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Perspectives of Home Care Nurses on Frailty and Resilience in Older Adults Living at Home

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Perspectives of Home Care Nurses on Frailty and Resilience in Older Adults Living at Home

by

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Abstract

The population of older adults is growing rapidly in the United States. As more people are living to an advanced age, they are often managing a multitude of chronic illnesses and disabilities while continuing to live at home. Frailty is a common condition that affects how one ages and the condition is associated with dependency and poor health outcomes. Resilience is considered to be a protective factor against health stressors that lead to frailty in older adults. Perspectives of home care nurses were obtained by semi-structured interviews which described how older adults live at home with frailty and demonstrate resilience. Thorne's (2005) method of Interpretive Description guided this qualitative inquiry. Home care nurses identified several contextual factors that contribute to frailty and promote resilience in older adults living at home. Home care nurses shared resilience building strategies that can be applied in nursing practice, education, and research.

Key words: frailty, resilience, home care, nursing, older adults, interpretive description

DEDICATION

I would like to dedicate this dissertation to my family. To my children, Kiera, Fiona and Colin, and to my siblings Amy McElrath, and Dr. Frederick Merkle. I could not have made it without you in my life.

I would also like to dedicate this study to all nurses. Especially nurses that patiently work with older adults with complicated lives who are trying to ‘make it’ while aging and living at home. May you continue your good work because you make the world a better place for so many older adults that are struggling.

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CHAPTER I

PERSPECTIVES OF HOME CARE NURSES ON FRAILTY AND RESILIENCE IN OLDER ADULTS LIVING AT HOME

Problem

The study of older adults is becoming increasingly relevant to modern society with increased longevity. Today there are 125 million people aged 80 years and older worldwide (World Health Organization [WHO], 2020). Many people are living to an advanced age while managing a multitude of chronic illnesses and disabilities. Advances in pharmaceuticals, biomedical technologies, and medical interventions contribute to older adults living longer with diseases that they would not have survived in the past. Also, people are tending to live overall healthier lifestyles with better attention to their diet and exercise which has extended length of life.

The U.S. Census Bureau (USCB, 2022) predicts a growth in the U.S. population of older adults that will soon outpace the growth rate of children by 2035. Over the past 10 years, the U.S. population of adults aged 65 and over increased from 37.8 million to 50.9 million, a 34% increase. The older adult population in the U.S. is projected to reach 83.9 million people by 2050 (USCB, 2022). This shift is expected to challenge policies and programs offered to older adults such as Social Security and Medicare, and will lead to greater demands for healthcare, in-home care, as well as assisted living and long-term care (USCB, 2022). The aging population is associated with an increased need and use of formal home health care services (U.S. Department of Health and Human Services [HHS], 2020). Healthcare finance experts predict that Medicare will be reducing acute care and hospitalization coverage in the current decade which will also lead to an increased need for outpatient and community services to be available to older adults

(Morse, 2019). Implementation of evidence-based management of older adults' health while living in community settings can reduce overall health care costs by keeping people well and out of hospitals (Yao et al., 2016).

The WHO (2020) has designated 2020-2030 as the decade of healthy aging. As the shift in distribution of the world's population toward older age advances, there is a need for research to better understand population aging and how to promote health and optimal function of older adults (WHO, 2020). Older-person-centered care should integrate an individual's functional ability with their intrinsic capacity (WHO, 2020). Exploring all the factors that are important to the optimal health and function of older adults needs emphasis as a research priority in the United States.

In the late 1980s, the term "frailty" began to be used in geriatric medicine and gerontology as a term to describe older adults that had chronic conditions which made functioning independently difficult. Frailty is associated with dependency and poor health outcomes such as hospitalization, institutionalization, and premature mortality (Rockwood & Howlett, 2019; Rockwood & Minitski, 2007; 2011). Research efforts to identify and define frailty in older adults continue (Rockwood & Howlett, 2019); however, there is no single generally accepted clinical definition for this condition. Clarity surrounding frailty continues to evolve due to disagreement by researchers and clinicians as to which factors lead to and contribute to frailty. Measurement methods to detect frailty in older adults are inconsistent (Dury et al., 2018). Frailty has not been operationalized in a way that accurately accounts for the complexity of the construct.

Like frailty, understanding the nature of resilience as it pertains to aging has been evolving for over 30 years. Wagnild (2003) describes resilience as a personality characteristic that can moderate the effects of stress and promote adaptation in older adults. After suffering from a

negative life event, a resilient person can cope better and may become stronger because of the experience. Resilience is associated with greater health and sense of well-being (Wild et al., 2011). Originally, resilience had been studied primarily in younger populations. Over time, this term has been explored through research in older adult populations. There is a lack of consensus about whether resilience is a trait, a process, or an outcome (Madsen et al., 2019). Measurement of resilience in older adults depends on context, and there still exists a vagueness in definition (Madsen, 2019). Frailty and resilience in older adults are complex constructs that influence a person's potential to remain living at home in later years (Nicholson et al, 2017). Research contributing to enhanced understanding of frailty and resilience in this population may provide the crucial knowledge to improve care management for older adults aging at home.

Aim of Study

The aim of this study was to identify contextual factors that contribute to frailty and resilience in older adults living at home in the community. Gathering perspectives of home care nurses who care for frail older adults in their homes was intended to help gain an in-depth understanding about how frailty and resilience present in older adults. A nursing lens observing the experiences of older people aging in place at home hoped to offer a new way to contextualize and evaluate frailty and resilience. It was anticipated that the narratives of home care nurses who regularly care for older adults could identify resources that are most beneficial, what processes nurses adopt for handling frailty in their clients, and creative ways nurses work with frail older adults living in the community to optimize their health and autonomy. Gathering the nurses' perspectives on managing frailty and promoting resilience was intended to collect valuable information about the health care system and organizational barriers that affect care outcomes for frail older adults.

Constructs Examined

Frailty

Frailty is a rapidly evolving and clinically relevant concept in the field of gerontology, the science of aging. The term frailty is defined in older people as "a clinically recognizable state of increased vulnerability, resulting from aging-associated decline in reserve and function across multiple physiologic systems such that the ability to cope with every day or acute stressors is compromised" (Xue, 2011, p. 1).

Frailty is a concern for aging adults who wish to remain independent and living in their own homes (Tocchi et al., 2017). The actual prevalence of frailty in older adults varies in respect to what definition is used. A consistent, reliable, and valid definition of frailty is controversial and not yet available (Bandeen-Roche et al., 2019; DeDonder et al., 2019). There are multiple interpretations of what frailty means depending on one's perspective about this complex concept (Tocchi, 2015). For instance, clinicians working in one specialty may view frailty in a different light than another health care specialist, or a person themself experiencing frailty. Frailty consists of a cluster of characteristics acquired by adults, typically but not always later in life, often following an acute health event or stressor. To find accurate measurement of physical frailty with satisfactory criterion, content, and construct validity, Bandeen-Roche et al. (2019) concluded that there remain unresolved conceptual issues in understanding and defining frailty.

The most popular perspective on what frailty is describes only the physical characteristics associated with the condition, such as unintentional weight loss, weakness, fatigue, slow walking speed and low physical activity (Fried et al., 2001). The construct of frailty, when using the perspective of the physical frailty phenotype by Fried and colleagues, states frailty results from diminished fitness in physiologic systems which causes vulnerability to adverse outcomes when

an individual is stressed physically. An individual may become frail due to a stressor and therefore at increased risk for adverse health outcomes such as falls, hospitalization, or death. More recently, researchers have noted the multidimensional nature of frailty and more holistic and integrative definitions of frailty, which incorporate the whole person (DeDonder et al., 2019; Gee et al., 2019).

Most of the research regarding frailty has been conducted to predict either long-term care placement, re-hospitalization, or mortality. The ability to prognosticate outcomes from studies that show an association between frailty and adverse health outcomes is helpful for clinicians in primary care and geriatrics. These health care providers must prepare patients for invasive health procedures or counsel them on advance care planning. Predicting outcomes from frailty instruments in public health and epidemiology settings may help determine resource allocation and services provided to the growing older adult population. Minimal work has been done in the United States to measure frailty in older adults living in the community.

Gobbens and colleagues (2010) were some of the first researchers to examine the holistic nature of frailty using conceptual and operational definitions from a systematic review. They were interested in determining how frailty is recognized in community dwelling older people so that the prevalence of this condition could be determined. Recognition of frailty out in community settings depends on the definition used. The argument Gobbens and colleagues (2010) made is that one could not know who frail people in the community are if they are not recognized as being frail. Their work concluded that frailty exists on a continuum and is a dynamic condition. Gobbens et al. (2010) further state that the definition of frailty needs differentiation from the terms ‘disability’ and ‘comorbidity’, which are similar, yet different in clinical meaning. Recognition and prevention of frailty by healthcare clinicians is an important

step toward the design of patient-centered care to reduce the risk of poor outcomes, and to maximize the health and function of aging patients.

One of the most comprehensive definitions states: "Frailty is a tenuous state of health that is the result of the complex interplay of physiological, psychological, social, and environmental stressors that increases an older adult's susceptibility to adverse health outcomes" (Tocchi, 2015, p. 79). This definition best summarizes the holistic view that nurses often take when caring for older adult clients.

Resilience

Resilience comes from the Latin words "resilire" which means to spring back and "salire" which means to spring up (Resnick, 2014). Resnick (2014) describes resilience as being pliant, or elastic in quality. An individual can stretch and transform physically, emotionally, and mentally after exposure to some stressor resulting in either dysfunction or restored health. Fry & Keyes (2010) state that resilient aging is the normal and exceptional development of adults in the face of risk, adversity, recovery, plasticity, and regenerative capacity of individuals regardless of their physical functioning or disease. Resilient aging is characterized by the need for a person to find balance between accumulating life experience, preserving personal resources gained from past adversity, and applying those resources to deal with important life challenges in the present. Resilience in aging is not necessarily about superior functioning, but it is about maintaining function or bouncing back from adversity as best as one can considering individual circumstances (Fry & Keyes, 2010; Hicks & Conner, 2014; Pruchno & Heid, 2015; Windle, 2012). Measurement of resilience in older populations is not as well established as it is in younger populations. Resilience research has been conducted for decades, but there still is not a consensus amongst researchers about how to operationalize the conceptual definition of

resilience, especially as it pertains to older adults who are living in the community. As people age, they become more heterogeneous and accumulate a wider variety of experiences and adversities. This further complicates the ability to explain factors that represent resilience traits and protective mechanisms that boost resilience in older people. Qualitative work has continued for the purpose of understanding whether resilience in later life is a trait, a process, or an outcome (van Kessel, 2013).

Resilience is a term that has been used in a variety of disciplines over a few decades (Madsen et al., 2019). In a literature review which looked at past research on interventions aimed at increasing resilience in older adults, Madsen et al. (2019) concluded that resilience has come to have different meanings in different contexts and remains a challenge to measure. The similarities within the 29 journal articles reviewed by Madsen et al. (2019) converged on the ideas that resilience in older adults is multi-level (individual, community, region) with interdependency across levels, cumulative (built over time) and contextual (social, cultural, and material resources matter). The multidimensional contexts and interrelated variables have historically made quantitative measurement of resilience quite challenging.

Research has shown that people who demonstrate resilience in aging have the capacity to adapt to a variety of life challenges, both large and small (Fullen & Gorby, 2016; Resnick & Inguito, 2011; van Kessel, 2013). It is common for stressful life experiences such as loss of function, bereavement, or loneliness to occur with aging (Tocchi, 2015). Researchers are investigating which factors contribute most to an individual's adaptation, recovery, and possible growth from adversity (Bolton et al., 2016; Whitson et al., 2016). Given the diversity of the types of adversity experienced throughout life, and the variety of positive adaptations to these adverse events, resilience may manifest itself in different forms at different ages, which makes accurate

measurement in older adults difficult (Cosco et al., 2016). Higher levels of resilience later in life have been associated with good outcomes such as decreased depression and anxiety (Connor & Davidson, 2003), higher levels of self-care behaviors (Wagnild & Young, 1990) and a sense of purpose in life (Wild, Wiles & Allen, 2011).

Living in the Community

The USCB (2022) reports high home ownership rate in all American older adult age groups (65-74, 75-84, and those over 85) compared to the entire general population. This is consistent with the trend that more people are living in their homes longer rather than moving to expensive assisted living or retirement communities. There are 65 million people aged 60 and older, and less than 5% live in institutional settings (Administration for Community Living [ACL], https://acl.gov/, 2022). Promoting health and wellness while preventing disease, disability, and functional impairment is a crucial public health initiative in the United States (Centers for Disease Control [CDC], 2022). Older adults face the greatest risk of living with disease and disability based on the acquisition of risks and stressors associated with aging. How to care for our aging population so that they can maintain optimal health and function while being able to safely remain at home is one of our major public health concerns. Surviving and thriving optimally throughout one's lifespan needs to be a goal priority for our contemporary society with the increase in life expectancy.

Attitudes toward Aging

Historically, old age has been viewed as a time when a person declines in physical and cognitive health, becomes frail, dependent, and therefore a burden to society (WHO, 2020). Stereotypes about aging exist, such as the perception of a long, slow process of decline and accumulation of chronic medical conditions and impairment. Human aging has traditionally been

regarded as a negative and deleterious process (Borras et al., 2020). More recently, aging has been viewed as a holistic lifelong growth process in both the laypersons' and professional healthcare literature. An example of this is as the baby boomer (those born between 1946 and 1964) generation ages, many of the previous attitudes toward aging have been shifting (Fried, 2014; Narushima et al., 2018). Raynor (2015) reports that the baby boomer generation is likely feeling ageism most acutely right now, and this generation is struggling to come to terms with ageism by trying to become more civically engaged and put their experience and expertise into good use.

A more positive view of aging has emerged with the concepts of "successful aging" and "healthy aging" (Bowling & Dieppe, 2005; Rowe & Kahn, 1998), which is becoming a goal for the large cohort of baby boomers. The public view of aging is structured by the ideals of self-sufficiency, working, staying active, participating in leisure activities, and having close contact with family and friends. This idealized model of adult aging is in stark contrast with the belief by younger cohorts of people about the negative and deleterious process of aging (Fried, 2014; Lindland et al., 2015). When it comes to understanding the reality of the shifting proportion of the aging population and planning for getting older, the American public still views aging as the inevitable process of deterioration, dependence, disability and digital incompetence that happens to individuals who have not taken care of themselves with regard to health or finances (Lindland et al., 2015).

Many Americans aspire to living well as they age, yet the path to achieving this goal is elusive to many people. Various important contextual elements relevant to the aging process are now being studied to determine what influences may support an individual path toward health and wellbeing rather than a path toward disability. The public's lack of understanding about the

realities of aging frequently impedes the efforts of professionals and organizations that are working to construct a policy environment which responds productively to the growing population of older adults in this country (Lindland et al., 2015). Accurately understanding the skills, capacities, and needs of our aging population and their families and caregivers can inform community-based solutions such as improved public policy, better housing, and supportive aging environments. Improved social and community programs may support older adults to live well and continue to contribute to the needs of society rather than be perceived as high consumers of resources (Lindland et al., 2015).

Home Health Care

Home health care in the United States is a government regulated program of care delivering health care services which are provided by interdisciplinary healthcare professionals in the patient's home when assistance, ongoing assessment, and care management is needed. Home health care includes skilled nursing care, physical therapy, occupational therapy, speech therapy, and social work services as well as home health aide assistance with functional issues. U.S. Census Bureau demographic data (2022) states that as adults age and continue to live at home, there is a demonstrated increase in difficulty for older adults to maintain self-care and independence. This is related to some form of disability (USCB, 2022).

Over 15% of those aged 65, 25% of those aged 75 to 84, and almost 50% of those aged 85 and older have serious difficulty walking or climbing stairs (USCB, 2022). The U.S. Census Bureau (2022) reports that disability with vision, hearing, cognition, self-care, and independent living is prevalent in non-institutionalized older adults living in their homes, reaching almost 50% of people aged 85 or older who are affected with one or more major functional deficits. The healthcare system in the United States is challenged to meet the rapidly growing needs of this

population in its current state. There is concern that the predicted need to care for older adults may exceed supply of qualified home healthcare providers placing older adults at risk for adverse outcomes. A greater understanding of the constructs of frailty and resilience in older adults living in the community can contribute to designing solutions to some of the anticipated strains on social and health care resources.

Research Question

The overarching research questions in this study were:

- How do home care nurses providing care to older adults at home in the community perceive frailty and resilience in their clients?
- How do home care nurses describe their experiences caring for frail older adults living at home in the community?
- How do home care nurses identify and describe resilience in frail older adults they have cared for in the community?

Sub questions are:

- How do home care nurses understand and define frailty in their patients?
- How do home care nurses manage care for frail older adults at home?
- What are some clinical practice approaches of home care nurses caring for frail older adults?
- How do home care nurses support resilience in frail older adult clients?
- How does the current healthcare system milieu influence how care is provided to frail clients at home?

Justification for study

Although there are many instruments to measure both frailty and resilience, these complex concepts have contextual elements that make quantifying these constructs very difficult. An added element in the complexity of measuring these constructs is the heterogeneity of older adults. So many different life experiences, backgrounds, and beliefs among older adults often obscures precise measurement of the phenomena of frailty and resilience.

In the literature, there are different perspectives about how to measure frailty and many researchers want to strictly focus on predicting health outcomes by measuring the physical deficits a person has experienced. Frailty research largely focuses on outcomes after the condition has already appeared in an older adult. Contextual factors that were thought to influence whether an older adult will become frail following an adverse health event or injury were discussed through in-depth qualitative inquiry of home care nurses that have witnessed patient illness and recovery experiences. The interplay between factors such as social interaction, lifestyle, and home environment may predict the risk of an older adult becoming frail (Dury et al., 2017). More work is needed to address older adults who may be in a state of 'pre-frailty' because early identification of what factors contribute to a person becoming frail could be meaningful in altering the course and trajectory of frailty (Hale, Santorelli et al., 2019). Home care nurses that were interviewed in this study provided valuable information describing how they perceived conditions that lead to frailty and resilience in their clients.

Debate still exists about whether frailty is purely physiologic and should be measured by physical and functional deficits, or whether frailty has psychosocial, and spiritual aspects in addition to physical (Bandeen-Roche et al., 2019; Hale, Shah & Clegg, 2019). It is suspected that frailty and resilience are related (DeDonder et al., 2019; Hale, Shah & Clegg, 2019), but the

relationship is unclear. How one phenomenon influences the other has not been widely studied in older adults living at home. The aim of this study was to identify contextual factors that contribute to frailty and resilience in older adults living in the community. Instruments of frailty largely focus on measuring physical and functional performance, but these do not connect psychological, social, or spiritual factors, which may influence the onset and trajectory of frailty. Future research needs to better understand the multidimensional and positive aspects of frailty in later life and expand from the predominant deficit-based view (Dury et al., 2017).

Most of the past research about resilience has revolved around meaning, characteristics, and internal and environmental factors that protect a person's resilience (Wagnild & Collins, 2009; Wild et al., 2013; Zhang et al., 2018). A meta-synthesis conducted by Bolton and colleagues (2016) looked at qualitative studies using older adult populations to determine resilience. This study extracted 70 different original resilience themes and constructs from 12 studies. Their work illustrates the complexity of resilience in older adult populations. The meta-synthesis of literature by Bolton et al. (2016) concluded that resilience can be sorted into three constructs: (1) protective factors, (2) vulnerability factors, and (3) adversities. The study by Bolton and colleagues (2016) concludes that empirical research must be conducted to build upon resilience theory in older adults. Research that considers the number and variety of unique protective factors that mediate and moderate resilience is necessary to add to the literature on this topic.

Qualitative study of resilient aging in older adults living at home has not been conducted widely in the U.S. Gaining the perspectives of home care nurses who described examples of resilience in older adults further has added to our current comprehension of this construct in a new way. Home care nurse participants offered a unique perspective on resilience in their older

adult clients. Nurses care for patients during the times when they are experiencing a significant illness or crisis. They follow patients with chronic conditions that stress them both physically and mentally. Nurses that can more effectively identify and nurture a patient's sources of resilience during stressful times and reduce their risk of becoming frail can help optimize recovery and overall quality of life for their patients while decreasing risk of negative outcomes such as hospitalization and increased health care costs.

Chronically ill and disabled older people disproportionately use healthcare resources when compared to stable and well older individuals. The Centers for Medicare and Medicaid Services (CMS) benefit available to older adults at age 65, is looking for ways to streamline and make care more affordable. A goal of CMS is to provide cost-effective care to older adults, especially because of the prediction that the U.S. population will continue aging and more people will become eligible to receive Medicare. U.S. healthcare dollars will have to be divided by more beneficiaries over time. Diminishing financial resources that fund CMS are leading to billions of dollars of debt for the United States economy (Morse, 2019). The United States government predicts that Medicare will be insolvent by the year 2026 rendering inpatient and outpatient medical bills that will not be fully covered after that time (Morse, 2019). This creates an urgent need to understand how frailty and resilience impact the ability of older adults to cope with aging at home, and how healthcare providers can assist in this process.

Researcher's Perspective

I have been a nurse for 32 years and have worked in various adult clinical specialties throughout my career. As a nurse practitioner, I specialized in the comprehensive primary care of older adults and participated as a team member on a formal multidisciplinary geriatric assessment team. In this role, I evaluated complex older adults living in the community. I have

also worked as a staff nurse for a large accredited, hospital affiliated home care agency in New Jersey. I have coordinated interdisciplinary home healthcare of older adults who were recovering from serious illness and injury. These clients had marked losses of function and independence as a result of their medical condition, and they required varied levels of skilled nursing care services and/or restorative physical and occupational therapy in their homes. I functioned as a nurse case manager and clinician who coordinated person-centered care to each individual. I have cared for clientele from many different backgrounds, which increased my awareness that some older adults were unable to remain safely independent at home due to frailty, yet some with similar diagnoses were able to become functionally independent (or nearly so) with support in order to stay in their own homes throughout their lives as they wished. I have often wondered how some older individuals remain resilient when faced with serious health challenges and circumstances while other individuals in similar situations are unable to re-cooperate and recover and in turn, become frail. Nurses caring for clients in their homes observe how various internal and external factors influence patient outcomes, and how frailty and/or resilience appears during a patient's course of illness.

While thinking about this problem and the design of this research, I suspected that interviewing nurses who provide skilled nursing care and management of older individuals in their homes could provide crucial information to the current understanding of how patients with frailty cope in their homes. Interviewing nurses who witness adaptive behaviors to serious, complex conditions was undertaken to provide information about how older adults recover and demonstrate resilience despite challenging situations. There is a lack of research delineating perspectives of home care nurses when exploring the constructs of frailty and resilience in older adults in the U.S.

Having experience in the areas of gerontology and home care helped to provide entry into the home care arena via professional connections and understanding of "the system". Semi-structured interviews allowed for discovery of lifestyle and environmental factors that home care nurses observe in their patients, which helped to explain the constructs of interest. I took measures to minimize bias, such as not personally knowing the nurses who participated prior to the interviews and not utilizing nurse participants who work for the home care agency where I had once worked. The interviews were conducted away from the homecare office to allow the nurses to speak candidly and without apprehension.

Relevance to Nursing

Frailty can be an expensive condition for a person if they need to purchase formal caregiving services or if home modifications are necessary for them to remain living at home. If frailty can be recognized, prevented, mitigated, and treated by nurses, this would reduce spending on care and complications resulting from frailty. Resilience appears to be an important personal internal resource that when strengthened and supported could help a person manage stressors, recover from illness, and maximize function. By improving understanding of frailty and resilience, nurses can develop interventions to decrease the suffering of older adults struggling to remain living at home. This could decrease healthcare expenditures for older adults requiring frequent health care provider office visits, out of pocket costs for personal assistance at home, and defer placement into costly assisted living or long-term care facilities.

CHAPTER II

LITERATURE REVIEW

Frailty as a Concept

The term "frailty" has been in use since the early 1990's in the United States. Formerly the term was often called "debility", "feebleness", "functional dependence" or "failure to thrive" in clinical settings where older adults received their care (Markle-Reid & Browne, 2003). Later this condition was given the term frailty, but it still represented a nebulous cluster of physiologic conditions that when present, threatened an older individual's ability to recover from illness or manage independent functioning. Frailty was recognized by the medical community and observed in individual patients who had varying degrees of physical deficit. A succinct definition for frailty is lacking due to the complexity of the condition; however, many clinicians rely on their clinical instincts enough to say "I know it when I see it" when labeling a person as frail. Identification of frailty in older adults has become more clinically relevant in the past 20 years because of our rapidly aging population. Frailty is linked with increased risk of functional decline, deterioration of health, disability, low quality of life, and even death (Andreasen et al., 2015; Muscedere et al., 2016). Recognizing early signs and potential for frailty in older adults living in the community may prevent negative sequelae. Understanding frailty has been made a larger priority in primary care and health care specialties that serve older adults during this past decade to target interventions and reduce costly unplanned hospitalizations (Kojima et al., 2019; Muscedere et al., 2016).

In an integrative literature review of frailty in older adults conducted by Markle-Reid and Brown (2003), six conceptual models of frailty were identified. Most of the earlier conceptual models developed by the medical and allied health specialties focused on pathophysiology and physical deficits in a frail individual. Early screening tools used to assess for frailty largely

focused on functional measures and physiologic observations to determine whether a person is or would become frail (Brown et al., 2000; Fried et al., 2001).

Early investigators of the concept of frailty were Fried et al. (2001), who collaborated on the Cardiovascular Health Study (CHS). Fried et al. (2001) published a landmark article that resulted from a secondary analysis of data obtained from the CHS where they identified a cluster of five physical variables that explained and operationalized frailty in a way that had never been done before. According to Fried et al. (2001), the physical phenotype of a frail person has at least three of these following five conditions: self-reported fatigue, unintentional weight loss, slowed walking speed, diminished muscle strength, and low physical activity. These physical features can be determined by subjective and objective measurements during client examination. The Fried et al. (2001) study has been most widely utilized by healthcare clinicians because it identifies specific physical criteria for frailty that did not previously exist. Fried et al. (2001) attempted to standardize a definition of frailty and differentiate the term from similar conditions like co-morbidity and disability. The Fried et al. (2001) study provided more clarity about what frailty looks like, but a more recent systematic review of frailty phenotype criteria, conducted by Theou et al. (2015), discussed that disability and chronic disease were important criteria to consider in addition to ways that physical frailty is determined.

In their systematic review, Theou et al. (2015) found that not many population-based data sets included the frailty phenotype criteria as measured in the original definition by Fried et al. (2001). In addition, sometimes physical criteria were measured by patient performance while in other studies these criteria were measured by self-report. In their attempt to determine variability in how the frailty phenotype is measured in 262 studies, they concluded that only 24 studies provided enough information to demonstrate all physical criteria were assessed. Therefore,

predictions about mortality and disability as a result of physical frailty was inconsistent across studies because of different classifications and operationalization of frailty. Fried's et al. (2001) frailty phenotype has been operationalized in over 262 different ways according to Theou et al., (2015). The conclusion from this seminal study was that "frailty is not synonymous with either comorbidity or disability, but comorbidity is an etiologic risk factor for, and disability is an outcome of, frailty" (Fried et al., 2001, M146). In other words, there are pathways to disability other than frailty. Likewise, living with comorbidities does not guarantee frailty. The terms are similar and related but should not be confused with one another. Although organizing physical attributes and correlating them with adverse outcomes such as re-hospitalization or death was helpful, the phenotype model does not completely address other important factors which may influence the presence of frailty in people.

Physical performance of balance, strength, range of motion, coordination of movement, and gait were measured by physical therapists Brown et al. (2000) to gain insight as to what degree these performance factors contributed to frailty and a person's relative ability to function. The physical performance testing provided an objective measure of disability, loss of independence and early mortality. Their conclusion was that physical frailty in old age could be reduced through appropriate exercise interventions such as balance and resistance training and activities that build endurance. Brown et al. (2000) also reported that physical frailty in older adults is multidimensional, and measurement of just one aspect of frailty does not provide adequate information about this complex phenomenon.

Aspects of frailty such as cognitive decline were not included in the frailty phenotype. Cognitive impairment measured by instruments such as the Folstein Mini-Mental exam (MMSE) or the Montreal Cognitive Assessment (MoCA) were often exclusion criteria for participation in

research about frailty (Dury et al., 2018). A research subject was expected to have the cognitive ability to participate in structured interviews or to complete questionnaires exploring the various types and severities of the condition. Intact cognitive function was a necessary component in many of the frailty studies. More recent work has shown that cognitive impairment, dementia and depression are important drivers of frailty (Lohman et al., 2015; Lohman et al., 2016; Rockwood et al., 2005; Wang et al., 2018). People with common neurodegenerative disorders associated with aging like Parkinson's disease, stroke, depression, or dementias were largely excluded from early studies on frailty. Researchers felt that participants need to demonstrate a good understanding of the questions, have the energy to answer, as well as stay on topic during the interview and not be preoccupied with other health conditions. Though useful for clinicians in certain settings, the Fried et al. (2001) frailty phenotype model lacks nuance and the ability to identify frailty amongst people suffering from those prevalent neurologic conditions common with aging. Fried et al. (2001) had recommended that research participants with Parkinson's disease, stroke, or cognitive impairment and those taking antidepressant medication should be excluded from study. These conditions in and of themselves could present as characteristics of frailty, thus interfere with measurement. Unfortunately, the Fried et al. (2001) study as well as other research studies using the same exclusion criteria lack representation from a very large segment of older adults with functional issues which would make them appear frail.

Rockwood and colleagues (1994), Canadian geriatricians, were the first to introduce a more dynamic model of frailty where functional deficits and functional assets were described to be in constant balance. If there were a higher proportion of deficits in relation to assets it would lead to functional imbalance, and frailty would likely result. The Frailty Index (FI) was created through their work with the Canadian Study of Health and Aging (CSHA) and they attempted to

quantify frailty. Rockwood and Minitski (2007) later tested the FI where older adults' deficits were identified during a clinical examination. The deficits could be gathered from an array of health problems such as client reported symptoms, number of chronic diseases, abnormal lab values, or disabilities. They identified 70 potential deficits in total. This research was complex, yet results correlated well with the Fried et al. (2001) phenotype measure of frailty in predicting mortality. A later study by Rockwood and Minitski (2011) acknowledged that older adults with frailty acquire neither the same deficits nor deficits at the same rate. The heterogeneity of older adults provided too many possibilities to formulate a succinct operational definition of frailty. Their findings supported that the number of deficits a person has is just as important as the type of deficit, and the proportion of deficits an individual accumulates overall is a significant predictor of risk for an adverse health outcome. The more deficits one has in proportion to assets predicts more risk and more frailty (Rockwood & Minitski, 2011).

Rockwood and Minitski (2007) contributed to the growing body of frailty research work and eventually determined that frailty exists along a continuum. Rockwood et al. (2000) and Rockwood and Minitski (2007) also saw frailty as a dynamic process where interacting factors such as caregivers, social resources, or the physical environment could influence fluctuations in the condition of frailty. In other words, frailty is not a binary condition that is viewed as either being present or not, but rather it is a dynamic state that typically affects older adults to varying degrees. An individual could be recognized as being frail at some points in their lives and become less frail over time, moving in and out of dependence and vulnerability in various areas of health and function.

Rockwood et al. (2005) introduced the Cumulative Deficit Model (CDM) to explain this observation. Rather than a purely physical phenotype described by Fried et al., (2001),

Rockwood et al. (2005) viewed frailty as an accumulation of risk. Rockwood et al., (2000) stated frailty is a complex interaction between physical and social systems, and measurement of frailty must be comprehensive enough to allow for dynamic interaction between an aging person's body and environment. Older adults have likely gone through more adversity during their lives than younger adults. They have accumulated experiences, health conditions, and traumas that may contribute to frailty and adverse health outcomes over time. Adults can move through different severities of frailty depending on what physical, social, or environmental threats exist in their lives. The lived experience and severity of frailty was moderated by resilience and psychological resources such as a positive attitude and personality strengths.

Later work integrated social, psychological, and environmental factors for a more holistic understanding of frailty (Dury et al., 2018; Rockwood & Howlett, 2019). Currently, there is increasing evidence that frailty may be reversible before disability leads to dependence, falls, nursing home admissions, and frequent hospitalizations (Hale, Santorelli, et al., 2019). Studies that look at the complex interactions between a person's physiology, psychosocial situation, and the environment are currently underway to better understand the development and progression of frailty (Dury et al., 2018).

Dury and colleagues (2018) conducted a mixed method research study using a purposeful sample of potentially frail community-dwelling older adults (over age 60) to identify life factors which balance deficits in areas of life that affect frailty. An example of a deficit that could make a person frail is lack of a social network for support. Potentially frail subjects from this study describe life changes that could worsen or improve their degree of frailty. The work by Dury et al. (2018) supports that frailty is a dynamic state and that areas of life like finances, personal relationships, and living situation can either contribute to or mitigate self-reported frailty in older

adults living in their communities. Becoming frail is associated with poorer health related outcomes due to diminishing reserves to recover from some health threat (Clegg et al., 2013; Ehlenbach, et al., 2015). “Frailty is a state of increased vulnerability to poor resolution of homeostasis after a stressor event, which increases the risk of adverse outcomes, falls, delirium, and disability” (Clegg et al., 2013, p. 752). Despite a body of research that has been done to understand frailty better, there remains no consensual definition for this condition. The accumulation of these physical deficits is what is seen empirically, yet no two frail individuals have the same exact degree of debility or risk.

Over the past 20 years, a plethora of frailty measurement instruments have been developed worldwide, yet there has not been one instrument with promise of being the one best frailty measure largely due to the numerous definitions of frailty and the complexity in operationalizing the construct. Dent and colleagues (2015) compared instruments and provided a critique of frailty measurements based on reliability and validity, time taken to perform measurement, data measured, whether special equipment or training was necessary to conduct measurement, and accuracy in the ability to predict health outcomes or mortality. Dent et al. (2015) concluded that frailty measurement instruments vary widely in quality, ease of use, and accuracy. In addition, Dent et al. (2015) found that some frailty measurement instruments were better for assessment and screening individuals in a clinical setting, while other instruments were better suited to population level screening. Overall, they found that there was no ideal way to measure frailty.

Tocchi (2015) constructed and proposed a new conceptual definition of frailty based on her concept analysis that reviewed 43 research articles pertaining to this issue. She stated, “Frailty is a tenuous state of health that is the result of the complex interplay of physiological,

psychological, social, and environmental stressors that increases an older adult's susceptibility to adverse health outcomes" (Tocchi, 2015, p. 79). From her analysis, Tocchi (2015) concluded that frailty is complex, multidimensional, involves a continuum of movement between different frailty states (pre-frail to severely frail), and is always a negative experience for the sufferer. Frailty exists on a spectrum and represents different risks to different individuals who experience it. There is no "one-size-fits-all" description or consequence of this syndrome.

There are several negative consequences of frailty which are described in the literature and have been summarized by Tocchi (2015). These negative consequences are disability, increased health costs, lowered subjective quality of life, increased risk of developing other illnesses, changes in care environment, and lowered ability to communicate health care wishes (Tocchi, 2015). Tocchi (2015) found terms which are highly related to but different than frailty in the literature. The terms disability, comorbidity and vulnerability share similarities with the construct of frailty. Frailty is multifactorial and results from "deficits in multiple systems and domains" (Tocchi, 2015, p.75) whereas disability usually results from a specific and identifiable cause with specific impairment. Tocchi (2015) states "vulnerability is an inherent characteristic of frailty, but frailty is not synonymous with vulnerability"(p. 75). In other words, a person who is labeled as frail is vulnerable, yet not every person who is vulnerable is frail. Comorbidity, the presence of two or more diseases in one person, is found to be a cause of frailty as well as a result of frailty. Tocchi (2015) states that there is consensus in the literature that the collective effects of multiple deficits in health significantly affects degree of frailty in an individual.

Self-Report of Frailty

There has been limited research about the multidimensional nature of frailty that includes psychological, social, functional, and health utilization factors in addition to the physiological

factors that characterize frailty. Research has shown that many older adults who would be designated as frail by a healthcare professional would not describe or consider themselves to be frail (Dury et al., 2018; Nicholson et al., 2017; Warmoth et al., 2016). Anecdotally, it is not uncommon for older adults with chronic illness to overestimate their abilities to function safely at home and to underestimate their risk for adverse health outcomes in doing so. In the qualitative portion of the study conducted by Dury et al. (2018), older adults who were interviewed appeared to feel less cognitively and physically frail than their peers and described their own deficits as 'normal aging'. Although the lived experiences of chronically ill older adults who remain in their homes in the United States are not yet well understood, frail older adults may inaccurately describe their own health status or needs. While recognizing their own physical symptoms of frailty, many older people do not identify as 'frail' even when they meet classification criteria on a standardized instrument (Warmoth et al., 2016).

Pan et al. (2018) found that widespread conceptualization of frailty amongst their older adult research participants differed from the healthcare professionals' appraisals of frailty. They found that study participants rejected the frail identity and instead applied a "modification of the definition of frailty in accordance with one's present situation so as to exclude oneself from the label of frailty" (Pan et al., 2018, p. 6). A frail older adult will often base their self-appraisal on subjective, previous self-conceptions and projections of how they remember themselves, providing an idealized version of their functional status and wellbeing. Screening for frailty and thus labeling someone as frail may be harmful if it stigmatizes the person or makes them avoid seeking care. Research that measures frailty by subjective self-report in older adults may be limited in its usefulness due to the mismatch with clinical findings and objective frailty measurements seen in the literature (Hale, Santorelli, et al., 2019). Hale, Santorelli, et al. (2019)

found that older adults with frailty self-report their health conditions and limitations inaccurately when compared to documented health records of their primary care physicians. Hale, Santorelli, et al. (2019) elaborated that underreporting of health deficits by older adults may occur because clinicians did not clearly explain a diagnosis or historical diagnoses were forgotten by the patient. However, Hale, Santorelli, et al. (2019) proposed that participants may have been concealing diagnoses because they did not believe they had the condition, or that they perceived it to be embarrassing and stigmatizing. Older people dislike when their deficits are the focus of health care encounters and their strengths and assets are not acknowledged. Rejecting the frailty label could be a way of coping with changes that occur with aging such as loss of independence, self-efficacy, and autonomy. Admitting to being frail and accepting the label may cause a decreased self-perception, therefore leading to further decline in function (Pan et al., 2018). Furthermore, positive life events (i.e., the birth of a grandchild) are thought to influence perceived frailty in a positive way. Positive events are strengths that provide balance away from the negative aspects of aging or becoming frail, and they also reinforce a sense of good quality of life, meaning in life, support, connection, and purpose (Dury et al., 2018).

While studies utilizing self-report by older adults has provided insight into the lived experience of living at home with frailty, home care nurses provided a clinicians' perspective in portraying these constructs. Exploring these constructs through the lens of a home care nurse provided a novel way to study frailty and resilience. Warmoth et al. (2016) studied perceptions of frailty in community dwelling older adults living in the United Kingdom. Ultimately, she discovered older individuals resisted self-identification of frailty and differentiated "being frail" with "feeling frail". "Being frail" was linked to objective clinical symptoms of having poor health and functional limitations. People dealt with it, "fought against it", and wished to be

viewed for what they were able to do, not what they were unable to do. They coped with being frail by emphasizing their abilities, comparing themselves to someone worse off, and attributing their condition to an event or cause. “Feeling frail” was different. Identifying with the “feeling frail” label was considered very negative. Those who felt frail were viewed by their peers to decline in health more rapidly because they saw their frailty as an inevitable and uncontrollable thing that happened with old age. According to the study participants, people who accept feeling frail “give up” and disengage socially and physically.

Frailty at Home

An important objective of health care system reform in the United States is to make it possible for the frail, ill, and disabled to remain safely in community settings for as long as possible (ACL, 2022). Not only is this a quality-of-life issue for these people, but it is also more cost effective to care for people in their own homes and bring services to them (ACL, 2022; Kojima et al., 2019; Stone, 2017). Qualitative studies have described the experience of living at home with frailty in old age and have mostly been conducted in the United Kingdom, Canada, Western Europe, Australia, New Zealand and a few Scandinavian countries (Andreasen et al., 2015; Gee et al., 2019; Nicholson et al., 2013; Nicholson et al., 2017; Pan et al., 2018). Currently there is little empirical work exploring how older adults manage being frail and living at home in the United States. There is also a paucity of studies that include perspectives of health care professionals such as home care nurses as they provide care to chronically ill, medically complex, and intractably frail older adults in the community.

Studies in the United Kingdom conducted by Nicholson et al. (2013; 2017) sought factors that are important to frail older adults in maintaining a reasonable quality of life at home. Nicholson et al., (2013) were interested in the temporal nature of frailty and their study also

sought to understand the experiences of home dwelling older adults with changing states of frailty over time. Creative adaptation to loss and changing circumstances as well as the multifactorial nature of frailty were illustrated in this study. Frail older adults were able to demonstrate the capacity to work with their situations despite losses in physical, social, and functional areas. Interestingly, adaptive behaviors and attitudes used to cope with negative circumstances are considered to be features of **resilience**. In the study by Pan et al. (2018), perceptions of older adults towards their own course of aging highlighted the importance of independence and resilience in reducing and preventing the chance of becoming frail.

Resilience

In a literature review conducted by MacLeod et al. (2016), the authors wrote that resilience as defined by the American Psychological Association (APA) is an adaptive process rather than a trait. Adaptation to adversity and bouncing back from stressful experiences demonstrates resilience. In their findings from the literature review, they conclude that older adults can and do experience a high capacity for resilience despite declining function, disability, and frailty (MacLeod et al., 2016).

Skilbeck et al. (2017) conducted an ethnographic study of the experience of older people living with complex health problems. Through observations and semi-structured interviews, they determined that people work very hard to maintain their routines while enduring the difficulties that come with fluctuating health and illness. Their work identified fear, anxiety, and uncertainty associated with changes in the health of these patients as a significant part of the frailty experience. The patients' perspectives on how they continually need to adjust to the fluctuations in their health highlights how adaptive these individuals are despite their fears and anxieties. Nicholson et al. (2017) point out that older people with frailty are survivors. They are quite

strong, resilient, and have developed strategies to deal with their vulnerabilities. Often medical and nursing interventions for this population focus on problems, diagnoses, and incapacities. When people get labeled as frail it may be a self-fulfilling prophecy which leads to further decline and disability. The "frail" identity is restrictive and does not account for the positive adaptations to changing circumstances that come with aging. The perspectives of visiting home care nurses who observe transitional experiences of older adults during fluctuations in health and circumstances has not been adequately studied. Nurses who provide skilled care in the home are able to observe details about a patient's life that cannot be seen in an institutional or office-based healthcare setting. Their observations offer a different way of understanding the interplay between frailty and resilience.

Much of the qualitative work on frailty and resilience has been done in the United Kingdom using small samples of older adults conducted in homes where they received support from community matron services. Community matrons are comparable to advanced practice nurses in the United States, but their practice setting is out in the community within a geographical "medical district" and linked with the National Health Service (NHS) in the United Kingdom. The community matron role arose in an attempt to reduce hospitalizations and emergency room visits as a cost containment effort. Community matron services at the patient home is paid for by the NHS, a free benefit to all citizens of the United Kingdom. Of note, the NHS home care benefits appear more liberal than Medicare benefits for American patients living with long-term conditions. The closest analogy to a community matron within the United States home care model is the registered nurse case manager who is responsible for coordinating interdisciplinary care and providing direct, temporary, skilled nursing care to patients at home. While the registered nurse case manager is not considered an advanced practice nursing role in

the United States, there is a good deal of autonomy in this position and the nurse is independent in assessing clients' healthcare and psychosocial needs in the home.

In the United States, home care nursing is provided to clients *after* an acute hospitalization, not as a preventative service. Visiting nursing/home care services are considered short-term and restorative in nature. Medicare is strict about monitoring patient progress within the prescribed care time frame to ensure individuals remain eligible for visiting home care nurses. Medicare is the primary payer of home care services in the United States for patients over the age of 65. Home care in the United States is only available to beneficiaries as a medically prescribed service following an acute change in a person's health resulting in homebound status. Home nursing services in the United States must be certified by a physician or advanced practice nurse as "reasonable", "necessary" and "medically appropriate" in order for Medicare to pay for the services rendered. This model does not fit those with intractable chronic illness who are burdensome to the health care system and require continuous care. Even though providing "ordinary" care like assistance with ambulation, helping maintain daily routines, and medication management in the home has been shown to be cost effective and socially beneficial to patients, home care in the United States is not designed for patients who are frail and require continuous support to remain in their homes. Home care services in the United States funded by Medicare is designed for patients to quickly recover and then be discharged to the family for long term caregiving. The expectation in the United States is that the family or other caregivers will assume care for their loved one and pay out-of-pocket to support frail family members so that they can remain at home if desired (Periyakoil, 2018).

In summary, the myriad contextual elements that produce and perpetuate frailty and resilience in older adults living at home are not well understood. Instruments exist that attempt to

measure frailty and resilience, but they do not provide a broad enough explanation for the different ways frailty and resilience may be expressed in heterogeneous older adults. Frailty and resilience have not previously been widely studied in older adults living at home in the United States. Qualitative study of frailty and resilience using the perspectives of home care nurses is considered a novel approach to examine these complex constructs. This research was undertaken with intent to better understand the various clinical aspects of caring for older adults receiving home care nursing and to add to the existing knowledge about frailty and resilience.

CHAPTER III

METHODS

The Research Approach

Qualitative research is widely used in nursing research as a means to understand phenomena for which we currently do not have a solid base of information. Qualitative analysis tends to be holistic and aimed at understanding the whole (Polit & Beck, 2018). Clinical constructs such as frailty and resilience are frequently studied quantitatively, but certain aspects are quite difficult to measure quantitatively and deserve to be explored qualitatively for a more refined clinical understanding. Knowing and understanding what types of nursing care and health services are most beneficial to older adults experiencing frailty and currently living at home in the U.S. is not well known. This study explored visiting home care nurses' perspectives about frailty and resilience in their older adult clients.

Prior to this study, there were no known studies that took the perspective of registered nurses working in the home care specialty into account when describing the concepts of frailty and resilience in older adults aging in place at home. Most of the current research published pertaining to frailty and resilience in older adults living in the community has been conducted outside of the United States. Previous research about frailty in this population has also been largely focused on physiologic symptoms and functional deficits. This qualitative study aimed to discover broader factors that nurses view as contributing to frailty and resilience in older adults. By describing nurses' observed experiences while conducting health care services in the homes of older adults, the data generated provided a nuanced and more holistic understanding of the phenomena. Nurses' observations of how older adults manage with health challenges in the home and what circumstances contribute to frailty and/or personal resilience were recorded.

Qualitative research is derived from the data gathered via interviews or observations of a particular population who have experience with the phenomenon under study (Polit & Beck, 2018). Home care nurses have many perspectives about how some clients manage at home while being frail, and also demonstrate resilience despite their challenges and circumstances. Using a nursing lens to describe the observed experiences of frail older people aging in place at home provided new information on this topic. The perspectives of home care nurses who regularly care for older adults identified some resources that are beneficial, what processes nurses adopt when addressing frailty in their clients, and creative ways nurses work with these older adults living in the community to optimize their health and autonomy. Gaining the nurse's perspective on managing frailty also provided valuable information about the health care system and organizational barriers that affect care outcomes for frail older adults.

Home care nurses have a unique perspective on resilience in their older adult clients. Nurses are with patients during the times when they are in high need, such as significant illness, crisis, or during a transition in care. They follow patients with chronic conditions that stress them both physically and mentally. Frail and vulnerable older adults who manage to live at home often demonstrate resilience (Nicholson et al., 2013; Warmoth et al, 2016). Home care nurses that can more effectively identify and nurture a patient's sources of resilience during stressful times and reduce their risk of becoming frail can help optimize recovery and overall quality of life for their patients. Home care nurses have experiences regarding the contextual aspects of frailty and resilience in older adults living at home. The results of the study can have implications for enhanced quality of care and suggest ways to decrease the risk of negative outcomes for patients such as hospitalization and increased health care cost.

Interpretive Description

Basic qualitative research is rich and descriptive. The primary goal of a qualitative study is to uncover and interpret how participants make meaning of their world (Creswell & Poth, 2018). The focus is not on prediction and control, but rather on description and understanding (Thorne, 2016). Interpretive description is a qualitative research method that was developed by Thorne et al. (1997) for generating grounded knowledge pertaining to clinical nursing contexts. Traditional qualitative methods include phenomenology, ethnography, grounded theory, and naturalistic inquiry—all of which have contributed to the development of interpretive description (Thorne, 2016). Interpretive description evolved because it was a qualitative analytic method that was especially suited for discovering new knowledge about clinical phenomena in the field of nursing.

Thorne (2016) wrote:

> "We desperately need new knowledge pertaining to the subjective, experiential, tacit, and patterned aspects of human health experience—not so we can advance theorizing, but so that we have sufficient contextual understanding to guide future decisions that will apply evidence to the lives of people" (p. 36).

According to Thorne (2016), interpretive description is a qualitative research approach that requires an integrity of purpose derived from an actual practice goal and an understanding of what we know and do not know using empirical evidence from all sources. Interpretive description as a method is particularly applicable to understanding aspects of clinical work and nursing practice phenomena. Qualitative research in nursing often involves description and interpretation about a shared illness or health phenomenon from the perspectives of those who live it and understand what it is like (Thorne et al., 1997). The result of a rigorous qualitative

inquiry that uses interpretive description methodology can generate new insight about a health care phenomenon. The researcher can utilize previous knowledge about a certain area of clinical practice and build upon it using inductive reasoning. Thorne et al. (1997) elaborates that interpretive description "acknowledges the constructed and contextual nature of much of the health-illness experience, yet also allows for shared realities" (p. 172). The shared realities of home care nurses who face clinical challenges while caring for frail older adults added to this body of research, and we have gained a deeper and more detailed understanding of the human condition.

Participants

The study participants consisted of 22 registered nurses (RNs) who were currently working or have worked as skilled home care nurses in the U.S. within the past five years. The home care nurses in this sample have worked in their specialty for at least six months and they all have had experience managing frail older adults in their homes. The sample of home care nurses was derived from different states within the U.S., with the majority of nurses practicing in New Jersey. The participants had a range of previous experience in other nursing specialties but were connected through their work experiences in caring for older adults who are living at home and dealing with the functional limitations of frailty.

Interpretive description does not have a specific rule for the number of participants that must participate in a qualitative research study. Upon collaboration with an experienced home care nurse who has also conducted qualitative research, it was recommended that a minimum of 20 RNs was a sufficient enough representation to describe the phenomena of frailty and resilience of older adults in their care. Thorne (2016) states that when certain phenomena occur commonly within clinical populations and what is needed is a more in-depth exploration of its

underlying subjective nature, then engaging with a small number of individuals with experience will produce information worth documenting. The perspectives of the sample of nurses were compared and examined to elicit their views about how frail older adults manage at home, and what makes some older adults resilient (or not) while they are coping with frailty.

Purposive sampling

Purposive sampling was utilized in this study. It is defined as the intentional selection of informants based on their ability to elucidate a specific theme, concept, or phenomenon (Robinson, 2014). Purposive sampling is a type of convenience sampling where research subjects are selected if they meet the criteria for the study and are willing to participate. The selection of individuals to participate in a purposive convenience sample is based upon their knowledge of a particular phenomenon for the purpose of sharing their knowledge. In this research study, convenience and purposive sampling was used to find experienced home care nurses to be interviewed. Potential participants were recruited via professional collegial relationships who then referred their home care nurse colleagues to participate in an interview with the researcher. Research participants were also asked to refer other nurses who meet the criteria for this study, so more subjects with home care experience caring for older adults could be included. This type of convenience sample is called snowball sampling (Polit & Beck, 2018) and led to recruitment of more nurses who met the criteria to participate in this study. Initially, contact information of a few potential research participants was obtained from former professional contacts, from solicitation on a home care nurses Facebook organization, and on LinkedIn, a professional networking social media site. Selection of participants was made based on a willingness to share and articulate experiences in caring for older clients receiving home care nursing services.

Selection of setting and procedures

Due to ongoing physical distancing guidelines mandated by most local governments related to the COVID-19 pandemic, video conferencing was the preferred method for conducting individual interviews. This study implemented a video conferencing application called doxy.me, which is widely utilized by health care professionals who conduct telehealth visits. Doxy.me is a secure telemedicine application which does not require the participant to download software or subscribe to any specific video conferencing applications. After the participant agreed to an interview either verbally or electronically (email or text message), the consent was sent. After the consent was signed by the participant and sent back, the researcher sent a personal "link" to the "waiting room" via email or text on a cell phone. The participant then clicked the link to connect with the researcher for the interview. The time and place of these video conferencing interviews was mutually decided upon between the researcher and the participant. The video portion of these conferences was not recorded to preserve the privacy of the participants. A secure Wi-Fi connection was utilized for additional security and privacy for the participants. Audio recording took place with a handheld audio recording device held next to the computer during the interview. It was a machine owned and accessed only by the researcher. Audio data from interviews was only played for transcription and analysis purposes.

One interview was conducted via telephone due to the personal preference of the participant. One research participant was unable to connect to their video camera on their laptop during the interview, but the interview was conducted via the doxy.me platform using audio only.

Gaining Access and Establishing Rapport

Having worked as a home care nurse in the past and having many professional contacts through previous work and academic settings, I was able to access home care nurses living in northern New Jersey. I was later also able to have home care nurses from Michigan, Missouri, New York, North Carolina and South Carolina participate due to snowball sampling and from shared participation in the "Homecare Nurses Rock" Facebook group. My experience in the specialties of home care nursing and gerontological nursing helped me to establish a rapport with study participants. From my understanding of the nature of the work being done as well as the challenges and complexities of care that must be provided, I was able to create an interview guide (Appendix A). The questions were reviewed with another experienced home care nurse for veracity. Through reading literature about frailty and resilience in older adults as well as the aforementioned collaboration with a seasoned home care nurse, it was determined the interview guide had meaningful and relevant questions for the home care nurse interviews.

The Question of Bias

Throughout the research process I acknowledged any previous ideas that I had about older adults living with frailty and receiving home care nursing services from prior professional experience. I consciously considered my views on resilience and frailty in older adults so that I could appreciate the participants' narratives from a neutral position. I was able to keep a journal to reflect upon my own background and thoughts in an effort to remain impartial during my data collection. This reflective journal was a useful reference as interviews and data collection progressed. The journal also provided a place to put personal opinions and prior nursing perceptions that would possibly interfere with data collection and interpretation.

Ethical considerations

The nurse participants were informed about the purpose and content of the study. They were informed that neither they nor their place of work would be identified. Participation was completely voluntary, and subjects were informed that they could withdraw from the research at any point in the study without explanation. The principle of protecting human subjects was honored by obtaining a verbal and/or written informed consent prior to enrollment into this study (Appendix B). Institutional review board (IRB) approval through Seton Hall University was obtained prior to starting this research study (Appendix E).

Participants were informed about the aim of the study, any potential risks of participation, any possible benefits to themselves or others that result from participating, that the interviews were to be audio-recorded, and that measures were to be taken by the researcher to protect their confidentiality. Interviews were conducted in a private place and audio data was not linked to the participant's name. A pseudonym and a numeric code were assigned to each audio file. Upon transcription, the written data was de-identified from the nurse participant's name to protect privacy. A pseudonym and a numeric code were assigned to the transcript which matched the audio file name. Audio data was saved on a USB key drive device by the researcher. All paper documents and audio-recorded data were and continue to be kept in a locked and secure location, accessible only to the researcher. Following completion of the study and upon graduation, the transcribed data will be stored for a period of at least three years in a locked file cabinet located in the locked office of the dissertation committee Chairperson. Only the researcher, Dissertation Chairperson, and dissertation committee will have access to interview data and audio recordings.

No distress or harm to the subjects was experienced as a result of their participation in this study. Likewise, no direct benefit to the participants resulted from participation in the study.

Study participants were given the researcher's email address and cell phone number and instructed to contact the researcher should they have any questions or concerns regarding their participation. All of the participants' questions were addressed immediately by the researcher during the interviews and there were no follow up conversations after the interviews were completed.

Data Collection and Analysis

As the researcher, I became the instrument through the collection of narrative data derived from the research participants during the interview process. In a qualitative research study, the researcher is the primary instrument for data collection (Creswell & Poth, 2018). The primary goal of this research design was to understand the perceptions of others regarding a problem, phenomenon, or concept. Semi-structured interviews allowed for the participants to describe their own interpretation of the issue being studied. Interviewing 22 home care nurses generated large quantities of data that provided a reasonable amount of exposure to many varied perspectives on the phenomena.

A set of open-ended questions was prepared in advance to be used as an interview guide (Appendix A). The questions were developed based on the researcher's professional knowledge as a former home care nurse having clinical experience with older adult clients. Depending on the participants' responses and the need for the researcher to further explore narrative comments, additional related questions were sometimes added for clarification. Interviews were audio recorded for the purpose of review by the researcher. Audio recordings were transcribed verbatim by the researcher as soon as possible following the interview. Field notes containing narrative data were written by the researcher promptly following interviews and notations were made about researcher observations and participant non-verbal communication during the

interview. Inconspicuous note taking occurred during the interview to add observations made by the researcher during the interview. Audio recording of interviews were played back by the researcher afterward to further extract and clarify narrative data to add to field notes and transcriptions. Interviews between researcher and participant occurred once, and the duration of each interview ranged between 40 and 65 minutes.

Interpretive description was the inductive analytic approach that was utilized in this study. Interpretive description is used to create ways of understanding clinical phenomena that may yield potentially useful implications for application (Thorne et al., 2004). It is a useful research method in dealing with complex and experiential questions in clinical and health-related practices such as nursing (Sandelowski, 2000; Thorne, 2016).

Thorne et al. (2004) stated that interpretive description:

> "provides a grounding for the conceptual linkages that become apparent when one attempts to locate the particular within the general, the state wishing the process, and the subjectivity of experience within the commonly understood and objectively recognized conventions that contemporary health care contexts represent as the temporal and symbolic location for health and illness." (Thorne et al., 2004, p. 2)

Constant comparison from note taking procedures was followed. The data collected was systematically reviewed and the words generated from the semi structured interviews of home care RNs was transcribed from audio recordings of each participant's response. Multiple subsequent reading of the data was employed by the researcher to generate categories from the words' relevant meanings, relationships to each other, and contexts. Earlier narratives and notes were compared to later narrative data for comparison in order to search for similarities, differences, and varieties of meaning. The process of inductive reasoning took place through

constant comparison of the data, where the narrated perspective of each participant was synthesized and organized by the researcher into categories or meanings. The categories were further organized and refined and newer data was compared to older data throughout the study. Dialogue with an experienced qualitative researcher who also had home care experience facilitated data analysis by discussion of the development and interpretation of findings from the study.

Lincoln & Guba (1985) stated that the process of constant comparison stimulates thinking from the researcher to develop categories that are both descriptive and explanatory. Concepts become further developed from the researcher coding and analyzing simultaneously, which integrates the categories into a coherent whole (Lincoln & Guba, 1985).

Qualitative data analytic software called Otter.ai was utilized to transcribe audio data. This program was able to generate a written transcription from audio data played into the researcher's laptop computer. The researcher listened again to the recorded interview while the software generated transcripts. The researcher read along on the computer screen while the audio was played into the computer which provided the opportunity for the researcher to edit and correct any transcription errors made by the software program. It also provided another opportunity to fully listen to the interview again and make further field notes for later analysis. Written transcripts and audio data were stored on a USB drive.

Rigor

Ely et al., (1991) stated that conducting trustworthy and credible qualitative research means that the processes of research are carried out fairly and represent the experiences of the people being studied as closely as possible. Concern for trustworthiness was paramount throughout this proposed research study. Ensuring that methods and procedures were carried out

in an ethical manner while protecting privacy and accuracy of the data are part of the rigor of qualitative research (Ely et al., 1991). While the terms reliability and validity are associated with quantitative research, trustworthiness is the appropriate term to describe standards of rigor in qualitative research. As the researcher, I took great effort to adequately represent the narrative data in a manner that supported credibility, dependability, and confirmability. Credibility refers to the idea that the claims the study makes are consistent with how the study was conducted (Thorne, 2016).

Collection of data from home care nurses working in a variety of agencies and geographic locations allowed for comparison from a variety of narrative sources. Dependability is a term used to describe the degree with which the research procedures and reports of findings are well documented so that the study can be followed by another person (Sandelowski, 1986). Confirmability refers to reflective behavior of the researcher so that pre-conceived ideas do not interfere with the data collection and interpretation. Representing the research subject's 'reality' by way of actively listening to the interviewees' responses was supported throughout the study. Interviewing subjects from varied home care agencies and geographic regions as well as keeping a reflective journal to bracket my opinions and feelings about the narrative data contributed to confirmability of the study. Keeping audio and written records produced verifiable and traceable evidence of detailed data collection and analysis. Member checking, or participant validation of the accuracy of my interpretation of the narrative, was performed at the end of each interview to summarize and assure that information obtained from participants was accurately understood and recorded. No participants in this study contacted the researcher for any reason following their interview, but the researcher's email and cell phone number was provided in the event there was need for further communication.

CHAPTER IV

FINDINGS: HOME CARE NURSES' PERSPECTIVES OF FRAILTY AND RESILIENCE IN OLDER ADULTS AGING AT HOME

Introduction

The aging population is associated with an increased need and use of formal home health care services (U.S. Department of Health and Human Services [HHS], 2020). Many patients who require home health services are experiencing frailty either due to some disease process or a reduction in their baseline level of functioning which is interfering with their recovery from an acute illness. Frailty is associated with dependency and poor health outcomes such as hospitalization, institutionalization, and premature mortality (Rockwood & Howlett, 2019; Rockwood & Minitski, 2007; 2011). This chapter provides an overview of the complexities, subtleties, and challenges home care nurses observe in older adults receiving home care who are experiencing frailty. This chapter also discusses the phenomenon of resilience and how this mitigates and influences the experience of frailty in older adults. Resilience is associated with greater health and sense of well-being (Wild et al., 2011). Frailty and resilience in older adults are complex constructs that influence a person's potential to remain living at home in later years (Nicholson et al, 2017). Home care nurses are in a unique position to provide holistic health care within a patient's home.

This study included 22 home care nurses who were interviewed to gain their perspectives about the phenomena of frailty and resilience experienced by older adults living at home and receiving skilled home care services. The study participants were currently working or have worked as skilled home care nurses in the U.S. within the past five years. The home care nurses in this study have worked in their specialty for at least six months and they all had experience managing frail older adults in their homes. The nurses who were interviewed practiced home

care nursing from between 2 and 39 years, and six of the nurse participants held advanced degrees; either a Master of Science in Nursing (MSN) or a Doctor of Nursing Practice (DNP). The sample of home care nurses was derived from six different states within the U.S., with the majority of nurses practicing in New Jersey. The nurse participants had a range of previous experience in other nursing specialties but were connected through their work experiences in caring for older adults who are living at home and dealing with the functional limitations of frailty. The nurses described how they recognize and manage frail patients and how they view patient resilience as an attribute that often mitigates and slows the onset and progression of frailty. Semi-structured interviews provided valuable information about patient care challenges, health care system barriers, and highlighted strategies that nurses use to care for frail older adults living and receiving health care in their homes.

Nurses' perceptions and descriptions of frailty

The nurse participants in the study identified many common characteristics of frail patients under their care. Nearly every one of the nurse participants in this study viewed frailty as prevalent and to some degree a natural part of life as one ages. Two nurse participants in this study who happen to be certified gerontological nurses felt that becoming frail was not "normal" aging. Physical or functional attributes used to describe an older adult who is experiencing frailty were "debilitated" ,"dependent on others for care", "weak", "fragile" and "vulnerable".

> It's usually someone that lives alone, and they're just very vulnerable because they don't have the strength and resources to take care of themselves, and they rely on other family members for the help, and they are very vulnerable. They are not always getting their needs met, for like basics, like food, being able to take care of themselves, like even a shower" (Nurse Ross).

All of the nurse participants who were interviewed stated that caring for frail older adults in the home care setting is common and frequent in their practice. They were all able to recollect

and describe situations and cases where they were responsible for the care of an older adult experiencing frailty. Frailty among older home care patients is complex according to many of the nurses who were interviewed. While all of the nurses described physical components of frailty, the majority also reported that frailty can also be psychological or related to social and financial circumstances. The nurses perceived frailty holistically, and described physical, functional, psychosocial, emotional and spiritual attributes of this condition in patients.

Physical attributes of frailty

Nurses described frail older adults as being thin, fragile, and weak. All nurse participants painted a picture of frail older adults as a person with diminished mobility, strength, and endurance to perform their daily functional tasks. Nearly all of the nurses interviewed mentioned poor nutrition as an underlying characteristic of a frail older person. Most of the nurses interviewed thought that poor nutrition was a major underlying cause of weakness, lack of energy, delayed recovery from acute illness, and difficulty with self-care observed in their frail patients. The causes for malnutrition were complex and multi-factorial. Older adults with frailty were described as having inadequate nutrition due to poor appetite, low intake of nutritious foods, difficulty preparing and eating nutritious food, or interference from their underlying disease process including symptoms or medication side effects.

All of the home care nurse participants stated that physically frail older adults had significant mobility issues. Trouble walking, difficulty moving safely in their living spaces, and having low endurance for any physical activity were common attributes of a frail person. Being homebound, a requirement for receiving home care services, is often caused by poor mobility and low endurance. Leaving the home for any reason requires significant help to protect a patient's safety and because of the taxing physical effort required to go out. Homebound older

adults that qualify for home care services frequently suffer from a sub-optimal nutritional state and impaired mobility.

Functional attributes of frailty

Nurse participants who provided care to frail older adults described that the majority of these individuals required substantial functional support in order to live safely and comfortably in their homes. Many patients were described as being partially to fully dependent on informal caregivers, like family members, in order to remain at home. Patients who were described as frail frequently needed assistance with their activities of daily living (ADLs) which include dressing, feeding, performing hygiene, and toileting oneself. Frail older adults were also described as having significant problems with higher order tasks called instrumental activities of daily living (IADLs). Performance of these higher order functional tasks are essential to being safe and independent at home. Examples of IADLs include shopping, cooking, using transportation, managing money, and having satisfactory executive functioning to be independent. A common descriptor of functional impairment due to frailty was: “It’s someone who needs a great deal of assistance in the home, somebody who has issues with mobility, someone who has issues with completing ADLs and IADLs” (Nurse Florio).

Many nurse participants commonly stated that when they identified functional problems or safety problems for patients, they would make recommendations for interdisciplinary services they could provide from the agency. These included physical and occupational therapies, social workers, and home health aide assistance. A majority of the nurse participants described frail older adults as being at high risk for exacerbation of their chronic illness and potential for injury due to the heavy burden of diminished physical mobility and functional impairments.

Psychosocial attributes of frailty

Lack of advance care planning and adherence. Frail homecare patients were perceived by over a third of nurse participants as being "unprepared for the future". They lived in homes that were not conducive to living independently as an older person with functional or mobility issues. Many home environments had steep stairs, poor lighting, and clutter. Homecare nurses stated that an inadequate home environment made people even more frail, because it was difficult for patients to move about safely or use assistive devices that would promote independent walking. Safer mobility in the home could help patients build endurance. Frail older adults who wished to remain in their homes often did not have the money to make necessary improvements and updates. More than one third of the nurse participants stated that sometimes patients just "want everything to stay the same" and would resist recommended care and would not make suggested home modifications despite having the finances to do so. They were resistant to adapting to their older bodies and accepting their older selves needing a more practical and comfortable home environment to live safely.

> They are making themselves more dependent by not doing what they should be doing to help themselves. That's how people become frailer because they are not trying or they have gotten to the point where they're not recognizing how frail they really are (Nurse Connor).

A patient's denial of deteriorating health and functioning was discussed by more than half of the nurse participants who were interviewed. Home care nurses who took care of these types of patients perceived that patients who did not accept the reality of their situation often did poorly because they did not partner with their home health providers or follow the prescribed plan of care.

Nurse Long said, "a lot of times I'll just tell our patients, like, you've tried it your way for "x" amount of time….give me a month of my way, and then we'll talk again and that's when,

you know, you tend to see a lot of improvement". Nurse Long also described that many frail older adults could benefit from palliative care or have a plan for hospice type care for future planning.

> Sometimes I tell my patients this is as good as I can get you, but I can get you more if you'll let me bring in palliative care because not only can I help you, but I can help your family and you're going to live longer, you're going to be happier and you're going to be better (Nurse Long).

Nurse participants described that homebound older adults trying to remain at home were often "unrealistic" about being able to age in place in their current environments. Many patients were described as not having enough resources including frequent caregiver support, adequate home modifications, or equipment-- which presented a safety risk. This increased safety risk puts patients at a risk for a fall, injury, or health complication which would increase their frailty. Nurse Krug described he has cared for older adults who are "adamant" about being at home, yet do not want to adhere to the recommended plan of care or make recommended safety and environmental modifications given by the nurses and therapists.

> A lot of times these patients are their own worst enemies. They get up without their walkers, they'll just ignore everything that they've been taught and they put themselves at risk to fall. They put themselves at risk to bottom out with their blood sugars, um, not wear their oxygen, not wear their CPAP, just all the things that go along with good health overall. And the non-compliance is the reason they were in the hospital in the first place and when they get home, they just continue to do the same thing (Nurse Krug).

Lack of adherence to the recommended the plan of care given by the home care nurse was viewed as a trait that accelerated frailty in patients by over half of the nurse participants. Many of the homecare nurses stated that frail patients commonly refused the services being offered and often needed to be convinced that they required more help. It was also common for older adults to defer recommended assistance to a time when "they really need it". The nurse participants sometimes felt like home was not a suitable place for some frail older adults to be

because they required more help and support than could be provided by the agency or caregivers. Home care nursing is a short term temporary service covered by Medicare. Any ongoing support for frail patients living at home past the care episode must be set up prior to discharge from the agency and then paid for out-of-pocket by the patient. Approximately one third of the nurses described patients who don't really see themselves as frail and subsequently do not ask for or accept recommended help. These patients seem to be unrealistic or in denial of their functional losses. In these situations, the nurse participants stated that they try to talk about things besides the patients' health at first, to get to know them as people. Knowing the patient is important so the nurse can personalize care, build trust, and establish a relationship. Once they have developed a rapport, the nurse can then try to get patients to accept recommended services. Nurses reported older adult patients often declined or did not ask for help from others because they said they did not want to "be a burden". The nurse participants perceived that frail older adults have difficulty coping with a loss of independence. Approximately one third of the nurse participants viewed denial of frailty or difficulty coping with it as "human nature". They understood that people wanted to do everything on their own like they always did, and often did not think of themselves as needing substantial help. More than half of nurse participants stated that it often took a crisis or a significant health setback to get patients to acknowledge they needed help.

Nurse participants frequently reported that they perceived "non-compliance" or "non-adherence" with a plan of care as a type of weariness in the patient trying to manage their health. Nurse participants frequently described that many frail older adult patients have multiple co-morbidities and they get "tired" of managing it all. Sometimes the mental state of the patient contributes to a feeling of defeat, and that there is no need to continue trying or striving for better

health. Nurse Inez described that some patients express to her "I'm done", meaning they are tired and do not wish to fight to restore their health. Nurse Inez stated:

> There's really nothing for them to fight for because a lot of people, like if there's nothing, if there's nobody to see how well you're doing, you're alone and you're isolated they're like, 'what's the point'? People tell me 'I'm so upset that I woke up today'….ugh.

Poor adherence or compliance is often thought to be most associated with a lack of patient knowledge, but more than half of the nurse participants reported that they thought patient non-compliance or non-adherence was due to poor mental health which increased frailty in their patients. Not caring about oneself due to poor mental health led to poorer physical health, increased frailty, and in some cases earlier than expected death. Nurse Jones gave an example in one of her clients who lived alone, had persistent mental health issues, and a lack of social support.

> He was non-compliant with his medications and non-compliant with following up with a specialist, and he was given all the services he could possibly receive at his fingertips but he chose not to continue because he was non-compliant and I feel like that led to his disease progressing and he ultimately, he did pass away a lot sooner than what was expected. I think there was just so many issues going on and I think he just really gave up (Nurse Jones).

Cognition and mental health. At times, a home care nurse was the first professional to pick up on memory problems because of their holistic assessments conducted in the home. The recognition of poor functioning and safety concerns within the home provided subtle contextual information about the mental health and cognitive frailty of the patient. Sometimes family members are not even aware of the patients' tenuous home situations and they may be in denial that there is a cognition problem. Over one third of nurse participants stated that dementia can make frailty worse and put a patient at greater risk for having a problem that could lead to frailty.

> A lot of times people do not recognize dementia, it happens so slowly that caregivers in the home don't realize it's happening or God forbid, if that elder is living on their own. Literally, I saw a case where a woman was feeding laundry soap to the dog because she

> had a box of laundry soap she thought was food. Dementia and memory loss will really have a negative impact on their ability to care for themselves and keep themselves in good shape…(Nurse Viola).

Furthermore, mental frailty as a result of dementia was described by nurse participants as complex, requiring holistic intervention and planning. It is not a simple plan of care that can be resolved with a few skilled home care nurse visits and often involved setting up long term caregiving and out of pocket services for patients and families.

Social isolation and loneliness. Many nurses described psychosocial and emotional characteristics of frailty such as "loneliness" "isolation" "feeling helpless" "feeling sorry for themselves" and "feeling hopeless" in their patients. Many frail patients were described as being depressed and struggling to live the way that they wanted. Poor mental health contributed to a person becoming frail. Poor mental health also made them less able to deal with their frailty.

Social isolation was a common theme for those experiencing frailty, and all of the nurses interviewed noted that the condition of frailty is worse for those individuals without a dedicated caregiver or regular social contact, like family. Nurse participants stated that social isolation frequently leads patients to feel sad, lonely, and contributes to poorer cognition due to lack of mental stimulation. "Someone is frail in their mindset or their outlook……[they are] hopeless, dependent, there may be no reason to go on….maybe all of their siblings have passed, and friends are now passing, and it's just them" (Nurse Scott).

Loss of social contacts was a common observation of nurses taking care of frail older adults. Often these frail patients have unmet needs because of their isolation, which worsens their frailty. "It spirals and makes them even more vulnerable" (Nurse Ross).

> I definitely think in a lot of ways I do think as people age and maybe lose their independence, and they're not able to drive, I think there is a frailty in a way because they lack socialization or interaction (Nurse Hart).

Social contact could be an informal caregiver such as a family member or spouse. These caregivers look after the well-being of the patient and give them regular support. Nurses also described formal caregivers, like home health aides, as being a consistent source of social contact that can also make a difference in a patient's outlook and level of frailty. Sometimes a home health aide or visiting nurse is the only social contact for a patient. Formal caregivers may be the only people who care about that patient or make them feel loved. This type of intermittent social contact was important to frail older adults. Having a home health aide who focused on caring for a frail older adult was very beneficial for patients without regular social contact, even if they only provided care for a few hours per week.

The COVID-19 pandemic was frequently mentioned by nurse participants as a barrier to social contact for vulnerable frail older adults confined to their homes. The restrictions put in place when COVID-19 began accentuated already existing social isolation for many homebound older adults receiving home care. Nurse participants described witnessing a decline in the mental well-being and cognitive functioning in their patients during the height of the pandemic. This contributed to the acceleration of frailty in older adults.

> I used to see a lot of patients in assisted living, you know, during COVID. Everybody just had a little bit of memory issues. Now, they have a lot of memory issues. If they had difficulty walking, now they are two person assists. It's the isolation and inactivity….they are almost like "why am I here, to just sit in my room all day?" I think they just started to give permission to their body to like, 'go'….like, who wants to live like that? (Nurse Inez).

Patients who were living with someone in the same household or who had some social contacts during the pandemic had a better time coping than patients who lived alone. Being able to interact with someone regularly and feel that there was support from someone who cared about them was beneficial to older adults. All of the nurse participants thought that social

interaction with others, either formal or informal caregivers, helped to slow the functional decline and progression of frailty in older adults.

Mental well-being and depression were mentioned by more than half of the nurse participants as being very important factors influencing frailty (and resilience) for older adult patients. Nurse participants consistently described cognitive status and mental health issues as important factors in performing ADLs and IADLs. It also influenced adherence and acceptance of the patient's plan of care. A patient's cognitive and emotional state had direct impact on their health and relationships which had to be addressed by home care nurses often. Sometimes nurse participants stated that they were the first health care provider to acknowledge and address emotional or cognitive health problems. Patients frequently do not report cognitive or emotional problems. "They're embarrassed and they sure as heck are not admitting to it, or they don't see it because it happens to them gradually, so they're not seeing the decline" (Nurse Florio).

Nurse participants were able to pick up on problems as they spent time delivering care to frail patients in their homes through observation, conversations, and seeing functional deficits first-hand. Homecare nurses observe the way a patient is functioning at home and use this as an indicator of cognitive and mental health problems. Outside of the home, a health provider must rely on patient self-report, and a functional deficit may be an overlooked and underreported problem. More than half of nurse participants reported that a frail patient's cognitive health also influenced their receptivity to care. Good mental health was described as essential to the effectiveness of patient teaching as well as patient openness to suggested interventions made by the nurse.

> There's depression and they just don't have even that will to keep them wanting to continue in life. [Said rhetorically] "I'm 87 years old, like, why am I still alive? I don't have anybody. I don't have family" I think it makes it really a drag…. (Nurse Jones).

Resilience

Resilience is a personality trait or a learned skill that people often develop after living through hardship, stress, and personal challenges. Older adults who suffer from acute or chronic health conditions often demonstrate resilience as they try to live with various physical, functional, and psychosocial issues associated with illness. All of the nurse participants reported that they often witnessed older adults exhibit resilience as they cope with illness and frailty. Several of the nurse participants shared stories and gave examples of how resilience was recognized as a strength of a patient and how the nurses attempted to foster that quality while delivering nursing care.

Nurses describe qualities of resilience

The nurse participants in this study were asked about their experiences when caring for older adults who demonstrate resilience. All of the nurses that were interviewed were able to recollect caring for older adults whom they thought were resilient and they gave many descriptions and characteristics of older adults experiencing resilience. The most common responses to the question of how to describe resilience were being “able to bounce back” “wanting to get better” being “motivated to get better” ,“being realistic with goals”, “engaged” and “willing to let others help”. “Like sometimes it’s amazing like how the human spirit can just move the person, one person moves forward where another person could have the same circumstances and just crumbles” (Nurse Ross).

Resilient older adults receiving home care were described as wanting a good quality of life and therefore were willing to participate in the plan of care. Many of the nurse participants thought that resilience was a personality trait, but it could be influenced by a supportive

environment. “If they still have goals, they seem to be more resilient and if they still have the things they enjoy in life, it kind of gives them the WILL” (Nurse Gordon).

Nurse participants were able to identify clinical situations where patients demonstrated resilience and most of the nurses stated that resilience was influenced by culture, background, previous lived experience, and significant relationships with people who supported them. Older adults who demonstrate resilience “keep themselves mentally stimulated, active, have tenacity and willpower and they are willing to push and do things for themselves” (Nurse Connor). Nurse participants observed that resilient older adults had “a lot to look forward to” (Nurse Everett). They described having regular social engagements, staying active mentally and physically, and trying to do all the things they were used to doing promotes resilience.

Many nurse participants reported that in order to impact a patient’s ability to be resilient, the patients must listen to the nurse, adhere to the plan of care, and be open to letting other people help them. Being resistant to care and the suggestions made by the nurse was described as interfering with patient resilience.

> Resistance to medical advice….not taking meds, not using safety measures, not calling for help, all of that contributes to problems that lead to frailty. Resistance [to our help] is like anti-resilience, and acceptance of your situation is a form of resilience (Nurse Connor).

Psychosocial aspects of resilience

Most of the nurses interviewed believed that resilience was a personality trait and not an entirely learned skill. People who appeared resilient were seen as “positive”, “open to trying things”, “happy”, “spunky” and “a joy to be around”. Resilient people were observed to “move forward”. People who were deemed to have low resilience were those that “felt sorry for themselves”, “helpless”. When faced with adversity “they don’t know where to start”.

Nurses stated that they worry less about resilient patients who are discharged after their homecare services are over. Resilient patients are "not going to fall apart" (Nurse Ross) and they will likely continue to get better after discharge.

> I do think, I mean, not to overuse the word resilience, but the reality is that they have had that behavior all their lives, by keeping perspective you could have the glass half full kind of person and the glass half empty and if their spirit is wanting to see that, that makes a huge difference in people's resilience and frailty. Like, so you are still physically frail but from a psychosocial perspective, you're definitely more engaged in your care…So I do see resilience as a huge, huge positive (Nurse Florio).

Nurse participants frequently stated that mental health and cognition in a patient influences their ability to be resilient. "It's a frame of mind, for somebody to embrace where they're at…accepting, accepting where they are at and having a mindset of 'you know what, I got this' and just having a positive take" (Nurse Donalds).

Nurses support resilience

Most of the nurses interviewed described that characteristics of resilient older adults were intrinsic qualities, or personality traits. There were several nurses who also thought that a person could become more resilient with the support of a nurse. Nurse participants explained they can help an older adult become more resilient by building a professional relationship of trust. Patients who felt unmotivated to try the nurses' suggestions regarding care were not viewed as resilient by several nurse participants. Nurses frequently described "setting the stage" when a patient came onto homecare service. They meant that early on in the episode of care, the nurse explained things and spent a great deal of time assessing individual needs and providing patient and caregiver education. They also referred to using their "soft skills" during patient communication. The nurse participants emphasized the importance of taking time to get to know the patients' personal interests, preferences for care, and personal goals in the first few home visits that the nurse makes. Spending time getting to know a patient and a family helped the

nurses plan well and anticipate needs. The rapport that is built while visiting a patient at home was seen as valuable and necessary to promote patient resilience. It took time and skill on the part of the nurse, but the rewards and outcomes were seen as much better when a rapport for care was established. According to the nurse participants, getting to know a patient, building the relationship, and working together with patients and caregivers was necessary to support resilience. Strategies to help these kinds of patients are to be a "cheerleader" and to show that you care so the person is motivated to try to get better. Nurses who observed older adults who are resilient said they had people around them that "cheered them on". When patients did not have family and friends for support, the nurse became the "cheerleader" for the patient and this was described as influential in a patient being resilient.

Nurse Hart discussed that home care nurses can help change a person's mindset when they feel defeated by their medical condition and think that they may never get better.

> I had this patient, he was a spina bifida patient who was extremely debilitated, he got a caregiver in the home through the program. When I saw the picture of the guy's wounds, I mean, I never thought we could get these healed, ever, like wow--and a nurse on my team went in there and she's like, 'This is no big deal. We got this'. Yeah, she is really that cheerleader and that mindset really puts the patient in a different place. Sometimes it's the little things that we do that really go a long way that just gives the patient that confidence to be like "okay" when they feel overwhelmed, small things we do can really help the big picture" (Nurse Hart).

More than half of the nurses who were interviewed also mentioned that nurses have the ability to motivate patients and help them be resilient. Although nurses could support resilience in a patient, it ultimately had to come from within the patient.

> "Bringing the person to a positive space is something I do all the time, but I'm spiritual, like I have found that like if they're in a negative self-talk space….I will often say at the end of our visit, I will say 'would you like to pray?' and no one has ever said no in like 40 years….I do think it's very therapeutic for patients to have somebody talk to about whatever…" (Nurse Florio).

Nurse Krug described a case of a patient whom he viewed as resilient. This patient had to take home intravenous antibiotics and the nurse said:

> We only had 'x' amount of visits to show him how to do it- and you know, at first he was being resistant, you know, saying: "I can't do this, I am not a nurse" yada yada yada, and finally we got through to him and then he realized he could do it with good reinforcement. He did great! You know, he had a good recovery but only because he took the initiative to do it. And it just takes time, and they get it. I tell him 'It belongs to you and you are going to have to maintain it, it is 100% on you' and once they get that, they tend to do better (Nurse Krug).

All nurse participants emphasized that they spent a great proportion of their home visit time providing patient and family education. Patients are given a lot of support and taught to perform self-care through education. Positive feedback and support given by the nurse and the healthcare team was seen as enhancing patient and family caregiver self-efficacy which nurses perceived as resilience. This empowered patients and gave them personal agency to manage their health situations with more confidence and helped them adhere to the plan of care. Nurse Inez emphasized that all kinds of support are essential to patient resilience.

> Support, a lot of support, we need people who are good at their jobs. Good social workers, great therapists, great nurses, a good doctor who really cares about you and helps you, we set up things, everything from transportation, medication delivery, Meals on Wheels….you know the saying it takes a village to raise a child? Well, it takes a village to bring people along for the rest of their lives, it really does (Nurse Inez).

Nurse Donalds shared an intervention to promote patient resilience.

> When you empower them with knowledge and how to care for themselves and do things they normally couldn't or wouldn't…there's never something that can't be done in nursing so we figure it out, especially in the home care setting, we pull out the dental floss and the paper clip and the gum and we make it happen (Nurse Donalds).

Barriers to Resilience

Nurse participants reported that depression and poor mental health are barriers to resilience. Nurse Viola said:

> I think depression definitely makes them less resilient. Some people don't have a diagnosis. I think depression is really underdiagnosed in elders. Doctors tend to say 'Well, let's give them an SSRI' and depression is so multi-faceted…during the pandemic we saw a huge increase and a lot of it was due to isolation.

"So many patients are depressed and those are the patients that really struggle and really aren't resilient because they're so vulnerable" (Nurse Gordon).

Several of the nurse participants also shared that they observed low resilience in clients when there was lack of support from a caregiver. The absence of having a caring person in life seemed to accentuate frailty and the nurses observed that without a devoted caregiver, patients did not care seem to care about themselves anymore. Their chances of bouncing back following an acute problem was not likely when they lacked a caring supportive person and it contributed to frailty.

> When someone doesn't have those people [caregivers] to help advocate for them and sort of give them that little push, these people are going to decline. That adds another layer of someone feeling like 'I can't physically do it' and now mentally they know they can't do it. Yeah, I think definitely when they feel loved and cared for, I do think there's a little bit more resilience for sure" (Nurse Hart).

Being both frail and resilient

More than half of the nurse participants believed that an older adult could be frail and resilient at the same time. Even if a person was deteriorating physically or cognitively, they could still have resilient qualities, even as their level of frailty increased.

> I think people want to be resilient. And their spirit may be resilient… And I do think they don't become frail as quickly, but I still believe they have co-morbidities and this contributes to frailty…they do better, but it doesn't alleviate the frailty, it just postpones it I think a little bit so I do think resilience is a significant factor in the trajectory of frailty (Nurse Florio).

Nurse Donalds explained:

> So, I just had a guy with prostate cancer and all kinds of other medical issues and he was hemiplegic from a history of CVA--I mean it was a really rough go on this guy…but he embraced where he was at. He was resilient. Is he going to get up a walk? No, but he can

> be resilient and frail and accept where he's at. He had come to that level of bravery and I think he's resilient.

Spirituality, hope, and having an "open mindset" were identified as important characteristics to have in order to be resilient following serious physical illness. "Having something to live for" was often cited by nurse participants as an attribute of an older adult demonstrating resilience while being frail.

Strategies for care

All of the nurse participants caring for older adults who are frail stated that it takes good conversational skills, often referred to as "soft skills", to be effective in nursing this population. Getting to really know who the patient is as a person was mentioned as very important by practically every nurse participant. Many of the nurse participants enjoy home care nursing because of the connections they are able to establish with their patients and the intimacy of going to an individual's home. Home care nurses enjoyed having prolonged contact over weeks or months versus just having minutes, hours, or days which is more typical in a hospital or office setting. The homecare nurses that were interviewed expressed that they took time in determining what health goals were important to patients through getting to know each unique situation. Many of the nurses who were interviewed emphasized that they provide "holistic" care for frail older adults- meaning that they always tried to understand patients' life circumstances, resources, abilities, and potential for improvement.

Several of the nurse participants emphasized allowing and teaching patients and their families to be as autonomous as possible by giving them a say in their plan of care was very important. The nurse participants stated that they ask the patient and their caregiver if they are agreeable to the plan of care that they create. This inclusion in the plan empowers patients to

self-manage as much as possible. Finding some way to connect with a patient so they can express their true selves was reported as a way to promote patient resilience. Allowing them to be a full person and not reduced to their health problems helps build rapport and trust between patient and nurse.

> I like to talk to them, even if it's not a frail person…I just have a conversation that doesn't have anything to do with why I'm there…they love hearing 'Oh, are you married? Where are you from? You have any pets?' Or if I see something in their house, like, you know we notice stuff in the house….they may have some of the Giants, or Dallas or Eagles stuff…I say 'oh, so you're a Dallas fan…' you know what I mean? People in their 70s, 80s and 90s, they really like to talk about their life right now, and what used to be, you know? (Nurse Inez).

A few nurse participants stated they spend extra time with frail older adults who are alone and lack social support.

> Some of the patients we see are just so lonely. I make sure that when I go into a client's home and I know that they haven't really seen anybody in a few days, I make sure I allot time to be there with them (Nurse Jones).

Every nurse that was interviewed had stories to tell about frail older adults who spent so much time alone and how it greatly affected their mental outlook, functioning, and ability to be resilient. One nurse stated it best: "Sometimes there is no family, sometimes we ARE the family" (Nurse Post).

Use of technology and going the 'extra mile'

Use of technology and telehealth options for care can expand services to frail older adults who need support managing their health at home. Older adults with frailty had an especially difficult time during times of mandated social distancing, which further impacted their level of frailty. A few nurses stated that they utilized some kind of telehealth platform to connect with patients in their homes during the COVID-19 pandemic. The intent of engaging with frail older adults via telehealth was to provide connection to the home care agency and continue supportive

nursing services during social distancing. One nurse participant described a community based social program that provided older adults with computers and tablets so that they could stay connected to friends, family, and medical providers. Providing access to technology can help some homebound older adults reduce isolation and stimulate cognition. Social workers and nurses often spend time setting up technology for patients and teaching them how to use it. A few of the home care nurse participants who discussed the use of technology in the homecare setting stated that it can be difficult for frail older adults to utilize fully. It could become a source of stress for patients rather than connect them, as it was intended. "Besides taking their vitals I'm looking at their pictures or fixing their phones and clearing voicemails" (Nurse Quinn).

> I think that if somebody is comfortable with technology it opens up the world for them-if they're comfortable with it. So again, to bring it to my mother [the patient exemplar]—she got a tablet, there was some kind of grant program in the city and she got a tablet. Somebody set her up with Facebook and we could Facetime with my kids and her great grandchildren and it's causing her so much stress! It's almost not worth the pleasure of seeing the kids because she gets so anxious about it! She doesn't know how to use it; she can't hear it…she says, "what buttons do I push?"…So it sits in the box (Nurse Quinn).

Many patients receiving homecare are covered by Medicare, which can be quite limiting with the amount of visits the homecare team is able provide. Often care lasts for only a few weeks and visits are as infrequent as one to two times per week. The nursing visit or time in the home is usually about 30 to 45 minutes long. Some agency nurses attempt to extend care with clients by using phone calls to check-in between visits. Providing communication and nurse access through telephone calls also helped frail older adults and their caregivers to be more independent and manage their conditions with greater confidence in preparation for the time they were discharged from homecare services. Extending care by scheduling nurse visits less frequently and providing intermittent phone calls when able allowed patients to stay on service for a greater number of weeks. Stretching out visits over a longer period of time within the 60

day episode of care is a strategy used by nurses so someone "has eyes" on the patient and they do not "fall through the cracks" (Nurse Florio). Not all nursing agencies are able to provide intermittent phone calls to patients. Some nurse participants mentioned that they worry certain older adults could have a set-back between infrequent visits unless someone is looking out for them. The agency nurses do not bill for these calls, but add occasional telephone calls as a courtesy, as a way to assess the patient, to extend nursing service, and possibly help the patient avoid returning to the hospital.

Many of qualities and characteristics of frailty and resilience that the nurse participants in this study described reflect what has previously been summarized in Chapter II, however, the findings here describe some of the broader determinants of the phenomena which are unique to the context of this study. There is a paucity of research that studies frailty and resilience in older adults who are homebound and aging at home. Social contact, mental health, caregiver support, sense of purpose, and sense of personal agency have been discussed as factors that greatly impact the experiences of frailty and resilience in older adults in this study as well as the recent literature. The homecare nurses' perspectives gathered in this study have brought forth greater detail and deeper understanding of the circumstances that improve or worsen frailty and resilience in older adults trying to remain in their homes. Descriptions about what nursing skills impact frailty were shared, and suggestions on how to best support older adults who are aging at home were collected. Chapter V will discuss findings related to the healthcare milieu and broader environmental factors that affect patient care and how that impacts overall frailty and resilience in older adult home care patients.

CHAPTER V

FINDINGS: NURSE PERSPECTIVES ON HOME CARE, REALITIES AND CHALLENGES

Introduction

Care of frail and dependent older adults with chronic conditions or recovering from acute illness at home is a major challenge for health care systems. Home care agencies provide multidisciplinary care to older adults during fluctuations in health and transitions in care, usually following a hospitalization. One of the main goals in providing skilled nursing care in a patient's home is to integrate multidisciplinary care following acute hospitalization to reduce unnecessary re-hospitalizations, emergency room visits, premature institutionalization and premature mortality. Home care nurses design and coordinate care in the home setting to restore an individual's health and function to the fullest potential so they can remain safe at home

Most Americans want to live independently and remain living in their own homes and chosen communities as they grow older (Administration for Community Living [ACL], 2022). Only four percent of Americans with significant functional disability and chronic illness are living in institutions (ACL, 2022). This means that the vast majority of older adults manage their health problems and functional disabilities at home. Older adults may be living with various degrees of frailty as they age at home. "Frailty is a tenuous state of health that is the result of the complex interplay of physiological, psychological, social, and environmental stressors that increases an older adult's susceptibility to adverse health outcomes" (Tocchi, 2015, p. 79). This definition best summarizes the holistic view that nurses often take when caring for older adult clients. One way to support older adults living at home with illness and frailty is to provide short term intermittent visiting nursing via Medicare accredited home care agency. Homecare nurses come into contact with older adult clients on a daily basis. Older adults make up approximately

82% of patients who receive skilled home nursing visits due to a new or deteriorating health condition (Centers for Disease Control and Prevention [CDC], 2023). Many older adults who receive skilled home care through a Medicare accredited agency are experiencing the onset or worsening of frailty from a sudden change in their health. In these situations, patients are expected to recover and their level of frailty is expected to improve. Some older adults receiving home care nursing are chronically frail and have had a health setback. Their underlying frailty impedes their recovery and can make nursing care at home quite challenging.

Nurse participants in this study described some of the factors that contribute to the onset and worsening of frailty in older adults living at home. One of the main research questions addressed how home care nurses describe their own experiences taking care of frail older adults at home. This included seeking a deeper contextual understanding of providing health care in patients' homes while also operating within the regulations of the current healthcare system. This chapter will explain the conditions influencing the delivery of nursing care to frail older adults within the context of a Medicare accredited agency, existing health care policies, various home and social settings, and the community resources available to patients trying to remain in their homes. A contextual understanding of the environment in which skilled nursing care is delivered in patients' homes is as important as knowing how these nurses view the phenomena of frailty and resilience in their patients. Nurses shared their perspectives on how the customs, rules and regulations governing delivery of nursing care in the home determines much of the care. This chapter will set the tone of the discussion about frailty and resilience in older adults by looking at the milieu of short term skilled home care nursing within our current healthcare system.

Future planning

Home care nurse participants in this study discussed many different patient situations to describe and illustrate their perspectives on frailty. Several of the nurse participants shared that putting a reasonable plan of care together for the short term was a challenge because certain clients need more help than what can be provided by short term, intermittent visiting nursing. "Home is not always the best place. It's sad, but really, I have seen different things that go on in most houses…It's just not safe, and it's not realistic. And sometimes it's dangerous, you know"? (Nurse Ross).

Nurse participants work with each situation to provide the best care that they can but shared that many older adults have not made clear plans about the eventuality that they may need perpetual help to live in their homes until the end of their lives. Lack of advance care planning was mentioned by about 50 % of nurse participants as contributing to declines in health and increased psychosocial stress which impacted frailty in older adult patients. Nurse Adams stated that frailty was impacted by lack of planning for the future:

> When you are in your 80s-- I don't know that I'll be able to, you know, go up and down stairs as I do right now. Maybe it is poor planning because a lot of people do not think ahead to those points in time where they may not be able to be as mobile, right, so they think they're gonna always remain the same… (Nurse Adams).

Nurse participants shared that there seems to be a lack of knowledge in the general public about how to plan well for aging, or that it is human nature to defer decisions about advance care planning because it is difficult for older adults to envision what functional losses may occur before they happen. Lack of knowledge about what people may expect when they become ill and their assumption that all of their care will be covered under Medicare has created strain for families and patients. The long term caregiving needs are not covered and many frail older adults

require ongoing formal help or supplementary help for their family caregivers which must be paid for out-of-pocket.

> People don't understand, no, Medicare doesn't pay for someone to come in and help you. People don't really research it. If the services aren't needed, they tend not to think about it until it you know, it's right, right there" (Nurse Jones).

Home care nurses usually identify whether a patient will need ongoing post-discharge care during the short and finite time a frail older adult is receiving skilled home care services. It takes time, sometimes weeks, to set up continuous care at home and families are often ill equipped to understand the process.

Nurse participants explained that older adults with chronic illnesses and frailty who are not experiencing an acute problem but are consistently having trouble managing their chronic health problems do not qualify for long-term or ongoing home care which is covered by Medicare. There are many older adults who are not doing very well at home but are not acutely ill nor have been recently hospitalized. Some nurses thought these patients may benefit from a nurse or social worker consultation to get the right services in place so they could remain at home, but currently do not qualify for skilled home care services under Medicare. They are caught 'in between'. Too frail to be at home without significant caregiver support, but not debilitated enough to go to a nursing home and not wealthy enough to afford assisted living or hired help at home.

> Many, many times home is not the right answer, but they are not ill enough to be placed in a skilled nursing facility, they are not wealthy enough to be in an assisted living facility, and now with COVID- that has contributed greatly to the isolation of people and has made people even more frail, there is no doubt about it (Nurse Florio).

Nurse Jones explained:

> It is a big issue as we get older, if you didn't save enough money or didn't have like long term care insurance, what are your options? I always say to myself like, what are our options as we get older? You have a nice nest egg so you can afford it? Or going into

> assisted living and getting you know, some care? Or third option is going into a nursing home? But really, those are our only three options in this world? Something needs to change for people who are older and can't live alone anymore. More services need to be covered because it's expensive to have someone come into the home.

Limitations of skilled home care and frail patients

There is a challenge in coordinating and accessing the appropriate level of care for older adults in their homes. Older adults wish to remain in their homes but often struggle to qualify for certain home care services, stay on home care service long enough once admitted, or obtain certain durable equipment which could support their function at home under Medicare guidelines. Many home care referrals come from community physicians or families reaching out to agencies asking for help giving care to older adults who are frail. Physicians and hospitals who make referrals to home care agencies sometimes do not fully understand how short-term home care works. This was identified as a major issue, without asking the nurse participants directly, by more than a third of those interviewed. The nurse participants had to explain to patients that referrals to homecare agencies that receive Medicare are only meant for short term, intermittent, skilled nursing care. Many frail older adults would be better served by ongoing "unskilled" personal care rendered by a home health aide rather than involving a registered nurse. There are some frail older patients who do not meet stringent criteria to have a visiting nurse provide skilled care and case management in the home, yet patients and caregivers are told by some physicians and providers that they can receive home care nursing if they are struggling to live at home. These clinicians may not understand how skilled home care is structured, reimbursed, and who may be appropriate for this service. One quarter of the nurse participants stated that they felt frustrated by referrals being made to the home care agency for cases which

did not require a registered nurse and therefore could not be considered "skilled" by Medicare guidelines.

> I feel like a lot of patients are dumped on us. They [discharge planners] don't want to deal with it so they'll just refer to homecare and no doctor is gonna say no. Doctors …they refer to us for a home health aide… it's so easy to do that from your doctor's office, yup, write a script for homecare, let them deal with it (Nurse Inez).

The conditions leading to frailty are often chronic and insidious. An older adult may have slowly declining health and gradually become frail over time to a point where they are unable to function independently. There is no acute need for a homecare nurse and Medicare determines that there is no "skill" for a nurse to provide care to someone who is gradually declining in health and ability. Nurse participants stated that physicians and many laypeople are not aware of the strict rules and limitations necessary to qualify patients for skilled home care services. A few nurse participants expressed frustration about this because they often were sent to a home to admit a patient who did not have clearly qualifying conditions for skilled home care nursing. It was a waste of their time and energy and a strain on limited staff. Some referrals are made for problems that could be managed directly at outpatient sites, or by the patient being taught how to manage themselves. Families should be educated that they must hire a caregiver directly and pay out-of-pocket for service. Nurse Inez stated that often the nurse must explain the terms of service to patients who were referred to home care. Most pre-admission referrals are accepted by the agency and it isn't until the nurse gets to the house and does a full assessment that they can see what is truly going on with a patient.

> So, we always go in to help. I mean, we explain from the beginning that this is short term intermittent care. We are not going to be there forever. So, we need to start making plans now, so you have your social workers and everyone involved and we do as much as we can in the short time we have. You talk to family members….I say 'listen, I understand your mom hasn't had a shower in a week but we are not a shower service'… (Nurse Inez).

The healthcare system impact on care of frail patients

The U.S. healthcare system is accustomed to short term acute episodic care, rather than long-term comprehensive care. Several nurse participants described that they sometimes felt a conflict about being able to continue services in the home because even though a frail patient got better while on homecare, they were still at high risk of relapse or decline once discharged.

> There is no family nearby and they're, say, an amputee… and they are there and they can't go from the wheelchair to the hospital bed by themselves. How can you [the nurse] just walk away from a person like that? But that's the person that doesn't qualify for Medicaid because they just make too much. They can't do a spend down because they need to take care of their living expenses. And it's like the ones that are caught in the middle. Don't have a lot of resources but are not below the poverty level…Those are the people that you just don't know what to do with them….there's nowhere for them to go (Nurse Ross).

Nurse Long explained:

> If they have the HMO managed Medicare and we have, like, only so many visits that we're allowed do, that's really frustrating…I don't feel like it always sets people up for success. Sometimes they just need a little bit more and, you know, you're the one seeing what they can do and how they have to do it, so operating within the confines of insurance, it's challenging.

Fragmentation of care or lack of care coordination was a problem with great impact on frail older adults. Coordinating services and planning care with limited resources in a complicated health system is difficult and could lead to delays in care. A delay in care or lack of supplies can lead to a patient becoming even more frail.

> I had a patient with esophageal cancer and she went to the hospital so they could put in a feeding tube before she started chemo treatment. Prior to the feeding tube she had minimal oral intake and she had lost a significant amount of weight. She went home with the feeding tube and the supplies did not come for a week after she was home…she was declining, BP dropping, getting dehydrated" (Nurse Gordon).

Another example of a systemic problem which contributes to frailty is poor care coordination. For example, Nurse Gordon stated:

> I have patients going into the hospital and they're being covered by the hospitalist, right, and they're supposed to be coordinating care, conferencing with the primary physicians but I don't think that always happens and, you know, they are taken off medications that they've been on for years, and then they go back home and they are uncomfortable taking the new med from a doctor they only saw for two days….it's overwhelming for them.

Nurse Krug gave an example stating:

> One of the biggest problems I see and that I really get irritated with is these SNFs (skilled nursing facilities) will discharge patients and it's very sloppy…They're [the patient] not given wound care supplies, they're not given meds, somebody has a new ostomy and all of a sudden they are at home and they were given a handful of appliances, but they don't know how to use it and the staff will tell them 'Well, home care will come in and take care of everything' and you know that isn't fair to us or the patient.

Four of the nurse participants shared that they experienced delays in getting a response from physicians who are called about their patients on homecare. Nurses out in the field caring for frail patients may call a physician to report an abnormal assessment finding or to request a treatment of some kind. Frequently there was a delay in a response to a phone call, sometimes for several days, despite multiple calls. Lack of prompt physician responses to nurses attempting to communicate vital information could lead to worsened frailty or rehospitalization for some patients. Lack of knowledge by physicians about what nursing care in the home entails was suspected to be the reason for the delay. A delay in care can result in patient deterioration which leads to increased frailty. "It's frustrating, not just the patients and the caregivers or what happens in their home is going to contribute to frailty, but also the response of the medical team" (Nurse Connor). She further explained:

> So when I call and leave a message for them, it could be days before they get back to me because to them… care at home is not emergent, right, and ok sometimes it's not emergent but you know what, right now the reason I'm calling you three times in one day is…..this is an issue, not like TED hose or something, I need you for med titration and stuff.

The amount of charting is also a burden for nurses. More than half of the nurses were very forthcoming in sharing about the expanse of time that was required for charting. Intricate software called Outcomes and Assessment Information Set (OASIS) documentation is utilized upon admission of a patient to home care to determine their level of acuity, how services will be planned, and the level of reimbursement for home health care by Centers for Medicare and Medicaid Services (CMS). It is a very involved and intricate tool which takes skill and time to complete accurately. A few of the nurses interviewed now only specialize in doing these detailed admissions to the agency rather than case managing and regularly visiting the same patients as they once did. Even as a documentation specialist, they stated OASIS takes them at least two hours to complete accurately. It requires several weeks of training to learn how to utilize the software. More than half of the nurses reported that they do charting at home after seeing patients all day. “There is no way I could stay in the home and do all that [charting], I would be there forever” (Nurse Krug). “Let me tell you, it’s disheartening that we spend 25% of our time in front of the patient and 75% of time in the computer system charting….it should be the opposite” (Nurse Donalds).

The amount of documentation that must occur to justify the need for skilled home care is becoming more and more of a burden. Nurses report onerous charting as a barrier toward getting to spend time with patients in their homes and fully understanding a patient’s individual needs. Being able to spend time building trust and rapport were viewed as highly important when providing home care to older adult clients. Short episodes of care, such as the patient only receiving a few nurse visits within a couple of weeks, limits the time nurses can spend providing restorative care over time. Services tend to end when the patient is no longer progressing quickly or insurance will no longer pay, although supportive services would still be of benefit.

> Sometimes I can feel like there's just not enough visits to be able to just be kind and compassionate. Some people just need more company, like when they first get home, just to allay their anxiety. Medicare does not pay for that (Nurse Ross).

Another participant stated:

> I wish I could sit with you [referring to patient] and listen to your stories, but the way that nursing is so short-handed now it doesn't…..the job does not allow you the time to listen to them and talk with them like they need. I don't know how to fix that (Nurse Unger).

Impact of social workers

Sixteen out of 22 nurse participants that were interviewed mentioned that social workers provided by their agencies were vital to their jobs as home care nurses. Social workers were extremely helpful in connecting frail patients with social supports and services within the community. Nurses were extremely grateful for having social workers available to help patients by putting together a plan of care or helping them to plan for personal care assistance or future living arrangements. One nurse participant stated he sometimes got "push back" from his agency managers for putting so many services in the home. He usually got a social service consult upon admission to start the process if he assessed that a frail patient may have long-term care needs.

> We have really good social workers in our health care [organization] and they can assist people whether it's with getting somebody to come into the home… 'cause usually our [Medicare accredited agency] home health aides go in for like, two visits. And then the occupational therapist kind of drives the boat from there if they need more…And even then, it's difficult to get them [insurance] to pay, so I'll do as much as I can for them and getting that social worker involved…once I do that, everybody sees that and nobody can just kind of push it aside, so to speak. Again, it is to make them [agency management] accountable more and they get a little angry at me but I don't care; I'm that advocate. I'm there for that patient to do what I can for them, especially when they're in situations where they may need food, they may need assistance with medications…I have seen some really bad situations in homes and it's really sad when you see how bad some people have to live (Nurse Krug).

Social workers could often talk with patients and get them to accept assistance for whatever functional issues they had. Social workers and nurses together can help patients and

families cope with unrealistic expectations they may have about returning to complete independence at home after services ceased. Helping patients and families accept the reality of their tenuous living situations and connecting them to ongoing community services was discussed frequently by nurse participants. The nurses interviewed emphasized the importance of social workers in the home care setting and that their jobs were made easier with the help of social workers. “I live and die by the medical social worker, I mean, some of the things they can pull off is just ridiculous, they’re incredible” (Nurse Long).

Impact of caregivers

All of the nurse participants reported that having a caregiver in the home was vital to a frail older adult being able to live at home. With the support of a committed caregiver, patients tend to eat more, move more, have increased mental stimulation, and enhanced safety at home.

> If the patient is willing to have a caregiver, a good relationship where they trust the person, they interact with them, I feel that their frailty diminishes. Now they’re eating, now they’re getting their medication when they are supposed to, now they’re getting more stimulation than they would in their home by themselves, they’re also being kept safe, somebody, they’re committed, has an eye on them (Nurse Connor).

Half of the nurse participants reported that there are not enough caregivers such as home health aides (HHA) able to serve frail patients who qualify for home care. Nurse Jones currently works for an agency that has a grant funded county wide program for chronically ill homebound and frail individuals who need assistance with their activities of daily living (ADLs).
“I think one of the issues is we can’t find caregivers…we have a stack of people who are eligible through this county grant, but we don’t have the caregivers to actually assign them to the client” (Nurse Jones).

Finding a “good” home health aide was challenging according to some of the nurses interviewed. At least a quarter of the nurse participants described home health aides who were

lacking training, who were inattentive to their patients, and did not provide a satisfactory standard of care. One nurse described having to go through many different home health aides that she hired to help care for her ill mother. As a nurse, she said that she has supervised and trained home health aides in the past, and that it was very difficult to find a caring and competent aide.

> And so having these people come into my home, you know and watching the sub-optimal care they gave to my mom…they didn't care, it was terrible. And so having to train them on how to take care of my frail mom, they didn't know what they were doing (Nurse North).

A few of the nurse participants said sometimes frail older adults do not make themselves a priority and they will not spend money to get personal care from a home health aide. Frail older adults who choose not to hire caregivers even when it would be beneficial often leads to them becoming more fragile, alone, and isolated.

> Some people don't have the money to get everything they need to get through the day, but sometimes people are quite well off but are reluctant to spend. They don't take care of themselves. I find a lot of them that are pretty well off. Their biggest concern is how much they are going to leave behind for their children so they don't want to pay the home health aides. They don't want to pay for cleaning the house, and then that burden puts them at risk (Nurse Ross).

The nurse as informal caregiver and professional caregiver

An interesting finding that came out in this study was how often the nurses who participated in the interviews described frailty and resilience using examples from their own family members. Not only did the nurse participants have experience taking care of frail older adults at home as professional nurses, but more than half also shared their experiences as a family member who was caring for an older person such as a parent, grandparent, aunt or uncle with frailty. This dual perspective acquired through assisting both one's own and another

family's frail older adult who needed caregiving at home provided a rich understanding of these nurse participants' two-fold experiences.

The nurse participants described situations involving parents, grandparents, aunts and uncles aging at home and needing various types of care and support due to frailty. Thirteen of the nurse participants spent more time describing what went on in their personal life caring for a frail older adult than what they did with actual patients during their interviews. There seemed to be a sense of affirmation when they used their personal lives and family members' experiences to illustrate the impact of frailty to older adults. They expressed frustration about finding competent paid caregivers for their family members. The nurse participants spoke of frail family members not being realistic about the level of care that they required and their resistance to have formal caregivers help them at home even when the nurse participant/family member thought it would be beneficial. This speaks to the fact that caregiving for others who are unable to care for themselves is almost a universal experience. It is very common to support frail older family members through informal caregiving and nurses are often both. Nurses have education and an understanding of the functions of the healthcare system for their professional work, but often expressed frustration with the system when it came to caring for family members. Finding trained nurses' aides, qualifying for appropriate services, convincing frail family members to accept formal help in the home were issues that many nurse participants experienced first-hand. The participants freely shared frustration about how to best support a frail older adult to remain functioning and living at home. One nurse that was interviewed described a situation she was currently having with her aunt who is aging, and who had some recent health problems.

> She can't be in the house alone anymore. This recent diagnosis (cancer) along with everything that's going on for her…it's a lot but she has always been that resilient person. She's bounced back from everything she has gone through until now. She's frail, you know, trying to get her to understand that you can't do it this way anymore. You need to

> be in a facility -and I am not saying a nursing facility- but I am trying to get her to you know, not relinquish, but let me step in, and I'll put you into a better place physically and mentally and emotionally and everything else is going to follow (Nurse North).

Limitations of caregivers

Some of the nurses expressed there was a gap in a type of caregiver service often needed by frail older adults. Often an older adult living at home is not debilitated enough to require daily or round-the-clock caregivers. They sometimes just need assistance intermittently for ADLs a couple of hours a day or a few times per week. They are not physically debilitated enough to go into a nursing home, and not wealthy enough to afford the type of care provided in an assisted living facility. Home health aides provided by a Medicare accredited agency during the time when a patient is receiving service is minimal. Often a patient will get an aide for a few hours a week for a couple of weeks only and any need for ongoing aides would necessitate private pay. Home health aides employed by a Medicare accredited home care agency have many limitations as to what types of care they are permitted to provide to patients. Some older adults experience frailty in other areas of functioning beyond needing physical assistance and bodily care. Many frail older adults living at home can manage most of their own physical care, but need the most assistance with transportation, shopping, making and traveling to appointments, using technology, organizing medications, and preparing meals. This type of executive functioning for managing a household and performing higher level tasks which are needed to live are called instrumental activities of daily living (IADLs). Needing assistance with IADLs and being homebound is often due to cognitive or mental health problems. Home health caregivers are not permitted to do many of these tasks due to limited liability and rules within their agencies. Home health aides often have a narrow scope of practice which focuses only on providing physical care

for a person and they cannot offer help for a patient who needs some assistance running a household from day to day.

> The certified nursing assistant (CNA) is medically geared, so where a person may just need a little bit of help around the house or picking up prescriptions or that type of thing, they can't do any of that. So, it's literally like get in the shower, check your feet, get dressed, and out (Nurse Long).

Home health aides may also be limited by language barriers, low literacy, and limitations in their formal training. Community volunteers can sometimes fill in the spaces and extend the caregivers' function, but nurses state there are limitations to what types of services can be provided to frail older adult who want to live at home. One nurse participant reported that older adults are often frail due to common sensory impairments like poor vision and hearing that come with advanced age. They do not necessarily have a major illness requiring a lot of physical care. This nurse expressed "many frail older adults just need help with the basic day to day things, not even big things, just the day to day…it's hard for them, where to turn, who to go to, like, who is gonna help?" (Nurse Quinn).

Limitations of services in the community

The home care nurses who were interviewed explained that frail older adults receiving home care nursing must be homebound. This means that there is either a safety risk, it is too arduous, or they require assistance of another person to leave home for any reason. Frail older adults usually experience impaired mobility. Once discharged from homecare services, lack of mobility often continues to limit function and independence of frail older adults. Mobility problems prevent frail older adults from using paratransit and community transportation services to get places. Frail older adults must be able to leave the home and get themselves to the curb so they can enter into a bus or van that will transport them where they need to go. Drivers of these

vans are not permitted to assist or touch the patients. Transportation solutions for people who no longer drive exist, but frail people who would qualify to receive transportation services often cannot utilize the service. “If they are living in high rises, it’s easier for them to get out of the home, yeah, so some of the access to services are because of the type of house they live in” (Nurse Post). Living in a home that is difficult to exit due to stairs, slope, or landscape prevents some frail older adults from using services in the community. This renders them continually homebound which worsens isolation, affects their mental health, and contributes to frailty.

The interviews with the home care nurse participants in this study revealed there are situational and environmental factors that impact frailty and resilience and these elements can greatly influence the lived experiences of patients. The home care nurse participants also reported that lack of advance care planning and lack of knowledge about the complicated healthcare system can impact a person’s level of frailty. The nurse participants described challenges in providing appropriate healthcare services to their patients and how they sometimes need to work with limited or misaligned resources. The perspectives that home care nurses provided about working within a health system or agency that was often found to be inflexible, or delivering nursing services that did not always fit the needs and circumstances of patients was illuminating. Chapter VI will analyze and interpret the factors that were identified, as well as provide suggestions for future research.

CHAPTER VI

DISCUSSION OF FINDINGS

Introduction

The objective of this study was to describe detailed contextual aspects surrounding the constructs of frailty and resilience in older adults using the perspective of the home care nurse clinician. The overarching research questions asked how nurses who provide home care to older adults perceived, identified, and described frailty and resilience in their clients. Interpretive description was the qualitative method that was utilized to gain nuanced information through the eyes of the home care nurse about how older adults live with frailty and resilience. This research study was undertaken to better understand the circumstances and conditions which led to or mitigated frailty and resilience in older adults living at home. It does not appear that any literature, up until this writing, has looked at the various contextual attributes of frailty recorded from actual observations by nurse clinicians managing acute or chronic illnesses of older adults living at home. Nor has resilience been examined and described in frail older adults living at home through the lens of a skilled home care nurse.

The perspectives of the home care nurse caring for frail older adults in their homes provided valuable descriptive data about this group of clients. The results of this study contributed knowledge as to ways in which nurses can better identify and treat patients who are managing health problems and disability while living at home.

Adaptation to circumstances, accepting one's health status, accepting the help that is being offered by the nurse and being flexible despite physical limitations were perceived as signs of resilience by the home care nurses. Older adults are often resilient despite being frail, and this

is not something that is physically visible or can be objectively measured in a valid and reliable way by currently available instruments.

Physical Frailty

The nurse participants' descriptions of physical characteristics which put older adults at risk for frailty largely echoed characteristics that are described in frailty literature such as weakness, thinness, fatigue, lack of good nutrition, poor mobility, and poor endurance (Fried et al., 2001; Lekar, 2018; Rockwood & Minitski, 2011). Frail older adults had difficulty performing their activities of daily living (ADLs) independently because of physical weakness and mobility problems. Physical frailty created many limitations for patients including causing them to be homebound, a major qualifying condition for receiving skilled home care services. The loss of weight and diminished muscle mass observed in frail individuals was perceived as being a result of inadequate nutrition and lack of mobility. Inadequate nutrition and lack of mobility also resulted from loss of muscle mass, loss of physical strength, and poor endurance when completing ADLs like cooking for and feeding oneself—a vicious cycle for older adults.

Physically frail older adults were perceived to need substantial caregiver support in order to recover well at home. Nurse participants felt that it was common that the patients' perceptions of their physical and functional abilities were unrealistic. They discussed the "human nature" of how people choose to see themselves and that patients who appear physically frail to a health care provider often did not view themselves as such. Physically frail older adults were labeled as "unsafe" to be home alone by the home care nurse, even if it was their right and their wish to be there. Nurse participants shared that patients who did not have a regular and devoted caregiver had a higher risk of poor self-care which led to poorer disease management, increased weakness, reduced tolerance to exercise, and not eating enough nutritious food; all of which led to

worsening frailty. Nurse participants voiced that patients who did not have a regular caregiver did not recover from illness as well as someone with a caregiver.

Building physical resilience

Being resilient when physically frail required the patient to accept their functional deficits and allow caregivers to help. Acceptance of one's limitations in physical strength, endurance and mobility was difficult for many patients. Nurse participants shared that it was not unusual for patients to turn away offers of help and assistance of a caregiver when offered. Resilient patients were reported to be more open to assistance and not resist the advice given by the nurse about how to maximize personal safety at home. According to nurse participants, building resilience in physically frail older adults required that they adhere to recommendations given by the nurse. Patients who were physically frail also needed to participate in physical therapy and to stay motivated to walk and do regular exercise. Nurse participants shared that they utilized their "soft skills" to build trust and rapport with patients.

The nurse participants reported that they worked to motivate patients by "cheering them on" and giving praise for doing the work of therapy. Home care nurses frequently involved social workers to help talk to patients about accepting more help in the home and setting up ongoing private pay care for when they are discharged from the agency. This strategy often improved cooperation and acceptance of recommended care by the patient. Rejection of recommendations caused frustration in home care nurses and they shared that it made managing patient cases more difficult. This sometimes shortened the time patients received home care services because they were discharged if they would or could not participate in the plan of care. The patients who had a self-interest to participate in their own care, accepted assistance, and were motivated to try were viewed as resilient despite being physically frail.

Cognitive Frailty

Nurse participants reported that difficulty with cognition impacted various domains of frailty in older adults. Being cognitively frail impacted physical frailty and psychosocial frailty because it created safety and functional problems for patients as well as impacted the patients' abilities to be socially active. Having less social interaction impacted patients' mental health, sense of well-being, and their motivation to improve health. Poorer cognitive functioning interfered with patients' ability to adhere to a plan of care, accept and retain patient education, have personal agency in chronic disease management, and perform functional tasks. Patients who experienced frailty in the cognitive domain often lacked insight about their capabilities, and this was also a potential safety risk. This was often connected to whether a patient was safe and had the ability to remain at home.

Older adults who had cognitive impairments were not able to do some of their Instrumental Activities of Daily Living (IADLs) safely, and this often led to loss of independence. A loss of independence was described by nurse participants as being very difficult for many older adults to face. Managing a household and doing day to day executive functioning tasks was such a challenge that it produced anxiety for some patients. Patients would underreport (or fail to recognize) difficulty with cognitive tasks and their lack of acknowledgment led to patients turning away offers of help and support. Patient anxiety about trying to function independently, lack of insight about their own cognitive deficits, and turning away help when offered was viewed by nurse participants to increase frailty and reduce resilience.

Patients with cognitive frailty were often not open to using newer technologies such as telehealth, iPads, smartphones, and in-home equipment to monitor health and connect with healthcare providers and family members. The ability to embrace and utilize newer technology to

manage health in the home or to connect with social networks was diminished in older adults with cognitive deficits. The underlying sources of cognitive problems are complex and multifactorial, but older adult patients with cognitive challenges were viewed by homecare nurses to not be as resilient as patients without cognition problems.

Building cognitive resilience

Cognitive resilience is difficult to build due to the complexity and various types of cognitive loss. Dementia related cognitive loss is progressive and requires significant advance care planning. Strategies that home care nurses utilized for cognitively frail patients involved educating and supporting family caregivers, anticipating risk for safety threats, and involving the social worker to help talk to the family about ongoing supportive services for the time when the patient is no longer receiving skilled home care. Involving other disciplines like occupational therapy was often initiated by nurse participants to assist patients and their caregivers to adopt self-care strategies in order to remain safe at home. While there are many innovative technologies being utilized to keep cognitively impaired older adults living at home, in many cases these tools have limitations in their usefulness over time if cognitive loss is progressive. Short-term resilience building efforts for cognitively impaired older adults may be more applicable to family caregivers so that they can anticipate and prepare for future health events and plan well before there is a crisis.

Psychosocial Frailty

Statements by nurse participants in this study described that an individual who is both physically and psychologically frail will struggle with everyday functioning more than an individual who is only physically frail. Nurse participants described common psychosocial circumstances that contributed to frailty such as lack of devoted caregivers, lack of social

support, loss of loved ones, feeling lonely, not having something to look forward to, and symptoms of depression. Losing independence and autonomy was perceived by home care nurse participants as very difficult for patients to accept. It was also perceived as having a big impact on older adults' social connections and mental well-being. Not having a sense of purpose or a reason to be motivated toward wanting better health was another theme that nurse participants mentioned frequently in the study.

Medicare eligible older adults participated in a study conducted by Musich et al. (2022), where characteristics of resilience, called "protective factors", were measured to see if higher levels of each protective factor correlated with increased quality of life, decreased healthcare utilization, decreased healthcare expenditure, and proactive preventive health action. The resilience protective factors that were measured were personal optimism, internal health locus of control, social connections, and sense of life purpose. Higher levels of each protective factor were associated with medium or high resilience in participants, but researchers found that having a sense of purpose in life was most highly correlated with a high level of resilience and better positive health outcomes (Musich, 2022). Having no perceived stress or self-reported depression were also associated with higher levels of resilience (Musich, 2022). Home care nurse participants observed that patients may not be motivated to improve health for themselves, but may be motivated to please a spouse, their children, or their grandchildren. Nurse participants reported frail older adults persisted with trying to restore and optimize their health despite frailty because they wanted to maintain relationships, participate in social gatherings, and attend family events. Nurse participants reported that older adults' social activity and maintenance of social relationships gave patients a sense of purpose which sustained their personal resilience.

Research studies have suggested that many psychosocial factors have an impact on frailty and should be included in instruments that measure frailty, but there are inconsistencies as to how to define psychosocial frailty and which of the many markers of psychosocial frailty should be included frailty measurement instruments (Escourrou et al., 2017). There are a multitude of situations that have psychosocial impact on older adults, so it is difficult to determine what factors have the most impact for people and should be measured in frailty assessment instruments. The findings in the current study did not identify which psychosocial attributes were the most important to consider in frailty measurement. If anything, it highlighted the extreme variability of psychosocial factors and the fact that they represent different things to different people depending on context of the older adults' lives.

Home care nurses described situations where older adults were lonely and that they experienced social isolation due to frailty and being homebound. Physical frailty created mobility problems which made leaving home a problem. Cognitive frailty sometimes limited the ability for older adults to have regular social relationships or function safely outside of the home. Both physical and cognitive frailty impacted psychosocial frailty because it created a limitation in global functional ability and restricted opportunities to be social outside of the home setting.

Social isolation and lack of a consistent and nurturing caregiver were discussed by nurse participants as one of the most common challenges for frail older adults recovering from illness. Informal caregivers, like family members, sometimes provided physical care, but home care nurses identified that emotional support and advocacy from a caregiver was as important as physical care for frail patients. The nurse participants reported that social disconnection led to lower motivation for a patient to physically care for oneself and to manage their chronic diseases. Many older adults with frailty lacked a devoted person who could be a "cheerleader" for them.

This is someone who would help motivate and support them through a health stressor. Lonely and isolated patients were perceived by home care nurses to be at serious risk for poorer mental health than someone with social connection.

Depressive symptoms like not eating well, neglecting self-care, low motivation to be active, and diminished sense of well-being were observed by nurse participants. Patients may be experiencing low physical self-esteem related to frailty which leads to further dependency which impacts psychosocial frailty. Nurse participants observed patients "giving up", using "negative self-talk" and not persevering toward better health when they were isolated and alone. Home care nurses perceived that patients needed a reason beyond themselves to be motivated to work on their recovery. Chronic disconnection and social isolation were viewed by nurse participants to worsen all aspects of frailty.

COVID-19 isolation accentuated feelings of loneliness in certain older adults and the nurses reported that it had an impact on patients' mental health and cognitive functioning. More older adults became socially isolated due to quarantine mandates and home care nurses saw an increase in physical, cognitive, and psychosocial frailty as a result.

Gale et al. (2018) investigated whether loneliness or social isolation are associated with the progression of frailty in older adults in the UK. Their study looked at older adults longitudinally at two year intervals over sixteen years using the Frailty Index (FI) instrument and physical frailty measures. They found that loneliness was a significant predictor of the progression of physical frailty, but it was not a risk factor for a change in score on the Frailty Index. Loneliness is a subjective experience and it is linked to mental health. One can be socially isolated but not lonely (Gale et al., 2018). Their study also concluded that social isolation and

loneliness were a result of frailty, but social isolation is not what causes frailty. Loneliness, not social isolation increased the risk of becoming frail.

Building psychosocial resilience

Building or maintaining psychological resilience was viewed by nurse participants as very important to frail older adults living at home. The nurse participants described strategies that they used for patients to help build their psychosocial resilience. Nurse participants appeared to be very attuned to the psychosocial struggles of their patients when they had the time to get to know each situation and who the patients were as people, not just as their deficits and medical diagnoses. Nurse participants took an interest in their patients' lives to show caring. Many nurse participants reported acknowledging a patient's preferences for care in the beginning of the nurse patient relationship which helped patients feel supported and valued. Nurse participants described personalizing care for patients and involving them in the plan as much as they could as a way to help build resilience.

Skilled home care is typically prescribed for older adults after hospital discharge or a change in health status. The uncertainty of whether one can function again at home after hospitalization often leads to stress and anxiety for older adults. Older people generally wish to stay in their own home for as long as possible, and high quality transitional care like skilled home care nursing can help older people with multiple chronic conditions adjust to being back in their homes. Hestevik et al. (2019) performed a qualitative meta-summary of 13 studies to better understand older persons' experiences of adapting to life at home following hospital discharge. Their research summary reported that older adult patients' needs are commonly not prioritized by health care professionals in the hospital because they are perceived as "too complex", time-consuming, and requiring special treatment (Hestevik et al., 2019). Hestevik et al. (2019)

reported that newly discharged patients felt that there was inadequate communication of information about their diagnosis and treatment between the hospital and other health providers. Newly discharged patients felt their discharge was rushed and important information was omitted or not well explained to them. Patients and their families were not asked to be involved in their own care process and reported not understanding part of the information received at the hospital prior to being sent home (Hestevik et al, 2019).

This was also perceived by some of the nurse participants in this study who described situations where patients were sent home abruptly without supplies and ill-prepared to manage themselves at home. Poor interprofessional communication, "sloppy discharge hand-offs" and unreturned phone calls interfered with nurses' abilities to build rapport with patients because they were stressed, rushed, and very busy trying to find missing but vital information. Nurse participants disliked when they did not have clear communication from other healthcare providers involved with patients because it created extra work which reduced the amount of time they needed to talk to the patients and caregivers adequately. Poor interprofessional communication interfered with nurses building psychosocial resilience because establishing trust and rapport with patients and caregivers was disrupted.

Patient resistance to the plan of care came up frequently in interviews of the nurse participants. They perceived that when frail older adults are experiencing a loss of independence and are asked to make many so many changes in their lives by various health providers, they may be feeling a loss of control. Another explanation for patient resistance to the plan of care is that perhaps they did not feel heard by health providers, and during their hospitalization they were not given the opportunity to take part in planning their own care. Now that they are home, they can exert their preferences and be in control again. Hestevik et al. (2019) reported that in

their meta-summary of patient interviews, home healthcare offered upon discharge was often disturbing to the patients' efforts to get back into their normal routines. Patients reported not getting the right type of care at the right time of day or right day of the week. Home care was perceived as disruptive and not available when patients needed it the most (Hestevik et al., 2019). This may be what nurse participants in this study perceived as patient resistance to the help being offered. It may actually be that patients felt more empowered to exert their personal wishes and care preferences at home. When healthcare providers push patients to fit into their own schedules and try to enforce prescribed care rather than invite patients to take part in making decisions for themselves, patients' sense of personal control is diminished which may dampen their personal resilience.

Nurses providing home care to older adults with social isolation stated that they sensed when patients needed more contact and would intuitively try to spend more time in the home with a patient during a visit if possible. Nurse participants helped patients cope with frailty and build resilience by using "positive" talk, easing their fear, acknowledging their feelings, helping them manage their anxiety, instilling confidence in their ability to improve a patient's situation, and offering to pray with them. Nurses often instinctually served as a "cheerleader" for patients who expressed feeling helpless or hopeless about their health situation. Some of the benefits patients gained through psychosocial resilience building were having a sense of hope, being able to identify of something they could look forward to, maintaining relationships, wanting/needing to be there for others, accepting their current situation, being willing to accept help, and feeling a sense of personal agency in managing their health. Higher psychosocial resilience appears to be beneficial to overall mental well-being and quality of life for frail older adults (Pruchno & Heid, 2015 ; Resnick, 2014; Wild et al., 2011).

Musich et al.(2022) found that the absence of perceived stress and depression were most strongly protective of personal resilience. Other protective factors like having a purpose in life, optimism, a sense of personal control, and social connections were correlated with higher levels of self-reported resilience (Musich et al., 2022). Associations between resilience and adherence to medication, utilization of emergency room (ER) and inpatient (IP) hospitalization were also studied. They found that low resilience contributed to higher utilization of ER and IP hospitalization and that physical health conditions (heart disease, chronic obstructive lung disease, and diabetes) were minimally affected by level of resilience (Musich et al., 2022). This reinforces that psychosocial factors are as meaningful or more meaningful than physical factors in determining resilience in this cohort of older adults and should be recognized and protected by nurses.

Helping patients use technology, like setting up Facetime or clearing voicemails so patients could connect with their outside support were examples of nurses trying to help patients maintain their social networks. Offering phone calls to on check patients in between visits were efforts to maintain connection as well. The nurse participants did not follow a protocol or some set of directions to help build resilience in this way. This was not a "billable" service or a thing that nurses could take "credit" for in their charting or extensive workloads. The home care nurses' descriptions of resilience building sounded like a natural, human, and instinctive approach to care for patients. It was an important way to support their patients when there were few friends or family members available to provide support.

Heavy workloads and busy schedules were barriers to home care nurses taking a bit of extra time to be present with patients who were socially isolated and at risk for loneliness. Nurse participants identified that social workers are vital members of the healthcare team for older

adults suffering with social isolation, lack of connection, and other psychosocial problems. The nurse participants perceived that involving a social worker was extremely valuable for connecting patients with community resources to provide additional support. A strong social worker presence on the home health team was perceived by nurses to build patient resilience and possibly helped reduce the subjective experience of loneliness in socially isolated patients.

Environmental frailty

Patients who lived in homes or communities that were not conducive to the progressive physical and functional changes that come with age were perceived by nurse participants as frailer than their counterparts who lived in "age friendly" homes and communities. Age friendly communities terminology covers eight domains where consideration of age can impact a person. These domains are housing, transportation, outdoor built environment, social participation and inclusion, civic participation, communication, community support and health services (https://ageing-better.org.uk/age-friendly-communities/eight-domains, 2023). An older adults' home environment was perceived by home care nurses to impact their physical, functional, and psychosocial frailty and their abilities to be resilient during a health stressor. Home care nurses faced concerning home environment situations which placed their patients at risk for poor safety, limited mobility, and social isolation if the home was located away from people or services in the community. Home care nurses stated that older adults often postponed making adaptive changes to their homes due to the cost or being reluctant to spend money on home modifications versus other needs. Older adult patients often downplayed their functional impairments or overestimated their ability to function safely in their homes. Nurse participants perceived that older adults who did not make any plans for adapting their home environment for aging were frailer and less resilient than those who planned ahead and were willing to make changes. Abrupt discharge to

home from the hospital or skilled nursing facility rehabilitation sometimes did not allow patients and their caregivers to adequately prepare the home environment ahead of the patients' arrival. Hestevik et al. (2019) reported that lack of specialized equipment necessary for safety and mobility at home such as walkers, commodes, adapted toilets, shower chairs etc. contributed to insecure and unsafe transitions to home. Nurse participants in this study shared stories of frail patients needing equipment to manage safely and delays in obtaining necessary equipment. Safety risks associated with poor transitions from hospital to home contributes to environmental frailty.

Some older adults lived in communities without a strong social network of neighbors or did not have a community of friends or family living nearby. Needing to travel long distances for medical appointments, the pharmacy, or stores was perceived as contributing to environmental frailty because it was difficult for patients to get their needs met. Services like ordering groceries online, delivery of medications, and telehealth provider visits are now widely available, but were not embraced or utilized fully by many older adults. Home care nurses described that some frail older adults became very anxious about using technology and felt overwhelmed by the process of setting it up or learning new things related to technology. Being able to get goods and services delivered to the home has become easier since the COVID-19 pandemic, however, the trade off in convenience meant patients were not interacting with people face to face out in the community. Getting out to necessary appointments was perceived by home care nurses as beneficial to a person's mental health, sense of autonomy, and personal agency. Even small conversations have mental health benefits to people who crave socialization, and lack of socialization with other people due to environmental barriers was viewed to make frailty worse by the nurse participants in the study.

The US healthcare system itself can be viewed as an environmental context to receiving home care and other community health services. Medicare, the federally funded health insurance program, is very specific and highly regulated surrounding the provision of healthcare to older adults. Nurses and other healthcare clinicians operate within the rules and guidelines put forth by Medicare when a plan of care is initiated for a homebound older adult. Services that are available to patients must be measurable and quantifiable in order to justify need. Qualifying for skilled home care nursing requires well documented necessity. Instruments like Outcome and Assessment Information Set (OASIS) are used to determine necessity, utilization, length of stay and reimbursement for homecare services.

Physical qualities of frailty are more tangible and tend to be more easily recognizable to nurses completing OASIS upon admission to home care. Collecting physical data is more straightforward than collecting psychosocial or cognitive data that impact frailty. Physical symptoms and deficits can often be more easily treated by healthcare clinicians because they are usually more discernible, tangible, and quantifiable. Collecting assessment data for OASIS is done at the start of home care, upon readmission following a hospitalization, or repeated if care must extend beyond 60 days. The OASIS may have limited truth value for assessing more subtle aspects of frailty like psychosocial, cognitive, and environmental changes that occur in patients over time. Nurses may not initially recognize cognitive or psychosocial frailty in their first assessment of a patient using OASIS because these qualities tend to become more apparent only after spending time caring for them and observing how they manage at home. OASIS may not truly capture the multitude of psychosocial and environmental aspects of frailty that can have great consequence to the overall frailty and resilience of older adults.

Clinicians operating within the confines of the greater healthcare system are sometimes limited as to what kind of care can and should be provided to patients. The healthcare environment has broader impact on frailty and resilience than what is visible at the individual level. Nurses learn to work within the practice environment that is established by the healthcare system. Some frail older adults continue to follow a trajectory of worsening frailty despite receiving home care services. The aging process can be difficult for some patients and even though they do not have a known terminal prognosis, it would benefit them to receive palliative or hospice care at home. Currently Medicare allows patients to be either receiving homecare services for restorative reasons, or to have hospice and end of life care. Older adults with frailty in multiple domains can be deteriorating, but not terminal in the sense that they could qualify for hospice. If a patient is placed in the hospice category, different Medicare insurance benefits cover care than if the patient was in the restorative care category. Designating a patient as a hospice recipient will forfeit or highly discourage them using the hospital for urgent health problems. Patients and families often do not understand how the system works and are not open to palliative care or transitioning to hospice unless it is strikingly clear that end of life is near.

The dichotomy of an "either" "or" situation, restorative nursing versus palliative/hospice care, is a systemic construct in home health. However, frail patients could benefit from both kinds of care. Having to operate within this dichotomy and work with resources that are approved within each arm of home care services was difficult for the home care nurse participants. Patients can benefit from both restorative and palliative interventions simultaneously, especially with a complex and dynamic condition like frailty. Rather than have clinician driven care across a smooth continuum until the end of life, the amount of skilled nursing, therapy, durable medical equipment, and home health aide time differs depending on

whether you are in restorative care or palliative care. The home care nurse must understand and operate within this healthcare environment to act in the best interest of the patient.

Finding the numbers of skilled and experienced nurses and health care team members who are educated and well versed in chronic care of older adults is another barrier to optimal care. “It takes a village” as Nurse Inez shared, and an experienced home care nurse teamed up with an experienced team of clinicians who understand geriatric conditions could provide the excellent supportive care that is needed.

Building environmental resilience

Living in a community that had “age-friendly” services builds environmental resilience. Senior buildings with amenities for older adults were mentioned by nurses as very helpful for patients who want to age where they live. Not all patients knew about available community services or how to access them, so home care nurses educated patients about community programs or referred patients and families to the social worker.

Sometimes recommendations were made to patients and families to consider moving because living at home is no longer feasible. A higher level of care and supervision was necessary to prevent a crisis. Having difficult conversations with patients and their families about future planning and moving to a higher support living situation may help patients function better in the long run and this impacts their resilience to health and life stressors.

Affordability of higher level of care living arrangements like assisted living or nursing homes was of great concern to nurse participants as well. Patients who need to move from their homes to supportive housing often cannot afford moving, nor can they afford to hire regular formal caregivers to help them in their own homes. Nurse participants discussed the dilemmas they faced when taking care of older adults who were “caught in between” being able to afford

the care they needed and qualifying for Medicaid or senior safety net programs based on financial need. Many patients did not fit into either category so they went without care-- which compromised safety, functional performance, mental health, and contributed to a progression of frailty. Nurse participants discussed there were fewer possibilities on an individual level for resilience building strategies in older adults with tenuous living situations. Connecting patients to publicly funded safety net resources for those who are at risk may offer a partial solution for older adults who need support while living at home. Programs that provide age-friendly communities, cities, and health systems (https://www.johnahartford.org/grants-strategy/current-strategies/age-friendly) can be utilized where available to help older adults remain at home (Chodos et al., 2019). Community services collaboration programs like Programs of All-Inclusive Care of the Elderly (PACE) (https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/PACE/PACE) is available in 31 states and it is designed to integrate care from outpatient to long-term with the goal of avoiding nursing home admissions (Chodos et al., 2019). These types of programs are not available to many older adults with frailty, and a workforce specialized in geriatric care is already limited and expected to be in even shorter supply as the proportion of older adults in the population grows (Waldon, 2018).

Home care nurses conduct home safety checks as a part of a holistic assessment at the start of care with a new patient. Identification of hazards within the home and recommendations to address modifiable home problems were provided. Helping patients purchase and set up durable medical equipment is a nursing intervention that promotes environmental resilience. Nurse participants rely on agency social workers who are consulted to connect patients with

programs that improve home safety, have builders make affordable home modifications, and offer transportation assistance.

Educating physicians about the roles and capabilities of the home care team would be a broad approach to reduce frailty because appropriate referrals and timely communication would decrease risk for patient problems. Utilizing visiting physicians was also mentioned by home care nurses as a broad solution to help certain physically frail patients. Not all communities have physicians who make house calls to frail homebound older adults. Nurse participants did make referrals to physicians who made house calls when patients were unable to leave their homes, and in some circumstances contacted mobile urgent care providers so patients did not have to go to the emergency department. External circumstances such as availability of competent workforce of caregivers, supportive housing, community services, and eligibility for charity and safety net programs are comprehensive environmental pieces that have far reaching impact on frailty and resilience for older adults. Building environmental resilience is important on a health policy and societal level as well as at the individual and local community level. As mentioned, nurse participants did not discuss involvement with broader aspects of environmental resilience building such as advocating for social programs designed for vulnerable older adults, however, home care nurses could be a valuable resource when designing community programs and policies.

Table 1.

This table summarizes prevalent factors which contribute to frailty in older adults living at home and resilience building activities carried out by home care nurses.

Factors contributing to frailty	**Nursing interventions to build resilience**
• Poor mental health • Low motivation to get better • Low sense of purpose • Negative "self-talk" • Resistance to recommended help • Subjective loneliness • Environmental concerns and lack of resources	• Mental health support through therapeutic communication and "positive talk" • Be a "cheerleader" to motivate • Help patients maintain social connections • Build trust and rapport • Personalize care • Connect to community resources

Frailty and low resilience

Previous studies showed that frailty is a dynamic process where interacting factors such as caregivers, social resources, or the physical environment could influence fluctuations in the condition of frailty (Rockwood & Minitski, 2007). Older adults who are experiencing frailty and low personal resilience had several qualities that were seen as detrimental to physical and emotional health by nurse participants. People with low resilience were viewed as being helpless and hopeless due to inadequate psychosocial resources like caregivers and community support. Older adults with low resilience did not know how to manage setbacks, did not participate fully in the plan of care and were at high risk for a worsening trajectory of frailty.

Frailty and high resilience

There appeared to be positive benefits observed in frail older adults with higher levels of resilience such as higher quality of life, greater mental health and well-being, reduced loneliness, and acceptance of their frailty and current state of health. Nurse participants described resilient

older adults using the same terms and qualities that are reported in resilience literature such as personal agency, acceptance, sense of purpose in life, and ability to adapt following adversity (Madsen et al., 2019). The ability to "bound back" and recover from illness when frail was determined to be better in patients who were identified as resilient. Older adult home care patients who were identified by nurse participants as resilient had attributes like a positive attitude, acceptance of their circumstances, pleasant to work with, and cooperative.

Resilient older adults appeared to be more realistic about their functional abilities and they were more accepting of suggested help and support. The ease of working with cooperative patients may have given the nurse participants the impression that they were resilient. Resilient older adults tended to cope better with being frail and had the attitude and motivation that they could get back to their previous activities and social lives. The nurses in this study perceived that frail but resilient individuals are better able to manage everyday issues than frail individuals who lack resilience.

Strengths of the study

This is the first known study using interpretive description to better understand the phenomena of frailty and resilience in homebound older adults from the nurses' perspective. The nurses that were interviewed had a wide range of clinical experience prior to practicing home care nursing. The home care nurse participants were from 13 different accredited home care agencies and 6 different states which added variety to the interviews. The collective experiences from the nurse participants added to the robustness of the data, and their narrative descriptions were credible because of the detailed stories they shared about patients. Their interviews provided contextual information about how frailty and resilience appear in older adults and about how nursing care of older adults is managed in the homecare setting. An especially interesting

finding in this study was how prevalent personal caregiving of frail older adults is, and how open the nurse participants were in sharing their own personal experiences and frustrations as informal family caregivers. More than half of the nurses interviewed had experience caring for a family member with frailty. This gave richness to the descriptions of frailty and resilience because the nurses were close to the topic having the lived experience as an informal caregiver too. This study contributes to a broader understanding about what elements facilitate and inhibit resilience.

Limitations

There were some limitations to this study. Participants were obtained through a convenience sampling method and nurses who thought that they had something important contribute to the study may have been more likely to agree to participate. All of the nurses were interviewed using a video conferencing application rather than in-person interview. This was by choice, largely due to convenience, efficiency of time, distance, and the nurses' desire to reduce risk of exposure to illness during a time when the COVID-19 pandemic was still prevalent. Interviews that were conducted in person may have been richer than those conducted via video conference due to the researcher being better able to observe body language and subtle communication gestures more easily in person.

Implications for Nursing and Future Research

Nurses must adapt to working within an existing healthcare system even if conditions are not ideal. Many of the conditions that misalign resources or provide barriers to ideal nursing care are uncontrollable to nurse clinicians, but we can learn to maximize our effectiveness and work smarter within the healthcare system we have. Homecare nurses are often the leaders of interdisciplinary teams that deliver home health care to older adults. We learn to collaborate and maximize all allowable resources to provide the best possible care for older adults who are aging

and wish to remain in their homes. Comprehensive assessments should identify and capitalize on patient strengths and resources rather than only focusing on deficits, risks, and problems. Aligning the appropriate type of caregiver to provide the necessary care can conserve limited resources. Practitioners on the healthcare team should know what each clinical role entails and how skilled home care services work across the continuum of care. Delays in care due to incomplete communication or imprecise transitions of care contributes to increased frailty risk since services may not be delivered in a timely and efficient way. Improving and smoothing transitions in care between hospital and home by clear and timely interprofessional communication would benefit both patients and clinicians. Therefore, striving to improve care transitions should continue to be a goal for healthcare team members.

The public's lack of understanding about the realities of aging frequently impedes the efforts of professionals and organizations that are working to improve a health care system that can respond productively to the growing population of older adults in this country. Unless a person or family is trying to navigate what healthcare, housing, or functional support services are available, the public generally has little idea what to expect when grappling with health issues in old age. In an effort to achieve machine-like efficiency in the delivery of healthcare, nurses are frequently not able to spend the necessary time to explain things to people. Lack of time with patients is taking the humanity and caring out of the job. Maybe this means that nurses and clinicians on the healthcare team need to be afforded enough time with patients to understand their self-perceptions, learn what their life goals are, and what is or is not working for them. This could lead to frank discussions and the construction of a real action plan to address what matters, discuss advanced care planning goals, and share what the capabilities of the health care system really are. Many of the nurse participants stated that patients who were not accepting help was

one of the most frustrating aspects of caring for frail older adults, but if there was a better understanding of what healthcare services are available and feasible for patients, different decisions that impact frailty and quality of life could be made. Being with vulnerable people in their humanity and knowing what patients and caregivers want for their health and lives rather than "force" a pre-determined plan that is "allowed" by insurers of healthcare may be more beneficial to frail older adults in the long run.

Educating nurses to initiate conversations about advance care planning and helping nurses gain confidence and competence to introduce the topic for discussion could be a potential solution to this problem. Education, training, and support of informal family caregivers by nurses can expand care since we are suffering a home health aide shortage as well as a national nursing shortage. Family caregivers provide billions of dollars of uncompensated care to people in our country. If there are no informal caregivers, frail patients go unsupported and suffer the consequences which can be a tremendous cost to the healthcare system.

Nurses that can identify all of a patient's protective factors as well as frailty risk factors can provide balanced care and try to strengthen sources of resilience as much as possible. Early identification of what factors contribute to a person becoming frail could be meaningful in altering the course and trajectory of frailty (Hale, Santorelli et al., 2019). Nurses must learn to identify frailty in all domains to give holistic support to older adults. Likewise, nurses can identify factors that are protective of patients' personal resilience during assessments of patients and deliberately plan to maintain and fortify those factors. Older adults with fewer protective factors such as optimal mental health, social support, and sense of purpose can be identified as "higher risk" and a more comprehensive and integrative plan of care should be initiated. Researchers consider one's personal resilience to be responsive to change rather than a fixed part

of a person's personality, therefore, if nurses obtain a greater awareness to assess for resilience and enhance it through resilience building interventions, they can develop clinical management protocols to give a better care (Musich et al., 2022). Frail patients with low resilience could be a target group for a set of specific and standardized interventions. Ongoing research that strives to standardized frailty measurement should continue to be supported. Better recognition and understanding of frailty in older adults can lead to prevention, better clinical management, and useful multidisciplinary interventions for the condition.

Addressing mental health needs of patients, especially those who have limited caregiver support, loss of social contacts, cognitive or mental health challenges is especially important. Taking time to identify and connect older adults to mental health clinicians would be optimal; however, there is a shortage of mental health clinicians with expertise in geriatric care at this time (Huh et al., 2021). Nurses can enhance their own personal knowledge about geropsychology through continuing education programs, and they can hone their "soft skills" like therapeutic communication and motivational interviewing to offer mental health support to older adults.

Research that addresses what specific psychosocial or environmental factors have the biggest impact on frailty can be conducted to further understand how to measure this complex condition. Research that studies specific resilience building interventions that nurses do for patients will guide practice and make resilience building a consistent standard of care. Studying how resilience building interventions benefit certain racial and ethnic groups may be important since this is such a broadly experienced phenomenon which needs to be contextualized for different cultural groups. Future qualitative research with older people, their families, and caregivers can help clinicians learn more about their understanding of the aging process. A better

understanding of the experiences of older adults living with frailty will further inform our existing body of knowledge.

Conclusion

This study broadened knowledge about how frailty and resilience are experienced by older adults who are living at home because frailty and resilience were described by home care nurses which added a new angle for viewing these phenomena. This study identified aspects of patient care such as clinician skill level, importance of certain home care and community resources, and Medicare regulations as surprisingly important contextual elements that impact a person's frailty. Home care nurses shared their views about how frail older adults adapt and manage their health at home which is valuable information that can guide clinical management of these challenging patients in the future. This study sought to find factors that could add to our current understanding of frailty and how the older adults' abilities to be resilient can be recognized and supported by nurses in the community. Home care nurses provided insight about what circumstances make their patients more resilient to health stressors and better able to manage functional deficits as well as the physical and mental decline so often experienced during the aging process. Through interpretive description, a new way of viewing various situations older adults face while trying to remain at home as they age has spawned other research ideas and potential nursing solutions for our fastest growing segment of society—older adults. Planning and caring for older adults in community settings involves so much more than medical decision making and physical care. Further research in the area of frailty and resilience will be crucial to improve quality of life and reduce economic pressure on the healthcare system as we strive to provide appropriate care to older adults.

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Appendix A

Interview Guide

If you hear the term frailty, what does that bring to mind?

What does the term frailty mean to you?

Can you tell me about a time you took care of someone who was frail?

What was that like?

How were you able to provide the care that is required for a frail patient?

Can you describe nursing strategies you use to plan care for someone who is frail?

What kinds of factors seem most important to the development or the resistance to becoming frail?

If you hear the term resilient, what does that bring to mind?

What does the term resilient mean to you?

Can you tell me about a time where you took care of someone who was resilient?

What was that like?

What circumstances do you believe helped this person be resilient?

Can you describe some clinical interventions you may have used that supported resilience in your patient?

Appendix B

LETTER OF SOLICITATION

Letter of Solicitation for Perspectives of Home Care Nurses on Frailty and Resilience in Older Adults Living at Home

You are being asked to participate in a qualitative study "Perspectives of home care nurses on frailty and resilience in older adults living at home" because you are a home care registered nurse who has personal first-hand experience with the research topic.

Affiliation

My name is Lisa Merkle Foley and I am a registered nurse with experience in the specialties of home health care and gerontology, the science of older adults and aging. I am a doctoral student at Seton Hall University College of Nursing. I am the nurse researcher who designed this study under the guidance of Dr. Bonnie Sturm, Associate Professor at Seton Hall University College of Nursing.

Purpose of the study

The purpose of this study is to explore and describe the perspectives of home care nurses about frailty and resilience in their older adult clients living at home. As a home care nurse who takes care of clients who may be experiencing these conditions, you have a valuable perspective to share about this topic.

Participation time

45-75 minutes

Study procedure

Upon verbal or electronic agreement to be interviewed, arrangements will be made between you and the researcher about how the interview will be conducted. The interview can be held in person, via a telehealth video conferencing application, or over the telephone. It is your choice as to which mode of interview is best for you and subsequent instructions about how to connect with the researcher will be provided. Informed consent for the interview will be collected immediately before the scheduled interview. During the interview you will be asked open ended questions about your experiences and perspectives providing home care to older adults living at home who may be experiencing frailty or resilience This interview will be audio-recorded, and as the participant, you will only be identified by a randomly assigned identification number. Your real name or personal information will not be used. Typical questions that you will be asked will be directly related to your clinical experience providing home care to clients in their homes. Any names mentioned in the interview will not be included in the typed transcript of the interview.

You will be given the option to follow up with the researcher with a phone call, text, or email if there is anything else that you would like to add to the interview. You will be given the contact information for the researcher if you would like to clarify or add to any statements you made during the interview.

Participation is voluntary

Participation in the qualitative study "Perspectives of home care nurses on frailty and resilience in older adults living at home" is completely voluntary. If you decide to participate, you may change your mind later and end your participation in the study or interview at any time. You do not need to provide any reason for wishing to end your participation.

Anonymity

Data will be collected without any identifying information. The data collected from each study participant will not be anonymous to the researcher. The researcher will eliminate all names and identifying factors from the interview so that it will not be identified by anyone else. Except for the signature on the consent form, your name will not appear in the research study. The consent form will be kept in a secure locked file cabinet in the researcher's office. It will be kept separate from your interview so that information from the interview cannot be linked to your consent form.

Confidentiality

No names, addresses, or other identifying information will be attached to the information that you provide. All recorded data will be stored on a USB memory key and kept in a secure locked file cabinet in the researcher's office. The recorded data will be kept for a minimum of three years after completion of the study. A typed manuscript of the data will be kept for a period of at least three years after completion of the study and then shredded and thrown away.

If you have any questions or would like to participate in the study, you may email me at lisa.foley@student.shu.edu or call me at (201) 572-xxxx.

Participant Signature_____

Appendix C

Written Script for Potential Study Participants

Hello,

My name is Lisa Merkle Foley and I am a doctoral student at Seton Hall University College of Nursing. _____ gave me your name and contact information.
I understand that you are a home care nurse and you may be interested in participating in my qualitative study "Perspective of home care nurses on frailty and resilience in older adults". The study will consist of an interview via either video conference (doxy.me telehealth app), telephone call, or in person at a place and time that is convenient for you and will afford us the opportunity to have a private conversation.

I have attached the Letter of Solicitation/Consent Form for the study for your review.

I will reach out to you on _____to answer any questions you may have and set up a date, time, and location for the interview.

Thank you,

Lisa Merkle Foley RN, MSN

Appendix D

Oral Script for Potential Study Participants

Hello,

My name is Lisa Merkle Foley and I am a doctoral student at Seton Hall University College of Nursing. _____gave me your name and contact information.

I understand that you are a home care nurse and you may be interested in participating in my qualitative study "Perspectives of home care nurses on frailty and resilience in older adults living at home". The study will consist of an interview lasting approximately 45-75 minutes which can be held at a time and location that is convenient for you and will afford us the opportunity to have a private conversation.

I will reach out to you on _____to answer any questions you may have and set up a date, time, and location for the interview.

Thank you,

Lisa Merkle Foley RN, MSN

Appendix E

Seton Hall University
Institutional Review Board
JUN 25 2021
Approval Date
Expiration Date
JUN 25 2022

SETON HALL UNIVERSITY
1 8 5 6

Informed Consent Form

Title: Perspectives of Home Care Nurses on Frailty and Resilience in Older Adults Living at Home

Principle Investigator: Lisa Merkle Foley MSN, RN

Department: Seton Hall University College of Nursing PhD program

Sponsor: This research is not affiliated with any monetary or non-monetary support.

Summary:

The following summary of this research is to help you decide if you would like to participate in the study. You have the right to ask questions at any time. The purpose of this study is to better understand how registered nurses who practice skilled home care services with older adults support and manage their clients with frailty in their homes. The research also aims to better understand how home care nurses recognize and support clients' resilience. You will be asked to participate in an interview with the principal investigator who will ask questions about your clinical experiences caring for older adults with frailty at home. I anticipate that you will be in this research study for a one-time interview, which is expected last from 45 to 75 minutes. The interview may take place in person, via a video conference (doxy.me), or on the telephone.
There is minimal to no risk anticipated for research participants.
There is no specific benefit to the participant who agrees to be in the study.

Purpose of the research study:

You are being asked to take part in this research study because you have clinical experience providing nursing care to older adults in their homes. The purpose of this study is to identify contextual factors that impact frailty and resilience in older adults living at home and receiving home health care. Your participation in this research study is expected to be for one interview which is expected to last about 45 to 75 minutes. You must have at least six months of experience as a registered nurse (RN) providing skilled nursing care in the home care setting. Current practice experience or recent past experience as a home care nurse is required.

What you will be asked to do:

Your participation in this research study will include:

- Having a conversation with the principal investigator about your experience as a home care nurse who cares for older adults.
- Answering open ended questions about the care that you provide and the observations you make caring for older adults with frailty.
- Answering open ended questions about any sources of personal resilience that your older adult clients may possess.
- If the interview is conducted in person, it will be done at a mutually agreeable time, in a private space that is convenient and conducive to talking.
- If the interview is conducted via video conferencing, it will take place at a mutually agreeable time in a private area of the researcher's home.