not on-site, interviews were conducted via phone. Family member data were collected by

the principal investigator and MSW support staff. Prior to interviewing family members, the

researcher obtained written- informed consent for both the quantitative and qualitative phases of

this study. On participant agreement, the interviewer proceeded to conduct the interview at that

time or scheduled a time at the participant's convenience.

Measures.

DV: Patient Health Questionaire-9. The Patient Health Questionnaire (PHQ-9; Kroenke

& Spitzer, 2002) is a 9-item multipurpose instrument that screens for signs and symptoms of

depression. This instrument is validated for use with older adult residents of nursing homes and

is currently used within this setting as a component of each individualized resident assessment

and care screening (Minimum Data Set; Centers for Medicare and Medicaid Services, n.d.).

Scores are on a 4-point Likert-scale from 1 (*Not at all*) to 4 (*Nearly every day*). Sum scores were

calculated. Higher scores indicate greater depression symptomology. This instrument reports

reliability (Cronbach's alpha, α) of .843.

  IV: Transportation. Transportation indicators that were included in this study are:

transportation disadvantage, transportation ranking of importance, cost of fuel, and travel time

from home to the facility. To capture these variables, family members were asked, "What is the

cost in fuel (in dollars) from home to the nursing home?," and, "About how long (time in

minutes) does it take you to travel from home to the nursing home at peak/off peak hours?"

  Furthermore, transportation was conceptualized using the Transportation Disadvantage

Assessment Tool, or TDAT. TDAT is a measurement tool that quantifies transportation

disadvantage. First developed in 2011 by Delbosc and Currie, this tool was a part of a larger

project in Australia that investigated transportation disadvantage, social exclusion, and well-

being. This original scale had a total of 18-items, however as these researchers explored the most

important elements of transportation disadvantage using a principal component analysis, just 16-

items were found to explain variance for the degree of difficulty associated with transportation

(Delbosc & Currie, 2011). These 16-items were attributed to four factors, which includes: 1)

Transit disadvantage, 2) Transport disadvantage, 3) Vulnerable/impaired, and 4) Rely on others.

The TDAT has since been adapted for use to test the, "hypothesis that a walkable neighborhood

environment helps to reduce transportation disadvantage and social exclusion" (Ma, Kent, &

Mulley, 2018). Scores are on a 5-point Likert-scale with responses ranging from 1 (*Not at all*) to 5 (*Very much so*).

Additionally, a follow-up question to each item ranks the importance of item contained in each factor. For example, participants are first asked, "How easy is it for you to cover the cost of transportation?," followed next by "How important is that to you?". The transportation ranking of importance captures participants' perception of the value of their transportation within the context of visiting a resident within the nursing home. Aggregate scores were taken as well as the secondary 16-ranking of importance questions, which were scored are on a 5-point Likert-scale with responses ranging from 1 (*Not at all*) to 5 (*Very much so*). Higher scores on the TDAT indicate greater transportation disadvantage. Higher scores of the transportation-ranking of importance questions indicate higher perceived value of the importance of transportation. TDAT base questions report a reliability score (Cronbach's alpha, α) of .938. TDAT ranking of importance questions report a reliability score (Cronbach's alpha, α) of .935.

Mediators: *Abbreviated Duke Social Support Index.* The abbreviated Duke Social Support Index (DSSI-11), shortened from the original 35-item instrument, is used to assess for perceived levels of social support. This abbreviated version "consists of all items on the two subscales of social interaction and subjective support" (Duke Instruments, 2018). Participants were asked questions within four subscales on a Likert-type response that includes: 0 (*None*) to 2 (*More than 2 people*); 0 (*None*) to 6 (*Seven or more times*); 0 (*Hardly ever*) to 2 (*Most of the time*); and, 0 (*Very dissatisfied*) to 2 (*Satisfied*). Scores ranged from 3 to 40 with higher scores indicating more perceived social support. This version has been validated for use with chronically ill and frail older adults (Koenig et al., 1993), and was used within the context of

family members visiting residents. This instrument reports reliability (Cronbach's alpha, α) of

.603.

  Visitation. Visitation of family member to resident in nursing home was captured through

an indicator of family visitation to the nursing home in the past two-weeks. Family participants

were asked this question on 5-point Likert-scale, with 1 "*Every day (7 days),*" 2 "*Every other day*

(3 to 4 days)," 3 "*Twice per week,*" 4 "*Once per week,*" and 5 "*Less frequently.*"

  Control Variable: Family Self-rated Health. Family self-rated health was controlled for

throughout this study. Family participants were asked to generally rate their health on a 5-point

Likert-scale from 1 (*Poor*) to 5 (*Excellent*).

Analysis Procedures

  Analyses were performed using SPSS version 25.0 (IBM Corp. Released 2017) and

Mplus latent variable modeling program (Muthen & Muthen, 2018). Descriptive analyses were

conducted to capture the demographic background of all participants in this study (see Table 1

and Table 2). Additionally, frequencies were conducted of each key variable in this study (see

Table 3). Bivariate correlation analyses were performed next, listed in Table 4. Hayes'

PROCESS V3.3 Macro Add-on was used to conduct the observed-variable mediation analysis

(Hayes, 2012). Data of residents and family members were merged. Data were cleaned and

examined for missing values using Little's Missing Completely at Random (MCAR) test (Little,

1988). Three items on the Transportation Disadvantage Assessment Tool (TDAT) were

removed, as these questions did not apply to the participants and yielded non-responses. Results

of the EM estimation analyses were found to be non-statistically significant, so any missing data

was imputed using the multiple imputation (MI) method in SPSS. Using this method allowed the

researcher to replace, "each missing item with two or more acceptable values, representing a

distribution of possibilities" (Allison, 2001 in Soley-Borey, 2012, p. 7). The primary analysis,

regression with a mediator, allows to understand the mechanism through with the independent

variable, in this case transportation, effects the dependent variable, depressive symptoms.

Results

Sample Characteristics

A total of 86 dyads participated in this study ($N=86$). Table 1 presents detailed

demographic results from all resident participants. Table 2 presents detailed demographic results

from all family member participants.

Table 1. *Demographic Characteristics of Resident Participants (n= 86)*

Variables	N(%)
Gender	
Male	23(26.7%)
Female	63(73.3%)
Age	
55-64 years old	10(11.6%)
65-74 years old	32(37.2%)
75-84 years old	24(27.9%)
85 years old and above	20(23.2%)
Race/Ethnicity	
Non-Hispanic White	74(86%)
Hispanic or Latino/a	2(2.3%)
Black or African-American and Other	10(11.6%)
(e.g., Mixed-race; American Indian	
Marital Status	
Single (never married)	12(14.0%)
Married, living together	3(3.5%)
Married, living apart	13(15.1%)
Divorced/separated	23(26.7%)
Widowed	35(40.7%)
Highest Level of Education	
Some high school	10(11.6%)
High school/GED	32(37.2%)
Some college credit, no degree	23(26.7%)
Trade school/Vocational program or	7(8.1%)
Associates degree	
Bachelor's degree and above	14(16.3%)
Self-Rated Health	
Poor	15(17.4%)

Fair	21(24.4%)
Good	31(36.0%)
Very good or Excellent	19(22.1%)

Resident demographics. The majority of residents were female (73.3%). Thirty-two

percent of residents were between the ages of 65 and 74 years old, with ages ranging between 55

and over 95 years old. Nearly all residents (86%) identify as non-Hispanic White, followed by

Black or African-American (9.3%), and Hispanic or Latino/a (2.3%). Nearly half of participants

(40.7%) were widowed. Residents' highest level of education ranged from some high school

(11.6%) to a bachelor's degree and above (16.3%). Each resident self-rated their health with

most reporting their health as good (36.0%), next to fair (24.4%).

Table 2. *Demographic Characteristics of Family Member Participants (n= 86)*

Variables	N(%)
Gender	
Male	30(34.9%)
Female	56(65.1%)
Age	
18-39 years old	11(12.8%)
40-49 years old	9(10.5%)
50-59 years old	25(29.1%)
60-69 years old	24(27.9%)
70 and above	17(19.8%)
Race/Ethnicity	
Non-Hispanic White	76(88.4%)
Hispanic or Latino/a	2(2.3%)
Black/African-American or Other	8(9.3%)
(e.g., Mixed-race; American Indian)	
Marital Status	
Single (never married)	17(19.8%)
Married, living together	43(50.0%)
Married, living apart	10(11.6%)
Divorced/separated	7(8.1%)
Widowed	9(10.5%)
Highest Level of Education	
Some high school	6(7.0%)
High school/GED	23(26.7%)
Some college credit, no degree	25(29.1%)
Trade school/Vocational program or	12(14.0%)
Associates degree	

Bachelor's degree and above	20(23.3%)
Self-Rated Health	
Poor	2(2.3%)
Fair	13(15.1%)
Good	31(36.0%)
Very good	24(27.9%)
Excellent	16(18.6%)
Relation to Resident in NH	
Spouse	10(11.6%)
Child	50(58.1%)
Sibling	12(14.0%)
Cousin	1(1.2%)
Aunt/Uncle or Other (e.g., POA, in-law)	13(15.1%)
Primary Mode of Transportation to NH	
Car	83(96.5%)
Bicycle	1(1.2%)
Other (e.g., Airplane)	2(2.3%)

Family demographics. Similar to resident participants, most family member participants were female (65.1%). Twenty-nine percent of family members were aged 50 to 59 years old. Nearly all family members identify as non-Hispanic White (88.4%), followed by Black or African-American (8.1%), and Hispanic or Latino/a (2.3%). Most family members were married, living together with their partner (50.0%). Participant's highest level of education varied, with nearly thirty percent (29.1%) of family having some college credit with no degree, followed by a high school diploma/GED (26.7%), and bachelor's degree or above (23.3%). Over half (58.1%) of family members were the child of the resident participant. Nearly all family members used a car (96.5%) as their primary mode of transportation to visit the nursing home.

Table 3. *Variables included in Analyses (N=86)*

Variables	Mean (SD)
Depression (PHQ-9)	2.47(5.13)
Transportation Disadvantage Assessment Tool	16.21(8.03)
Transportation Ranking of Importance	61.58(8.00)
Travel Time	2.34(1.11)
Cost	14.39(58.69)
Social Support (DSSI)	20.96(7.69)
Visitation	3.23(1.33)

Transportation and Depressive Symptoms

Transportation of family members. Family member participants in this study reported their perceived transportation cost one-way from their home to the resident in their respective facility. Costs were recorded in dollar amount, where the total amount ranged from $0.10 to $350.00. Travel time to the facility were recorded in time in minutes. Family member travel times ranged from, "Less than 10 minutes" to "60 minutes+" (see Figure 2).

Figure 2. *Travel Time to the Nursing Home*
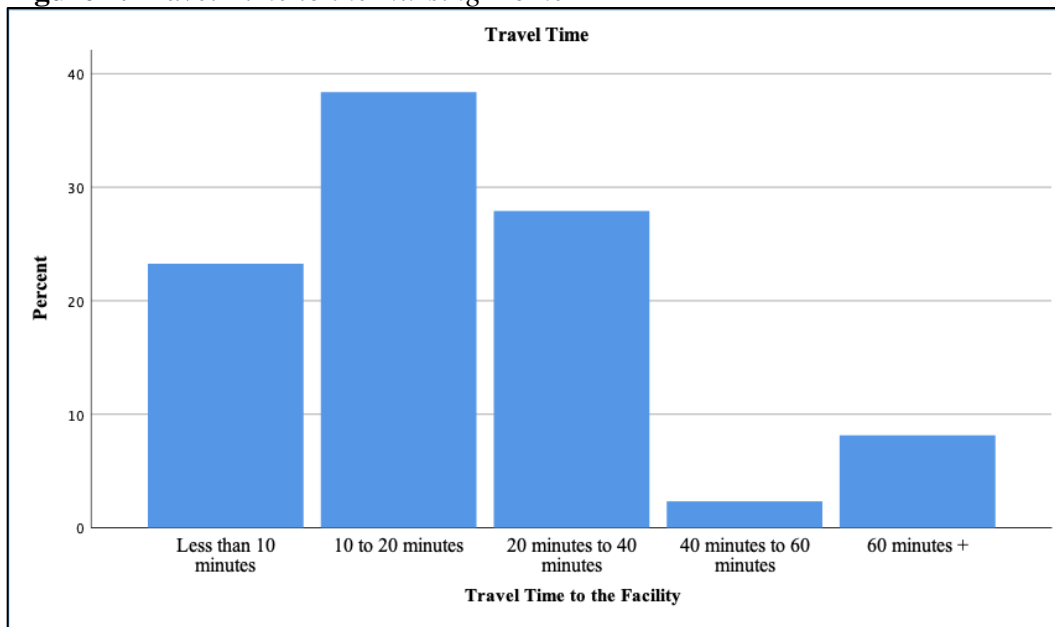
Figure 3. *Family Visitation Frequency to the Nursing Home*
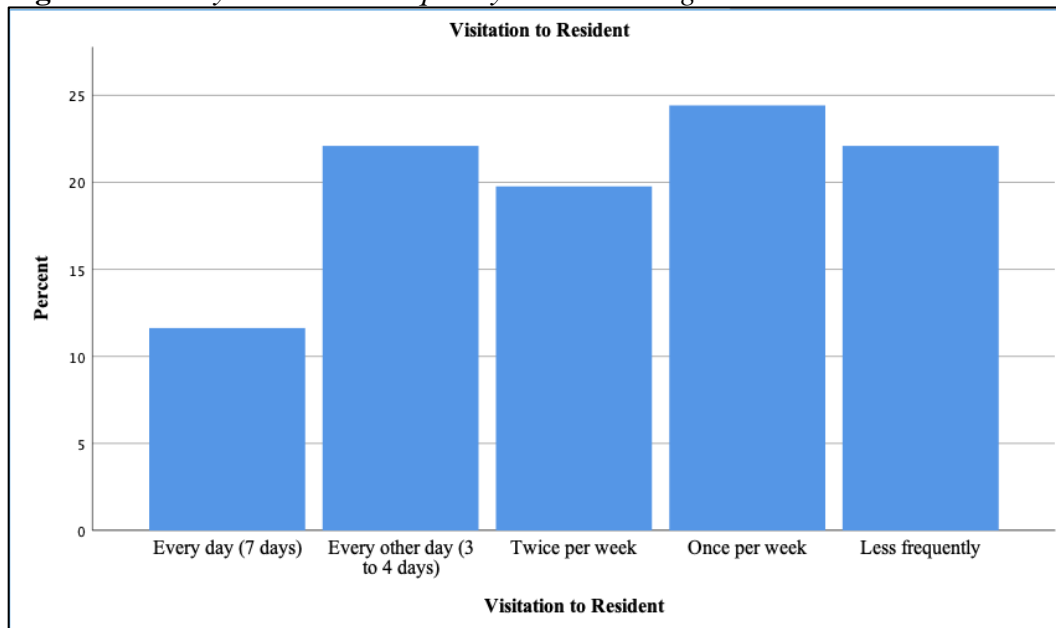
Figure 4. *Family Visitation and Travel Time*
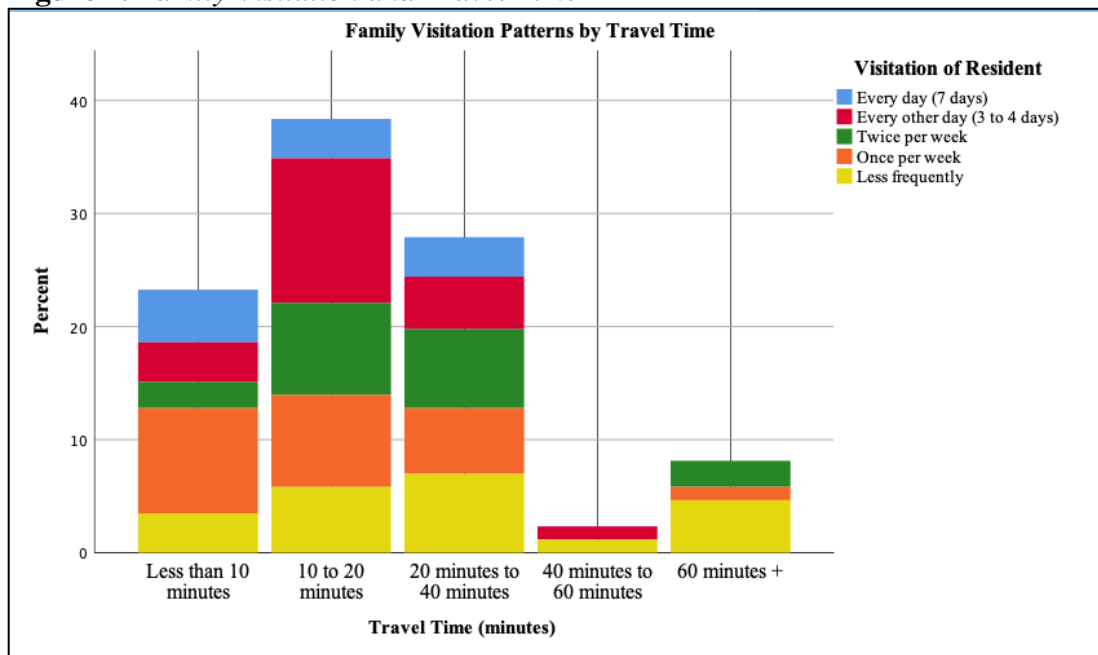
Figure 3 illustrates the travel time of family members visiting residents in long-term care. Across each category, most family members' travel time to the facility from home were "10 to 20 minutes" (38.4%), followed by 20 to 40 minutes (27.9%), "Less than 10 minutes" (23.3%), over 60 minutes (8.1%), and "40 to 60 minutes" (2.3%). Next, family visitation frequency was explored

through the variable, "How many times in the past week did you visit the nursing home?" Participants' visitation patterns ranged from "Every day (7 days)" in the past week, to "Less frequently" in the past week. Across each category, the greatest percentage of family members (24.4%) stated they visited "Once in the past week." Next, 22.1% of family members stated they visited far less frequently than once per week (e.g., once every two weeks, once per month). A total of 17 family members (19.8%) stated they visited 3- to 4- times over the past week. Finally, ten participants of the final sample (11.6%) reported visiting every day over the past week (see Figure 3).

Finally, travel time with visitation patterns were explored (see Figure 4). Across family member participants, travel time ranged from "Less than 10 minutes" to visit the nursing home to "60 minutes+." Results found that family members with a travel time of "Less than 10 minutes" to their resident in the nursing home visitation patterns range from "Every day (7 days)" in the past week to "Less than once per week." Most frequently, family members reporting a travel time to the facility of "Less than 10 minutes" visit "Once per week." Family members reporting a travel time of "10 to 20 minutes," the most common travel time to visiting their loved one (38%), most frequently report visiting "Every other day (3- to 4- days)" in the past week. Nearly 30% of family member participants report a travel time of "20 to 40 minutes" to the nursing home, where family most often report visiting "Twice per week" in the past week. Very few family members (2%) reported that their travel time to the facility took "40 to 60 minutes," where these family members visit "Every other day" or "Less than once per week" across the past week. Lastly, less than 10% family member participants in this study report a travel time of "60 minutes or greater" to visit their resident. No family members with a travel time of greater than 60 minutes report visiting on a daily basis or every other day (3 to 4 days) in the past week.

Confirmatory factor analysis of the Transportation Disadvantage Assessment Tool.

Next, a confirmatory factor analysis (CFA) was conducted on the Transportation Disadvantage Assessment Tool to assess for fit with the population in study. This CFA was conducted using the Mplus latent variable modeling program (Muthen & Muthen, 2018). This method of structural equation modeling was appropriate as there were underlying theoretically driven factors existing on the items included within the final model based on the relationships between variables in the development of this instrument (Albright & Park, 2009; Delbosc & Currie, 2011). A number of fit indices were used to examine model fit of the TDAT to the participants in study. The goodness-of-fit indices used in this model estimation, which are noted to be good for a one-time model fit, are: comparative fit index (CFI), non-normed fit index (Tucker-Lewis fit index; TLI), and the root mean square error of approximation (RMSEA) (Schreiber, Stage, King, Nora, & Barlow, 2006). Cut-off criteria for each of these fit indices include: CFI ≥ .95 for acceptance; TLI ≥ .95 can be 0 > TLI > 1 for acceptance (Schreiber et al., 2006, p. 330), and RMSEA < .06 to .08, which is consistent across literature (Chen, Curran, Bollen, Kirby, & Paxton, 2008; Kenny, 2015).

Results of the analysis reveal that the original factor structure is not supported. Factor 1 model fit indices report $\chi^2 = 13.107$, $p = .0224$, $CFI = .952$, $TLI = .903$, $RMSEA = .053$. Factor 2 model fit indices report $\chi^2 = 3.811$, $p = .1487$, $CFI = .986$, $TLI = .957$, $RMSEA = .208$. Model fit indices of Factor 3 report $\chi^2 = 5.519$, $p = .0633$, $CFI = .950$, $TLI = .851$, $RMSEA = .101$. Factor 4 contains just 3-items, which is not suitable for analyses of goodness-of-fit indices. As such, the variable "Transportation" was operationalized using the Transportation-ranking of importance follow-up questions on the TDAT.

Correlations. First, all variables: Transportation (transportation disadvantage, transportation ranking, cost, and travel time; IV), depressive symptoms (PHQ-9; DV), social support (DSSI; M), and visitation (M) were tested for association using Pearson's correlation. Pearson's correlation tested the extent in which variables are linearly related to one another (Hall, 2015). Results of Pearson's correlation coefficient are reported in Table 4.

Table 4. *Correlations Among Continuous Predictor Variables, Mediation Variables, and Outcome Variable*

Variables	1	2	3	4	5	6	7
1. Depression symptoms	-						
2. Social support	.309**	-					
3. Visitation	.046	-0.29	-				
4. Transportation-ranking	-.072	-.205	-.022	-			
5. Transportation disadvantage	.004	.084	.012	-.144	-		
6. Cost	-.125	.006	.228*	.070	-.061	-	
7. Travel Time	-.129	.103	.253*	.035	-.010	.883**	-

**Correlation is significant at the 0.01 level (2-tailed).
*Correlation is significant at the 0.05 level (2-tailed).

Despite variables not being significantly correlated with depressive symptoms, literature states that there does not need to be a direct effect of *X* on *Y* in order to establish mediation (Zhao, Lynch, & Chen, 2010).

Mediating effect of social support and visitation. Regression analyses were used to investigate the hypothesis that visitation and social support mediates the effect of transportation of family members on depressive symptoms of residents in nursing homes.

Model 1. The first model included travel cost, visitation, social support, and depressive symptoms. Results indicate that travel cost was not a significant predictor of social support ($b = 0.00$, $t(75) = 0.4032$, $p > .05$), and this travel cost was also found to be a non-statistically significant predictor of visitation ($b = 0.00$, $t(75)=1.86$, $p > .05$). The indirect effect was tested

using a percentile bootstrap estimation approach with 5000 samples. Results indicated that the indirect coefficient was non-significant (B = -0.01, SE = .01, 95% CI = -0.323, 0.011). As such, travel cost was removed from the model.

$Model$ 2. The second model included travel time, visitation, social support, and depressive symptoms. Results indicate that travel time was not a significant predictor of social support (b = 0.01, t (81) = 0.4032, p > .05, and travel time was also not a significant predictor of visitation (b = 0.00, t (81) = 2.21, p > .05). Results indicated that the indirect coefficient was non-significant (B = -0.009, SE = .01, 95% CI = -0.031, 0.011). Again, travel time was removed from subsequent models.

$Model$ 3. The third model included transportation-ranking of importance, visitation, social support, and depressive symptoms. Results indicate that transportation ranking was not a significant predictor of visitation (b = 0.00, t (83) = 0.3091, p > .05), and this visitation was also found to be a non-statistically significant predictor of depressive symptoms (b = 0.22, t (83) = 0.52, p >.05). The indirect effect was tested using a percentile bootstrap estimation approach with 5000 samples. Results indicated that the indirect coefficient was non-significant (B = -0.01, SE = .04, 95% CI = -0.142, 0.005). As such, this indicator of visitation was removed from the model to achieve the most parsimonious model.

$Model$ 4. This final model fit included transportation-ranking, social support, and depressive symptoms of residents (see Figure 5 below). Results indicate that transportation-ranking was a significant predictor of social support (b = 0.23, t (82) = 2.39, p < .05), and that social support was a significant predictor of depressive symptoms (b = -0.19, t (83) = -2.35, p < .05), all while controlling for family member's self-rated health. The indirect effect was tested using a percentile bootstrap estimation approach with 5000 samples. Results indicated that the

indirect coefficient was significant ($B = -0.04$, $SE = .03$, 95% $CI = -0.121$, -0.004). These results

indicated the meditational role of social support in the association of transportation-ranking and

depressive symptoms, thus the hypothesis was partially supported.

Figure 5. *Final Mediation Model*

Path a
$b = 0.23$, $p < 0.05$

Social support (DSSI)

Path b
$b = -0.19$, $p < 0.05$

Transportation-ranking

Symptoms of depression (PHQ-9)

Path c'
$b = -0.05$, $p > 0.05$

Total effect (c): $b = -0.10$, $SE = 0.0713$, $p = 0.18$
Direct effect (c'): $b = -0.05$, $SE = 0.0736$, $p = 0.4511$
Indirect effect (ab): $b = -0.05$, Boot $SE = 0.0312$, $CI_{95\%} = -0.121$, -0.004
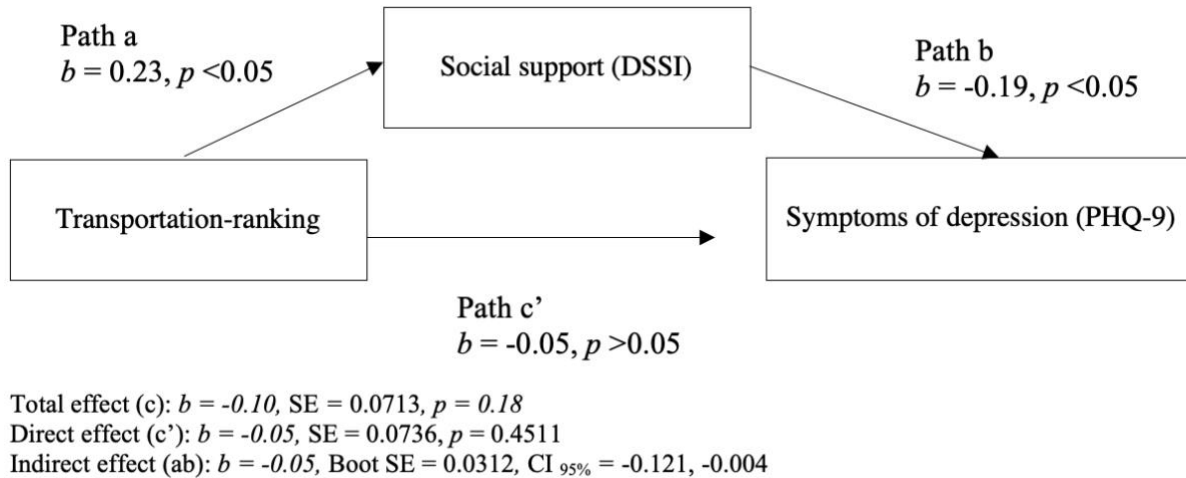
Discussion

This study sought to examine the relationship between transportation (e.g., travel time,

travel cost, transportation disadvantage, and transportation-ranking) and depressive symptoms of

residents in nursing homes. The final model explored the following two hypotheses: (1)

Perceived transportation-ranking has an effect on depression symptoms of residents in nursing

homes, mediated by visitation; and (2) Perceived transportation-ranking of family has an effect

on depression symptoms of residents in nursing homes, mediated by social support. Results

showed that transportation was not directly associated with depression of residents in nursing

homes. However, results of this study highlight the mediating role of social support in the

association of transportation-ranking and depressive symptoms. Thus, hypothesis 1 was not

supported and hypothesis 2 was partially supported, as there were significant indirect effects

between the predictor, mediator, and outcome variables, but no full mediation.

Findings from this study show that transportation-ranking is significantly associated with higher levels of social support, and higher levels of social support are significantly associated with lower levels of depressive symptoms among residents. The direct effect in this study is interpreted as independent of transportation-ranking and social support, where no evidence was found to support the effect transportation-ranking has on depressive symptoms.

The concept of transportation is quite complex. This was, as of the writing of this article, the first study to explore the relationship between any concept of transportation, in this case, travel time, travel cost, transportation disadvantage, and transportation-ranking, on mental health outcomes (depression symptoms) of residents in long-term care nursing homes. This study adds to the literature base on the concept of transportation as an issue to participate in social activities and spend time with loved ones, which is found across existing studies (World Health Organization, n.d.).

Family members' transportation-ranking was evident in resident feelings of social support. Considering that family members, by in large, utilized cars as their primary mode of transportation (96.5%) and given scant transportation mode alternatives in the area this study was conducted, family members may have endorsed harnessing this sense of autonomy in their responsibility to support their loved ones in long-term care. Across the three communities involved in this study, just one presented public transportation options for family members, which is Fort Worth. This transportation alterative to car ownership is limited in nature and does not support active transportation (e.g., walking, bicycle riding), placing the transportation burden back on the individual.

These findings support the use of the Social Determinants of Mental Health (Allen et al., 2014) as a framework for exploring various factors of mental health of residents in nursing

homes, as transportation is a key component of the built environment that has an overall impact on mental health outcomes of residents. No previous studies have explored features of transportation of community-dwelling individuals on residents of nursing homes, and perhaps these findings can be interpreted similarly to earlier studies that have found residents' feeling they were trapped and couldn't develop a sense of home because they lacked freedoms (Rinjaard et al., 2016). The flexibility and ability of resident family members to provide social support to residents could be interpreted as an indicator of a resident's own sense of freedom while their mobility is limited and constrained due to organizational rules and characteristics.

As noted in many earlier studies, social support of family is inextricably linked to a sense of belonging and inclusion (Goodman et al., 2013). Older adult residents who do not endorse belonging and a sense of support within this setting are at a high risk for developing symptoms of depression, which are in addition to an already heightened risk for mental illness due to this living arrangement. The social support of family can encompass acquainting staff members to resident preferences, personal, and emotional histories (Norris, 2000). Additionally, this social support and personal understanding of a resident may help to ameliorate other mental illnesses and challenges in health, as family members have been identified, in seminal works, as key personnel in the identification and provision of *preservative care*, where: "family members maintain the residents' identity and dignity (Bowers, 1988)" (In Powell et al., 2017).

In this study, the concept of visitation was operationalized asking family members of their visitation patterns of the past two-weeks. Noted in earlier studies (e.g., Gaugler, 2005), the theme and understanding of visitation of family to residents in nursing homes has been a challenge. Very early studies took a focus on visitation to nursing homes, where it was operationalized as "frequency." One study collected data from family members assessing

visitation on a weekly basis (National Center for Health Statistics, 1977, 1979), whereas another early study (Gottesman, 1974) described visitation in the past-month, or month prior to interviewing. Despite these earlier examinations of visitation to residents in nursing homes, it has been noted that the, "frequency or duration of visits were often not described" (Gaugler, 2005, p. 107), thus making the operationalization of this variable a challenge.

Overall, this research is important to understand the various contextual factors (e.g., transportation) that have in resident depression symptomology, as depression of residents in nursing homes is an epidemic (Centers for Disease Control and Prevention, 2014). These findings may warrant further exploration into both factors of depression associated with nursing home residents, as well as features of transportation of resident family members.

Limitations

Despite the significant findings in this study, a number of limitations of this research project are worth noting. First, the sample included in the final analysis is a relatively small sample size, which yields low statistical power. Second, resident participants were initially identified by staff within each facility, which may have led to sampling bias. After each participant was identified by staff they were subsequently approached and asked if they were interested in participating in the study, however this staff identification of resident may have led to the selection of highly functioning residents with fewer cases of mental illness (e.g., depression). Third, all participants in this study had a family member who participated and who visited from time to time. As such, there may have been measurement errors in assessing for transportation disadvantage, whereas sampling family members who did not visit could have led to an increased number of family members with challenges and barriers to transit.

Finally, the majority of resident participants in this study reported no symptoms of depression. This may have been in part to the high functionality of residents chosen by each respective facility who then volunteered to participate in this study. Additionally, very few family member participants reported challenges or barriers in transportation access to visit their resident in the nursing home. This lack of transportation disadvantage led to scant variation in the results of transportation disadvantage. These results indicate that the TDAT (Delbosc & Currie, 2011) was not a good indicator of transportation in the mediation model, whereas transportation-ranking was ultimately used as the indicator of transportation in the final model fit.

Implications for Future Research and Practice

The information and knowledge gathered from this study have significant implications for future research. These findings are useful to help understand transportation perceptions that lead to social support of residents in nursing homes, and how this has an effect on depressive symptoms. This study provided evidence to see the effect that perceived transportation ranking of importance has on resident social support and symptoms of depression. Additionally, these findings uncovered that transportation access and opportunities of family members are complex. Future research ought to extend beyond family members to examine the perceptions of transportation from a variety of stakeholders involved in nursing homes, such as residents and staff. Establishing a strong transportation assessment tool that may be reliable against an aging population in high-density suburban, low-density urban environments, and rural communities can help to best understand dimensions of community connectedness. Transportation assessments in the US have continued to fall short (Pyrialakou, Gkritza, & Fricker, 2016), where gaining a well-rounded perspective of this as a social problem in communities may facilitates

social engagement and enhance overall well-being of community members dwelling at-home and those residing in institutionalized settings. Moreover, continued exploration on travel behaviors (e.g., travel time) and visitation patterns warrant greater attention, as the majority of family member participants in this study lived within 40- minutes travel time to the facility, yet visitation patterns were inconsistent across cohorts. Gathering data on travel burden mitigation strategies may inform programming within communities and long-term nursing homes for low-cost interventions that can have meaningful, positive health outcomes for family members and residents in nursing homes.

These results have implications for practicing professionals in the fields of social work, health care, and transportation planning. Transportation is a multi-dimensional concept that warrants greater attention. Those from professions that includes transportation planning, civil engineering, and social work each have a vested interest in promoting social equity and enhancing the lives of marginalized, vulnerable populations (Miller, Murphy, Cronley, Fields, & Keaton, in press). Social workers in particular are tasked with ensuring each resident attain their highest level of psychosocial well-being, and a recent policy analysis (Miller & Hamler, 2019) impresses the need to include nursing home social workers on the interdisciplinary team to assist in the development of person-centered care plans. It is only through these care plans that social workers can work in tandem with nursing home staff to assess resident needs and family member needs, including transportation access and opportunities to visit the facility. Moreover, populations (i.e., racial and ethnic minorities, persons of low-socioeconomic status, older adults) are especially challenged with disadvantages and mental illness, where the social connection driven by transportation may be particularly necessary to achieve overall well-being.

This study also has implications for social workers employed in discharge planning roles outside of nursing homes. A significant portion of residents in nursing homes are admitted to these care facilities directly from a hospital. It is often the role of the social worker at hospitals and skilled nursing facilities (SNFs) to navigate these larger healthcare systems, offer support for care transitions, and place ultimately refer residents to long-term care facilities. (Sims-Gould, Byrne, Hicks, Franke & Stolee, 2015). Social workers discharging patients should aim to gather transportation-access and related transportation information from patient family members to ultimately inform the decision-making process of selecting a nursing home for their loved within an acceptable and accessible travel boundary.

Conclusion

In conclusion, this study is very innovative and timely given the changing landscape of the population of persons age 55 and above. This research harnesses features of multiple disciplines including: social work, transportation planning, and nursing. Tapping into concepts from each profession that are guided by values to enhance and serve the community-at-large allowed for this complex study to be conducted. Further work to expand on locations of a study of this nature in communities of similar residential densities with largely car-driven community members (e.g., Western OH, Atlanta, GA) may uncover the association features of the built environment (transportation) on the daily living of largely isolated and near-forgotten population of aging older adult residents of nursing homes.

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Chapter 4: The Experience of Family Member's Transportation to Visit their Relatives in a

Nursing Home: A Qualitative Study

The Experience of Family Member Transportation to Visit their Resident in a Nursing Home: A

Qualitative Study

Introduction

Maintaining social engagements, social relationships, and social connections within the

community can be accomplished through access to transportation and transportation

opportunities (Delbosc & Currie, 2010; Fields et al., 2019). This is the same for the maintenance

of relationship between family and residents in NHs; family visitation to residents in NHs is

mainly driven by transportation access (Port et al., 2001; Port, 2004). Previous research supports

the relationship between transportation, social support, and visitation of residents in NHs (Miller,

2018); however there is no empirical research to date that explores this relationship of family

member transportation as a means to visit their loved one in long-term care, and the influence

this transportation has on visitation. This article chapter presents findings from a qualitative

study, the second phase of a mixed-methodological study, that expands on family members'

experiences of transportation access and opportunities as a means to visit a family member

resident in nursing home care.

Review of the Literature

Extant literature has found that a lack of transportation access greatly impedes family

members' visitation to residents in nursing homes (Miller, 2018). This is especially salient

among community members living in rural areas, whereby transportation opportunities are a

concern (Henning-Smith, Evenson, Corbett, Kozhimannil, & Moscovice, 2017). More broadly,

transportation disadvantage is a social issue whereby individuals and groups experience ongoing

difficulties associated with accessing and maintaining transportation, and while transportation is

a vital component of community connectedness, transportation assessments within United States

communities have continued to fall short (Pyrialakou, Gkritza, & Fricker, 2016). This concept of transportation is critical for livable communities (AARP, n.d.). According to the World Health Organization (WHO; n.d.), transportation is vital for accessing social opportunities and connections, civic participation, housing, employment, respect and inclusion. For already at-risk populations (e.g., persons with disabilities, age-related constraints, geographical constraints, or socio-economic status; Shay et al., 2016; U.S. Government Accountability Office, 2003), the concepts of transportation and mobility contribute to a larger aim to reduce social exclusion, thus enhancing quality of life and well-being (Mack, 2016; WHO, n.d.). Furthermore, transportation is key to linking community members despite any pre-existing restrictions to transportation.

Research across the professions of transportation planning, health care, and social work, has cited transportation barriers as a cause of missed health care appointments, a lack of health care access, and missed medications (Syed, Gerber, & Sharp, 2014). These missed appointments increase the risk of chronic illness and disease, as well as poor health outcomes (Syed, Gerber, & Sharp, 2014). A lack of transportation access and travel time has also been associated with a lack of receiving mental health services, challenges in getting to work, and participation in recreational and social activities (Texas Council for Developmental Disabilities, 2015). The U.S. Department of Health and Human Services (2009) noted that for those with preexisting low-socioeconomic status, "these barriers to employment and self-sufficiency were exacerbated by a lack of reliable and affordable transportation" (p. 8).

While much research has examined the role of transportation and mobility on healthcare access, employment, and even visitation to residents in nursing homes, no qualitative research to date has explored community members lived experiences of transportation as a means to visit their loved ones in nursing homes. Thus, challenges in transportation, or transportation

disadvantage, may impact family members' both ability and desire to visit their loved one within a nursing facility and participate in the crucial aspects of care. The purpose of this qualitative research is to develop an in-depth understanding of transportation access, opportunities, and mobility, as it relates to visitation of residents in nursing homes, allowing for an in-depth picture and analysis of transportation (Creswell & Poth, 2018).

Methods

This study is part of a larger study and is the second phase of a sequential mixed-methodological research project. The first phase of this two-phase study design sought to confirm the following two hypotheses: (1) Transportation of family has an effect on depression symptoms of residents in nursing homes, mediated by visitation; and (2) Transportation of family has an effect on depression symptoms of residents in nursing homes, mediated by social support. Results showed that transportation-ranking was associated with depressive symptoms of residents in nursing homes mediated by social support, however visitation was not found to be a significant indicator in the proposed model. As such, these findings support this explanatory design to use significant or non-significant results, and surprising findings, to guide the purposive sampling for selecting a sub-sample of individuals based on scores on the transportation measure used in the first phase of this study (Creswell & Plano Clark, 2018; Morgan, 2014; Morse, 1991).

Sample

Eligible participants were purposively sampled to participate in this study. To be eligible for participation and meet inclusion criteria, family member participants were: over the age of 18 years old and visit the nursing home from time to time, as reported by the resident. The University of Texas at Arlington Institutional Review Board approved this study in early-May

2018 (*UTA IRB#: 2018-0486*). Data was collected between end-of-May 2018 and January 2019.

Family members (*N=11)* were purposively selected to participate in this qualitative portion of

this study. The sample size of 11 participants was chosen as multiple-case study designs are

encouraged to have six to ten cases in total (Yin, 1994). Moreover, Yin (1994) articulates that

study participants, "should be selected explicitly to encompass instances in which the

phenomena under study are likely to be found" (Zach, 2006, p. 9), whereby family members who

had no challenges with visitation to the facility and family members who had great challenges

with visitation were purposively selected for this follow-up study.

Data Collection

Qualitative data were collected through individual interviews with family members. Prior

to interviewing family members, the researcher obtained written-informed consent for this phase

of this study. Additionally, the interviewers obtained verbal consent via telephone. Upon

participant agreement, the interviewer proceeded to conduct the interview at that time or

scheduled a time at the participant's convenience.

Guided by a case study approach (Creswell & Poth, 2018), a semi-structured interview

guide of four questions was developed to ask family members to describe their greatest

challenges and opportunities to transportation access and mobility. This case study approach

allowed for the researcher to explore and uncover trends in a bounded system (Mills, Durepos, &

Wiebe, 2010), in this case, the experience of family members visiting their loved ones in long-

term care nursing homes. A sample size of 11 participants ($N = 11$), assisted in uncovering rich,

in-depth experiences of family members visiting residents.

Family members were asked to describe their most positive and negative experiences of

transportation access and mobility. Interview probes were used to clarify participant statement,

obtain more details, and re-direct focus (Kennedy, 2006). Data was collected by the principal investigator of this study. Interviews took between fifteen to thirty minutes in total. Each interview was recorded and transcribed verbatim.

Analysis

Qualitative data were analyzed using data sources from interview transcriptions, transcribed verbatim, and researcher notes. Data were then organized and managed using Atlas.ti v.8 (Friese, 2019). A conventional content analysis approach was used to study the qualitative data (Hsieh & Shannon, 2005; Miles & Huberman, 1994). Paragraphs, phrases, and words were organized according to the interview guide, and then subsequently coded using an "open, prospective approach guided by the study's research questions" (Towsley, Beck, Dudley, & Pepper, 2011, p.1-14). The primary investigator in this study conducted an initial analysis. Next, the data were triangulated with an outside researcher to better understand the emerging themes to avoid biases. This analysis approach is appropriate for this study, as there is no literature to date that explores these research questions. Furthermore, credibility was enhanced through peer debriefing (Creswell & Miller, 2000). Results include direct quotes from participants with their respective anonymous identification to note differentiation between respondents.

Results

Demographic Characteristics

Most family member participants in this qualitative study were female (63.6%). Twenty-seven percent were aged 60 to 60 years old. Nearly all participants identify as non-Hispanic White (72.7%), followed by Black or African-American (27.3%). Participant's highest level of education varied, with over thirty percent (36.4%) of family having a bachelor's degree, followed by some high school (27.3%). A portion of participant's (3.64%) self-rated their health

as "Fair." Over half (63.6%) of family members were the child of the resident they visited. Most

of the participating family members used a car (72.7%) as their primary mode of transportation

to visit the nursing home, compared to bicycle (1.2%) and other (e.g., airplane, van service;

2.3%). Table 1 reports all demographic characteristics of family member participants from this

study.

Table 1. *Demographic Characteristics of Family Member Participants (N=11)*

Variables	N(%)
Gender	
Male	4(36.4%)
Female	7(63.6%)
Age	
18-39 years old	3(27.3%)
40-49 years old	1(9.1%)
50-59 years old	2(18.2%)
60-69 years old	3(27.3%)
70 and above	2(18.2%)
Race/Ethnicity	
Non-Hispanic White	8(72.7%)
Black or African-American	3(27.3%)
Highest Level of Education	
Some high school	3(27.3%)
High school/GED	2(18.2%)
Some college credit, no degree	2(18.2%)
Bachelor's degree and above	4(36.4%)
Self-Rated Health	
Poor	1(1.9%)
Fair	4(36.4%)
Good	2(18.2%)
Very good	1(1.9%)
Excellent	3(27.3%)
Relation to Resident in NH	
Spouse	2(18.2%)
Child	7(63.6%)
Sibling	1(9.1%)
Other (e.g., POA, in-law)	1(9.1%)
Difficulty in Paying for Basic Needs	
Not at all	7(63.6%)
Somewhat	2(18.2%)
Very well	2(18.2%)
Employment Status	
Full-time	4(36.4%)

Retired	2(18.2%)
Unemployed	3(27.3%)
Primary Mode of Transportation to NH	
Car	8(72.7%)
Bicycle	1(9.1%)
Other (e.g., airplane, van service)	2(18.2%)

Analysis of the family members' experiences with transportation access to and from visiting their loved one resulted in a total of seven primary themes. These themes include: 1. *Car access,* 2. *Alternative modes,* 3. *Flexibility,* 4. *Travel time,* 5. *Actual cost,* 6. *Collateral cost,* and 7. *Health and Mobility.* Additional findings from the data found a subsequent two- ancillary themes that came out of the initial seven influencing themes, which includes: *Maintained relationships* and *Fractured relationships*. Figure 1 is a visual representation of emergent and ancillary themes from the current study.

Figure 1. *Emergent Primary Themes and Ancillary Themes*
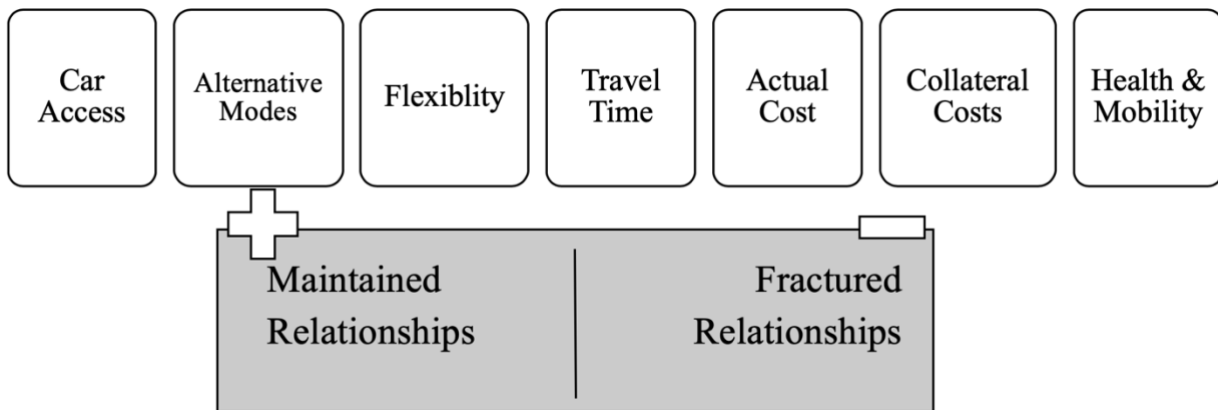
Car Access. Many of the family member participants shared that one of the most influential factors to visiting a loved one in the nursing home was the fact that they were able to and had access to a car as their primary mode of transportation.

One family member, daughter to a resident, shared:

I have the access to do that. It's no problem. I physically am able to do that because I'm fit

and I'm really ... Those are good things. I'm healthy. I'm able to do what I need to do. The

benefits for me are even greater to be able to go see my mother even though she is in

long-term care and that wasn't a choice. Do I necessarily like it? Would I rather my

parents be together? Of course, I would. But, you know, life happens and you have to

make choices (P2312).

Another participant shared similarly in that they both had access to a car and they were

physically able, so therefore they could visit, stating: "I don't have any problems even with one

car because of the way we schedule things together to be able to have access to my mother. I

don't have any disabilities so, therefore, I don't have any issues regarding getting to my mother"

(P2008). Another participant who, at one time relied on a bus as her primary mode of

transportation to visit her mother, shared positive regard to now having access to a car, sharing:

"So having this new car, it just opened the door for possibilities…" (P2086).

Alternative Modes. A number of family members ($n=3$) relied on alternative modes of

transportation and this was found to limit visits. One resident's wife stated that her: "Greatest

challenge was just getting a ride" (P2312). Another stated that, "someone else would have

trouble getting there without a car. No transportation there. No bus route…To get. If they have to

depend on someone bringing them or catching a ride. If they didn't have transportation

themselves" (P2128). Finally, one family shared an alternative option stating that they would use

a train, but that isn't an option: "passenger trains. I don't know. They don't up in this part of the

country, but maybe they do central and southwestern trains. I think they still run. That would be

the only way I could get there, yeah" (P2133).

For those family who did rely on alternative modes of transportation, their feedback was overall undesirable. The daughter of a resident shared her experience using the Greyhound stating that, "When I took the Greyhound? Okay, that was a truly terrible experience." Moreover, "It was always so expensive because I was trying to bring my mom gifts and things that she would need and so the Greyhound would charge you for all of the luggage you would have to bring" (P2086). Another family who relied on a van service to visit her spouse shared their experience, saying: "Very limited access that was very disappointing and disgusting is that I didn't always have transportation available to go see him. That was a big downer for me" (P2123).

One resident's daughter who relied on the bus from time to time stated that their travel was disjointed because of transfers, where a resident's daughter stated, "… we've got to take three buses to get there" (P2311). Finally, one participant, son of a resident, relied on a bicycle as their primary mode of transit stating, "Yeah. I have a lot of outstanding tickets for ... outstanding driving tickets that I have not paid off. So my only mode of transportation right now is a bicycle" (P2519).

Flexibility. Those family members that had car access were able to visit and many found that their flexibility was due to this transportation option. Some family could visit when they most needed to, as well as when they desired to. Getting to the facility in a moment's notice allowed family to not only visit around their own schedule depending on free time and flexibility but could also get to the facility in case of any emergency. A family member stated, "I can get to her or if there is ever an emergency and she needs to come to me, I can go to her and get her" (P2312). Similarly, another resident's daughter stated, "I think that with the car, if there is an emergency, if my mom gets sick or I get that phone call that she's dying. If I get that phone call, I

can get to her in a dependable way. If I need to absolutely drop everything and get to her I can"
(P2086).

Transportation access and opportunities were positive for family members to get to the
facility in need, as well as to follow through with desired trips that weren't necessarily cases of
emergency. Access to a car was positive to family members, as they were able to have control
over their visitation schedule; One family member shared:

> Well I own my own vehicle. So if I get on a whim and I just really want to go visit her, I
> can do it at any point in time. I don't have to wait on a set schedule. I can leave at any
> point in time during the day. So that's nice, and then getting over there to the facility.
> They don't have a set, specific hours that you can't or can come in, usually. You can go in
> at any time. So, I mean, that helps (P2516).

The daughter of another resident stated, "I have some access to two cars so I always have
a car available. I'm retired so I have complete control over when I travel and I can go at a
moment's notice since I have to or plan accordingly for doctors visits or other activities that we
need to do" (P2025). One resident's husband, who lived very close, stated that there was no
issues in traveling to the nursing home, which he did on a daily basis, stating: "Well, it wasn't
bad, because, like I said we stay right across the freeway, on the other side of the freeway. So,
there was no problem getting there" (P2128).

Travel Time. Family reported negative aspects of transportation, regardless of the mode.
A family member who relied on a car shared that although she had a car, it could be a challenge
if she traveled all the distance to visit her mother to have something happen, stating: "one of the
negative things of me having a car is that if I do go down there and I get stuck or if I get in a
wreck or something, I'm stuck there because I have no family there anymore. My mom is the

only one who'd be able to help me and she can't help me because she's in a nursing home"

(P2086). Another family member shared that it isn't feasible to visit often, and this is mainly

because: "Well, for one just distance. It's a three and a half hour drive one way, so that would be

one contributing factor" (P2025). Another stated, "Just that ... the distance, and then once you get

there, you're just like okay now I'm here and I gotta spend time with my family ... and usually

you're tired after four and a half hour trips, so tired and just ready to get moving. Yeah" (P2516).

These drives are not only long-distances for some, but also stressful. One participant shared,

"May I just say stressful drive, like I said it's three and a half hours on a very busy highway on

I35" (P2025). Finally, the daughter of a resident stated, "But I do live six hours away from there.

So the problem would be the time travel…" (P2086).

Actual Cost. The actual cost of traveling to the nursing home to visit a loved one was

found to be a significant contributor that prohibited transportation and transportation options.

One family member stated, "Of course there's a cost related to gasoline and car maintenance and

those types of things as well, so that would be a couple negatives" (P2025). The daughter of a

resident, who is a student and has a job, states that she has to think a lot about her financial

situation and plan before visiting, sharing: "So, like I said, I am in school, and I don't have a

dependable ... I have a job. But it's not enough money for me to make trips like that, so I haven't

really been able to go down there and see my mom". She also shared, "I think that money would

be a challenge" (P2086).

Another resident's family member, at times, would take another family member to visit

their resident, but on a fixed income it just wasn't always feasible, stating: "So it's kind of hard

to come up with the cash to buy the gas to take him back and forth" (P2312). Ultimately the cost

of transportation became too great for one family member, whereby they had to reduce their

visits and shortening their stays, sharing:

> I have been going about once every four weeks trying to extend that out to every five or
>
> six weeks at this point because of the cost of the nursing home went up ten dollars a day,
>
> so that equates to about $300 more a month out of pocket for us. So I have tried to offset
>
> some of that expense by going a little less often or not staying quite as long (P2025).

Collateral Costs. On top of the actual cost of transportation for gasoline to travel a far

distance to the facility, family also shared that the costs of their visits were compounded by

indirect costs of having to source lodging during their visit, where a family member reported:

"Yeah,… and then I also have to find a place to stay" (P2086). One participant stated that their

most negative experiences were, "Probably a mix of the time and the cost. I mean gas isn't super

expensive, but there's more with it than just the gas to get there ... we actually had to find a place

to stay and have the money to be able to do that" (P2516).

Another family member shared: "And then I guess a third would be somewhat of a

monetary restriction. I have to stay in a hotel room when I'm there so that costs anywhere

between $150-$200 a night. And my visits are shortened because of that restriction too" (P2025).

She went on to share that: "But certainly if I lived closer I'd feel that I could visit more often for

shorter times but more often and not have as much expense on hotels or gasoline" (P2025). One

participant reported that they did what they could to offset these indirect costs of visiting their

loved one in the nursing home, as able, however it was sometimes in lieu of a longer visit, for

example: "Trying to reduce the cost of the hotel by a night or so when I do go. Coming home

late in the afternoon instead of staying over a night and coming home the next morning, that type

of thing."

Health and Mobility. A few family members shared that they have their own pressing health and mobility challenges which is directly related to their experiences with transportation access, in turn linked to their visitation. One family member, brother of a resident, states, "The fact is I'm 78 years old. I've had three back operations. I'm going to have a knee replacement Friday…I can't really walk…So, I'm not really in a position to travel, you know, at the moment" (P2133), which was due to physical barriers where he also stated: "Well, at this point in time, I'm not sure I could complete a trip…You know, physically" (P2133). During good times, one family member relies on assistive equipment to aid her visitation to the facility. This half-sister stated, "I have a scooter, a walker to get around with. And when I feel good, them things work really good for me in getting in and out of the nursing home" (P2312). While another participant, spouse of a resident shared their mobility impacting visitation, where he stated: "I can't get around like I used to" (P2132).

Maintained Relationships. These influences of visitation to and from the nursing home were found to be greater than simply having car access, being faced with the challenge of travel time, and dealing with actual and collateral costs. These visits extended beyond the tangibility of seeing a loved one to make a lasting, positive impact on the lives of both residents and their family. One family member shared simply that their visits, "It's positive on the days that I can go" (P2312). The son of a resident who relied on a bicycle didn't let anything get in his way of visiting and maintaining the relationship with his mother, where he stated: **"**No. Just she's my mother. So I want to visit her as often as I can" (P2519). Another family member, daughter of a resident, stated that getting to spend the time is the biggest benefit, stating: "I'm able to spend the one-on-one time with her that is so wonderful. That has made this huge difference in my life, in our lives. So as far as I'm concerned that's the biggest benefit for me regarding being able to have

the mobility and the transportation that I can do that" (P2008). Another family shared, "We may not like the facility, but we love our parents, or people that are in there" (P2516). Some family felt it was ultimately their responsibility and duty to uphold these relationships with their family, stating: "She's my mother. I love her. I respect her" and "I take care of my mom and dad. That is my job… Though they each have different problems of their own, including their advanced aging, they have to come first on my schedule" (P2008), as these relationships were maintained by family members' access to transportation.

Fractured Relationships. Some family shared that while it is hard to visit due to travel time, they would increase visitation if the circumstances were different. The results of the inability to visit led to fractured, strained relationships between family and resident. One resident's daughter stated, "Just if I lived a lot closer, I would probably visit a whole lot more frequently, like at least once a week. But it's so far away that's obviously just can't happen, so unfortunately. I wish" (P2516). Another family member stated, "Yes, I used to see her ... I mean, anytime I would run in to town, I could go by and see her. Multiple times a week, if I wanted to. And now I see her, only when we're out long enough in school, for me to go down there and stay" (P2073). Family would like to visit more, but just aren't able. One resident's child stated, "Yeah, it's a challenge for me to get down there. I mean I don't go as much as I would like to go because I'm not able" (P2312). Another family member who relied on a van service with limited opportunities to visit stated that if they had access, "The outcome would have been real great, that way I could have had more chances to gone and seen, visit with him. Which is what he was needing as well. That would have been the greatest outcome of it is if I could have had more times of transportation of being able to go visit him more often" (P2123).

Discussion

The findings from this study provide interesting points for discussion. The main focus of this study was to examine how transportation influenced family members' visitation and visitation experience to residents in nursing homes. Each participant in this follow-up study were purposively sampled to include those with no challenges in transportation, who were able to visit daily, as well as those who had extenuating transportation experiences.

Family members reported that car access was instrumental in their visitation. For family members with car access, visitation was frequent. Previous research has documented similar findings in that transportation access is related to visitation (Bern-Klug, 2008; Choi et al., 2008; Port et al., 2001; Port, 2004). Research (Port, 2004) has identified that transportation access, regardless of travel time and distance to the facility, was most predictive of visitation. Despite these findings, this study extends beyond the current literature to highlight that car access was vital for the opportunity to visit, whereas conversely (alternative modes of transit) were indicative of presenting issues to visit. These findings are endorsed by literature that has found car ownership to be associated with a sense of autonomy and other perceived benefits (Ellaway, Macintyre, Hiscock, & Kearns, 2003).

Alternative modes of transit were used by three of the 11 family member participants in this study (*n*=3). For these family members without personal car access, a van service, bus system, bicycle, or other (e.g., train, airplane) was the only mode of transportation as an option to visit their loved ones. Port (2004) has noted that nursing homes likely have "overlooked ride systems or other transportation solutions for family caregivers" (p. 775). An early study (Friedemann, Montgomery, Maiberger, & Smith, 1997) explored services offered to nursing home resident-family members found that facilities largely have not focused on interventions

related to the transportation of family members. Since this time, the overall concept of transportation as it relates to resident family members has continued to be under-researched.

Family members' visitation were found to be largely influenced by flexibility in their ability to visit. This flexibility may have been due in part to retirement status, job commitments, and perhaps linked to car access, as well as travel time. These results are similar to previous findings (see Miller, 2018 for review) that identified persons of low socioeconomic status, coupled with the associated economic instability, were more likely to experience several barriers to visitation. Family members with low income are likely to experience greater barriers to transportation, and transportation alternatives, which may impact this visitation to a resident in long-term care. Persons who are *transportation disadvantaged* often experience greater pulls from other family members, and increased family challenges that may impact the relationship to the resident in the nursing home, thus decreasing flexibility in scheduling to visit a loved one (University of Minnesota, n.d.). Travel time is also a significant contributing factor to flexibility. For family members who reported one hour- to four hour- time travel to visit a loved one, increased visitation was just not feasible.

Findings from this study extend beyond what we already know to uncover how cost, both actual cost and collateral cost, are greatly linked to car access, transportation access, and opportunities to visit. Family members who were auto-dependent shared their challenges with the cost of gasoline to travel to visit their loved one in long-term care. Furthermore, lengthier travel times were associated with higher costs in gas, and travelers needed to consider any incidentals that may take place when traveling far distances. This cost of transportation was associated with other financial obligations that had to be considered when traveling, such as lodging. Family members that lived out of town had to plan ahead for stays in hotel and

strategize on length of visit, as that was the determining factor for the former two challenges associated with their visit.

The final theme to emerge from this study was *Health and Mobility*. It is important to note that nearly half (45.4%) of the participants in this study were age 50 years old and above. These high levels of physical challenges and issues in mobility are not new findings, however these challenges had not yet been connected to transportation access in the context of visiting residents in nursing homes. These findings make for an interesting discussion regarding age-friendly communities and equity in transportation solutions. A recent study (Adorno, Fields, Parekh, Cronley, & Magruder, 2015) conducted in Arlington, TX, a high-density suburban environment, found that certain populations of older adults were at a significant disadvantage of transportation due to decreased abilities.

Beyond the primary themes in this study emerged two ancillary outcomes of transportation access of family members on visitation to loved ones in nursing homes, including: 1. *Maintained relationships* and 2. *Fractured relationships.* The transportation of family members to residents in nursing homes allows for visitation, thus leading to socioemotional engagement, the provision of social support, and a reduction in feelings of isolation for residents (Gaugler, 2005). Family members shared that they loved their parent or spouse, and their visitation was priority. Conversely, family members who had greater transportation access challenges, higher travel times, thus reduced opportunities to visit, they stated their desire to visit more frequently. The inability to visit as often when compared to those with no transportation barriers was found to take a toll on relationships and strain the family dynamic.

Limitations

A few limitations are worth noting in this study. First, the sample size in this study is adequate yet quite small. Additional family members were identified from the larger sample of 86 to participate in this follow-up, however a significant portion opted out of volunteering when contacted for this qualitative follow-up. Second, there were a total of 11 nursing homes in the original study, but family member participants in this qualitative study are from only two of the three communities included in the sampling strategy. This, again, was due to non-answering or refusal to participate in the qualitative follow-up survey despite expressing interest upon participation of the first phase in this larger study.

Implications for Research and Practice

Findings from this study highlight family members' challenges and opportunities to visit their loved ones in nursing homes. The visitation patterns to residents in nursing homes were disproportionately different between participants who had transportation access and the financial means to travel the distance plus arrange lodging, as required. This research has significant implications for future studies. The role of transportation is critical to connect community members for both social opportunities and relationship maintenance, as highlighted in this study. It is also imperative for job development and engagement in daily activities.

Future research ought to extend beyond family members to examine the perceptions of transportation access and opportunities from a variety of stakeholders in nursing homes. Extending beyond resident-family members to include residents' transportation services to social activities, and staff-members' transportation access to their facility may help to better understand the impact transportation has on this particularly isolated population of residents in nursing homes. Additionally, a social network analysis examining the relationship of transportation to

network of residents across various nursing home settings may help to detect transportation as a structural component of a resident's larger social system.

This study also has implications for practitioners, including social workers, transportation planners, and allied health care professionals. Transportation planners ought to continue to explore innovative transportation assessments that include particularly at-risk, marginalized, and isolated populations, such as residents in nursing homes and older adults. As the population within the United States, and worldwide, continues to age at a rapid pace, researchers across disciplines (e.g., transportation planning, civil engineers, social workers) will need to continue to explore new ways to improve the overall quality-of-life for community-members.

Conclusion

The findings from the current study identified that transportation of family members impedes and facilitates visitation to residents in nursing homes. This visitation has an impact on family relationships, quality of relationships, finances, and perhaps even feelings of disappointment, as family members noted their wishes in visiting, but were not able to given current circumstances. These results contribute to the existing body of literature that noted both travel time and transportation access as barriers to visitation, highlighted in the article titled: "Investigating Barriers to Family Visitation of Residents in Nursing Homes: A Systematic Review" (Miller, 2018). Furthermore, these results extend what we already know by identifying the impact these visits have on family members and their relationship to residents. Future research to explore assessments to understand the needs of community members, especially those aging, as these are necessary to allow a better understanding of this complex concept of transportation.

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Chapter 5: Conclusion

Summary of Findings

Overall, this study aimed to explore the concept of transportation of family members in the community visiting their loved ones in long-term care nursing homes. This was achieved through the three articles presented in this research project. In the introduction, a review of the literature describes the growth in the population of older adults and the variety of living arrangements of seniors with a targeted focus on nursing home care. Next, the literature review expands on consequences of nursing home care, which includes social isolation, loneliness, and an increased risk of depressive symptoms. Family members visiting their loved ones in long term care is vital to counteract these consequences, which is described next in the introduction. Additionally, the Social Determinants of Mental Health framework is expanded on in this section. These theoretical underpinnings guided the sequential mixed-methodological study that is the basis of articles two and three.

The first of three articles was a systematic review of the literature that investigates the various barriers that family members experience in visiting their loved ones in nursing homes. The primary objective of this article was to: (1) identify and summarize the barriers most reported to family visitation, and (2) synthesize the findings to determine which barriers are most often reported in literature, and which may pose the greatest challenges to family involvement. Using the Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009) methodology to guide this study, a final sample of 15 articles (N=15) uncovered seven barriers to family visitation of residents in nursing homes (Miller, 2018). These barriers include: psychological, health, staff to family member relationship, employment/finances, travel time, access to transportation, and other.

Findings from this systematic review of the literature endorse that, of the barriers discovered, transportation access and travel time are significant to family visitation and are under-studied in research. Additionally, these findings do not address the impact such barriers have on residents who live in nursing homes. Residents in nursing homes are at an increased risk for depression symptoms and depression, due in part to other aspects of aging. Given these circumstances, a deeper examination of the various factors contributing to these symptoms is warranted. Family visitation has been found to counteract these mental health concerns, and as transportation is key for family members to visit, the connection between transportation access and depressive symptoms of residents in nursing homes is important.

Article two of this study presented phase one of a sequential mixed-methodological study. This phase consisted of a mediation analysis of the effect of family member transportation on depression symptoms of residents in nursing homes. This article sought to explore the following hypotheses: (1) Transportation of family has an effect on depression symptoms of residents in nursing homes, mediated by visitation; and (2) Transportation of family has an effect on depression symptoms of residents in nursing homes, mediated by social support.

These research questions were explored through surveys with resident-family member dyads. First, 11 nursing homes in North Central Texas endorsed their support of my partnering with their facility to interview residents and resident family members. Next, staff members from each facility selected residents who met inclusion criteria for this study (inclusion criteria are listed in Chapter 2). Nursing home residents then identified a family member that visited from time to time as a potential participant to complete the dyadic component of this study. Upon obtaining family member contact information, each family member had the opportunity to volunteer or refuse to participate, as they chose.

Resident participants who volunteered in this study were interviewed using a number of instruments. First, each resident was screened for cognition using the Mini-Mental State Examination (MMSE; Folstein & Folstein, 1975). After screening was complete, so long as participant passed the cognitive test (scores ranging 24-30), they were then interviewed on concepts of social support (Duke Social Support Index; Duke Instruments, 2018), participation in nursing home activities, family visitation, and symptoms of depression (Patient Health Questionnaire; Kroenke & Spitzer, 2002). Family member participants were interviewed using the Transportation Disadvantage Assessment Tool (TDAT; Delbosc & Currie, 2011), other aspects of transportation related to travel time and cost of fuel, as well as visitation patterns to and from the facility. Data were collected from a final sample of 86 dyads (*N*=86*)* were collected, then analyzed to answer the research questions listed above.

In this study, it was hypothesized that transportation would have an effect on symptoms of depression, mediated by social support and visitation. Results of the final mediation model using transportation-ranking and the indicator "visitation" were not statistically significant, which may have been due to a measurement error in how the concept of visitation was operationalized. It is important to note that the concept of "visitation" in earlier studies examining patterns of family visitation have not reported details in how this was conducted. Moreover, this study was exploratory in nature and the first of its kind to explore any associations between these variables. However, results of this study highlight the mediating role of social support in the association of transportation-ranking and depressive symptoms. These findings are useful to help understand transportation perceptions that lead to social support of residents in nursing homes, and how this has an effect on depressive symptoms. This research is important to understand the various contextual factors (e.g., transportation) that are associated

with residents' depression symptomology, as depression of residents in nursing homes is a growing epidemic (Centers for Disease Control and Prevention, 2014).

The third article in this set is a qualitative analysis of family members' experiences with transportation access and opportunities to visit residents in nursing homes. This article reports findings from phase two of the sequential mixed-methods study and uncovers a number of positive and negative aspects of transportation access and opportunities. The primary research question in this article is: What are family members' experiences with transportation, in the context of traveling to and from their loved ones' nursing home? This study included a total sample of 11 family member participants (*N*=11), with the main focus to examine the influence of transportation on visiting residents in the nursing home. Participants were sampled from the first phase in this larger study that included 86 nursing home resident-family (*N*=86) member dyads across 11 nursing homes in North Central Texas (see Chapter 3).

A total of seven primary themes emerged from this data. An additional two ancillary themes came out of these findings, too. The primary themes in this study are: 1. *Car access,* 2. *Alternative modes,* 3. *Flexibility,* 4. *Travel time,* 5. *Actual cost,* 6. *Collateral cost,* and 7. *Health and Mobility.* The two ancillary themes that came out of the initial seven influencing themes are: 1. *Maintained relationships* and 2. *Fractured relationships*. Overall, family members reported car ownership as a significant influence of visitation to residents in nursing homes. Car ownership, coupled with travel time, was found to be a strong influencer of consistent visitation, so far as some family visiting every day. The *Actual cost* and *collateral cost* associated with visiting residents in nursing homes were found to influence visitation ability and patterns. Moreover, this visitation, by in large, had an impact on the relationships between family and residents. Family members who were able to visit, provide social support, and get to the facility

reported improved relationships for the family and family articulated that these visits were positive for the resident, too. These transportation opportunities allowed family members to maintain relationships with their aging family members who were in an especially isolated environment. Conversely, family members who had extenuating influences that prohibited visits reported *Fractured Relationships* with residents. One family even stated that they were not able to visit their resident when they really needed him, which was a negative consequence.

A negative finding related to transportation access and mobility included physical health concerns. It is important to note that nearly half (45.4%) of the participants in this study were age 50 years old and above. These high levels of physical challenges and issues in mobility are not new findings, however these challenges had not yet been connected to transportation access rather simply as a barrier to visit in the context of traveling to residents in nursing homes. These findings make for an interesting discussion regarding age-friendly communities and equity in transportation solutions. A recent study (Adorno, Fields, Parekh, Cronley, & Magruder, 2015) conducted in Arlington, TX, a high-density suburban environment, found that certain populations of older adults were at a significant disadvantage of transportation due to abilities. This current study certainly adds to the existing body of literature and extends beyond this with implications for policy, practice, and research.

Limitations

There are limitations that should be noted across each of the three articles presented here. Limitations within the systematic review of the literature (see Chapter 1) include the focus just within the United States. While this was done deliberately due to standardizations in care and policies (e.g., Nursing Home Reform Act, Centers for Medicare and Medicaid Services), similar studies conducted within other nations may have confirmed findings. These findings may have

contributed to the two barriers, transportation access and travel time, that informed Chapters 3 and 4 of this larger study, as transportation systems vary greatly across the globe. Furthermore, this study did not take into account the profit status of each facility or whether they accepted Medicare/Medicaid reimbursement funding. A deeper exploration into organizational characteristics of each facility may lead to new findings.

There are also a number of limitations to note in Chapters 3 and 4 (Articles 2 and 3). Chapters 2 and 3 consist of Phase One and Phase Two of an exploratory, sequential mixed-methodological study (Creswell & Plano Clark, 2018). As such, the limitations from these two phases are going to be presented together here. First, each nursing home identified potential participants for this study, which may have led to sampling bias. Facility staff may have selected participants with the fewest concerns including least symptoms of depression, or any other mental health issues, as well as those who had family visiting on a consistent and frequent basis. Next, nursing home resident participants were not screened for length of stay within the nursing home. This has been found to influence visitation patterns of families; One study conducted by Yamamoto-Mitani, Aneshensel, & Levy-Storms (2002) revealed that as resident length-of-stay increases, frequency of family visitation decreases. Including a construct that assessed for length of stay per each resident would have strengthened this study.

Third, participants abilities or limitations to participate in nursing home activities were not assessed. Residents' were screened on their knowledge of activities taking place within the facility, but this study did not inquire directly about their ability to do so. A significant number of residents who volunteered in this study had partial- or full-body paralysis due to a stoke or other health condition. This may have impacted their ability to participate in facility activities, which also may have influenced perceived levels of social support.

Finally, perceived levels of social support among persons in the facility were not controlled for based on resident- or staff- relationship. Residents identified whether they felt social support, but this did not demarcate staff-support/staff-relationships from family members. Many residents had a roommate who may have been the primary contributor for their perceived social support. Alternatively, residents may have had strong relationships to staff members that tended to their personal needs on an on-going, daily basis, which was not noted within the constraints of this study.

<div align="center">

Policy, Practice, & Research Implications

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Implications for Policy

Social Work Policy Implications. Findings from this study have significant implications for policy, including social work/health care policy and transportation-related policy. Current statistics report that there are over 15,500 nursing homes that are certifiable by Medicare- and Medicaid (CMS, 2015). It is the job of each nursing home to ensure that each resident age well, regardless of health status, cognitive status, and payor source. Noted throughout this study, residents are a vulnerable, at-risk, isolated population. These individuals need considered attention and to be placed at the center of their care, as identified as the culture change movement of "Person-Centered Care" in the Nursing Home Reform Act policy. The next section describes this act and the updated policies.

The Nursing Home Reform Act was enacted in 1987 however despite the changing landscape and increased utilization of nursing homes, has remained relatively unchanged until 2016 (Castle & Furgeson, 2010). The inactivity in these rules and regulations were confirmed by the Centers for Medicare and Medicaid, whereby the NHRA, "have not been comprehensively

reviewed and updated since 1991, despite substantial changes in service delivery in this setting"
(Medicare and Medicaid Programs, 2016).

There has since been a final action rule to change how nursing homes operate,
implemented across three phases to address shifts towards quality of care, life, and services in
long-term care, include additional sections to amend this federal action rule, including a segment
on Comprehensive Person-Centered Care Planning (§ 483.21), a Compliance and Ethics Program
(§ 483.85), and staff Training Requirements (§ 483.95) (Medicare and Medicaid Programs,
2016). Moreover, the provision has expanded to define "abuse," "exploitation," "mistreatment,"
"neglect," "person-centered care," "resident representative," and "sexual abuse" (Centers for
Medicare and Medicaid Services, 2016).

Although it is too soon to see the impact these policy changes have had on residents
within long-term care these changes, especially the "Comprehensive Person-centered Care
Planning (§ 483.21)," which requires facilities to develop care plans with an interdisciplinary
team and focuses on the person at the center and meets standards of quality care (Centers for
Medicare and Medicaid Services, 2016), this policy has implications for resident well-being,
including mental health and wellness. Only by these person-centered care plans can nursing
homes look to improving the service delivery system and extend improvements beyond factors
within the nursing home as a means-to-an-end to improve resident quality of life (Miller &
Hamler, 2019), for example exploring this concept of transportation access and opportunities of
family members.

Furthermore, as the landscape of the nursing home population changes, the importance of
family visitation may become increasingly important. Among minority groups, African-
American older adults are the largest group to utilize nursing home care (Miller & Hamler,

2019). Roughly fourteen percent of the total nursing home population identify as African-American and roughly five percent of the nursing home population identify as Hispanic/Latino (CMS, 2015). Being of minority race/ethnicity, the risk factors associated with poorer quality of care and lower quality of life increase in facilities, as "minorities experience a disproportionate burden of preventable disease, death, and disability compared with non-minorities" (CDC, 2017; Miller & Hamler, 2018). Thus, the visitation of family members to minority status residents may be especially important. Most often older adults of minority status age at-home in place and are cared for by loved ones, as the filial responsibility of African-American, Hispanic/Latino, and Asian cultures are much greater than compared to Caucasian families (Apesoa-Varano, Gomez, & Hinton, 2015; Miller & Hamler, 2019; Potter, Roberto, Brossoie, & Blieszner, 2017; World Health Organization, 2017). Lastly, persons of minority status are at greater risk for transportation barriers and challenges, and overall transit disadvantage (Zhao & Gustafson, 2013), which includes transportation and transit access to visit loved ones in nursing homes.

Transportation Policy Implications. This study also has policy implications related to transportation planning and transportation aspects of the built environment. The American Recovery and Reinvestment Act (ARRA), in 2009, funded billions of dollars towards transportation programming and planning (Federal Transit Administration, 2019). Enacted by President Obama, this piece of legislation aimed with special consideration on assisting both urban and non-urban communities to establish infrastructure in support of transportation alternatives for persons without vehicles, "persons with disabilities, people with low income, and senior citizens to have basic mobility to access medical, employment and leisure locations" (U.S. Department of Transportation, 2015). Focus of many programs and initiatives within this larger act aimed to alleviate the challenges and barriers to transportation inequity.

The political landscape has changed significantly within the past 10 years since enactment of this legislation and given the current state of the political climate, the need for transportation alternatives for older adults, persons of low socioeconomic status, and persons with disabilities has increased significantly (National Center on Senior Transportation, 2010). The scope of the study presented here was conducted on a very small scale that took place in three communities across North Central Texas, and although these findings are not generalizable across America, they may highlight a greater need for transportation alternatives at the local and regional levels here than compared to other cities across America. The growth of this sprawling metroplex is projected to, "add 1.5 million households, 4.0 million people in those households, and 2.3 million non-construction jobs" (Vision North Texas, n.d., p. 75) by the year 2030. Moreover, these projected population increases are becoming increasingly diverse and includes our aging Americans (Vision North Texas, n.d.). Thus, coming up with alternative transportation solutions, such as subsidized ride-sharing options must be at the forefront of research efforts. Transportation alternatives that include ride-sharing (e.g., Lyft, Uber), as well as the utilization of Autonomous Vehicles (AVs), may be an innovative solution to address transportation challenges and barriers for persons with transportation limitations, such as access or ability.

Implications for Research

Findings from this study present strong implications for future research. First, it should be noted that this study was exploratory in nature with the aim of looking at the concept of transportation of family visiting their loved one in a nursing home. Findings from the systematic review of the literature (Miller, 2018) showed that transportation access, or conversely transportation disadvantage, as well as travel time were two contributing barriers to family members visiting the nursing home. This review informed the operationalizing variable,

transportation disadvantage, which used the Transportation Disadvantage Assessment Tool (TDAT; Delbosc & Currie, 2011). The initial model analysis (see Chapter 2) using a portion of the TDAT tool, travel time, travel cost, and transportation-ranking, were not statistically significant to visitation, however findings from the qualitative follow-up confirm that transportation access is complex, costly, and coupled with visitation warrants further research.

Throughout the data collection process additional variables and concepts were captured, which may lead to new and alternative findings related to transportation, including distance in miles from work to the facility and home to the facility, as well as social supports perhaps aside from family members. Other variables that were assessed for in this study include the star rating of each nursing home, zip codes of family members' home and workplace, as well as cost per each trip to their resident's facility from work/home during peak and off-peak hours. Finally, other aspects of social support were captured from each resident to include resident participation in facility provided activities and events.

To extend findings from this study, future work ought to focus on residents in nursing homes that are not Alert and Oriented to person, place, and time (A&Ox3), as the majority population in long-term care has a diagnosis of mild cognitive impairment (MCI) or dementia (Gaugler, Yu, Davila, & Shippee, 2014). Key stakeholders beyond residents of facilities warrant attention in studies related to transportation access and opportunities. As discussed in the background and discussion of each article presented here, transportation systems shape how community-members and individuals operate on a daily basis. Challenges and barriers to transportation creates inequities in employment (U.S. Department of Transportation, 2013), which may impact the retention rate of nursing home staff. The staff turnover rates in nursing homes, particularly of frontline staff workers, are very high which has an impact on health care

costs, quality of care delivery to each resident, and overall workplace relationships, thus, future studies may explore the role of transportation access and opportunities on this population, which is integral for resident well-being.

Furthermore, these findings lend to further examination of these transportation challenges in access and opportunities through the theoretical lens of intersectionality. The intersectionality framework, conceptualized in the late 1980's, enhances the explanation and experience of heterogenous populations who experience persistent and chronic issues of social justice and inequality (Crenshaw, 1994). This theory continues to be critical in exploring the lived experiences of historically marginalized populations where social positions and membership into social categories, such as race, gender, social systems, and processes (i.e., gendering), have "multiple shared characteristics (e.g., age, gender, and nationality) elicits within-group boundaries (Lau & Murnighan, 1998)" (p. 1) that emphasizes between group and within group challenges (Atewologun, 2018). Findings from this study were congruent with earlier literature that states most often the caregiving responsibility falls onto the daughter of the older adult (AARP, 2015), which may be especially true for racial and ethnic minority nursing home resident children.

Implications for Practice

This study also has significant implications for social work practice. Social support, social connectivity, and relationships between nursing home residents and their family members is an area of research rooted in the practice and field of social work. Two of the foremost ethics and values guiding this profession are: the importance of human relationships, and dignity and worth of the person (National Association of Social Workers [NASW], 2019). According to the National Association of Social Workers:

…relationships between and among people are an important vehicle for change. Social

workers engage people as partners in the helping process. Social workers seek to

strengthen relationships among people in a purposeful effort to promote, restore,

maintain, and enhance the well-being of individuals, families, social groups,

organizations, and communities (NASW, 2019).

The relationship between family members visiting their loves in nursing homes is a social

work issue. For instance, social workers at Meals on Wheels are tasked with integrating care

coordination to sure their clients and individuals have access to transportation options to health

care appointments, medication retrieval, and traveling to group settings, such as a senior center,

to encourage adequate social interactions and connectivity. These transportation options can

expand to include more choices for clients, such as the visitation of a loved one in long-term

nursing home care, if the family member is unable to transport themselves.

Additionally, the social worker in the nursing home is tasked with ensuring each resident

attains their highest level of psychosocial well-being possible. Nursing home social workers aim

to identify the psychosocial, emotional, and mental needs of each resident. The social worker can

identify and assess these needs during each resident's individualized care plan. Upon

identification and assessment of resident needs, the nursing home social worker can use their

unique skillset to address if family visitation would improve resident well-being overall. When

transportation access is in fact a presented barrier to visiting the nursing home, the social worker

can leverage their community connectedness to find vouchers or assistance to increase family

members' ability to visit the nursing home.

Beyond social workers practicing within nursing home settings, social workers in

community and administrative practice (CAP) positions may be especially crucial for integrating

change within the communities they serve. Social workers at various agencies working across the

lifespan such as Area Agencies on Aging, Housing Shelters, Meals on Wheels, Senior Centers,

and the like, can work towards identifying and screening clients to ask if they have a family

member who resides in long-term nursing home care. As noted earlier, transportation

disadvantage is closely linked to persons of low socioeconomic status, on top of other social

pressures, where the persons utilizing these services may be at a higher need for assistance with

transportation.

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Appendices

Appendix A

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Appendix B

Recruitment Script for Study – Nursing Home Sites

Hi, my name is Vivian J. Miller.

I am a doctoral student in the School of Social Work at the University of Texas at Arlington and I am conducting a new research study that I wanted to speak with you about today. Could we talk for a few minutes? *If yes, the following will be presented:*

As a part of my dissertation study in the School of Social Work at the University of Texas at Arlington, I am interested in interviewing 20 residents in your facility, and their family members, a set of interview questions related to transportation, travel patterns and behaviors, social support, and depression outcomes. I am partnering with 6 facilities across the DFW area. This study does not take any time of your staff members, rather the interviews will be conducted by myself or a member of the research team. I am a Licensed Master Social Worker in the state of Texas and have practice experience as a nursing home social worker.

Would you be interested in partnering with us on this study? If yes, please tell me the best way to follow-up with you and your facility.

If not, thank you for your time.

Appendix C

Nursing Home Letters of Support

College Park
Rehabilitation and Care Center

April 12, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm College Park Rehabilitation & Care Center support of Vivian J. Miller, LMSW (PI) and the research project entitled: "Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

College Park Rehabilitation & Care Center staff will ask residents who fit the study inclusion criteria if they would be interested in participating in speaking with Vivian J. Miller, LMSW (or one of the social work research team members) about the study. If residents grant the staff permission, then Vivian J. Miller, LMSW will be given a list whist in College Park Rehabilitation & Care Center of the names of potential volunteers. This list of potential names will remain within the facility. None of the staff at College Park Rehabilitation & Care Center will be assisting with participant recruitment, but rather we will refer potential study participants that might be interested in the project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet with the participants individually to discuss the research study as well as to obtain written consent for participation.

The study procedures, including interviews with residents of College Park Rehabilitation & Care Center and their family members/caregivers, will take place with College Park Rehabilitation & Care Center in their facility by Vivian J. Miller, LMSW (or one of the social work research team members). The staff at College Park Rehabilitation & Care Center will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

Keith Fuchs

HERITAGE OAKS
Residence & Rehabilitation Center

April 18, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm Heritage Oaks Nursing & Rehabilitation Center of Arlington's support of Vivian J. Miller, LMSW (PI) and the research project entitled: "Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

Heritage Oaks Nursing & Rehabilitation Center staff will ask residents and their responsible parties who fit the study inclusion criteria if they would be interested in participating in speaking with Vivian J. Miller, LMSW (or one of the social work research team members) about the study. If residents / responsible parties grant the staff permission, then Vivian J. Miller, LMSW will be given names of potential resident /family members who are interested in this research project. This list of potential names will remain within the facility. None of the staff at Heritage Oaks Nursing & Rehabilitation Center will be assisting with participant recruitment, but rather we will refer potential study participants that might be interested in the project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet with the participants individually to discuss the research study as well as to obtain written consent for participation. Before contact with residents or family members Vivian J Miller LMSW and her research team members will allow Heritage Oaks Nursing and Rehabilitation Center to do a background check. They also agree to give a copy of her paper to the administrator at Heritage Oaks Nursing and Rehabilitation uponcompletion of her study.

The study procedures, including interviews with residents of Heritage Oaks Nursing & Rehabilitation Center and their family members/caregivers, will take place with Heritage Oaks Nursing & Rehabilitation Center in their facility by Vivian J. Miller, LMSW (or one of the social work research team members). The staff at Heritage Oaks Nursing & Rehabilitation Center will not be involved in data collection or data analysis.

If you have any questions, please let me know,

Sincerely,

Erich Wahl LNFA

DFW Nursing & Rehab

"Where Caring Hearts Meet Caring Hands"

900 W. Leuda St, Fort Worth, TX 76104
817 332-7003

April 19, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
Arlginton, Tx. 76010

To Whom It May Concern:

I am writing to confirm DFW Nursing & Rehabilitation's support of Vivian J. Miller, LMSW (PI) and the research project entitled: "Transportaion, Social Support by Family Visitation, and Drpression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

Dfw Nursing & Rehabilitation's staff will ask residents who fit the study inclusion criteria if they will be interested in participating in speaking with Vivian J. Miller, LMSW (or one of the social work research team members) about the study. If residents grant the staff permission, then Vivian J. Miller, LMSW will be given a list whist in DFW Nursing and Rehabilitation of the names of potential volunteers. This list of potential names will remain within the facility. None of the staff at DFW Nursing and Rehabilitation will be assisting with participant recruitment, but rather we will refer potential study participants that might be interested in the project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet with the participants individuallyto discuss the research study as well as to obtain written consent for participation.

THe study procedures, including interviews with residents of DFW Nursing and Rehabilitation and their family members/caregivers, will take place with DFW Nursing and Rehabilitation in their facility by Vivian J. Miller, LMSW (or one of the social work research team members). The staff at DFW Nursing and Rehabilitation will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

1

Audrey Anderson
Administrator

Town Hall Estates ~ Arlington, Inc.

May 7, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm Town Hall Estates' support of Vivian J. Miller, LMSW (PI) and the research project entitled: "Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

Town Hall Estates' staff will ask residents and their responsible party who fit the study inclusion criteria if they would be interested in participating in speaking with Vivian J. Miller, LMSW (or one of the social work research team members) about the study. If residents and their responsible party grant the staff permission, then Vivian J. Miller, LMSW will be given a list whilst in Town Hall Estates of the names of potential volunteers. This list of potential names will remain within the facility. None of the staff at Town Hall Estates will be assisting with participant recruitment, but rather we will refer potential study participants that might be interested in the project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet with the participants individually to discuss the research study as well as to obtain written consent for participation.

The study procedures, including interviews with residents of Town Hall Estates and their family members/caregivers, will take place with Town Hall Estates in their facility by Vivian J. Miller, LMSW (or one of the social work research team members). The staff at Town Hall Estates will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

aS Weatherford
Healthcare Center

May 21, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
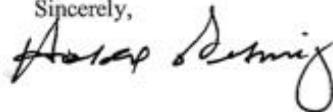Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm Weatherford Healthcare's support of Vivian J. Miller, LMSW (PI) and
the research project entitled: "Transportation, Social Support by Family Visitation, and
Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

Weatherford Healthcare's staff will ask residents and their responsible party, who fit the study
inclusion criteria, if they would be interested in participating in speaking with Vivian J. Miller,
LMSW (or one of the social work research team members) about the study. If residents and their
responsible party grant the staff permission, then Vivian J. Miller, LMSW will be given a list of
the names of potential volunteers. This list of potential names will remain within the facility.
None of the staff at Weatherford Healthcare will be assisting with participant recruitment, but
rather we will refer potential study participants that might be interested in the project. Vivian J.
Miller, LMSW (or one of the social work research team members) will meet with the participants
individually to discuss the research study as well as to obtain written consent for participation.

The study procedures, including interviews with residents of Weatherford Healthcare's and their
family members/caregivers, will take place with Weatherford Healthcare's in their facility by
Vivian J. Miller, LMSW (or one of the social work research team members). The staff at
Weatherford Healthcare's will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

Clayton Brummett, Administrator

521 West 7th Street ■ Weatherford, Texas 76086 ■ Tel: (817) 594-8713 ■ Fax: (817) 594-4654

Renaissance Park
Multi Care Center

4252 Bryant Irvin Road / Fort Worth, Texas 76109
(817) 738-2975 / FAX (817) 731-7002 / LCCA.com/renaissancepark

June 26, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm Renaissance Park Multi Care Center's support of Vivian J. Miller, LMSW (PI) and the research project entitled: "Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

Renaissance Park Multi Care Center's staff (i.e. Social Work) will ask residents and their responsible party and/or family member who fit the study inclusion criteria if they would be interested in participating in speaking with Vivian J. Miller, LMSW (or one of the social work research team members) about the study. If residents and family members grant the staff permission, then Vivian J. Miller, LMSW will be given a list whist in Renaissance Park Multi Care Center of the names of potential volunteers. This list of potential names will remain within the facility. None of the staff at Renaissance Park Multi Care Center will be assisting with participant recruitment, but rather we will refer potential study participants that might be interested in the project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet with the participants individually to discuss the research study as well as to obtain written consent for participation.

The study procedures, including interviews with residents of Renaissance Park Multi Care Center and their family members/caregivers, will take place with Renaissance Park Multi Care Center in their facility by Vivian J. Miller, LMSW (or one of the social work research team members). The staff at Renaissance Park Multi Care Center will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

ARLINGTON

Residence and Rehabilitation Center

405 Duncan Perry Road Arlington, Texas 76011
Phone: 817.649.3366 Fax 817.633.3513
www.arlingtoncarecenter.com

July 17, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm Arlington Residence and Rehabilitation Center's support of Vivian J. Miller, LMSW (PI) and the research project entitled: "Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

Arlington Residence and Rehabilitation Center's staff will ask residents and their responsible party who fit the study inclusion criteria if they would be interested in participating in speaking with Vivian J. Miller, LMSW (or one of the social work research team members) about the study. If residents and their responsible party grant the staff permission, then Vivian J. Miller, LMSW will be given a list of potential volunteer names within Arlington Residence and Rehabilitation Center. This list of potential names will remain within the facility. None of the staff at Arlington Residence and Rehabilitation Center will be assisting with participant recruitment, but rather we will refer potential study participants that might be interested in the project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet with the participants individually to discuss the research study as well as to obtain written consent for participation.

The study procedures, including interviews with residents of Arlington Residence and Rehabilitation Center and their family members/caregivers, will take place within Arlington Residence and Rehabilitation Center's facility by Vivian J. Miller, LMSW (or one of the social work research team members). The staff at Arlington Residence and Rehabilitation Center will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

Lisa Dean, LBSW, LNFA
Administrator Arlington Residence and Rehabilitation Center

River Oaks

Health and
Rehabilitation

August 13, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm River Oak Health and Rehab's support of Vivian J. Miller, LMSW (PI)
and the research project entitled: "Transportation, Social Support by Family Visitation, and
Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

River Oak Health and Rehab's staff will identify residents and their responsible party/family
member who fit the study inclusion criteria that may be interested in participating in speaking
with Vivian J. Miller, LMSW (or one of the social work research team members) about the
study. Vivian J. Miller, LMSW will be given a list of resident names whist in River Oak Health
and Rehab of the names of potential volunteers. This list of potential names will remain within
the facility. None of the staff at River Oak Health and Rehab will be assisting with participant
recruitment, but rather we will refer potential study participants that might be interested in the
project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet
with the participants individually to discuss the research study as well as to obtain written
consent for participation.

The study procedures, including interviews with residents of River Oak Health and Rehab and
their family members/caregivers, will take place in their facility or via phone/email by Vivian J.
Miller, LMSW (or one of the social work research team members). The staff at River Oak Health
and Rehab will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

LNFA

2416 NW 18th Street • Fort Worth, TX 76106
Phone (817) 626-5454 • Fax (817) 740-1100

Westside Campus of Care
1950 S Las Vegas Trail White Settlement, TX 76108
Tel (817) 246-4995

Westside Campus of Care

August 17, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm West Side Campus of Care's support of Vivian J. Miller, LMSW (PI) and the research project entitled: "Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

West Side Campus of Care's staff identify residents and their responsible party/family member who fit the study inclusion criteria that may be interested in participating in speaking with Vivian J. Miller, LMSW (or one of the social work research team members) about the study. Vivian J. Miller, LMSW will be given a list of resident names whist in West Side Campus of Care of the names of potential volunteers. This list of potential names will remain within the facility. None of the staff at West Side Campus of Care will be assisting with participant recruitment, but rather we will refer potential study participants that might be interested in the project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet with the participants individually to discuss the research study as well as to obtain written consent for participation.

The study procedures, including interviews with residents of West Side Campus of Care and their family members/caregivers, will take place in their facility or via phone/email by Vivian J. Miller, LMSW (or one of the social work research team members). The staff at West Side Campus of Care will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

Lesley Scott-McGinnis, LBSW
Social Services

Trinity
HEALTHCARE RESIDENCE ®

September 24, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
Box 19188
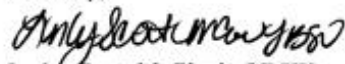Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm Trinity Healthcare Residence's support of Vivian J. Miller, LMSW (PI) and the research project entitled: "Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

Trinity Healthcare Residence's staff will identify residents and their responsible party/family member who fit the study inclusion criteria that may be interested in participating in speaking with Vivian J. Miller, LMSW (or one of the social work research team members) about the study. Vivian J. Miller, LMSW will be given a list of resident names whist in Trinity Healthcare Residence of the names of potential volunteers. This list of potential names will remain within the facility. None of the staff at Trinity Healthcare Residence will be assisting with participant recruitment, but rather we will refer potential study participants that might be interested in the project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet with the participants individually to discuss the research study as well as to obtain written consent for participation.

The study procedures, including interviews with residents of Trinity Healthcare Residence and their family members/caregivers, will take place in their facility or via phone/email by Vivian J. Miller, LMSW (or one of the social work research team members). The staff at Trinity Healthcare Residence will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

817-246-4953
Administrator

SENIOR CARE
HOLLAND LAKE

November 30, 2018

The University of Texas at Arlington
Office of Regulatory Services
202 East Border Street, Suite 201
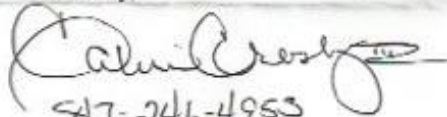Box 19188
Arlington, TX 76010

To Whom It May Concern:

I am writing to confirm Senior Care at Holland Lake's support of Vivian J. Miller, LMSW (PI) and the research project entitled: "Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study."

Senior Care at Holland Lake's staff will identify residents and their responsible party/family member who fit the study inclusion criteria that may be interested in participating in speaking with Vivian J. Miller, LMSW (or one of the social work research team members) about the study. Vivian J. Miller, LMSW will be given a list of resident names whist in Senior Care at Holland Lake of the names of potential volunteers. This list of potential names will remain within the facility. None of the staff at Senior Care at Holland Lake will be assisting with participant recruitment, but rather we will refer potential study participants that might be interested in the project. Vivian J. Miller, LMSW (or one of the social work research team members) will meet with the participants individually to discuss the research study as well as to obtain written consent for participation.

The study procedures, including interviews with residents of Senior Care at Holland Lake and their family members/caregivers, will take place in their facility or via phone/email by Vivian J. Miller, LMSW (or one of the social work research team members). The staff at Senior Care at Holland Lake will not be involved in data collection or data analysis.

If you have any questions, please let me know.

Sincerely,

Donna Tillman
Administrator
Senior Care at Holland Lake
1201 Holland Lake Drive
Weatherford, TX 76086
817-598-0160

Appendix D

UTA Institutional Review Board Form 1

THE UNIVERSITY OF TEXAS AT ARLINGTON
INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN SUBJECTS

IRB FORM #1: PROPOSAL FOR NON-EXEMPT RESEARCH INVOLVING HUMAN SUBJECTS

Faculty, staff, students, or employees who propose to engage in any research, research development, testing or evaluation with human subjects must have review and approval of that activity by the Institutional Review Board (IRB) prior to initiation of that project. The IRB is responsible for safeguarding the rights and welfare of subjects who participate in research activities. If you require further assistance in completing this form or need additional information, please contact Regulatory Services at 817-272-3723.

For activities involving humans that may not be research such as class projects, program evaluation, oral histories, or quality improvement, click here to review the ultimate project chart.

Please refer to the IRB Submission Checklist, in particular, for requirements for Human Subjects Protection (HSP) Training and Conflict of Interest (COI) Disclosures. **Incomplete status on HSP Training and COI Disclosures may delay the review process, and must be completed prior to protocol approval.** HSP Training is required every 3 years, and COI Disclosures must be recertified for each new non-exempt IRB submission.

SECTION A: GENERAL INFORMATION

1. **Non-UTA Protocol Personnel:** *Enter all individuals that are NOT affiliated with UT Arlington who will interact or intervene with the human subjects for the research study OR who will access identifiable subject data. UTA affiliated personnel should be listed on #3 of the protocol page in the electronic submission system (Profiles).*

   In the electronic submission system, upload a completed Non-UTA Collaborator Form and Human Subject Protection training for each listed Non-UTA individual.

Name:	Organization:	Role (Co-PI, Collaborator, etc.):	Covered Individual?*
N/A			Yes or No
N/A			Yes or No
N/A			Yes or No

*Covered individuals are responsible for the conduct, design, or reporting of this research study per COI Policy.

2. **Expected Start Date:** April 30, 2018 *(You are not authorized to start any research on human subjects including subject recruitment until the IRB has approved the research protocol.)*

3. **Expected Completion Date:** May 1, 2019

SECTION B: FUNDING

4. **Is the study funded?** ☒ Yes ☐ No ☐ Pending   **If yes, indicate the funding source(s):**

   External: ☐ **FEDERAL (Specify Sponsor:)**   ☐ **State (Specify Sponsor:)**

   ☐ **INDUSTRY SPONSORED (Specify Sponsor:)**

   Grants & Contracts Bluesheet Number from Mentis:

   Internal: ☐ **UTA Departmental Account** ☐ **Researcher's Personal Funds** ☒ **Other:**

National Institute for Transportation for Livable Communities (NITC) is funding most of this project, at $15,000 to cover expenses for the recipient while working on this dissertation. Hogg Foundation for Mental Health is also funding $1,500 of this project to be used for participant incentives, gas reimbursement to and from nursing home sites, and statistical software program for data analysis. Neither of these funding sources have a blue sheet from the Office of Grant and Contract Services and were disbursed directly to the Principal Investigator, Vivian J. Miller.

SECTION C: SUMMARY OF THE RESEARCH PROTOCOL

5. **List the primary research questions, hypotheses, and / or objectives guiding this study.**

The primary objective guiding this study is to examine the link between transportation, the social support by family members/caregivers, and depression among residents of nursing homes, using a set of interview questions for data collection to better understand the impact of transportation on visitation patterns, perceived level of support by residents, and perceived feelings of depression by residents. To this end, this study seeks to answer the following three (3) research questions:

1. How does transportation of family members directly affect mental health outcomes (e.g., depression) of residents in nursing homes?
2. How does transportation of family members indirectly affect depression outcomes of residents in nursing homes through the mediation role of family social support by visitation?
3. What is the direct effect of family social support by visitation to depression outcomes of residents in nursing homes, both challenges and opportunities to transportation, as well as positive and negative experiences of transportation?

6. **Describe the general overall research design for the project, including a brief review of the existing literature or pilot data that supports the research questions and proposed procedures.**

This project will utilize a mixed-methodological design to examine the relationship between transportation and depression outcomes of residents in nursing homes, as well as family social support by visitation and transportation patterns. Creswell and Plano Clark (2018) write that mixed-methods research is uniquely posited to address problems in social and health sciences and that the use of quantitative or qualitative approaches alone is inadequate to address the complexities of each field. This explanatory sequential mixed-methodology design has many advantages and is the most straightforward of the mixed methods design (Creswell & Plano Clark, 2018).

Study data will be collected in two ways via two phases. First, face to face interviews will be conducted with residents of nursing homes on demographic characteristics, cognition, social support of residents by visitation, and depression among residents of nursing homes. Face to face or phone interviews will be conducted with the resident responsible party/family members on quantitative data, which includes demographics, transportation-related behaviors, and perceived familial transportation burden of nursing home residents' family members. Finally, social support programming offered by the nursing facility will be gathered based on questions to the resident and their facility activities calendar to inform phase two.

Second, based on scoring from phase one of this study, family members will be selected for a follow-up, in-depth face-to-face qualitative interview. The goals of these qualitative interviews are to identify both positive or negative aspects of transportation that present the greatest challenges and opportunities to visitation.

Data will be collected at 6 nursing home sites in three cities: Arlington, Fort Worth, and Weatherford, Texas. A purposive sample of 120 resident-caregiver dyads (total sample of 240 participants) who reside in Medicare and Medicaid certifiable nursing homes across these three communities will be selected to participate. The nursing home staff will have no part in participant recruitment or any research processes. All recruitment activities will be conducted by the researcher at UTA.

In phase one of this study, resident participants will be asked a set of interview questions including demographic information, cognition, social support, depression, and visitation patterns of family members. Family member participants will be asked a set of interview questions including demographic information, transportation disadvantage, weekday mobility and access, and weekend mobility and access.

Quantitative data will be analyzed using SPSS v. 25.0.

In phase two of this study, the follow-up portion of this study, family member participants will be asked a series of qualitative, open-ended questions to identify both positive or negative aspects of transportation that present the greatest challenges and opportunities to visitation.

Qualitative data will be analyzed using Atlas.ti qualitative software.

7. **Describe the role, experience and qualifications of all protocol personnel (including UTA and Non-UTA personnel) in regards to the proposed research procedures and specific study population.**

Name:	Role (Co-PI, Faculty Advisor, etc):	Qualifications, Experience, & Training:	Covered Individual?*
Vivian J Miller	PI	Vivian Miller is a LMSW and Doctoral candidate in the school of Social Work. Vivian has practice experience working with older adults in a variety of settings, including nursing homes.	Yes or No
Noelle Fields	Faculty Advisor	Dr. Noelle Fields is an Assistant professor and LCSW in the School of Social Work. Dr. Fields primary research interests are in gerontology, with a particular focus on family caregiving and dementia, home and community-based services for older adults, and technology and aging.	Yes or No
Amber O'Dell	Graduate Student Support Staff	Masters-level Social Work student. This student has practice experience at a Geriatric Psychiatric facility and has a particular focus in the mental health- concentration in the School of Social Work at UT Arlington.	Yes or No

Covered individuals are responsible for the underlined conduct, underlined design, or underlined reporting of this research study per COI Policy.

SECTION D: PROCEDURES & METHODOLOGY

8. **CHECK ALL RESEARCH PROCEDURES INVOLVING HUMAN SUBJECTS BELOW:**

Note: If instructions request materials to be uploaded, all requested documents should be completed and submitted as attachments using the white box located underneath #5 – Form Attachments in the electronic system (Profiles). Click the file names within the white box to make the "Browse / Upload" button appear.

☐ **Analysis of Existing Data:** *State in #9 the source of the existing dataset; the variables within the dataset; the time frame for the collection of the data; and reason why it was originally collected. Upload Form 3 if obtaining Informed Consent from prior subjects is not practicable.*

☐ **Analysis of Existing Specimens (Blood, hair, tissue, saliva, etc.):** *State in #9 the source and type of the existing samples; whether samples are individually identifiable; procedures for specimen transport, storage, and destruction; the time frame for the*

collection of the samples; and reason why they were originally collected. Upload [Form 3](#) if obtaining Informed Consent from prior subjects is not practicable.

☒ **Questionnaire or Survey:** *State in #9 the topic of the questions and whether the data collected could impact the subjects' financial standing / employability / reputation if a data breach occurs; the survey medium to be used (online, paper, etc.); and whether individually identifiable information will be collected about subjects. Upload finalized survey instruments.*

☐ **Interview:** *State in #9 the duration of the interview; the topic and whether the data collected could impact the subjects' financial standing / employability / reputation if a data breach occurs; whether individually identifiable information will be collected about subjects; and whether audio / video recording will occur. Upload finalized questions / prompts.*

☐ **Focus Group:** *State in #9 the duration of the focus group; the discussion topic and whether the data collected could impact the subjects' financial standing / employability / reputation; any special privacy issues for the group setting; whether individually identifiable information will be collected about the subjects; and whether audio / video recording will occur. Upload finalized focus group questions / prompts.*

☒ **Audio/Video Recording of Subjects:** *State in #9 the type and method of recording; how recordings will be managed, stored, & destroyed; plans for transcription; and whether the data recorded could impact the subjects' financial standing / employability / reputation.*

☐ **Observations of Private Behavior:** *State in #9 the setting for the observations; the specific types of observation data that will be collected about the subjects; whether individually identifiable information will be collected about the subjects; and whether audio / video recording will occur. Upload copies of observation data collection sheets.*

☐ **Behavioral, Cognitive or Perceptual Experiment:** *State in #9 all the steps involved with the experiment, including any stimuli that will be presented to the subjects and all of the different data collection methods that will be used to collect subject data. Upload copies of the data collection instruments.*

☐ **Psychological Test(s):** *List and describe the test(s) to be administered in #9 and upload finalized copies of each test.*

☐ **International Research:** *State in #9 the international setting(s) and context; the local cultural norms for research, age of majority, and any special localized risks; any local regulations that might impact the research; the languages in which the research study will be conducted; and whether approval is required from a local IRB Committee or comparable ethics board (see the [OHRP International Compilation of Human Research Standards](#) for assistance). If local approvals are required, explain this process and the current approval status.*

☐ **Educational Test(s) or Educational Comparisons:** *State in #9 the type(s) of instructional strategies, techniques, curricula, or classroom management plans to be studied (and which are experimental); the specific classes or setting(s), with explanation of the*

different subject groups and control groups and how students are assigned; description of educational interventions and materials used; and all the types of subject data & data collection methods to be used. Upload tests and educational materials.

☐ **Induction of Mental Stress:** *State in #9 the type of stress (unwanted feelings, embarrassment, depression, anger, academic, etc,); procedures for the induction of stress; and behavioral endpoints.*

☐ **Deception or Incomplete Disclosure:** *State in #9 the procedures and justification for the incomplete disclosure / deception; any undisclosed risks that may be more than minimal; the plan for debriefing subjects when possible; & any opportunities for subjects to exclude their data once the deception is revealed. Upload Form 3 to request a waiver of some or all elements of consent.*

☐ **Collection of Blood:** *State in #9 the frequency & amount of draw(s) and methods of collection (i.e. venipuncture, venous catheter); procedures for transport, storage, and destruction of collected blood samples; and plans for potential future research use. Upload Form 5 if a Tissue Repository will be created.*

☐ **Collection of Other Biological Specimens (Hair, tissue, saliva, etc.):** *State in #9 the type of specimen(s) and methods of collection; procedures for transport, storage, and destruction of collected specimens; and plans for potential future research use. Upload Form 5 if a Tissue Repository will be created.*

☐ **Induction of Physical Stress:** *State in #9 the type of stress (exercise, physical performance, etc,); procedures for the physical stress and/or exercise; and potential endpoints for safety.*

☐ **Medical & Clinical Imaging:** *State in #9 the modality and procedures for the imaging; a description of the imaging equipment used; types of images to be collected; and the amount of energy introduced to subjects.*

☐ **Induction of Heat and/or Cooling Modalities:** *State in #9 the device / method of heating or cooling; the temperature range of each method; amount of energy introduced to the subject; and whether microwave technology is used.*

☐ **Genetic Research:** *State in #9 the DNA samples to be collected; the coding / labelling system for samples; plans for sample storage and retention; description of planned analysis (i.e. microarray, RNA sequencing); plans for return of results to subjects, if applicable.*

☐ **Noninvasive Physical Measurements:** *State in #9 the measurements to be collected from the subjects (i.e. heart rate, height, weight, temperature) and equipment or devices needed to collect the measurements.*

☐ **Drugs and/or Biologics:** *State in #9 the layman's explanation for using the drug; the type of drug and procedures for administering it; the FDA approval status of the drug; and specific data to be collected about the drug (i.e. safety, effectiveness, effect on structure*

or function). Upload the drug package insert / Investigator's Brochure / documentation.

☐ **Medical Devices:** *State in #9 the layman's explanation for using the device; the type of device and procedures for using it; the FDA approval status of the device; and specific data to be collected about the device (i.e. safety, effectiveness, effect on biological function). Complete Form 4 for Devices and upload along with the device manual / documentation in the electronic system.*

☐ **Clinical Trial** *(A research study in which one or more human subjects are prospectively assigned to one or more interventions (which may include placebo or other control) to evaluate the effects of those interventions on health-related biomedical or behavioral outcomes)***:** *State in #9 the health condition or disease to be studied (physical or behavioral); all medical or behavioral procedures & interventions; subject groups (control group, intervention groups, etc); and randomization procedures.*

☐ **Other:** *Explain in #9 all research procedures involving human subjects not listed above.*

9. **Procedures:** *Describe the step-by-step procedures that will be used to answer the research questions from #5. Include details on all methods that will be used to collect human subject data from the beginning to the end of the study, such as what data will be collected; when and where the data will be collected; and the data collection instruments that will be used. Refer to your selection(s) in #8 for additional details to include here.* **Use clear, concise layman's language that can be easily understood by persons outside your field; provide definitions for any technical terms. Add pictures if needed.**

This research team consists of UTA Doctoral Candidate, Vivian J Miller, LMSW (PI), and one support staff member (graduate MSW student in the School of Social Work) who has completed their training for Human Subjects Protection. The research team will recruit a total of 120 nursing home residents and 120 nursing home resident family members (responsible party) for this study. The nursing home staff will not be involved in the recruitment processes. They have agreed to provide us with the names of persons interested in volunteering for the study who meet study inclusion criteria. Nursing home staff will identify 20 residents who are alert & oriented to person, place, and time (A&Ox3), and who have a family member that visits the facility. They will ask permission from nursing home residents before they share resident names with us (please see attached document "Nursing Home Recruitment Script"). The agency staff will provide Vivian J. Miller, LMSW with the names of the resident and their family member and will leave this list of names at the nursing home site, and then shred the list after the informed consent is completed with the participants during the scheduled visit. Regardless of participation, the list will be shredded. The nursing home staff will not provide specific information related to the study to the participants and will not ask the participants to sign consent forms. The agency staff will state that any questions need to be directed to Vivian J. Miller, LMSW. A letter of support from the nursing home sites participating in this study is provided in our IRB application that outlines the agency's role in the project (please see attached document "*Nursing Home Name* – Letter of Support"). Vivian J. Miller, LMSW and/or a member of the research team (support staff) will follow up with interested persons at the nursing home

and will begin the formal consent process. The research team is responsible for all recruitment activities. This will involve face-to-face meetings and phone calls with the potential participants, discussion of the proposed study and procedures, any risks or benefits associated with participation, incentives, and so forth (please see attached documents "Recruitment script - family" and "Recruitment script – resident").

If the potential participant would like to volunteer for the study, they will be asked if they would like more information on the proposed study. If yes, and if they present an interest, they will be first be provided more detailed information on the study. Then, they will be provided time to ask questions and gather more information on the study before being asked to sign the IRB approved consent form. From this, the researcher will then schedule a date/time convenient to the participant to meet for a 60 to 90-minute interview. All meetings with residents of the nursing homes will take place in the participants' room within the nursing home or within another room in the facility, if they so choose, to protect the privacy of the participant. Family members have the option to participate in the interview with or without their resident.

Residents who volunteer to participate will be enrolled without knowing whether their family member will participate. The researcher, or support staff, will follow-up with the resident family member and inquire whether or not they are interested in participating the study.

The following figure is a chart, which explains a list of topics covered within this study and the corresponding scale/measures used in interviews for each. Also included in this figure is the associated research question.

Topic	Scale/Measure	Research Question
Cognition	Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975). This survey assesses for cognition.	While the nursing home staff will provide the researcher with a list of potential participants who are alert and oriented to person, place, and time, the researcher will control for this variable when conducting statistical analyses from results of this study.
Social Support	Abbreviated Duke Social Support Index (DSSI). This survey assessed for perceived-levels of social support.	Research question 2 is associated with social support, examining the mediating role of social support by visitation.
Depression	Patient Health Questionnaire-9 (PHQ-9)	Research questions 1 and 2 are associated with depression, examining the perceived levels of depression

		among residents of nursing homes.
Visitation Patterns	Nursing Home Visitation Patterns	Research questions 1, 2, and 3 are associated with visitation patterns. These patterns examine the frequency, duration, and travel behaviors associated with the family member visiting the resident.
Transportation	Transportation Disadvantage Assessment Tool (TDAT), adapted from (Currie, 2011)	Research questions 1, 2, and 3 are associated with transportation. This tool, used within the context of travelling to and from home and the nursing home and work and the nursing home, identifies key features of transportation as related to visiting their nursing home resident.

Again, interviews with the resident will take place in the resident room. In order to promote the safety of the UTA research team members, face to face meetings will be conducted during the hours of business operation of the nursing home.

Interviews with the resident family members will take place either in face to face in the nursing home, via telephone, or via online questionaire (Qualtrics) delivered to their email address. If the interview takes place in the nursing home, it will be conducted in the resident room with the resident present, or in another room within the nursing facility. Residents have the option to participate in the interview with or without their family member. Family members have the option to participate in the interview with or without their resident.

Approximately 30 days after collection of data using interviews is complete, select participants will be asked to participate in a follow-up qualitative study (phase two) (please see document attached "Qualitative follow-up interviews". Participants will indicate on the informed consent form that they agree for these qualitative follow-up interview. These qualitative follow-up interviews will be audio recorded. All participants will agree on the informed consent document to be audio recorded, should they be selected for the follow-up study.

None of the study data (e.g., recordings, transcripts, or other data) will be given to the study sponsor. These audio recordings and will be managed by remain confidential and will only be accessed by the members of the research team. The audio files will be transcriped by members of the research team and by Rev.com, which has an encryption on all files, adhering to confidentiality agreements, and will be deleted upon request. All files will be

stored in password protected, encrypted files stored on UTA issued mobile tablet devices that are also encrypted as per the UTA Office of Information Technology, and files will be backed up from the tablets onto the UTA-computers. The privacy of participants will be protected at all times. Records with names and other identifiable information will be stored separately from the interviews in password protected encrypted files on laptop of the primary investigator. Study data will also be backed up on the JDRIVE for access to the UTA IRB, if needed. Confidentiality will be maintained using standard procedures in human subjects research. The signed consent forms will be kept in a locked file cabinet in the office of Dr. Noelle Fields, Faculty Advisor to Vivian J. Miller, for a duration of three-years after completion of the study. Data will be transcribed by the Primary Investigator and hired support staff. The data recorded could not impact the subjects' financial standing, employability, reputation, or services currently received.

10. **Duration:** *Indicate how many participation sessions, interactions, or follow ups are expected for each subject participant, including the amount of time required for each visit and how long their total participation is expected to take (weeks, months, years, etc.) over the entire duration of the study.*

The duration of the study is 60 days. There will be 3 to 4 interactions between a member of the research team and the study participant. The first interaction is to meet the prospective volunteers and provide more information on the study and to answer all questions related to this research project. Next, during this second visit should the participant volunteer, the research team will obtain informed consent from prospective volunteers and to schedule a time for the interview. The third interaction will be the interview portion of this study will take approximately 60 to 90-minutes, either conducted face to face at the participants' nursing home residency or via telephone. For persons eligible and selected for the qualitative follow-up, a fourth interaction will take place. This third interaction will take approximately 60 to 90 minutes, approximately 60 days from the start of the study.

11. **Location(s) and Site(s):** *Specify all locations where research procedures are expected to take place and which study procedures will take place at each site. If any part of this study will be conducted in an institution or location administratively separate from UTA, indicate the institution(s) and upload a site permission letter.*

This study will take place in 7 Medicare/Medicaid certifiable nursing home sites across North Central Texas. This includes 2 nursing homes in Weatherford, Texas, 2 nursing homes in Fort Worth, Texas, and 2 nursing homes in Arlington, Texas. The following is a chart of nursing home sites (3) that have agreed to participate in this study (please see attached document "*Nursing Home Name* – Letter of Support"). Three more nursing home sites will be added later via modification requests after permission has been granted.

Nursing Home Site Name	City	Administrator
College Park Rehabilitation & Care Center	Weatherford, TX	Keith Fuchs

Heritage Oaks Residence & Rehabilitation Center	Arlington, TX	Erich Wahl
DFW Nursing and Rehab	Fort Worth, TX	Audrey Anderson
NURSING HOME	*Weatherford, TX*	*[name]*
NURSING HOME	*Arlington, TX*	*[name]*
NURSING HOME	*Fort Worth, TX*	*[name]*

12. **Alternatives to Participation:** *Describe subjects' available options if they choose not to participate in the research study and clarify whether individuals that decline participation will still be subjected to the intervention (even if subject data is not collected for research purposes). If research involves students, describe their alternatives to obtain course / extra credit if applicable. If research involves a health intervention, clarify whether individuals that decline will continue to receive standard care.*

There are no alternative procedures offered for this study. However, participants can elect not to participate in the study or quit at any time at no consequence. Participation in this study will not impact any services they receive or the care received within their place of residence. This will be emphasized in the recruitment process (please see attached documents "recruitment script – family" and "recruitment script – resident").

SECTION E: POPULATION & ENROLLMENT

13. **Please indicate which, if any, of the following are involved:**

☐ **UTA Students**

☒ **Adults competent to consent for themselves (non-UTA)**

☐ **Individuals with Impaired Decision Making Capacity:** *Upload Form 2A.*

☐ **Pregnant Women, Fetuses, Women Undergoing In-Vitro Fertilization, or newborns:** *Upload Form 2B.*

☐ **Prisoners (Individuals involuntarily detained in a penal institution):** *Upload Form 2C.*

☐ **Children (Under 18 or the local legal adult age)***: Upload Form 2D.*

☐ **Non-English Speaking People:** *Upload the consent form and all applicable materials translated into the native language(s) of the research subjects. Explain the qualifications of the translator.*

☐ **Other potentially vulnerable groups***: Explain below.*

14. **Inclusion Criteria:** *List all criteria for including subjects, and explain the methods you will use to determine whether a subject is eligible based on your criteria (i.e. pre-screen, medical chart review). If your*

study is/will be funded, ensure that the inclusion criteria listed here match the details in your proposal.

Inclusion criteria for the resident sample selection will include: (1) resident of a Medicare/Medicaid certifiable nursing home within one of the three selected communities listed above; (2) age 55 and older; (3) English-speaking; (4) able to communicate in functional English; (5) without cognitive impairment; and, (6) provide informed voluntary consent. This sample will include only residents who reside in long-term NH care and do not intend to discharge back into the community.

Inclusion criteria for the responsible party/family member sample selection will include: (1) English-speaking; (2) age 18 and above; (3) provide informed voluntary consent; and, (4) visit their family member within the Medicare/Medicaid certifiable nursing facility.

15. Exclusion Criteria: *Explain any specific factors or contraindications that would make a subject ineligible to participate in this study, even if they would otherwise meet the inclusion criteria listed above. If your study is/will be funded, ensure that the exclusion criteria listed here match the details in your proposal.*

Participants who do not meet above criteria will be excluded from this study.

16. Number of Subjects: *Provide an estimated number of subjects (or subject records/data sets) you intend to enroll over the course of the study. You may provide a projected range. If the study is more than minimal risk to subjects, provide statistical justification for the selected number of participants.*

The estimated number of subjects intended to enroll in this study are 120 residents of nursing homes and 120 family members. An a priori power analysis using the statistical power analysis program G*Power indicates that 89 total subjects are needed to have 90% power for detecting a medium effect size (f=0.25) when employing the traditional .05 criterion of statistical significance for conducting regression with 12 variables as control variables. To allow for 10% room of refusing rate or other missing data, the researcher put 31 more cases into the sample. Altogether, it is proposed to collect data from 120 participant-dyads for this study.

17. Subject Recruitment: *(i.e. Direct Person-to-Person Recruitment; Invitation Letter / Email; Website or Social Media / Listserv; Printed Flyers; Telephone Script; In-Class Presentation; Cover Letter; Subject Pool, i.e. SONA, Mechanical Turk, Research Match; external organizations; Snowball Sampling) Describe how you will identify and contact potential subjects. Explain the process for obtaining the contact information for any potential participants that you intend to contact directly. Upload permission letters / emails as needed from individuals or organizations providing access to private contact information for potential subjects. Upload a copy of all recruitment flyers, ads, scripts, emails, social media posts, etc. in Profiles.*

A purposive sample of 120 residents of nursing homes and family member-dyads will be included in this study. Inclusion criteria for the resident sample selection will include: (1) resident of a Medicare/Medicaid certifiable nursing home within one of the three selected

communities listed above; (2) age 55 and older; (3) English-speaking; (4) able to communicate in functional English; (5) without cognitive impairment; and, (6) provide informed voluntary consent. This sample will include only residents who reside in long-term nursing home care and do not intend to discharge back into the community. Inclusion criteria for the family member sample selection will include: (1) English-speaking; (2) age 18 and above; (3) provide informed voluntary consent; and, (4) visit their family member within the Medicare/Medicaid certifiable nursing facility.

The UTA researcher will recruit resident and family member participants from the community partners, nursing homes within Arlington, Weatherford, and Fort Worth, Texas via face to face meeting, via telephone, and via online questionaire (Qualtrics) delivered by an email (see recruitment scripts attached). The researcher will attempt to recruit the resident and the family member. The resident may be approached first to ask if they have interest in participating in the study. If the resident expresses interest in the study, their family will be contact. In the instance that the resident and family member are together upon the follow-up visitation with the resident, the researcher will ask both the resident and their family member on interest about study participation while they are together. The nursing home staff will not be engaged in the recruitment process of study participants or any other aspects of the research process. They have agreed to provide us with the names of persons interested in volunteering for the study who meet study inclusion criteria. They will ask permission from the participants before they share their names with us. The facility staff will provide Vivian J. Miller, LMSW with a list of names, we will keep this list of names at the nursing home site, and then shred the list after we consent the participants. Regardless of participation, we will shred the list. The agency staff will not provide specific information related to the study to the participants and will not ask the participants to sign consent forms. The nursing home staff will state that any questions need to be directed to Vivian J. Miller, LMSW. A letter of support from the agencies are provided in our application that outlines the agency's role in the project. Vivian J. Miller and the research team member will follow up with interested participants and will begin the formal recruitment process. A maximum of 120 residents of nursing homes and 120 family members who meet inclusion criteria will be enrolled in this study.

SECTION F: INFORMED CONSENT

Note: Signed consent forms must be filed under lock and key during the research and for a period of 3 years after the closure of the IRB protocol (if unfunded). For funded research, the consent forms must be kept for the length established under the terms and conditions of the award. These consent forms must be available for inspection by the UTA IRB or Federal Agencies.

Note: Any data collection materials presented to the research subject may not ask the subject to provide information about another human being who has not undergone the informed consent process, including the immediate family of the subject.

If you do not plan to obtain informed consent from subjects; will not disclose all information about the study up front; or will not obtain a signed version of the consent form, upload Form 3.

18. Informed Consent: *Describe the informed consent process, including when, where, and how subjects will be consented. If children or mentally disabled or incapacitated persons will be subjects, also explain the assent process. Upload finalized copies of all consent, assent, and / or oral consent script documents in Profiles. Templates are available for <u>written adult consent</u>, <u>online adult consent</u>, and <u>parents and children</u> in the electronic submission system underneath #5, Form Attachments.*

Informed consent will be obtained with prospective resident participants face to face at their residency. During the initial meeting with potential participants, they will indicate their interest in participating in the study and be provided with study details and information. They will be given the opportunity to ask any questions about the study. They will also be given the opportunity to take time to consider whether or not they wish to participate in the study. If that is the case, the researcher will schedule a time to follow-up with the participant and meet again to discuss their interest in participating. Upon the participant ensuring their interest in the study, they will be given an opportunity to sign the consent form (see document attached "Resident ICD proposal").

Informed consent will be obtained from the prospective family member face to face should they be at the nursing home facility. During the initial meeting with potential participants, they will indicate their interest in participating in the study and be provided with study details and information. They will be given the opportunity to ask any questions about the study. They will also be given the opportunity to take time to consider whether or not they wish to participate in the study. If that is the case, the researcher will schedule a time to follow-up with the participant and meet again to discuss their interest in participating. Upon the participant ensuring their interest in the study, they will be given an opportunity to sign the consent form (see document attached "Family ICD proposal"). Informed consent will be obtained verbally from the prospective family member via phone should they not be present at the facility. Should the family member participate via online questionnaire, they will have the option to download and print a copy of the informed consent to retain for their records.

> **18a. Verbal Consent:** *If appropriate, describe your rationale for obtaining oral consent or assent instead of written consent. Upload a copy of the information to be read and given to the subjects.*

Informed consent for prospective resident participants who are unable to write their consent due to issues with dexterity will be given the opportunity to provide oral consent instead of written consent (see Form 3, Section B). Informed consent for prospective family members will be obtained via telephone and will be given the opportunity to provide oral consent instead of written consent (see Form 3, Section B). For family members who participate via online questionnaire, they will have the option to download and print a copy of the informed consent to retain for their records.

> **18b. Native Languages:** *If non-English speaking subjects will participate, list all languages into which the Informed Consent or short form consent will be translated, along with the*

qualifications of the translator for each language. Upload copies of all translations in the Profiles system.

N/A

SECTION G: COMPENSATION & COSTS

Note: You are responsible for maintaining accurate and confidential records regarding the payment of your subjects. Per Accounting Services procedures, compensation must be documented for tax purposes using a W-9 form unless an exception is granted by the Accounting department. Exception requests are submitted through UTA Flow. Contact Accounting Services at acctservices@uta.edu with questions about this process.

19. **Compensation:** *Describe any compensation, monetary or otherwise, to subjects for participation. This can include monetary payments, gift cards, course/extra credit, raffle prizes, goods or services, donations to charity, etc. Describe how and when during the course of the study you will provide or*
    transmit the compensation to the subjects, and how confidentiality will be maintained in the process of providing payment or compensation to subjects (for example, use of coding in payment log books/receipts). If you intend to hold a raffle, explain when you expect that the raffle will be drawn, and how participants will be contacted if they win the drawing.

All participants will be entered into a raffle for the chance to win 1 of 35 gift cards, each valued at $20.00, to a retail establishment, Walmart. The raffle drawing will take place once all interviews in phase one of the study has been completed. Participants will be contacted via face to face visit or by phone if they win the drawing. The researcher will hand-deliver the gift card to the resident or family member if they win.

Required W-9 information will be collected from the resident or family member if they win upon delivery of the gift card. This information will be obtained using a Gift Card Receipt. This information will be stored securely in the locked offices of Dr. Noelle Fields, Faculty Advisor on this project.

20. **Costs:** *Describe any costs or expenses (monetary or non-monetary) subjects will incur as a result of participation.*

    N/A

SECTION H: RISKS & BENEFITS

21. **Risks to Subjects:** *Explain any potential risks to subjects, including physical risks (i.e. fainting, falls, infections, muscle soreness, pain, broken bones, physical fatigue, headache, burns, medication side effects); psychological risks (i.e. depression, anger, feelings of stress, feelings of guilt, embarrassment, or less of self-esteem); social risks (i.e. potential damage to financial standing, reputation, or employability); and / or risks to privacy & confidentiality (i.e. exposing someone as a research subject, release or breach of sensitive data).*

The following are potential risks that participants in this study may be exposed to. Participants in this study may have the potential to be exposed to minimal psychological risks due to the sensitive nature of the interview questions. Additional risks include the subjects' privacy, if both the family member and the resident will be together during the interviews. Finally, confidentiality may be a potential risk if data is lost or stolen while the researcher is at the facilities.

If residents or family members experience feelings of distress or discomfort based on the nature of questions asked, for residents the researcher will report it immediately to the nurse, social worker, or staff member on duty, and for family members the researcher will report it to the Tarrant County Area Agency on Aging, which has resources for family caregivers (817) 258-8081).

If a participant reports they have had thoughts of hurting themselves or suicide, the researcher will immediately report this directly to a facility nurse, social worker, and/or responsible staff member within the nursing home.

> **Strategies to Minimize Risks:** *Explain the strategies that the research team will use to minimize the possibility of occurrence for the risks listed above. Specify whether the study procedures in part or as a whole may present a greater level of risk than those ordinarily encountered in subjects' daily life or during the performance of routine physical or psychological examinations or tests.*

To minimize the risks the primary researcher, a Licensed Master Social Worker, and research assistant, a researcher, will establish rapport with the resident and their family members. The intent of the study is not to cause any change in mood, rather to gather information using the survey instruments attached herein. The researcher, and support staff, will remain in close contact with the facility social worker and nursing staff, should additional interventions need to take place.

> **Possibility for Coercion or Undue Influence:** *If any part of this study has the potential for coercion of the subject, or if the investigator may have undue influence over the subject's choice to participate by nature of an existing relationship (i.e. teacher & student, manager & employee, doctor & patient), explain the circumstances and describe proposed safeguards to minimize the risk of harm.*

To minimize the risks of unduly pressured, the researcher and support staff will emphasize the voluntary nature of this study. If the researcher ascertains that the resident or their family member does not wish to participate, they may choose to drop-out from the study at any time. Moreover, the resident and their family member may choose to be interviewed individually, or as dyads, as they choose, and may discontinue the study at any time without consequences.

> 22. **EH&S Considerations:** *Specify whether the study involves any hazardous materials, locations, or equipment that is relevant to the health and safety of either the subjects or the protocol personnel (i.e. handling of human blood/body fluid/tissue, chemical or biological hazards,*

radiation/X-rays, lasers, or carcinogens). Describe any related authorizations or approvals from the UTA Environmental Health & Safety Office.

N/A

23. **Direct Benefits to Subjects:** *List potential benefits that may accrue to the study subjects as a result of their participation, if any.*

Participants may benefit from the social interaction and engagement in this research project. We also anticipate participants may contribute to the development and improvement of transportation systems in terms of zoning and transit system routes, specifically bus and train routes near nursing home sites. Improved transportation will allow members of the community across the lifespan (e.g., grandchildren visiting grandparents) to stay connected and will allow entire communities to age well. The subjects may also have no direct benefits from participating in this study.

24. **Overall Benefits:** *Describe the expected or potential benefits of this study to the field / to society at large.*

It is hypothesized that access and opportunities to transportation will increase social support by visitation, thus influencing depression outcomes among residents of NHs. Transportation planning has been challenged to examine the impact transportation system outcomes have on health and has yet to examine this connection between transportation and institutionalized older adults' mental health outcomes; this assessment of mental health outcomes represents a key performance measure for all environmental justice populations. The importance of gaps in transportation for family members visiting residents of NHs will be measured to understand how transportation planning impacts mental health outcomes in a particularly isolated population. Well-connected regions and communities can improve social equity by providing access to social opportunities to improve health outcomes for residents of NHs and community-members, alike. Discharge planners and allied health care professionals (e.g., social workers) tasked with placing hospital and skilled nursing facility patients into long-term NH care can use these findings to locate facilities on bus and rail lines for transportation disadvantaged family members.

Furthermore, findings from this study will inform future transportation planners in terms of zoning and transit system routes, specifically bus and train routes near these facilities. Improved transportation will allow members of the community across the lifespan (e.g., grandchildren visiting grandparents) to stay connected and will allow entire communities to age well. Moreover, these findings can be used to inform future studies, such as positive health outcomes and access to opportunities for the employees at these nursing facilities, for instance to examine the relationship between transportation access, travel time, and workforce retention at NH facilities.

SECTION I: PRIVACY & CONFIDENTIALITY

25. **Subject Privacy:** *Explain how the privacy of subjects will be protected during the course of the study. Privacy refers to an individual's desire to control the extent, timing, and circumstances of sharing oneself physically, behaviorally, or intellectually with others (i.e. subjects may not want to be seen entering a place that might stigmatize them, such as a pregnancy counseling center; subjects may want a private interview room when discussing sensitive topics).*

Members of the research team will ask participants of their preferred location for the interview (e.g., in their room with the door closed to maintain privacy, or in a closed-conference room). Members of the research team will be the only ones who will know or have access to the partipants' names (residents of the nursing home and their family member). Although some identifying information, such as age, gender, and ethnic background will be noted and the interview guide does include participant identifiers (e.g., date of birth, address, workplace address), the names of the participants will be coded to protect confidentiality (i.e. each participant will be assigned a unique study identifier/number. We will create an unique, anonymous identification number (ID) for each respondent. The unique ID will be comprised of a coded version of the individual's initials and his or her birth month and birth day. Each letter of the alphabet will stand for a number, e.g., A=1, B=2, etc. For example, a respondent named Jane Doe who was born on Jan. 1 would have a unique ID of 10411, in which 10=J, 4=D, 1=Jan., and 1=1. The researcher will ensure that an unique ID is developed, should any two individuals with both the same initials and same birth month and birth day be participating in the study.

26. **Confidentiality & Data Security:** *Explain the precautions that will be taken to protect the confidentiality of the data collected and to inform subjects of the parties who will or may have access to identifiable subject data. All paper documents must be managed and stored in the specified building and room number on the UTA campus unless the IRB grants approval for an alternate location. For data that is collected, managed, analyzed, or stored via electronic means, all data from research projects supported by UTA (and therefore belonging to UTA) must be maintained on UTA servers. The UTA Office of Information Technology has many resources, including the J Drive and UTA Box. Per federal regulations, all documents must be maintained and kept secure for at least 3 years after the close of your IRB protocol.*

Data will be collected on a mobile device tablet using Qualtrics Offline Survey app. The data will be anonymized, password protected and encrypted. Data will then be downloaded to UTA-encrypted laptops for further analysis. All interview recordings and transcriptions (i.e. data files) will remain confidential and will only be accessed by the members of the research team. All data files will be stored in password protected, encrypted files stored on UTA issued mobile tablet devices that are also encrypted as per the UTA Office of Information Technology, and files will be back up from the tablets onto the UTA-issued laptops. The privacy of participants will be protected at all times. Records with names and other identifiable information will be stored separately from the interviews in password protected encrypted files on UTA issued laptops. Study data will also be backed up on the JDRIVE for access to the UTA IRB, if needed. Confidentiality will be maintained using standard procedures in human subjects research. The signed consent forms will be kept in a locked file cabinet in the office of Dr. Noelle Fields (Faculty Advisor; SSW Bldg. A Rm 112 B) for a duration of three years after the close of the study.

28a. Legal Limits to Confidentiality: *If any part of this study could result in the potential identification of child abuse, elderly abuse, communicable diseases, or criminal activities that would / could not have been otherwise identified, explain this possibility and estimate the likelihood of disclosure. Describe the plan of action that you will take if this occurs. In rare circumstances when research reveals these issues, confidentiality should be maintained to the extent that the law allows.*

Since members of the research team will be entering the nursing homes of participants for data collection, there may be a chance that a member(s) of the research team may witness abuse, neglect or exploitation of elders or persons with physical or intellectual-developmental disabilities. Note: Members of the research team who will be entering nursing homes are all social workers who are mandated reporters of abuse, neglect, and exploitation of elders, children, or persons with a physical or intellectual-developemntal disability according to Texas Statues relative to mandatory reporting laws. First we, will enter this language (research team's responsibility for reporting to esignated state authority if we suspect abuse, exploitation, or neglect of an elder, person with physical or intellectual-developmental disability, or child abuse) into the study's informed consent form (see attached informed consent documents) and reviewed as part of the consent process. If the person is in immediate danger, we will call 911, otherwise, we will contact the Long Term Care Ombudsman at 1-877-323-6466 to report our concerns as indicated.

27. Data Sharing: *If you intend to share, release, or present any <u>identifiable</u> subject data from this study, explain where, when, and to whom the identifiable information will be shared, presented or released, and how this will be communicated to the subjects beforehand.*

N/A

Appendix E

UTA IRB Approval Letter

UNIVERSITY OF
TEXAS
ARLINGTON

OFFICE OF RESEARCH ADMINISTRATION
REGULATORY SERVICES

May 17, 2018

Vivian Miller
Dr. Noelle Fields
School of Social Work
The University of Texas at Arlington
Box 19129

IRB No.: 2018-0486
Study Title: *Transportation, Social Support by Family Visitation, and Depression of Older Adult Nursing Home Residents: A Mixed-Methods Study*
Expiration Date: **May 4, 2019**

Modification Approval Date: May 17, 2018

ADMINISTRATIVE MODIFICATION APPROVAL

The UT Arlington Institutional Review Board (UTA IRB) or designee reviewed and approved the modification(s) to this protocol on the date listed above according to UTA IRB Standard Operating Procedures. Therefore, you are now authorized to implement the changes to your research. The modification(s), indicated below, was/were deemed minor and appropriate for administrative review:

- Added Amber O'Dell, Graduate Support Staff, to IRB protocol personnel
- Revised the Form 1 to add Amber to the personnel list

As Principal Investigator of this IRB approved study, you are reminded that the following items are your responsibility throughout the life of the study:

UNANTICIPATED ADVERSE EVENTS
Please be advised that as the Principal Investigator, you are required to report local adverse (unanticipated) events to The UT Arlington Office of Research Administration; Regulatory Services within 24 hours of the occurrence or upon acknowledgement of the occurrence.

INFORMED CONSENT DOCUMENT
The IRB approved version of the informed consent must be used when prospectively enrolling volunteer participants into the study. Unless otherwise determined by the IRB, all signed consent forms must be securely maintained on the UT Arlington campus for the duration of the study plus a minimum of three years after the completion of all study procedures (including data analysis). The complete study record is subject to inspection and/or audit during this time period by entities including but not limited to the UT Arlington IRB, Regulatory Services staff, OHRP, FDA, and by study sponsors (as applicable).

REGULATORY SERVICES
SERVICES

The University of Texas at Arlington, Center for Innovation
202 E. Border Street, Ste. 201, Arlington, Texas 76010, Box#19188
(T) 817-272-3723 (F) 817-272-5808 (E) regulatoryservices@uta.edu (W) www.uta.edu/rs

UNIVERSITY OF
TEXAS
ARLINGTON

OFFICE OF RESEARCH ADMINISTRATION
REGULATORY SERVICES

MODIFICATIONS TO THE APPROVED PROTOCOL
All proposed changes must be submitted via the electronic submission system and approved prior to implementation, except when necessary to eliminate apparent immediate hazards to the subject. Modifications include but are not limited to: Changes in protocol personnel, changes in proposed study procedures, and/or updates to data collection instruments. Failure to obtain prior approval for modifications is considered an issue of non-compliance and will be subject to review and deliberation by the IRB which could result in the suspension/termination of the protocol.

HUMAN SUBJECTS TRAINING
All investigators and personnel identified in the protocol must have documented Human Subjects Protection (HSP) training on file prior to study approval. HSP completion certificates are valid for 3 years from completion date; the PI is responsible for ensuring that study personnel maintain all appropriate training(s) for the duration of the study.

STUDY CLOSURE
Please notify Regulatory Services once your study is completed to begin the required 3-year research record retention period.

CONTACT FOR QUESTIONS
The UT Arlington Office of Research Administration; Regulatory Services appreciates your continuing commitment to the protection of human research subjects. Should you have questions or require further assistance, please contact Regulatory Services at regulatoryservices@uta.edu or 817-272-3723.

REGULATORY SERVICES
SERVICES

The University of Texas at Arlington, Center for Innovation
202 E. Border Street, Ste. 201, Arlington, Texas 76010, Box#19188
(T) 817-272-3723 (F) 817-272-5808 (E) regulatoryservices@uta.edu (W) www.uta.edu/rs

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Appendix F

Informed Consent Document (Resident)

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UT Arlington

Informed Consent Document

PRINCIPAL INVESTIGATOR

Vivian J. Miller, LMSW, Doctoral Candidate, The University of Texas at Arlington, 211 South Cooper Street, Box 19129, Arlington, TX 76019

TITLE OF PROJECT

Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study

INTRODUCTION

You, a resident of a nursing home, are being asked to participate in a research study that explores the role of transportation on the mental well-being of residents of nursing homes, and how other factors such as social programming and social support by family visitation influences mental health. Your participation is voluntary. Refusal to participate or discontinuing your participation at any time will involve no penalty or loss of benefits to which you are otherwise entitled. Please ask questions if there is anything that you do not understand.

PURPOSE

The specific purpose of this research study is to gather information from residents of nursing homes and their family members to measure the impact transportation system outcomes have on institutionalized older adults' mental health. As such, your family member (responsible party) will also be asked to participate in this study. The purpose of this research is to examine how transportation access and mobility of family members directly affect mental health outcomes (e.g., depression) of residents in nursing homes, how transportation access and mobility of family members indirectly affect depression outcomes of residents in nursing homes through the mediation role of family social support by visitation, and what the direct effects of family social support by visitation have on depression outcomes of residents in nursing homes, both challenges and opportunities to transportation access and mobility, as well as positive and negative experiences of transportation access and mobility.

DURATION

There are two phases to this study. The first, in which, should you volunteer to participate, you will be asked to engage in a face-to-face interview with a member of the research team that will

take approximately 60 to 90 minutes in duration. If selected for second phase of this study, the follow-up interview will take approximately 60 to 90- minutes in duration.

NUMBER OF PARTICIPANTS

The number of anticipated participants in this research study is 240.

PROCEDURES

The procedures which will involve you as a resident research participant include:

IRB Expiration Date: 5/4/2019 v. 2018-0486

UT Arlington

Informed Consent Document

1. 1) Participate in one face-to-face with a member of the research team. This interview will include a series of surveys. These surveys include demographics (e.g., age, race, level of education), cognition, feelings of depression, levels of social support, and family members' visitation patterns to the nursing home. The interview will last approximately 60 to 90-minutes in duration.
2. 2) From these survey findings, you may be selected to participate in a follow-up qualitative interview. If selected, you will be asked a series of questions related to your experience with transportation. This interview will last approximately 60 to 90-minutes in duration. With your permission, this interview will be audio recorded. All interview recordings and interview transcriptions will remain confidential and will only be accessed by the members of the research team. All data files will be stored in password protected, encrypted files stored on UTA issued laptops that are also encrypted as per the UTA Office of Information Technology. The audio files will be deleted once the transcriptions are completed. If you decline to be recorded during the interview but still wish to participate, a member of the research team will interview you without audio recording the interview.
3. 3) As noted above, your family member (responsible party) is also being asked to participate in this study. Your interview may take place with or without your family member present, this is your choice.

POSSIBLE BENEFITS

By participating in the study, we anticipate that you may benefit from the social interaction and engagement in this research project. We also anticipate you may contribute to the development and improvement of transportation systems, such as in terms of zoning and transit system routes, specifically bus and train routes near your facility. Improved transportation will allow members of the community across the lifespan (e.g., grandchildren visiting grandparents) to stay

connected and will allow entire communities to age well. However, you may also have no direct benefits from participating in this study.

POSSIBLE RISKS/DISCOMFORTS

The anticipated risks of participating in this study are minimal. You may experience psychological discomfort due to the sensitive nature of the questions, specifically in the questionnaire that asks about feelings of depression. Should you experience any discomfort, please inform the researcher. Should your response to questions on this interview suggest you are at danger to yourself, the researcher will immediately notify the nurse, social worker, and/or staff within your nursing home of residence. You have the right to quit any study procedures at any time at no consequence. If you experience emotional distress during the interview, members of the research team may refer you to the agency social worker and/or additional services through the Area Agency on Aging. The Area Agency on Aging provides information and assistance, benefits counseling, ombudsman and case management for senior citizens: (817) 258-8081, 210 East 9th Street; Fort Worth, Texas 76102.

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COMPENSATION

UT Arlington

Informed Consent Document

For your participation in the interview, you will be entered into a drawing to win one of 35 gift cards, each valued at $20.00 to Wal-Mart. Should you be selected in the drawing, you will receive the $20.00 gift card after the interview is completed. As a participant, you are responsible for reporting this incentive as taxable income when you file your taxes with the U.S. government.

ALTERNATIVE PROCEDURES

There are no alternative procedures offered for this study. However, you can choose not to participate in the study or quit at any time at no consequence.

VOLUNTARY PARTICIPATION

Participation in this research study is voluntary. You have the right to decline participation in any or all study procedures or quit at any time at no consequence.

CONFIDENTIALITY

Every attempt will be made to see that your study results are kept confidential. A copy of this signed consent form and all data collected from this study will be stored in the locked offices of

Dr. Noelle Fields in the UTA School of Social Work (Committee Co-Chair and Advisor for Doctoral Candidate, Vivian J. Miller) for at least three-years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a participant. However, the results of the study will only provide a summary of the findings and will not include any information that will identify you as a study participant. Additional research studies could come from the information you have provided, but your information will not be linked to you in anyway; it will be anonymous. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA Institutional Review Board (IRB), and personnel particular to this research have access to the study records. Your records will be kept completely confidential and private according to current legal requirements. They will not be revealed unless required by law, or as noted above. The IRB at UTA has reviewed and approved this study and the information within this consent form. If in the unlikely event it becomes necessary for the Institutional Review Board to review your research records, the University of Texas at Arlington will protect the confidentiality of those records to the extent permitted by law. By law, social workers are mandated reporters of suspected elder abuse or neglect. The only exception to confidentiality in this study is if there is a suspicion of elder abuse or neglect and the researchers will be mandated to report this to the Long-term Care Ombudsman.

CONTACT FOR QUESTIONS

Questions about this research study may be directed to Vivian J. Miller: (216) 534-5650. Any questions you may have about your rights as a research participant or a research- related injury may be directed to the Office of Research Administration; Regulatory

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UT Arlington

Informed Consent Document

Services at Contact for Questions section to 817- 272-3723 or regulatoryservices@uta.edu.

As a representative of this study, I have explained the purpose, the procedures, the benefits, and the risks that are involved in this research study:

_____
Signature and printed name of principal investigator or person obtaining consent Date

CONSENT

By signing below, you confirm that you are 18 years of age or older and have read or had this document read to you. You have been informed about this study's purpose, procedures, possible benefits and risks, and you have received a copy of this form. You have been given the

opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue participation at any time without penalty or loss of benefits, to which you are otherwise entitled.

_____

SIGNATURE OF VOLUNTEER DATE

AUDIO RECORDING OF INTERVIEW (Check one) ☐Yes No ☐
IRB Expiration Date: 5/4/2019 v. 2018-0486

Appendix G

Interview Script (Resident)

Demographic Survey (RESIDENT)

1. What is your age?
   o 65 to 74 years old
   o 75 to 84 years old
   o 85 to 94 years old
   o 95 years +
2. Gender
   o Female
   o Male
   o Other (please specify):
3. What is your race/ethnicity?
   o Non-Hispanic white
   o Hispanic or Latino/a
   o Black or African-American
   o Native American or American Indian
   o Asian/Pacific Islander
   o Other (please specify):
4. What is your marital status?
   o Single (never married)
   o Married, living together
   o Married, but living apart
   o Divorced
   o Separated
   o Widowed
5. Medical Insurance Benefits (can they check all that apply?)
   o Medicaid
   o Veterans Administration (VA) benefits or TriCare
   o Private long-term care insurance you purchased for your own individual coverage, not provided by the government or an employer
   o Private pay
   o Other (please specify):
6. What is your highest level of education?
   o No schooling
   o Some high school, no diploma
   o High school graduate, diploma or equivalent (GED)
   o Some college credit, no degree
   o Trade school/technical education/vocational program
   o Associates degree
   o Bachelor's degree
   o Master's degree
   o Doctoral degree

7. In general, would you say your health is
   o Poor
   o Fair
   o Good
   o Very good
   o Excellent

Family Visitation

8. Over the past two weeks, how often did your family member/caregiver visit you?
   o Every day (7 days)
   o Every other day (3 to 4 days)
   o Twice per week
   o Once per week
   o Less frequently (please specify):
9. At what time of day does your family member/caregiver typically visit you?
   o Morning (between 8 AM and 11:30 AM)
   o Mid-day (between 11:30 and 1:30 PM)
   o Afternoon (between 1:30 PM and 5 PM)
   o Evening (between 5 PM and 8 PM)
   o Night (8 PM and later)
   o Other (please specify):
10. About how long does your family member visit for when they come?
   o Less than 30 minutes
   o 30 minutes to 1 hour
   o 1 to 2 hours
   o 2 to 3 hours
   o 3 hours or longer
   o Other (please specify):
11. Overall, do you consider visits with family quality time well spent?
   o 1 - Not at all
   o 2 – A little bit
   o 3 – somewhat
   o 4 – quite a bit
   o 5 – very well

Cognition

Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975)

Instructions: Score one point for each correct response within each question or activity.

Maximum Score	Patient's Score	Questions
5		"What is the year? Season? Date? Day? Month?"
5		"Where are we now? State? County? Town/city? Hospital? Floor?"
3		The examiner names three unrelated objects clearly and slowly, then the instructor asks the patient to name all three of them. The patient's response is used for scoring. The examiner repeats them until patient learns all of them, if possible.
5		"I would like you to count backward from 100 by sevens." (93, 86, 79, 72, 65, ...) Alternative: "Spell WORLD backwards." (D-L-R-O-W)
3		"Earlier I told you the names of three things. Can you tell me what those were?"
2		Show the patient two simple objects, such as a wristwatch and a pencil, and ask the patient to name them.
1		"Repeat the phrase: 'No ifs, ands, or buts.'"
3		"Take the paper in your right hand, fold it in half, and put it on the floor." (The examiner gives the patient a piece of blank paper.)
1		"Please read this and do what it says." (Written instruction is "Close your eyes.")
1		"Make up and write a sentence about anything." (This sentence must contain a noun and a verb.)
1		"Please copy this picture." (The examiner gives the patient a blank piece of paper and asks him/her to draw the symbol below. All 10 angles must be present and two must intersect.)
30		TOTAL

Interpretation of MMSE:

Method	Score	Interpretation
Single Cutoff	<24	Abnormal
Range	<21	Increased odds of dementia
	>25	Decreased odds of dementia
Education	21	Abnormal for 8th grade education
	<23	Abnormal for high school education
	<24	Abnormal for college education
Severity	24-30	No cognitive impairment
	18-23	Mild cognitive impairment
	0-17	Severe cognitive impairment

Interpretation of MMSE Score:

Score	Degree of Impairment	Formal Psychometric Assessment	Day-to-Day Functioning
25-30	Questionably significant	If clinical signs of cognitive impairment are present, formal assessment of cognition may be valuable.	May have clinically significant but mild deficits. Likely to affect only most demanding activities of daily living.
20-25	Mild	Formal assessment may be helpful to better determine pattern and extent of deficits.	Significant effect. May require some supervision, support and assistance.
10-20	Moderate	Formal assessment may be helpful if there are specific clinical indications.	Clear impairment. May require 24-hour supervision.
0-10	Severe	Patient not likely to be testable.	Marked impairment. Likely to require 24-hour supervision and assistance with ADL.

Social Support

Abbreviated Duke Social Support Index (DSSI)

Satisfaction with social support:
1. Do you feel you have a definite role (place) in your family and among your friends?
2. Does it seem that your family and friends (i.e. people who are important to you) understand you?
3. Do you feel useful to your family and friends (i.e. people who understand you)?
4. When you are talking with your family and friends, do you feel you are being listened to?
5. Do you know what's going on with your family and friends?
6. Can you talk about your deepest problems with at least some of your family and friends?

Social Interaction:
7. How many times during the past week did you spend time with someone who does not live with you, that is, you went to see them or they came to visit you or you went out together?
8. Other than members of your family, how many persons in your local area do you feel you can depend on or feel very close to?
9. How many times did you talk to someone, friends, relatives or others on the telephone in the past week (either they called you or you called them)?
10. About how often did you go to meetings of clubs, religious meetings or other groups that you belong to in the past week?
11. How satisfied are you with the kinds of relationships you have with your family and friends?

*(**Scoring**: The researcher has contacted the Psychiatry Department (Dr. John Beyer) at Duke University at (919) 684-5616 to obtain scoring instructions for this instrument.)*

Nursing Home Social Support Programming

1. How often does this facility provide social support programming its residents?
   0 – not at all
   1 – several days
   2 – more than half the days
   3 – nearly every day
2. Does this facility provide a variety of social programs (e.g., ice cream socials, movies, physical activities per resident ability, friendly-visitors, outings, etc.)?
   1 - Not at all
   2 – A little bit
   3 – somewhat
   4 – quite a bit
   5 – very well
3. Does the facility offer social support programs provided by community volunteers (e.g., students groups or student organizations, the local rotary club, corporate volunteer programming, etc)?
   1 - Not at all
   2 – A little bit
   3 – somewhat
   4 – quite a bit
   5 – very well
4. [Additional questions, as fitting]

Depression

Patient Health Questionnaire-9 (PHQ-9)

Over the past two weeks, how often have you been bothered by any of the following problems?
1. Little interest or pleasure in doing things?
    o   0 – not at all
    o   1 – several days
    o   2 – more than half the days
    o   3 – nearly every day
2. Feeling down, depressed, or hopeless?
    o   0 – not at all
    o   1 – several days
    o   2 – more than half the days
    o   3 – nearly every day
3. Trouble falling or staying asleep, or sleeping too much
    o   0 – not at all
    o   1 – several days
    o   2 – more than half the days
    o   3 – nearly every day
4. Feeling tired or having little energy
    o   0 – not at all
    o   1 – several days
    o   2 – more than half the days
    o   3 – nearly every day
5. Poor appetite or overeating
    o   0 – not at all
    o   1 – several days
    o   2 – more than half the days
    o   3 – nearly every day
6. Feeling bad about yourself - or that you are a failure or have let yourself or your family down
    o   0 – not at all
    o   1 – several days
    o   2 – more than half the days
    o   3 – nearly every day
7. Trouble concentrating on things, such as reading the newspaper or watching television
    o   0 – not at all
    o   1 – several days
    o   2 – more than half the days
    o   3 – nearly every day
8. Moving or speaking so slowly that other people could have noticed? Or the opposite – being
    so fidgety or restless that you have been moving around a lot more than usual
    o   0 – not at all
    o   1 – several days
    o   2 – more than half the days
    o   3 – nearly every day

9. Thoughts that you would be better off dead or of hurting yourself in some way
    o   0 – not at all
    o   1 – several days
    o   2 – more than half the days
    o   3 – nearly every day

Scoring: Depression Severity at 0-4 none, 5-**9** mild, 10-14 moderate, 15-19 moderately severe, 20-27 severe

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Appendix H

Informed Consent Document (Family Member)

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UT Arlington

Informed Consent Document

PRINCIPAL INVESTIGATOR

Vivian J. Miller, LMSW, Doctoral Candidate, The University of Texas at Arlington, 211 South Cooper Street, Box 19129, Arlington, TX 76019

TITLE OF PROJECT

Transportation, Social Support by Family Visitation, and Depression Outcomes of Residents in Nursing Homes: A Mixed-Methods Study

INTRODUCTION

You, a family member of a resident of a nursing home, are being asked to participate in a research study that explores the role of transportation on the mental well-being of residents of nursing homes, and how other factors such as social programming and social support by family visitation influences mental health. Your participation is voluntary. Refusal to participate or discontinuing your participation at any time will involve no penalty or loss of benefits to which you are otherwise entitled. Please ask questions if there is anything that you do not understand.

PURPOSE

The specific purpose of this research study is to gather information from family members (responsible parties) of residents in nursing homes to measure the impact transportation system outcomes have on institutionalized older adults' mental health. The purpose of this research is to examine how transportation access and mobility of family members directly affect mental health outcomes (e.g., depression) of residents in nursing homes, how transportation access and mobility of family members indirectly affect depression outcomes of residents in nursing homes through the mediation role of family social support by visitation, and what the direct effects of family social support by visitation have on depression outcomes of residents in nursing homes, both challenges and opportunities to transportation access and mobility, as well as positive and negative experiences of transportation access and mobility.

DURATION

There are two phases to this study. The first, in which you will be asked to participate in a face-to-face interview with a member of the research team that will take approximately 60 to 90 minutes in duration. If selected for second phase of this study, the follow-up interview will take approximately 60 to 90-minutes in duration.

NUMBER OF PARTICIPANTS

The number of anticipated participants in this research study is 240.

PROCEDURES

The procedures which will involve you as a family member research participant include: 1) Participate in one face-to-face or phone interview with a member of the research

team. This interview will include a series of surveys, including demographics (e.g.,

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UT Arlington

Informed Consent Document

age, race, level of education, etc), travel behaviors, transportation patterns, and visitation patterns to the nursing home site. The interview will last approximately 60 to 90-minutes in duration.

2. 2) From the survey findings, you may be selected to participate in a follow-up qualitative interview. If selected, you will be asked a series of questions related to your experience with transportation. This interview will last approximately 60 to 90-minutes in duration. With your permission, this interview will be audio recorded. All interview recordings and interview transcriptions will remain confidential and will only be accessed by the members of the research team. All data files will be stored in password protected, encrypted files stored on UTA issued laptops that are also encrypted as per the UTA Office of Information Technology. The audio files will be deleted once the transcriptions are completed. If you decline to be recorded during the interview but still wish to participate, a member of the research team will interview you without audio recording the interview.
3. 3) As noted above, your family member (resident of the nursing home) is also being asked to participate in this study. Your interview may take place with or without your resident present, this is your choice.

POSSIBLE BENEFITS

By participating in the study, we anticipate that you may benefit from engagement in this research project. We also anticipate you may contribute to the development and improvement of transportation systems in terms of zoning and transit system routes, specifically bus and train routes near your facility. Improved transportation will allow members of the community across the lifespan (e.g., grandchildren visiting grandparents) to stay connected and will allow entire communities to age well. However, you may also have no direct benefits from participating in this study.

POSSIBLE RISKS/DISCOMFORTS

The anticipated risks of participating in this study are minimal. You may experience psychological discomfort due to the sensitive nature of the questions. Should you experience any discomfort due to this, please inform the researcher. You have the right to quit any study procedures at any time at no consequence. If you experience emotional distress during the interview, members of the research team may refer you to the agency social worker and/or additional services through the Area Agency on Aging. The Area Agency on Aging provides information and assistance, benefits counseling, ombudsman and case management for senior citizens: (817) 258-8081, 210 East 9th Street; Fort Worth, Texas 76102.

COMPENSATION

For your participation in the interview, you will be entered into a drawing to win one of 35 gift cards, each valued at $20.00 to Wal-Mart. Should you be selected in the drawing, you will receive the $20.00 gift card after the interview is completed. As a participant,

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UT Arlington

Informed Consent Document

you are responsible for documenting/reporting this incentive as taxable income when you file your taxes with the U.S. government.

ALTERNATIVE PROCEDURES

There are no alternative procedures offered for this study. However, you can choose not to participate in the study or quit at any time at no consequence.

VOLUNTARY PARTICIPATION

Participation in this research study is voluntary. You have the right to decline participation in any or all study procedures or quit at any time at no consequence.

CONFIDENTIALITY

Every attempt will be made to see that your study results are kept confidential. A copy of this signed consent form and all data collected from this study will be stored in the locked offices of Dr. Noelle Fields in the UTA School of Social Work (Committee Co-Chair and Advisor for Doctoral Candidate, Vivian J. Miller) for at least three-years after the end of this research. The results of this study may be published and/or presented at meetings without naming you as a participant. However, the results of the study will only provide a summary of the findings and will not include any information that will identify you as a study participant. Additional research

studies could evolve from the information you have provided, but your information will not be linked to you in anyway; it will be anonymous. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA Institutional Review Board (IRB), and personnel particular to this research have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above. The IRB at UTA has reviewed and approved this study and the information within this consent form. If in the unlikely event it becomes necessary for the Institutional Review Board to review your research records, the University of Texas at Arlington will protect the confidentiality of those records to the extent permitted by law. By law, social workers are mandated reporters of suspected elder abuse or neglect. The only exception to confidentiality in this study is if there is a suspicion of elder abuse or neglect and the researchers will be mandated to report this to the Long-term Care Ombudsman.

CONTACT FOR QUESTIONS

Questions about this research study may be directed to Vivian J. Miller: (216) 534-5650. Any questions you may have about your rights as a research participant or a research- related injury may be directed to the Office of Research Administration; Regulatory Services at Contact for Questions section to 817- 272-3723 or regulatoryservices@uta.edu.

IRB Expiration Date: 5/4/2019 v. 2018-0486

UT Arlington

Informed Consent Document

As a representative of this study, I have explained the purpose, the procedures, the benefits, and the risks that are involved in this research study:

_____
Signature and printed name of principal investigator or person obtaining consent Date

CONSENT

By signing below, you confirm that you are 18 years of age or older and have read or had this document read to you. You have been informed about this study's purpose, procedures, possible benefits and risks, and you have received a copy of this form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue participation at any time without penalty or loss of benefits, to which you are otherwise entitled.

SIGNATURE OF VOLUNTEER DATE

AUDIO RECORDING OF INTERVIEW (Check one) ☐Yes No ☐

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Appendix I

Interview Script (Family Member)

Demographic Survey (FAMILY MEMBER)

1. What is your age?
   o 18 to 29 years old
   o 30 to 39 years old
   o 40 to 49 years old
   o 50 to 59 years old
   o 60 to 69 years old
   o 70 to 79 years old
   o 79 and above
2. Gender:
   o Female
   o Male
   o Other (please specify):
3. What is your race/ethnicity?
   o Non-Hispanic white
   o Hispanic or Latino
   o Black or African American
   o Native American or American Indian
   o Asian/Pacific Islander
   o Other (please specify):
4. How are you related to the resident?
   o Child
   o Sibling
   o Cousin
   o Aunt/Uncle
   o Other (please specify):
5. Marital status:
   o Single (never married)
   o Married, living together
   o Married, but living apart
   o Divorced
   o Separated
   o Widowed
12. What is your highest level of education?
   o No schooling
   o Some high school, no diploma
   o High school graduate, diploma or equivalent (GED)
   o Some college credit, no degree
   o Trade school/technical education/vocational program
   o Associates degree
   o Bachelor's degree

- o Master's degree
- o Doctoral degree

13. In general, would you say your health is
- o Poor
- o Fair
- o Good
- o Very good
- o Excellent

14. Do you experience difficulty in paying for basic needs, such as food, housing, medical care, and heating?
- o 1 - Not at all
- o 2 – A little bit
- o 3 – somewhat
- o 4 – quite a bit
- o 5 – very well

15. What is your current employment status?
- o Full-time
- o Part-time
- o Homemaker, no pay
- o Retired
- o Unemployed

16. If employed, how many hours do you work at your paid job?
- o Less than 10 hours per week
- o Ten to 20 hours per week
- o Twenty to 30 hours per week
- o Thirty to 40 hours per week
- o Forty hours +

Nursing Home Visitation Patterns

17. Over the past two weeks, how often did you visit your resident?
- o Every day (7 days)
- o Every other day (3 to 4 days)
- o Twice per week
- o Once per week
- o Less frequently (please specify):

18. At what time of day do you most often visit?
- o Morning (between 8 AM and 11:30 AM)
- o Mid-day (between 11:30 and 1:30 PM)
- o Afternoon (between 1:30 PM and 5 PM)
- o Evening (between 5 PM and 8 PM)
- o Night (8 PM and later)
- o Other (please specify):

19. About how long do you visit for?
- o Less than 30 minutes
- o 30 minutes to 1 hour

    o 1 to 2 hours
    o 2 to 3 hours
    o 3 hours or longer
    o Other (please specify):

20. What is your workplace zip code?
21. About how far (distance in miles) is it to travel from work to nursing home?
    o <5 miles
    o 5 to 10 miles
    o 10 to 15 miles
    o 15 miles to 20 miles
    o 20 miles +
22. About how long (time in minutes) does it take you to travel from work to nursing home at peak hours (during rush hour)?
    o <10 minutes
    o 10 to 20 minutes
    o 20 minutes to 40 minutes
    o 40 minutes to 60 minutes
    o 60 minutes +
23. About how long (time in minutes) does it take you to travel from work to nursing home at off-peak hours (NOT during rush hour)?
    o <10 minutes
    o 10 to 20 minutes
    o 20 minutes to 40 minutes
    o 40 minutes to 60 minutes
    o 60 minutes +
24. Do you most often stop at the nursing home during your commute home from work?
    o 0 – not at all
    o 1 – several days
    o 2 – more than half the days
    o 3 – nearly every day
25. Lunch: Do you visit your resident during your workplace-lunch break?
    o 0 – not at all
    o 1 – several days
    o 2 – more than half the days
    o 3 – nearly every day
26. What is your home zip code?
27. About how far (distance in miles) is it to travel from home to nursing home?
    o <5 miles
    o 5 to 10 miles
    o 10 to 15 miles
    o 15 miles to 20 miles
    o 20 miles +
28. About how long (time in minutes) does it take you to travel from home to nursing home at peak hours (during rush hour)?
    o <10 minutes
    o 10 to 20 minutes

- o 20 minutes to 40 minutes
- o 40 minutes to 60 minutes
- o 60 minutes +

29. About how long (time in minutes) does it take you to travel from home to nursing home at off-peak hours (NOT during rush hour)?
    - o <10 minutes
    - o 10 to 20 minutes
    - o 20 minutes to 40 minutes
    - o 40 minutes to 60 minutes
    - o 60 minutes +

30. What is your primary mode of transit to travel to the nursing home from home or work?
    - o Car
    - o Bus
    - o Train
    - o Bicycle
    - o Walking
    - o Other (please specify):

31. What is your preferred mode of transit to travel to the nursing home from home or work?
    - o Car
    - o Bus
    - o Train
    - o Bicycle
    - o Walking
    - o Other (please specify):

32. If you had another mode of transportation (e.g., preferred mode noted in question number 34), would you feel inclined to visit your nursing home resident more often?
    - o Not at all
    - o A little
    - o Moderately
    - o Very
    - o Unknown
    - o Refused

Transportation

This tool is used within the context of travelling to and from home and the nursing home and work and the nursing home.

Transportation Disadvantage Assessment Tool (TDAT), adapted from (Currie, 2011):

The construct is: Transport Disadvantage (TD); Definition: Transport disadvantage is the multi-dimensional experience of having frequent transportation mobility and access problems influenced by both intrinsic and extrinsic factors.

TD includes the following components across the item pool:
o   Physical exclusion – the physical nature of the transportation system may create physical and psychological barriers to access by people with impaired mobility, hearing or sight.
o   Geographical isolation - dispersed locations (e.g., goods and services, social networks) may limit the ability to carry out activities in the immediate area.
o   Economic exclusion - problems with travel costs.
o   Time-based exclusion - juggling multiple responsibilities, especially for caregivers such as older adults who parent children or care for a partner, can result in high levels of time poverty.
o   Fear-based exclusion - some people may feel fear and worry when travelling.
o   Space exclusion - some security and space-management strategies discourage socially excluded individuals from using public transportation spaces.
1.   How easy do you find covering the cost of your transportation?
    o   1 - Not at all
    o   2 – A little bit
    o   3 – somewhat
    o   4 – quite a bit
    o   5 – very well
-   How important is this item to you?
    o   1 - Not at all
    o   2 – A little bit
    o   3 – somewhat
    o   4 – quite a bit
    o   5 – very well
2.   How easy do you find getting to places quickly?
    o   1 - Not at all
    o   2 – A little bit
    o   3 – somewhat
    o   4 – quite a bit
    o   5 – very well
-   How important is this item to you?
    o   1 - Not at all
    o   2 – A little bit
    o   3 – somewhat
    o   4 – quite a bit

- o   5 – very well
3. How easy do you find being able to travel when you want to?
     - o   1 - Not at all
     - o   2 – A little bit
     - o   3 – somewhat
     - o   4 – quite a bit
     - o   5 – very well
- How important is this item to you?
     - o   1 - Not at all
     - o   2 – A little bit
     - o   3 – somewhat
     - o   4 – quite a bit
     - o   5 – very well
4. How easy do you find having to rely on others for transportation?
     - o   1 - Not at all
     - o   2 – A little bit
     - o   3 – somewhat
     - o   4 – quite a bit
     - o   5 – very well
- How important is this item to you?
     - o   1 - Not at all
     - o   2 – A little bit
     - o   3 – somewhat
     - o   4 – quite a bit
     - o   5 – very well
5. How easy do you find being able to get around reliably?
     - o   1 - Not at all
     - o   2 – A little bit
     - o   3 – somewhat
     - o   4 – quite a bit
     - o   5 – very well
- How important is this item to you?
     - o   1 - Not at all
     - o   2 – A little bit
     - o   3 – somewhat
     - o   4 – quite a bit
     - o   5 – very well
6. How easy do you find being able to physically get on/off of buses/trains or into a car or a van?
     - o   1 - Not at all
     - o   2 – A little bit
     - o   3 – somewhat
     - o   4 – quite a bit
     - o   5 – very well
- How important is this item to you?
     - o   1 - Not at all

- o   2 – A little bit
- o   3 – somewhat
- o   4 – quite a bit
- o   5 – very well
7. How easy do you find buses/trains/car/paratransit being available at night?
    - o   1 - Not at all
    - o   2 – A little bit
    - o   3 – somewhat
    - o   4 – quite a bit
    - o   5 – very well
- How important is this item to you?
    - o   1 - Not at all
    - o   2 – A little bit
    - o   3 – somewhat
    - o   4 – quite a bit
    - o   5 – very well
8. How easy do you find buses/trains/car/paratransit being available on weekends?
    - o   1 - Not at all
    - o   2 – A little bit
    - o   3 – somewhat
    - o   4 – quite a bit
    - o   5 – very well
- How important is this item to you?
    - o   1 - Not at all
    - o   2 – A little bit
    - o   3 – somewhat
    - o   4 – quite a bit
    - o   5 – very well
9. How easy do you find buses/trains/car/paratransit operating frequently?
    - o   1 - Not at all
    - o   2 – A little bit
    - o   3 – somewhat
    - o   4 – quite a bit
    - o   5 – very well
- How important is this item to you?
    - o   1 - Not at all
    - o   2 – A little bit
    - o   3 – somewhat
    - o   4 – quite a bit
    - o   5 – very well
10. How easy do you find finding transportation so you can travel?
    - o   1 - Not at all
    - o   2 – A little bit
    - o   3 – somewhat
    - o   4 – quite a bit
    - o   5 – very well

- How important is this item to you?
  - o 1 - Not at all
  - o 2 – A little bit
  - o 3 – somewhat
  - o 4 – quite a bit
  - o 5 – very well
11. How easy or difficult do you find being able to make bus/train connections?
  - o 1 - Not at all
  - o 2 – A little bit
  - o 3 – somewhat
  - o 4 – quite a bit
  - o 5 – very well
- How important is this item to you?
  - o 1 - Not at all
  - o 2 – A little bit
  - o 3 – somewhat
  - o 4 – quite a bit
  - o 5 – very well
12. How easy do you find feeling safe from theft/attack when traveling?
  - o 1 - Not at all
  - o 2 – A little bit
  - o 3 – somewhat
  - o 4 – quite a bit
  - o 5 – very well
- How important is this item to you?
  - o 1 - Not at all
  - o 2 – A little bit
  - o 3 – somewhat
  - o 4 – quite a bit
  - o 5 – very well
13. How easy do you find needing help to get around on your own?
  - o 1 - Not at all
  - o 2 – A little bit
  - o 3 – somewhat
  - o 4 – quite a bit
  - o 5 – very well
- How important is this item to you?
  - o 1 - Not at all
  - o 2 – A little bit
  - o 3 – somewhat
  - o 4 – quite a bit
  - o 5 – very well
14. How easy or difficult do you find being able to understand where to go?
  - o 1 - Not at all
  - o 2 – A little bit
  - o 3 – somewhat

- o   4 – quite a bit
- o   5 – very well
- How important is this item to you?
  - o   1 - Not at all
  - o   2 – A little bit
  - o   3 – somewhat
  - o   4 – quite a bit
  - o   5 – very well

15. How easy or difficult do you find finding the time to travel when you need to?
  - o   1 - Not at all
  - o   2 – A little bit
  - o   3 – somewhat
  - o   4 – quite a bit
  - o   5 – very well
- How important is this item to you?
  - o   1 - Not at all
  - o   2 – A little bit
  - o   3 – somewhat
  - o   4 – quite a bit
  - o   5 – very well

16. How easy or difficult do you find finding someone to provide assistance when transportation is available?
  - o   1 - Not at all
  - o   2 – A little bit
  - o   3 – somewhat
  - o   4 – quite a bit
  - o   5 – very well
- How important is this item to you?
  - o   1 - Not at all
  - o   2 – A little bit
  - o   3 – somewhat
  - o   4 – quite a bit
  - o   5 – very well

Additional Transportation Measures

Weekend mobility	- Travel time (auto & transit) from home to NH facility - For transit, quantify waiting time separately from in-vehicle time
Weekend access	Cost (fuel, transit fare and Uber/Lyft fare)
Weekday mobility	- Change in Travel time (auto & transit) from home to NH facility to work for am peak or the reverse for pm peak - For lunch hour, travel time from work to NH to work during mid-day peak - For transit, quantify waiting time separately from in-vehicle time
Weekday access	Cost (fuel, transit fare and Uber/Lyft fare) – AM peak, PM peak and lunch hour

Appendix J

Qualitative Interview Guide

1. What are some of your greatest challenges to transportation access and mobility?
2. What are some of your greatest opportunities to transportation access and mobility?
3. What are some of the most positive experiences of transportation access and mobility?
4. What are of the most negative experiences of transportation access and mobility?

Probing/Follow-up Questions

1. Can you please tell me a bit more about that...?
2. Could you say more about that...?
3. What do you mean by...?
4. What did you do then...?/What would you do then...?
5. Why do you think that is the case...?
6. What do you think would happen...?
7. What sort of impact do you think...?
8. How did you decide...?
9. What is the connection between... and...?
10. What if the opposite were true?