EXPLORING THE PREDICTORS OF WELL-BEING AND ADVANCE DIRECTIVES AMONG ELDER ORPHANS: A MIXED METHODS STUDY

by

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ABSTRACT

Exploring the Predictors of Well-Being and Advance Directives Among Elder Orphans: A Mixed Methods Study

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Elder orphan is a term popularized by the media to describe the more than 22% of community-dwelling US adults aging alone with limited social support, social isolation, multiple chronic health issues, and childlessness. Elder orphans who have not initiated advance directives are at risk of becoming *unbefriended*, having no able or willing family or friends to make medical decisions during acute injury or medical crisis. The purpose of this explanatory sequential mixed-methods study was to understand the determinants of well-being and advance care planning. A cross-sectional analysis of members (n = 368) of an online Facebook group of elder orphans was conducted followed by an interpretative phenomenological analysis of in-depth interviews with (n = 6) volunteer participants.

Hierarchical regression revealed income, adverse childhood experiences, discrimination, social network, and multiple health issues were found to be significant predictors of well-being among elder orphans, whereas mid-life events were not significant predictors of well-being among elder orphans. Contradictory to prediction, higher levels of well-being increased the likelihood of having advance directives while perceived risk of incapacitation had no influence

on the likelihood of having advance directives. The qualitative follow-up interpretative phenomenological analysis revealed four sub-ordinate themes: (1) the road to elder orphanhood: making meaning of the past; (2) a sudden halt: caregiving experiences and consequences; (3) connecting and trying to connect; and (4) barriers and future concerns. This study represents a unique and valuable examination of an under-studied group of older adults, who are often unidentified by health care professionals.

Keywords: aging, elder orphan, unbefriended, advance directives

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DEDICATION

To my parents (Mahendra and Jyoti Parekh): Thank you for instilling in me the courage, strength and, most importantly, compassion to work with populations that are often marginalized and ignored. Thank you, Dad, for helping me understand that an education is more than reading a book or solving a math problem- it is developing a knowledge base through meaningful relationships and influencing social change. Thank you, Mom, for allowing me to be me by creating a stable, loving home even during some of the most difficult times. Both of you are the most resilient, positive people I know. It is an honor to be your daughter. I love you both. You are my everything.

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Chapter 1

Introduction

Statement of the Problem

Aging alone is not a new phenomenon; however, when coupled with limited social support, social isolation, multiple chronic health issues, and childlessness, it has taken on a new, palpable identity. Carney, Fujiwara, Emmert, Liberman, and Paris (2016) recently popularized a term for older adults who are aging alone with limited social support—*elder orphans*. Elder orphans are community-dwelling older adults who live by themselves, are childless, or have limited contact with their adult children, and may have limited social networks of family and friends (Carney et al., 2016; Montayre, Montayre, & Thaggard, 2018). A recent review by Montayre et al. (2018) described the topic of elder orphans as "an under-developed topic within gerontology and health disciplines" (p. 3) and noted that no published empirical research studies exist in this area. The little we know from review and news articles about elder orphans suggests that they are a population with masked risks due to their current stable status. Yet they are at risk of outliving their caregiver, being isolated in later adulthood, and being susceptible to multiple chronic health issues with limited social support; they may also have a general lack of awareness and preparedness for other possible adversity in the latter years of life (Carney et al., 2016). It is estimated that, in the United States, elder orphan or individuals at risk of becoming elder orphans comprise more than 22% of the community-dwelling older adult population aged 65 and over (Carney et al., 2016). This figure points to a troubling future for elder care.

The words of the famous Robert Barrett Browning sonnet, "Grow old with me! The best is yet to be…" (Browning, 1917, p. 106) speak to our primal desire for companionship as we age; however, the reality is that many of us will spend our golden years alone. Several reasons

account for the uptick of elder orphans in the United States. The total size of the baby boomer population, compared to other generations, makes this cohort particularly noteworthy. The oldest boomers, born between 1946 and 1964 (Merriam-Webster, 2018), turned 65 in 2011, and this post-World War II generation may constitute a large proportion of the elder orphan population (Ortman, Velkoff & Hoga, 2014). In 2029, when the youngest boomers will have reached the age of 65, they will comprise 20% of the entire US population (Colby & Ortman, 2014). Although boomers have historically been on the frontline of much societal change, they are approaching ages in which they are likely to experience several life course transitions. Over one-third of baby boomers have no children, and this population is particularly vulnerable to aging alone with little to no social support (Carney et al., 2016; Lin & Brown, 2012). Furthermore, during the aging process, individuals are likely to lose friends and loved ones to migration, morbidity, mortality, lifestyle changes, and other adverse events that may terminate their relationships (Angel, 2011). The effects of relationship loss over time, some intermittent and others cumulative, are also more likely to become pronounced during old age. Other factors that contribute to becoming an elder orphan include increased life expectancy, geographic dispersion, the disintegration of the nuclear family, economic and retirement challenges, rising inequality, and multiple chronic health conditions (Angel, 2011). Gender, ethnicity, disability, socioeconomic status, and marital status are factors that further influence who is aging alone.

In 2017, 13.8 million or 28% of all noninstitutionalized older adults were living alone in the United States; of these 9.3 million are women (Administration for Community Living, 2017). Older women live alone at more than double the rates of their male counterparts, affecting almost half of women over the age of 75. Widows outnumber widowers by more than three times. As of 2017, there were 8.9 million widows compared to 2.5 million widowers. The numbers of

divorced and separated older adults in the United States have steadily risen from 5.3% in 1980 to 15% in 2017 (Administration for Community Living, 2017). Persons who abuse substances or who are mentally ill are more likely to live alone and be socially isolated from friends and family (Meis, 2004). Older adults who live alone are more than three times more likely to live in poverty than older adults living with family (Administration for Community Living, 2017).

Older adults who are aging alone are at risk for many adverse physical and mental health outcomes. One such risk is having no family or friends during acute injury or medical crisis. This can be even more devastating if the elder orphan has not initiated advance directives prior to a medical crisis that leaves them incapacitated. Incapacitated older adults who lack advance directives (i.e., living will or health care proxy) and have no able or willing family or friends to make health care decisions for them are referred to as unbefriended (Parekh & Adorno 2017; Pope, 2012).

In 2016, the American Geriatric Society issued a call to create model legal standards for patients who are at risk of becoming unbefriended and identified elder orphans as the population of older adults who are most at risk (Farrell et al., 2017). Older adults who do not have decisional capacity and have no surrogate decision maker face a myriad of safety problems, ranging from recurring placement and inappropriate settings to over- and under-treatment. Some health care professionals have described unbefriendedness as one of the biggest public health threats of the 21st century (Bandy, Helft, Bandy, & Torke, 2010; Pope, 2012).

Connor et al. (2016) identified elder orphans as a "critical window of opportunity" (p. 131) for health care professionals seeking to develop prevention programs that mitigate the risk of older adults becoming unbefriended. The descriptive or anecdotal nature of much of our

knowledge about elder orphans makes it difficult to develop targeted interventions to mitigate the risk of becoming unbefriended among this population.

Purpose

The purpose of this study is to develop a foundation for understanding elder orphans in the United States. It does so by examining the determinants of well-being through the lens of life course and cumulative advantages/disadvantages theory while identifying the factors that influence advance care planning among this population. A two-phase mixed-methods approach is utilized to answer the proposed research questions (Creswell & Plano Clark, 2017). In the first, quantitative phase of the study, the research questions focus on factors that influence well-being throughout the life course and advance care planning among a sample of elder orphans. In the second, qualitative phase of the study, participants from an online Facebook group completed open-ended, in-depth telephone interviews to explore the lived experiences of elder orphans and to further investigate the results from quantitative analyses.

Four complementary theories were utilized to examine the factors that influence well-being throughout the life course and advance care planning among elder orphans. A large body of research exists on older adults and life course theory (Kim & Moen, 2002; Moen, 1996; Moen, Robison, & Dempster-McClain, 1996), cumulative advantage disadvantage theory (Dannefer, 2003; Willson, Shuey, & Elder, 2007), capabilities theory (Coast et al., 2008; Stephens, Breheny, & Mansvelt, 2015), and the health belief model (HBM; Ferraro & Kelley-Moore, 2003; Hanson & Benedict, 2002). However, no studies have examined elder orphan populations using these four theoretical frameworks. Together, these theories provide a roadmap to better understand the cumulative advantages and disadvantages throughout the life course that influence well-being and advance care planning.

This research has significant implications for practitioners and policymakers engaged in efforts to develop community-based prevention models and legislative pathways for elder orphans at risk for becoming unbefriended. An understanding of the factors throughout the life course that influence current levels of well-being and advance care planning is critical to developing health behavior change interventions that are holistic in nature and acknowledge the unique perceptions and beliefs of elder orphans. Furthermore, elder orphans provide a unique opportunity to reduce the overall number of unbefriended older adults in the United States. Elder orphans may share many of the same characteristics as unbefriended older adults but continue to have the capacity to make medical decisions. Thus, prevention programs that address the barriers faced by elder orphans in initiating advance directives and developing meaningful relationships with individuals who can serve as surrogate decision makers in the event of medical crisis or acute injury may reduce the overall number of unbefriended older adults in the United States.

As autonomy and self-determination are fundamental to an individual's well-being, the development of legislative pathways, prevention models, and supportive services for this growing older adult population is vital to social work practitioners, policymakers, and scholars. Finally, Carney et al. (2016) describes elder orphans as unrecognizable due to the clinician's inability to recognize or know how to address the needs of this population. Thus, this study represents a unique and precious opportunity to examine an under-studied group of older adults, who are often unrecognizable to health care professionals. By building awareness of the pressing issues facing individuals aging alone, findings from this study can be used to develop appropriate screening and assessment tools that help identify at-risk elder orphan populations.

Key Concepts

This present study seeks to address this gap by examining how life course factors influence current levels of well-being, and how well-being and perceived risk of incapacitation influence advance care planning among a sample of older adults who identify with the term *elder orphans*. More specifically, this present study is focused on understanding the predictive factors for unbefriendedness and the interplay among three key variables (well-being, perceived risk of incapacitation, and the likelihood of having an advance directive) to better understand the factors throughout the life course that influence well-being and advance care planning among a growing older adult population aging alone with little to no social support.

Well-Being

Well-being is a multidimensional construct with no single definition; it is a multifaceted and complex construct that encompasses, among other things, aspects of mental and physical health (Centers for Disease Control and Prevention [CDC], 2016). Another essential component of well-being is financial freedom, which is important throughout the life course but can be particularly important during the latter years of life when employment opportunities are reduced by choice or other factors.

Women who age alone are particularly at risk for financial problems later in life; they experience a substantial loss of income throughout their lives due to lower-paid jobs, irregular employment, child birth, widowhood, and divorce, which impacts their late-life well-being (Budig & England, 2001; Kalmigin, 2007; Klinenberg, Torres, & Portacolone, 2013). The various life transitions that threaten economic stability over the years may have a cumulative effect on reducing aging women's levels of well-being (Kalmigin, 2007). According to cumulative advantage disadvantage theory (CAD), the cumulative advantages and

disadvantages that occur across the lifespan impact current levels of well-being. From this perspective, the cumulative disadvantages spanning from childhood to late life (e.g., early sexual abuse or current economic disadvantage) may play an important role in explaining low levels well-being among elder orphans (Willson, Shuey, & Elder, 2007).

As this study focuses on a predominantly female sample, it is germane to understand the factors that explain variance in a well-being variable that includes questions about women's financial freedom. For the purposes of this present study, well-being is operationalized as a composite of an individual's perception of meaningfulness and well-being (subjective well-being) and financial freedom (such as having the freedom and opportunity to make financial choices and decisions).

Perceived Risk of Incapacitation

According to the health belief model (HBM), perceived risk refers to an individual's appraisal of the likelihood of experiencing an incapacitating disease, illness, or adverse event (Strecher & Rosenstock, 1997). Research shows that high risk perceptions are associated with increased motivation to adopt protective health behaviors (Mullens, McCaul, Erickson, & Sandgren, 2004). This is because threat and self-efficacy are associated with self-protecting behaviors, whereas denial and avoidance are linked to low risk perceptions. Therefore, risk perceptions and well-being become important factors in health behavior change interventions. Although a considerable body of research illustrates that interventions successfully change risk perceptions and produce subsequent positive increases in health behaviors (Fisher & Fisher, 1992; Riman & Real, 2003; Steinberg, 2004), limited research gives attention to how risk perceptions influence advance care planning among older adult populations.

Advance Directives

The literature on the precise motivators and barriers to advance directive initiation is scant. Thus, there is limited empirical research about how best to develop interventions that address successful completion of advance directives, particularly among elder orphans. When an incapacitated individual does not have an advance directive, states rely on a hierarchy statute that lists family and friends in differing orders as potential surrogate health care decision-makers (Hopp, 2000). Therefore, the most vulnerable, at-risk patients are those who lack advance directives and family or friends who are available or willing to make health care decisions on their behalf. Few studies have considered the interconnections between well-being, risk perceptions, and advance care planning.

Chapter 2

Literature Review

This chapter offers a foundational understanding of elder orphans by providing a comprehensive review of the literature related to aging alone with limited social support. Additionally, an overview of the risk factors and characteristics associated with this population is presented. The literature on barriers to advance directive initiation is explored.

Elder Orphans

A growing number of older adults who live alone are identifying with the term elder orphan. It first appeared in academic literature in 1994 (Soniat & Pollack, 1994), resurfaced briefly in 2005 (Varner, 2005), and became an established concept in the field in 2016 (Carney et al., 2016). The term likely builds upon the term *geriatric orphan*, first mentioned in 1997 by Dr. Thomas Cuyegkeng, in a seminar on the problems of severely isolated older adults who were discharged with no one to provide care at home. He defined the geriatric orphan as "any elderly person over the age of 65 who was isolated to some degree from family members" (Meis, 2004, p. 3).

Although the term elder orphan is much more recent, the concept of aging alone is certainly not a new one. Tunstall (1966) conducted a study of 538 older British adult men and women. In perhaps one of the earlier definitions of elder orphan, Tunstall's criteria for defining "old and alone" included (a) living alone, (b) social isolation, (c) loneliness, and (d) anomie (i.e., being cut off from the broad social values of one's society).

More recently, Meis (2004) conducted a qualitative study of geriatric orphans, in which he interviewed 38 adults, aged 65 and older, who were "extremely isolated" (p. 36). In his study, participants described dealing with numerous losses, including their health and mobility and the deaths of those dearest to them. Older adults with greater access to resources and social connectivity were better able to meet basic needs. Many older adults in the study yearned to return to work to feel needed and worthwhile (Meis, 2004). Those with physical limitations and health issues that kept them homebound were most likely to report loneliness and other risks associated with aging alone (Meis, 2004).

Carney et al. (2016) popularized the concept of elder orphans. They understood this group to be a unique set of older adults who are independent most of their lives but who are often unprepared for future medical problems as they age and experience declining health. Using the US Census and University of Michigan's Health and Retirement Study, Carney et al. estimated the prevalence of elder orphans 65 years and older at approximately 22% of the community-dwelling older adult population in the United States. While empirically examining the prevalence of elder orphans, Carney et al. (2016) also offered practical approaches and solutions for clinicians and health care professionals to identify and develop health care plans that meet the diverse needs of older adults at risk of becoming elder orphans.

Ziettlow and Cahn (2015) discussed the misconceptions surrounding older adults who are aging alone, and the potential negativity associated with the term elder orphan. They concluded that older adults' intentional preparation for aging played a critical role in their well-being in late-life. They advocated for the expansion of community resources, intergenerational connections, and paid caregiving to include family and friends. They claim that not all older adults aging alone are isolated and at risk; however, they discuss the need for additional

awareness of the risk for elder abuse among vulnerable older adult populations (Ziettlow & Cahn, 2015).

A few studies have drawn attention to health care providers' lack of awareness about the limitations that older adults face in accessing support. Soniat and Pollack (1994) noted the paucity of services available to older adults who are aging alone with limited support. Their study focused on cognitively impaired older adults who receive care from formal services and advocated for increased clinical assessment and research to better understand the issues facing older adults aging with limited support. Varner (2005) discussed the actions and skills necessary to begin to identify elder orphans within health care settings. He also encouraged increased advocacy for older adults, specifically so that health care providers can identify and provide services to them. Online news sources have discussed legal, caregiving, housing, and transportation issues faced by elder orphans (Marak, 2017). In a recent article, Marak (2017) referred to elder orphans as *solo agers*. Ianzito (2017) pointed to the role of popular assumptions about aging in expectations that all older adults will have family or others to care for them. He further discussed how these assumptions often resulted in limited to no services for the most vulnerable older adult populations and provided tips for aging without a caregiver.

Other studies have identified certain populations that face specific challenges in receiving care during late life. Schlecht (2018), who also defined elder orphans as an at-risk older adult population with future care concerns, discussed the issues around reduced family caregivers in contemporary society. The shift away from traditional forms of elder care in this country, in which family caregivers provided most long-term care, have led to the emergence of unique caregiving needs for older adults who are increasingly aging alone. She further explains how these issues will disproportionality impact baby boomers and LGBTQ older adult populations.

Contemporary Challenges and Aging

Due to the lack of empirical studies on elder orphans, there is little evidence indicating the age cohort to which elder orphans belong. Indeed, Carney et al. (2016) described elder orphans as "hiding in plain sight" (p. 1). This invisibility is likely due to elder orphans comprising part of a younger older adult population (baby boomers), who may not exhibit the risk factors associated with aging alone without support. It is thus important to identify the issues confronting the aging boomer population. The sections below discuss the factors related to contemporary aging that contribute to the concept of the elder orphan.

Baby Boomers

Many of the challenges related to aging today stem from the sheer number of individuals who will turn 65 in the next 25 years. Knickman and Snell (2002) examined demographic data and reviews about projected challenges of caring for frail older adults in 2030 and found that advancing medical technology, organizing social services, and altering the cultural view of aging will be critical to developing age-friendly communities. They further concluded that to meet the future long-term needs of baby boomers, social and public policy shifts must begin soon. Boomers represent approximately 76 million people, and their unique needs will dictate how we deliver care, reimburse services, and develop new models of care (Knickman & Snell, 2002).

Changes in health. It is unclear if boomers will experience elevated health risks due to debilitating conditions, increased disability, and morbidity rates as compared to previous generations. Remarkably, only a handful of studies have empirically addressed these questions. Using data from the National Health Interview Survey (NHIS), Lakdawall, Bhattacharya, and Goldman (2004) found that during an eight-year span (1984–1996), disability rates among adults aged 40–59 were lower than previous generations, potentially due to changing family dynamics

and work schedules. The participants, however, needed increased help in personal care routines, as personal care may be linked more to personal preference than disability (Lakdawall et al., 2004). In another study using NHIS data, researchers found that both poor health and mortality rates trended downward among older adults born between 1946 and 1962 (Martin, Schoeni, Freedman, & Andreski, 2007). These mixed results suggest that a more nuanced inquiry is necessary.

Using data from the Health and Retirement Study (HRS), Soldo, Mitchell, Tfaily, and McCabe (2007) found that older adults had far worse health and functioning conditions in 2004 than older adults in 1992. The study linked the vast differences in outcomes to socioeconomic changes (e.g., retirement and pension changes) and shifts in aging policy (Soldo et al., 2007).

Several important points regarding physical health for older adults should be made. First, examining outcomes over relatively long periods of time allows for a more complete understanding of well-being and health among older adult populations. Secondary data sets that allow for an examination of data points at various time periods can be helpful to such inquiries. Second, measures may move in opposite directions: declines in disability may not be directly related to chronic health conditions. Results from several studies support that late-life disability has declined among younger boomer populations as chronic health conditions have increased (King, Matheson, Chirina, Shankar, & Broman-Fulks, 2013; Shankar, McMunn, Demakakos, Hamer, & Steptoe, 2017). Ultimately, results from recent studies reveal that "no single indicator is a pure measure of health" (Martin, Freedman, Schoeni, & Andreski, 2009, p. 1).

The past decade has seen substantial advances in medicine and science. As a result, people are now living into their 70s, 80s, and beyond. Many of these older adults live alone, carve their own paths, and strive to be as independent as possible. However, many of the

diseases that plagued previous generations, including syphilis, tuberculosis, polio, and small pox, have been replaced by chronic diseases including heart disease, obesity, cancer, stroke, Alzheimer's disease, and diabetes (Jones, Podolsky, & Greene, 2012). Despite the availability of effective treatments, people are generally experiencing a broad spectrum of negative health consequences related to such chronic diseases (Reddy, 2016).

In 2017, the Center for Medicare and Medicaid Services (CMS) reported that two out of three older adults in the United States have multiple chronic conditions and are at greater risk of impaired day-to-day functioning. Individuals who live alone, have a limited or nonexistent social network, and have multiple chronic conditions are at particularly high risk for comorbidities, which can lead to multiple hospitalizations or premature mortality (CMS, 2017)

Chronic diseases impact people's everyday lives, often inhibiting their performance of instrumental *activities of daily living* (ADLs), such as shopping, taking medicines, and preparing meals. As individuals experience further declines in health, more routine ADLs, such as getting dressed and maintaining personal hygiene, also become troublesome (CMS, 2017). Chronic disease among older adults is related to a host of other concerns, including disaster preparedness (Aldrich & Benson, 2008), health literacy (Wolf, Gazmararian, & Baker, 2005), hearing loss (Dalton, Cruickshanks, Klein, & Klien, 2003; Hughes et al., 2001), perceived isolation (Cornwell & Waite, 2009), social disconnectedness (Cornwell & Waitie, 2009), well-being (Ostir, Markides, Peek, & Goodwinto, 2001), and caregiving burden (Garlo, O'Leary, Van Ness, & Fried, 2010).

Linking physical and mental health. The first director of the World Health Organization statement, "without mental health there can be no true physical health" (p. 1), intimately linked mental and physical health (Kolappa, Henderson, & Kishore, 2013).

Neuropsychiatric conditions, such as depression, dementia, and Parkinson's disease, account for over a quarter of disability-adjusted life years, which is the sum of years survived with an illness and years lost to illness (Prince et al., 2007). Studies indicate that depression in older adults is overwhelmingly a result of multiple health issues, which ultimately lead to disability (Bruce, 2001). According to the population-attributable fraction, 69% of all cases of disability are related to mental health conditions among older adult populations, suggesting that failing health is a strong predictor of depression among this population (Prince et al., 2007). In a population-based study that examined the relationship between disablement and depression in late-life among older adults over 65 years of age ($N = 889$), lack of contact with friends was directly linked to depression, which moderated the relationship between disability and depression (Prince, Harwood, Thomas, & Mann, 1997). Furthermore, marriage among men was considered a protective factor but was considered a risk factor among women (Prince et al., 1997). Low social support and social participation were predicted by maintenance of depression (Prince et al., 1997).

The chronic health issues associated with mental health concerns can be debilitating to those who are aging alone. Older adults aging alone are vulnerable to developing feelings of loneliness and depression (Victor, Scambler, Bond, & Bowling, 2000). Depression is a major public health issue and is often comorbid with other chronic health issues, which can worsen with associated health outcomes (Moussavi et al., 2007). The burden of mental health disorders is often underestimated because of the lack of attention given to the connectedness between mental illness and physical health (Prince et al., 2007). These connections, between mental and physical health problems, may be bidirectional. Mental health disorders are linked to communicable and non-communicable disease and contribute to a significant amount of injury

(Mezuk, Eaton, Albrecht, & Golden, 2008; Prince et al., 2007). Contrarily, chronic health conditions such as diabetes, arthritis, and heart disease can increase the risk of mental health issues (Prince et al., 2007). Thus, the mental health and well-being of elder orphans may be a part of their vulnerability to potentially debilitating physical health problems that require care and advance care planning.

Multiple studies have shown the link between physical and mental health. High obesity rates may be influenced by depression or other related mental health conditions, particularly in women (McElroy et al., 2004). The "Jolly Fat" hypothesis suggests that there is a greater stigma to being overweight for women than men (Palinkas, Wingard, & Barrett-Connor, 1996). A population-based study of 2,245 community-dwelling men and women between the ages of 50 and 89 found an inverse relationship between weight and depression for men but not for women (Palinkas et al., 1996). Weight played a critical role in mental health, and noteworthy differences between men and women were revealed through a more nuanced analysis. A meta-analysis that examined links between obesity and depression reported a significant link between them (Luppino et al., 2010), and further reported that an increase in clinically diagnosed depression was found to be predictive in developing obesity. Other factors that have been linked to worsening physical and mental health issues among older adults include loneliness (Coyle & Dugan, 2012; Steptoe, Shankar, Demakakos, & Wardle, 2013), social isolation (Coyle & Dugan, 2012; Steptoe et al., 2013), widowhood (Onrust & Cuijpers, 2006; Wilcox et al., 2003), familial disputes (Fingerman, Pillemer, Silverstein, & Suitor, 2012), childlessness (Kendig, Dystra, & van Gaalen, 2007; Ross, Mirowsky, & Goldsteen, 1990; Zhang & Hayward, 2001), financial instability (Angel, Frisco, Angel, & Chiriboga, 2003), and divorce (Brown & Lin, 2012).

Living Alone

According to a Pew Research Center study (2016), over 24% of older adults live alone. The same study found that, in 2014, the majority (55%) of older adults living alone were unmarried (Pew Research Center, 2016). There is, however, variability by gender. Although women continue to outnumber men in living alone, the number of women living alone since 1900 has declined, compared to their male counterparts. Currently, over 34% of women aged 65 and older live alone, while only 18% of men in the same age group live alone. The oldest old population (aged 85+) who live alone has modestly risen, accounting for 2.4 million older adults in the United States. Considering older adults overall, there has been a decrease of the number of older adults living alone; this has been mostly fueled mostly by the rise of multigenerational households. It is important to note, however, that those who are never married and do not have children do not benefit from this trend (Stepler, 2016).

Older adults who live alone are linked to their assessment of their well-being. Research suggests older adults living alone report poorer health (Karicha, Iliffe, Harari, Swift, Gillmann, & Stuck, 2007), difficulties in instrumental and rudimentary activities of daily living (Lawton & Brody, 1969; Ng, Niti, Chiam, & Kua, 2006), worse memory and mood (Karicha et al., 2007), poor diet (Karicha et al., 2007), and multiple falls (Karicha et al., 2007). Gender plays a critical role in the assessment of well-being among older adults living alone. For example, the social and financial lives of older adults living alone differs greatly according to gender. In 2014, 2.2 million or 18% of older adults who lived alone were poor, compared to 6% of older adults who lived with others. Although women, regardless of living situation, are more likely to live in poverty than men, older women living alone account for 1.6 million individuals in the United States, while older men account for only 600,000 individuals in the United States (Stepler, 2016).

Older women who live alone have more developed social lives than their male counterparts. Men who live alone experience considerably more social isolation than women. Approximately half (48%) of men who live alone are satisfied with their friendships, compared to 71% of women who live alone.

Perceptions about living alone influence well-being. In an exploratory study that examined older adult women's (N = 53) perceptions of living alone, Eshbaugh (2008) found vast variability in participants' views, even though a plurality (37.7%) viewed living alone in a positive light. The positive feeling of living alone among these women stemmed from their newly gained independence, while the less desirable aspects of living alone were identified as lack of companionship (62%), no help with housework (36%), and fear of falls or getting injured (30%).

Older adults who live alone are often unable to age in place because of multiple chronic health issues. These conditions can restrict engagement and enjoyment with family and friends, further isolating those who live alone. The lack of mobility can further narrow an older adult's world and increase the risk of depression and other related mental health concerns (Webber, Porter, & Menec, 2010). Older adults who live alone and have multiple chronic health issues are also at risk for institutionalization.

Living alone with multiple health issues, financial difficulties, limited social support, and poverty can be detrimental to well-being. Moreover, older adults living alone with multiple health issues are particularly at risk for falls (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004). Experts have described falls in older adults as a slippery slope that leads to many adverse health and mental health issues (Fried et al., 2004). Falls are preventable with appropriate in-home assessment, adequate social support, and modifications to the home environment.

Clinical care must integrate aspects of both physical and mental health, particularly in the development of interventions targeting older adults who are aging alone. These older adults are more vulnerable to loneliness and depression, and as depression is a strong predictor of physical diseases such as cardiovascular disease and cancer (Alexopoulos, 2005; Prince et al., 2007), their physical well-being is also at risk of being compromised. Strong social networks can help reduce the risk of depression and increase well-being (Victor et al., 2000). It is thus critical to develop interventions that bolster social networks among older adult populations who are aging alone.

Social Network and Connectivity

Social networks are defined as social connections, bonds, and links between people (Valente, 2010). Social networks can offer social support, but they also have other functions, such as social influence, companionship, and social comparison. These social connections have various functions and levels of quality. For example, social networks or linkages between people are a starting point; however, the extent to which the interactions are meaningful depends on how well the network members interact, experience diversity, proximity, and the extent to which they share power equally (Valente, 2010). Furthermore, the characteristics of the relationships within the network are critical to its quality. The measurement of various constructs within social networks focus on traits such as the quality, function, and characteristics of the relationships within them. For older adults, a strong social network is, furthermore, an important protective factor against being unbefriended.

In recent years, boomers looking to engage with same-age peers have flocked to social media sites for connectivity. According to a survey by the Pew Research Center (2016), boomers are the fastest-growing generation to adopt new technology and social media. Over 57% of boomers now use social media sites like Facebook and LinkedIn, while only 23% of silent

generation (born 1920–1940) use social media (Jiang, 2018). Between July 2015 and December 2016, an estimated 8.6 million boomers joined Facebook in the United States alone (Jiang, 2018)

Baby boomers are using social media to stay connected with family and friends, join groups of individuals with similar interests, and seek information and knowledge. Facebook hosts several boomer-specific groups, including the Elder Orphan Facebook Group, Northeast Philly baby boomers, Boomer Benefits, and Viva Fifty in English. According to a study of 222 Australian adults over 55 years old, increased use of the Internet as a communication device was associated with lower levels of loneliness, yet older adults who tend to experience higher levels of emotional loneliness are the most likely to use the Internet to seek social interaction (Sum, Mathews, Hughes, & Campbell, 2008). Internet use has also been linked to depression in older adulthood **(**M'hiri et al., 2105**).**

Pathways to Becoming an Elder Orphan

Marital status and childlessness are critical to deciphering the potential risk and vulnerabilities facing a growing number of boomers, who represent the world's largest older adult population aging alone (Lin & Brown, 2012). Using the US Census from 1980, 1990, and 2000 and the 2009 American Community Survey (ACS), Lin and Brown (2012) found that the percentage of boomers who are unmarried has steadily increased in the past three decades—almost doubling from 1980 to 2009. The gender gap in marriage rates, however, has decreased. In this study, more than a quarter of boomers lived alone, and one-third were predicted to reach the age of 65 while childless. Overall, the findings revealed that boomers who live alone and are childless experienced more economic, health, and social disadvantages than their cohabitating counterparts. This monumental study reveals the importance of better understanding the

pathways that lead to singlehood and childlessness, and the potential consequences and risk factors associated with varying marital statuses and childlessness.

Divorce and Health Outcomes

The divorce rate in the Unites States has doubled since the 1960s (National Center for Health Statistics, 2016). Consequently, it is critical to gain an understanding of the impact of divorce on various dimensions of older adulthood and to develop holistic interventions for divorced individuals who experience adverse physical and mental health issues. Although the height of divorces in modern history occurred when baby boomers were in their early 20s and 30s, little attention has focused on baby boomers' marital status and its impact on old age. Divorce is a transitional period during which the departure from previously known routes and roles may result in the loss of friends and family and financial security (Amato & Rogers, 1997). Additionally, divorced individuals, particularly men, have a higher risk of adverse relationships with their children because they may miss much of their children's formative years (Amato & Rogers, 1997). As a result, they may struggle to develop meaningful relationships with their children throughout their lives (Amato & Rogers, 1997).

The loss of these close relationships can be especially impactful as men enter old age. To further complicate the issue, we know little about older men and the loss of social relationships throughout the life course and their ability to transition to new roles successfully after the loss of a spouse either through divorce or widowhood. Divorced women and widows have their own challenges as they enter old age. It is well documented that women tend to experience financial instability after a divorce or the loss of a partner (Wallerstein & Kelly, 2008). As they age and enter retirement, divorced women have issues related to their financial well-being. Regardless of age and years married, women experience a 20% decline in their income after a divorce, while

men experience a 30% increase in their income post-divorce (Jenkins, 2008). Historically, the laws and policies affecting divorced individuals have not been favorable to recipients of social security benefits (Meyer, 1996). Moreover, only a small number of divorced women take advantage of the social security benefits after the divorce of a spouse partially due to the lack of awareness about the availability of such benefits (Fonesca, Mullen, Zamarro, & Zissimopoulos, 2012). While important to the financial well-being of older adults, pensions can be complex and difficult to divide after a marriage has dissolved. Older women are disproportionately impacted by these laws and policies (Fonesca et al., 2012). Whereas women are more likely than men to experience financial instability after a divorce, they enjoy stronger relationships with their adult children (Kaufman & Uhlenberg, 1998). Little is known about how financial instability in old age among divorced women impacts relationships between parent and their adult children as it relates to increased financial burdens on the adult children.

Widowhood and Late Life

Widowhood is also a transitionary period in older adults lives that can have adverse consequences. Beckman and Houser (1982) found that widowed, childless older women had decreased mental health and well-being outcomes than widowed mothers, and childlessness had no significant effect on married women who became widows. This suggests the combination of being widowed and without children is detrimental to the well-being of older female populations. Koropeckyj-Cox (1998) reported similar findings using data from the National Survey of Families and Households, concluding that the experience of parental status is best understood within the context of marital status. In other words, marriage may be a buffer against adverse outcomes in late life. Marriages, however, do eventually dissolve, due to a spouse's death or divorce; thus, developing preventive and supportive interventions that address loneliness,

depression, and preparedness among married older adults may help mitigate the risk of severe mental and physical health outcomes related to the loss of a partner in late-life.

Additionally, less is known about the complexities related to depression, loneliness, and living alone after the loss of a spouse in late life. Feelings of depression and loneliness may be obvious responses to losing a companion; however, research demonstrates that the loss is experienced in a much more complex and multifaceted way among certain older adults from previous generations (Luanaigh & Lawlor, 2008). Research on older men and widowerhood suggests that men have a more difficult transitional period after the loss of a spouse than their female counterparts (Bowling, 1987). Van Den Hoonaard (2009) conducted 26 qualitative interviews with widowed men and found that a perceived sense of masculinity influenced older men's ability to accept their widower status.

Never-Married Older Adults

Pinquart (2003) examined loneliness and social support systems among married and never-married older adults and found that unmarried older adults are more dependent on siblings, friends, and neighbors than married older adults and are particularly reliant on their neighbors during emergency situations. Fostering and building neighborhood and community resources and strengthening sibling relationships may be beneficial for older adults who are unmarried and childless. However, older adults who are unmarried and have functional limitations are more likely to experience loneliness and fractured social networks (Pinquart, 2003). This is due to their own withdrawal from family and friends for fear of being burdensome (Pinquart, 2003).

Childlessness

Childlessness, regardless of material status, can also influence late-life outcomes. According to the US Census (2012), nearly 19% of women aged 40–44 are childless, compared

to 10% who were childless in 1980; one-third of people aged 45–63 are single. Moreover, the majority of older adults, particularly baby boomers, who live alone are unmarried and childless (Lin & Brown, 2012).

Adult children play a vital role in caring for their aging parents. Historically, older adult parents depended upon on their adult children as an old-age insurance policy—security during times of difficulty later in life. Adult children in the United States and throughout the world have been and continue to be tasked with providing incremental support when parents are no longer able to do so. Yet the number of childless older adults has increased in recent years (Zhang & Hayward, 2001). This raises critical questions about who will care for the growing number of childless older adults and whether childlessness in old age will impact all individuals in the same way.

Historically, parenthood was viewed as a protective factor and a buffer against negative stressors throughout midlife and old-age; however, varying pathways into relationships and parenthood have influenced the quality of intergenerational relations (Barber, 2000). In other words, the departure from traditional family and parenting arrangements has potentially influenced the levels of social support in late life.

It is also important to understand pathways to childlessness among older adult populations. Childless older adults are a heterogeneous group with varying reasons for not having children. Each of these subgroups of childless older adults may have divergent experiences from one another and diverse late-life outcomes. Some of these reasons include an active decision to not have children, outliving their children, infertility, and lost contact with family due to disputes and disturbances (Qu & Weston, 2001).

Outliving children. Older adults who outlive their children are particularly noteworthy in this discussion. Individuals who outlive their children experience a major unexpected turning point in their lives. Within this group, a number of individuals experience an additional major loss: the death of their spouse. Although this group does not experience social disapproval and often gains sympathy, they may experience adverse physical and mental health outcomes late in life (Dykstra & Hagestad, 2007). Bures, Koropeckyj-Cox, and Loree (2009) examined diverse parenthood trajectories and late-life outcomes using multiple secondary data sets and found that older women who outlived their children had some of the worst physical and mental health outcomes in late life.

Impaired familial relationships. Another vulnerable group of older adults is older adults who are no longer in contact with their children. Burnes et al. (2009) described older adults who lose contact with their children, regardless of marital status, as a vulnerable group because the relationship is often severed due to conflict or disappointment. The literature available in this area is scant, and it is thus critical to better understand how familial conflict impacts late-life outcomes.

Non-traditional families. Research has focused on the emotional and instrumental support that older adults receive from their biological children but has ignored the support from stepchildren and adoptive children (Schwarz, Trommsdorff, Albert, & Mayer, 2005). Although adoptive parents have the same legal obligations as biological parents, stepparents' relationships are most often dependent on when they entered the stepchild's life and whether they have a positive relationship with the child's biological parent (Sweeney, 2010). Thus, all three parenting modes (adoptive, biological, and step) are different avenues to parenthood that can result in differences and vulnerabilities among subgroups of older people.

Varying parental and marital pathways. Social surveys rarely distinguish between different parenting statuses, ignoring the nuances that may result in varying pathways among older adult populations. These varying pathways bring challenges but also opportunity for support during older adulthood, particularly if those relationships are cultivated throughout the life course. The complex interplay of varying parental and childlessness statuses is further complicated by their respective differing definitions. As Bures, Koropeckyj-Cox, and Loree (2009) observed, there are inconsistencies and imprecision in how childlessness and parental status have been defined in the literature, which makes it difficult to obtain adequate information about the varying parental pathways and their influence on caregiving relationships and late-life outcomes.

Having children has historically been strongly correlated with marital status. Although this is rapidly changing, an understanding of the interplay of marital status and childlessness on well-being outcomes among older adults provides insight into the multidimensional, complex social relationship trajectories of individuals and families. Additionally, gender differences continue to play a critical role in understanding late-life outcomes between varying marital, parental, and childlessness statuses (Hansen, Slagsvold, & Moum, 2009). As mentioned above, limited literature is available in this area, although a few existing studies have examined these complex interplays (Bures et al., 2009; Larsson & Silverstein, 2004). These studies are likely a response to the increasing proportion of childless older adults and the concerns regarding potential issues related to childlessness in late life uncovered by popular news sources and social media.

Older adults who are childless and unmarried compared with older adults who are childless and married may have varying levels of social support throughout their lives. In a study

that examined unmarried and married childless older adults, Johnson and Catalano (1981) found that married childless couples experience more social isolation than their non-married childless counterparts and are less likely to be institutionalized. Further, unmarried childless older adults experienced far less support once discharged from the hospital (Johnson & Catalano, 1981). This finding has interesting implications as it relates to varying support systems during different stages of older adulthood. Older adults who are unmarried and childless may experience less social isolation than their married childless counterparts; however, during illness or hospitalization their supports may dwindle. This is further supported by a study across several countries on childlessness and marital status among older adult populations (Koropeckyj-Cox, 2007). The findings from this study reveal that childlessness is not an issue among never-married or married individuals until near the end of life when familial ties are central to caregiving roles. As family is central to caregiving during critical times of need, bolstering family relationships, including with nieces and nephews for persons who are unmarried and childless, may be critical to their well-being and sustained social support in the event of medical crisis or acute injury (Eggenberger & Nelms, 2007). Furthermore, negative perceptions of childless older adults may influence their well-being. Age-friendly initiatives that focus on expanding or providing accessibility for older adults with functional limitations are critical in helping change negatively influenced perceptions about aging alone (Adorno, Fields, Parekh, & Magruder, 2016). These initiatives can facilitate open dialogue about self-perceived burden and its role in aging well, particularly among childless, unmarried older adults (McPherson, Wilson, & Murry, 2007).

Diversity Among Elder Orphans

Diversity among elder orphans was described above with differences related to marital status and childlessness. Gender and racial or ethnic differences further contribute to disparity in

older adults. One study found that the inequality and health disparities among boomers are nearly 15% greater than their parents at the same age (Easterlin, Schaeffer, & Macunovich, 1993).

Although female boomers are described in the literature as well-educated, healthy, and economically secure, disparities exist within this population, particularly among single mothers (Yamokoski & Keister, 2006). According to Curtis and Rybczynski (2015), female boomers entering retirement suffer large decreases in well-being. They further discuss how policy changes need to address longstanding inequalities in the labor market to begin to overcome these differences as people age.

Gender is a significant factor in understanding late-life outcomes among older adults who live alone. Hughes, Bennett, and Hetherington (2004) examined the dietary habits of older men living alone and found that barriers to healthy diets included having poor cooking skills and low motivation to change eating habits. In a study of both older men and women who resided in the region of Augsburg, Germany, researchers found that living alone is an independent risk factor for mortality for men but did not find similar results for women (Kandler, Meigsinger, Baumert, & Lowel, 2007). It is important to note that in this study older men who lived alone were more likely to smoke, less educated, and had fewer children and friends than their female counterparts (Kandler et al., 2007). Therefore, it is unclear whether living alone for these men increased mortality or whether their lifestyle contributed to their mortality (Kandler et al., 2007). In a Pew Research Center (2016) survey of individuals aged 65 and older ($N = 409$), over 12 million older adults who resided in assisted living or in their own homes in the United States lived alone. Most of these older adults living alone were women (69%). Men, however, experienced more adverse physical and mental health outcomes than women who lived alone. This is partially due to the differences in men's social lives: men who live alone are more likely to experience social

isolation and are less satisfied with the frequency and magnitude of their friendships (Victor et al., 2000). Furthermore, men are less likely to volunteer and participate in community events compared to their female counterparts (Van Willigen, 2000). Although older men are more at risk of having adverse physical and mental health issues when living alone, the sheer number of women aging alone makes this a predominantly gendered issue that needs further investigation.

Diversity in the baby boom generation manifests in other forms of health disparity. African Americans, for example, experience dementia at higher rates than Whites, get diagnosed less frequently, and, when diagnosed, receive less treatment (Hall, Johnson-Turbes, Fuller, Niles, & Cantey-McDonald, 2016). The Alzheimer's Association has implemented interventions to address health disparities among African American boomers. The Healthy Brain Initiative (HBI) is an example of a community-based intervention that seeks to engage and educate African American boomers about health-protective behaviors and the heart-brain connection (Anderson, Day, & Vandenberg, 2011).

Similar to African Americans, Hispanic boomers may experience greater health disparities than their White counterparts. A study that utilized the 2007 California Health Interview Survey to examine the health status of Hispanic boomers found that as boomers of Mexican origin moved into old age, the cumulative disadvantages experienced in their lives resulted in worse physical and mental health outcomes in late life (Villa, Wallace, Bagdasaryan, & Aranda, 2012).

Family Caregiving

According to the National Alliance for Caregiving and American Association of Retired People (AARP, 2012), over 43 million family caregivers provide unpaid care to older adults in the United States. These individuals were predominantly female: 60% of care recipients and 75%

of the caregivers. However, the number of available, willing, and able caregivers is on a decline. As boomers enter old age, one caregiver will be available for every five older adults in need of care (Van Houtven & Norton, 2004). Furthermore, issues such as geographic dispersion, rising economic inequality, and familial conflict are changing the way care is provided, and a growing number of older adults who have children are identifying with the term elder orphan.

Long-distance caregivers account for 15% of family caregivers; and these numbers are projected to double by 2020 (National Council on Aging, 2006). A MetLife (2004) study estimated that there are as many as 5 million long-distance caregivers in the United States. The distance-decay hypothesis asserts that longer distances between caregiver and care recipient are directly related to fewer hours spent with the care recipient (Mulder & van der Meer, 2009). In a sample of caregivers ($N = 703$) who reside in Canada, travel time greatly impacted the amount of care provided by caregivers (Joseph & Hallman, 1998). Similar findings related to family caregiving and distance were found in a sample of dementia cases and referral samples (Thompsell & Lovestone, 2002). Other studies have suggested that distance does not impact the amount of care provided by caregivers (Baldok, 2000; Watari, Wetherell, Gatz, Delaney, Ladd, & Cherry, 2006). In a qualitative study ($N = 12$), distance caregivers successfully provided sufficient care through phone calls, letters, and visits (Baldock, 2000).

Despite the mixed results, some researchers have suggested that geographically distant children may be less aware of the increased debility and emotional needs of their parents, thus making long-distance caregiving less responsive than proximate care to the everyday needs of the care recipients (Joseph & Hallman, 1998). Parker, Call, Dunkle, and Vaitkus (2002) explicated the relationship between military officers and separation from aging parents and found that geographic separation contributed to the need for care planning and increased feelings of

worry and anxiety among caregivers. Worries subsided when siblings shared caregiving responsibilities and a sufficient care plan was in place for their aging parents. Harrigan and Koerin (2007) described long distance caregiving as both "painful and rewarding" (p. 13). Previous findings indicate that rewards of long distance caregiving included the fulfillment of personal obligation and satisfaction and the quality of time spent with care recipients to ensure that good care was provided (Cagle & Munn, 2012). The burdens included stress, depression, declining health, anxiety, social impairment, and emotional stress (Cagle & Munn, 2012). Together, both long-distance and local family caregivers can provide sufficient support to ensure that the needs of their older family members are met; however, the struggles involved in caring for older adults can take a toll on the caregiver's physical and mental health, particularly when caregiving is a *solo* job.

Providing care to local family members is not without challenges. Roff, Martin, Jennings, Parker, and Harmon (2007) found that co-caregiving, especially when one sibling is local and the other is long distance, can be challenging, and disagreements among siblings are common. Others have found that co-caregiving arrangements, whether long distance or local, reduce levels of stress among caregivers and provide more sustained care for the care recipients (Kodwo 2009; MetLife, 2004). Despite these findings, sibling caregiving experiences and relationships are relatively complex, and further investigation is necessary to understand how those relationships influence quality of care.

Other Factors Related to Being an Elder Orphan

In this study, I examine various aspects that influence elder orphans' current levels of well-being. These factors offer a holistic understanding of the lives of elder orphans. These factors include adverse childhood experiences, social isolation, and perceived risk.

Adverse Childhood Experiences (ACEs)

Adverse childhood experiences (ACEs), which includes incarceration, parental psychopathology, family dysfunction, substance abuse, and domestic violence, are linked to well-being among older adult populations (Von Cheong, Sinnott, Dahly, & Kearney, 2017). Although the majority of research has focused on adolescents or young adults, a growing body of research has examined the impact of early childhood trauma on late-life outcomes, particularly chronic health conditions (Murphy, Steele, Steele, Allman, Kastner, Dube, 2016). Chronic health problems, such as cardiovascular disease and diabetes, are the leading cause of death in the United States and can play a critical role in one's overall well-being (Bauer, Briss, Goodman, & Bowman, 2014). ACEs have shown to have pronounced effects on cardio-vascular health (Sachs-Ericsson, Rushing, & Sheffler, 2015), thus preventive efforts to reduce the number of individuals with such life-threating diseases should incorporate prevention and intervention strategies related to ACEs.

Childhood experiences are also predictors of perceived health status in late life (Shah, Barsky, Vailiant & Waldinger, 2014). Specifically, individuals' childhood environments can predict their health in late life, controlling for concurrent objective health and neuroticism (Shah et al., 2014). This study indicates the importance of early trauma on long-term mental and physical health outcomes.

Social Isolation

Social isolation has been described as worse for one's physical health than smoking a pack of cigarettes a day (Wilkinson & Marmot, 2003). Additionally, social isolation may help determine which individuals take the initiative to execute advance directives, but little is known about the relationship between social isolation and advance care planning. Being isolated

connotes that one has few meaningful social relationships. As initiating an advance directive is an act that involves several steps and requires engagement in various social situations, it is likely that isolated older adults are less inclined to engage in advance care planning.

No known research studies examine the relationship between social isolation/social networks and advance care planning; however, research about social isolation and lack of social support suggests that social isolation, particularly in late life, can have an adverse impact on multiple dimensions of life, such as passive coping, risk for hypertension, slower wound healing, and poorer sleep efficacy (Cacioppo & Hawkley, 2003).

Perceived Risk

Individuals' perceptions of risk are highly influenced by their emotional and mental health. Positive and negative emotions differentially influence perceptions of disease risk in the context of making medical decisions. For example, mammography messages have been shown to be more persuasive for happy than sad people when the messages are framed in terms of health gains (Ferrer et al., 2015). Other kinds of perceptions (e.g., perceived discrimination) among older adult minorities may be intertwined with feelings of emotional stress, which may create barriers to seeking medical attention and advance care planning (Williams, 2007).

Advance Care Planning

A well-known way of protecting oneself from becoming unbefriended is initiating advance directives. The Patient Self-Determination Act requires all health care facilities, both in-patient and out-patient, to inform patients about living wills and durable power of attorney for health care. Furthermore, under the PSDA, community organizations must provide educational resources about advance care planning to their constituents. The goal of providing educational

resources within communities is to promote discussion and decision-making prior to acute injury or medical crisis (Patient Self-Determination Act, 1990).

Despite these efforts, few individuals in the United States have advance directives (Hammes, Rooney, & Gundrum, 2010). This was formally recognized by a report issued in 2008 by the US Congress called *Advance Directives and Advance Care Planning.* The report outlines the failures of advance care planning efforts in the United States (US Department of Health and Human Services, 2008). Barriers to advance care planning are well documented. Wallace et al. (2007) found physicians' barriers to advance care planning with older adults included religion, personal attitudes, and ethnicity. Other researchers have also explored the vital role of the physician in advance care planning. Morrison and Meier (2004) found that primary reasons for patients to complete advance directives had to do with their relationship with their physician and the physician's willingness to discuss advance care planning. In a landmark study that examined barriers to advance care planning, Morrison et al. (1994) proposed five physician barriers: limited knowledge about advance directives, preconceived beliefs about advance directives, discomfort about advance directives, time constraints, and concerns about compensation. Considerable literature has continued to explore these barriers (Hofmann et al., 1997; Novack et al., 1997). Ethnic and cultural barriers are discussed extensively in the literature (Giger, Davidhizar, & Fordham, 2006; Krakauer, Crenner, & Fox, 2002). Other studies have examined the correlation between advance care planning and income, gender, insurance coverage, and education (Gordon & Shade, 1999; Schickedanz et al., 2009).

There are a growing number of elder orphans whose lack of decision-making capacity is coupled with the absence of a surrogate or a living will (Kim, Appelbaum, Jeste, & Olin, 2004; Pope, 2015). Despite this growing problem, little to nothing is known about how elder orphans

become unbefriended older adults, the factors that predict which elder orphans are more likely to become unbefriended, or what types of interventions may mitigate the risk of becoming unbefriended. Unbefriended older adults may share many of the same characteristics as elder orphans; however, elder orphans retain the capacity to make health care decisions. Elder orphans may be at high risk of becoming unbefriended, and interventions to bolster their social relationships, education about advance directives, and the implementation of preventive physical and mental health programs could play an important role in safeguarding them from becoming unbefriended.

Pope and Sellers (2012) outlined the legal advances concerning medical decision-making for patients who lack a surrogate and advance directives. As autonomy and personal capacity for self-determination are the underpinnings of informed consent doctrine upon which patients' rights are executed in the health care decision-making process in the United States (Parekh & Adorno, 2017), some jurisdictions have erected legal pathways to support such values. Advance directives or living wills are examples. Pope and Sellers (2012a) discuss the critical nature of rigorous search methods and capacity assessments before assessing decision-making mechanisms for individuals who are at high risk of becoming unbefriended. They point to the importance of utilizing established autonomy-protective legal pathways to decision making. A successful program in Minnesota pairs at-risk elderly residents with resident volunteers who are trained to recognize and work with isolated older adults who have little to no social support (Pope & Sellers, 2012). The evaluation of the Minnesota program revealed that almost 60% of individuals named a health care agent and/or completed health care directives while in the program (Pope & Sellers, 2012). Other suggestions included developing a physician order for life-sustaining treatment (POLST) registries to assist in tracking the wants and wishes of at-risk

older adult populations (e.g., elder orphans) (Pope & Sellers, 2012). Pope (2017) states, "the best way to avoid these risks is to avoid becoming unbefriended in the first place" (p. 17).

Older adults who have limited to no social support and do not have advance directives are at risk of health care decisions being made for them that do not reflect their values, wishes, or desires. Several states, including Tennessee and West Virginia, give attending physicians the discretion to select the "best-qualified" individuals to make the critical end-of-life health care decisions, underscoring the influential role of the physician in the health care system (Kim et al., 2004). By contrast, Colorado and Hawaii have no hierarchy; instead, the physician can seek out interested parties to act on behalf of the patient. If older adults have few social relationships, it is often difficult to find someone willing to serve as a surrogate decision maker (Pope, 2015). In the best-case scenario, all interested individuals, who had a prior or current relationship with the patient, convene to decide who will be the most appropriate decision-maker. In Delaware, close friends are included in the default statute; if no family is able or willing, the law permits an adult who has demonstrated exceptional care and concern for the patient, is aware of the patient's personal values, and is able to make health care decisions (Pope & Sellers, 2012). Although the addition of "close friend" to the hierarchy statue offers further protection for vulnerable older adult populations, many older adults populations like elder orphans may have lost all social ties and no longer have any willing or able family or friends to make medical decisions. Although some high-risk older adult populations have relationships with care providers, non-professional care providers are often prohibited from serving as surrogates. Care providers/clinicians who do not know the patient are often tasked with making difficult decisions for patients in the hospital setting (Kolan, 2010).

There is scant literature to describe the problem of unbefriended patients and, consequently, several states have recently begun to discuss the issue due to the growing number of older adults aging alone. Both Colorado and Washington have produced white papers that outline the potential issues that could arise when there is no legislative process and no prevention programs to address this developing issue (American Medical Directors Association, 2003). These reports highlight the limited studies in this area and the lack of outcome data from the states that have existing statutes. While some states may be able to modify or adopt the statutes of another state and develop mechanisms to address the issue of a growing unbefriended population, this may not be applicable in all situations, as each state addresses its own unique circumstances. Furthermore, there is no mention of mechanisms to prevent older adults, such as elder orphans or homeless older adults, from becoming unbefriended in the first place.

Having advance directives and adequate social support is not only critical to one's self determination and autonomy, it ensures that one does not experience the possibility of unwarranted variations in health care (White, Johnson, & Bernard, 2012). Empirical evidence suggests that variation in health care is related to both the physician's personal choices as well as the characteristics about the patient's illness (Quill & Brody, 1996). White et al. (2012) contest that variations in health care for unbefriended persons is ethically problematic as patients receive different care based on several factors that have nothing to do with the patient's best interest. As personal physician preferences substantially influence medical decision making, it is likely these decisions are not aligned with the patient's preferences or best interest. Therefore, neither the substituted judgment nor best interest standard is taken into consideration. Empirical data on homeless populations suggests that homeless populations tend to prefer more aggressive life sustaining treatment than clinicians typically prescribe (Norris et al., 2005). White, Johnson, and

Bernard (2012) examined the impact that making medical decisions has on clinicians and how the psychological intensity that many clinicians may experience during the decision-making process impacted their professional assessments, possibly leading to unwarranted variation in care.

Ethical issues arise when health care professionals make decisions for patients with no legislative pathway to justify or guide their decision-making process (Gleen, 2015; Karp, 2003). Only a handful of states currently have legislative pathways to decision making for unbefriended patients, and older adults who are at risk of becoming unbefriended should be proactive about developing adequate support systems and initiating advance directives in the event of a medical crisis or acute injury (Parekh & Adorno, 2016). While clinicians are often embedded in the traditional medical model, the goals of the administrative hospital or facility and the goals of the patient may differ. The normative decision-making process allows the clinician to provide the patient or the surrogate decision-maker with the ability to choose between the various medical options that the physician presents. The communication between the clinician and the decision-maker is critical in developing a treatment plan that best meets the needs of the patient. As this process is impeded for unbefriended patients, medical decision-making can be a cumbersome process for clinicians. Conflict of interest, patient preferences, guardianship issues, and lack of legislative guidelines, are barriers to decision-making in the best interest of the patient (White, Johnson, & Bernard, 2012).

Although vulnerable older adult populations will continue to fall through the cracks and legislative pathways are needed to address this growing issue, prevention strategies offer a more comprehensive solution. Prevention strategies were lightly discussed in the literature on this topic, and more substantial attention needs to be given to how high-risk older adult populations

can receive supportive services so they do not become unbefriended in the first place. Furthermore, research that focuses on the factors that contribute to individuals becoming unbefriended will aid in our understanding of the process.

Summary

The pathways to elder orphanhood are complex and diverse. Older adults who live alone are one of the fastest-growing older adult populations is the United States; however, aging alone with little to no support is a relatively new phenomenon. This is partially due to the large number of older adults in recent years who are childless, have outlived their caregiver, and are divorced or widowed. As the numbers of older adults living alone increases, so too will the number of older adults with complex health and mental issues. Not all older adults who identify with the term elder orphan experience the negative consequences often associated with living alone in late life; however, the sheer number of older adults aging alone brings our attention to this growing and potentially urgent issue. Therefore, it is important to understand the factors throughout the life course among this population that could put them at risk of becoming unbefriended. Furthermore, sociopolitical, cultural, economic, and structural systems are unprepared to care for this growing older adult population. Demographic dispersion, outliving one's caregiver, hostile familial relationships, economic hardships, and the fractured built environment have increasingly played a role in social isolation among older adult populations. The current literature review examined the empirical knowledge of the factors that influence levels of well-being among elder orphans and the factors associated with becoming an unbefriended older adult among this population. To examine this under-researched population, a theoretical foundation is necessary. The following chapter provides a theoretical base of support for the present study.

Chapter 3

Theoretical Foundation

In this chapter, I employ an overarching life course perspective and a sociohistorical and cultural lens consistent with social constructionism to examine the macro, mezzo, and micro influences throughout the life course to develop a foundational understanding of well-being and advance care planning among an elder orphan sample. Additionally, I incorporate the cumulative advantage/disadvantage (CAD) framework to better understand how early childhood advantages and disadvantages influence outcomes throughout the life course. Next, I utilize the capabilities approach to understand the role of financial freedom as a component of well-being and as it relates to decision-making. Last, I apply the underlying concepts of the health belief model to understand how perceived risk influences advance care planning. Collectively, this conceptual framework helps explain the dynamic social processes involved in factors that influence well-being among a high-risk population of older adults.

Life Course Theoretical Framework

The examination of life experiences through a sociohistorical and cultural lens was not a widely accepted idea until the 1960s (Giele & Elder, 1998). During this time, scholars became interested in how individual lives unfold throughout the life course and how structural and individual conditions impact outcomes (Kuh, Ben-Shlomo, Lynch, Hallqvist, & Power, 2003). Social scientists began exploring cultural and psychological factors that contributed to human behavior. The impetus for such complex investigations came from sociopolitical changes and demographic shifts during a transformative period in US history. These changes initiated a new

inquiry of the human experience and its environmental influences. Initial research on the life course was not only limited in its investigation, it was also temporal in nature and concentrated either on specific subgroups or discrete trajectories. The life course approach was distinct from the research of earlier social scientists such as Thomas and Mead (1934) who investigated more linear life experiences, such as marriage or the onset of a disability, but whose research was confined to a somewhat predictable trajectory that did not occur in everyone's life.

While sometimes seen as synonymous, life span and life course are distinct concepts. Life span focuses on inner life, linearly, while life course focuses on trajectory, transitions, and turning points throughout the life course (Neugarten, 1985; Van Geert, 1994). The realization of their difference by forward-thinking social scientists like Elder and Geile (1998) was monumental and created the interplay of these two conceptual frameworks, which is known today as life course theory. Life course theory has emerged as a prominent theoretical framework in various disciplines including history, sociology, social work, anthropology, medicine, and psychology (Giele and Elder, 1998).

Key Concepts and Application of Life Course Theory

Life course theory helps guide complex inquiries within various sociohistorical, cultural, and regional contexts. Key concepts include (a) location in time and place; (b) linked lives; (c) human agency; and (d) times of lives (Giele & Elder, 1998). Furthermore, three related principles and concepts are particularly useful to understanding elder orphans: trajectory, transitions, and turning points (Giele & Elder, 1998).

The concept of *location in time and place* examines how events take place in an individual's life and shapes perceptions, choices, and opportunities. This concept is analogous to person-in-environment in social work and is linked to the idea that an examination of a person is

not adequate without an examination of the environment in which behaviors, actions, or ideas emerged (Giele & Elder, 1998). For example, singlehood occupies a unique space. While not a geographic space, singles' social world and everyday routines may differ from individuals with life partners. Thus, the unique social environment of singles can influence their well-being. As mentioned earlier, living alone is linked to several adverse physical and mental health outcomes. According to Gubrium (1972), "singles constitute a distinct type of social personality in old age" (p. 47) because they may experience social isolation and loneliness at higher rates than their single counterparts. He postulated that humans are social beings for whom creating familial relationships is central to their well-being.

The concept of *linked lives* is critical when examining elder orphans. Linked lives refer to an integration of social relationships that shape how individuals interpret events throughout the life course (Bengtson, Elder Jr, & Putney, 2012). Individuals may vary in the degree to which they integrate their lives with others, or they may experience disruption of relationships under certain circumstances, either by choice (e.g., divorce) or not (e.g., death of a spouse); this may ultimately lead to divergent outcomes (Giele & Elder, 1998). The lives of older adults who are both unmarried and childless may be uniquely linked and continually provide reciprocal influence on and by each other in the ongoing process of human development, potentially leading to late-life vulnerabilities or disadvantages.

Older adults who are childless, unmarried, and living alone may experience extreme vulnerabilities, which can influence end-of-life planning and care. For example, this population may not plan as adequately for the end of life; research suggests most individuals who plan for end-of-life care discuss their care with their family (Steinhauser et al., 2000). It is plausible that those without such social supports may be less likely to plan for end of life. Therefore, assessing

how well an individual is connected within cultural, institutional, social, psychological, and sociobiological levels of social integration contributes to our understanding of the factors that influence well-being and advance care planning among this population. The ways in which these aspects of life are integrated and internalized, however, will vary based on individual levels of advantage and disadvantage (Elder, Johnson & Crosnoe, 2004).

Families generally play a critical role in an individual's level of social integration. Some individuals experience smooth, interwoven connections throughout their life, resulting in positive outcomes, while others show incoherence and disruption, resulting in less harmonious outcomes (Elder et al., 2003). These experiences can have a cumulative impact on an individual's life course and may lead to an increased risk for social isolation and health-related issues. As elder orphans are considered one of the most at-risk populations of becoming unbefriended, partly due to the lack of social connectivity in their lives, they likely experience higher levels of distress, stress, and vulnerability during the latter stages of older adulthood.

Human agency refers to an individual's ability to set goals and make decisions. Examining human agency through a life course lens provides insight on the impact of personal motives on decision-making (Elder et al., 2003). This may translate into decisions about having secure housing, maintaining economic security, having healthy relationships, and initiating advance directives. An individual's goal-seeking behavior throughout their life may help explain some of their future outcomes; however, biological and structural barriers play a critical role in determining individual outcomes as well. Therefore, specific choices depend on opportunities and constraints, which are influenced by life course events and experiences, such as job loss, divorce, or death of a child.

The concept *timing of lives* in life course perspectives highlights the role that the timing of various events plays in an individual's life and the willingness to strategically adapt to changing times. Timing of events can involve a series of events that happen over a certain period (transition), the close of a chapter in life for a new phase (trajectory), or a momentous incident concerning a sudden change that may produce long-lasting effects (turning points; Giele & Elder, 1998). How one handles these time-sensitive life course moments can establish a foundation for future outcomes. While little empirical evidence exists about elder orphans, considerable research has shown that the increase in older adults among homeless populations is partially due economic downturns (Elder et al., 2003; National Coalition of the Homeless, 2009). This major and abrupt life event forced some older adults to a new phase or trajectory in life and likely will have an impact on their well-being throughout their life course (Giele & Elder, 1998). Similarly, various trajectories or turning points in an elder orphan's life, which led to their single status (e.g., death of a spouse, personal choice, divorce), may influence their well-being at multiple stages in life.

These key concepts in life course theory provide a roadmap for investigations of complex life histories of diverse populations. Social scientific investigations benefit from the examination of various social phenomena through a life course lens due to the fluid nature and focus on person-in-environment inquiries. The life course perspective has emerged as one of the most useful perspectives in aging because it seeks to understand how individual lives unfold over time. Additionally, the utility, adaptability, and variability of life course theory across race, gender, socioeconomic status, region, and ethnicity allows for assessment of aging within a contemporary context (Giele & Elder, 1998). Furthermore, the flexibility of the life course theoretical framework allows for multitheoretical inquiries. I thus incorporate various other

theoretical concepts into this framework to bolster our understanding of the factors that influence well-being and advance care planning of elder orphans.

Cumulative Advantage/Disadvantage

Due to the temporal nature of both age and cumulative advantage/disadvantage (CAD) theory, gerontologists have utilized CAD to study processes of individual and cohort aging. CAD was not recognized as a viable theoretical framework until longitudinal investigations discovered that diversity increased as people aged. Hence, CAD became a prominent theoretical framework in the field of aging and has continued to contribute to emerging aging issues since the late 1970s (Wilson, Shuey, & Elder, 2007). CAD has also gained popularity in recent years in the fields of economics, psychology, and sociology (DiPrete & Eirich, 2001; Taylor, 2008).

CAD has proven to be most valuable in aging inquiries when used in tandem with life course theory (Giele & Elder, 1998). The central premise of CAD is that adverse overlapping inequalities early in life cumulate as negative outcomes later in life. Furthermore, CAD also explores the potential moderating relationship between broader institutional contexts on the cumulative effects of micro-level processes. However, CAD's most notable contribution is its ability to examine interrelated, but distinct, conditions such as heterogeneity, diversity, poverty, and inequality.

Research provides several examples of the application of CAD to late-life outcomes. In a large nationally representative sample, Ferraro and Kelly-Moore (2003) found that obesity early in life was significantly associated with increased comorbidity (health inequality) in late adulthood. Others have found inadequate health access early in life is associated with negative outcomes, such as high levels of stress and deteriorating physical health late in life (Blazer, 2003; Shonkoff et al., 2012). While economic distress may fluctuate throughout the life course, it

has been shown to be a strong predictor of chronic health issues and health access during older adulthood (Wilkinson & Marmot, 2003). These studies suggest that an examination of cumulative disadvantages throughout the life course is critical to understanding late-life outcomes or late-life risk trajectories. According to CAD, the social, economic, and structural gap grows over the life course (Wilson, et al., 2007). Therefore, a multidimensional framework that examines the advantages/disadvantages over the life course and the real opportunities to exercise personal functioning provides a robust and comprehensive framework for a deeper investigation of this growing older adult population.

Although CAD has not been empirically applied to the elder orphan population, it may be particularly useful due to its focus on the life course; it may also help to explain early life vulnerabilities or disadvantages that lead to the risk of multiple health complications, economic challenges, and social isolation late in life (Wilson, et al., 2007). Adverse late-life outcomes may not simply result from recent life events or conditions (such as, homeless or no living relatives), but rather from a lifetime of negative structural, environmental, and biological events or conditions, which accumulate throughout the life course and may result in negative outcomes. In this present study, the impact of childhood trauma on both the physical and mental health and the interwoven links between childhood experiences and late-life outcomes are explored.

Capabilities Approach

First articulated by Sen (1987), the capabilities approach is a flexible, multipurpose theoretical framework used to conceptualize, measure, and evaluate issues such as poverty, individual well-being, social arrangements and social injustices, and policies about social change in society. The capability approach provides a comprehensive perspective on the normative role of social ties, resources, and deprivation, each of which affects the capability to achieve valued

functionings (Sen, 1992). Frequently used in the field of human development, a capabilities approach rests on two normative claims:

1) the freedom to achieve *well-being* is a critical, moral imperative; and

2) the freedom to achieve *well-being* lies within a person's *capabilities* and *functionings.*

(Robeyns, 2011, p. 1)

Freedom refers to the capacity to *do* this or *be* what the individual *values* (e.g., *beings* and *doings*). Capabilities are notions of positive freedom: the *real opportunities* that individuals possess regarding the life they may lead. Furthermore, capabilities represent a person's freedom to attain functionings, such as good nutrition, good health, self-respect, financial stability, and social integration (Sen, 1996).

Functioning is a triumph, whereas a capability is the capacity to accomplish (Sen, 1996). According to Sen (1996), optimal well-being is when an individual has a choice to live as he or she chooses. Consequently, a person's ability to live a good life rests on the *choices* made by the individual and the real prospects that the individual has for making a decision and for taking an explicit action. Hence, an individual's capability is a mixture of achievable functionings.

In this context, poverty is understood as deprivation in the capability to live a good life, whereas financial freedom is understood as a real opportunity to live a good life. Thus, I conceptualize financial freedom as a fundamental component to well-being. Financial freedom provides real opportunities across the life course and can be particularly important during the latter years of life when one is less likely to pursue occupational opportunities. Therefore, the well-being variable in this study incorporates the key concepts of financial freedom, which allows individuals to make choices and achieve functionings that meet personal needs.

When individuals lose the ability to exercise their functioning (i.e., exercise desired action) due to diminished capabilities (i.e., decreased real-life opportunity) over time, their vulnerabilities are compounded and lead to the loss of value for life (Sen, 1996). The freedom to achieve an optimal life throughout one's life course is a critical component of well-being. According to Sen (1996), the pursuit of freedom is "well-being freedom." Elder orphans may be deprived of well-being because they may experience multiple barriers to exercise their functioning ("being and doing" capability). Functioning requires resources—personal physiology, social norms, and physical environment—which are the inputs to function, and their value depends on individual ability to convert them into valuable functioning. In the case of elder orphans, however, they may experience diminishing resources throughout their life course due to life experiences such as divorce, death of a spouse, or loss of family and friends through death or other tragic events that could lead to financial instability and loneliness (Sen, 1996).

Key Concepts of Capabilities Approach

The concept of *conversion factor* is a key theoretical driving force in the capabilities approach. Conversion factors include the environmental, personal, and social characteristics that enable functioning (Sen, 1996). Another important idea in capability approach is the notion of human diversity. This is vital to understanding the lives of individuals who may not able bodied, are not from the dominant ethnic or racial groups, are childless or single, or have compromised health issues. Individuals from historically marginalized groups, people with disabilities, and homeless individuals are at increased risk of multiple vulnerabilities. Therefore, multiple vulnerabilities, combined with aging alone, can rarely be understood by frameworks that are only interested in a unitary homogenous perspective of aging.

The capabilities approach also helps aggregate different dimensions of well-being. In the case of elder orphans, there are significantly more women than men who live alone and experience financial instability due to fluctuating employment histories, divorce, and historic discriminatory employment procedures (Knodel & Ofstedal, 2003); yet men typically have worse well-being outcomes than women (Pinquart & Sörensen, 2001). This may be due to the differences in quality of relationship and social support that women experience as compared to men. Prior studies indicate that women report long-lasting, meaningful relationships throughout the life course with friends, family, and children, whereas men are less likely to report the positive influence of these relationships (Antonucci & Akiyama, 1987).

Nussbaum (2001) and others expand on Sen's ideas and are interested in how the basic concepts of capabilities theory applied to specific populations such as women and older adults. While Nussbaum primarily examined how capabilities theory can be applied to women in developing countries, her work has been a useful tool for examining older adults, particularly vulnerable older adult populations. Lloyd-Sherlock (2002) published a study applying Nussbaum's capabilities approach and life course theory to older adults in developing countries and put forth a new framework that utilizes suitable concepts from both life course theory and Nussbaum's version of the capabilities approach distinguishes the differences between older adults' internal and external capabilities. This framework is particularly useful when examining the life course of elder orphans. Because the factors that influence well-being among elder orphans do not typically happen overnight or in a vacuum, particularly without ecological or biological barriers, it is necessary to understand how these various elements of the human experience intersect.

Health Belief Model

The health belief model (HBM) is the most commonly used theoretical framework to determine health behavior, personal beliefs, and perceptions related to disease and illness (Harrison, Mullen, & Green, 1992). The HBM was developed in the 1950s to explain why public health medical screenings for tuberculosis were not effective (Hochbaum, 1958) and has been foundational in developing prevention education programs for vulnerable populations (Rawlett, 2011).

The following constructs underpin HBM: perceived seriousness, perceived susceptibility or risk, perceived barriers, and perceived benefits (Rawlett, 2011). Each of these concepts can be utilized individually or in combination to better understand or explain health behavior. Perceived risk is one of the most powerful perceptions in promoting individuals to adopt healthy behaviors (Schwarzer & Fuchs, 1995). Given this and for the purposes of this study, perceived susceptibility or risk is utilized to understand the likelihood of engaging in advance care planning among elder orphans.

HBM can evaluate elder orphans' risk perceptions about disease and illness, thus providing insight into their likelihood to engage in advance care planning. Furthermore, HBM can provide guidelines for health care professionals to address reasons for low initiation end-of-life planning. Advance care documents may serve as a protective factor at the end of life for elder orphans. Thus, a more nuanced understanding of elder orphans' perceptions related to risk of adverse health outcomes may provide insights that result in targeted interventions for this growing population of older adults.

Conceptual Framework

To understand the multiple risks factors that influence the well-being of elder orphans, life course theory served as an overarching theory or grand theory. The following theoretical perspectives further guided this study: (a) cumulative advantages/disadvantages theory; (b) capabilities theory; and (c) health belief model.

Issues such as interpersonal differences and needs throughout the life course, normalization of problems and illnesses of aging, and homogenous definitions of aging hamper the understanding of subjective perceptions and experiences of older adults who are aging alone with limited social supports (Schaie, 2005). The social, cultural, or the environmental constraints early in the life course can lead to decreased well-being (Cornwell & Waite, 2009; Fiori, Antonucci, & Cortina, 2006; Lubben & Gironda, 2003). The CAD framework, combined with a life course perspective examines how early life circumstances impact late life outcomes. Capabilities theory helps conceptualize well-being to include financial freedom, a key contributor to living a good life.

By using the multifaceted theoretical framework, this study intends to gain a deeper understanding of the factors that influence well-being throughout the life course and of the relationship between perceived risk of incapacitation, and well-being and advance care planning. These distinctions move us forward from viewing older adults as a homogenous group with common demands and experiences, to a more balanced perspective that views late life as a fluid, multifaceted, diverse phenomenon. The conceptual model (Figure 3.1) provides a visual representation of the intersecting key concepts of all four theoretical frameworks and how its application can be utilized to understand the factors that influence well-being and advance care planning among elder orphans, which is the focus of this study.

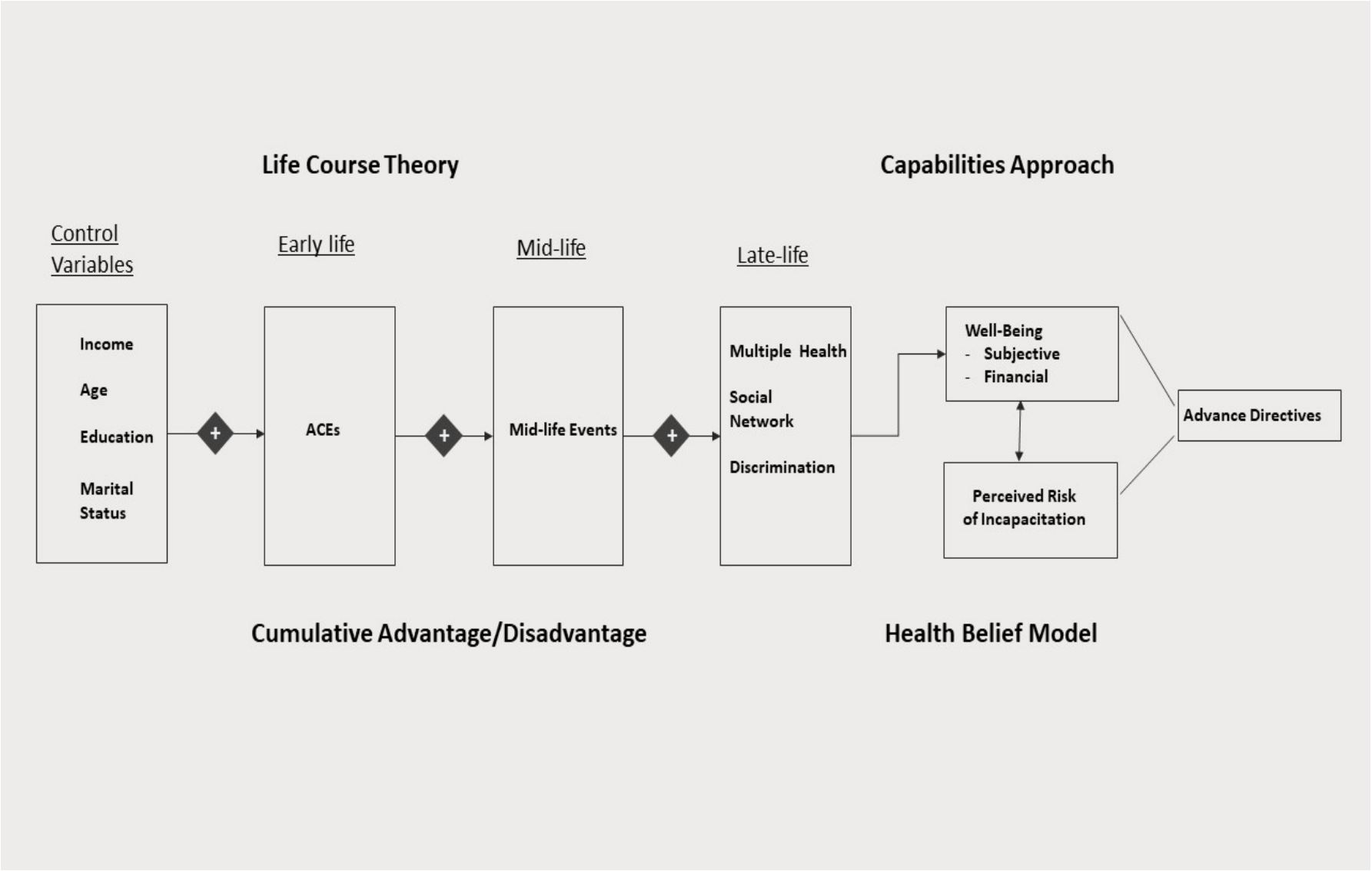

Figure 3.1 Conceptual framework for elder orphan well-being and advance care planning.

Research Questions and Hypotheses

This present study is an examination of the following research questions:

Research Question 1: Do demographic variables (age, marital status, socioeconomic status, and education) predict levels of well-being among elder orphans?

Research Question 2: Do ACEs scores predict levels of well-being among elder orphans?

Research Question 3: Do mid-life scores predict levels of well-being among elder orphans?

Research Question 4: Do late-life factors (discrimination, multiple heath issues, and social network) predict levels of well-being among elder orphans?

Research Question 5: Is there a significant correlation between perceived risk and levels of well-being among elder orphans?

Research Question 6: Controlling for marital status, age, and education, do levels of well-being and perceived risk of incapacitation influence the likelihood of elder orphans having advance directives?

Research Question 7: What is the lived experience of elder orphans who are members of the Elder Orphan Facebook group (qualitative thematic analysis)?

Research Questions 8: Do the qualitative findings provide a more in-depth understanding of the factors that predict well-being throughout the life course and advance care planning among elder orphans (qualitative thematic analysis)?

Hypotheses are presented for each research question.

Hypothesis 1: Demographic variables (age, income, education, marital status) are significant predictors of well-being among elder orphans. Null hypothesis: Demographic variables (age,

income, education, marital status) are not significant predictors of well-being among elder orphans).

Hypothesis 2: Adverse childhood experiences (ACEs) are a significant predictor of well-being among elder orphans. (Null hypothesis: Adverse childhood experience (ACEs) are not significant predictor of well-being among elder orphans).

Hypothesis 3: Mid-life events (divorce, death of a child, death of parent or spouse, or major financial changes) are significant predictors of well-being among elder orphans. Null hypothesis: Mid-life events (divorce, death of a child, death of parent, or major financial changes) are not significant predictors of well-being among elder orphans.

Hypothesis 4: Late-life experiences (social network, discrimination, multiple health issues) are significant predictors of well-being among elder orphans (Null hypothesis: Late-life experiences (social network, discrimination, multiple health issues) are not significant predictors of well-being among elder orphans).

Hypothesis 5: The lower the perceived risk of incapacitation, the higher the level of well-being among elder orphans. (Null hypothesis: There is no relationship between perceived risk of incapacitation and levels of well-being among elder orphans).

Hypothesis 6: Lower levels of well-being and higher levels of perceived risk of incapacitation will increase the likelihood of participants having advance directives. Null hypothesis: Levels of well-being and of perceived risk of incapacitation are not significant predictors of well-being among elder orphans.

Hypotheses are not provided for qualitative questions to allow themes to emerge from the lived experience of the participants.

Chapter 4

Methods

This study addresses research gaps by developing a theoretical and conceptual understanding of the relationship between cumulative life course experiences, interconnections among elder orphans' well-being, perceived risk of incapacitation, social network, discrimination experience, health issues, and the likelihood of the possession of advance directives, as well as the influence of age, marital status, socioeconomic status, and education. The research topics were examined using a mixed-methods approach, which incorporates both quantitative and qualitative analyses, utilizing a sample of older adults who identify as elder orphans and are members of the Elder Orphan Facebook group (hereafter referred to as the EOF group).

This study employed a mixed-methods design (Creswell & Plano Clark, 2017), which is a procedure for integrating the analyses of both quantitative and qualitative data within a single study. A mixed-methods approach captures the interaction of positivist (quantitative) and constructivist (qualitative) approaches (Curry & Nunez-Smith, 2015). More specifically, an explanatory sequential mixed-methods design was utilized for this study (Creswell & Plano Clark, 2017; Figure 4.1). Two phases, as described below, compromised this mixed-methods research design.

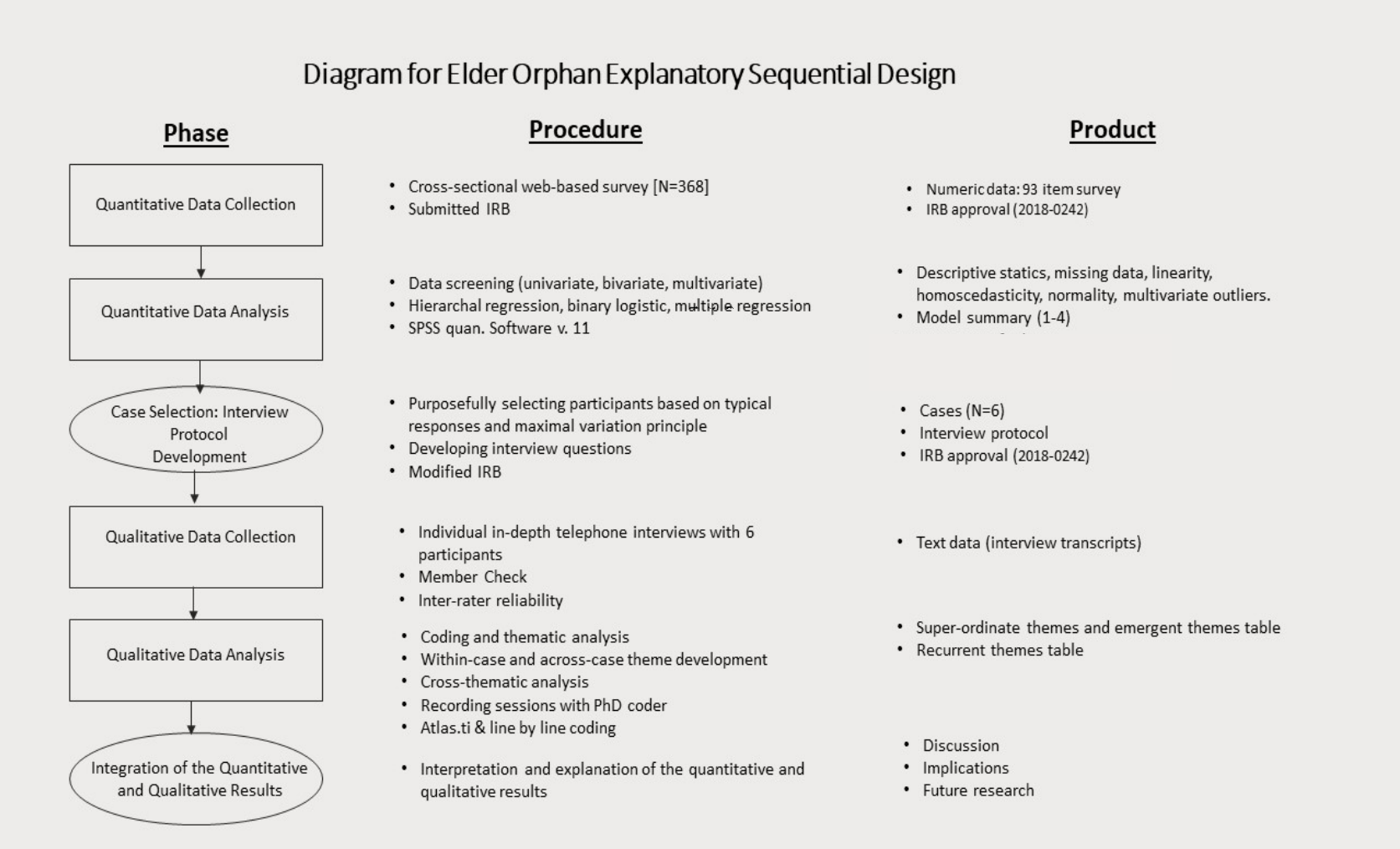

Figure 4.1. Diagram for elder orphan explanatory sequential design.

The first phase of the design calls for the collection of quantitative, or numerical, data. This began with the an 93-item survey posted to the EOF group. The survey explored the associations among several theoretically driven variables and scales, including life course factors (early, mid-life, and late-life), well-being, discrimination experiences, health issues, perceived risk of incapacitation, social network, and the likelihood of the possession of advance directives.

The second, qualitative phase of the study further explored these associations to enhance or better explain the quantitative results. Phase 2 comprised in-depth individual interviews with volunteer members of the EOF group. Participants volunteered to take part in this phase in response to a question in Phase 1.

The rationale for integrating both the quantitative and qualitative phases of the study was to create a comprehensive understanding of elder orphans, who, to date, have been largely ignored in scientific research. In this study, the quantitative phase allowed for an exploration of complex predictive influences on and/or intercorrelations among the key study variables (e.g., well-being, perceived risk of incapacitation, and advance directives). The qualitative phase was used to gain deeper insight about the relationships identified from the inferential data analyses. Thus, the quantitative results provided an initial understanding of the research problem, while the qualitative results helped provide a nuanced understanding of the quantitative phase of the study. Furthermore, in the qualitative phase, both the selection of the participants and the development of the open-ended questions were based on the results from the quantitative phase. Finally, the results of the quantitative and qualitative phases were integrated in the discussion (see Figure 4.1).

Quantitative Method

The following key areas are discussed in the sections below: (a) sample and sampling methodology, (b) data collection process, (c) operationalization of variables and measures, and (d) data analysis strategy.

Study Design

The design of this study was a cross-sectional web-based survey of participants aged 55 and older, who are members of the EOF group, and identify with the term elder orphan. A cross-sectional design allowed for an analysis of a representative subset of elder orphans at a specific point in time. In this quantitative phase of the study, two multivariate analyses were conducted. A hierarchical regression was conducted to identify which life course events or experiences, if any, were significant predictors of well-being among a sample of elder orphans. In a similar fashion, a hierarchical binary logistic regression was conducted used to predict the likelihood of the possession of advance directives based on elder orphan's perceived risk of incapacitation and well-being.

Sample and Sampling Methodology

Certain groups are often excluded from research because they are hard to reach (Shaghaghi, Bhopal, & Sheikh, 2011). Elder orphans have been identified as one such group. Researchers have labeled them a group that is "hiding in plain sight" (Carney, 2016, p. 1) and as hard to reach or hidden because they may stop accessing necessary preventive health services, cease attending social activities, or have limited contact with friends and family (Carney, 2016). This reality often makes it difficult for agencies to develop relationships with or identify this population. Additionally, some older adults who live alone may not even identify with the term elder orphan or know they are at risk of potential adverse health and mental health issues as they

age. Current advancements in Internet-based recruitment strategies are eroding these former barriers to studying elder orphans. Social media outlets such as Facebook make it possible to identify, access, and recruit hidden or hard-to-reach groups of older adults who use social media (Alessi & Martin, 2010; Hallett, Nicholson, White, & Duncan, 1999; Rhodes, Bowie, & Hergenrather, 2003).

An Internet-based recruitment strategy was employed for this study. I sought out potential sites that house groups of individuals with common interests and experiences (i.e., Reddit, Facebook, Twitter) and located a group on Facebook comprised of older adults who identify as elder orphans. At the time of the study, the EOF group had a little over 7,000 members, including approximately 5,000 active members. According to Facebook, an active member is a registered user who has logged on through the main site or a third-party site within the last 30 days.

The membership criteria for The EOF group includes:

1. Being childless or having limited to no contact with their adult child;
2. Living alone;
3. Having limited social support; and
4. Being unmarried or not living with a partner.

To be eligible for the quantitative phase of the study, participants had to meet the same criteria as the criteria for membership in the EOF group. The total sample size for the quantitative phase was 442, which represented a response rate of 8.8% of the active membership of the EOF group. The 442 participants in Phase 1 were able to volunteer for the second, qualitative phase of the study during the quantitative phase. All participants were informed through the quantitative survey that only selected individuals from the volunteer group would be

invited to participate in the individual interview during the second phase. Participants chosen for the qualitative study had to meet the inclusion criteria for the quantitative results. Seven participants were purposively sampled from a group of 196 volunteers who had consented to being interviewed during the quantitative phase of the study. One of the 7 participants was excluded from the analysis due to failure to meet one of the inclusion criteria: no external support from adult children. To protect the anonymity of the participants in the quantitative phase of the study, each participant was assigned an identifying number in place of a name during the data entry phase. To keep participants names confidential in the qualitative phase of the study, participants were given pseudonyms. This study was approved by the Institutional Review Board (IRB) of the University of Texas at Arlington (2018-0242; Appendix A). Signed consent forms were obtained from all participating individuals. (See Appendix B for the consent form for this study.)

Data Collection

To gain access to the EOF group, I contacted the moderator of the group via Facebook. The moderator served as the liaison in this study. The EOF group page is a private page, therefore I did not have direct access to this group. Due to the inability to access the group directly, the liaison and I worked closely together to develop the appropriate protocol and procedures for the research study, which included the liaison communicating weekly with the EOF members about the study (to increase participation). Additionally, the liaison and I had weekly meetings to discuss any issues that arose during the duration of the study. Furthermore, the liaison was included in the IRB as a community partner on the project. In collaboration with the liaison, a draft version of a survey was developed and piloted to 79 members of EOF group between January 5 and January 12, 2018. Pilot survey results, feedback from pilot participants,

and additional discussions between the liaison and myself were utilized to refine the final survey. The final survey included 93 items composed of Likert-scale responses and independent questions supported by the literature (Appendix C). The survey was administered via the Qualtrics platform and managed by the liaison via Facebook.

Data collection took place between April 15 and May 6, 2018. The survey was posted and pinned on the EOF group page. Pinning the survey allowed the post to remain active and at the top of the page for the duration of the study. Active e-mail addresses were obtained from participants who chose to be entered in the six $50 Walmart gift card drawings. The drawings were conducted at the end of the survey (May 6, 2018). The liaison mailed all six gift cards to participants on June 3, 2018.

Operationalization of Variables and Measures

In this section, I operationalize each of the study variables and described how they were measured. (See Appendix C for the complete survey that was administered to each elder orphan in this study).

Well-being. Well-being is a multidimensional, holistic construct that integrates all aspects of both mental and physical health (CDC, 2016). It is centered around an individual's perception of the state of the meaningful and good things in one's life, such as finances and ability to access reliable information and resources. The standpoint in this study is that well-being is a multidimensional construct that encompasses the influence of social, economic, and psychological factors. I used the life course perspective to examine how factors, spanning from childhood to late-life accounted for variance in the well-being of elder orphans. The CAD framework assessed how disadvantages and advantages accumulate throughout the life course and influence levels of well-being among elder orphans. Capabilities theory helped to further

explain the role of financial freedom in an individual's ability to live a good life, particularly as they aged.

In this study, well-being was used both as an outcome variable (hierarchical regression) and a predictor variable (hierarchical binary logistic regression). Well-being was used as an outcome variable to examine the degree to which life course variables (early, mid-life, late-life) explained current levels of well-being among elder orphans. Well-being and perceived risk of incapacitation were used as predictor variables to understand their influence on advance care planning. For the purposes of this study, well-being is operationalized as subjective well-being and financial well-being. These two constructs are described below.

Subjective well-being. Perceived mental health (how one evaluates one's own mental health) has been linked to factors that include ethnicity, social class, family, support, service use, and community belonging (Alegria et al., 2002; Cornwell & Waite, 2009; Nygren et al., 2005). In older adults, depression is prevalent and disabling (Fiske, Wetherell & Gatz, 2009). Furthermore, over half of older adults experience their first onset of depression in late life. Cumulative disadvantages later in life can manifest into extreme vulnerabilities. Research has linked cumulative disadvantages through a life course perspective to late-life depression (Dannefer, 2003).

Financial well-being. Researchers have linked the lack of financial freedom to intimate partner violence, functional limitations in late life, and mortality and morbidity, particularly among women (Kahn & Pearlin, 2006). Baby boomer female-headed households are vulnerable to adverse financial hardships in late life. Lack of planning for retirement is a major contributor to late-life financial hardship. According to Lusardi and Mitchell (2011), financial literacy is strongly and positively associated with retirement planning. Lack of planning and financial

literacy later in life can lead to limited choices and freedom. Financial well-being across age groups reveals that "having control over day-to-day, month-to-month finances, having the capacity to absorb a financial shock, being on track to meet one's financial goals and having the financial freedom to make the choices that allow one to enjoy life" are essential elements to overall well-being (Commercial Financial Protection Bureau, 2015, p. 5). Measuring financial well-being is crucial to helping one achieve it.

WHO-5 scale. The World Health Organization (WHO) Five Well-Being scale (WHO-5; WHO Collaborating Centre in Mental Health Psychiatric Research Unit, 1998) was used to measure subjective well-being among elder orphans. The WHO-5 was developed to measure subjective quality of life related to a positive mood (good spirits, relaxation), vitality (being active and waking up fresh and rested), and general interest (being interested in life activities). The WHO-5 used in this study is a version of the scale that was collapsed to a 5-item scale from a 28-item scale and measures both positive and negative aspects of subjective well-being (WHO Collaborating Centre in Mental Health Psychiatric Research Unit, 1998). For the purposes of this study, lower scores indicate lower well-being. The internal reliability of the WHO-5 has been demonstrated in previous studies on older adults with Cronbach's alphas of 0.77 and 0.87 (Pracheth, 2015; Wu, 2014).

Commercial Financial Protection Bureau (CFPB) financial well-being scale. The CFPB financial well-being scale (Consumer Financial Protection Bureau, n.d.). has both a long and short version. For the purposes of this study, the long version (10 items) of the scale was utilized. Studies show that the standard 10-item version of the scale provides a higher level of relatability and precision and is preferable to use. Due to the unique scoring of the scale, which

takes both working and non-working individuals (e.g., retired, disabled) into account, it is directly comparable across age groups.

The subscales and questions that comprise the well-being scale are presented in Table 4.1. Lower participant response values indicated lower levels of well-being.

Table 4.1

Subscales for Elder Orphan Well-being Scale

Scale	Items
WHO-5 Subjective Well-Being	I have felt cheerful and in good spirits. I have felt calm and relaxed. I have felt active and vigorous. I woke up feeling fresh and rested. My daily life has been filled with things that interest me.
CFPB Financial Well-Being	I could handle a major unexpected expense I am securing my financial future Because of my money situation, I feel like I will have the things I want in life I can enjoy life because of the way I'm managing my money I am just getting by financially I am concerned the money I have or will save won't last Giving a gift for a wedding, birthday or other occasions would put a strain on my finances for the month I have money left over at the end of the month I am behind with my finances My finances control my life

Note. Subjective well-being scale is the WHO (Five) Well-Being Index, by WHO Collaborating Centre in Mental Health Psychiatric Research Unit, 1998, retrieved from https://www.psykiatri-regionh.dk/who-5/Documents/WHO5_English.pdf. Financial well-being scale is the CFPB Financial Well-Being Scale, by Consumer Financial Protection Bureau, n.d.., retrieved from https://www.consumerfinance.gov/data-research/research-reports/financial-well-being-scale/.

ACEs. Adverse childhood experiences (ACEs) can be categorized into three forms: sexual, emotional and physical. These experiences, both positive and negative, can have a vital impact on one's late-life outcomes. Although most research on ACEs has focused on adolescents and young adults, experts have also linked ACEs to a variety of late-life adverse outcomes including: chronic disease, mortality, morbidity, risky health behaviors, and depression (Chapman, Whitfield, Felitti, Dube, Edwards, & Anda, 2004; Dube, Felitti, Dong, Giles, & Anda, 2003; Schilling, Aseltine, & Gore, 2007). However, no known studies have examined the association between ACEs and late-life outcomes among older adults who identify as elder orphans.

Families play a critical role in an individual's level of social integration. Some individuals will experience smooth, interwoven connections throughout their lives resulting in positive outcomes; others will show incoherence and disruption resulting in less harmonious outcomes (Elder et al., 2004). Often these positive and negative experiences influence one's well-being throughout the life course. However, very little is known about these negative experiences and their impact on the well-being of elder orphans.

For the purposes of this study, ACEs was used as a predictor variable of elder orphans' current levels of well-being (Adverse Childhood Experience Questionnaire, n.d.). Since, many of these critical social components of life have a direct impact on physical and mental health, it is important to apply a holistic perspective and analysis to better understand the role of ACEs. Both a CAD and life course theoretical perspective informed the selection of the ACEs scale. The internal reliability of the ACEs scale has been demonstrated in previous research on older adults with a Cronbach's alpha of .9 (Schilling et al., 2007).

Mid-life events. Divorce, death of a child, major transitions (e.g., multiple moves and job changes) and economic instability are influential experiences throughout the life course and may build upon early life experience to shape one's overall well-being (Elder et al., 2002). Although these events can be critical throughout the life course, they may be particularly impactful in mid-life. This may be because of one's desire to create stability and family life during mid-life is strong (Levinson, 1977). When these fundamental elements of stability and family life change, they may have a lasting impact on one's physical and mental health. For example, one of the most destructive sets of events in a family's life is the multiple negative consequences associated with divorce (Uhlenberg, 1989). Research suggests the death of a child is linked to adverse physical and mental health outcomes among parents and often leads to divorce particularly in midlife (Elder et al., 2002). Economic and job instability often are conjointly associated with depression, suicidal ideation, and social isolation (Brown & Harris, 2012). Guided by life course theory and CAD, a mid-life scale was created for this study (Table 4.2). Sum scores were calculated, and higher scores indicated more adverse events in mid-life.

Table 4.2

Mid-Life Scale Item Events

Events
Divorce
Death of a spouse
Death of a parent
Major financial changes (i.e., loss of a job)

Late-life experiences. Late-life experiences, the last step in the hierarchical regression analysis, were conceptualized as social network, experiences with discrimination (e.g., ageism), and the presence of multiple health issues.

Social networks. Social networks are links to social support and social support provides emotional, instrumental, and informational support, thus strong social networks are critical to well-being (Fiori et al.,2006).

The Lubben Social Network Scale-6 (Lubben et al., 2006) included six items. Scores range from 0 to 30 with higher scores indicating more social engagement (see Table 4.3). Scoring was as follows: None = 0; one = 1; two = 2; three or four = 3; five through eight = 4; nine or more = 5. In the analysis of the life course factors that explain current levels of well-being, social networks served as a predictor variable (hierarchical regression). The internal reliability of the Lubben Social Network Scale-6 has been demonstrated in previous research on older adults with a Cronbach's alpha of .83 (Lubben et al., 2006).

Table 4.3

Lubben Social Network Scale-6 (LSNS-6)

Items
How many relatives do you see or hear from at least once a month?
How many relatives do you feel at ease with that you can talk about private matters?
How many relatives do you feel close to such that you could call on them for help?
How many friends do you feel at ease with that you can talk about private matters at least once a month?
How many friends do you feel at ease with that you can talk about private matters?
How many friends do you feel close to such that you could call on them for help?

Note. From "Performance of an abbreviated version of the Lubben Social Network Scale among three European community-dwelling older adult populations," by J. Lubben et al., 2006, *The Gerontologist*, *46*(4), 503-513, doi:10.1093/geront/46.4.503

Multiple health issues. Physical health is a critical dimension to overall well-being. The first overarching goal for the Healthy People 2020 decade is to "attain high-quality, longer lives free of preventable disease, disability, injury, and premature death "promoting quality of life, healthy development, and health behaviors across life stages" (Healthy People, 2020, p. 1). The

variance in physical health has a tremendous impact throughout the course of an individual's life. Early onset of a disease or illness can have long-term consequences not only on one's physical health but also on various other aspects of life such as occupational opportunities and abilities, social relationships, and economic status.

Later in life, physical health can play an even more critical role in shaping well-being. For example, studies have linked chronic pain and falls to quality of life and well-being in the lives of older adults (Chodzko et al., 2009; Stathi, Fox, McKenna, 2002; Stevens, Corso, Finkelstein, & Miller, 2006). Variations in health utilization and older adults have recently received attention (Gruneir et al., 2016). Ponce et al. (2006) found that 41% of older adults with linguistic barriers had an increase of delayed medical care. An examination of various aspects of one's physical health across the lifespan can provide a better understanding of the cumulative advantages and disadvantages an individual may experience later in life. Multiple health issues were measured using a 20-item scale composed of common chronic health issues and health conditions as outlined by the Centers for Medicare and Medicaid (Centers for Medicare & Medicaid Services, 2017).

Perceived risk. As mentioned previously, individuals' perceptions of the risk of becoming incapacitated are highly influenced by their emotional and mental health. Positive and negative emotions differentially influence perceptions of disease risk in the context of making medical decisions (Ferrer, Klein, Lerner, Teyna, & Keltner, 2015). An 8-item scale was developed to measure the perception of the risk of becoming incapacitated based on the health belief model (Hanson & Benedict, 2002). Items were scored on a scale of 0 (*unlikely*) to 2 (*extremely likely*). Higher scores indicated increased perceptions of a risk of incapacitation (see Table 4.4).

Table 4.4

Perceived Risk of Incapacitation Scale Items

Items
Car accident or inability to drive
Loss of support system (death of family member or friend)
Multiple chronic health issues
Dementia or cognitive related issue
Loss of housing
Financial instability or economic hardship
Mental health condition
A fall or other physical limitations

Discrimination. Older adults, like other populations, experience discrimination on many levels. Older adults from historically marginalized populations are particularly vulnerable to multiple-level discrimination; however, research suggests that a wide range of older adults report experiencing age-based discrimination (Gee, Pavalko, & Long, 2007). Age-based discrimination is referred to as *ageism*. Ageism was first defined by Butler (1975) as a "systematic stereotyping of and discrimination against people because they are old" (p. 32). According to a content analysis, which examined publicly assessable Facebook pages that focused on older adults, the majority of the descriptions about older adults were negative age stereotypes (Levy, Ching, Bedford & Navrazhina, 2012).

In this study, discrimination was measured by asking participants how often in their everyday life did they think that they would experience discrimination (e.g., race, gender, religion, sexual orientation or age). Responses were scored from 0 (*unlikely*) to 3 (*very likely*). The intent of this question was to gain an overall understanding of elder orphans' experiences with discrimination and the impact on their levels of well-being.

Advance directives. The possession of advance directives was measured by asking participants if they had a living will (i.e., about the types of medical treatment they would want to receive if they were unconscious or somehow unable to communicate) or if they had a health care power of attorney (a legal health care decision maker in the event they could not make decisions for themselves).

Demographic information. The demographic variables measured in the study were race, gender, education, income level, employment status, and marital status. Gender and race are not utilized in this study because most of the participants identified as White and female. The homogeneity of the sample prohibited analysis on these factors. The remaining demographic variables were used as predictors and control variables in the hierarchical regressions in quantitative data analysis.

Data Analysis Strategy

The following section describes the quantitative analytic strategy utilized for the study.

All descriptive and inferential quantitative analyses were calculated using SPSS data analytic software (IBM, 2012, v. 24.0). The quantitative analyses were computed in four steps:

1. Preparation of data for analysis including missing data analyses;
2. Sample characteristics and descriptive statistics including reliability testing and transformation of variables;
3. Bivariate analyses, which included a Pearson's product-moment *r* correlations and the Spearman's rank correlation test; and
4. Multivariate analyses and hypotheses testing, which included hierarchical regression and, hierarchical binary logistic regression.

Part 1. Missing data can influence the results of a study (Westfall & Henning, 2013). An MCAR test was run to determine whether missing values are randomly distributed. The MCAR test provides a Little's MCAR test chi-square equation. If the test is not statistically significant ($p > 0.05$), then values are missing completely at random; whereas, if the test is significant ($p < 0.05$), then values are not missing completely at random, and the null hypothesis is rejected (Little, 1998). The results of the test indicated the missing values were not randomly distributed ($p < .05$).

A missing data imputation method was used to handle the missing data in this study. This approach to missing values looks for patterns (monotonicity) in the missing data to determine if the data are systematically or randomly missing (Little, 1998). To minimize biases in the data, cases that had significant missing values were eliminated using trimming procedures. Next, the remaining incomplete values were imputed using a five-step multiple imputation technique. This technique uses the filled-in variable from one step as a predictor in all subsequent steps (Scheffer, 2002). The goal of this procedure is to try to find an iteration that best fits the data that is available. The missing imputation method was conducted with all the variables used in the quantitative analyses. The SPSS missing data imputation module was used for imputation. The module uses linear regression for continuous variables and logistic regression for categorical variables (Hayes & Matthes, 2009).

Part 2. I computed descriptive statistics to determine the basic features of the key variables in this study. Skewness and kurtosis were calculated for the continuous variables. Severe skewness (less than or equal to -3 or greater than or equal to 3) is problematic because it violates assumptions of normal distribution (Westfall & Henning, 2013). Histograms and scatter plots were also created to assess the normality of the distribution of each continuous variable. To

ensure that the variables met assumptions of normality, transformation was applied to continuous variables prior to the inferential statistical analyses. Ranges, means (*M*), and standard deviations (*SD*) were also calculated for each key continuous variable. Frequencies and percentages were computed for all categorical variables (See Appendix D for the box plots and histograms for the raw scores and Appendix E for the imputed scores).

Part 3. Bivariate Pearson correlations test the strength of the association between any two variables. In this study, Pearson correlations were calculated between the key continuous scale variables: age, education, income, gender, marital status, ACEs, mid-life events, discrimination, multiple health issues, and social networks. Spearman's rank correlations were computed to examine the strength of the relationship between the categorical scale variables: well-being, perceived risk, multiple health issues, advance directives, and marital status.

Part 4. Part 4 includes a hierarchical regression, and a hierarchical binary logistic regression.

Hierarchical regression. A hierarchical regression analysis involves comparisons of a series of nested regression models (Lankau & Scandura, 2002). Hierarchical regression modeling is used to determine whether certain predictor variables account for variance in a dependent variable, accounting for other variables. This is accomplished by comparing a series of regression models, where each step of the model builds upon previous steps via the successive inclusion of additional predictor variables in each step. The newly added models are preferred if there is a significant increase in the value of corresponding R^2 statistic (i.e., the proportion of variance in the dependent variable that is explained by the model) (Lankau & Scandura, 2002). Hypotheses (1-4) associated with demographic variables, life course factors (early, mid-life, and late-life), and well-being among elder orphans were tested by comparing a series of four models

with increasing numbers of predictor variables added to each subsequent model. Table 4.5 below outlines the variables included in each successive hierarchical model.

Table 4.5

Models of Hierarchical Regression

Model 1: Well-being = Intercept + Age + Education + Income + Marital Status
Model 2: Model 1 + ACEs
Model 3: Model 2 + Midlife Experiences
Model 4: Model 3 + Discrimination + Multiple Health Issues + Social Networks

Hierarchical binary logistic regression. Hierarchical binary logistic regression is used to predict the likelihood of a single binary outcome based on multiple predictor variables (Abu-Bader, 2010) in a similar fashion as a hierarchical regression analysis is conducted. For the purposes of this study, control variables were age, education, and marital status. Predictor variables were perceived risk of incapacitation and well-being. The binary dependent variable was the likelihood of having advance directives or not. Table 4.6 below outlines the variables included in each successive hierarchical model.

Table 4.6

Models of Hierarchical Binary Logistic Regression

Model 1: Age + Education + Marital Status
Model 2: Model 1 + Well-being + Perceived Risk of Incapacitation

Quantitative Summary

The quantitative test results improved the understanding of life course factors that influence well-being, as well as the interplay among well-being, perceived risk of incapacitation, social networks, and the likelihood of having an advance directive among elder orphans. As this present study is the first known empirical study on individuals who identify with the term elder orphan, an examination of several theoretically driven interconnections among the key study variables can direct future research and intervention plans. Thus, this study involves a comprehensive analysis of the factors that influence well-being and advance care planning among a growing older adult population; elder orphans.

Qualitative Method

The following key areas will be discussed in sections below: (1) study design; (2) sample and recruitment strategy; (3) interview protocol development (4) data collection and analysis; (5) evaluation criteria; and (6) ethical considerations.

Study Design

To provide a robust analysis of this relatively unexplored area of gerontological research, an interpretative phenomenological analysis (IPA) framework (Smith, Flowers, & Larkin, 2009) was employed for collecting and analyzing the data in the second, qualitative phase of this study. The interpretative phenomenological analysis (IPA) explores how individual life experiences change over time and how participants interpret and make meaning of their lived experiences (Smith, Flowers, & Larkin, 2009). The IPA framework also allows for an exploration of how participants make sense of the world in which they live. This approach allows for an in-depth analysis of the participants' perspectives on the experiences or factors that led to their personal identification as an elder orphan. IPA is considered an idiographic approach; this approach

allows for a detailed inquiry into the lives of the participants (Smith et al, 2009). The aim of this approach is to write a detailed description of the perceptions, experiences, and understandings of the participants.

In the IPA framework, a participant's perceptions are central to the exploration of their experiences; thus, the measurement of an expanded definition of well-being was appropriate for this study. Both the researcher and the participant play a critical role in the IPA analysis, such that the researcher's primary goal is to obtain an insider perspective on the issues throughout the participant's life that have influenced the participant's experiences. Conversely, the participant's goal is to gain an in-depth understanding of how and why certain factors have influenced the phenomena being studied.

This process is considered a double hermeneutic or a two-stage interpretation process, whereby the participant attempts to make sense of his or her experiences and the researcher attempts to ascertain an inside perspective on the lived experiences of the participants. Therefore, IPA has an emphasis on 'sense-making' by both the participant and the researcher (Smith et al, 2009). Together, the researcher and the participant are engaged in a dualistic inquiry into the lived experience of the participant as it relates to the research questions and foci of the study.

Sampling and Recruitment Strategy

An IPA study is typically conducted with a relatively small sample. The aim of this methodology is to find a moderately homogenous sample to examine convergence and divergence in detail. I used critical case sampling, a type of purposive sampling that involves the selection of a small number of those cases that best illustrate the phenomenon of inquiry to "yield the most information and have the greatest impact on the development of knowledge" (Patton, 2002, p. 236). As mentioned earlier, participants from the quantitative phase of the

study volunteered to participate in the qualitative phase. A total of 196 participants volunteered; however, seven participants were selected and six were included for the analysis. Since all the participants identified as elder orphans and shared several similar characteristics, maximal variation strategy ensured equal representation of individuals with varying well-being scores, perceived risk and advance directives results. Due to the purposive sampling of the individual interviews, data saturation was not the aim of the individual interview data collection. To be eligible for the qualitative phase of the study, participants had to have completed the quantitative survey and volunteered for the second phase of the study. Potential participants were informed that the qualitative interview would be conducted via a 30-45-minute telephone call, and that they would receive a $25 Walmart card for their participation. The interviews were conducted between May 21 and May 25, 2018. The liaison mailed gift cards to participants on June 4, 2018. I conducted member checks with the majority of participants following the completion of the qualitative data analysis. Member-checking confirmed that I acquired a comprehensive and accurate picture of participants' lived experiences.

Interview Protocol Development

The results from the quantitative phase influenced the development of the interview protocol in the qualitative phase. As the primary goal of the second qualitative phase of this study was to gain a deeper understanding of the results of the first phase (Creswell & Plano Clark, 2017). I wanted to understand the relationship between the key study variables and why certain predictor variables differently contributed to well-being. Furthermore, I was interested in exploring the role of well-being in advance care planning. Lastly, the qualitative phase allowed for an exploration of social media's role in participant's well-being and the significance of the term elder orphan in their lives. Ten open-ended questions explored the role of the primary

study variables: adverse childhood experiences, mid-life events, multiple health issues, advance directives, and social networks (See Appendix F for the qualitative interview guide). Questions about discrimination experience and perceived risk of incapacitation were not explicitly asked, however, the open-ended format of the questions allowed for an exploration of these variables.

Data Collection and Analysis

My goal was to create an unconstrained environment wherein participants could share their rich experience and discuss factors throughout their life course that contributed to aging alone with little to no social support. As such, participants were contacted via phone or email to schedule an interview date and time. Verbal consent was obtained on the telephone prior to the start of the scheduled interview. I audio recorded and transcribed each interview (Creswell and Clark, 2017). In-depth individual qualitative interviews were conducted with each participant using a predetermined interview guide with open-ended, semi-structured questions and prompts for additional information.

Cross case analysis. Due to the flexibility of the IPA approach, I conducted the cross-case analyses utilizing various commonly used methods employed in the IPA data analysis process. The multimethod cross-case analysis was guided by the theoretical framework presented in Chapter 3. The aim of this approach was to identify statements consistent with theory and to allow for a comprehensive understanding of the perceptions and experiences of elder orphans. As such, I first examined the patterns and connections within the data. The *abstraction* analytical process allowed for the development of superordinate themes (higher-level themes) by clustering emergent themes. Next, the *polarization and function* techniques allowed the identification of oppositional relationships between emergent themes and the specific function of each. Furthermore, the *contextualization* approach allowed for the emergence of key life events within

cases that contributed to the factors or experiences influencing current levels of well-being, risk of incapacitation, and advance care planning among elder orphans. The life course and CAD theoretical lens helped provide an understanding of the temporal and cumulative nature of experiences and how they influenced several aspects of the lived experience among elder orphans. During this process, I fully immersed myself in the data by *reading and re-reading* participants transcripts and listening to audio recordings several times. I conducted a qualitative thematic analysis of transcribed interviews. By using a line-by-line coding process, I began with open coding to develop a codebook. A PhD-level research assistant and I independently coded the data and, separately, developed a list of preliminary codes. We identified significant statements and merged these into units of meanings, and further distilled these statements into emergent themes. Moving from tentative codes to final codes was an iterative process where we continuously revised, refined, and merged codes to generate a subset of themes (Creswell & Plano Clark, 2017). Initially, we identified 235 significant statements from the interviews. We met on several occasions to collapse these into 14 clusters of meaning, which were further reduced to nine themes. Following additional discussion, we ultimately arrived at four super-ordinate themes that included twelve associated emergent themes. All meetings with the research assistant were audio-recorded for future reference.

Evaluation Criteria

The research team consisted of three individuals: a PhD-level social work research associate experienced in qualitative research, the moderator of the EOF group, and me, the principle investigator. By using criteria for rigor in qualitative research as established by Lincoln and Guba (1985), we achieved credibility (veracity of results) through member checks and triangulation using additional data from the quantitative surveys that allowed participants to

include open-ended responses. External validity (dependability) was achieved through peer-review and briefing discussions with the research team. We used thick, rich descriptions to ensure transferability of results. Confirmability was achieved through reflexivity in which we continually checked our biases. Inter-rater agreement was computed with both researchers agreeing 85% of the time and differences were discussed until consensus. We utilized audio recordings and field notes maintained during the data collection and analysis process to achieve confirmability.

Ethical Considerations

After the completion of the quantitative analyses, I obtained University Institutional Review Board approval for second phase of the research. I obtained a verbal, informed consent from each participant. To gain entrée to the EOF community, I posted a recruitment notice on the EOF page describing my credentials as a researcher in aging. Fictitious names were used to conceal participants' identities. Reporting of results will ensure the stories shared do not contain identifying details of the participants.

Integration of Results

Although data analysis for quantitative and qualitative data were conducted separately, points of integration occurred during sample selection, qualitative instrument development, data analysis and data interpretation. The qualitative phase provided a strong explanation of specific results from the quantitative phase of the study. Selection of the participants was dependent on the quantitative analysis, which helped achieve meaningful understanding of the factors that influence current levels of well-being among elder orphans and the role of perceived risk of incapacitation, and well-being in having an advance directive or not. Furthermore, the

quantitative phase facilitated the development of the qualitative interview guide. Thus, there is a strong connection between the two phases which will be explored in the discussion.

Chapter 5

Results

The goal of this chapter is to present the results of the data. First, I cleaned the data and prepared them for the analysis. Second, I provide an overview of the sample characteristics and the descriptive statistics for the predictor and dependent variables. In this section I report the reliability analysis for each scale. Following the reliability analysis, I conduct the preliminary statistical bivariate analyses – Pearson's product-moment correlation and Spearman's rank test. Last, I present the results of the hierarchical regression and the hierarchical binary logistic regression including the hypotheses testing and results.

Preparation of Data for Analysis

A total of 442 cases were extracted from Qualtrics. Twenty-one cases (married and living with partner) were eliminated due to not meeting inclusion criteria. The remaining 421 cases were evaluated for patterns of missing responses using the missing imputation patterns function on SPSS. This analysis revealed there were no cases without missing data; 36% of the cases had at least one missing variable, and 10% of values were missing. It is also important to note that over 60% of cases with missing data were missing only one variable. Further, a Little's chi-square test was conducted and revealed that the patterns of missing data were significant ($\chi^2(296) =388.727$, $p<0.001$) which suggests that the data was not missing completely at random (Little, 1998). Although, data with greater than 5% missing values can be problematic, systematically missing data, regardless of size, can significantly impact results (Abu-Bader, 2011). Consequently, data imputation methods were employed. First, trimming methods eliminated 52 cases. Trimming allowed the researcher to eliminate cases that had a significant amount of the

values missing. These cases were predominantly a function of incomplete surveys (greater than 35% of survey was not complete), which typically had missing values toward the end of the survey. After the completion of this procedure, less than 3% of data were missing randomly and thus, "similar results can be obtained using multiple procedures (Tabachnick & Fidell, 2007). Therefore, multiple imputation methods were utilized which resulted in no missing cases across all the variables of interest.

Sample Characteristics and Descriptive Statistics

Sample Characteristics

Females comprised 98% of participants in this study, ranging in age from 55 to 82 years old (M = 65.49, SD = 5.45). The sample resided throughout the United States (n=363, 98.7%; Midwest (n =85, 22.6%), Northeast, (n = 78, 20.7%), Southwest (n =82, 21.8%), Southeast (n =64, 17.0%), West (n =62, 16.5%)) and outside of the United States (n =5, 1.3%) (see Figure 5.1). A majority of the sample had an education level of bachelor's degree or higher (n = 265, 72%). Two-fifths of the participants were divorced (n =149, 41%) and one-fifth were widowed (n =73, 20%), and over one-third had never been married (n =133, 36%). The most frequently observed range of income was $20,000 to $34,999 ($n$ =78, 21%) (see Table 5.1).

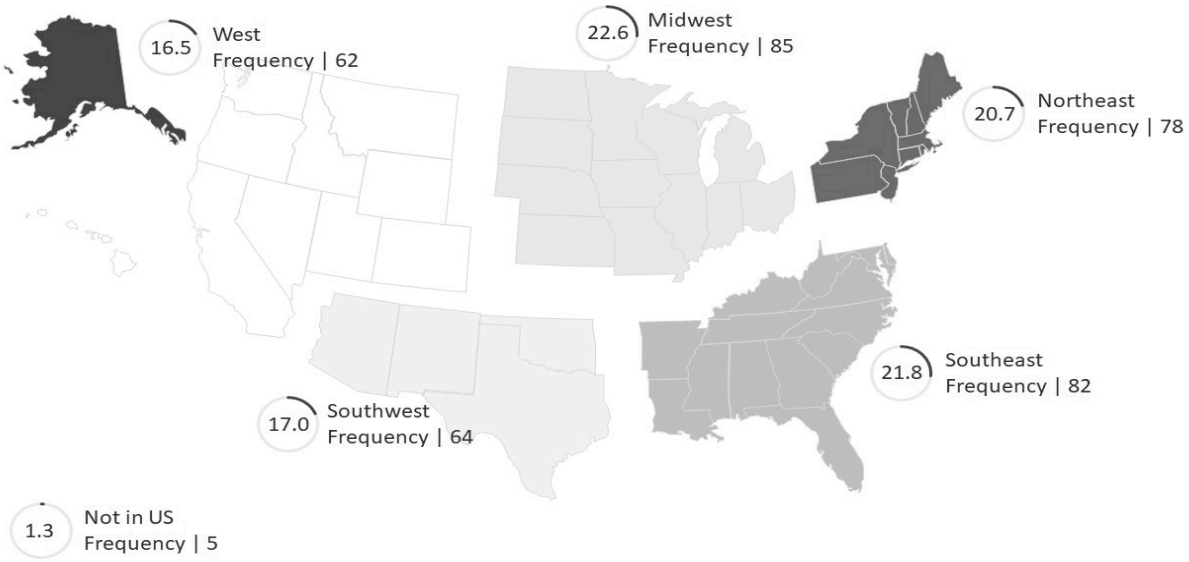

Figure 5.1. Map of respondents' locations.

Table 5.1

Frequency Table for Sample Characteristics

Variable	*n*	*%*
Gender		
Female	359	97.55
Male	9	2.45
Education		
High school graduate	11	3.0
Completed some college	48	13.0
Associate degree	36	9.8
Bachelor's degree	128	34.8
Master's degree	115	31.3
Ph.D., law or medical degree	22	6.0
Other, please specify	8	2.2
Income		
Less than 20,000	69	18.8
$20,000 to $34,999	78	21.4
$35,000 to $49,999	69	18.8
$50,000 to 74,999	74	20.1
$75,000 to $99,000	45	12.2
$100,000 to 149,000	21	5.7
$150,000 to $199,999	3	.8
$200,000 or more	5	1.4
Marital Status		
Divorced, living alone	149	40.5
Separated, living alone	6	1.6
Widowed, living alone	73	19.8
Never Married	133	36.1
Other	7	1.9
Employment		
Disabled, not able to work	25	6.8
Retired	185	50.5
Not employed, not looking for work	9	2.4
Not employed, looking for work	12	3.3
Employed, working 1-39 hours per week	63	17.1
Employed working 40 hours or more per week	72	19.6

Descriptive Statistics for Dependent Variables

Advance directives. Advance directives responses were originally coded as "Yes," "No," and "I don't know." However, for analysis purposes, "I don't know" responses were recoded to "No" responses. The most frequently observed category of advance directive was "Yes" (n = 202, 55%).

Well-being scale. The Well-being scale was constructed using the WHO-5 scale and the CFPB Financial Well-being scale. The WHO-5 scale consisted of the following 5 questions measured on a Likert scale ranging from 0 to 5 with lower scores indicate lower levels of well-being.

- I have felt cheerful and in good spirits.
- I have felt calm and relaxed.
- I have felt active and vigorous.
- I woke up feeling fresh and rested
- My daily life has been filled with things that interest me

The questions responses were: "all of the time," "most of the time," "more than half of the time," "less than half of the time," "some of the time," or "at no time." The items in the scale were found to have a high level of internal reliability (Cronbach's alpha = .912). The WHO-5 scale is displayed in Table 4.1.

The CFPB Financial Well-Being scale consisted of the following 10 questions measured on a Likert scale ranging from 0 to 5 with lower scores indicate lower levels of well-being

- I could handle a major unexpected expense
- I am securing my financial future
- Because of my money situation, I feel like I will never have the things I want in life
- I can enjoy life because of the way I'm managing my money
- I am just getting by financially

- I am concerned that the money I have or will save won't last
- Giving a gift for a wedding, birthday or other occasion would put a strain on my finances for the month
- I have money left over at the end of the month
- I am behind with my finances
- My finances control my life

The questions responses were: "completely," "very well," "somewhat," "very little," or "none at all" for questions 1 to 6 and "always," "often," "sometime," "rarely," or "never" for questions 7 to 10. The items in the scale were found to have a high level of internal reliability (Cronbach's alpha = .927). Table 4.1 shows the financial well-being scale that was used in this study.

The items in the *overall* well-being scale, comprised of all questions above, were found to have a high level of internal reliability (Cronbach's alpha = .925).

Descriptive Statistics for Predictor Variables

The predictor variables described in this section are discrimination, multiple health issues, mid-life scale, social network scale, ACEs, and perceived risk of incapacitation.

Discrimination. Discrimination was measured using a single question ("In your everyday life, how likely do you think it is that you will experience discrimination?" (e.g., because of your race, gender, religion, sexual oriental or age). Response options were "likely," "neither likely nor unlikely," and "very likely," Higher response values indicated higher likelihood of discrimination. The most frequently observed category for discrimination was likely (n = 107, 29%).

Multiple health issues. The multiple health scale consisted of 20 commonly known health issues. Participants indicated which of the health issues they were currently or previously diagnosed with by a health care provider. The participants' score was computed as a sum of the

number of issues they indicated they were currently or previously diagnosed with by a health care provider. “Has a health care provider informed you that you have any of the following health problems or diagnoses (currently or in the past)? Select all that apply”). Twenty possible options were presented to the participants for selection (Anxiety, Arthritis, Dementia/AL or any other type of Dementia, Asthma, Breast Cancer, Cancer, Depression, Diabetes Type I or II, Heart disease and/or heart attack and/or heart bypass surgery, Hypothyroidism, High blood pressure (hypertension), Major depressive disorder, Obesity, Stroke, Angina pectoris, Chronic heartburn/GERD, COPD, Irritable Bowel Disease, Osteoarthritis, Other (please list). Multiple health issues were dichotomously recoded to three or fewer illnesses and four or more illnesses. The most frequently observed category for multiple health issues was four or more illnesses (*n* = 191, 52%) (See Table 5.2.)

Table 5.2

Frequency Table Predictor Variables

Variable	*n*	*%*
Discrimination		
Very likely	84	22.83
Likely	107	29.08
Neither likely nor unlikely	93	25.27
Unlikely	84	22.83
Missing	0	0.00
Multiple Health Issues		
3 or fewer health issues	173	46.88
4 or more health issues	191	51.99
Missing	4	1.13

Mid-life events. Mid-life was measured using a single question (“Below is a list of events that can happen in an individual's life that can shape their life trajectory. Please indicate if any of these events happened to you during your midlife (40's & 50's) Yes or No for each

statement"). Seven possible options were presented to the participants for selection (Divorce, Death of a spouse, Death of a parent, Death of a child, Major financial changes [i.e., loss of a job], A major move, Other, please specify). Mid-life was transformed into a continuous variable ranging from 0 to 7, indicating the number of responses the participant selected. The observations for mid-life had an average of 3.85 (*SD* = 1.06, Min = 2.00, Max = 7.00). The items in the scale were found to have a low level of internal reliability (Cronbach's alpha = .158). Descriptive statistics are presented in Table 5.3.

Social network scale. Frequency and closeness of participant's contact or social network was measured using the Lubben Social Network Scale-6, which consists of 6-item self-report Likert scale. It is equally weighted, using the following six questions:

- How many relatives do you see or hear from at least once a month?
- How many relatives do you feel at ease with that you can talk about private matters?
- How many relatives do you feel close to such that you could call on them for help?
- How many of your friends do you see or hear from at least once a month?
- How many friends do you feel at ease with that you can talk about private matters?
- How many friends do you feel close to such that you could call on them for help?

The questions responses were: "none," "one," "two," "three" or "four," "five through eight," and "nine or more". The observations for Social network had an average of 1.43 (*SD* = 0.54, Min = 0.00, Max = 3.09). The items in the scale were found to have a high level of internal reliability (Cronbach's alpha = .821). Summary statistics are presented in Table 5.3.

ACEs. ACEs scale is a self-report retrospective equally weighted 10-item scale that measures traumatic childhood events that happen prior to the age of 18 (i.e., sexual abuse, verbal

abuse, physical abuse, parental divorce). Scores were summed to create a composite score. The observations for ACEs had an average of 1.44 (*SD* = 0.98, Min = 0.00, Max = 3.48). The items in the scale were found to have an adequate level of internal reliability (Cronbach's alpha = .698). Summary statistics are presented in Table 5.3.

Perceived risk of incapacitation. Perceived risk of incapacitation was measured on 8-point scale and consisted of questions that ask the respondent about the likelihood of an event occurring in their lives (e.g., major illness, fall, car accident). The observations for perceived risk had an average of 0.80 (*SD* = 0.31, Min = 0.00, Max = 1.83). Summary statistics are presented in Table 5.3.

Table 5.3

Summary Statistics for Well-Being and Mid-Life and Social Network Scales

Variable	*M*	*SD*	*n*	SE_M
Well-being scale	34.36	13.42	368	0.29
Mid-life events	3.85	1.06	364	0.02
Social network scale	1.43	0.54	368	0.01
ACEs	1.44	0.98	2208	0.02
Perceived Risk of incapacitation	0.80	0.31	2172	0.01

Transformed variables. Continuous scale variables were evaluated for normality. All variables met assumptions for normality except ACEs, social network, perceived risk (see Appendix D). The ACEs scale was significantly positively skewed (Skew=.740, SE=.122). To correct for the skewness, responses were raised to the .6 power. This transformation proved to be successful (Skew=-.015, SE=.122). Social network was also positively skewed (Skew=.447,

SE=.127), and respondents were raised to .7 power to correct for skewness. This transformation proved to be successful (Skew=-.017, SE=.127). Perceived risk was positively skewed (Skew=.530, SE=.131), and respondents were raised to .86 power to correct for skewness. This transformation proved to be successful (Skew=-057., SE=.131). Log transformation was not utilized in this study because it does not allow for relevant inferences to be drawn from a standard statistical test, as would have been performed on the raw data (Feng, Wang, Lu, Chen, He, Lu & Xiu, 2014). (See Table 5.4.)

Table 5.4

Comparative Statistics for Transformed Variables

Variable	Mean	S.D.	Range	Kurtosis/S.E.	Skew/S.E.
ACEs	2.35	2.08	8.0	-.349/.243	.740/.122
ACEs*	1.44	.979	3.48	-.937/.243	.015/.122
Social Net	1.75	.899	5.00	.014/.253	.447/.127
Social Net*	1.43	.547	3.09	-.200/.253	.017/.127
Perceived Risk	.769	.391	2.00	.328/.261	.530/.131
Perceived Risk*	.794	.315	1.62	.252/.261	-.057/.131

Note: Transformed variables are labeled with *

Bivariate Analyses

Both the Pearson's correlation and Spearman's rank test can be useful statistical techniques prior to conducting multivariate analyses. In this study, examining the strength of the relationship among the variables provided additional insight on the utility of the variables for the multivariate analyses.

Pearson's Product-Moment r Correlation

Pearson's product-moment *r* correlations were conducted to assess the relationship (strength) between continuous predictor variables (e.g., age, income, ACEs, mid-life, social network, discrimination, perceived risk) and continuous outcome variables (well-being and

social network). A Pearson correlation requires that the relationship between each pair of variables be linear (Conover & Iman, 1981). This assumption is violated if there is curvature among the points on the scatterplot between any pair of variables (Conover & Iman, 1981) (Appendix D). As mentioned above, the preliminary analysis showed the relationships between the variables to be linear, except for the following variables: perceived risk, ACEs, and social network. After the transformation of those variables; all variables utilized in the present study had a normal distribution.

The Pearson's correlation coefficient was computed at the .05 level using a two-tailed significance tests for all the variables. There were several significant relationships between the outcome and predictor variables. There was a significant positive correlation between age and well-being ($r_p = 0.154$, $p = .014$), which suggests a small effect size. This indicates that as age increases, well-being tends to increase. Additionally, there was a significant positive correlation between education and well-being ($r_p = .202$, $p < .001$), which suggests a small effect size. This indicates as education increases, well-being score increases. Income in the last 12 months was significantly positively correlated to well-being ($r_p = .449$, $p < .001$), suggesting that as income increases, well-being scores increase. This indicates a moderate effect size. Additionally, there is a significant negative relationship with total mid-life scores and well-being scores ($r_p = -.128$, $p = .050$), which suggests that as mid-life scores decrease, well-being scores increase. This indicates a small effect size. Furthermore, there is a significant negative relationship between discrimination and well-being scores ($r_p = -.209$, $p < .001$), which suggests that as discrimination decreases, well-being increases. This indicates a small effect size. There is a significant negative relationship between ACEs scores and well-being scores ($r_p = -.279$, $p < .001$), which suggests that as ACEs decreases well-being scores increase. This indicates a small effect size. Social

network and well-being scores are significantly positively correlated, (r_p = .407, p < .001) and indicates a moderate effect size, which suggests that as social network increases, well-being increases. Alternatively, employment and well-being scores are not correlated (r_p = -.005, p > .930) and indicate that type of employment has no influences on well-being scores. Additionally, there is a significant negative correlation between perceived risk and well-being score (r_p = -0.375, p < .001), which indicates a moderate effect size and suggests that as perceived risk decreases, well-being scores increase. Last, there was a negative correlation between perceived risk and social network (r_p = -.196, p < .001), which indicates a small effect size and suggests that as social network decreases, perceived risk increases (see Table 5.5).

Table 5.5

Pearson Correlation for Main Study Variables

	Well-being	Perceived Risk
Age	.154*	-------
Education	.202*	-------
Income	.449***	-------
Mid-life	-.128	-------
Discrimination	-.209***	-------
ACEs	-.278***	-------
Social Network	.407***	-.196**
Perceived Risk	-3.75***	-------
Employment	-0.005	-------

Note N=368; * p<.05,**p<.01,***p.<001

Spearman Rank Correlation

To examine the strength of the relationship between two ordinal variables, the appropriate analysis is a Spearman rank correlation. The assumption, when using a Spearman rank correlation, is that the variables have a monotonic relationship with each other (Conover & Iman, 1981). If the variables shift either from negative to positive or from positive to negative,

the association is violated. Additionally, Cohen's standard was assessed to determine the strength of the relationship. An association between two nominal variables is strong at .50 or larger, moderately associated at 0.30 to 0.49, and weak at 0.10 to .29 (Cohen, 1988). There were several significant relationships between nominal level variables; however, marital status and well-being (r_p = .0.33, p -=.533) are not correlated. Alternatively, advanced directive and well-being scores are positively correlated, and indicate that having an advance directive tends to increase well-being scores (r_p = .205, p < .001). As expected, chronic illness and well-being scores are significantly negatively correlated (r_p = -.281, p < .001) and suggest that as multiple illness scores decrease, well-being scores increase (Table 5.6).

Table 5.6

Spearman Correlation for Main Study Variables

	Marital Status	Chronic Illness	Advanced Directive
Well-being	**.**033		.205***
Perceived Risk			-.037

Note N=368; * p<.05, **p<.01,***p.<001

Multivariate Analysis & Hypotheses Testing

In this section I present the results of the hierarchical regression, hierarchical binary logistic regression, and hypothesis testing.

Hierarchical Regression

Research Question 1: Do demographic variables predict current levels of well-being among elder orphans?

Research Question 2: Do ACEs scores predict current levels of well-being among elder orphans?

Research Question 3: Do mid-life scores predict current levels of well-being among elder orphans?

Research Question 4: Do late-life factors (discrimination, multiple heath issues and social network) predict current levels of well-being among elder orphans?

Hypothesis 1: Demographic variables (age, income, education, marital status) are significant predictors of well-being among elder orphans (Null hypothesis: Demographic variables (age, income, education, marital status) are not significant predictors of well-being among elder orphans).

Hypothesis 2: Adverse childhood experience (ACEs) are a significant predictor of well-being among elder orphans. (Null hypothesis: Adverse childhood experience (ACEs) are not significant predictor of well-being among elder orphans).

Hypothesis 3: Mid-life events (divorce, death of a child, death of parent, financial instability) are significant predictors of well-being among elder orphans. Null hypothesis: Mid-life events (divorce, death of a child, death of parent, financial instability) are not significant predictors of well-being among elder orphans).

Hypothesis 4: Late-life experiences (social network, discrimination, multiple health issues) are significant predictors of well-being among elder orphans (Null hypothesis: Late-life experiences (social network, discrimination, multiple health issues) are not significant predictors of well-being among elder orphans).

As stated previously, the multidimensional framework presented in Chapter 3 guided the selection of variables and the appropriate statistical technique to best test the hypotheses

presented above. Hierarchical regression allowed for an analysis of various time points throughout an elder orphan's life and the influence of those time points on current levels of well-being. To conduct a hierarchical regression analysis and have valid results, assumptions of normality must be met. The assumption of linearity was met by plotting a scatterplot of the studentized residual (Appendix D). Violations of homoscedasticity were not a concern because non-linear variables (ACEs and social network) utilized in this analysis were transformed prior to conducting this analysis (Appendix E). In addition, normality was examined by assessing the variance inflation factors (VIFs) which were calculated to detect the presence of multicollinearity between predictors for the regression model. As high correlation among predictor variables can result in low statistical power, unreliable results and difficulty interpreting results, predictors with VIFs greater than 10 should not be included in the analysis (Abu-Bader, 2010). However, in this present study, the assumption of multicollinearity was deemed to be met. VIF scores for all predictor variables in models 1-4 were significantly less than 10 (Table 5.7). Lastly, box plots revealed that there were no extreme outliers (Appendix D).

Table 5.7

Collinearity Statics in Hierarchical Regression Models

Model	Tolerance	VIF
Step 1:		
Income	.924	1.083
Age	.959	1.042
Education	.902	1.108
Separated Alone	.973	1.028
Widowed Alone	.833	1.200
Never Married	.810	1.234
Other	.959	1.042
Step 2:		
Income	.911	1.097
Age	.947	1.056
Education	.901	1.110
Separated Alone	.971	1.030
Widowed Alone	.781	1.203
Never Married	.952	1.281
ACEs	.919	1.088
Step 3:		
Income	.907	1.103
Age	.934	1.071
Education	.898	1.113
Separated Alone	.969	1.032
Widowed Alone	.830	1.204
Never Married	.703	1.422
Other	.952	1.051
ACEs	.919	1.089
Midlife	.853	1.172
Step 4:		
Income	.816	1.225
Age	.911	1.097
Education	.866	1.155
Separated Alone	.952	1.050
Widowed Alone	.819	1.222
Never Married	.703	1.422
Other	.933	1.072
ACEs	.857	1.167
Midlife	.852	1.174
Discrimination	.880	1.136
Multiple Health Issues	.941	1.062
Social Network	.875	1.143

To conduct a hierarchical regression, each step or model is compared with the previous model. The newly added models are preferred if there is a significant increase in the value of corresponding R^2 statistic (the proportion of variance in the dependent variable that is explained by the model). The final, complete model allows for a holistic understanding of the influence of each predictor variable on the outcome variable. The complete model (model 4) includes all the variables entered in the previous models (models 1-3).

Model one comprised of demographic variables: age, education, income and marital status. Based on life course and CAD theories, variables associated with stages of life (early, mid-life, late-life) were entered in chronological order in models 2 through 4. Model 2 included the addition of the ACEs scale. Model 3 included the addition of the mid-life event scale. Model 4 (late-life) included the addition of multiple health issues, discrimination and social network scale.

Model comparison. The hierarchical multiple regression analysis consists of model comparisons. As mentioned earlier, each step was compared to the previous steps to understand the influence of the additional variables within each model. This is accomplished by examining the R square change. A comparison of models within this present study revealed the control variables (education, age, separated and living alone, widowed and living alone, never married, other and income) were a significant predictor of well-being scores [R^2 of .246, F (7, 360) = 16.755, p=11.] and accounted for 24.6%, of the variance in well-being scores. Age (β= .440, p<0.001), and income (β= 3.593, p<0.001) were found have a significant positive relationship with well-being scores (as age and income increased, well-being scores significantly increased). Education (β= .801, p =.114), separated and living alone (β= -2.583, p=.600), widowed and

living alone (β= .523, p =.757), never married (β= 1.596, p=.262), and other (β= -4.230, p=.357) were not significant predictors.

In the second model, ACEs was found to have a significant negative relationship with well-being scores (β= -2.708, p<0.001) (as ACEs score increased, well-being scores significantly decreased) after controlling for Age (β= .387, p=0.001), income (β= 3.406, p<0.001), education (β= .718, p =.148), separated and living alone (β= -1.696, p=.725), widowed and living alone (β= .175, p =.916), never married (β= .457, p=.747), and other (β= -2.511, p=.578). There was a significant increase in R^2 of 3.6% with the addition of ACEs (Model 2 R^2 = .282, Sig F Change < .001).

In the third model, Midlife Events did not have a significant relationship with well-being scores (β= -1.096, p<0.080) after controlling for Age (β= .363, p=0.001), income (β= 3.358, p<0.001), ACEs (β= -2.713, p<0.001), education (β= .670, p =.176), separated and living alone (β= -2.090, p=.664), widowed and living alone (β= .261, p =.874), never married (β= -.365, p=.806), other (β= -2.514, p=.576), and ACEs (β= -2.713, p < .001). There was a non-significant increase in R^2 of .6% with the addition of Midlife Events (Model 3: R^2 = .288, Sig F Change = .080).

In Model 4, discrimination was found to have a significant negative relationship with well-being scores (β= -1.183, p =.033) (as discrimination increased, well-being scores significantly decreased), multiple health issues was found to have a significant negative relationship with well-being scores (β= -4.980, p<0.001) (as multiple health score increased, well-being scores significantly decreased), and social network was found to have a positive relationship with well-being scores(β= 6.253, p<0.001) (as social networks increased, well-being scores significantly increased) after controlling for Age (β= .280, p=0.009), income (β= 2.499,

p<0.001), education (β= .630, p =.18), separated and living alone (β= -4.8 p=.289), widowed and living alone (β= -.447, p =.773), never married (β= -.321, p=.817), other (β= -2.085, p=.576), and ACEs (β= -1.693, p = .006), and Midlife Events(β=-1.085 p = ..063) There was a significant increase in R^2 of 9.7% with the addition of discrimination, multiple health issues, and social networking (Model 4 R^2 = .385, Sig F Change < .001).

The fourth model accounted for a significant proportion of variance in well-being scores (R^2 = .385, Adjusted R^2 = .364, Sig < .001). See Table 5.8 for model coefficients.

Hypothesis # 1: The null hypothesis that demographic variables (education, income, age, marital status) do not predict well-being is rejected.

Hypothesis #2: The null hypothesis that early childhood experiences do not predict well-being is rejected.

Hypothesis #3: The null hypothesis that mid-life experiences do not predict well-being fails to be rejected.

Hypothesis #4: The null hypothesis that late-life events (discrimination, social network, multiple health issues) do not predict well-being is rejected.

These findings suggest early life and late-life life course factors significantly predict well-being among elder orphans, while mid-life factors were not predictive.

Table 5.8

Hierarchical Multiple Regression on Well-being Among Elder Orphans

Model		Unstandardized Coefficients		
		B	Std. Error	Sig.
1	(Constant)	-10.356	7.834	.187
	Age	.440	.115	.000
	Education	.801	.506	.114
	Income	3.593	.392	.000
	SeparatedAlone	-2.583	4.916	.600
	WidowedAlone	.523	1.687	.757
	NeverMarried	1.596	1.420	.262
	Other	-4.230	4.589	.357
2	(Constant)	-1.493	7.937	.851
	Age	.387	.113	.001
	Education	.718	.495	.148
	Income	3.406	.386	.000
	SeparatedAlone	-1.696	4.809	.725
	WidowedAlone	.175	1.651	.916
	NeverMarried	.457	1.414	.746
	Other	-2.511	4.503	.578
	ACEs	-2.708	.640	.000
3	(Constant)	4.934	8.719	.572
	Age	.363	.113	.001
	Education	.670	.494	.176
	Income	3.358	.385	.000
	SeparatedAlone	-2.090	4.801	.664
	WidowedAlone	.261	1.647	.874
	NeverMarried	-.365	1.485	.806
	Other	-2.514	4.490	.576
	ACEs	-2.713	.638	.000
	Midlife Events	-1.096	.624	.080
4	(Constant)	12.372	8.543	.148
	Age	.280	.107	.009
	Education	.630	.470	.180
	Income	2.499	.379	.000
	SeparatedAlone	-4.800	4.519	.289
	WidowedAlone	-.447	1.548	.773
	NeverMarried	-.321	1.386	.817
	Other	-2.085	4.234	.623
	ACEs	-1.693	.617	.006
	Midlife Events	-1.085	.583	.063
	Discrimination	-1.183	.552	.033
	Multiple Health Issues	-4.980	1.153	.000
	Social Network	6.253	1.101	.000

Correlation: Perceived Risk of Incapacitation and Well-Being

Research Question 5: Is there a significant correlation between perceived risk and levels of well-being among elder orphans?

Hypothesis 5: There is a significant negative relationship between perceived risk and levels of well-being among elder orphans. (Null hypothesis: There is no relationship between perceived risk and levels of well-being among elder orphans).

To test Hypothesis 5, a Pearson's correlation was conducted. Results indicated a significant negative correlation between perceived risk and well-being score ($r_p = -0.375$, $p < .001$), which suggests that as perceived risk of incapacitation decreases, well-being scores increase (this was a moderate effect size).

Hierarchical Binary Logistic Regression

Research Question 6: Controlling for marital status, age, and education, what is the probability an elder orphan will have advance directives given his or her levels of well-being and levels of perceived risk of incapacitation?

Results

Results indicated after controlling for marital status, age, and education, the overall model was significant ($\chi^2(2) = 8.203$, $p = .017$, Nagelkerke R Square = .157). Higher levels of well-being increase the likelihood of having advance directives by .25% ($B = 0.24$, p = .009). Perceived risk did not significantly influence the likelihood of having advance directive ($B = -.044$, p = .908). See Table 5.9 for equation coefficients.

Table 5.9

Hierarchical Binary Logistic Regression Results with Perceived Risk of Incapacitation and Well Being Predicting Advance Directives Controlling for Marital Status, Age, and Education

Variables in the Equation

	B	S.E.	Wald	df	Sig.	Exp(B)
DivorcedAlone(1)	-1.017	.870	1.366	1	.242	.362
SeparatedAlone(1)	1.216	1.408	.746	1	.388	3.375
WidowedAlone(1)	-1.333	.893	2.230	1	.135	.264
NeverMarried(1)	-.692	.871	.631	1	.427	.501
What is your age?	.075	.022	12.079	1	.001	1.078
Level Of Education	.232	.091	6.441	1	.011	1.261
Perceived Risk	-.044	.383	.013	1	.908	.957
Well Being	.024	.009	6.809	1	.009	1.025
Constant	-5.753	3.272	3.092	1	.079	.003

Hypothesis 6: Lower levels of well-being and higher levels of perceived risk of incapacitation will increase the likelihood of participants having advance directives. (Null hypothesis: Lower levels of well-being and higher levels of perceived risk of incapacitation are not significant predictors of well-being among elder orphans).

Qualitative Results

The goal of this qualitative interpretative phenomenological analysis (IPA) is to obtain a detailed and nuanced understanding of the lived experiences of elder orphans who are members of the EOF group. I gathered data using semi-structured phone interviews with (*N=6)* participants. By utilizing the principles of IPA, I moved from the individual instances to the development of emergent themes, which provide an understanding of the essential features of the phenomena – aging alone with limited social support. I then utilized an abstraction method which allowed me to cluster the emergent themes by identifying patterns between themes. Finally, I was able to put the themes together under higher level themes (super-ordinate themes). Research Question 7 is presented in this chapter and explores the lived experience of elder

orphans. Research Question 8 is presented in the final discussion chapter and explores how the qualitative findings provide a more in-depth understanding of the factors that predict well-being throughout the life-course and advance care planning among elder orphans. The research question (Question 7), demographic information and thematic analysis are presented in this chapter.

Sample Characteristics

The participants in this study are members of the EOF groups and self-identify as elder orphans. Five of the participants are women and one is a male (Table 5.10). The ages of the participants ranged from 63 to 73 years, with an average age of 68 years. All the participants reported having no children and are currently single. Half of the participants have a bachelor's degree and the other half have a graduate or master's degree. Five of the participants self-identified as Caucasian, and one identified as African American. Half of the participants have been living alone for over 40 years and the other half have been living alone for over 10 years. The participants in this study lived throughout the United States: Austin, TX (1), Holly, Michigan (1), Birmingham, Alabama (1) Hampton, Virginia, (1) Dallas, Texas (1) Boston, Massachusetts. (See Table 5.11.)

Table 5.10

Demographics for the Six Participating Elder Orphans

Participants	Age	Race	Gender	Marital Status	Level of Education	Employment Status
Jamie	73	White	Female	Divorced	Bachelors	Retired
Olivia	70	White	Female	Widowed	Bachelors	Part-time
Janet	71	White	Female	Never Married	ABD	Looking for work
Kim	63	Black	Female	Never Married	Masters	Full-time
Evelyn	64	White	Female	Never Married	Masters	Retired
Adam	64	White	Male	Never Married	Bachelors	Full-time

Table 5.11

Individual Characteristics of Six Elder Orphans

Participants	Years Living Alone	EOF Membership	Advance Directive	Location
Jamie	41	6 months	Yes	Austin, TX
Olivia	10	1.5	No	Holly, MI
Janet	50	1.5	Not sure	Birmingham, AL
Kim	22	1	Yes	Hampton, VA
Evelyn	46	1.5	Yes	Dallas, TX
Adam	40	3 weeks	No	Boston, MA

Thematic Results for Question 1

Results for Research Question 1: What is the lived experience of elder orphans who are members of the Elder Orphan Facebook group?

The qualitative data analysis, which sought patterns between emergent themes, yielded four super-ordinate themes, each representing distinct experiences throughout the life course of

elder orphans. The super-ordinate themes included twelve associated emergent themes which are displayed in Table 5.12.

Table 5.12

Summary of Super-ordinate Themes and Emergent Themes

Super-ordinate Theme	Emergent Themes
The Road to Elder Orphanhood: Making Meaning of the Past	The Role of Family of Origin Knowing Self Romantic Disappointments
A Sudden Halt: Caregiving Experiences and Consequences	Lost Time, Space and Opportunities Solo Job Career and Financial Consequences Life after Caregiving: "realizing I am alone"
Connecting and Trying to Connect	The Role of Family and Friends Facebook "a lifeline"
Barriers and Future Concerns	Health Concerns Role of Finances Lack of Planning/Advance Care Planning

Super-ordinate Theme 1: The Road to Elder Orphanhood: Making Meaning of the Past

Participants provided thorough accounts of how their "home environment," may have influenced their status as an elder orphan. They acknowledged how "unhealthy relationships" between their parents may have contributed to never marrying. Others were able to "finally recognize" the impact of having a mentally ill parent. Participants also reflected on personal attributes that may have contributed to their elder orphan status. Several participants identified themselves as "introverts" or being "hard headed" and/or "not wanting to settle." Additionally, interpersonal romantic disappointments had a significant impact on a number of elder orphans in this study. I explore the following emergent themes in greater detail below: The *role of family of origin, knowing self, interpersonal disappointments*.

Emergent theme 1: role of family of origin. The elder orphans in this study disclosed that experiences in their early childhood had an impact on them. Several participants shared that their formative years were critical in shaping late-life outcomes. However, three participants shared that family of origin may have influenced their relationships or lack of relationships, and revealed the lack of understanding and impact on their relationship outcomes until much later in life.

Olivia, a 70-year-old widowed woman, shared how she started dating again after the death of her mother and husband, and realized that her issues with men were much deeper than she imagined. She noted the following revelation:

> I was in the process of dating someone three years ago who is a covert narcissist. And not realizing that my biological father, who was dead since the time I was 40, his shadow was still hanging over my head. And it was just because I guess I can stand back and be objective about things and watching another person's behavior triggered so many thoughts and feelings that I cleared that whole shadow out of my head, by meeting a stranger at age 68. It is something that I didn't know that was holding me back. I think, had it not been that cloud over my head I probably would have accomplished a lot more, professionally… I think my whole life I was always held back, wanting not to be visible.

Janet, a 71-year-old woman who never married, also shared how her father's authoritative personality may have contributed to her never marrying. She explained:

> Later on my mom told me that she thought my dad being tough on me was one of the reasons that I didn't marry…. I mean she felt that way… My dad did push me. He pushed me to get good grades, he was really upset when I left graduate school before finishing my dissertation and getting my PhD.

On the other hand, Karen emphasized the effect of an unhealthy marriage and intense caregiving responsibilities on her current outlook and status.

> My parents didn't particularly get along, and my brother, I don't think they had a really healthy relationship, I think that affected both my brother and me. He didn't marry until he was just under 50, he was 49 I think. I think that affected both of us, and then I didn't have a teenage-hood. I had a good childhood, but I didn't have a good teenage-hood because I became a caregiver then. My mom got cancer, they thought she would live three months. They were wrong…… I think that has affected my choices I don't want a whole lot of responsibility. I haven't for a long time.

Emergent theme 2: knowing self. Knowing self emerged as a theme due to few participants' ability to trace back the reasons they were single, and/or childless and living alone. The reasons stemmed less from their family of origin and more from an intrinsic belief of self-identity.

Evelyn revealed that early on she knew "she was better off by herself." She stated, "I'm better off by myself than with someone who isn't good for me. She shared how she was "hard headed," and decided to forgo a few romantic opportunities because they were not a match, and she did not want to succumb to social pressures associated with dating. She noted:

> I don't want to support someone. I had that opportunity and I said no. Twice in fact. I had that opportunity twice, and that just wasn't what I wanted. I think a lot of women choose the safe route, and that's to be socially acceptable and married and all that stuff. It's not socially acceptable to have never married, people ask you what's wrong. But I just tell them, I didn't want to be a frequent flyer. That I figured if I ever married that it would be permanent, and I haven't met the one.

Kim shared that although she grew up close to her cousins and as an only child, it prepared her to live by herself, which she really enjoyed. She stated, "I think just being an only child I've always been able to find things for me to do. I've just managed to read, or write things down, or I've always managed to entertain myself without any problem." She later stated, "I come into this apartment and just literally my whole psyche just says "Ahh, peace and quiet!" I mean, I can deal, I deal with people every day. I'm becoming more of an introvert than an extrovert but the majority battles that."

Similarly, Adam, attributes living alone and not marrying to being an only child. However, he also reveals how coming to terms with his identity might have also contributed to not finding someone. He shares:

> I think part of it goes back to the fact that I was an only child, so I was used to being by myself in terms of not having siblings. Plus, it took a long time for me to admit that I was gay, and that kind of held me back from, perhaps, living with anyone. Plus, I'm naturally selfish, maybe. I like things my way. The worst times in my life was when I had to have a roommate, and I absolutely hated it!

Emergent theme 3: romantic disappointments. A few participants shared their negative relationship histories within the context of aging alone. Participants questioned the viability of partaking in a romantic relationship in the future as they reflected on the past. For example, Janet described how two bad romantic encounters influenced her current way of thinking. She shared:

> I was engaged to be married when I was 28 and 29 and he called off the wedding about a week before and I'm sure that had a huge effect on me. I've got a lot of good male friends but hardly ever let myself, only once more get really involved with somebody…Yeah and

> then the second person in my 40's that I got involved with was an alcoholic and it took me a year to figure that out, because I just never been around alcoholism. We stayed together about eight years and after that it was like, anyone wants me then they come after me I'm not giving anything else.

Jamie was also candid about her relationship history. She shared that her divorce was one of the most impactful events in her life, shaping her life trajectory in many ways. She expressed feeling lonely and sad at times about aging alone but she was sure she did not want to be in a relationship again. She stated, "When I left him I just never even contemplated getting married again. It seemed like it was unhappy." But later, Jamie revealed how she had a boyfriend shortly after her divorce, but it did not work out as well. She noted:

> Well, I had a boyfriend after the time I left my husband until 10 years later. And it turned out I was only crazy about him because I was crazy (referring to her diagnosis of bipolar disease) Because he turned out to be very bad for me, and he managed to mess up my entire 40's and 30's.

Adam discussed how he had "three great romances," all which "crashed and burned." He revealed:

> There was this guy I was sort of romantically involved with, and he was the second love of my life. But he was a drug addict, and he had no self-esteem. He eventually OD'd and that was a big traumatic event of my 40's. It was June 4, 1998, a week from now, it will be 20 years…Those are the interpersonal things that have marked my life.

Super-ordinate Theme 2: A Sudden Halt: Caregiving Experiences and Consequences

Caregiving is a central theme in this study. Five out of the six participants were family caregivers. Caregiving for a few of the participants spanned several decades and some were

family caregivers for multiple family members throughout their lives. All the caregivers shared a sense of responsibility for being the "one" in the family to take care of their parent or spouse. However, solo caregiving brought on tremendous stress. Some of the participants shared how "caregiving stress" impacted their physical and mental health in late-life. Additionally, participants shared how caregiving had taken a toll on their financial well-being and their career opportunities and pursuits. Almost all the participants felt that while they were glad to be the primary caregivers in their family for their loved ones when needed most, they felt they "lost a lot," in the process due to the tremendous responsibility and time associated to caring for multiple family members and often over long periods of time. I explore the following emergent themes in greater detail below: *loss of time, space and opportunities, solo job, career and financial experiences and consequences and life after caregiving.*

Emergent theme 1: loss of time, space and opportunities. Participants discussed how caregiving was "all encompassing," and occupied all their time. They rarely had time to engage in other activities besides the day to day caregiving activities. Others discussed how caregiving spanned over several decades and took a toll on every aspect of their lives and resulted in missed opportunities.

Olivia noted the following:

> Well for a 10-year period, between age 53 and 63. My mom and my husband were both sick and dying, and my husband was dying of end-stage Parkinson's and my mother had stage IV lymphoma and then she had a small heart attack and she needed custodial care. So, my husband was at home and between two other hospitals my mom was 27 miles north of me at home with another hospital, and I worked in medical sales 60 miles away. So needless to say, in a 10-year period of time my whole outsides…. really shopping was

> run to the grocery store, the smallest one I could find, and run in. I was usually a four item or less limit on buying; I didn't have time. My entire travel experience in that time was two weddings, two Christmas parties at my sister's in South Bend, both 200 miles away, and two business trips. That was about it, and go to church on Sunday, sometimes.

Kim stated, "mom got ill and I had to start caregiving, right before I got my first actual classroom. So, she didn't have a chance to see the third graders that I know she would have loved that."

Evelyn discussed her immense caregiving responsibility at the young age of 13; she was the primary caregiver for both of her parents at various periods throughout her life. She shared:

> When, mom started getting better, my father had a heart attack. So, mom took over the business, and I stayed home with him. I think that has affected my choices. I don't want a whole lot of responsibility. I haven't for a long time. I'd rather not be department chair. I'd rather just be one of the Indians.

She later stated, "I think that it's been a whole lot heavier than I would have liked. It hasn't been continuous. They finally got their act together. They finally got healthier before they got sick again."

Emergent theme 2: solo job. Caregiving for all five participants was a solo job. Participants revealed that although they enjoyed being the primary caregivers for their parents or other family members, it was at times disappointing that they themselves had no real help. Two of the six participants in the study were only children, so they knew when their parents fell ill they would organize and provide care. However, four participants that had siblings, their own single status often dictated why they were "the chosen ones." For example, Evelyn shared:

> I had been more of a caregiver than I knew at the time…. It was a lot to go through. I do have a brother, but he was no help because he was living in San Francisco, and dealing with things, before and after and after they died. I love him, but he travels and it's just not, you know…

Although Janet had a bustling career, she was the "one" in her family to care for her parents. She attributes this to being the single one in her family. She stated, "My brothers were both married and had kids, so I knew I was the one that that would take care of my parents."

Kim discussed how she was called on by her family when someone fell ill. She shared:

> I'm the one that had always been called, "Kim, can you do this? Kim, can you do that?" When I had my aunt and uncle, these are the parents of my cousin in Philly, when I get the call from them saying they're in trouble, I'm the one that the family reached out to.

Although Kim did not explicitly state that she felt that the reason that family counted on her to do the caregiving in their family; she made reference to being the only child in her family and the obvious responsibilities that go with that.

Emergent theme 3: career and financial consequences. Participants experienced significant loss due to their extended caregiving responsibilities. Several participants spoke about how caregiving changed their entire life trajectory, the most notable discussed issue was the loss of income and job stability. As caregiving often spanned decades, it was difficult for elder orphans to have stable employment while being the primary caregiver for one or both parents. Only a few participants revealed that losing their job also meant losing their identity and their social networks.

Janet had several financial and career losses associated with caring for her mother, particularly as her caregiving spanned over a decade. She stated:

> I left there [a job] to take care of my mother in her transition and started my own consulting firm and it took a good two years to get that, to the point that I was making any money. Ever since then it's been up and down and up and down…

She contemplated on the lost opportunity and the associated depression. She stated,

> I think when you spend a lot of your life really caring about working your way up in the work world, when things start slowing down when you hit your 50's and 60's, it's hard. You get…. I didn't get depressed, but I got sad and I was looking as if I'd stayed in New York I could be doing this and this and this, and here I am stuck in Birmingham, Alabama." (Janet in this quote is referring to her New York job she quite when her mother first needed care).

She later revealed:

> Then, she [mom] started having some little bouts of pneumonia and then she had a really bad month where she was in the hospital for two weeks. I had to give up one consulting gig at that point because I just knew that she was more important.

Similarly, Kim shared: "Things such as my mom getting sick. And I had to do, for me, the unthinkable. Tell someone on a job that I had. My mother is more important than this job. I am going to be with her."

Adam discussed how he spent his savings for his mom's long-term care when she ran out of money. He stated, "I had to dip into a lot of savings to take care of my mother…. She was in a nursing home for years, and we ran through a lot of money and half of mine, that's set me back."

Emergent theme 4: life after caregiving: "realizing I am alone." Evelyn acknowledged that she became depressed after her parents passed away within "six weeks of each other," and, for the first time, realized she was alone. This was a difficult revelation for

Evelyn. She shared in the following statement: “Believe it or not, when they died I thought “Oh my gosh, I have no one to go to now.” I was taking care of them they weren’t taking care of me.” Kim had a similar revelation related to the death of her mother. She said, “I feel like I have to grow up now,” And that just cinched it for me.”

Similarly, Janet revealed that although she has two brothers, when her parents died she felt that she no longer had a familial foundation. She noted:

> My mom died in July 2016, and that point I realized that I’m by myself. I do have two brothers, but they don’t live anywhere near me. Both of them have children and I know at some point I’m just gonna be on my own.

Several participants discussed their depression after their parents died and the resulting realization that they were the only ones left and had to figure out life by themselves. For example, Evelyn revealed that after her parents died she realized she was all alone, depressed and had nobody to depend on. She stated, “I don’t have anyone that I can depend on from day to day. If I lose my keys I’m in trouble.”

Super-ordinate Theme 3: Connecting and Trying to Connect

Participants discussed the role of their family, friends and social media within the context of aging alone. Several of the participant’s family lived in states that were hundreds of miles from the participants. While most of the participants felt their family would be there for them in an “emergency situation,” they did not feel they could count on them on a day to day basis. Most of the participants had come to terms with this reality; however, several yearned for deeper connections with their family, particularly their siblings. Participants had strong friendship networks. Friends played an important role in the lives of elder orphans in this study but friends were also not always available. Friends were more readily available on a day to day basis; yet,

holidays and other occasions, which are typically spent with family, were particularly difficult for a few elder orphans. A few participants expressed oppositional statements when describing their relationships with both their family and friends. On one hand, family would be there if needed; however, visits were infrequent and communication sporadic. Additionally, some participants experienced smooth, integrated relationships with their communities while others did not.

Social media, specifically the EOF group, allowed participants to connect with other elder orphans throughout the country and helped them realize that they were not the only ones aging alone. Several participants discussed the negative aspects of social media, including Internet addiction/the Internet serving as the sole form of social connectivity and concerns about negative political messages. Notwithstanding, most elder orphans continued to enjoy social media.

Emergent theme 1: the role of family and friends. Jamie expressed her desire to have stronger relationships with both her family and friends; however, she expressed barriers to these relationships. For example, Jamie stated, "Well, I have sisters, but I don't see them very often. Maybe once or twice a year. Yes. I live far away, and it cost money to make the trip." Although she believed her sisters would be there for her in the event of an emergency. She said, "I have two sisters left. One of them is 72, and the other one is in her 60s. Both of them would come down here in a heartbeat if I asked them to."

Olivia also spoke about her relationships with her sisters and stated that although she feels they are close maybe the reality is different. She noted:

> I have two sisters, four years younger and 12 years younger. The one sister lives 27 miles away. The other one lives 200 miles away. We're close, but ... There's another thing about social media. In the 21st century, everybody has their own life. So, despite the fact that I can say we're close family, and if I have an emergency, like when I ended up in the hospital I texted my nephew. He says, "anything you need, and I'll be there." Well I didn't need him, but at the same token….

Karen discussed how she has friends but no longer has family she can count on. Either they have died, live too far away from her, and/or are occupied with other family members. She shared:

> I was an only child, yes. I had close friends, but there are several of us that are close, but no family. My closest family member is four miles away from me, and she's busy with her grandchildren and great-grandchildren. All of my cousins, there's only four of us left, and my cousins are spread out throughout the United States.

When speaking about why he believes he is an elder orphan Adam shared:

> I don't have any brothers or sisters. My parents are both dead. My closest relatives live in New York and in Maine, so it's 200 miles between me and my cousins, who are the closest relatives I've got. I am kind of by myself.

Jamie revealed that although she is close to her one friend who provides her with support, her friend's marital status impedes on their ability to meet as frequently as she would like. She shared:

> We're just close friends, and we do everything together…. She is teaching me to use a cane so I can start being more independent. She is a good of friend of mine. The problem

is that she's married, so I don't spend as much time with her as I would if she wasn't married."

Jamie also spoke about her limited social connects and how she feels "cut off" from activities because she is no longer employed. She stated, "Well, I don't go as many places. I don't see as many people. Not having a job means I don't have anything to do every day."

On the other hand, Olivia expressed that she had strong social networks and friends. She shared:

> As for friends, I have a few close friends. I have one friend from work that is 10 years younger than I am, going through issues, and we talk almost every day. I'm like her counselor in some ways. And three or four friends from school that continue being friends. We don't see each other as often. We get together to lunch once in a while, but we support one another. And of course, when I was going through school, I was the nerdy girl who really had very few friends, but then when we did our 50th high school anniversary celebration, everybody

Similarly, Janet shared how long-term friendships have been instrumental in her life; however, she is still contemplating whether being close to her nieces as she ages would be in her best interest. She shared:

> I have really good friends, I mean my college roommate and I have been really good friends for over 50 years now and I have a good friendship group here that's pretty supportive. I've been trying to make up my mind whether I was gonna stay in Birmingham or whether I was gonna move somewhere else and whether I needed to get closer to my nieces? There are a lot of questions I've asking myself.

Though Janet desired to be closer to her nieces, she recognized that she did not have a close relationship with her brothers. She stated, "We're okay. We're not close, close but we get together every once in a while, but it's not they would call me if I was sick. (referring to her brothers)

Karen also spoke about the strength of her friendships. She discussed a group of women that are all either "single, widowed, never married or divorced," who got together to support each other. She shared:

> My group. There's five of us, and I call us the Circle of Fifth. We're just friends. We're from two different churches. And two of us are musicians. Firths, because they're chords. But we get together, and we're all single by either widowhood or divorce or whatever. We get together and we'll celebrate birthdays. And just, we have a ball! When we are, and we all pretty much are, let me think- Yeah all of us are elder orphans.

Emergent theme 2: Facebook "a lifeline." Participants shared the role social media, especially the EOF group, has played in their lives. The EOF group has helped elder orphans connect with each other. Through the communication with other elder orphans, participants shared that they were able to better deal with the depression they experienced during caregiving and the loss of their parents. For example, Evelyn shared:

> It [EOF group] has expressed a lot of the bad feelings I was having. The depression went away, when I saw elder orphan I just went, "Hey! Finding out, there were so many and there was a group and so many of them are dynamic. I have met with people. The depression's gone.

She later shared that the EOF group has helped her deal with her depression but also recognized that too much "social media time" is unhealthy. She shared:

> I think I spend too much time on social media, on Facebook. Yeah. I probably do. Especially in the past. Like I said now I'm pretty socially active because I'm in a show now. I probably spend too much time communicating on the computer and not in real life. I think it's healthier to spend time with people than it is to spend on Facebook.

Adam spoke about the benefits of connecting with others on Facebook and the importance of limited social media engagement. He shared:

> I've got political friends, too, all over the place, through Facebook. a lot of other people. I've got all these friends that ... People that I knew when I was a kid, or in high school. Whatever. Haven't really given a thought to in 40 years, and suddenly they're back. It enriches your life. It really does. I don't spend hours and hours on Facebook, but I'm on it at least once a day.

Janet revealed that she was once "addicted" to social media. She stated, "After the election, I got addicted to social media because I was just trying to keep up with whether we were gonna have the United States of America."

She later shared her thoughts about the importance of face-to-face interactions vs. social media She shared:

> Well, when … in reading a lot of the things that you posted on elder orphans, I know there's a thing about being independent but I'm seeing a lot of people that don't, and when

> I get down in the dams I have to force myself too, but you have to force yourself to get up and do so. Facebook and LinkedIn and that kinda thing is okay, but social interaction and those social relationships I think are critically important

Participants recognized the benefits of social media yet, were also able to clearly see how Facebook alone was not enough, and interpersonal social interactions were critical to well-being. Thus, when participants were able to self-regulate and combine their use of social media and develop meaningful face-to-face relationships, they were more satisfied with social media and its benefits.

Super-ordinate 4: Future Concerns: Health, Finances, Social Isolation and End-of-Life Planning for the Future

Participants shared their concern for future health issues, mostly related to familial disease, falls, obesity and having a stroke. A majority of participants shared they were most concerned about maintaining their health as they aged and felt hypervigilant about addressing potential health issues. Finances are a central supporting theme in this study. Participants were troubled about their finances and their ability to pay for future medical costs. Their day-to-day living expenses as they age were central to their experience of aging alone with limited social support. Several of the participants in the study were employed either full-time or part-time and two of the six participants had retired for short periods of time and returned to work because of financial issues or Medicare eligibility. Additionally, participants had varied experiences with advance care planning. I explore the following emergent themes in greater detail below: *Health concerns, Financial concerns, Planning for the future.*

Emergent theme 1: health concerns. Jamie discussed how experiencing recurrent falls made her fearful and limited her social activity. She stated.” Well, for some reason recently I’ve

been falling down a lot. It's gotten to the point where I'm actually afraid to go anywhere, because whenever I go somewhere I fall down."

Similarly, Kim revealed that she wears a brace because she is afraid of falling. She shared that while concerned about the future, at the moment it has not limited her activity. Kim shared:

> I was walking down the steps with a group of people after one of our meetings, and as I'm walking down I feel light-headed. I held on to the banister, and I immediately tumbled down four steps. My fear of falls would be if I am ... I'm on the second floor of an apartment, and the only time I really would fear falling would be if I'm holding something in my hand and I'm conscious as to grabbing hold of the banister and just taking my sweet time going down the steps.

Kim also discussed the issues she has experienced in assessing health care:

> No, because the dentist that I had been going to for 35 years, the insurance company ... He doesn't fall under that insurance company. I just had to change everything ... Let me rewind that. The insurance company, ACA, and it's not the same insurance. Because Blue Cross/Blue Shield dropped out of Virginia, and the only insurance company that would be for the Hampton Roads area was Optima. And what is frustrating is I have to wait until I'm 65 if I want to try to get Blue Cross/Blue Shield again under Medicare.

Adam discussed the health issues he has been experiencing since the age of 55:

> I have arthritis which is bad and getting worse. It is just osteoarthritis. It's not a real killer like rheumatoid arthritis, but it is pretty much everywhere, in all my joints, in varying degrees. It's worse in my knees, its minimal in my fingers, that kind of thing. But it is there.

Olivia discussed how she has been healthy until the age of 70. She shared:

> I was doing well till age 70, and I actually went to a dinner, like I was doing well until I turned 70. She later revealed that her declining health might have something to do with the caregiving stress she experienced for 10 years. She stated, "And now being held back a little bit with this oh, a little chronic fatigue, fibromyalgia, which is probably coming in from all that stress over that 10-year period, and why I run away to the lighthouse to get spiritual, more fulfillment that way."

Evelyn discussed her future health concerns as it relates to her perceived risk. She shared:

> I think I could have a stroke. I think that's probably the most likely way I'll go. I had some heart tests last year, and they you know, the doctor thought I had had a heart attack and so he made me take a bunch of tests, and I have no heart disease at all. So it was real scary, but that's probably not the way I'll go. That's why I want you know, I want the long-term care. I need to get somebody to be an advocate. know that you can hire advocate companies or whatever, and I need to do that as well. I have not yet.

Emergent theme 2: financial concerns. Outliving money was a concern among a few of the participants.

Evelyn expressed her concerns about not having enough money to care for herself as she ages. She shared that after her mother died, she had several failed jobs because of the tremendous caregiving responsibility and had to utilize some of the inheritance her mother left for her. She revealed:

> I ended up having to pull some money out of what she had left me that I had and even though it was not a lot it was still much more than I needed to go out because I have one parent that lived till 86 and another until 102 and I'm like, " I'm gonna run out of money way before I die.

On the other hand, Kim revealed that she is still is concerned about paying off old debt. She stated, "I wish I could finish paying IRS those student loans". Kim further discussed how feels financially insecure. She shared,

> My basic needs are being met. I worry about my rent going up. I'm still paying IRS for the year before, and I haven't started last year's taxes because not enough was taken out… It's kind of dicey (referring to her financial situation). I don't feel isolated, but I don't feel as comfortable as I would like to feel.

Janet was also concerned about her financial future. When discussing whether she has any future concerns, she stated, "It's all finances, as long as I can work and have, like I've got a consulting contract issue with a small organization that I'm doing all of their grant writing, and they can only afford a 1000 a month, that helps tremendously."

Emergent theme 3: planning for the future "I was a kid of the 60's so didn't plan."

Participant experiences varied with end-of-life planning and the initiation of advance directives. For a few participants, their parent's death was a "wake up call" that they were now alone, and they should start planning for end-of-life issues. While others were not as concerned about planning for the future, one participant was strongly against advance directives because he felt the issues around advance directives were too politicalized and possibility not in the best interest of patients.

Olivia discussed that although she knew about advance directives and understood the importance of them, she did not have them. She shared:

> Advance directives are documents you fill out for either your health care or your hospital care in advance of need, so that some ... and I don't have one, can you believe that? I

> don't have one because for some reason I keep forget ... I have this monster mailbox. You wouldn't believe the mail… So something like advance directives, I've got the documents sitting on the table and, especially when I went in the…. it's like a will. I don't think about those things till I get on an airplane.

Jamie revealed that she has advance directives but the cost of them was a barrier. She stated, "Well, I got them about a year ago. I've always had trouble getting them because it cost money. But now I was able to find some place that did it for free, so I got them about a year ago."

Adam, on the other hand, discussed how he had not planned well financially and had fears associated with his lack of planning. He noted:

> No. Not in the least. I've never planned. I've never been very good with planning for the future, or with money. That's one of my great weaknesses, I think…It makes me think of being destitute at the age of 85, or whatever, because ... You get the Social Security statements every year, saying, "You'll get this much money," "You'll get that much money." None of it is enough. I don't really have.

A short while later, Adam began to discuss his concerns about end-of-life issues. He shared:

> I've thought about it. I hesitate to burden someone with that decision. If I left it ... That's definitely an advanced directive, though, because if I made one, it would be my decision. I honestly don't know. I think that there's a pressure that's been building in society for quite some time to make people die as quickly as possible, and as conveniently to others as possible. I'm not sure I want to do that. I don't think it ... If an advanced directive were to say, "I don't want to be resuscitated," maybe I do want to be resuscitated. I would defy it. I do think there's a lot of all this emphasis on a

> good death. A lot of it is for the convenience of the medical profession, and I don't agree with that as a reason to just up and leave the Earth. I think the pressure's going to grow as people of my generation get older and older. It's like, "All right, die already." That kind of thing. No. I don't intend to.

Janet shared similar concerns about not planning soon enough. She noted:

> That's what I meant about having to start planning soon enough. When you live in New York, a quarter to half your income goes to where you live. I've been saving a lot. I started a small … I was getting a raise every year, not huge, but I wasn't really saving money, and then the time I was in Florida, I did get a 503D which is a for non-profits…but I didn't do a whole lot else besides that, and I liked the things.

Janet later shared, “I chose not to get married and not to have a family, it's on me, but, I was one of the kids of the 60’s that didn’t start planning ahead soon enough. I like to say it that way.”

A few of the participants discussed how the death of their parents was a motivator to “get paperwork in order.” Although they had planned, they continued to be concerned about the expenses associated with end-of-life costs. Participants discussed their fear associated with nobody being there to do “all the little and big things,” associated with caring for someone at the end of life. Who will pay my bills, or who will organize my transition from one place to another? Several participants described doing these things for their parents and not having children or grandchild made it difficult and often “scary,” for participants to think about their future caregiving needs.

Chapter 6

Discussion

Integration and Discussion of Mixed-Methods Findings

The purpose of this mixed methods explanatory sequential study is to identify factors throughout the life course that contribute to well-being, and to better understand the motivators for advance care planning among elder orphans. In the quantitative phase, income, ACEs, discrimination, social network, and multiple health issues were found to be significant predictors of well-being among elder orphans, whereas mid-life events were not significant predictors of well-being among elder orphans. Contradictory to prediction, higher levels of well-being increased the likelihood of having advance directives while perceived risk of incapacitation had no influence on the likelihood of having advance directives.

The qualitative follow up, interpretative phenomenological analysis (IPA), revealed four sub-ordinate themes: (1) the road to elder orphanhood: making meaning of the past; (2) a sudden halt: caregiving experiences and consequences; (3) connecting and trying to connect; and (4) barriers and future concerns. The theme sudden halt: caregiving experiences and consequences, had the most significant impact throughout the life course on elder orphans relative to other themes. Typically, caregiving responsibilities began in mid-life; however, the consequences of caregiving for several years or decades can influence various aspects of well-being throughout the life course (Cagle & Munn, 2012). The findings from the qualitative analysis indicate several dimensions of well-being were impacted by being a caregiver: relationships, career, income, health and advance care planning.

These findings are consistent with both life course theory and cumulative advantages/disadvantage theory (CAD). In other words, early childhood experiences can influence mid-life and late-life experiences, choices and opportunities. CAD, in conjunction with life course theory, provided a holistic framework for understanding the systematic tendency for interindividual divergence with the passage of time. Systematic tendency specifies differences in characteristics not simply as a result of the complexity of individual experiences, but rather a result of collective (such as cohort) trajectories. Although both CAD and life course theory are centrally relevant for individual inquiries, the examination of intracohort distribution of significant features, their pathways over time, and the forces that produce them, can offer further insight into a phenomenon of interest: factors that influence well-being and advance care planning among baby boomer elder orphans.

Thus, both CAD and life course theory together provide a nuanced understanding of how variability over time results from systematic processes. The experiences of the participants in the qualitative phase of this study demonstrate this. Five of the six participants were family caregivers at some point in their lives; among this group of elder orphans, individuals experienced significant career loss and economic instability due to their extensive caregiving responsibilities over lengthy periods of time. The loss of employment opportunities due to the participants' caregiving responsibilities produced predicable patterns of sequencing and temporal movement within organizations. This concept is referred to as tournament mobility: an individual falling behind within an organization, which leads to disadvantages throughout the life course (Dannefer,1987). These disadvantages combined with gender inequality and gendered cultural expectations can be increasingly detrimental. As most of the participants in this study are female and belong to the baby boomer cohort, findings from this study can be better understood through

a cohort and gendered perspective. CAD and life course theory provided an ideal framework to better understand factors throughout the life course that influence current levels of well-being among the elder orphan sample in this study.

Key Variables

Findings from the present study affirm that demographic factors and key life events influence late-life outcomes among elder orphans. Additionally, well-being and perceived risk of incapacitation are critical constructs in understanding advance directive initiation among elder orphans. Major findings from this study are addressed below through the following variables of interest: demographic variables, ACEs, mid-life events, late-life events (multiple health issues, social network, discrimination), perceived risk of incapacitation, and well-being (subjective and financial).

Demographic Variables

Socioeconomic status. In the final hierarchical regression model, annual income was found to significantly predict well-being scores, indicating that higher annual income predicts higher levels of well-being throughout the life course among the elder orphans in this sample. This finding was further corroborated through the thematic qualitative analysis. Financial concerns, most often related to annual income, were an emergent theme in the qualitative results. Five of the six participants revealed that their annual income influenced various aspects of their well-being including physical and mental health, the ability to develop meaningful relationships, engagement in various types of entertainment, and concerns about the future.

These findings are consistent with previous research on poverty and older adults and suggests that older adults living alone are three times more likely to live in poverty compared to their cohabitating counterparts. While poverty rates have decreased among older adults in the last

three decades government and employers are less accountable for the provision of retirement, exposing older adults to financial risk during retirement (Klinenberg, Torres & Portacolone, 2013). Research on the 2008 recession's impact on well-being outcomes among older adults indicates that the recession had a significant impact on older adult's level of depression, anxiety, and physical well-being (Wilkinson, 2016). Furthermore, research suggests that 38% of Black women and 41% of Hispanic women who live alone are poor (Klinenberg, Torres & Portacolone). This is concerning, as the number of older minorities is predicted to increase substantially in coming years (US Census, 2014).

Marital status. Findings from this study reveal marital status is not a significant predictor of well-being among elder orphans in this sample. Regardless of marital status, women are more socially active, maintain relationships with family and friends, and cultivate new interests throughout the life course compared to their male counterparts (Steptoe et al., 2013). However, as mentioned above, older women experience more financial difficulties, which limit their choices and opportunities (Szanton et al., 2013).

Older men represented less than 2% of the quantitative and qualitative samples in this study which suggests that men may be less likely to join social media platforms for community and support. Although there is little to no research on older men's activity on social media, existing research does suggest that older men are more socially isolated than their female counterparts (Steptoe et al., 2013). Social integration interventions for men aging alone can help prevent social isolation that can lead to deteriorating mental or physical health. Additionally, the vulnerabilities of older adults aging alone differ by socioeconomic status, gender, race and ethnicity. Thus, older adults aging alone can have very different outcomes based on a combination of characteristics. For example, older White men are more comfortable

economically than their Black and Hispanic male counterparts, while White, widowed, older men, living alone face the greatest risk of suicide (Bilsker & White, 2011). Furthermore, these numbers differ greatly for those over 85 years of age as their needs and reasons for living alone may not be due to individual choice (Stek et al., 2004). Childlessness is yet another factor that, combined with solitary living and advanced age, may be detrimental to well-being (Stek et al., 2004).

ACEs

Quantitative results indicated that higher levels of adverse childhood experiences predicted lower levels of well-being. The qualitative analysis revealed that half the participants experienced verbal abuse and extremely authoritative parenting styles, and witnessed parental disputes, all of which had a lasting impact on their well-being. Two of the participants revealed that they continue to go to therapy to better understand their childhood issues. One woman spoke about her narcissistic father and his impact on her interpersonal relationships.

These findings, to some extent, are consistent with research on ACEs and late-life outcomes. When using the baseline database from Ireland, researchers found 23.7% of older adult participants reported at least one ACE. ACE scores were also associated with higher levels of depressive symptoms (Cheong, Sinnott, Dahly, Kearney, 2017). There is significant research that shows early childhood abuse and neglect are associated with declining physical and mental health issues. However, we know less about ACEs' influence on financial well-being. The outcome variable in this study consists of a financial well-being scale and a subjective well-being scale. A recent study examined the relationship between ACEs and financial well-being and found older adult participants with higher ACEs scores were living in households below the federal poverty level (Metzler, Merrick, Klevens, Ports, & Foed, 2016). Older women who live

alone and who experienced childhood adversity, including childhood trauma, abuse, and neglect may be at elevated risk for experiencing poverty late in life. As poverty is associated with negative physical and mental health outcomes across the life course, it is essential to better understand the links between adverse childhood experiences and late-life financial well-being.

Mid-Life Events

Adverse midlife events were not a significant predictor of well-being in this study. The lack of variance may have been impacted by our ability to detect significant changes in the outcome variable. Furthermore, it is likely the results were influenced by the low Cronbach's alpha of the scale items ($\alpha = .158$). While the mid-life scale was developed in conjunction with the community liaison and guided by life course theory and CAD theoretical framework, caregiving did not develop as a significant life course event in our discussions. However, caregiving emerged as a super-ordinate (overarching) theme in the qualitative analysis. As mentioned previously, five of the six participants in the qualitative study were family caregivers.

Though the quantitative mid-life scale was not predictive of well-being, the qualitative data provided unexpected results, which helped gain a deeper understanding of the potential mid-life factors that influence well-being among elder orphans. As mentioned above, caregiving during mid-life emerged as a super-ordinate theme in this study. Research suggests that the average caregiver is a woman in her late 40s, works outside of the home, and provides at least 20 hours of care to her loved one (Family Caregiving Alliance, 2016). The associated stress, physical strain, competing demands, and financial hardship of caregiving are well documented and are now viewed as a public health concern (Family Caregiving Alliance, 2016). However, most available studies on well-being of caregivers have not exclusively focused on solo family caregivers, thus we know very little about the unique consequences and experiences of single

family caregivers. The findings from the qualitative study reveal that solo caregiving had a tremendous impact on elder orphan's relationships, job security, and economic security. Furthermore, after the death of their parents, the elder orphans in this study often realized, for the first time, that they were alone, which often resulted in depressive symptoms and feelings of loneliness and social isolation.

Other factors may have influenced the reasons why mid-life events were not found to be predictive. Over 45% of marriages end in divorce in the United States (Amato, 2010; Cherlin, 2010). Peak rates of divorces in the United States occurred when boomers were in their 20s and 30s (Brown & Fen, 2012). Baby boomers divorced and remarried in large numbers, and now, as they approach their 60s and 70s, are again experiencing large numbers of divorce, usually because of a second marriage. Although divorce is a transitional period in one's life and can be as impactful on one's well-being, most divorces within the boomer generation occurred several years ago, thus the effect of divorce may be less significant as years pass. Additionally, divorce is becoming a common occurrence in the United States, which may influence older adults' acceptance of it and potentially lessen divorce's negative impacts. Furthermore, qualitative research on divorce has found that individuals that have been married for several years divorce due to having grown apart and separate on amicable grounds (Brown & Wright). Research suggests the death of a child is linked to adverse physical and mental health outcomes among parents and often leads to divorce particularly in midlife (Elder et al., 2002). In the quantitative sample, less than six elder orphans had experienced the death of a child. On the other hand, over 25% had experienced major financial challenges. Economic and job instability often are conjointly associated with depression, suicidal ideation, and social isolation (Brown & Harris, 2012). The findings from the qualitative study suggest that older adults in this sample were

primarily concerned about their economic stability and employment opportunities and further emphasize the critical importance of financial well-being among older adults aging alone.

Late-Life Experiences

The addition of discrimination, multiple health issues, and social network in the hierarchal regression accounted for 9.7% of the variance in well-being scores. Literature on social networks suggests well-being is associated with the number of confidantes and quality of relationships in late life (Schwarzbach, et al., 2014). The number of confidantes is particularly important as one ages and in the event of acute injury and medical crisis. Members of ones' social network (i.e., family and close friends) can serve as health care surrogates in the event of medical emergency and incapacity. Thus, a strong social network is an important protective factor against being unbefriended. The qualitative findings, however, did not indicate that older adults with stronger social networks were more likely to have advance directives. In fact, the two elder orphans that did not have advance directives had stronger social networks than the elder orphans with weaker social networks. Although these results provide insight into the motivators for the initiation of advance directives, the small sample may have yielded inconsistent results. On the other hand, strong social networks did influence well-being in the quantitative findings.

Experiences with discrimination (based on race, gender, religion, sexual orientation, or age) were found to be significant predictors of well-being in the quantitative analysis. Over half of the quantitative sample indicated they were either "likely" or "very likely" to experience discrimination. Although there were not specific questions in the quantitative survey for each type of discrimination (race, gender, religion, sexual orientation, or age), the qualitative analysis revealed that participants experienced age-based and gender discrimination. However, discrimination did not emerge as a theme in the qualitative data. A few participants who

experienced discrimination revealed difficulty finding a job as an older woman. Age-based discrimination is also prevalent on social media. Levy et al., (2012) found that Facebook explicitly forbids race, religion, and sexual orientation discrimination, but is silent on age-based discrimination.

Having multiple health issues was a significant predictor of well-being in the quantitative analysis. Over half of the sample had four or more health issues. In 2017, Center for Medicare and Medicaid Services (CMS) reported that two out of three older adults in the United States have multiple chronic conditions and are at greater risk of impaired day-to-day functioning. Individuals who live alone, have a limited or non-existent social network, and have multiple chronic conditions are at particularly high risk for comorbidities (CMS, 2017). Such medical problems can lead to multiple hospitalizations or premature mortality. Although health concerns were identified as an emergent theme in the qualitative analysis, elder orphans in the qualitative sample were less concerned about multiple health issues than they were falls, access to adequate health care, and declining future health.

Perceived Risk of Incapacitation

Findings from the quantitative analysis reveal perceived risk of incapacitation was not a significant predictor of having advance directives. Based on the health belief model (HBM), I predicted that higher levels of perceived risk of incapacitation would significantly increase the likelihood of having advance directives. Although there are no known studies on perceived risk of incapacitation and advance directive initiation, research on perceived risk of incapacitation and vaccination against hepatis B (de Wit et al, 2005), and condom use to prevent HIV infection (Belcher et al., 2005) reveal higher perceived risk resulted in greater likelihood of engaging in preventative behaviors. In other words, when individuals believe they are at greater risk for a

disease or illness, they are more likely to do something to prevent it from occurring. In most cases, higher perceived risk is associated with healthier behavior; however, the opposite can also occur. When people believe they are not at risk from an illness or disease, they may avoid preventive behaviors. Research on older adults and HIV suggests that older adults, in general, do not believe they are susceptible to HIV infection and are, therefore, less likely to practice safe sex (Maes & Louis, 2003). In another study of tanning and skin cancer, individuals who tan perceive themselves as being at higher risk for skin cancer, yet this high perceived risk was not a motivator to stop tanning (Lamanna, 2004). According to the HBM, when perception of risk is combined with an immediate threat (perceived threat), behaviors often change. As advance directives are not associated with an immediate risk and are typically related to future planning, individuals may be less likely to initiate advance directives unless there is an immediate risk or threat. It is difficult to know when a person may be in a situation in which they are unable to make their own health care decisions. Having advance directives is a protective factor, particularly, as it relates to self-determination and autonomy within the context of health care decision making. Results from the qualitative data on perceived risk of incapacitation reveal mixed findings. Of the three participants who had advance directives, two were motivated to initiate advance directives after the death of their parents. One participant noted that her need for control resulted in initiating advance directives. However, she later discussed the financial barriers she experienced in obtaining advance care documents. Two participants stated they did not have advance directives. One attributed not having advance directives to "forgetting to do it," while the other participant felt that advance directives were less about protecting himself and more about the health care industry trying to protect itself. One of the six participants was not sure if she had advance directives.

Well-Being

Findings from the quantitative analysis reveal well-being is a significant predictor of having advance directives. Contradictory to prediction, higher levels of well-being increased the likelihood of having advance directives by 0.25%, suggesting elder orphans with higher levels of subjective and financial well-being were more motivated to obtain advance directives, compared with older adults who had lower levels of well-being. The qualitative analysis revealed advance directives initiation was associated with personal choice, opportunity, and "not getting around to it." Additionally, the qualitative results revealed participants often had to pay for the initiation of advance directives. This requirement may be a barrier to the accessibility of advance directives for certain groups, thus negating the influence of well-being on advance directives initiation. The research on advance directive initiation suggests that family and health care professionals play a critical role in influencing the initiation of advance care directives (van der Stenn et al., 2014).

Limitations of Study

There are several noteworthy limitations to this study. First, the sample of elder orphans is a relatively homogenous group in terms of gender (predominately female) and race (predominately White). Additionally, this sample comprised only members of the EOF group who self-identify as elder orphans, thus limiting the generalizability of the results. A sample more representative of the population of elder orphans as a whole would yield higher levels of external validity.

Second, all data was self-reported by older adults who identify as elder orphans on Facebook, thus data is reliant on the honesty of the participant, how the person is feeling or faring at the time he or she takes the survey, and the person's ability to accurately recall past life events and circumstances. Recall timeframe may have impacted the accuracy of the data in many

ways, as several of the questions on the survey required that participants recall their past. A few of the questions may have elicited strong emotional responses and potentially decreases the accuracy of the results.

A third limitation is the relatively small sample size of the qualitative data. Due to the time allotted to collect the data and the resources available to conduct the qualitative research, a small sample was obtained for the qualitative phase of the study. Although the goal of the qualitative phase was not to reach saturation, the results yielded perceptions on most of the factors that influence well-being and advance care directives initiation. Additional participants could have provided a more in-depth understanding of the phenomena of interest.

Implications

As the number of older adults aging alone continues to increase, while the number of caregivers per care recipient decreases, we will face a growing number of older adults who are at risk of becoming unbefriended. Elder orphans have been identified as a population at risk for becoming unbefriended; however, no empirical studies or primary research on the topic of elder orphans have been published.

This research provides a seminal foundation to the emerging field of research on at-risk older adult populations. By examining the factors that influence well-being throughout the life course and the motivators for advance care planning among elder orphans, this study provides critical information on important transitionary periods in at-risk elder orphan's lives. Since many of these older adults' function on the baseline, they may be hard to recognize by clinicians and often slip through the cracks until eventually becoming unbefriended. Thus, findings from this study can aid practitioners in identifying patients who are at risk of becoming unbefriended. The

findings can also provide opportunities to develop community-based prevention programs that are targeted to the unique needs of at-risk older adult populations.

Additionally, only a handful of states currently have legislative pathways to health care decision-making for unbefriended patients (Parekh & Adorno, 2016). Attending physicians typically make these difficult decisions. Because regulatory procedures typically govern medical care, the development of systematic mechanisms to medical decision-making for unbefriended individuals is critical to their care and well-being. Findings from this study can help states develop policies that meet the growing needs of elder orphans who may be at elevated risk of becoming unbefriended.

This study has broader significance in its ability to provide the first in-depth empirical analysis of elder orphans. There is a severe lack of studies that focus on the conceptualization of risk of becoming unbefriended and this poses theoretical challenges at the methodological level, as attempts to measure the risk of becoming unbefriended are non-existent. The very nature of being unbefriended connotes that there are no existing or found records of the individual; therefore, it is virtually impossible to trace the risk factors associated with becoming unbefriended. Furthermore, unbefriended individuals are incapacitated so they are not able to communicate their lived experiences with practitioners, policymakers, and researchers, which makes it impossible to gain an understanding of the events that led to their unbefriended status. Lastly, there are no known hospitals or health care facilities that identify patients as unbefriended on discharge paperwork, which makes it difficult to gain a retrospective understanding of the factors that lead to a patient's unbefriended status. Therefore, the present study provides a novel approach to understanding the potential risk of becoming unbefriended among an at-risk population of older adults.

Future Research

Several potential areas for future research efforts emerged from this study. Building on this research, I plan to conduct the following studies:

1) A multilevel path analysis testing the conceptual framework presented in this study.
2) A handful of states have enacted decision-making legislative pathways for unbefriended patients. I plan on exploring the context in which policies for unbefriended, incapacitated older adults has been adopted as a policy solution.
3) A latent transition analysis to identify classes of older adult populations with higher and lower risk for living alone with little to no support.
4) A qualitative interpretative phenomenological analysis (IPA) exploring the lived experience of ($N = 30$) elder orphan family caregivers.

Conclusion

Through a two-phased mixed-methods approach, this study examined an important transition period in elder orphans' lives, which provides valuable insight into the phenomena of unbefriendedness. By examining the factors throughout the life course that predict well-being, this study provides building blocks for future investigations that seek to develop a holistic understanding of the growing number of older adults aging alone with limited social support. Furthermore, this study is timely, as recent national media reports have brought attention to the problems associated with aging alone with limited support. This dissertation strives to bring awareness to the growing problem of aging alone, including identifying individuals that are at high risk of becoming unbefriended, and to draw attention to an under-developed area in gerontological research.

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APPENDIX A

University of Texas at Arlington IRB Approval Letter

April 12, 2018

Rupal Parekh
Dr. Vijayan Pillai
School of Social Work
The University of Texas at Arlington
Box 19129

IRB No.: **2018-0242**
Title: *Exploring the Domains of Vulnerability Associated with Becoming an Unbefriended Older Adult: A Mixed-Methods Study*

Modification Approval Date: April 12, 2018

MODIFICATION APPROVAL

The UT Arlington Institutional Review Board (UTA IRB) or designee reviewed and approved the proposed 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 list of approved study modifications is limited to the following:

- Extensively revised the assessments and content of the Elder Orphan Assessment Instrument
- Added a question to collect optional contact information for anyone who would like to be contacted for a future paid follow up interview
- Revised the consent form to increase the duration of the study; to remove the references to "Anonymous" data since now identifiers will be collected; and to change the type of gift card offered to a Visa or Mastercard gift card

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.

NOTIFICATION OF FEDERAL FUNDING SOURCES
Note that this project is not covered by UTA's Federalwide Assurance (FWA) and the researcher has indicated it will not receive federal funding. You must inform Regulatory Services immediately if the project may or will receive federal funding in the future, as this will require that the protocol be re-reviewed in accordance with the federal regulations for the protection

May 18, 2018

Rupal Parekh
Dr. Vijayan Pillai
School of Social Work
The University of Texas at Arlington
Box 19129

IRB No.: **2018-0242**
Title: *Exploring the Domains of Vulnerability Associated with Becoming an Unbefriended Older Adult: A Mixed-Methods Study*

Modification Approval Date: May 18, 2018

MODIFICATION APPROVAL

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- Added procedures for a study Phase 2; selected participants who completed the online survey will be recruited for a qualitative phone interview lasting 30-45 minutes
- Added a recruitment script / email for reaching out the potential Phase 2 participants, as well as a new verbal Informed Consent and the qualitative interview questions and probes

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

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May 18, 2018

Rupal Parekh
Dr. Vijayan Pillai
School of Social Work
The University of Texas at Arlington
Box 19129

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APPENDIX B

Informed Consent Form

UT Arlington

Informed Consent Document

PRINCIPAL INVESTIGATOR

Rupal Parekh, PhD Candidate, School of Social Work, The University of Texas at Arlington, 211 South Cooper Street, Box 19129, Arlington, TX 76019

TITLE OF PROJECT

Exploring the Domains of Vulnerability Associated with Becoming an Unbefriended Older Adult: A Mixed-Methods Study.

INTRODUCTION

You are being asked to participate in a research study about elder orphans from your perspective as an older adult. 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 you do not understand.

PURPOSE

The purpose of this study is to begin the process of gaining a deeper understanding of older adults that are aging alone and identify as elder orphans. This study will explore the factors throughout the life course that influence well-being among elder orphans and to better understand advanced care planning and the role of social support and networks in the lives of elder orphans.

DURATION

Participation in this study will last approximately 30-45 minutes. You will be asked to participate in one interview that will take place at a convenient time for you in your home. We will also make one follow up phone call with you in order to briefly discuss the themes found in the interview transcript (approximately 2 weeks after the interview takes place).

NUMBER OF PARTICIPANTS

The number of anticipated participants in this qualitative part of the study is 6-10 participants.

PROCEDURES

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

1. Participating in one 30-45 minute interview
2. Sharing your thoughts and concerns related to being an elder orphan

3. Participating in one follow up phone call to review the themes in the interview transcript

The interview will be digitally audio recorded. After the interview, the digital audio recording will be transcribed, which means they will be typed exactly as they were recorded, word-for-word, by the researcher. The digital audio file will be kept with the transcription for potential research involving elder orphans and impactful events throughout their life course, levels of wellbeing and advanced care planning experiences. Neither the recording nor the transcription will be used for any future research purposes not described here.

POSSIBLE BENEFITS

By participating in this study, you will be providing critical information to help gain a deeper understanding of older adults aging alone. Your input will contribute to much needed research in this under-researched area.

POSSIBLE RISKS/DISCOMFORTS

There are no perceived risks or discomforts for participating in this research study. Should you experience any discomfort please inform the researcher, you have the right to quit any study procedures at any time at no consequence.

COMPENSATION

We will provide a $25.00 MasterCard or Visa gift card.

ALTERNATIVE PROCEDURES

There are no alternative procedures offered for this study. However, you can elect 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. Should you choose not to complete all study procedures, you will still receive the $25.00 gift card.

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 including transcriptions and digital audio files from this study will be stored in the locked offices of Rupal Parekh for at least three (3) 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. 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.

CONTACT FOR QUESTIONS

Questions about this research study may be directed to Rupal Parekh at (918) 859-9897 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 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 (Check one) ☐ Yes ☐ No

APPENDIX C

Elder Orphan Facebook Survey (Quantitative)

Elder Orphan Facebook Survey Tool

Start of Block: Default Block

Q0 My name is Rupal Parekh, and I am researcher and graduate student and at The University of Texas at Arlington School of Social Work Arlington and research study titled, "Exploring the Domains of Vulnerability Associated with Becoming an Unbefriended Older Adult: A Mixed-Methods Study The purpose of this study is to develop a stronger understanding of older adults that are aging alone and have limited support within the U.S. We know that elders aging alone are often a hidden population, so your voice is important in understanding the needs of this population. While the experiences of all older adults are of critical importance to future research, the inclusion criteria for this study is older adults 55 years old and older, living alone and with little to no support from family or friends. It is our hope the results from this research will lead to stronger surveys for all older adult populations. The procedures that you will follow as a research subject are to answer questions in a confidential online survey, and it should take about 25-30 minutes. There are no perceived risks or direct benefits for participating in this study. Several questions on this survey are sensitive in nature such as questions about your health and if you have had any traumatic experiences. At the end of the survey, there are several national hotlines available to you should you experience any stress. There are no alternatives to this research project, but you may quit at any time. You must be at least 18 years old to participate. Your responses will be kept confidential with access limited to the research team. Upon the completion of this survey, you will have the option to enter a weekly $50 drawings for a Visa or Master card. A drawing for a 2 $50 Visa or Mastercard card will take place weekly until the end of the study. Visa or Mastercard gift cards will be mailed at the end of each month. If you choose to participate in the raffle, you will include your email on the following page and all gift cards will be mailed to you. We may publish, present, or share the results, but your name will not be used or collected. If you have questions about the study, you can contact me at parekhru@uta.edu. For questions or concerns, contact the UTA Research Office at 817-272-3723 or regulatoryservices@uta.edu. By clicking on the button below, you indicate your voluntary agreement to participate in this online survey.

- ○ Yes (1)
- ○ No (2)

Skip To: Q1 If My name is Rupal Parekh, and I am researcher and graduate student and at The University of Texas... = Yes

Q1 What is your age?

_____

Q2 What is your gender

- ○ Male (1)
- ○ Female (2)
- ○ Other (3) _____

Q3 What is your marital/relationship status?

- ○ Married (1)
- ○ Living with a partner (2)
- ○ Divorced, living alone (3)
- ○ Separated, living alone (4)
- ○ Widowed, living alone (5)
- ○ Never Married (6)
- ○ Other (7) _____

Q4 Are you Hispanic, Latino, or Spanish origin?

- [ ] No (1)
- [ ] Yes (2)

Q5 What is your race? For the purposes of this question, persons of Spanish/Latina origin may be of any race.

- ○ White (1)
- ○ Black or African American (2)
- ○ American Indian or Alaska Native (3)
- ○ Asian (4)
- ○ Native Hawaiian or Pacific Islander (5)
- ○ Other (6)

Q6 What is your citizenship status

- ○ Naturalized Citizen (1)
- ○ Non-citizen (2)
- ○ Other (3) _____
- ○ Native-Born Citizen (4)

Q7 What country were you born in?

- ○ U.S. (1)
- ○ Foreign Born, please specify (2) _____

Q8 What is your highest level of education?

- ○ Completed some High (1)
- ○ High school graduate (2)
- ○ Completed some college (3)
- ○ Associate degree (4)
- ○ Bachelor's degree (5)
- ○ Master's degree (6)
- ○ Ph.D., law or medical degree (7)
- ○ Other, please specify (8) _____

Q9 What is your employment status?

- ○ Employed, working 40 or more hours per week (1)
- ○ Employed, working 1-39 hours per week (2)
- ○ Not employed, looking for work (3)
- ○ Not employed, NOT looking for work (4)
- ○ Student (5)
- ○ Retired (6)
- ○ Disabled, not able to work (7)

Q10 What was your total household income before taxes during the past 12 months?

- ○ Less than $20,000 (1)
- ○ $20,000 to $34,999 (2)
- ○ $35,000 to $49,999 (3)
- ○ $50,000 to $74,999 (4)
- ○ $75,000 to $99,999 (5)
- ○ $100,000 to $149,999 (6)
- ○ $150,000 to $199,999 (7)
- ○ $200,000 or more (8)

Q11 In the last 12 months, was there at least one time when you didn't have enough money to meet your basic needs?

- ○ YES (1)
- ○ No (2)

Q12 In the last 12 months, has any utility company shut off your services for not paying your bills?

- ○ Yes (1)
- ○ No (2)

Q13 In the last 12 months, did you ever eat less than you felt you should because there wasn’t enough money for food?

- ○ Yes (1)
- ○ No (2)

Q14 In the last 12 months, did you receive any of the following? (Please select all that apply to you)

- [ ] Food Stamps (1)
- [ ] SSDI (Social Security Disability Insurance (2)
- [ ] SSI (Supplementary Security Income) (3)
- [ ] Social Security (4)
- [ ] Unemployment Insurance (5)
- [ ] None/NA (6)

Q15 Are you currently covered by any of the following health insurances? (Please select all that apply to you)

- ○ Government insurance (that is, Medicare, Medicaid [including all state or federal Medicaid-type programs), (1)
- ○ Veteran's Administration health plans, military medical plans, or other government-reimbursed care[e.g. Indian Health Service] (2)
- ○ Commercial insurance (that is, fee-for service, PPO, HMO, prepaid or similar). (3)
- ○ None or self (4)

Q16 Are you disabled?

- ○ No (1)
- ○ Yes (2)

Skip To: Q18 If Are you disabled? = No

Q17 If you are disabled, Is your housing modified to meet your needs?

- ○ No (1)
- ○ Yes (2)

Q18 Do you have secure housing?

- ○ No (1)
- ○ Yes (2)

Q19 Have you ever been at risk of being homeless

- ○ No (1)
- ○ Yes (2)
- ○ I am homeless (3)

Skip To: Q21 If Have you ever been at risk of being homeless = No

Q20 If you ever have been homeless, during what time in your life?

- ○ Childhood (1)
- ○ Midlife (40's 50's) (2)
- ○ Late-life (55+) (3)

Q21 Do you fear of losing your housing?

- No (1)
- Yes (2)

Q22 Has your house ever been foreclosed on?

- No (1)
- Yes (2)

Q23 Have you ever been evicted?

- No (1)
- Yes (2)

Q24 Have you ever served on active duty in the US Armed Forces, Reserves, or National Guard?

- Never served in the military (1)
- Only on active duty for training the Reserves or National Guard (2)
- Now on active duty (3)
- On active duty in the past, but not now (4)

Q25 **Does the community where you live heave the following? (Please select all that apply)**

- ☐ Access to community information in one central source (1)
- ☐ Access to reliable medical care (including mental health) (2)
- ☐ Access to social services agencies (3)
- ☐ Walkable streets (4)
- ☐ Reliable Public Transportation (5)
- ☐ Senior Centers (6)
- ☐ Home and Community Based Services (7)
- ☐ Community information that is available in a number of different languages (8)
- ☐ Community information that is delivered in person to people who may have difficulty or may not be able to leave their home (9)
- ☐ Free access to computers and the Internet in public places such as the library senior centers or government buildings (10)
- ☐ Clearly displayed printed community information with large lettering (11)

Q26 **Are you the primary caretaker for your grandchild or does a grandchild live with you?**

- ○ No (1)
- ○ Yes (2)

Q27 **Please indicate the current level of stress in your life:**

- ○ Low (1)
- ○ Medium (2)
- ○ In general I feel that I can cope well with stress (3)
- ○ I do not cope well with stress (4)

Q28 **When did you last go to your doctor for a routine wellness exam?**

- ○ Within this year (1)
- ○ Last year (2)
- ○ Two years ago (3)
- ○ Three years ago (4)
- ○ Four years ago (5)
- ○ More than five years ago (6)
- ○ I don't know (7)
- ○ Never (8)

Q29 **What are your means of transportation? (Please check all that apply)**

- [ ] Personal automobile (1)
- [ ] Friend, relative, or neighbor (2)
- [ ] Public transportation (3)
- [ ] Medicaid transportation (4)
- [ ] Other (5)

Q30 If you don't drive a car, why not? (Please check all that apply)

- ○ Can't drive due to a medical/physical condition (1)
- ○ Can't afford a car (2)
- ○ Can't afford gas/insurance (3)
- ○ Lost driver's license (4)
- ○ I can access everything I need w/o car (5)
- ○ Other (6)
- ○ I drive a car (7)

Q31 Do you have the freedom to travel to the places you want to travel?

- ○ No (1)
- ○ Yes (2)

Q32 In the past year, how may trips have you made to the health facilities below?

	0 (1)	1-2 (2)	3-5 (3)	6-10 (4)	11-20 (5)	20 + (6)
Routine health check up (1)	○	○	○	○	○	○
Chronic health care (2)	○	○	○	○	○	○
Emergency room (3)	○	○	○	○	○	○

Q33 In the past year, how many trips to a health care facility below were missed or delayed because you could not drive or did not have a ride?

	0 (1)	1-2 (2)	3-5 (3)	6-10 (4)	11-20 (5)	20+ (6)
Routine health checkup (1)	○	○	○	○	○	○
Chronic health care (2)	○	○	○	○	○	○
Emergency Room (3)	○	○	○	○	○	○

Q34 Are your activities limited in any way because of a physical, mental, or emotional problems?

○ No (1)

○ Yes (2)

Q35 **How would you rate your physical health?**

- ○ Excellent (1)
- ○ Very Good (2)
- ○ Good (3)
- ○ Fair (4)
- ○ Poor (5)

Q36 **How would you rate your mental health?**

- ○ Excellent (1)
- ○ Very Good (2)
- ○ Good (3)
- ○ Fair (4)
- ○ Poor (5)

Q37 Please indicate for each of the five statement which is closest to how you have been feeling over the last two weeks. Notice the higher numbers mean better well-being

	All of the time (1)	Most of the time (2)	More than half of the time (3)	Less than half of the time (4)	Some of the time (5)	At no time (6)
I have felt cheerful and in good spirts (1)	○	○	○	○	○	○
I have felt calm and relaxed (2)	○	○	○	○	○	○
I have felt active and vigorous (3)	○	○	○	○	○	○
I woke up feeling fresh and rested (4)	○	○	○	○	○	○
My daily life has been filled with things that interest me (5)	○	○	○	○	○	○

Q38 Below are a number of events that may have happened during your childhood. Select Yes or No for each of the events below

While you were growing up, during your first 18 years of life:

	Yes (1)	No (2)
Did a parent or other adult in the household often swear at you, insult you, put you down, or humiliate you (1)	○	○
Did a parent or other adult in the household often push, grab, slap, or throw something at you or ever hit you so hard that you had marks or were injured? (2)	○	○
Did an adult or person at least 5 years older than you ever touch or fondle you or have you touch their body in a sexual way or try to have oral, anal, or vaginal sex with you? (3)	○	○
Did you often feel that no one in your family loved you or thought you were important or special? or Your family didn't look out for each other, or support each other? (4)	○	○
Did you often feel that you didn't have enough to eat, had to wear dirty clothes, and had no one to protect you? or Your parents were too drunk or high to take care of you or take you to the doctor if you needed it? (5)	○	○
Were your parents ever separated or divorced? (6)	○	○
Was your mother or stepmother often pushed, grabbed, slapped, or had something thrown at her? or Sometimes or often kicked,	○	○

bitten, hit with a fist, or hit with something hard? or Ever repeatedly hit over at least a few minutes or threatened with a gun or knife? (7)		
Did you live with anyone who was a problem drinker or alcoholic or who used street drugs? (8)	○	○
Was household mentally ill or did a household member attempt suicide? (9)	○	○
Did a household member go to prison? (10)	○	○

Q39 In your everyday life, how likely do you think it is that you will experience discrimination (e.g., because of your race, gender, religion, sexual oriental or age

○ Very Likely (1)

○ Likely (2)

○ Neither likely no unlikely (3)

○ Unlikely (4)

Q40 People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

	None of the time (1)	A little of the time (2)	Some of the time (3)	Most of the time (4)	All of the time (5)
Someone to give you information to help you understand a situation (1)	○	○	○	○	○
Someone to turn to for suggestions (2)	○	○	○	○	○
Someone to help you if you were confined to bed (3)	○	○	○	○	○
Someone to take you to the doctor if you needed it (4)	○	○	○	○	○

Q41 Have you fallen in the past 6 months?

○ No (1)

○ Yes (2)

Q42 Do you have 3 or more chronic diseases?

○ No (1)

○ Yes (2)

Q43 Do you take 5 or more medications?

- ○ No (1)
- ○ Yes (2)

Q44 Do you consider yourself to be religious or spiritual?

- ○ Yes (1)
- ○ No (2)

Q45 On a scale of 0 to 10, with 0 being no pain at all and 10 being the worst possible pain, how would you rate your pain on the average during the last week

- ○ 0 (0)
- ○ 1 (1)
- ○ 2 (2)
- ○ 3 (3)
- ○ 4 (4)
- ○ 5 (5)
- ○ 6 (6)
- ○ 7 (7)
- ○ 8 (8)
- ○ 9 (9)
- ○ 10 (10)

Q46 If you live alone, please check all the reason you live alone

- ☐ I want to live alone (1)
- ☐ My spouse/partner who I lived with passed away (2)
- ☐ I am single (3)
- ☐ I do not live alone (4)
- ☐ Other (5)

Q47 If you live alone, how many years have you lived alone?

- 1-5 (1)
- 5-10 (2)
- 10-15 (3)
- 15-20 (4)
- 20 + (5)
- I don't live alone (6)

Q48 Do you have written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate? (living will) Or do you have a legal health care decision-maker in the event you can not make decisions for yourself? (health care power of attorney) These documents are called Advanced directives.

- No (1)
- Yes (2)
- Don't know (4)

Q49 If you have an advanced directive, please indicate all the reasons, why you have one. (Please select all that apply)

- [ ] I was sick and the health care professionals (doctor, social worker, nurse, etc.) suggested I get advanced directives (1)
- [ ] I had a family member or friend or I heard of someone who had an good experience because they did not have one. (2)
- [ ] I was told by friends and/or family that I needed advanced directives (3)
- [ ] Other, (please list) (4) _____
- [ ] I don't have advanced directives (5)

Skip To: Q50 If If you have an advanced directive, please indicate all the reasons, why you have one. (Please sel... = I was sick and the health care professionals (doctor, social worker, nurse, etc.) suggested I get advanced directives

Q50 If you do not have an advanced directive, why? choose one

- ○ Doesn’t apply; I have an advance directive (1)
- ○ Never thought about signing one (2)
- ○ Don’t know what advance directives are (3)
- ○ Do not need it because I’m in good health (4)
- ○ Have not gotten around to it (5)
- ○ Do not need it because my family knows my wishes (6)
- ○ Some other reason (7)

Q51 If you don't have written instructions about your health care preferences or you have not identified a health care surrogate on your behalf, (doctors, nurses, social workers, etc.) may have to make health care decisions for you. What event or events in your life do you believe could lead you down such where you were unable to make your health care decisions?

Please rate the following events on how likely they could happen to you and lead you down a path where you might not be able to make your own health care decisions.

1-strong possibility, 2, possibility, 3, unlikely.

PLEASE BE SURE TO CIRCLE A NUMBER FOR EACH EVENT BELOW. For the "other" categories, please list events that may happen in your life that could lead you down path where you might not be able to make your health care decisions.

	Extremely Likely (1)	Moderately likely (2)	Unlikely (3)
Car accident/or inability to drive (1)	○	○	○
Loss of support system (death of family member or friends (2)	○	○	○
Multiple chronic health issues (3)	○	○	○
Dementia/or cognitive related issues (4)	○	○	○
Loss of housing (5)	○	○	○
Financial instability or economic hardship (6)	○	○	○
Mental health condition (7)	○	○	○
A fall or other physical limitations (8)	○	○	○
Other, please be specific (9)	○	○	○
Other, please be specific (10)	○	○	○
Other, please be specific (11)	○	○	○

Q52 Which of the following is your biggest concern about end-of-life care? (choose one)

- Where I will receive care (1)
- Who will provide care (2)
- The cost of care (3)
- My comfort and dignity (4)
- The pain I might experience (5)
- I do not have any concerns (6)
- Some other concerns, please specify (7) _____
- I don't know (8)

Q53 Besides your physician, who do you think you would trust making health care decisions (end-of-life) on your behalf if you were unable to? (choose one)

- Social Worker (1)
- Lawyer (2)
- Clergy (minster, rabbi, priest, etc.) (3)
- Nurse (4)
- Bioethicst (5)
- Team of diverse health care professionals (6)
- Don't know (7)

Q54 Have you identified a caregiver that is YOUNGER than you in the event that you need care

- No (1)
- Yes (2)

Q55 Do you believe you can take care of yourself?

- Definitely yes (1)
- Probably yes (2)
- Might or might not (3)
- Probably not (4)
- Definitely not (5)

Q56 During your childhood, did you ever have the following (check all that apply)

- [ ] A chronic illness (1)
- [ ] Cancer (2)
- [ ] Obesity (3)
- [ ] Other illness, please specify (4) _____
- [ ] Homeless (5)
- [ ] Did not have good means of transportation (6)
- [ ] Did not have enough money to pay our bills (7)
- [ ] Did not have enough to eat (8)
- [ ] None of these (9)

Q57 Below is a list of event that can happen in an individual's life that can shape their life trajectory. Please indicate if any of these events happened to you during your midlife (40's & 50's) Yes or No for each statement

- [ ] Divorce (1)
- [ ] Death of a spouse (2)
- [ ] Death of a parent (3)
- [ ] Death of a child (4)
- [ ] Major financial changes (i.e., loss of a job) (5)
- [ ] A major move (6)
- [ ] Other, Please specify (7) _____

Q57 **Please indicate how safe you feel walking alone in the area near your home**

- ○ Very safe (1)
- ○ Fairly safe (2)
- ○ Neither safe no unsafe (3)
- ○ Very unsafe (4)

Q58 In a typical week, on how many days do you do any MODERATE activities (causes small increases in breathing or heart rate) for AT LEAST 30 minutes such as brisk walking, bicycling at a regular pace, gardening, etc.?

- ○ 1-2 days (1)
- ○ 3 days (2)
- ○ 4-5 days (3)
- ○ 6-7 days (4)
- ○ I don't typically do any moderate exercise (5)

Q59 How many hours of sleep do you typically get a night?

- ○ Less than 7 hours (1)
- ○ 7-8 hours (2)
- ○ More than 8 hours (3)

Q60 Do you have children?

- ○ No (1)
- ○ Yes (2)

Skip To: Q62 If Do you have children? = No

Q61 If you have children are you in contact with them?

- No (1)
- Yes (2)
- Infrequently (3)

Q62 Do you have family or friends that help you cope with life's challenges?

- No (1)
- Yes (2)

Q63 Do you have someone to help you make medical decisions?

- Yes (1)
- No (2)

Q64 Do you have someone to help with bills, financial decisions?

- Yes (1)
- No (2)

Q65 Do you have someone that can help you in a crisis?

- Yes (1)
- No (2)

Q66 Are you veteran in the military?

- ○ Yes (1)
- ○ No (2)

Q67 Do you have a person you would call on upon an emergency situation?

- ○ Yes (1)
- ○ No (2)

Q68 Do you have a home health aide to help with personal care such as bathing, dressing, and other activities of daily living?

- ○ Yes (1)
- ○ No (2)

Q69 Do you need help with bathing, dressing, shopping and paying bills?

- ○ Yes (1)
- ○ No (2)

Q70 Do you feel sad?

- ○ Yes (1)
- ○ No (2)

Q71 Do you feel lonely?

- ○ Yes (1)
- ○ No (2)

Q72 What is your top choice for housing as you grow older?

- ○ Affordable assisted living (1)
- ○ Shared housing - Rent a room and share the home owned by someone else (2)
- ○ Tiny affordable house in a village of people like you (3)
- ○ Share a home with multiple like-minded roommates (4)
- ○ Stay in my home (5)
- ○ Move in with family (sibling, offspring, other family member) (6)

Q73 Which of the following are your basic health care and wellness needs at home (choose all that apply)

- ☐ Physical therapy and rehabilitation (1)
- ☐ Chronic disease management (2)
- ☐ Activities of daily living (Bathing, grooming, meals, transportation) (3)
- ☐ In-home visits by a physician (4)
- ☐ Home health care monitoring (check vitals) (5)

Q74 Community amenities - Whether living at home or in a 55+ community, what 2 amenities are most important to have nearby? (Pick two)

- [ ] Hospital and health care (1)
- [ ] Wellness Center with gym (2)
- [ ] Shopping and grocery (3)
- [ ] Bus stop or metro line (4)
- [ ] College or University (5)
- [ ] Park with outdoor activities (6)
- [ ] Social connections (7)
- [ ] The arts, theater, concerts (8)
- [ ] Work (9)

Q75 What technology will be most important as you age? (choose all that apply)

- [ ] Medical alert (1)
- [ ] Home security (2)
- [ ] Online access to personal records and legal documents (3)
- [ ] Telehealth to check health vitals like blood pressure and diabetes (4)
- [ ] Telemedicine online appointments with a physician (5)
- [ ] App to access shared rides (Uber/Lyft) (6)
- [ ] Social connection like Facebook and others (7)

Q76 How will you pay for long-term care? (choose all that apply)

- [ ] Out of pocket (1)
- [ ] LTC insurance (2)
- [ ] Savings and investments (3)
- [ ] Reverse mortgage (4)
- [ ] Life insurance or Life settlement (5)
- [ ] I don't know (6)

Q77 What is your favorite form of travel?

- Take a cruise (1)
- Destination train trip (2)
- Local destination via car (3)
- Walking or bike tour (4)
- Tour package like Road Scholar (5)

Q78 What type of telephone do you have?

- Landline only (1)
- Landline and cell-phone (2)
- Only a cell-phone (3)

Q79 What type of cell-phone do you have?

- One that makes calls-phone only? (1)
- Calls and texts? (2)
- Calls, texts, and data access? (3)
- Calls, texts, data, and apps? (like an iPhone or Samsung Galaxy) (4)
- Calls, texts, data, apps, and medical alert (5)
- I do not own a cell-phone. (6)

Q80 Do you use

- ○ iPhone (1)
- ○ Android (2)
- ○ I do not own a cell-phone (3)

Q81 Please answer the following 6 questions

	Completely (1)	Very well (2)	Somewhat (3)	Very little (4)	Not at all (5)
I could handle a major unexpected expense (1)	○	○	○	○	○
I am securing my financial future (2)	○	○	○	○	○
Because of my money situation, I feel like I will never have the things I want in life (3)	○	○	○	○	○
I can enjoy life because of the way I'm managing my money (4)	○	○	○	○	○
I am just getting by financially (5)	○	○	○	○	○
I am concerned that the money I have or will save won't last (6)	○	○	○	○	○

Q82 Please answer the following 4 questions

How often do each of the following apply to you?

	Always (1)	Often (2)	Sometimes (3)	Rarely (4)	Never (5)
Giving a gift for a wedding, birthday or other occasion would put a strain on my finances for the month (1)	○	○	○	○	○
I have money left over at the end of the month (2)	○	○	○	○	○
I am behind with my finances (3)	○	○	○	○	○
My finances control my life (4)	○	○	○	○	○

Q83 Listed below are a number of difficult or stressful events that sometimes happen to people. Check off each event you have experienced. Be sure to consider your entire life (childhood through adulthood) as you go through the list of events

- ☐ • Natural disaster (for example, flood, hurricane, tornado, earthquake) (1)
- ☐ • Fire or explosion (2)
- ☐ • Transportation accident (for example, car accident, boat accident, train wreck, plane crash) (3)
- ☐ • Serious accident at work, home, or during recreational activity (4)
- ☐ • Exposure to toxic substance (for example, dangerous chemicals, radiation) (5)
- ☐ • Physical assault (for example, being attacked, hit, slapped, kicked, beaten up) (6)
- ☐ • Assault with a weapon (for example, being shot, stabbed, threatened with a knife, gun, bomb (7)
- ☐ • Sexual assault (rape, attempted rape, made to perform any type of sexual force or threat of harm)ct through (8)
- ☐ • Other unwanted or uncomfortable sexual experience (9)
- ☐ • Combat or exposure to a war-zone (in the military or as a civilian) (10)
- ☐ • Captivity (for example, being kidnapped, abducted, held hostage, prisoner of war) (11)
- ☐ • Life-threatening illness or injury (12)

- ☐ • Severe human suffering (13)
- ☐ • Exposure to sudden, violent death (for example, homicide, suicide) (14)
- ☐ • Serious injury, harm, or death you caused to someone else (15)
- ☐ • Any other very stressful event or experience (please list) (16)

_____

Q84 Please answer the following questions about your social network (including both kind/family and non-related individuals, including close friends, neighbors and who you are related, either by birth or marriage

	None (1)	One (2)	Two (3)	Three or four (4)	Five through eight (5)	Nine or more (6)
How many relatives do you see or hear from at least once a month? (1)	○	○	○	○	○	○
How many relatives do you feel at ease with that you can talk about private matters? (2)	○	○	○	○	○	○
How many relatives do you feel close to such that you could call on them for help? (3)	○	○	○	○	○	○
How many of your friends do you see or hear from at least once a month? (4)	○	○	○	○	○	○

How many friends do you feel at east with that you can talk about private matters? (5)	○	○	○	○	○	○
How many friends do you feel close to such that you could call on them for help? (6)	○	○	○	○	○	○

Q85 Please answer the following 3 questions

	Strongly agree (1)	Agree (2)	Neither agree nor disagree (3)	Disagree (4)	Strongly disagree (5)
I am able to influence decisions affecting my local area (1)	○	○	○	○	○
I am free to express my views including political and religious views (2)	○	○	○	○	○
I am free to decide for myself how to live my life (3)	○	○	○	○	○

Q86 Do you have access to the health care of your choice?

○ Yes (1)

○ No (2)

Q87 Has a health care provider informed you that you have any of the following health problems or diagnoses (currently or in the past)? Select all that apply:

- [ ] Anxiety (1)
- [ ] Arthritis (2)
- [ ] Dementia/AL or any other type of Dementia (3)
- [ ] Asthma (4)
- [ ] Breast Cancer (5)
- [ ] Cancer (6)
- [ ] Depression (7)
- [ ] Diabetes Type I or II (8)
- [ ] Heart disease and/or heart attack and/or heart bypass surgery (9)
- [ ] Hypothyroidism (10)
- [ ] High blood pressure (hypertension) (11)
- [ ] Major depressive disorder (12)
- [ ] Obesity (13)
- [ ] Stroke (14)
- [ ] None of these health problems (15)

- [ ] Angina pectoris (16)
- [ ] Chronic heartburn/GERD (17)
- [ ] COPD (18)
- [ ] Irritable Bowl Disease (19)
- [ ] Osteoarthritis (20)
- [ ] Other (please list) (21)

_____

- [ ] None of these health problems (22)

Q88 Check all that apply

- [ ] People are often unfriendly to me (1)
- [ ] Things are going my way (2)
- [ ] I am not open with my family (3)
- [ ] I feel depressed (4)
- [ ] I have a hard time getting going (5)
- [ ] I have difficulty sleeping (6)
- [ ] I often do not feel like eating (7)
- [ ] I often overeat (8)
- [ ] I often feel like things are piling up (9)
- [ ] I do not feel happy (10)
- [ ] I feel tense (11)
- [ ] I get sudden feelings of panic (12)
- [ ] My family criticizes me (13)
- [ ] I feel like things are going my way (14)
- [ ] I have experienced intimate partner violence (15)

Q89 **Which region of the country do you live in?**

- ○ • Midwest - IA, IL, IN, KS, MI, MN, MO, ND, NE, OH, SD, WI (1)
- ○ • Northeast - CT, DC, DE, MA, MD, ME, NH, NJ, NY, PA, RI, VT (2)
- ○ • Southeast - AL, AR, FL, GA, KY, LA, MS, NC, SC, TN, VA, WV (3)
- ○ • Southwest - AZ, NM, OK, TX (4)
- ○ I do not live in the United States, Please specify (5) _____
- ○ West - AK, CA, CO, HI, ID, MT, NV, OR, UT, WA, WY (6)

Q90 **Would you like to participate in an individual interview? I will be contacting a select few individuals interested in participating in a 30-45-minute phone interview. All participants that participate in the follow up interview will receive a $25.00 Visa gift card. Interviews will be conducted during the first two weeks of May. PLEASE provide your email and/or phone number in the box next to the YES if you want to participate**

- ○ Yes (1) _____
- ○ No (2)

Q91 Would you like to enter the raffle? (If you choose to enter the raffle, please provide your email next to the YES box and you will automatically be entered in weekly drawings for 3 weeks for a $50 Visa or Mastercard gift card.

- ○ Yes (1) _____
- ○ No (2)

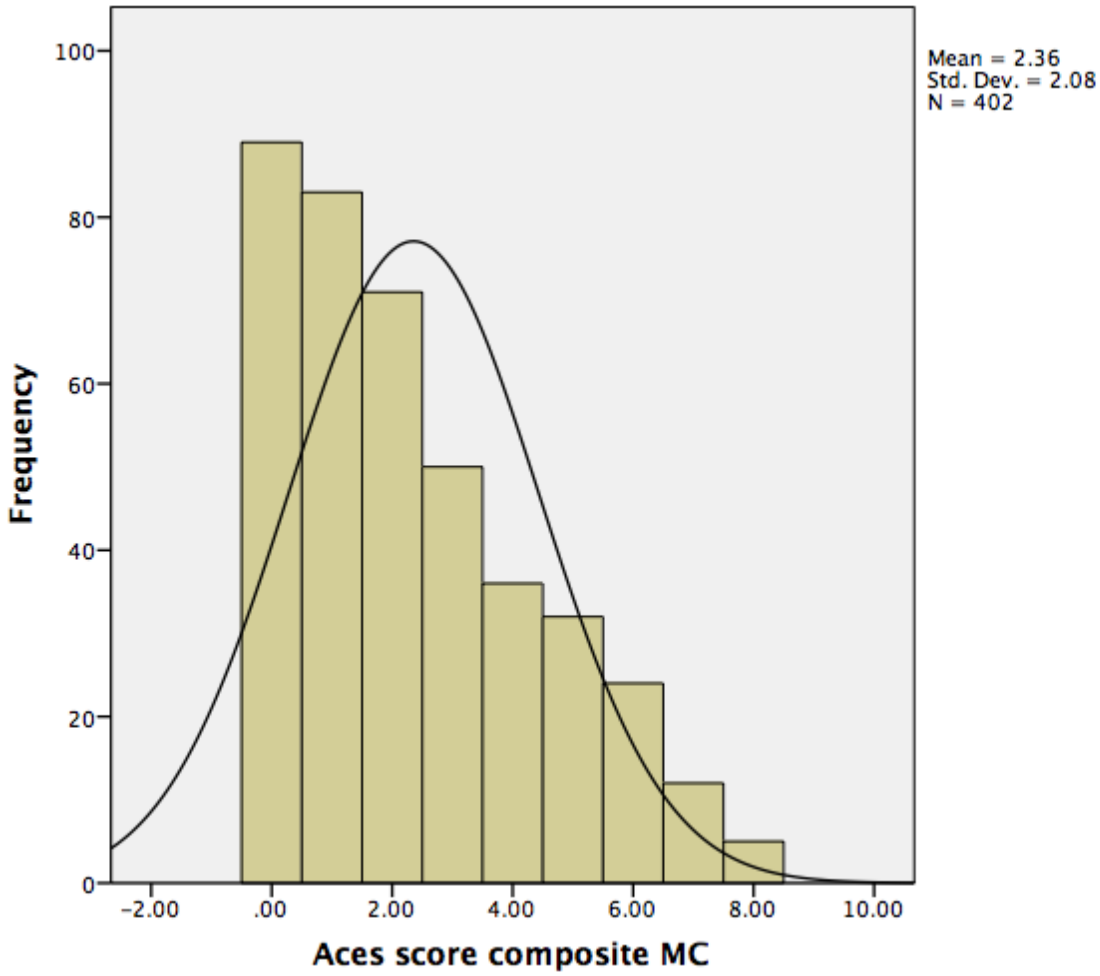
End of Block: Default Block

APPENDIX D

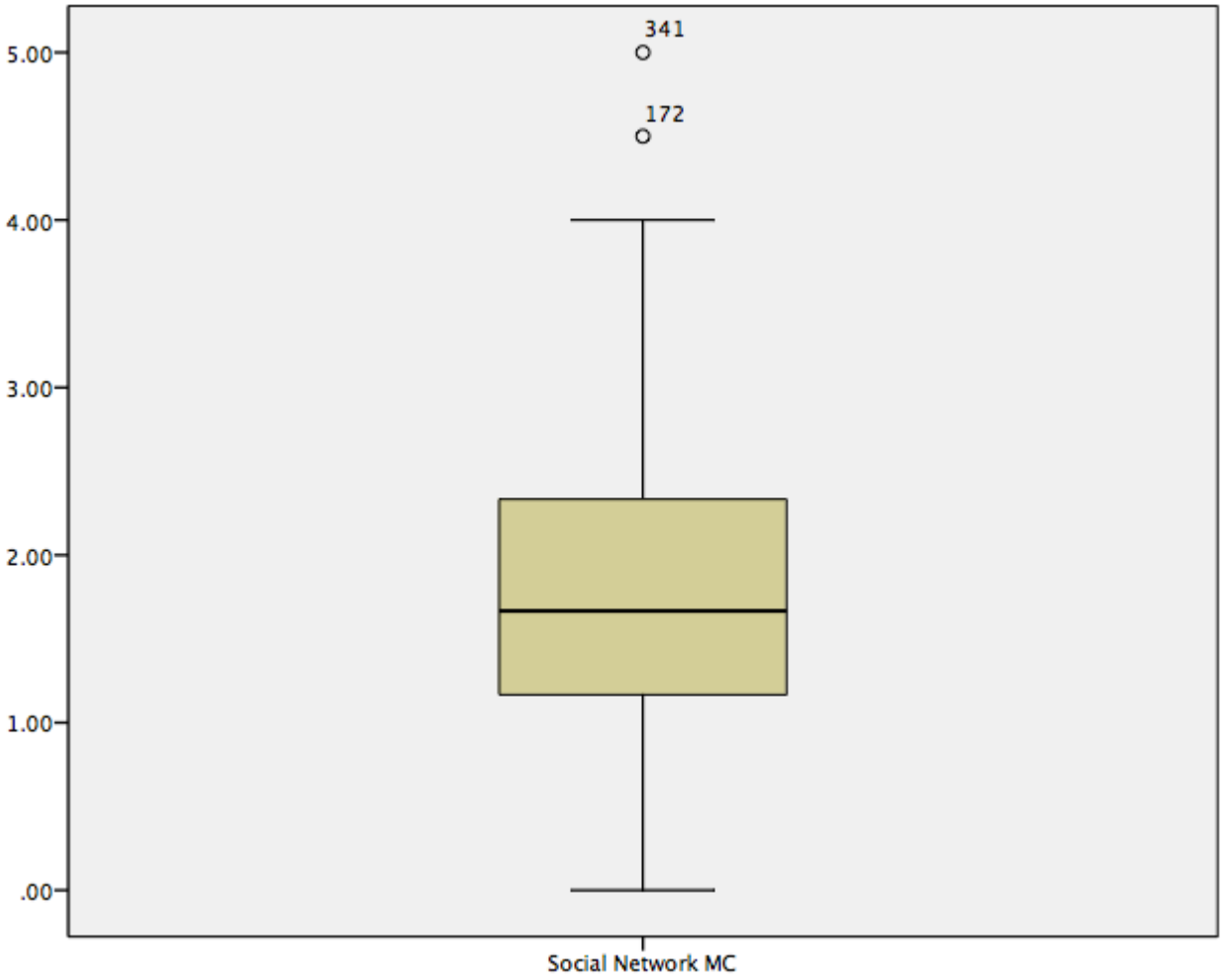
Box Plots and Histograms for the Transformed ACEs, Social Network, and Perceived Risk Scales

Boxplot for the transformed ACE's Scale

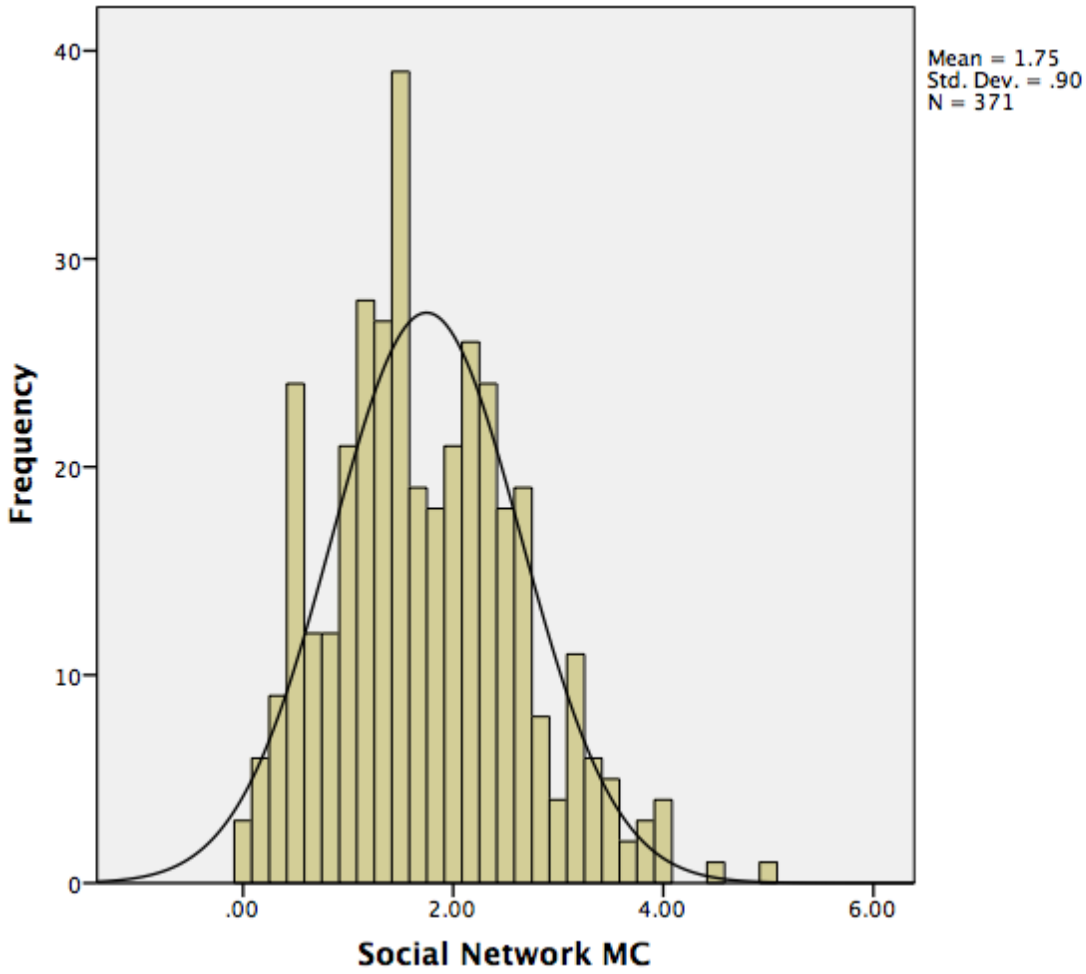
Histogram for the transformed ACE's Scale



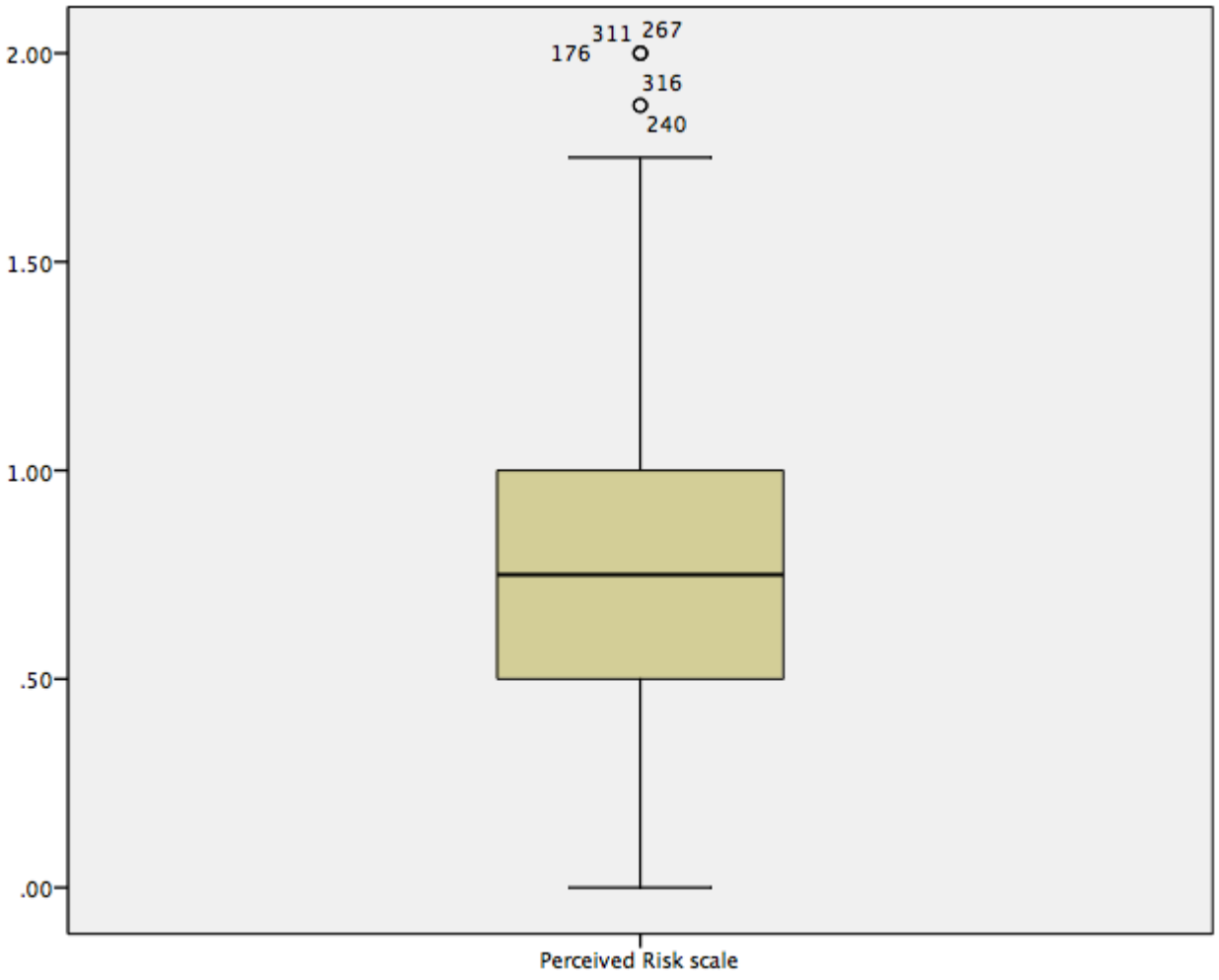
Boxplot for Transformed Social Network Scale



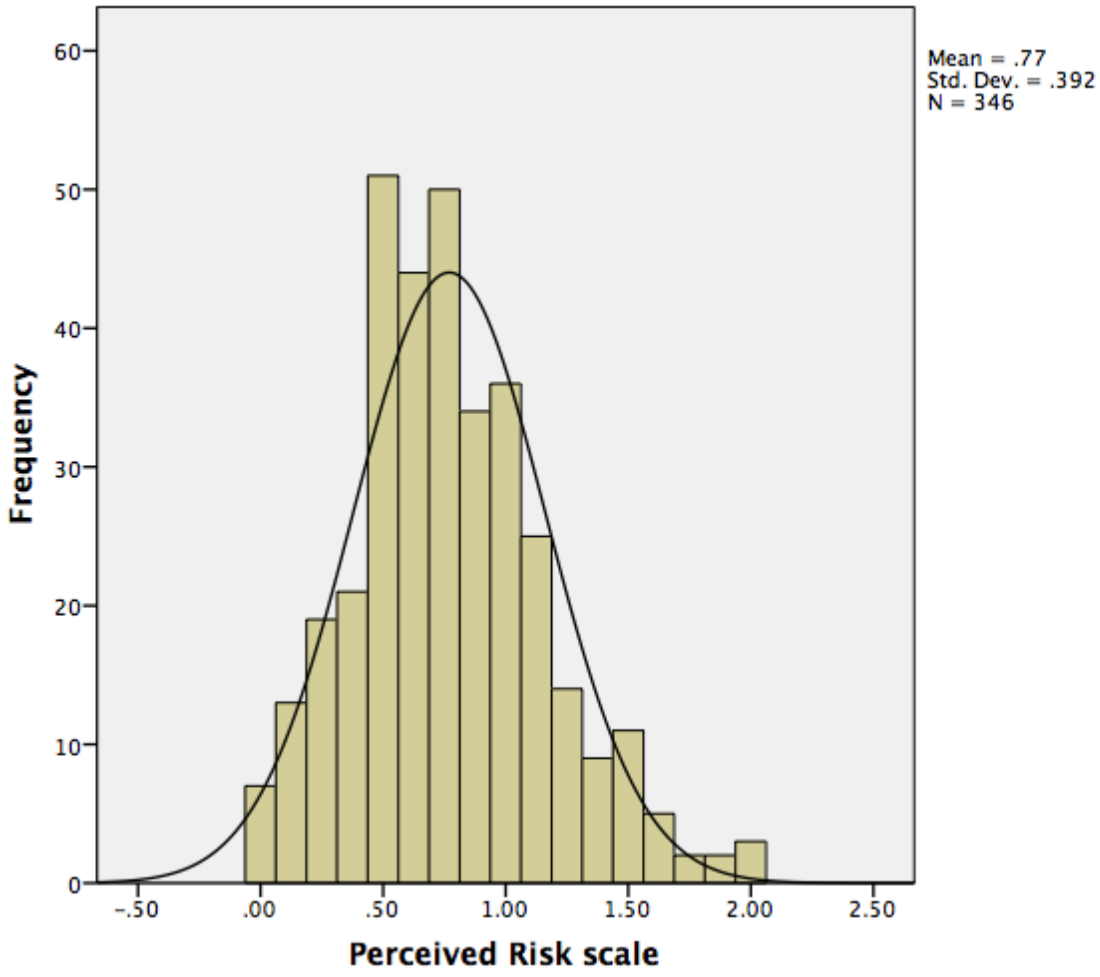
Histogram for Transformed Social Network Scale



Boxplot for Transformed Perceived Risk Scale



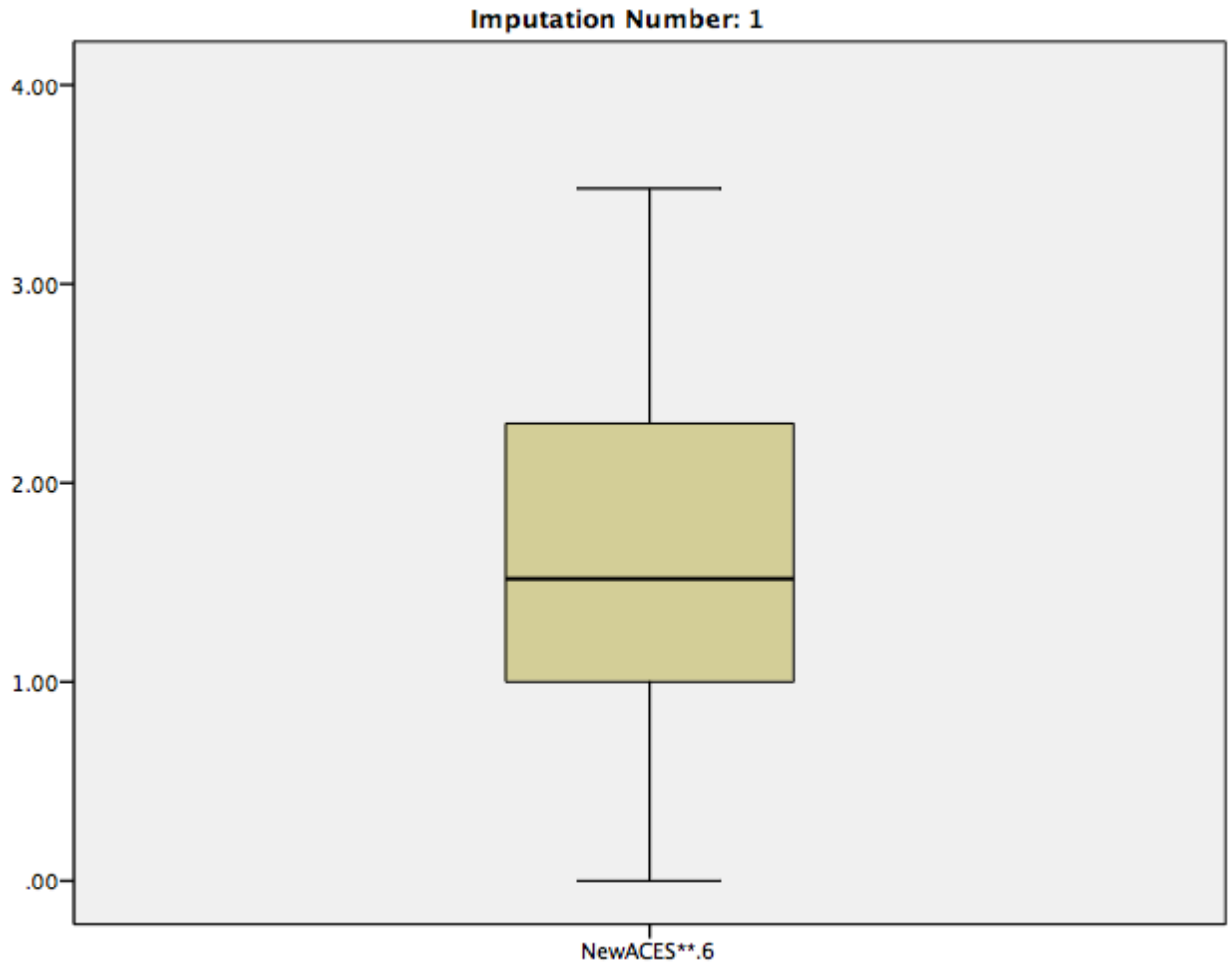
Histogram for Transformed Perceived Risk Scale



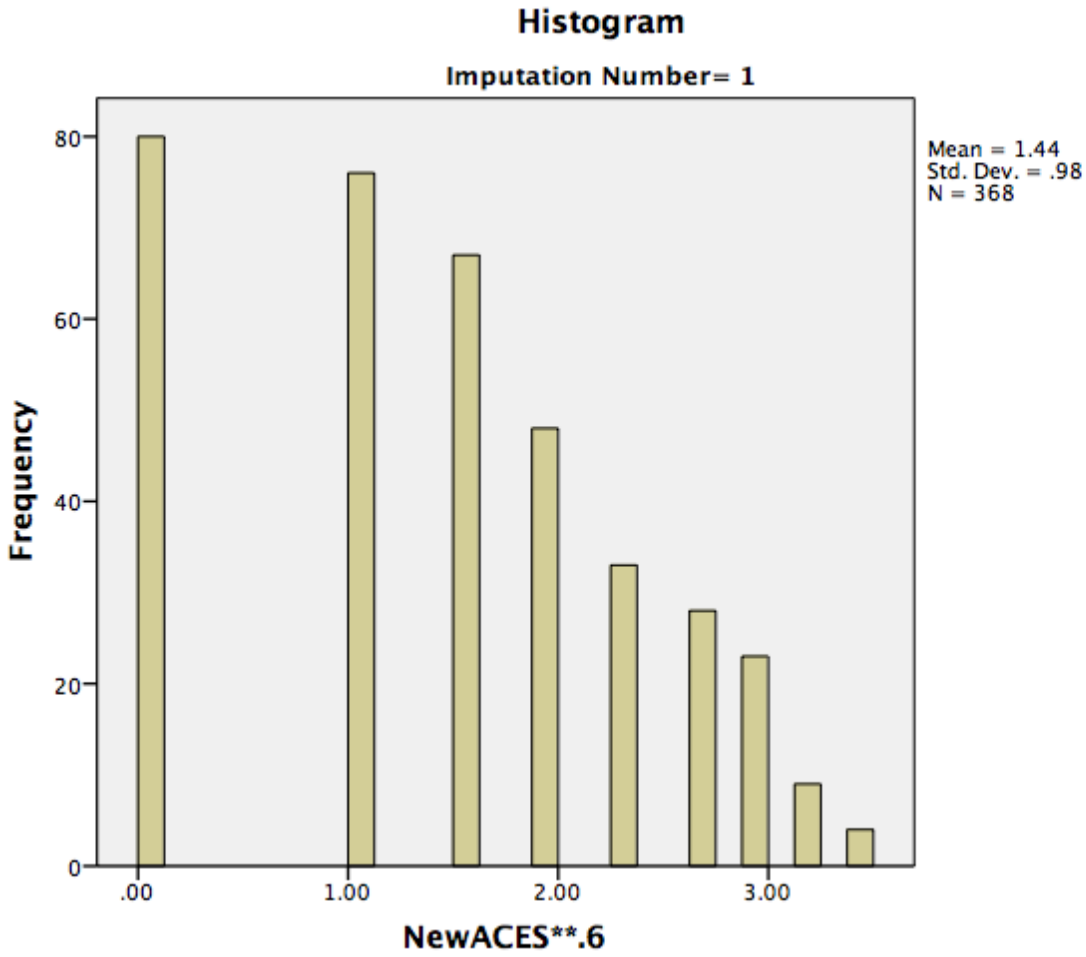
APPENDIX E

Box Plots and Histograms with Imputation for Missing Data for the ACE's, Social Network, and Perceived Risk Scales

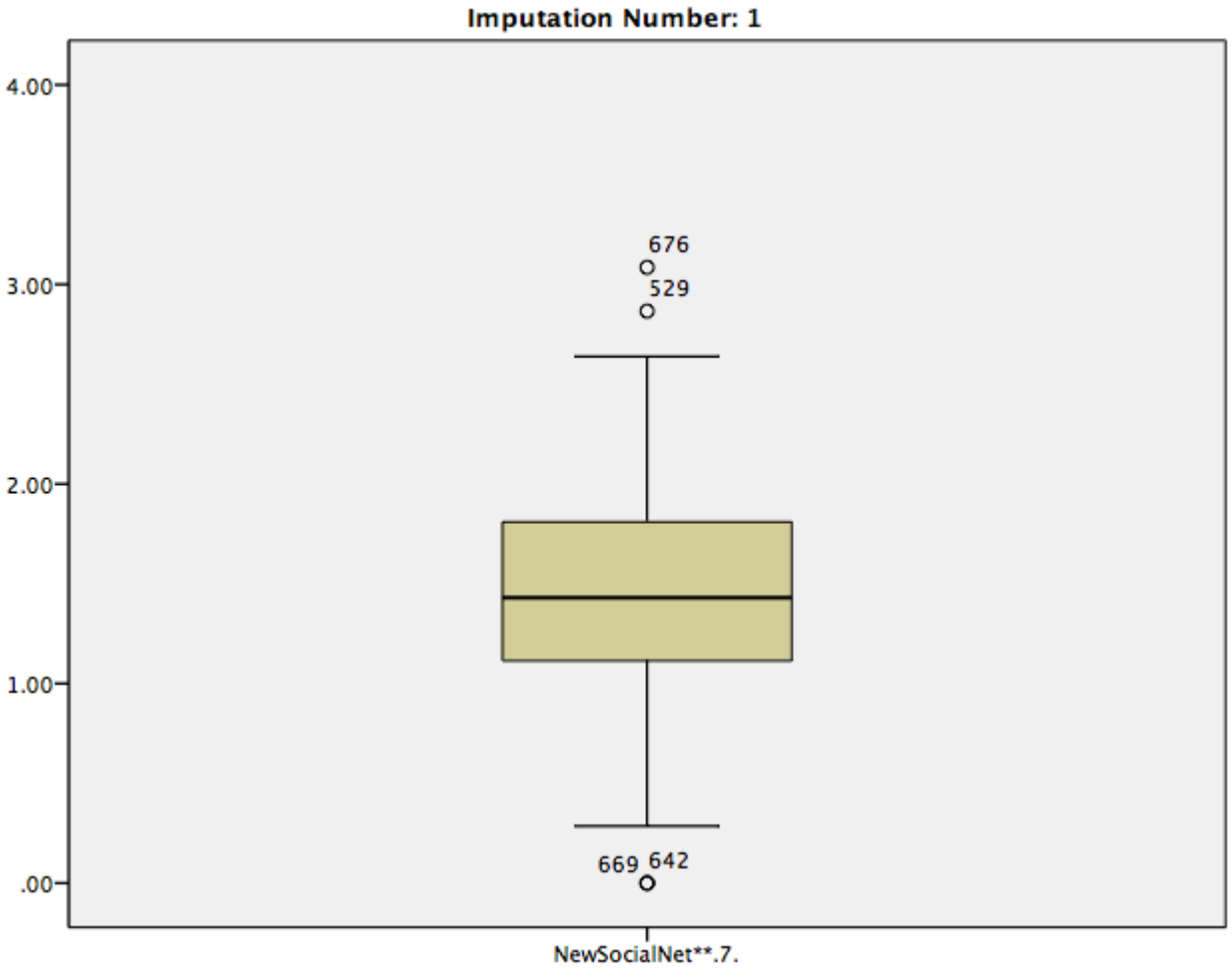
Boxplot for Imputed ACE's Scale



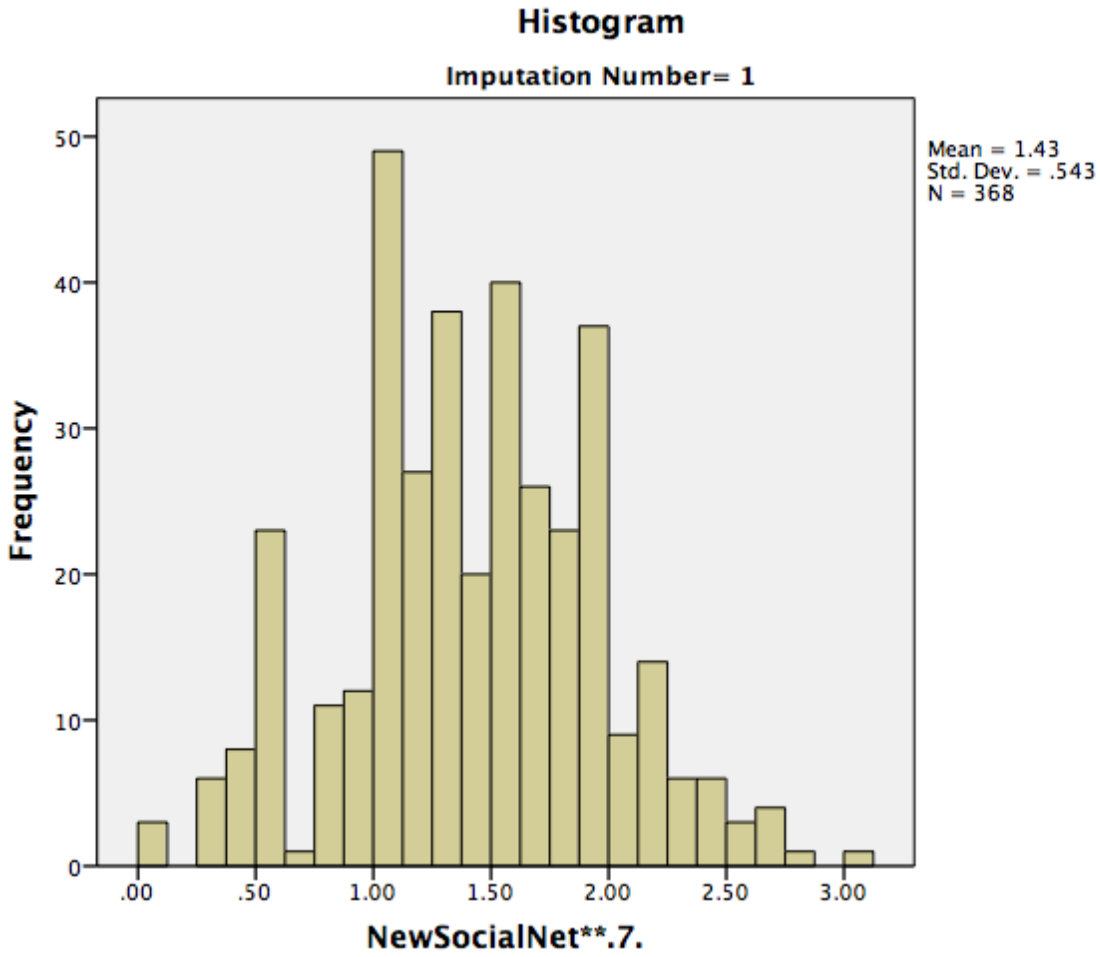
Histogram for Imputed ACE's Scale



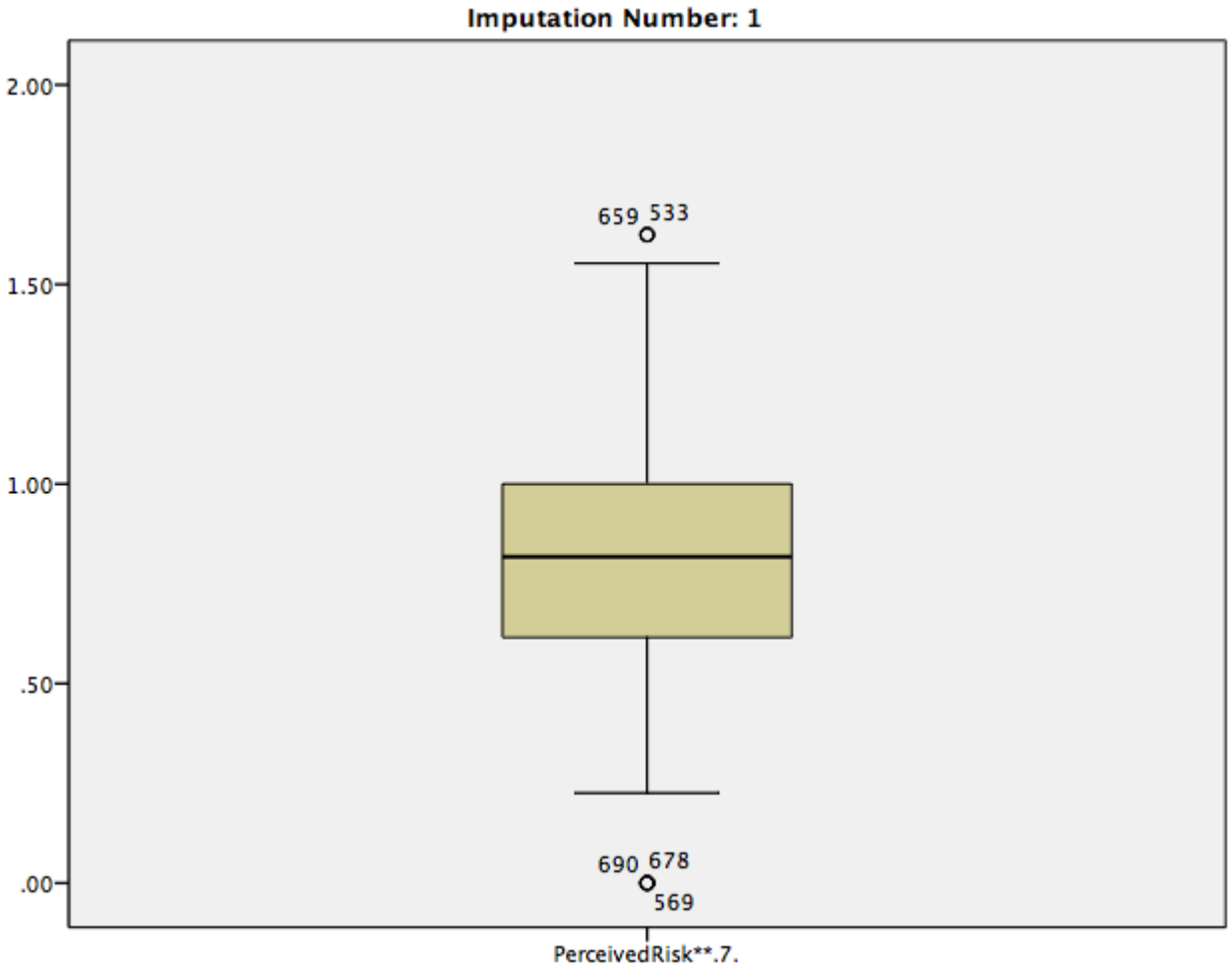
Boxplot for Imputed Social Network Scale



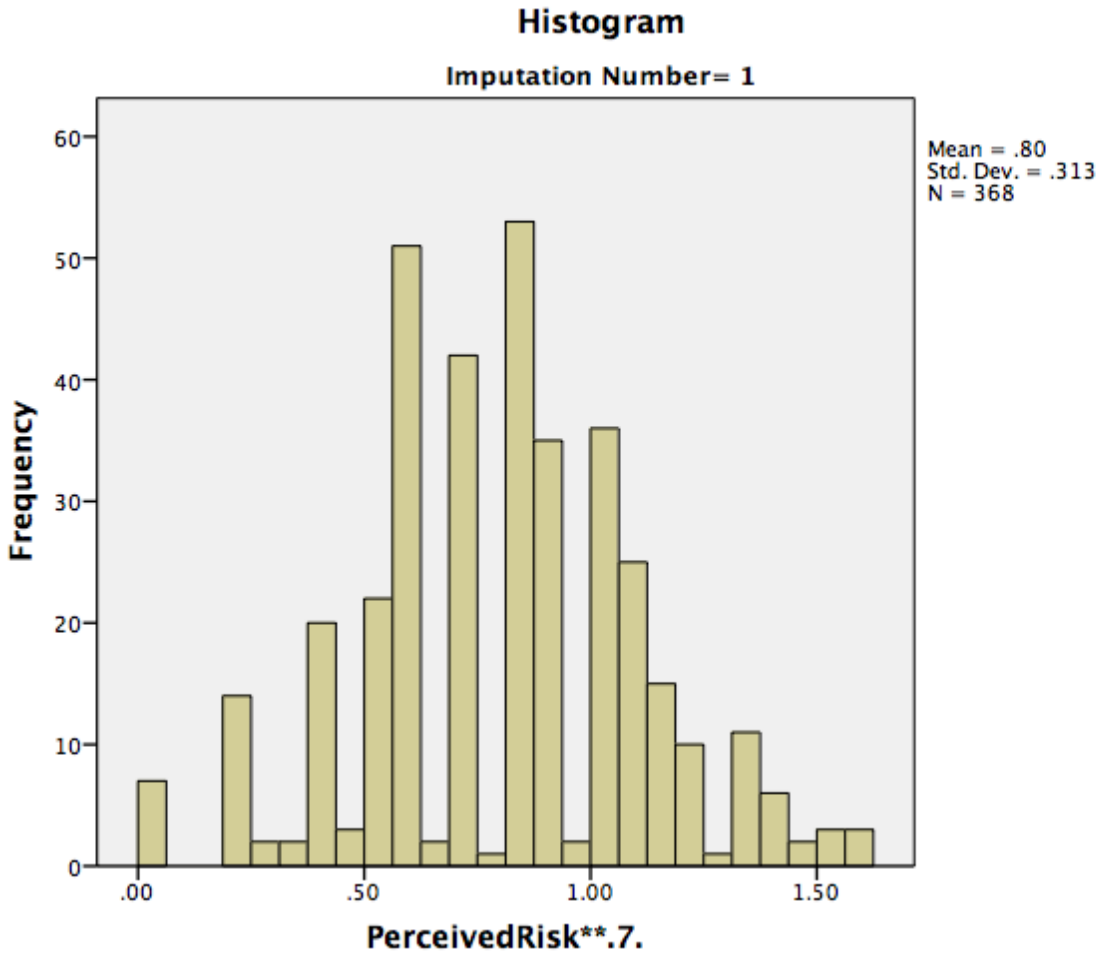
Histogram for Imputed Social Network Scale



Boxplot for Imputed Perceived Risk Scale



Histogram for Imputed Perceived Risk Scale



Appendix F

Elder Orphan Qualitative Interview Guide

Elder Orphan Interview Guide

Demographic Information:

- Age
- Race/ethnicity
- Employment Status
- How many years living alone?
- I'm interested in learning about your experiences as an Elder Orphan or why you identify with the term elder orphan.
- Can you tell me why you decided to join the Elder Orphan Group and how long you have been a member?
- What does the term elder orphan mean to you or how would you define the term elder orphan?
- Also, can you tell me why you identify as an elder orphan?
- Do you believe your life satisfaction has changed as you have gotten older? And if it has, how has it changed? Can you tell me how your age has influenced your life satisfaction?
-
- Do you believe you basic needs are met – food, bills, etc. How has having or not having your basic needs in late life impacted your life satisfaction?

- Can you tell about your childhood and how it plays a role in your life satisfaction currently? Are there any events that were particularly impactful?
- Can you tell me about your specific experiences or events?

- Are there any events (divorce, death of a child, etc.) in your midlife (40's, 50's) that were particularly impactful? Any if so how have they impacted you?
    - Can you tell me about your specific events?
- Do health issues (chronic illness, etc.) play a role in your overall life satisfaction?
    - Can you tell me about how your current health has impacted you?

- I'm interested in hearing more about any other events throughout your life that you believe currently impact your day to day life? Can you tell me any events that have really shaped who you are today, maybe even contributed to you identifying as an elder orphan?

- Can you explain to me what you believe advanced directives are?
- Can you tell me more about your experiences around advanced directives? If you have one, why? If you don't, why do you believe you don't?
- Do you think it's important to have advanced directive?
- Is there anything else you want to tell me about your experiences with advanced directives?
- Is there anything you are concerned about or feel you are at risk for as fair as your health or overall wellbeing?
- Can you tell me about how social media- particularly Facebook has played a role in your life? Is there anything you want to tell me specifically about the Elder Orphan Facebook Group? Anything particularly impactful about being a member of the Elder Orphan Facebook Group?

- Can you tell me more about your relationships with others? Family, friends and how they have played a role in your life?
- Do you feel like you can count on family or friends?
- Are you satisfied with your relationships, if so why? If not,why?
- Would you trust family or friends to make medical decisions for you?
- How would you want medical decisions made for you if you were not able to make them yourselves?
- Can you tell me if you are concerned about anything in particular as you age (end of life decision making, etc)
- Can you tell me if you feel you have prepared adequately for the end of life? Can you tell me more about that?
- Is there anything else you would like to share with me?