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# Older Adult Caregivers' Lived Experiences With Debilitated Chronically Ill Relatives in a Rural Southern County

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Older Adult Caregivers' Lived Experiences With  
Debilitated Chronically Ill Relatives in a Rural Southern County

by  
Nancy Dameron

An Applied Dissertation Submitted to the  
Abraham S. Fischler College of Education  
in Partial Fulfillment of the Requirements  
for the Degree of Doctor of Education

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2019

## **Approval Page**

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## Statement of Original Work

I declare the following:

I have read the Code of Student Conduct Academic Responsibility as described in the *Student Handbook* of Nova Southeastern University. This applied dissertation represents my original work, except where I have acknowledged the ideas, words, or material of other authors.

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Nancy Dameron

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Name

May 26, 2019

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Date

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I would like to express my deep gratitude to my sister, Patty Jackson, for her never ending encouragement to keep me inspired by reminding me of the importance of this research. I would also like to extend my special thanks to the “Church Bunch” for their older adult humor, their valuable stories, and contagious laughter.

## **Abstract**

Older Adult Caregivers' Lived Experiences With Debilitated Chronically Ill Relatives in a Rural Southern County. Nancy Dameron, 2019: Applied Dissertation, Nova Southeastern University, Abraham S. Fischler College of Education. Keyword: caregivers, caregiver role, chronic illness, baby boomers

By 2030, the last of the baby boomer generation will reach the age of 65, which will expand the older adult population to more than 70 million in the United States. Based on the inflated numbers of the older adult population and the noted decreased birth rate in the younger population, fewer health-care providers will be available to teach, prepare, train, and assist caregivers in the ongoing care of their ill relatives.

The problem investigated in the study involved the present upsurge of the older adult population living longer and contributing to a shortage of health-care providers for older adults. Baby boomers account for 40% of active registered nurses entering into retirement. This qualitative study aimed to identify older adult caregivers' lived experiences with debilitated chronically ill relatives in a rural southern county, as well as to explore the trend of elderly caring for the elderly and the possible unfortunate outcomes and challenges related to the reduction in health professionals for family caregiving.

The findings of this study indicated the lived experience of elderly caregivers for elderly patients is characterized by stress, resentment, and frustration. Caregiver participants spend the majority of their days providing care for others, with little time left for themselves. There is a sense of constantly feeling overwhelmed by circumstances but with no good alternative solution. Compounding this was the feeling that they had to take the verbal abuse and sometimes physical aggression that their husbands and brothers displayed toward them, which was how these men expressed their resentment and frustration. Receiving such aggression made participants resentful of their patients and frustrated with the patients and the circumstances of providing care.

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## **Chapter 1: Introduction**

### **Introduction**

Chapter 1 begins by preparing to explore the lived experiences of older adult caregivers and their debilitated chronically ill relatives in a rural southern county. One or more relatives in the household may have a chronic illness, but one individual serves as the primary caregiver to another relative, notwithstanding the problems associated with that person's own health issues. This chapter offers a problem statement related to longevity of the older adult population and the challenges for health-care professionals. The next section offers a phenomenon of interest associated with elderly caring for the elderly and explores this elderly experience to understand the complexities of the roles as elderly caregivers to ill relatives with compromised autonomy. In addition, this study called attention to the trend of the decreasing number of health-care professionals interested in caring for the elderly by viewing the background of the problem in southern rural area characteristics. Evidence of deficiencies and the meaning of disease processes are explored and identified for the purpose of the study.

The 21st-century aging of the baby boomers, advanced technology, and improved medications are enabling frail individuals to live much longer than they did in the 20th century. A proactive attitude is required to accomplish a positive outcome for the well-being of the aging population. According to the Institute of Medicine (2008), by 2030, the last of the baby boomer generation will reach the age of 65, which will expand the older adult population to more than 70 million. Based on the inflated numbers of the older adult population and the noted decreased birth rate in the younger population, fewer health-care providers will be available to teach, prepare, train, and assist caregivers in the ongoing care of their ill relatives with chronic debilitating disorders.

The Institute of Medicine (2008) created a committee with a threefold approach. First, the committee's purpose was to improve the geriatric competence of the entire health-care workforce. Second, the Institute of Medicine committee endeavored to increase the recruitment and retention of geriatric specialists and caregivers and, third, to improve the way care is delivered. Patient education is also an integral component for increasing the competence and confidence of clients in self-management and caregiving for their elderly relatives (Bastable, Gramet, Jacobs, & Sopezyk, 2011).

### **Statement of the Problem**

The problem investigated in this study involved the present upsurge of the older adult population living longer and contributing to a shortage of health-care providers for older adults. The evidence of existing trends in the reduction of health-care providers for the growing older adult population in rural southern counties is causing fewer resources to be available to the older adult. Moreover, this trend for older adults to take care of each other creates unfortunate outcomes related to the reduction in health professionals for family caregiving. Because of the shortage of health-care providers, the stress levels and lack of coping skills for the caregiving relatives are a challenge. In addition, these caregivers face a lack of information and education available in the rural south, versus southern urban areas, to help them adequately care for their ill relative.

The insufficient number of providers who can give information regarding community services and support for the caregiving relative and the older adult with a debilitating illness creates excessive stress and hardship. This problem may be alleviated by the availability of adequate quality resources and providers to support older adults in their community. The increase in chronic and incurable diseases requires clients and their families to become informed participants while managing their daily challenges and

illnesses. Client teaching can facilitate a client's response to illness and disability (Bastable et al., 2011).

In confirming this problem statement, Patricia Gellasch compiled a study explaining that the nursing shortage will continue to be a major problem affecting health-care delivery in the years to come (Gellasch, 2015). Gellasch further reported that baby boomers control the registered nursing workforce and account for 40% of active registered nurses entering into retirement. Furthermore, "in 2011, nursing schools were unable to accept 60,000 qualified applicants as a result of budgetary constraints and insufficient numbers of faculty, clinical preceptors, and clinical sites" (Gellasch, 2015, p. 63).

According to Werner (2011), 47.6% of the older population living outside a metropolitan or micropolitan statistical area reside in the southern states. In the south, when older adults do not live in cities or urban areas, they most likely live in the southern rural areas. This setting can make the instrumental activities of daily living difficult for the older adult population to achieve. This difficulty is recognized by the caregiver not having the support of nearby health-care agencies or other individuals needed to assist in the instrumental activities of daily living.

The instrumental activities of daily living are imperative for the older population living in rural areas to be able to initiate. Examples of such activities include food preparation, self-feeding, bathing and dressing, keeping areas free of bacteria, and keeping ill relatives safe from harm. Similarly, living in rural areas generates a challenge for home health agencies and paid caregivers. Home health agencies have several patients to see in a single day, but, in rural areas, the agencies do not always have enough time in the day to care for all their patients because of distance and driving time. It is sometimes

problematic for home health professionals to reach rural homes in their vehicles. This researcher was in route to see a patient in a southern rural area and had to drive through the middle of a field with no roads to reach the patient. Because the researcher did not see a tree stump covered with weeds, she ran over it, and the tree stump impaled the floorboard of the back seat.

In a 2014 U.S. Department of Health and Human Services report to the U.S. Census Bureau, racial and ethnic minority populations have increased from 17.5% to 21.2% for older adults in 2013 and are projected to increase 28.5% by 2030 (Administration on Aging Administration for Community Living, 2014). Between 2013 and 2030, the White population aged 65 and older is projected to increase by 50%, compared with a 123% increase for older adults in racial and ethnic minority populations, such as Hispanics, African Americans, American Indians, Native Alaskans, and Asians (Administration on Aging Administration for Community Living, 2014).

Researchers for the U.S. Department of Health and Human Service also reported that, in 2013, over 9.6% of older adults were below the poverty level; during 2012, the previous year, the poverty rate was 9.1%. The increase can be partly contributed to medical out-of-pocket expenses in the poverty calculations (Administration on Aging Administration for Community Living, 2014). These statistics support research related to the increasingly vulnerable and diverse older population. Additionally, these key points in continuing trends may well trend into a plurality nation with the non-Hispanic White population becoming the largest single group with no group in the majority (U.S. Census Bureau 2012b) and bringing with it an increase in poverty and vulnerability.

Not only is there a shortage of nurses, but there is also a shortage of knowledge in nursing (Larson, 2016). The health education industry has been warned for the past 5 to

10 years about giving nursing graduates the increased knowledge they need to keep up to speed with the upcoming retirement of one million nurses over the next decade (Larson, 2016). The scope of practice laws, currently for nurse practitioners, limits their range of practice. Nevertheless, nurse practitioners are more likely to work in rural areas, in which the need for health-care services has grown linked to expanded coverage under the Affordable Care Act. In rural areas, there are also fewer doctors compared with the nursing providers (Larson, 2016). This demonstrates the need to bring nursing knowledge to a level required to be more involved in managing certain types of patients, such as those with chronic debilitating illnesses.

Factors contributing to the shortage include the health-care demands from the elderly population and the retiring baby boomer registered nurse workforce (Gellasch, 2015). The complex nursing requirements coupled with variables of job satisfaction for nursing are the main reasons nurses are leaving the profession (Gellasch, 2015). Some of these variables of job satisfaction are “scheduling; insufficient staffing; lack of positive reinforcement from peers, leaders, and others within the profession; and taxing physical labor demands” (Gellasch, 2015, p. 64). Novice nurses are targets for workplace violence, explicitly verbal abuse, and bullying. Even though novice nurses are vulnerable, experienced nurses can also be victims, hence the well-known term known only by nursing: “Nurses feed on their own” (Gellasch, 2015, p. 66).

### **Phenomenon of Interest**

The lack of a sufficient health-care workforce to offer education and support has created the catalyst for the phenomenon of the elderly caring for the elderly. To make the best use of resources, and aid their expansion in meaningful ways, it is necessary to understand the plight of the phenomenon of the elderly caring for the elderly. Through

professional observation and experience as a home health care and hospice nurse caring for the elderly, and through extensive research in national, state, and local publications, this researcher acknowledges that minimal community resources are available to support the needs exemplified by the elderly caring for the elderly. The narrative of the lived experiences of elderly individuals in a rural southern county will increase our understanding of their need for improved communications, services, and healthier solutions. Community support is needed for the elderly individual caring for an elderly relative with a chronic debilitating illness.

### **Background of the Problem**

The focus of the study was to investigate the perceptions of older caregivers in terms of their expressed needs regarding stress, coping, and essential resources that assist them with strategies for the care of their older adult ill relative. This researcher has observed a number of health-care providers through meetings with colleagues in different hospitals about rural southern counties. The researcher's professional experience was evidenced by working as a professional health-care provider and studying in this specialty for over 20 years. According to government publications, the deficiency of health-care providers causes a number of caregiving problems. The U.S. Census Bureau (2012a) reported that the chance of spending nights in the hospital was 17% for people 65 and older. Even though 80% of older adults reported regular prescription use, and 92% had visited a health-care provider within the year, according to this report, they were not likely to have hospital stays for complications (U.S. Census Bureau, 2012a).

The U.S. Census Bureau (2015) projected that the population aged 65 and older is expected to more than double between 2012 and 2016. This population will represent one in five U.S. citizens (U.S. Census Bureau, 2015). In 2014, meanwhile, 58.6% of people

65 and older were married and living in their homes. In 2014, 72% of older men and 49% of older women were more likely to be married. Over half of the older adults in 2014 lived with their spouses in their homes (U.S. Census Bureau, 2011). From the 2008 report of the Institute of Medicine, by 2030, the last of the baby boomer generation will reach the age of 65, which will expand the older adult population to more than 70 million. Based on this researcher's long lived experiences with working as a health-care professional and advocating for older adults, it is this researcher who is willing to pursue avenues for better outcomes. This researcher predicts that soon, more than 60% of older couples over 65 will have debilitating diseases, be married and living together in their homes, and caring for each other.

The U.S. Census Bureau, supported by the National Institute on Aging, conveyed in 2011 that the nation's 90-year-old and older population nearly tripled over the past 30 years and reached 1.9 million in 2010 (U.S. Census Bureau, 2011). Over the next 40 years, this population is projected to more than quadruple. Between 1980 and 2013, the centenarian population experienced a larger percentage of increase than did the total population. The likelihood of living in a nursing home increases with age; however, only 3% of individuals in their 70s are nursing home residents (U.S. Census Bureau, 2011).

The U.S. Census Bureau's Demographic and Housing Report for a county in the rural south estimated that 14% of the 65- to 85-year-old population lived in their homes versus a noninstitutionalized health-care facility (U.S. Census Bureau, 2015). According to the U.S. Census Bureau's Social Characteristics in a nonspecific area of the rural south, of the 10,588 noninstitutionalized population of individuals 65 years and over, 3,866 have a disability, 33.9% of households have more than one individual aged 65 or over, and the percentage of grandparents responsible for their grandchildren is 69.9%

(U.S. Census Bureau, 2015). With this information, research has shown that the older adults will possibly care not only for their debilitated relatives but may also be raising grandchildren. Raising grandchildren in the older years of life has a different set of challenges, and to add caregiving for grandchildren with spousal caregiving would be a recipe for caregiver breakdown, stress, and all that stress embodies.

In the typical southern county in which this researcher lives, health-care providers serve two or more other counties and a small, underserved town with the support of (a) one small Level II hospital; (b) community services and coalition for health and wellness, providing a focus on health and wellness for children and mothers; (c) a private volunteer organization assisting families and patients of all ages with overdue electric bills, car payments, and mortgages (but that does not help individuals in their homes or provide transportation); and (d) an adult day care restricted to veterans only. To comply with Medicare and Medicaid guidelines, home care agencies can send a caregiver into the home to provide care and instruction for a very limited time frame. Private home care agencies and caregivers do not accept insurance and often require payment in cash. A common practice in this rural southern community is to find a caregiver by word of mouth with the hope that the caregiver will be responsible, knowledgeable, and trustworthy.

In this same rural area, which is characteristic of the rural south, the Area Agency on Aging serves as many as three counties and a town. The agency does offer a well-designed and easily understandable website with multiple articles and references for caregiver burnout and daily living activities for the older adult. To have knowledge of this agency's support, an older individual would require access to a computer and be competent enough to maneuver through the website. If older adults meet low-income

status, they will qualify for a few hours of weekly assistance with cleaning and respite. Unfortunately, in the rural south, the older adult is frequently not computer literate and may not even own a computer. Many older adults are just above the low-income criteria, which causes them to fall through the cracks of bureaucracy and go without sufficient services to support their daily living. These situations and statistics about the elderly population are growing every year and contribute to the phenomenon of the elderly caring for the elderly.

### **Deficiencies Noted in the Evidence**

The deficiencies noted in this study on the elderly caring for the elderly emphasized the importance of documenting actual lived experiences of elderly adult couples going through the caregiver and disease processes. It is difficult for the elderly caregivers to understand the changes that may take place within their ill relative, relating to mood, attitude, habits, and alertness as they go through their disease process. Disease processes are varied, depending on each patient and family situation. However, disease processes primarily take one of three pathways (i.e., curative, palliative, or hospice), as reported by the health continuum across the life span chart (Dameron, 2010a).

The curative pathway has a healed disease process outcome, meaning the patient is repaired and back to wellness. The pamphlet entitled *What is Palliative Care? Future Solutions Now* describes palliative care and the disease process to the health-care professional, the patient, and the family in order to develop an appropriate care plan that provides comfort care and is not curative in nature (Dameron, 2010b). Palliative care plans are for patients with chronic or noncurative illnesses with treatments shifting from curative to comfort. These patients may continue to receive aggressive treatments, such as chemotherapy, radiation therapy, dialysis treatments, or blood transfusions (Dameron,

2010b).

Hospice provides services to patients with a terminal disease who have less than a 6-month life expectancy. Patients receiving hospice services have completed the stages of aggressive treatments, including, but not limited to, chemotherapy, blood transfusions, or radiation therapy. The hospice philosophy is not to hasten death nor prolong life (Dameron, 2010b). The pamphlet created by this researcher was for the purpose of patient information in the rural southern county home and workplace of the researcher. Actual lived experiences will guide the way for health-care educators and professionals to create services and resources for families in similar situations using the latest technology, such as a service recently formed in January 2005 under the leadership of Louis W. Sullivan, M.D., former U.S. Secretary of Health and Human Services. The Sullivan Alliance (2017) will provide an additional workforce of well-trained, educated health professionals to deliver quality health care. This labor force will reduce health disparities and increase economic strength for the culturally competent care to the public that the organization serves (Sullivan Alliance, 2017).

Researchers support, related to their literature, the need for a larger health-care workforce to deliver the education and meet the needs of older adult caregivers and their ill relatives (Bastable et al., 2011). This researcher, along with the lived experiences of older adult caregivers and their debilitated chronically ill relative in a rural southern county, has provided additional research to report the voices of older adults as they share their experiences, concerns, and needs regarding strategies, services, and programs. For older adults to prolong their health and autonomy effectively, a better understanding and awareness of trends and issues that affect this vulnerable population is required. Horton and Johnson (2010) presented additional literature that highlighted the trends that need

improvement to eliminate such barriers as under education and low salaries for the health care workforce that serves older adults (Horton & Johnson, 2010). Furthermore, deficiencies in the United States include health-care barriers and the lack of health-care personnel for older adult care. It is evident that more research is required to meet the needs of the larger population of older adults.

In addition, health-care provider shortages continue to be a challenge in the United States. The deficiency is more reflected in the rural areas, such as the rural south. The misdistribution is a persistent problematic deficit facing the nation's health-care system (Rural Health Information Hub, 2017). It is essential for rural health-care facilities to focus on being proactive in their strategic plan for recruiting and retaining personnel. Successful recruitment and retention can increase staff to ensure that services are provided in rural areas. Rural facilities could offer compensation, benefits, and other incentives to candidates for the health-care workforce (Rural Health Information Hub, 2017).

Introducing rural students to a health-care career can accomplish the education and training of the rural health-care workforce. Education and training can be provided in rural areas through nursing and allied health education in rural colleges and rural training tracks, which are residency programs designed to train physicians for real practice (Rural Health Information Hub, 2017). Rural training tracks provide an opportunity for rural hospitals to partner with similar programs to train students to practice in rural areas. Programs such as rural training tracks are intended to help lessen the ongoing shortages of primary care physicians in rural areas (Association of American Medical Colleges, 2015).

A study conducted by Lin, Beck, Fomej, Hummer, and Master (2012) focused on

late-life disability trends by measuring activities of daily living, such as bathing and toileting, and instrumental activities of daily living, such as shopping and cooking. The demographic information in the study demonstrated three chronological dimensions: age, period, and cohort. The third chronological dimension of cohort “describes a unique set of individuals who both are born into a social system during a similar time period and experience similar social experiences over their life course” (Lin et al., 2012, p. 2158). The authors demonstrated a trend in the study and concluded that sequential cohorts of older adults became more disabled over time (Lin et al., 2012). It is most likely this trend will continue, particularly in rural areas of the south. More accounts of older adults with disabilities will create an overall burden for geographic areas of the south that have lower numbers of nursing homes in use.

In their research, Samuel, Glass, Thorpe, and Szanton (2015) indicated that education and higher levels of income are related to fewer disabilities, better nutrition, and health care. These authors noted that skills gained from education and knowledge of healthy living may protect the older adult from disabilities related to household safety and unhealthy habits. Samuel et al. also pointed out that educational disparities commonly found in rural areas of the south are associated with poor nutrition and increased disabilities. The 2014 U.S. Department of Health and Human Services report showed that, in 1970, 30% of older Whites and 9% of older African Americans were high school graduates. Between 1970 and 2014, the percentage of older adults who completed high school rose from 28% to 84% (Administration on Aging Administration for Community Living, 2014).

### **Audience**

This study benefits the older adult population, the families, educators, and health-

care service providers and professionals. The results of this study add an older adult perspective and voice to a larger conversation about the need for educational health-care strategies that will increase the health-care workforce. According to the U.S. Census Bureau (2015), the projected population of individuals 65 to 69 years of age will grow from the current population of 16,094 to 20,397 by 2030. The trend of a growing older adult population living longer with chronic diseases has profoundly affected the rural south. The literature indicates that an insufficient number of health-care providers has caused a scarcity of programs and resources to assist elderly caregivers with education and support for the care of their elderly relatives.

### **Definition of Terms**

For the purpose of this applied dissertation, the following terms are defined.

**Age.** For the purposes of the study, this term refers to the “biological processes that ultimately lead to disease, disability, or death” (Lin et al., 2012, p. 2157).

**Ageism or ableism.** This term refers to discrimination against aging and disabilities (Martinson & Berridge, 2015; World Health Organization, 2017).

**Baby boomer.** This term refers to the generation born between 1946 and 1964. These individuals make up approximately one fourth of the U.S. population. This generation influences demographic trends and social structures, which affects caregiver roles (Moon & Dilworth-Anderson, 2014).

**Medical home.** This term refers to a model started by Carilion Clinic in Vinton, Virginia, as a pilot test. The medical home is a renovation of a health-care clinic that changes the focus to patient education, patient engagement, and lifestyle changes to address chronic diseases. By 2009, Virginia had the first patient-centered medical home department of family and community medicine (Aston, 2015).

**Period.** Lin et al. (2012) stated that this term “reflects changes in sociocultural, economic, technological, and environmental factors that may affect the entire population at a given time simultaneously but perhaps not equally. A drought may lead to increased food prices, which largely affects those with lower incomes” (p. 2157).

### **Purpose of the Study**

The purpose of this study was to better understand the central phenomenon of stress and coping anxiety related to the well-being of elderly caregivers and their relatives with debilitating chronic illnesses. The topic identified involved the health-care phenomenon of the elderly caring for the elderly. This phenomenon is recognized when one or more older adults in the household has a debilitating disease and one individual has the role of primary caregiver for the ill relative, notwithstanding the fact that they also most likely have other health issues. The design of this qualitative study emphasized a theoretical and descriptive approach (Creswell, 2015). The theoretical method is a grounded theory in stress and coping developed by Richard S. Lazarus in 1981. However, this existing theory would be modified based on views of participants. A descriptive approach incorporates a detailed description, such as older adults in a rural southern county subject to the phenomenon of the elderly caring for the elderly.

The participants in this study were elderly individuals in a rural southern county with shared lived experiences, one with a debilitating disease and the other in the role as primary caregiver for the ill relative. The research interviews took place in the participant’s home, possibly at the kitchen table with a cup of coffee. In the south, that is the area in which most people are comfortable. This arrangement allows the participant the ability to care for the relative and to talk privately if needed. An alternative site for a caregiver’s interview was a private conference room in a doctor’s office or church

setting. This interview technique has been field tested by this researcher many times over during the hospice professional career of this researcher and has been found to be very effective.

This qualitative case study was based on the aged population and aging relatives who are living longer with at least one chronic illness, and one person in the household has taken on the role of caregiver. The participants in the study were elderly individuals, with one being a caregiver to another relative who had a debilitating chronic illness. The debilitating chronic illness may include, but not be limited to, chronic obstructive pulmonary disease, congestive heart failure, Alzheimer's disease, or end-stage cancer. The phenomenological qualitative study defined the central theory of this research. A purposeful sampling approach was used to select participants who facilitated a detailed understanding of this phenomenon (Creswell, 2015). The selected participants provided valuable information that expressed their personal lived experiences related to the phenomenon of the elderly caring for the elderly. This insight will enable the researcher to better understand and manage the stated phenomenon and give a voice to individuals who experience elderly caring for the elderly.

## Chapter 2: Literature Review

### Introduction

The health-care phenomenon of the elderly caring for the elderly involved an exploration of the lived experiences that illustrate the insightful stories from the elderly caring for each other. The voice given to this population came from a stage in life that many people do not understand until they have experienced it. This researcher recalled being asked by a colleague: What happens to the elderly when they care for each other? The answer given was very simply: They die. As a health-care professional, this researcher responded in this way because of the poor outcomes observed, many times over, in a professional career. For example, while this researcher was working in a medical-surgical hospital unit, an 80-year-old female was admitted because of a fall at home. The 80-year-old husband allowed his wife to lie on the floor for 4 days before calling for help. The husband fed and cared for his wife on the floor, as best as possible, not thinking to call 911 until 4 days had passed.

The literary review related to the purpose of this study, which was to explore the lived experiences of older adults in a rural southern county. This phenomenon was recognized when one or more adults in the household had a debilitating disease and another had the role of primary caregiver for the ill relative, notwithstanding the fact that they also may have health issues. In addition, the literary review interrelated with the problem statement investigated in this study. This review presented the upsurge of older adults living longer and contributing to a shortage of health-care providers for older adults. The evidence of existing trends in the reduction of health-care providers for the growing older adult population in rural southern counties is causing less recourse to be available to the older adult.

The review of the literature was divided into topics that demonstrate the purpose of this study. Stress and coping problems are experienced by family, friends, and caregivers, as well as health-care workers, when caring for the elderly patient with a chronic or debilitating illness, morbidity, and mortality. The focus targeted older adults who live longer with chronic diseases to better understand the stress, coping, anxiety, and educational capacity related to the well-being of the elderly caregiver. In addition, the review pointed out topics related to the nursing shortage in the rural workforce. The topics included theoretical perspective, caregiver compassion, developmental models, baby boomer generation, consequence of nursing shortage, life expectancy, identification of gaps, limitations, ageism and ableism, stress and coping, polypharmacy, end-of-life care, and, lastly, gerontology health informatics.

The theoretical perspective clarifies the effects stress and coping have on decision making skills for the older adult caregiver. To help understand this narrative, this researcher reviewed the stress and coping theory of Richard Lazarus (1981, 1998). The topic of caregiver compassion related to patient suffering and caregiver faithfulness and guilt. The wedding vows, “until death do you part,” may take on a more somber connotation in an older adult married couple than in a newly married young couple. The developmental model alludes to social support and thoughtful decision making. Caregivers in rural settings have found that community culture can provide an environment for the developmental changes experienced by older adults and community support for self-continuity in their own homes (Geboy, Moore, & Smith, 2012).

The baby boomer generation is most important when discussing older adult age groups. The baby boomers made a superlative difference in every decade since their birth; therefore, older adulthood is no exception. Life expectancy is also increasing and

causing a ripple effect. This increased life expectancy is related to advances in treatments and medications that help people live longer lives but not necessarily independent lives. This current situation comes at a time of a decreasing number of health-care professionals to care for the increasing number of older adults. The identification of gaps and limitations was important for this study related to the quality of care for older adults in order to create awareness and solutions. Ageism and ableism were explored as a cause for the decrease in young people not pursuing opportunities in the health-care worker force. Caring for an older adult, for some, may be perceived as unfulfilling work.

### **Theoretical Perspective**

The central research questions of Lazarus (1981) were found to be of great importance beginning with the Korean War and World War II. Some soldiers in these wars developed an emotional disorder that prevented them from firing their weapons (Lazarus, 1981). Moreover, in ordinary life, Lazarus observed stressful effects, such as severe anxiety, blocking the thought process of overworked health-care workers. Lazarus was concerned with the way that stress impaired human functioning. In his research, he found three outcomes that occurred under stress: (a) no effects that could be measured, (b) weak performance, and (c) enabling.

The theoretical perspective in this research was based on the problems of high stress and coping when older adults are the primary caregivers for their relative with a debilitating chronic illness. The problems stipulated in this study were grounded in the stress and coping theory, originally developed by Richard S. Lazarus in 1981, and primarily used to study his central research questions: “Under what conditions of stress does deterioration of functioning occur? Who are the people most vulnerable to such deterioration?” (Lazarus, 1998, p. 181).

The definition of the stress and coping theory was illustrated by the idea that people selectively understood and shut out that which is threatening or too much to handle. This idea implied that a person has sensed the threat and, to cope, has unconsciously chosen avoidance. This ego-defense mechanism helped to explain the concept of the unconscious. The theory of Lazarus (1981) was a result of measuring prolonged stress in the vulnerable population of individuals and observing their encompassed dysfunctional ways of living and adjusting to their stressful environment. The subjective theoretical framework of the stress and coping paradigm of Lazarus intended to understand the causes of distress and dysfunction and uncover how stress impaired individual functioning. An understanding of the scientific study of emotion, stability, and cognitive characteristics was needed to recognize the ways that stress affected individuals. These influences are prominent in relationships, environment, vulnerability, and aging (Lazarus, 1981, 1998).

The relative serving in a support role as caregiver experiences different types of pathogenic stressors that may change with age as he or she provides support care to address the illness, morbidity, and mortality of a loved one. Stress and coping consequences were essential components in the study and research of the phenomenon of the elderly caring for the elderly. The available pool of caregivers, including health-care workers as well as family members, is growing smaller related to the decline of the young adult population and the increase in the aging population. The statistical trend of elders living longer with chronic illness is increasing as the baby boomer population ages. This population paradigm causes stress and coping problems for both the patients and their caregiving family member or friend.

The approach of Lazarus (1981) to stress and coping developed into being

explicitly cognitively phenomenological. In the past, coping was viewed as a product of emotion, and the emotion was viewed as an ambition. Lazarus argued that emotions and stress are products of the cognitive ways that a person interprets the environment or relationships, or both. In other words, cognition can affect emotion, and emotion can affect cognition. The theoretical perspective of Lazarus contributes to filling the gaps in the delivery of specialized health care in rural areas for the elderly caring for the elderly, such as older relatives caring for another. Among this vulnerable population, motivation, emotion, drive, cognitive ability, and interaction with task demands all affect the relationships, environment, and the cognitive ability of older relatives who take care of another (Lazarus, 1981, 1998).

### **Caregiver Compassion**

The caregiver compassion was related to patient suffering and was based on multiple factors, including age, ethnicity, lifestyle, and education. The objective of one of the studies was to “stimulate discussion and research about patient suffering and caregiver compassion” (Schulz et al., 2007, p. 11). The intent was to recognize the unique role of the families in the caregiving experience and to provide new directions for intervention research, clinical practices, and social policy (Schulz et al., 2007). This research demonstrated that greater caregiver compassion links with less patient suffering, and less caregiver compassion links with more patient suffering. It can be difficult for the caregiver to exhibit compassion day after day after day, which causes misunderstanding and anguish for the ill relative.

### **Models**

In addition, a compatible study by Berg and Upchurch (2007) presented a “developmental-contextual model of couples coping with chronic illness across their

adult life span” (p. 920). This developmental model pointed out potential ways in which different couples cope during lifespan phases. The research approached the coping issues in chronic illness by providing social support viewpoints, and it explored caregivers who pooled their resources for joint coping efforts. The approach of older adults to self-management of daily symptoms varied widely in evaluation processes of symptoms or illnesses. These adults were thoughtful decision makers in managing their health, considering the symptoms, evaluating treatment alternatives, and selecting the approach that they believe is likely to be most beneficial (Arcury et al., 2012).

Age, ethnicity, lifestyle, and education were related to significant differences in how older adults treated symptoms and selected commonsense models for treating their daily symptoms. Common-sense models used in the general and older adult population included prayer, herbs or supplements, body-based and manipulative methods (e.g., chiropractic or massage therapy), rest, reduced activities, and over-the-counter medicines (Arcury et al., 2012). In recent years, there has been an influx of acute care hospital closures in rural areas. The current rise in rural hospital closures gave way to the questions of how such closures will impact the older adults and what the reasons are for the hospitals closing. The hospitals did not anticipate the economic and demographic trend prior to the closure. In addition, factors that decreased the financial sustainability of local hospitals were found to be high poverty and uninsured rates, a payer mix dominated by lower paying Medicare and Medicaid coverage, and higher rates of populaces ages 65 or older. Hospitals were not able to adapt quickly enough to a new service delivery and payment model (Wishner, 2017).

Rural hospital closures can have significant implications for older adults who live in communities of these rural hospitals. Implications for the rural population can be

reduced access to emergency care, departure of physicians and nurses, and longer transportation time to hospitals further away and finding transportation back to their homes after discharge (Wishner, 2017). Some of the rural population may even delay or forgo care all together. New models could improve access to care in the rural settings. Health transformation models have been discussed at state levels to address the unique challenges of delivering high-quality health care in rural communities, including freestanding emergency departments. Wishner (2017) stated, “New health-care delivery models are being piloted in many rural communities and Congress is considering several new initiatives” (p. 9). Moreover, it is important to invest resources to support community needs assessments that could specifically focus on the health-care needs of the aging population (Wishner, 2017).

### **Living in Place**

As examined in the Population Division of the United Nations projects, by 2050, the world’s population will have more people 60 years and older than people 15 years of age and younger for the first time in human history. A period of advancement in health and economic success has paved the way for the longevity of extended healthy living and postponed aging (Geboy et al., 2012). These authors noted that improved longevity raises philosophical questions regarding the societal consequences of the extension in the life cycle of older adults. An estimated 84% of adults over 50 want to remain in their own homes while aging. Living in place involves a sense of belonging, the expression of self, and feelings of psychological security.

Social exchanges experienced over the course of long-time residency generate a strong alignment toward the residential environments of choice for older adults, which are their own homes located in neighborhoods and communities. In rural settings,

community culture can provide a rich environment for the developmental changes experienced by older adults and community support for self-continuity in their own homes (Geboy et al., 2012). However, living in place in the rural settings with societal consequences may be detrimental when it comes to longevity and elderly caring for the elderly. In a rural environment, community support may be steeped in community culture, which unfortunately gives way to challenges because living in place in a rural area is subject to distance isolation.

### **Meeting the Needs of the Baby Boomer Generation**

This literature reviewed integrated baby boomer research because the Institute of Medicine researchers recognized the current impact of the baby boomer generation on this country. The number of adults aged 65 and older in the United States will almost double between 2005 and 2030 (Institute of Medicine, 2008). Most older adults have chronic illnesses that require visits to care providers at least annually. The management of chronic illness depends on coordination and team-based care by these providers. The problem statement for the researchers at the Institute of Medicine pointed out that the number of older adult patients can potentially overwhelm the number of physicians and other professionals who will be available unless more is done to ensure an adequate supply of health-care professionals for gerontology (Institute of Medicine, 2008).

Influences such as adequate benefits, personal fulfillment, excitement, and opportunity to help others are important when undergraduate students select a career (Eshbaugh, Gross, Hillebrand, Davie, & Henninger, 2013). According to research, 78.9% of students who responded to the 2013 research study by Eshbaugh et al. (2013) indicated that employment opportunity was either important or very important to career choice. Fewer students (68.4%) indicated that an in-demand career was either important or very

important. Although many students cited interest as a reason for pursuing a career, students could only view a career as fitting their interests if they were aware of that career (Eshbaugh et al., 2013).

The study conducted by Eshbaugh et al. (2013) indicated that approximately only half of the undergraduate students at a university with a gerontology program could define gerontology, which could be problematic when recruiting students to the field. The demand for educated professionals with expertise in aging has increased, and it is most important to recruit and train gerontological professionals who are passionate about elders and serving their needs. The authors noted that, by being provided with accurate and indepth information about the field of gerontology, students may understand the importance and rewards of a career in that field as they consider their future in health care. Only 2% of new nurse graduates reported that they would specialize in gerontology. The lack of providers in this specialty area results in uninspiring clinical settings and a shortage of role models (Eshbaugh et al., 2013).

The objective of this study was to seek answers on how to meet the needs of the increasing older adult population. To approach this problem, researchers at the Institute of Medicine formed a committee task force called the Committee on the Future Health Care Workforce for Older Americans. Guided by John W. Rowe, the committee collected statistical data and conducted surveys with medical students, pharmacists, nurses, and social workers to approach this problem (Institute of Medicine, 2008). A lack of skills and resources to understand physical symptoms of patients with advanced cancer and other diseases exhibited by older adults may cause psychological distress for both the patient and family caregiver, such as a relative who is also elderly. Family caregivers need practical information provided by health professionals on what symptoms to

monitor, how to interpret the symptoms accurately, and when to contact a professional. These skills will enable the elderly caregivers to provide optimal care and maintain their own health and well-being.

The older adult population will benefit from a continuum of care in health promotion and palliative care (Institute of Medicine, 2008). According to this report, only 20% of medical students receive palliative care training, and 39% feel unprepared to address patient fears. Less than 1% of nurses and pharmacists and less than 4% of social workers specialize in geriatrics. Informal caregivers such as family members or friends, receive very little, if any, training, which causes an increase in stress and coping problems. The consequences of the phenomena of elderly caring for the elderly are greatly influenced by the baby boomer generation. The continuum of health-care diagram, created by this researcher, was for the purpose of patient information in the rural southern county home and workplace of this researcher.

### **Nursing Shortage**

Snavely (2016) proposed that there were several factors leading to the nursing shortage. First, during the economic recession of 2007 to 2009, registered nursing employment increased because the nursing workforce that had not been working or had been only working part-time returned to the workforce full time. As the economy recovered, those nurses who went back to work during the recession returned to part-time work or to not working at all. Second, Snavely observed that significant numbers of nurses were aging and nearing the point of retirement. The author stated, “The National Council of State Boards of Nursing reports 55% of the RN workforce is age 50 or older; the Health Resources and Services Administration projects that 1 million nurses are eligible for retirement in 10-15 years” (Snavely, 2016, p. 98). The baby boomer

generation of 1946 to 1964 was followed by a remarkable drop in the American birth rate, leaving a ripple effect in the nursing workforce (Snaveley, 2016).

Third, the nursing schools reported substantial shortages in faculty, thereby restricting nursing programs from enrolling an optimum number of new students. Snaveley (2016) stated, “At the beginning of the 2014-2015 academic year, over half of all United States nursing schools reported a cumulative total of 1,236 full-time faculty vacancies in their programs” (p. 99). Snaveley’s fourth observation was a high attrition rate among nurses. Nursing is incredibly stressful, causing a high nurse attrition rate and fast burnout. The average turnover rate of registered nurses in 2014 was 17.2% from 13.5% in 2011 (Snaveley, 2016).

Fifth, the 2010 Census showed that the 65 and older population grew faster than the total United States Census population in 2015. With this fact came the challenge of the elderly requiring more chronic health-care services and consuming more resources than the younger population (Snaveley, 2016). Last was the Affordable Care Act, causing an additional eight million Americans to become eligible for health insurance and putting a strain on the nursing workforce (Snaveley, 2016). All of these factors could cause the nursing workforce shortages to become catastrophic. Nurses play a critical role in the delivery of safe, quality care within the health-care system. The skills, advanced knowledge, interventions, and compassion, as well as the impact that nurses exhibit within communities, rural areas, and in the lives of patients and their families, are unparalleled. It is imperative for the United States to match supply with demand for nursing, or significant unfavorable consequences will cause patient suffering and caregiver breakdown (Snaveley, 2016).

## **Life Expectations**

When couples marry and repeat their marriage vows, they cannot appreciate the significance of “in sickness and in health.” Couples expect to become caregivers for their children and parents but not so much for each other. Little research has focused on patient suffering as a unique and independent contributor to the health and well-being of family or caregivers (Schulz et al., 2007). Negative effects on the emotional and physical well-being of caregivers and the elderly patient relative include the knowledge of the patient seeing the caregiver struggle and the caregiver seeing the ill patient relative suffer (Schulz et al., 2007).

In 2008, researchers for the American Association of Colleges of Nursing developed competencies and curricular guidelines to ensure that nursing students would be able to provide the intense care needed for patients in the 21st century. As the percentage of patients increased in age and chronic diseases, the American Association of Colleges of Nursing became aware of the demand for geriatric nursing care. In 2010, the American Association of Colleges of Nursing introduced the *Recommended Baccalaureate Competencies and Curricular Guidelines for the Nursing Care of Older Adults* and nine Gerocompetency Essential Statements related to the care of the older adult. Entry-level professional nurses compose the workforce that must ensure that the older adults receive optimal nursing care. As of 2005, only a third of baccalaureate nursing programs had a required course in geriatric nursing (American Association of Colleges of Nursing, 2010). At the present time, baccalaureate institutions are encouraged to offer stand-alone gerontological courses for their students in order to become the catalysts for changing the stigma of caring for the elderly and increasing interest in this profession.

### **Identification of Gaps and Limitations**

Significant gaps exist in the quality of care for older adult patients as measured by patient-reported performance in delivering processes of care. Also important for older adults is the quality of communication that specifically encourages them to ask questions and clearly understands the answers, thus ensuring that they have vital information about their medications and continuum of care. Patient surveys are a necessary component in assessing and improving the quality of care for older adult patients who represent an increasing percentage of the population. These patients may have multiple chronic conditions, numerous medications, and impairment in hearing, vision, or cognitive functioning, which leads to a greater reliance on the health-care system for support of self-care (Hess, Lynn, Conforti, & Holmboe, 2011).

To make measurable improvements in health care, physicians must be equipped with the knowledge and skills needed to recognize, understand, and respond effectively to patients as individuals and not just to their symptoms. Counseling and communication skills will also assist physicians in building therapeutic relationships with their older patients and increase the likelihood that these patients will adhere to their physician's recommendations. Not only are Internal Medicine and Family Medicine physicians primarily involved in health care for the elderly, but physicians with other professional specialties will also provide care for older adults. These doctors will need training in practice system features that ensure the competent care that the special needs of older adult patients require. Gathering and regularly reviewing feedback from older adult patients about their experiences of care could be aided by a technology window through which improved care begins, regardless of the specialty choices of the health-care professional who cares for these elderly patients (Hess et al., 2011).

Unpaid family members or friends provide nearly 90% of noninstitutional long-term care (Berridge, 2012). Berridge (2012) calculated that family caregivers would have earned nearly \$660,000 over a lifetime in lost wages, social security, and pension benefits. Paid care is often prohibitively expensive at a per-hour average cost, but it is widely preferred over nursing homes. Long-term facilities and community-based care are commonly out of the reach for the middle class and are basically unavailable to those who qualify for Medicaid, according to Berridge. The often unrealistic expectation that family members and friends can provide high levels of care has led to a significant unmet need. Among the elderly population is one fifth to one third of the population with a need for personal assistant services. According to federal statistics on dangerous professions, truck driving is the only profession ranked more dangerous than that of the occupation of a nursing home aide; however, health insurance coverage for nursing home aides is lower than that for most other occupations (Berridge, 2012).

Fields, Bigbee, and Bell (2015) explored the relationship between rural provider-to-population ratios in rural population health in the United States using counties as the unit of examination. This team of researchers explained that maintaining an adequate health-care workforce institutes one of the most serious and persistent challenges currently facing rural health care. This problematic topic has been well documented in relation to shortages and maldistribution issues in most health-care professions, including nursing. The investigation revealed that 7,512 ZIP codes, with total populations of over 5.8 million, had no physicians, physician assistants, or nurse practitioners (Fields et al., 2015). This study demonstrated that county-level living had a conflicting relationship between life expectancy and rurality. Additionally, the study found “lower levels of health-care providers per capita in rural communities, with disparities mostly increasing

as rurality increases” (Fields et al., 2015, p. 240).

### **Ageism and Ableism**

Ageism and ableism refer to discrimination against aging and disabilities. The baby boomer generation has called attention to the judgment regarding aging and disabilities. According to Martinson and Berridge (2015), a successful aging model avoids recognizing diseases and disabilities as good aging and considers them to be undesirable or bad aging. An elder with a debilitating disease or disabilities should not be subjected to moral judgments by society or blamed for bad aging. The broader paradigm of successful aging models should give way to the needs that encompass conditions in which people can thrive, on their own terms, as they age (Martinson & Berridge, 2015). This research validated the need for a renewed connotation for a successful aging model.

Ageism is also diversely noted as minority population’s age. In a study of African American family caregivers from rural communities in the southeastern region of North Carolina, it was found that elderly female caregivers experienced difficulty providing care because of the role reversal of the relatives (Smith-Johnson, Davis, Burns, Montgomery, & McGee, 2015). Role reversal contributed to the elderly male patient being uncooperative, causing the person caring for the patient to become frustrated with caregiver strain. According to the research, it was revealed that caregivers received little to no formal or informal support from professionals or community agencies (Smith-Johnson et al., 2015). These caregivers received intermittent help from family and neighbors, but this assistance was not adequate to give them the necessary support needed for care (Smith-Johnson et al., 2015). The degree of stress and coping saturation may influence the quality of life for the caregiver and, in turn, decrease the ability for being a caregiver to the relative. Nursing implications are needed for education and training to be

made available for a satisfactory knowledge base for the care of the relatives and the caregivers themselves.

### **Stress and Coping**

Caregiver strain across the continuum of care for chronic diseases is exacerbated by the characteristics of symptoms. For instance, at-home-alone care for patients with chronic obstructive pulmonary disease without direct supervision is frightening for some family or friend caregivers when the patient suffers from breathlessness caused by the symptoms of chronic obstructive pulmonary disease. Weighing the pros and cons of caregiver strain frequently leads to a neutral outcome with patient preference as the deciding factor of whether to remain in hospital care or to choose hospital-at-home care. Although remaining in the hospital may relieve the caregivers from responsibilities performed by hospital staff, the caregivers often experience strain from traveling to and from the hospital and being separated from their loved ones. Hospital-at-home care requires more skill and engagement by the caregiver, but it also provides a quiet, familiar environment more frequently preferred by both the patient and caregiver (Utens et al., 2014).

Family members who assume highly stressful caregiving responsibilities for loved ones with chronic disabilities are at risk for mental and physical health problems and, subsequently, are at increased risk for mortality equal to someone who has a history of cardiac disease (Perkins et al., 2012). Enhancing the health, quality of life, and well-being of caregivers is undoubtedly connected to the health, quality of life, and well-being of the disabled and chronically ill older adult population (Perkins et al., 2012). Difficult treatment decisions may need to be made when an older adult is diagnosed with a chronic illness. Both the patient and caregiver cope with this decision making in different ways.

These treatment decisions have been researched for the developmental and chronological timeline in the process of coping (Berg & Upchurch, 2007). Data were collected on a variety of chronic diseases from patients of diverse adult ages who were in different stages of their disease process. The data may provide a framework for understanding how couples cope with chronic illness and for determining when spousal involvement is beneficial or harmful to both the patient and spousal adjustment (Berg & Upchurch, 2007).

### **Well-Being of the Caregiver**

Furthermore, assistance to address the stress and coping anguish of the elderly caring for the elderly was shown to be paramount in the research by Gitlin, Reever, Dennis, Mathiew, and Hauck (2006), which examined short-term and long-term care to improve the well-being of the caregiver. Spousal care provided to frail older adult partners can be stressful and result in a range of well-documented negative consequences (Gitlin et al., 2006). Three short-term and long-term care centers were used to conduct their study: two adult day services plus centers and one center that offered routine day care services. The adult day services plus model is a “low-cost care management intervention designed to enhance family caregiver well-being” (Gitlin et al., 2006, p. 630). The average age of caregivers is 62.6 years of age. Most caregivers are daughters or wives of the impaired patient (Gitlin et al., 2006). This study demonstrated that caregiver case management has significant benefits for the caregivers and their impaired relatives.

As previously identified in the report of the Institute of Medicine, the older adult population’s demographic trend is diverse. The authors of another study, funded by the Evidence-Based Disease Prevention Program of the U.S. Administration on Aging, spoke to this trend (Gitlin et al., 2006). Research showed that, “with training and support,

persons with chronic disease can learn strategies to effectively self-manage their illness symptoms, and that self-management result in important benefits” (Gitlin et al., 2006, p. 630). The participants were members of senior centers and area churches that provided baseline interviews as well as 4-month interviews following the study. After 4 months of research, a 47.8% improvement in physical activities, a 50.6% improvement in cognitive symptom management, and a 41.2% improvement in social role function were reported (Gitlin et al., 2006, 2008).

The seriousness of the burden for the caregiver varies with the time that is required for care and the degree of the symptoms. Higher anxiety is projected for caregiver burdens, according to a study that followed its participants for 5 years (Jaracz et al., 2015). Furthermore, because caregiver-related factors seem to be crucial for the degree of burden, more attention should be given to caregivers during the early months and also later during caregiving. Professionals such as clinicians, family physicians, or community nurses should recognize caregivers’ needs for education and practical training and, if appropriate, provide them with comprehensive information, care guidelines, and support (Jaracz et al., 2015).

To focus further on the stress and coping theory, Folkman and Moskowitz (2004) emphasized the stress and coping theory of Lazarus in 1981 and highlighted the cognitive component of stress and coping. Their research studied the different types of stress and the different levels of coping by individuals, such as those in the category of caregiving, that revealed many different sources of stress. The authors found that caregiving stress includes adjusting to illness progression, the shifting of responsibilities from the patient to the caregiver, unexpected improvement in the patient’s health, and role conflict. These insights help to understand the caregivers’ perspectives on what they cope with in their

daily lives. The study reported the primary challenges for researchers and emphasized the coping theory that features the importance of measuring approaches and focuses on positive, effective outcomes. In summary, their research explained that the study of stress and coping is complex but that researchers must persist in the understanding of who thrives under stress and who does not. Then interventions must be created to help people better handle both acute and chronic stress (Folkman, Lazarus, Pimley, & Novacek, 1987; Folkman & Moskowitz, 2004).

### **Polypharmacy**

Polypharmacy denotes taking multiple medications to treat the symptoms of other medications or taking several medications for the same ailment, usually by older adults. Medications touch almost every aspect of care and treatment for the chronically ill older adult, and taking medications as prescribed is a complex task. Complex dosage schedules and multiple prescriptions taken at different frequencies are exacerbated by frequent changes in medication dosage and frequency (Marek et al., 2013). Marek et al. (2013) noted that, as the prescribed doses of medication increase, the extent to which medications are taken as prescribed decreases as well. The authors stated that chronic conditions such as depression and dementia that affect cognition are associated with problems in medication self-management, especially among the oldest of the old.

Forgetting to take medicine is a common problem. Marek et al. (2013) observed that physical and sensory impairments can inhibit the opening of medication bottles or blister packs, reading labels and educational materials, and swallowing large pills. Effective patient education on medication management for older adults may be optimized with the use of medication planners, reminder devices, and medication dispensers. Further analysis of self-management interventions to assist frail older adults

demonstrated the need for a care coordinator to support patient medication management, including communication with prescribers and pharmacists (Marek et al., 2013).

The results of a study conducted by Marek et al. (2013) provided evidence that care coordination has a valuable effect on cognitive function, depressive symptoms, functional status, and quality of life in both the mental and physical functioning of chronically ill older adults. Care coordinators were current on all medications, medical diagnoses, and prescribing providers, and they clearly understood the self-management ability of each participant. With a focus on medication management, the nurse coordinator connected with chronically ill elderly participants via planned weekly telephone calls and biweekly visits to the home. Assisting older adults with medication management has the potential to improve their quality of life (Marek et al., 2013).

Positive and negative forms of social control by family and friends to promote better behaviors for controlling chronic disease, such as high blood glucose levels, may have potentially negative consequences. Recent research has demonstrated that greater social control by family members or friends compromises psychological well-being by producing frustration and threats to personal autonomy and that it may backfire and result in poor disease management and depression. Further, an elderly individual with a debilitating illness is often required to accept certain degrees of dependency on others through years of physical or mental frailty as he or she pursues, achieves, and enjoys life. This condition demonstrates that the quality of life of older adults with disabilities depends on the extent to which they maintain their lives with dignity and a sense of control. For older adults with late-life disabilities, focusing on what they can still do becomes especially important to their feelings of fulfillment and contented autonomy (Carr & Komp, 2011).

## Caregiver Roles

In a 1997 presentation to the Alzheimer's Association, former First Lady Rosalynn Carter stated, "There are only four kinds of people in the world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers" (Petty, 2015, p. 69). Mrs. Carter's 1997 statement was confirmed in 2011 by the Public Policy Institute of the American Association of Retired Persons: "At any given time, more than 42 million family caregivers in the United States are providing care to an adult with limitations in activities of daily living" (Petty, 2015, p. 69).

Petty's (2015) research showed that nearly 62 million Americans provide care some time during the year. Further, the average caregiver works outside the home and provides 20 hours per week of unpaid care to a loved one for an average of 5 years. As the researcher stated, "80% of care recipients are relatives or friends older than 50 years; an estimated value of \$450 billion annually is contributed by family caregivers to the health care economy" (Petty, 2015, p. 69). There is realization that one in four Americans have made commitments to their family member or friend. The fact that these family members or friends experience acute and chronic illness reflects the complexity of life outside of public view (Petty, 2015).

Of the estimated 4.5 million American Alzheimer's patients, approximately three million live at home. An estimated 75% are cared for by family members or friends who undergo extremely challenging and time-consuming tasks that may be physically demanding or unpleasant. Furthermore, family routines and dynamics are frequently disrupted, and many caregivers become isolated from family and friends as they are confronted with the declining health of loved ones. As a result, Alzheimer's disease

caregivers experience considerable burden and stress, which results in compromised physical and mental health at higher levels than age-matched controls (Eisdorfer et al., 2003).

The caregiving burden of Alzheimer's disease is a public health issue in the United States and will rise exponentially as the projected number of Alzheimer's patients increases to as many as 16 million by 2050 (Bank, Arguelles, Rubert, Eisdorfer, & Czaja, 2006). Mixed results have emerged from research studies that a community-based psychoeducational program aimed at teaching Alzheimer's disease caregivers to manage behavior problems was effective in reducing caregiver depression. However, caregiver ability and knowledge determine positive outcomes greater than individual training experiences (Eisdorfer et al., 2003).

Although variations in levels of distress, burden, and depression in Alzheimer's disease caregivers are differentiated by ethnicity, education, and financial resources, a commonality among Alzheimer's disease caregivers who provide care for patients at home is influenced by the interrelationships among four variables: the caregiver-patient relationship, caregiver values, caregiver coping resources and strategies, and discontinuities in patient behavior (Eisdorfer et al., 2003). A better understanding of the need to support caregivers' physical and mental health directly corresponds to the caregivers' level of effective care provided to their Alzheimer's disease patients versus institutionalizing the patient. To influence the functionality and well-being of both the caregiver and the Alzheimer's disease patient positively, interventions must involve the physical and social environment within the larger social context of the caregiver, including selected family and friends, physicians, and service providers (Eisdorfer et al., 2003).

Families and friends may be willing to help, but, for the most part, they are unprepared for the task of caregiving (Petty, 2015). Petty (2015) noted that these informal caregivers lack knowledge about the illness, are unfamiliar with strategies for disease management, and are unequipped to provide for activities of daily living, such as bathing, eating, toileting, and dressing. In addition, caregivers often lack the ability to provide the instrumental activities of daily living, such as transportation, financial management, shopping, and housekeeping. Complicated care needs create a knowledge gap that becomes a barrier to caregiver empowerment (Petty, 2015).

Further, the patients may not assume some of their own care for which they are capable because they grow dependent on others providing that care and may be fearful of alienating the caregiver (Petty, 2015). Caregiver empowerment factors include availability, involvement, willingness, good health, prior knowledge, external resources, and lack of high stress. Petty (2015) stated that understanding the dynamics of the caregiver's commitment is critical to a safe plan for patient discharge and life at home. With the help of community resources and an alternate strategy, some patients may manage their chronic illness independently. Excellent care and outstanding outcomes at home are possible when caregivers are empowered by the health community with support at the beginning of their commitment, encouragement as their confidence increases, and satisfaction with positive aspects of the caring relationship (Petty, 2015).

Equally important are differences between primary and secondary caregivers. With that fact in mind, Barbosa, Figueiredo, Sousa, and Demain (2011) showed the variances between caregiving responsibilities in a cross-sectional study that compared the effectiveness of coping strategies of primary and secondary informal caregivers of dependent elderly people living at home. The authors designed a sociodemographic

questionnaire to collect background data on primary and secondary caregivers and cared-for persons. The data included problem-solving strategies, emotional-cognitive strategies, dealing with the consequences of stress, coping effectiveness, and patient characteristics (Barbosa et al., 2011).

The results of this study indicated that both informal groups found various strategies related to problem-solving coping to be useful. Relying on their own expertise and experience was the most helpful method for both groups of caregivers (Barbosa et al., 2011). In relation to strategies for dealing with the consequences of stress, it was found that maintaining interests outside of caregiving and keeping a little time for oneself were perceived as particularly helpful mechanisms for both subsamples. Overall, these authors found that secondary caregivers perceived emotional-cognitive coping as less useful. However, they found that caregivers, whether primary or secondary, must be supported if they are to continue to provide care without becoming ill themselves (Barbosa et al., 2011).

In keeping with the dialogue about caregiver roles, a study published by Oxford University studied two baby boomer caregiver groups that took care of people with dementia and those without dementia (Moon & Dilworth-Anderson, 2014). The results of the two studies indicated that the caregiver group studied with dementia patients experienced greater burden and strain from dementia caregiving compared to the caregiver group of patients without dementia. High blood pressure and arthritis were the most prevalent chronic diseases found in both caregiving groups. Reduced social activity for both groups was associated with the caregivers' feelings of depression or hopelessness. However, informal support that family or friends provided had a positive effect on both caregiving groups' emotional well-being (Moon & Dilworth-Anderson,

2014).

In 2012, over 15 million unpaid family members or friends cared for people with dementia. This number will double by 2050, and more caregiver support will be needed for people with dementia (Moon & Dilworth-Anderson, 2014). Tailored interventions for various dementia stressors, such as memory, behavior, and communication problems, as well as conflict and role strain, will help baby boomer caregivers to cope with stress and, subsequently, to protect their own physical and mental health. Health professionals should emphasize the importance of self-care and a healthy lifestyle among baby boomer caregivers, as well as the importance of maintaining relationships with their friends, families, or neighbors through phone calls or family reunions to create a healthy balance between caregiving and their own lives (Moon & Dilworth-Anderson, 2014).

### **Home Environment**

The ongoing subject of home environment preference for the phenomenon of the elderly caring for the elderly featured an additional study on this matter. The research of Wahl, Fange, Oswald, Gitlin, and Iwarsson (2009) explored two questions: “What is the recent evidence supporting a relationship between home environments and disability-related outcomes? What is the recent evidence regarding the effects of home modifications on disability-related outcomes?” (p. 355). Data were collected from peer-reviewed original publications and articles published between January 1, 1997, and August 31, 2006. As for the first research question, evidence did not “exist for a relationship between the home environment and disability-related outcomes” (Wahl et al., 2009, p. 355). As for the second research question, overall, there was “evidence that improving the home environment reduces disability-related outcomes” (Wahl et al., 2009, p. 363).

Hence, the review from a 2007 gerontology handbook by James Blackburn and Catherine Dulmus provides an evidence-based approach to theory, practice, and policy. These authors noted that the field of adult development and aging is moving forward at a fast pace. This gerontology handbook could serve as a primary or secondary text for undergraduates and graduate students across disciplines, as well as a resource for practitioners. The handbook is broken into five parts: Part I: Global Aging, Part II: Evidence-Based Theory, Part III: Evidence-Based Health Practice, Part IV: Evidence-Based Family and Community Practice, and Part V: Global Challenges for an Aging Population (Blackburn & Dulmus, 2007). Mrs. Carter's attention to family caregivers in 1997 subsequently helped with the basic understanding of the family caregiver's quandary. However, much help is still needed for this population. Hence, it is imperative to identify the significance of this qualitative research.

### **End-of-Life Care**

An important outcome measure of end-of-life care involved the caregivers' experiences of care (Lendon et al., 2015). Assessing performance and evaluating quality of care at the end-of-life experience is particularly relevant because it is a time with significant variation in health-care application and quality, and health-care systems are challenged to respond effectively to the intense needs of seriously ill persons (Lendon et al., 2015). However, a systematic review reported that 46% of surveys administered to family members or close relatives and a variety of content areas in numerous survey instruments were used to measure satisfaction with and experiences of care, which are important components of quality for this field. This report conveyed surveys that were more comprehensive than others, and certain content areas were used more consistently across surveys, such as "information and care planning, care provided, overall

experience, symptom management, and psychological care” (Lendon et al., 2015, p. 904). Other aspects that were also considered important but were rarely assessed across surveys included “financial need, environmental aspects of the care setting, and caregiver and bereavement support” (Lendon et al., 2015, p. 904).

Caregiving is more widespread in older adults. Moreover, individuals may be caring for relatives with diseases that are often prolonged, such as nonmalignant debilitating illnesses. Additionally, more than half of older adults have three or more chronic conditions (Turner et al., 2016). Turner et al. (2016) stated, “Older adults are increasingly providing end-of-life care to spouses at home and often do so for long periods of time, while also trying to manage their own illnesses and disabilities” (p. 421). Turner and her research partners completed a qualitative study to explore the experiences of the older adult while caring for a dying spouse at home.

The outcome of this research group demonstrated high levels of resilience and the ability to adapt to their caring role; however, their own needs were not always met. Furthermore, the willingness to care is hardened by the ability to care. Complications such as physical and emotional strain, coping with crises, support availability, adaptability, and resilience all influenced the experience of caring for a relative with a life-threatening illness. The findings of this study reported a need for developing supportive interventions specifically for older adult caregivers (Turner et al., 2016). Moreover, this researcher saw a need for supporting both the patient and caregiver as an integrative unit of care. The family was a critical source in assessing end-of-life care experiences because of their presence during the advanced stages of illness and intensive care prior to death. Consistent survey structure and content, as well as the timing of survey administration, are vital to evaluating patient care and assessing informed and patient-centered decision

making to provide care that is simultaneously high quality and cost effective.

### **Gerontology Health Informatics**

Using the Internet as a forum for information exchange and provision of services has made computers and the Internet essential to everyday living for people of all ages. Even though cognitive challenges occur with age, anxiety is frequently experienced in new learning situations, and some older adults have doubts about their ability to learn something new. It has become common in community settings such as public libraries and senior centers to offer adult computer classes. Some older adults of all ethnic and socioeconomic groups change their attitudes about computers and utilize newly acquired computer and Internet skills to find online health resources to help guide their health-related discussions and decisions (Crzja, Lee, Branham, & Remis, 2012).

The development of electronic information systems can change support-care delivery. Telecommunications in health-care include apps, wearable and ingestible devices, as well as digital hospitals and mobile devices that provide a rich and diverse experience to better link technology and clinical outcomes. Technologies that transform support-care methods currently exist, are being developed, and are moving forward, but the barrier to improving care is health-care's adoption of technology. Technology provides advantages and opportunities to enhance patient experience and medical outcomes (Tiaki, 2016). Furthermore, family therapy delivered at home in a clinical environment is extremely expensive and difficult to achieve, and it has been found successful only when combined with access to local resources and online support groups. Moreover, caregivers felt empowered by having control of the type and amount of support they could readily access through simple computer-telephone technology. Individualized technology support maintains potential treatment gains and is an

extremely cost-effective way to provide continuously accessible support without having to leave home (Eisdorfer et al., 2003).

The cumulative literature has illustrated the benefits of ethnically diverse telecommunications-based support groups as one part of a multicomponent intervention to (a) provide caregivers with access to social support, information, and resources; (b) reduce isolation; and (c) overcome multiple logistical barriers that prevent attendance in face-to-face support groups (Bank et al., 2006). Bank et al. (2006) noted that caregivers could find value in online support groups and may benefit from emotional support, useful information shared by other caregivers, and the social aspects of the group, which may provide a break from caregiving responsibilities. As technology advances and user skills improve, videoconferencing will simulate a more realistic face-to-face group interaction with same-language users.

The value of technology will grow in importance as both the number and diversity of older adult patients and their caregivers becomes greater (Bank et al., 2006). Although older caregivers may lack computer skills and confidence to access the computer-telephone technology, many are still interested in receiving training in the overall use of computers (Lee, Craja, & Sharit, 2015). This training will enable electronic access to a variety of individualized support on an as-needed basis. With the increase in technology for older adult caregivers, barriers will need to be overcome. The training and instructors for this population will be costly, along with the cost and purchase of devices.

A preferred level of active communication participation was not always achieved during consultations with health-care providers because patients and caregivers do not indicate their information needs, and health-care providers may not know exactly what information an individual patient requires. A question prompt list is an evidence-based

list of questions that patients and caregivers receive before a consultation. From this list, they can select questions that are relevant to them to ask during their consultations, thus increasing patient participation. Patients and their caregivers become more involved in tailored communication interventions when they combine the content of the question prompt list with the patients' own circumstances and preferences for information (Brandes et al., 2014). Optimal communication with the health-care provider is one of the most important elements of elder care for both patients and caregivers. Research has supported using more personally relevant information by combining the content of the question prompt list and the needs of the patients and caregivers related to this combination to improve psychological outcomes and reduce levels of anxiety (Brandes et al., 2014).

Individualized and personally worded questions remove barriers to important discussions that need to take place. An even greater value can be gained with an online question prompt list, on which patients and caregivers indicate their information needs. From the responses, health-care providers can adapt the content of the consultation prior to a computer-telephone technology meeting with the patient and caregiver (Brandes et al., 2014). As health care moves into the future, technology will increasingly be a tool for feedback from the patient to the provider. The older adult population will need training for this new world and how to navigate through the electronics.

## **Discussion**

The literature review search process confirmed the current impact of the baby boomer generation has presented this country with many challenges. The average caregiver works outside the home and provides 20 hours per week of unpaid care to a loved one for an average of 5 years (Petty, 2015). The author noted that older adults live

longer with chronic diseases, such as diabetes, congestive heart failure, and chronic obstructive pulmonary disease. However, consequences accrue with the opportunity to live longer. Caregivers often lack the ability to provide instrumental activities of daily living, such as transportation, financial management, shopping, and housekeeping. Complicated care needs create a knowledge gap that becomes a barrier to caregiver empowerment (Petty, 2015).

Meanwhile, the numbers of health-care providers were inadequate to serve the increasing elderly population, and home environments are often not adequate to meet the health-care needs of the elderly. Frequently, older adults with chronic diseases live alone or with their relatives. These coexistences provide the catalyst for a phenomenon of elderly caring for the elderly, complicated by high stress and coping issues. Elderly caregivers living with the elderly patients and experiencing caregiving strain can be found to have an increased mortality risk of 63% within 5 years. The caregiver strain can be an independent risk factor for the mortality rate of caregivers (Rottenberg, Baider, Jacobs, Peretz, & Goldzweig, 2016). This discussion emphasizes the importance of an adequate nursing staff for comprehensive support as a holistic unit of care.

### **Research Questions**

The purpose of this research study was to better understand the central phenomenon of stress and coping anxiety related to the well-being of elderly caregivers and their relatives with debilitating chronic illnesses. To achieve this goal, and based on the above literature review, the questions that drove this study were developed from the lived experiences of older adult caregivers and their debilitated chronically ill relatives in a rural southern county, which may identify common needs and themes. There were five different concerns when collecting qualitative data: trustworthiness, ethical

considerations, potential research bias, limitations, and record data. The central phenomenon was best understood by using the five steps to identify participants and sites to be studied.

With the required permission obtained, the decision was based on what types of information would best answer the research questions (Creswell, 2015). The central research question asked the following: What are the lived experiences of the older adults who are caring for their chronically ill relatives? Three supporting research questions were as follows:

1. How have older adult caregivers created and adapted to daily routines and coping strategies for their ill relative and the caregiver?
2. How have chronically ill, older adult patients created and adapted to daily routines and coping strategies for their ill relative and the caregiver?
3. What teaching and training strategies do older adult individuals, both caregiver and ill relative, feel would be helpful in their circumstances?

## **Chapter 3: Methodology**

### **Aim of the Study**

The aim of this study was to explore the lived experiences of older adult individuals in a rural southern county. The topic identified was the health-care phenomenon of the elderly caring for the elderly. This phenomenon was recognized when one or more older adults in the household had a debilitating disease and another had the role of primary caregiver for the ill relative, notwithstanding the fact that the caregiver may also have other health issues. In Chapter 3, the researcher detailed the methodology, including the research design and specific methods and procedures employed to construct and interpret the data used to address the central research question and supporting questions for this study. The central research question asked the following: What are the lived experiences of the older adults who are caring for their chronically ill relatives? Three supporting research questions were as follows:

1. How have older adult caregivers created and adapted to daily routines and coping strategies for their ill relative and the caregiver?
2. How have chronically ill, older adult patients created and adapted to daily routines and coping strategies for their ill relative and the caregiver?
3. What teaching and training strategies do older adult individuals, both caregiver and ill relative, feel would be helpful in their circumstances?

### **Qualitative Research Approach**

In light of the broad aim to understand the lived experiences of older individuals in which one suffers with chronic illness and another provides care, the researcher used a qualitative approach with a phenomenological research design in this study.

Phenomenological researchers, or phenomenologists, are concerned with the lived

experiences of people as they think about their experiences and what they mean. Phenomenology was premised on the notion that lived experience gave meaning to a person's perception of a phenomenon. Thus, the purpose of a phenomenological inquiry was to fully understand lived experiences and the perceptions of these experiences (Polit & Beck, 2008). Interpretive phenomenology, sometimes called hermeneutics, stresses the interpretation and understanding, not just describing, of human experiences (Polit & Beck, 2008). The objectives of interpretive phenomenological research are to cross the threshold into another's world and to determine the real-world wisdom, possibilities, and understanding found there. Interpretive phenomenologists often rely on indepth interviews with individuals who have experienced the phenomenon of interest (Polit & Beck, 2008).

A qualitative approach with a phenomenological research design was appropriate for this study, as this study was designed to explore the nature of the participants' interactions and relate their experiences of their roles as an elderly caregiver for an ill relative suffering from a loss of autonomy. As this was a qualitative phenomenological study, the researcher conducted interviews with the caregiving individual of the elderly relative suffering with chronic illness. The researcher used the central and supporting research questions described earlier to create the qualitative interview protocol used to collect data for this study (see Appendix).

The interview protocol included questions to elicit the experiences and perspectives of elderly individuals on providing care for their chronically ill relative, which was used to address the phenomenological research questions. After data were collected, the researcher conducted an interpretive phenomenological analysis following the guidance of Pietkiewicz and Smith (2014). The findings from this study were

grounded in the real-life experiences of elderly individuals caring for their elderly relatives. The outcome of this study involved the candid, indepth interviews with individuals who have experienced the phenomenon of interest based on preestablished trust and rapport, with the traditional approach of gathering and analyzing data (Polit & Beck, 2008).

### **Participants**

The researcher used purposeful homogeneous sampling in this study. In purposeful homogenous sampling, researchers look for participants with defining characteristics of their caregiving experiences to focus on the central and supporting research questions (Pietkiewicz & Smith, 2014). In this study, participants were selected because they were elderly individuals who were caring for their chronically ill elderly relatives who were included in this study. One relative was required to provide at least 4 hours of care per 24 hours, such as personal care, meal preparation, or other caregiving activities, and needed to reside in a rural county. As such, participants were required to be a significant other or part of a household in which at least one relative had a diagnosis of a chronic debilitating illness.

Individuals were excluded from this study if they were involved in any other research study or if they were both chronically ill and providing care for one another. They were also excluded if there were caregivers other than a relative providing care to the chronically ill individual. The researcher presented demographic information of the participants and the relationship of their patient. Furthermore, codes were used to refer to the participants. The same coding nomenclature was used for consistency and to reference back to know which participant was being referenced.

The research site for this study was flexible. After participants were identified and

recruited and after they elect to take part in the research study, the researcher scheduled their interviews. These were scheduled at a private location and at a mutually convenient time. Possible locations might include participants' homes, a selected room in the medical facility of their family physician, or a meeting room in their local church. These settings ensured privacy during the interviews while allowing participants to care for their relatives at the same time, if necessary.

Once Institutional Review Board approval was obtained, the researcher contacted the physician who had a professional awareness of different individuals who met the qualifications for the study. A medical home physician offered to initiate contact of older adult individuals. The initial contact consisted only of providing the potential participants with a recruitment flyer that introduced the study and contained information about the researcher. If individuals were interested in participating in this study, they could contact the researcher via the contact information provided on the recruitment flyer, through phone call, or by email. When they contacted the researcher, she provided them with a copy of the informed consent form, and a provision of recruitment was mailed to the candidates. If the first round of recruitment failed to yield an adequate number of participants, a secondary round of recruitment was to be attempted via the same methods.

No limitations on ethnicity or financial ability were placed on participants, although, in terms of demographic information, all participants were from a local rural southern county. The researcher interviewed participants for this phenomenological study following the guidelines of Guest, Bunce, and Johnson (2006). In their study, the authors found that, in qualitative research studies consisting of relatively homogenous samples, data saturation could be found between six and 12 interviews. Data saturation for this study was defined by the codebook development. This researcher monitored any newly

created code frequencies. Data saturation was determined when a point in the data-collection produces had little or no change to the codebook. The researcher was confident, given the large geographic area, that the number of participants selected for this study was sufficient to explore the lived experiences of older adult relatives in a rural southern county with one person serving as caregiver for an elderly relative who had a debilitating chronic illness.

### **Data-Collection Tools**

The interview is an important data-collection tool in qualitative phenomenological studies and was used for data collection in this research study. Interviews for qualitative research have advantages and disadvantages. Some advantages are that they provide useful information when the researcher cannot directly observe participants, and the researcher permits participants to describe detailed personal information (Creswell, 2015). A disadvantage could have been that the participants gave the interviewer the answers they think the interviewer wanted to hear. Furthermore, the participants may be uncomfortable with the presence of the interviewer, which could have affected the responses (Creswell, 2015). The only instrument used in the completion of this qualitative phenomenological study involved field notes along with an interview protocol that the researcher created. An interview protocol was a form designed by the researcher that contained instructions for the process of the interview, the questions to be asked, and space to take notes of responses from participants.

Jacob and Furgerson (2012) offered practical suggestions for writing an interview protocol to elicit useful data and for conducting the interview, such as using a script, creating open-ended questions, and beginning with easy and basic questions. Furthermore, it is imperative to make good connections with the individual being

interviewed. Making good connections will encourage individuals to share more of their story with a result of better data. The interview protocol for this study was designed to facilitate open discussions between the researcher and the caregiver about living with and providing care for a relative with a chronic debilitating illness, the impact of the chronic illness on the relative through the eyes of the caregiver, the caregiver's motivation for providing care, and the support that he or she received from others, such as family and health professionals. Open-ended questions encouraged participants to expand their answers and to give them the opportunity to deviate to other subjects (Jacob & Ferguson, 2012). For example, one of the first questions was a grand tour-style question or icebreaker, which Creswell (2015) stated is easy to understand and causes participants to reflect on experiences.

The interview protocol included the name of the project, time, date, place, interviewer, and participant. It also contained a description of the project and interview questions. There was space in the protocol for researcher field notes and observations. These can be important for the researcher in later stages of data collection and analysis to help frame results and emerging themes (Creswell, 2015). The researcher field tested the interview protocol with three professional colleagues to obtain feedback on the interview questions, which was used to clarify any questions if needed prior to conducting the interviews.

Data collection for this study involved the researcher communicating directly with human subjects. The Code of Federal Regulations, Title 45, Public Welfare Department of Health and Human Services' National Institutes of Health Office for Protection From Research Risks and Part 46 Protection of Human Subjects require that a review by the Institutional Review Board be conducted before any research activities involving human

subjects commence (U.S. Department of Health and Human Services, 2006). In accordance with the Code of Federal Regulations and Institutional Review Board, this researcher selected two health professional experts in the field of gerontology and one expert in field testing research to provide feedback on the quality of the interview questions in connection with this topic. The physician who was allowing the recruiting flyers in his office, a nursing practitioner of gerontological studies, and the chair of this dissertation committee were the three professional experts for this task. These experts were not provided data; however, they allowed the researcher to determine the validity of the instrument (U.S. Department of Health and Human Services, 2006).

### **Procedures**

The procedures for this research study were based on the central research question and supporting questions. Data collection in a research study involves a number of steps, such as obtaining research approvals, identifying and recruiting participants, conducting interviews, and following up with participants (Creswell, 2015). Further, Creswell (2015) noted that qualitative data collection involves direct contact with people and their personal views. The method may involve recording and spending time in private homes or at community site (Creswell, 2015). The first step of this research study was to secure approval from the researcher's dissertation committee and the Institutional Review Board of Nova Southeastern University to conduct the study. No potential participants were contacted prior to obtaining this approval.

The researcher identified the participants with the help of the local medical home family practice physician, who agreed to identify and invite qualifying individuals to participate in the study after approval by the Institutional Review Board was obtained. The physician identified individuals who met the criteria and who the physician felt

would be able to communicate in an interview. The researcher gave the physician's office manager copies of the recruitment flyer, and the office manager gave them to the prospective participants in the office. These recruitment flyers had the researcher's contact information so that participants could contact the researcher if they wanted to participate in the study.

After the final participants were selected and they agreed to participate, the researcher contacted the participants to schedule an interview and to remind the participants that they were volunteers and could withdraw at any time without any explanation or penalty. Pseudonyms were assigned to each participant for data confidentiality. After participants were selected and recruited, and after they signed the informed consent form for this study, the researcher scheduled the face-to-face interviews. The researcher scheduled the interviews around each participant's availability. The location was selected by using feedback from the participant and encouraging a quiet, comfortable setting where the participant could concentrate without interruptions or distractions.

The next step in the data-collection procedure was to interview participants. The researcher had a notebook for keeping interview notes. With the permission of participants, the researcher audio recorded the interviews. In the event the participant did not agree to be recorded, the researcher used the written notes only. In case the researcher was using only the field notes for collection of the data, the researcher was prepared to use the technique of engaging the participant with eye contact while writing notes. This procedure was to facilitate effective communication and capture the content of the interview.

The researcher announced the beginning of the interview, and the audio recorder

was turned on if participants had agreed. If participants did not consent to being recorded, the researcher recorded their answers to the interview questions by hand during the interview and had participants review these responses for clarity and accuracy immediately following the interview. The researcher followed the interview protocol, asked the questions from the interview protocol, and used probing questions as necessary to elicit greater depth of discussion from participants. The interviews took approximately 1 hour. During the interview, the researcher recorded the conversation if allowed and made observational notes of behaviors and body language. The researcher concluded the interview by asking participants if they had any final thoughts that they would like to share and giving them the opportunity to do so. After this, the researcher told participants that the interview was over and stopped the audio recording if necessary. The researcher thanked participants and checked that all necessary contact information was exchanged for follow-up and member checking.

### **Data Analysis**

Following data collection, the researcher used interpretive phenomenological analysis as the method of data analysis. This procedure focused on the thoughts, feelings, opinions, support, and emotions of the lived experiences of older adult caregivers and their debilitated chronically ill relatives in a rural southern county. Crist and Tanner (2003) described hermeneutic interpretive phenomenology based on Heidegger's philosophy. The primary goal of researchers using interpretive phenomenological analysis is to examine how individuals make sense of their experiences and to identify the essential mechanisms of phenomena or experiences that make them exclusive or different from others (Pietkiewicz & Smith, 2014). This method of data analysis was appropriate when the research question asked for meanings of a phenomenon with the purpose of

understanding the human experience (Crist & Tanner, 2003).

The analytical process in interpretive phenomenological analysis is often described in terms of a double hermeneutic or dual interpretation process. This meant that, while participants were making a meaning of their world, the researcher was decoding that meaning. This was done to understand what an experience was like from the participants' perspectives through an indepth examination of those perspectives in their unique context (Pietkiewicz & Smith, 2014). According to Pietkiewicz and Smith (2014), this was a three-step process of analysis. First, the researcher moved line by line through the interview transcripts, coding salient passages related to the research questions. This involved several passes through all transcripts to ensure thoroughness of coding. Second, the researcher began to create clusters out of those coded themes that reflected some degree of similarity to one another.

Once all codes were examined and placed into an appropriate theme, the researcher examined these newly created themes for additional similarities and differences. Third, the researcher began placing these themes according to their similarities and differences into larger conceptual themes that describe an overarching concept. This was an iterative process whereby the researcher moved back and forth between the three levels (i.e., codes, themes, and conceptual themes) to ensure that these overarching concepts adequately captured the appropriate codes. Discrepant data, or those codes that seemed to contradict the themes and conceptual themes, were considered in the data analysis and described. The researcher used NVivo Version 11 to facilitate data organization and analysis. The NVivo model is a computer-assisted, qualitative data-analysis software program available to assist qualitative researchers with the exploration, coding, and categorizing of data. This program lends itself well to interpretive

phenomenological analysis and other forms of qualitative data analysis.

The researcher used an interpretive phenomenological analysis to analyze data for this research study following the guidance of Pietkiewicz and Smith (2014). Through this process, the researcher first generated a list of codes from the interviews. These codes represented salient passages of text related to the research questions. Following this, the list of compiled codes from all interviews was thoroughly reviewed and the researcher examined the relationships among and between the codes. Codes that were closely related were placed into categories, and the researcher gave each category a short, descriptive title. These categories became the themes. Following this, the researcher examined these themes more deeply, looking again for relationships among and between these newly-created categories. The researcher placed similar themes together into themes and titled them, thereby generating the thematic structure for the findings. This thematic structure is presented as follows:

1. The central research question (What are the lived experiences of the older adults who are caring for their chronically ill relatives?) generated the overall themes of caring for self, life is full of anxiety, resentment and frustration, and resources for caregiving.

2. Supporting Research Question 1 (How have older adult caregivers created and adapted to daily routines and coping strategies for their ill relative and the caregiver?) generated the themes that life is full of anxiety and caring for self. Supporting themes for the theme that life is full of anxiety included (a) anxiety about partner's cognitive ability, (b) anxiety over finances, and (c) feeling overwhelmed. The supporting theme for caring for self was little time to relax.

3. Supporting Research Question 2 (How have chronically ill, older adult patients

created and adapted to daily routines and coping strategies for their ill relative and the caregiver?) generated the single theme of resentment and frustration, with no discernible supporting themes.

4. Supporting Research Question 3 (What teaching and training strategies do older adult individuals, both caregiver and ill relative, feel would be helpful in their circumstances?) generated the single theme of resources for caregiving, with no discernible supporting themes.

This process of data reduction from participant interview transcripts to conceptual themes allowed the essence of the experience of the phenomenon under study to emerge.

### **Ethical Considerations**

Ethical consideration for this qualitative research study was particularly sensitive to the study's participants. The collection of data involved interview transcriptions and recordings, which were locked in a cabinet in the locked office of this researcher to protect the participants' right to privacy. The storage data would be kept in the locked cabinet of the office for 3 years, after which time it would be destroyed by the researcher. The researcher showed respect to the participants by adherence to the principles of self-determination and full disclosure by describing the nature of the study to the participants. With respect for the participants' right to self-determination, the researcher required an informed consent. This procedure allowed the participants to accept or decline participation voluntarily. As a qualitative researcher, the ethical principle of beneficence was practiced. This researcher was prepared to terminate the research if there was reason to suspect harm upon continuing. The principles of justice and fair treatment were used throughout this study. The researcher treated the participants in a nonprejudicial manner and honored all agreements made with them.

This researcher applied these ethical considerations directly to this study. For example, each ill relative had the opportunity to understand that an interview would take place, but only the caregiver would be interviewed. If that arrangement was not acceptable to each relative, then the individuals were not in the study. Nonetheless, if the ill relative was not able to understand or was in a noncommunicative state, then the caregiver made the decision whether to be a part of the study. Each participant was asked to read and sign a consent and confidentiality form. Another very important part of this study was to assign a pseudonym for every participant to help with the coding, analysis, and reporting ensure confidentiality.

### **Trustworthiness**

Qualitative research and trustworthiness understood the rigor of naturalistic inquiry, meaning it was a natural situation that was uncontrolled instead of in a controlled laboratory environment. Guba and Lincoln (1982) understood this was an inquiry design with emergent data. Moreover, all four of the trustworthiness criteria were met by naturalistic inquiry (Guba & Lincoln, 1982). Trustworthiness was an important component of qualitative research. The researcher took steps to demonstrate trustworthiness by following the guidance of Guba and Lincoln. According to the authors, there are four components of trustworthiness relevant to qualitative research: (a) truth-value equals credibility, (b) applicability equals transferability, (c) consistency equals dependability, and (d) neutrality equals confirmability (Guba & Lincoln, 1982).

Credibility was accomplished when the study accurately reflected the “interpretation of human experience that people who also shared the same experience would immediately recognize” (Thomas & Magilvy, 2011, p. 151). Transferability in a qualitative research study referred to how broadly the findings of a study were applicable

to other contexts (Thomas & Magilvy, 2011). Dependability was when another researcher can follow the decision-making process used by the researcher, such as through an audit trail, when the researcher detailed the purpose of the study, discussed how and why the participants were selected, and described how the data were collected and the length of time the data collection lasted.

Lastly, confirmability occurs when the previously described aspects of trustworthiness are established (Thomas & Magilvy, 2011). In this research study, the researcher established trustworthiness through member checking and data triangulation. In member checks, the researcher provided a summary of the thematic results to participants for them to verify that the results captured what they wanted to convey in their interviews. Through triangulation, this researcher examined the consistency of different participants' data from within the same interviewing method (Polit & Beck, 2008).

### **Potential Research Bias**

Bias was a concern because it could threaten the researcher's ability to reveal the facts and provide a true reflection of participants' experiences and perceptions of a phenomenon. This researcher established a mechanism to detect whether biases had undermined the study evidence. The mechanism to reduce or eliminate bias for this study was the process of bracketing by maintaining a reflexive journal. Bracketing is defined as "the process of identifying and ceasing preconceived beliefs and opinions concerning the phenomenon under study" (Polit & Beck, 2008, p. 228). Through reflexive bracketing, researchers attempt to identify internal suppositions to facilitate greater transparency.

Furthermore, this clarification of the researcher's preconceptions, assumptions, and suppositions enhances the integrity and trustworthiness of the phenomenological

research (Polit & Beck, 2008). To bracket effectively, the researcher identified any interests that might have been taken for granted and clarify any personal values and areas of bias that might have impacted the data collection or analysis. The researcher identified and wrote down any areas of possible role conflict and made note of gatekeepers' opinions and attitudes toward the research (Polit & Beck, 2008). Furthermore, the researcher noted any personal feelings that suggested a lack of partiality (Polit & Beck, 2008).

## Chapter 4: Results

The purpose of this qualitative phenomenological study was to explore the lived experiences of older adult caregivers who were taking care of their older adult debilitated relatives in a rural southern county. Central to this purpose was the health-care phenomenon of the elderly caring for the elderly and exploring the experiences the individuals shared in interviews. The researcher explored a central research question and three supporting questions through this interpretive phenomenological study. The central research question was as follows: What are the lived experiences of the older adults who are caring for their chronically ill relatives? The three supporting research questions were as follows:

1. How have older adult caregivers created and adapted to daily routines and coping strategies for their ill relative and the caregiver?
2. How have chronically ill, older adult patients created and adapted to daily routines and coping strategies for their ill relative and the caregiver?
3. What teaching and training strategies do older adult individuals, both caregiver and ill relative, feel would be helpful in their circumstances?

The voice given to this population came from a stage in life that many people do not understand until they have experienced it. Based on this phenomenological study, the researcher reported a description of the essence of experience. Individuals who assume highly stressful caregiving responsibilities for loved ones with chronic disabilities are at risk for mental and physical health problems and, subsequently, are at increased risk for mortality equal to someone who has a history of cardiac disease (Perkins et al., 2012).

### Participant Profiles

The sample size consisted of 13 participants who lived in a rural southern county.

The selected participants represented older adult caregivers in their early 60s to their early 80s. The participants were caregivers of their brother, mother, sister, father, wife, partner, or husband. Participant 1 is a caregiver to her sister who has a terminal illness. She received little training when she became her sister's caregiver. She and her daughter learned how to do basic care-related tasks, such as turning patients and providing tube feedings via YouTube videos on the Internet. She struggles with the lack of resources available, such as more help with care for her sister and a lift chair. Participant 1 describes her stress level as very high, and she has little available to her in the way of self-care. She sleeps in 20-minute intervals and relies on her daughter stepping in to help out when she gets overwhelmed.

Participant 2 takes care of her brother, who is suffering from a terminal illness. She receives help from other sisters when they are available but is otherwise responsible for caring for her brother. She received some training on changing colostomy bags and other care basics from the nurses at the hospital. She describes the days she takes her brother to chemo as stressful but uses his time in treatment to relax or go shopping. She says her stress level varies from medium to high and attributes this to her brother's mood and if he is having a good day. She would like some resources to help her care for her brother, such as a ramp from the house to the yard, but otherwise believes she has worked out a good care routine over the last 12 years of caring for her brother.

Participant 3 is a man who cares for his wife, who suffers from severe confusion. In addition to caring for his wife, Participant 3 also provides part-time care for his elderly father. Participant 3 has lung cancer, which involves chemotherapy. He describes a typical day beginning very early in the morning depending on what time his wife awakens. He naps when his wife does, as he must keep an eye on her at all times, so she

does not leave the house on her own. Participant 3 is most upset by the fact that he is no longer free to enjoy the activities he once did, such as fishing and walking with his dog in the wood. He has no time to take a break to care for himself, and, even during his chemotherapy treatments, he is not alone. His stress levels are medium to high, and he would like to have the money to hire nursing help for his wife. His interview came to an abrupt end when his wife wandered out of the house to go to her favorite restaurant and he had to follow after her.

Participant 4 cares for her husband, who is suffering from a terminal illness. In addition to caring for her husband, Participant 4 works full time as a nurse. A typical day for Participant 4 begins early because she has to get her husband set with meals prior to leaving for work. She has help from a nursing assistant but worries each day when she comes home from work what her husband might have done that day. His disease impacts his thought processes, and Participant 4 has come home from work to find him rewiring their 300-pound television, painting parts of the hall a different color, and ordering hundreds of dollars' worth of musical instruments. Three times a week, Participant 4 helps her husband with at-home treatments after she puts in a full day of work. The process takes over 4 hours, after which she has to clean up and write notes while her husband goes to bed. On nontreatment days, Participant 4 works on call. She does not have time to care for herself and describes herself as looking older than she is. She says she cries a lot, and her stress level is very high all the time. She believes her stress level might be helped by money, which would ease the amount she has to work and help her pay bills in the absence of her husband's salary.

Participant 5 is a caregiver for his partner with severe respiratory difficulties. An accident several years ago involved oxygen therapy. The accident left the patient

debilitated. Participant 5 suffers from severe back pain but does not see a doctor for his condition. Participant 5's partner is still able to help with bills and some light household activities, which provides Participant 5 some relief, but he is responsible for the majority of her care. He has friends in the community, and he enjoys walking the dogs to care for himself. He does not describe himself as having a particularly high level of day-to-day stress. Participant 5 says that he has the material resources he needs to care for his partner but worries about his ability to continue providing care in the future due to financial and insurance concerns.

Participant 6 cares for her husband. She suffers from back and knee pain but does not see a doctor for this. Her husband suffers from a debilitating impairment. She says they do not do a lot of activities out of the house anymore. She does not believe her stress overall is high, and she finds time to relax and watch television, work puzzles, and go bowling. Her daughter helps with some care, but Participant 6 expressed frustration that her son helps very little. Participant 6 said having more money would help so that she could send her husband to adult day care, but this service is cost-prohibitive. She is concerned for the future when her husband deteriorates to a point where she must clean up after him.

Participant 7 cares for her elderly mother and father, both suffering from terminal illnesses. Participant 7 retired to move in with and care for her parents full time. Providing care for both parents is an all-day activity for Participant 7, and she has little time to take for herself. At one point, she tried to return to work part time but was unable to maintain the schedule, as working part time and caring for her parents caused her additional stress. Occasionally, Participant 7's daughter will visit and help her, but the daughter lives out of town, so this is infrequent. With enough sleep, Participant 7

describes her base stress level as medium, but this increases without enough rest, which is more often the case. She prays for strength as a means of relaxation. Participant 7 could not articulate what she thought might help her situation because she is glad to be able to help her parents despite not being prepared to do so.

Participant 8 provides care for her husband. Participant 8 is responsible for all her husband's daily care activities, including bathing and taking him to doctor appointments, as well as all household work. Her husband is often angry with her. Participant 8 said that, because she always must be ready to follow her husband around if he gets up and wanders off, she cannot go anywhere or do anything alone. She has a daughter, who lives out of town, who can help when she visits. When her daughter is in town, Participant 8 will visit with friends and her church family. She is afraid to drive so often feels isolated. Participant 8 says her stress level is always the highest it can be. She would benefit from help from an adult day care center but does not have the financial means to do this. She does not feel like the Veterans' Administration helps as much as they should with her husband's care or medical expenses.

Participant 9 takes care of his wife, who suffers from a respiratory illness. In addition to caring for his wife, Participant 9 is raising his granddaughter. Participant 9 starts his day early by making breakfast for his granddaughter before school and then later prepares breakfast when his wife awakens mid-morning. His wife enjoys using the computer, so she spends her day doing this while Participant 9 works on household activities, such as gardening, which he enjoys. He says he stays busy between his activities and household tasks, such as cooking and cleaning. Participant 9 has heart problems but describes himself as in good health for his age, which he attributes to his granddaughter, whom he clearly adores. His life is low stress, despite caring for two

individuals. Participant 9 says that attitude is everything and believes in staying positive no matter the circumstances. He enjoys activities with his friends who he meets weekly for lunch. Although he would prefer not to be his wife's primary caregiver, he recognizes that life cannot always be controlled, and caring for his wife is part of his journey.

Participant 10 cares for her elderly parents. Participant 10 retired to care for her parents and moved in with them, along with her dog. Participant 10 says a typical day begins early with making breakfast for and then bathing both parents. Then she prepares lunch and, while her parents sleep in the afternoon, she does housework before fixing dinner. This is complicated on days when her parents have doctor appointments; she brings both parents to any appointments and they navigate well with their walkers. She says she has no life and that being her parents' caregiver is all-consuming. Participant 10 says her stress level is 10-10 most days, but she relaxes by playing with her dog in the evening. She has no relief as her only sibling is deceased, as is her husband, so there is no one else to care for her parents.

Participant 11 is her husband's caregiver. Participant 11 had to retire when her husband became ill, which meant the loss of both incomes. She feels she always has to have an eye on her husband so that he does not wander off. Participant 11 has had to teach her husband basic skills, such as tooth brushing and showering. Her stress level is so high she has broken teeth and has nerve damage in her arm as a result. Participant 11 does not want to burden her children with the responsibility of caring for their father, so she does not ask them for help. Her husband has started drinking and easily becomes angry with Participant 11. She says she feels sometimes as if her husband has already died because he does not remember most of their life together. Participant 11 has financial concerns because it is hard to make ends meet, and she would like someone to

help her with care, but her husband will not allow it.

Participant 12 cares for her husband, who suffers from a terminal illness. She says her husband is not bedridden and can do a lot for his self, such as drive. Participant 12 says her husband has a very short temper and frequently and easily gets angry with her. Although she does not mind caring for her husband, Participant 12 says that her husband's attitude gets on her nerves. She says her son occasionally accompanies her and her husband to the doctor but does not like doctors so usually will not go. Participant 12 has a stress level that is pretty high, which she attributes to her husband's depression and anxiety, both of which make him angry. She would like to be able to call on someone else to help her sometimes but also does not want to bring anyone else into the home because she does not believe her husband's condition is anyone else's business.

Participant 13 cares for her older brother. Her brother was in the hospital for a while but was aggressive toward the nurses, so she removed him and brought him home with her. She says her brother stays in bed most of the time but can walk with a walker when he is up. Despite this, she is responsible for fixing his meals and has to help him with toileting. Her brother has become physically aggressive with her, and she sometimes needs to get away from him, but she loves him because he is family so believes it is her responsibility to care for him. Participant 13 has a very high stress level, especially during periods when her brother is physically aggressive. To relax, she plays bingo on the weekend to win some money. She wishes her brother was more cooperative and less aggressive so she could put him in a nursing home.

### **Interview Process and Data Analysis**

The 13 interviews were 45 to 60 minutes long. The researcher explained the paperwork, reviewed the purpose of the study, and discussed the research procedures at

the beginning. The participant signed the consent form after the researcher discussed it and explained the study was voluntary and participants could withdraw at any time. To begin each interview, the participant and the researcher exchanged contact information, and the researcher explained the need to record the interview and take notes. The audio recorder was turned on, and the researcher asked the open-ended questions to which the participants responded. The researcher explained that also taking field notes to include details and observations might need to be included in the report from the interview. The researcher made sure the participant knew that the transcription of the interview would be sent to them by email or U.S. mail for changes or permission to use as is. The interviewee was given an opportunity to ask questions and add information at the end of the interview.

**Data saturation and transcription.** Data saturation occurs when no new information is generated from an interview. Data saturation was reached in the 13th interview in this qualitative phenomenological study. All the themes had been mentioned and discussed in the first 12 interviews. When the researcher finished recording all 13 of the indepth interviews, the audio recordings were transcribed. The transcription of the interviews marked the beginning of the data-analysis process. The Microsoft Word documents that resulted were created after each interview. They were stored on an external hard drive for the sake of security to safeguard the data. The original interview and field notes for each participant were placed in a manila folder and locked in a file cabinet in the researcher's office.

**Internal reviews.** The researcher validated the audio recordings of the interviews at least two times by writing down what each interviewee said as a part of the data analysis. The transcriptions were validated by internal checks as the researcher made sure

the transcription was correctly transcribed and in detail. The researcher wrote notes in the margin to help remember any significant information. A few minor changes such as punctuation were made to aid the comprehension of the interview and to help the coding of the data and its analysis.

**External reviews.** The researcher conducted member check by emailing or U.S. mailing the transcriptions to the participants and requested that they change or approve the transcripts and return them to the researcher in five business days. Ten participants returned the transcriptions with no changes, and three returned the transcriptions in 5 days with only minor questions or comments. This action concluded the external reviews. The transcribed documents numbered 52 pages and the field notes were 26 pages, forming a total of 78 pages of data.

**Data-analysis process.** The researcher used a qualitative methodology to find and identify emerging themes after the member check of the interview transcriptions was completed and validated. The data analysis was executed on the collected data with the use of NVivo 11. The researcher used this software program to code the data, identifying themes that emerged along with certain words common to all of the interviews. When the researcher was able to compare and contrast information from the interviews and field notes through NVivo 11, it was possible to comprehend which experiences were common to all participants. The researcher did not load the field notes into NVivo 11 so that certain ideas would not be counted twice.

In addition, NVivo 11 loaded the interview transcripts after they were validated, which helped to identify themes. The program also allowed the researcher to perform a word search to show words and phrases that were common to all interviews. For example, word searches, such as caregiving, elderly, overwhelmed, anxiety, frustration,

and stress, were identified. The researcher could see the themes that had been identified manually were confirmed by NVivo 11. Data nodes were then added to NVivo 11 from the themes, and the researcher was able to code the interview transcripts. Color stripes made it easy for the researcher to find appropriate quotes from the participants to add to the discussion.

## Findings

Interpretive phenomenological analysis yielded four themes: (a) life is full of stress and anxiety, (b) caring for self, (c) resentment and frustration, and (d) resources for caregiving. Two themes contained supporting themes, but the other two did not. All themes addressed at least one supporting research question, and all themes, when taken together, addressed the central research question.

**Theme 1: Life is full of stress and anxiety.** The researcher generated this theme based on the number of participants who shared their stress and anxiety and because of the number of stress-related coded statements in the interview transcripts. Participants' lives were characterized by an almost constant state of anxiety, and 12 of 13 participants spoke of this (see Table 1). All but one participant described living in a state of medium to high stress.

Table 1

### *Responses Related to Theme 1*

Item	No. participants	Coding frequency
Life is full of anxiety		
Anxiety about patient's cognitive ability	5	7
Anxiety over finances	9	11
Feeling overwhelmed	12	39

The first theme addressed Supporting Research Question 1, which asked the following: How have older adult caregivers created and adapted to daily routines and coping strategies for their ill relative and the caregiver? This theme is about the anxiety and overwhelmingness that participants described experiencing in their day-to-day lives. Participants worried about their futures and the futures of their loved ones. They were concerned with the state of their finances and insurance. Participants described their days as beginning early and ending late, full of caretaking, housekeeping, and doctor appointments, leaving little time for participants to relax and destress. Participants spoke of the sources of their anxiety in different ways. They spoke of their fears about their financial situation, the constant worry about the patients for whom they were providing care, and the stress that being a full-time caregiver takes. These different forms of stress led to the generation of three supporting themes in support of this theme: anxiety about patient's cognitive ability, anxiety over finances, and feeling overwhelmed.

*Anxiety about patient's cognitive ability.* Five of 13 participants cared for patients with impaired cognitive ability. These participants experienced anxiety about the cognitive functioning of their patients because, for many, the patient would act irrationally or make poor decisions, meaning caregivers had to be on constant watch. The interview with Participant 3 was cut short when his wife, suffering from dementia, suddenly got up and wandered out of their house, heading for her favorite restaurant that the couple frequents sometimes multiple times a day. He stated, "Well, I guess that is all the time I have for the interview," as he left for the restaurant with his wife.

Participant 4 experiences anxiety every day when she returns home from work because she does not know "what to expect my husband has gotten into" around the house that day while she has been at work. Participant 4 stated, "I find myself having

anxiety in the afternoons as I drive home from work.” Participant 4 believes that her husband is trying to be helpful, but, because “his mind is not that clear,” what he believes to be helpful can, at best, result in small mistakes and, at worst, injury to him. She spoke of an incident when he wanted to touch up some paint spots on a wall but used the wrong color of paint. Another time, Participant 4’s husband tried to rewire the television that weighed a significant amount and it fell on top of him, leaving him bruised all over.

Like Participant 4, Participant 6’s husband has some form of cognitive impairment. The doctor has confirmed this, although he has not confirmed a diagnosis of Parkinson’s, which is what Participant 6 believes her husband has. Participant 6 worries about the current state her husband is in, as he suffers from complications of diabetes in addition to cognitive impairment. However, Participant 6 seemed more concerned about what the future might hold for the couple. Participant 6 is anxious about how to care for her husband when his health declines, recognizing “he is not going to get any better.” Participant 6 stated, “I will worry about that when or if it happens, but not now,” indicating that Participant 6 recognizes this will become a greater concern later while acknowledging this is something that is already on her mind.

Participants 11 and 13 also care for patients with cognitive impairment. Participant 11 said after her husband’s bout with meningitis and encephalitis, he was left with only three quarters of his brain function and this continues to decline. Participant 11’s husband has no memory and Participant 11 had to teach him, as best Participant 11 could, how to function and complete daily tasks. Her husband responds in anger, which upsets her. Participant 11 said that, because of her husband’s cognitive impairment, he will get up and wander out of the house in the middle of the night, which causes her significant stress to the extent she has “never slept with both eyes,” as she said.

Participant 13 experiences similar anger from her patient, who is her brother. Participant 13 said her brother “has mental problems,” which she believes his wife’s death the prior year exacerbated.

*Anxiety over finances.* Nine participants shared the financial worries they experience as caregivers. Based on their statements, participants worried about the current state of their finances and their financial outlook for the future. For two participants, Participant 7 and Participant 10, this anxiety may be attributed to the fact that these caregivers had retired to care for their patients who were, in both cases, their elderly parents. Some participants shared financial concerns related to insurance and Medicaid in terms of the resources unavailable to them because of inability to pay. “We need a lift chair,” said Participant 1, “but insurance will not pay.” This frustrated Participant 1 because the insurance company had previously said it would pay for the lift chair, but then “they switched the rules.” Participant 5 has used available community help and friends in the absence of money to pay for needed resources. “Me and the next door man built the ramp we got now,” said Participant 5, but then indicated the ramp was not good. Participant 5 is concerned for when Medicaid runs out later this year and what this might mean for his ability to provide care for his partner.

Participant 8 worried that the Veterans’ Administration was not doing “what they should,” in Participant 8’s view. Participant 8 has to use savings to care for her husband because the Veterans’ Administration has told her that her husband does not qualify for Veterans’ Administration benefits, which frustrates her because “he served his country.” Participant 8 and her husband were told they did not qualify for Medicaid because their social security income is too high. She is anxious about what will happen in the future when the savings dwindle, as they already cannot afford to pay full price for care at this

time.

Other participants spoke in more general terms about their money fears.

Participant 3 would like to be able to have helped caring for his wife but does not have the money nor a way to obtain the money required for this. Participant 4 worries because medical bills “are piling up.” As a nurse, Participant 4 still has some income, but, with the loss of her husband’s income, paying the mortgage and bills is now very stressful for her. Participant 11 also felt the stress of bills piling up, stating, “I could use money to help pay bills.” This statement indicated that Participant 11 might be experiencing difficulties making ends meet, which is a source of stress for her and other participants.

***Feeling overwhelmed.*** All but one participant made statements that indicated life as full-time, round-the-clock caregivers was overwhelming for them. As Participant 1 said, life is “stressful and overwhelming.” Participants described their daily routines of caregiving for their patients, often describing little down time during participants’ days and leading to the conclusion that they were often overwhelmed. Participant 3 cares for his wife. Participant 3 stated the following:

[Our day] starts anywhere from 5:00 a.m. to 10:00 a.m. She may fall asleep at 4:00 p.m. and wake up at 2:00 a.m. and want to roam around. I take a nap when she does. She will say, “I am going home,” gets her coat, and walks out the door into the car. I think when she says home, she means her mama’s. I have to get her out of the car and back in the house because I can’t take her to her mama’s in the middle of the night.

Although Participant 4 is retired, Participant 4 continues to work, which adds another level to the daily stress and overwhelm she feels as a caregiver who also maintains a career as a nurse. Participant 4 said, “Everything is on my shoulders now.”

Participant 4 shared her exhausting daily routine:

I get up early in the morning and set my husband up with food for the day. On Mondays, Wednesdays, and Fridays, when I get home from work I have to go into the dialysis room we made for him. It takes about an hour to get the osmosis and dialysis machines cleaned and ready for this dialysis. I get him the dialysis chair, complete all the protocols, access his fistula, start his dialysis, and continue the dialysis protocols throughout the process. During that time, I am constantly completing protocols; I cook supper, and feed him supper while he is on dialysis and watching television. This goes on for 4-1/2 hours. Then, I go through the protocols to remove him from dialysis and he goes to bed. I stay up, clean, and pack the machines, and write my notes from the procedures. By that time, it is two or three in the morning before I would get to bed. On the days I am not giving my husband dialysis, I am pulling call for my job as a nurse and go on calls at any time during the night and work the next morning all day. This goes on week after week.

Participant 5 and Participant 7 do not mind the routine of caring for their patients, despite feeling overwhelmed. Both participants believed it was their responsibility for providing care and were willing to do so no matter what it took. Participant 5 stated the following:

[I] get up, take sugar, fix medicine, fix breakfast or go to the store to get something. I got to get zip ties to fix the walker. Change bed, wash clothes, get a pan of hot water for bath, clean bedside toilet. She ain't got nobody else. They sent her home from hospital with something I could catch, but I still did everything.

Participant 5 recognized that his partner did not have anyone else to help her, so the work all fell to him and he said, “It don’t bother me nothing.” Participant 7 felt that, as the daughter of two elderly parents requiring care, her responsibility was to care for her parents. Participant 7 described caregiving as “an all-day thing,” but she did not seem to mind the work, stating, “I just want to see them through.”

For patients who have regular doctor’s appointments, days quickly become even more overwhelming for caregivers. Participant 10, who cares for two parents, described this routine:

I get up early before them, fix breakfast, and then get them up to eat. After breakfast, I bathe them both. By the time I finish the morning routine it is time to fix lunch. After lunch, they take a 2-hour nap. During that time, I clean the kitchen, do the laundry, and straighten up the house and start dinner. After dinner they watch television and I get them ready for bed. This is, of course, if they do not have a doctor’s appointment. I take them both to each other’s doctor’s appointments so they can get out some. On those days, I take them out to lunch. They are both on walkers, so I get them the walkers out of the car, and they can do okay.

Participant 12 also described overwhelming days of care made more complicated by doctor appointments. Participant 12 said, because of her husband’s condition, she spends a good amount of time cleaning up after episodes of incontinence. “I have to clean him up and wash clothes every day,” said Participant 12. Participant 12’s husband requires constant oversight so he does not fall, so, in addition to cleaning him, laundering clothes, doing household chores, and chopping wood, Participant 12 must have an eye on her husband. The son does not want to be involved in doctor appointments and visits, so

this job falls to Participant 12, although Participant 12 said her husband is able to drive to the doctor.

Participant 9 presented a discrepant case within this theme. Participant 9 is an elderly man who cares for his wife while simultaneously raising the couple's 11-year old granddaughter. Unlike other participants, Participant 9 seemed content and happy with his caregiving role. He enjoys taking care of his granddaughter, whom he describes as "a good thing for me." Participant 9's wife did not experience the resentment and frustration common in other participants' patients. "She doesn't complain at all and does not mind being waited on," Participant 9 said. In addition, despite having heart problems requiring stents, Participant 9 said, "I am doing good for 80 years old," which he attributes to his granddaughter, who "keep me on my toes."

Participant 9 believes that attitude is everything, and, although he wishes he did not have to be his wife's caregiver and that they were not in this situation, he said, "There is nothing that I could change that would make a difference." Participant 9 stated the following:

You have to adjust your attitude in the situation you are in. The roles have changed, and we have accepted that. I believe in ACE: A is attitude, C is for choice, and E is for effort. Everything is done with love....You can't always control what happens to you, but you can control how you react to them. This comes from a lot of soul searching. You have to prepare yourself and make an attitude adjustment. I would not like it if I had to bathe her and if she was bedbound. But I would adjust my attitude and do it.

**Theme 2: Caring for self.** Nine participants made statements related to self-care, or lack thereof, which supported the creation of this conceptual theme. This conceptual

theme was defined by the little time participants had to care for themselves. Caregiver participants spent most of their days providing care for their patients, which meant little time that caregivers could take for themselves to relax and recharge. Across interviews, one discernible supporting theme emerged in support of this theme: little time to relax. The second theme, caring for self, also addressed the first supporting research question. Table 2 illustrates the coding frequencies for this theme.

Table 2

*Responses Related to Themes 2 to 4*

Item	No. participants	Coding frequency
Caring for self		
Little time to relax	9	11
Resentment and frustration	7	13
Resources for caregiving	2	4

Participants spent so much time during the day, day after day, caregiving for patients, which many described having little time left to focus on themselves and their own care. Two participants, Participant 7 and Participant 8, manage to sneak in some time for prayer each day. Participant 8 said, “I prayed. I have no time to relax.” Other participants are less lucky, and, for two participants, caretaking impacted sleep. Participant 1 spoke of sleeping in 20-minute increments, and Participant 12 said, “I relax when I sleep” and at no other time. Participant 10 enjoys playing with her dog once her parents are asleep at night, and this relaxes her.

Participants who had some occasional help from others were able to spend more time taking care of themselves or doing things they enjoyed. Participant 2 takes her

brother to his chemotherapy appointments. Participant 2 said, “Chemo days are hard days, but, once I get him settled at the clinic, I can relax and go to the mall or something like that. He is never ever left by himself.” Participant 6 has a daughter who lives out of town but comes in to help as much as possible. Participant 6 stated the following:

When my daughter had him for a few days, I just did nothing but just rested. I relax by watching television, doing puzzles, bowling sometimes, and going out to eat some. I watch football every Sunday, which is how I relax.

Participant 13 also occasionally gets out of the house to relax, playing bingo on Friday and Saturday nights to win some money.

**Theme 3: Resentment and frustration.** Seven participants made statements supporting the generation of this theme, but no discernible supporting themes emerged. These contributions and coding frequencies are highlighted in Table 2. This theme is about the frustration felt by both participants and those for whom they are providing care about their current situation. These statements were often in reference to the resentment and frustration patients felt about their current medical status. However, within these statements was a more subtle subtext: Caregiving participants were also frustrated and resented their caregiving role. The third theme addressed Supporting Research Question 1, like the first two themes. This third theme also addressed Supporting Research Question 2, which asked how older adult patients created and adapted to daily routines and coping strategies.

Participant 3 expressed frustration over the lack of information she received from doctors upon beginning this caregiving journey. As Participant 3’s sister uses a feeding tube, her medications must be crushed for delivery. However, Participant 3 found out later that the medications were time released and, therefore, should not be crushed. She

was frustrated that no one told her and stated, “Someone should have told us, and the doctor should know better than to order meds that could not be crushed.” Participant 3 used to enjoy taking walks with his dog and fishing. “Sometimes handling her gets on my nerves pretty bad,” Participant 3 said; “I don’t get a break; she always wants to be with me.” Even when Participant 3 is at his own chemotherapy treatments, he does not get a break, as his wife goes with him. “It takes total dedication,” said Participant 3, noting that he no longer has time to see his friends because of the work.

Participant 4 experienced a shift in household roles when her husband became ill and could no longer work as the breadwinner of the family. “It is very hard for him watching me do all I have to do,” Participant 4 said. “It makes him angry at me and really angry at everything and everybody,” Participant 4 noted of her husband’s mood now that he is the patient. Participant 8 and Participant 12 made statements that astutely characterized the dual resentment and frustration felt by caregivers and patients. This seemed to be a cycle of negative reinforcement, wherein the resentment and frustration felt by the patient led to feelings of resentment and frustration the caregiver. Participant 8 stated the following:

While caring for him, he would get very angry. He will say, “Get out, go to hell, you do not do anything.” He will take his four-prong cane, pick it up, point it at me, and say, “I will show you what you can do.” I never let him corner me in a room; he is very strong and will hit. I am always careful with what I say and do around him. I cannot go nor do anything. He gets up any time at night and I have to get up with him. Sometimes he gets mad at night and I will leave the bed and go in the living room. I pray to God to give me strength and wisdom to keep him home as long as I can. One time I was crying, and he asked me, “Why are you

crying?” I said, “You yelled at me.” He said, “I didn’t do that, I am sorry you are crying, I don’t want people to hate me.” He just doesn’t understand.

Similarly, Participant 12 stated, “He has a short temper and is angry at me all the time. I don’t mind doing and caring for him, but his attitude gets on my nerves.”

Interestingly, none of the male participants caring for their wives noted wives expressing anger in the way that female participants did of their husbands. Although husbands were frustrated by their new caregiving roles, this frustration had more to do with the fact they could no longer enjoy the activities they once did because caregiving took up all of their time. For those wives taking care of their husbands, the frustration seemed to be more about the anger and resentment their husbands expressed toward them. Participant 11 noted that her husband “knows I will take his anger,” and, although none of the other female participants noted this outright, Participant 11’s theory may extend to these other female participants who bear the brunt of their husband’s anger. Even Participant 13, who cares for her brother, said, “I have to watch because when he gets mad, he will hit me. I leave him alone sometimes to get away from him.” Participant 13 believed the source of her brother’s anger was his inability to no longer do what he liked to do. Participant 13 indicated that she would put her brother in a nursing home if he were more cooperative, but no nursing homes will take him now because he is so combative.

**Theme 4: Resources for caregiving.** Although only two participants spoke specifically of their teaching and training needs, their statements were important to include the address of this supporting research question. The fourth theme, resources for caregiving, addressed the third supporting research question, which asked about the teaching and training strategies older adults felt would be helpful in their circumstances.

Table 2 includes the coding frequencies for Theme 4. Participant 1 needed more education and support for caregiving. When learning to suction and use tube feeding, Participant 1 said “No one explained how to take care of [my sister].” Participant 1 wanted to know “how to keep her comfortable” and shared an example when, early on in the caregiving process, Participant 1 “did not know to leave her up for tube feeding,” which led to aspiration. Rather than learning from a nurse or doctor, it was a friend of Participant 1 who told her that patient’s head should be elevated for 1 hour after a tube feeding to prevent the patient from aspirating.

Participant 9, who cares for his wife, also wanted more education. He does well at caring for his wife but says, regarding any information he needs, “I will have to research it.” Participant 9 said, “I would like as much education as I could get to help me take care of her. I have not been presented with any information.” Participant 9 believed this was especially important because caregivers are a “semi- to anti-social group,” given that most of their day is spent at home providing care. Participant 9 would like to see more information for caregivers published somewhere easily accessible so they can teach themselves.

### **Summary**

The lived experience of elderly caregivers for elderly relatives is characterized by stress, resentment, and frustration. Caregiver participants spend the majority of their days providing care for others, with little time left for themselves. For daughters responsible for the care of both parents, this stress is even greater because they have to negotiate care, household chores, and doctor appointments. There is a sense of constantly feeling overwhelmed by their circumstances but with no good alternative solution. The daughters interviewed felt responsible for caring for their parents and that this was not the

responsibility of anyone else. Wives caring for their husbands and brothers were also in a constant state of stress and overwhelm.

Compounding this was the feeling that they had to take the verbal abuse and sometimes physical aggression that their husbands and brothers displayed toward them, which was how these men expressed their resentment and frustration. Receiving such aggression made these female participants resentful of their patients and frustrated with the patients and the circumstances of providing care. Yet, one participant emerged as a discrepant case and provided a counterpoint to the other participants. Although this participant was not happy that he had to be a full-time caregiver to his wife, he had accepted his role and adjusted his attitude to make the best of the situation. His wife seemed content with the situation, which may have also impacted this participant's outlook.

## **Chapter 5: Discussion**

Many older adults have chronic illnesses that require visits to care providers. The Institute of Medicine (2008) pointed out that the number of older adult patients can potentially overwhelm the number of physicians and other professionals who will be available unless more is done to ensure an adequate supply of health-care professionals for gerontology. Additionally, older adult populations living longer contribute to a shortage of health-care providers and fewer resources for older adults in rural southern counties, necessitating at-home care by elderly relatives. This study provided an excellent opportunity to explore the lived experiences of older adult caregivers and their debilitated chronically ill relatives. Caregiving for relatives among the elderly involves a relative having a chronic illness, wherein one serves as the primary caregiver to another, notwithstanding the problems associated with the caregiver's own health issues. The purpose of this qualitative phenomenological study was to explore the lived experiences of older adult caregivers who are taking care of their older adult debilitated relatives in a rural southern county.

### **Interpretation of the Findings**

Data were collected and analyzed based on the central research question and supporting questions. The central research question asked the following: What are the lived experiences of the older adults who are caring for their chronically ill relatives? The three supporting questions were as follows:

1. How have older adult caregivers created and adapted to daily routines and coping strategies for their ill relative and the caregiver?
2. How have chronically ill, older adult patients created and adapted to daily routines and coping strategies for their ill relative and the caregiver?

3. What teaching and training strategies do older adult individuals, both caregiver and ill relative, feel would be helpful?

Analysis of the data revealed four themes: (a) life is full of stress and anxiety, (b) caring for self, (c) resentment and frustration, and (d) resources for caregiving. Two themes contained supporting themes, but the other two did not. All themes, when considered together, addressed the central research question. Findings are interpreted in relation to the findings of previous research below.

**Life is full of stress and anxiety.** The theme for life is full of stress and anxiety involved participants' worry about partners' cognitive abilities, financial anxiety, and feeling overwhelmed. Such stress and anxiety were illustrated by Participant 1 when she said, "Most of the time [her stress level was] higher than 10," with 10 representing the highest level of stress. This finding supports the stress and coping theory of Lazarus (1981) in relation to the effect stress has on decision making skills for older adult caregivers. Lazarus was concerned with the way that stress impaired human functioning and observed that stressful effects, such as severe anxiety, interfered with the thought processes of overworked health-care workers. In a 5-year study, Jaracz et al. (2015) also found that anxiety was related to caregiver burdens.

Findings also revealed that stress and anxiety stemmed from participants' worry about partners' cognitive abilities. Folkman and Moskowitz (2004) furthered the theory of Lazarus by emphasizing the cognitive component of stress. Their research focused on various types of stress and found that caregiving stress included adjusting to illness progression, the shifting of responsibilities from the patient to the caregiver, unexpected improvement in the patient's health, and role conflict (Folkman & Moskowitz, 2004). Participants of the present study reported worry over partners' cognitive abilities. For

example, Participant 4 stated the following:

I found boxes delivered to the house where he had ordered several hundred dollars' worth of musical instruments. And yet another time, he decided to rewire the back of the television. The television fell on him and bruised him all up. I find myself having anxiety in the afternoons as I drive home from work.

Not knowing what to expect as a result of her partners' impaired cognitive functions caused Participant 4 great stress and anxiety.

**Caring for self.** The theme of caring for self included concerns of inadequate sleep, little time to relax, and receiving help from others. Mostly, participants spent much of their time providing care for their relatives, which meant little time that caregivers could take for themselves to relax and recharge. Older adults' approach to self-management of daily symptoms varied widely in evaluation processes of symptoms or illnesses. These adults were thoughtful decision makers in managing their health, considering the symptoms, evaluating treatment alternatives, and selecting the approach that they believe is likely to be most beneficial (Arcury et al., 2012). Older adult caregivers have been found to use prayer, herbs or supplements, body-based and manipulative methods (e.g., chiropractic or massage therapy), rest, reduced activities, and over-the-counter medicines (Arcury et al., 2012). A few of the participants stated they used prayer to relax, and walking was a way to recharge, but most did not have the time to engage in self-care strategies. High stress and anxiety may influence the quality of life of the caregiver and, in turn, decrease their ability to provide care for their relatives. Additionally, some caregivers reported receiving intermittent help from family and neighbors, but this assistance was not adequate to give them the necessary support needed for them to engage in self-care (Smith-Johnson et al., 2015).

**Resentment and frustration.** The theme of resentment and frustration involved negative feelings that caregivers had toward their roles as caregivers, feelings of no appreciation from their relatives, and the amount of time spent on caregiving. For example, Participant 3 stated, “Sometimes handling her gets on my nerves pretty bad. I don’t get a break; she always wants to be with me.” This finding partially supports previous research wherein caregivers can experience frustration as a result of role reversal. In a study of African American family caregivers from rural communities of North Carolina, it was found that elderly male caregivers experienced difficulty providing care because of role reversal, wherein husbands were now caring for their wives (Smith-Johnson et al., 2015). Role reversal contributed to elderly males becoming frustrated with their new roles as caregivers, leading to frustration and resentment toward their wives.

**Resources for caregiving.** Resources for caregiving, which included the need for teaching and training for older adult caregivers, was another important theme that emerged. Participant 9 was able to adjust himself to the new situation but articulated the need for information and training as future medical needs and caregiving became more complicated as the wife moves through her disease process. Participant 1 talked about turning to YouTube for learning about caregiving. Although two participants indicated they received training for specific tasks (i.e., colostomy care and hemodialysis), overall resources for caregiving were still required.

The finding of the need for resources for caregiving supports the research of Smith-Johnson et al. (2015), who also found that caregivers received little to no formal or informal support from professionals or community agencies. Additionally, Petty (2015) found that families and friends may be willing to help, but, for the most part, they are unprepared for the task of caregiving. Petty noted that these informal caregivers lack

knowledge about the specific illnesses, are unfamiliar with strategies for disease management, and are unequipped to provide for activities of daily living, such as assisting with bathing, eating, toileting, and dressing. In addition, caregivers themselves can lack the ability to provide the instrumental activities of daily living, such as transportation, financial management, shopping, and housekeeping. In short, complicated care needs create a knowledge gap that becomes a barrier to caregiver empowerment (Petty, 2015).

### **Literature and Practice Supported by Findings**

Researchers for the Institute of Medicine (2008) recognized the current impact of the baby boomer generation on this country. The number of adults aged 65 and older in the United States will almost double between the years of 2005 and 2030 (Institute of Medicine, 2008). Many older adults have chronic illnesses that require visits to care providers, at least annually. The management of chronic illness depends on coordination and team-based care by these providers. The problem statement for the researchers at the Institute of Medicine pointed out that the number of older adult patients can potentially overwhelm the number of physicians and other professionals who will be available unless more is done to ensure an adequate supply of health-care professionals for gerontology (Institute of Medicine, 2008).

Influences such as adequate benefits, personal fulfillment, excitement, and opportunity to help others are important when undergraduate students select a career (Eshbaugh et al., 2013). According to research, 78.9% of students who responded to a 2013 research study indicated that employment opportunity was either important or very important to career choice. Fewer students (68.4%) indicated that an in-demand career was either important or very important. Although many students cited interest as a reason

for pursuing a career, students could only view a career as fitting their interests if they were aware of that career (Eshbaugh et al., 2013). A study conducted by Eshbaugh et al. (2013) indicated that approximately only half of the undergraduate students at a university that has a gerontology program could define gerontology, which could be problematic when recruiting students to the field.

The demand for educated professionals with expertise in aging has increased, and it is most important to recruit and train gerontological professionals who are passionate about elders and serving their needs. The authors noted that, by being provided accurate and indepth information about the field of gerontology, students may understand the importance and rewards of a career in that field as they consider their future in health care. Only 2% of new nurse graduates reported that they would specialize in gerontology. The lack of providers in this specialty area results in uninspiring clinical settings and a shortage of role models (Eshbaugh et al., 2013).

The objective of this study was to seek answers on how to meet the needs of the increasing older adult population. To approach this problem, researchers at the Institute of Medicine formed a committee task force called the Committee on the Future Health Care Workforce for Older Americans. Guided by John W. Rowe, the committee collected statistical data and conducted surveys with medical students, pharmacists, nurses, and social workers to approach this problem (Institute of Medicine, 2008). A lack of skills and resources to understand physical symptoms of patients with advanced cancer and other diseases exhibited by older adults may cause psychological distress for both the patient and family caregiver, such as a spouse who is also elderly. Family caregivers need practical information provided by health professionals on what symptoms to monitor, how to interpret the symptoms accurately, and when to contact a professional. These

skills will enable the caregivers to provide optimal care and maintain their own health and well-being. The findings in this study established that caregivers caring for themselves were also important for the welfare of both the caregivers and their patients.

The older adult population will benefit from a continuum of care in health promotion and palliative care (Institute of Medicine, 2008). According to this report, only 20% of medical students receive palliative care training, and 39% feel unprepared to address patient fears. Less than 1% of nurses and pharmacists and less than 4% of social workers specialize in geriatrics. This study supports that informal caregivers such as family members or friends, receive very little, if any, training, which causes an increase in stress and coping problems. The consequences of the phenomenon of elderly caring for the elderly are greatly influenced by the baby boomer generation. The continuum of health care diagram, created by this researcher, was for the purpose of patient information in the rural southern county home and workplace of this researcher.

In a 2016 research study, Snavelly proposed there were several factors leading to the nursing shortage. First, during the economic recession of 2007 to 2009, registered nursing employment increased because the nursing workforce that had not been working or only working part time returned to the workforce full time. As the economy recovered, those nurses who went back to work during the recession returned to part time or not working at all. Second, Snavelly observed a significant number of nurses are aging and nearing the point of retirement. The author stated, “The National Council of State Boards of Nursing reports 55% of the RN workforce is age 50 or older; the Health Resources and Services Administration projects that 1 million nurses are eligible for retirement in 10-15 years” (Snavelly, 2016, p. 98). The baby boomer generation of 1946 to 1964 was followed by a remarkable drop in the American birth rate, leaving a ripple effect in the nursing

workforce (Snavely, 2016).

Third, the nursing schools reported substantial shortages in faculty, thereby restricting nursing programs from enrolling an optimum number of new students. The author stated, “At the beginning of the 2014-2015 academic year, over half of all United States nursing schools reported a cumulative total of 1,236 full-time faculty vacancies in their programs” (Snavely, 2016, p. 99). Snavely’s fourth observation was a high attrition rate among nurses. Nursing is incredibly stressful, causing a high nurse attrition rate and fast burnout. The average turnover rate of registered nurses in 2014 was 17.2% from 13.5% in 2011 (Snavely, 2016).

Fourth, the 2010 Census showed the 65 and older population grew faster than the total United States census population in 2015. With this fact came the challenge of the elderly requiring more chronic health care services and consuming more resources than the younger population (Snavely, 2016). Last, was the Affordable Care Act causing an additional eight million Americans to become eligible for health insurance and putting a strain on the nursing workforce (Snavely, 2016). All of these factors could cause the nursing workforce shortages to become catastrophic. Nurses play a critical role in the delivery of safe, quality care within the health care system. The skills, advanced knowledge, interventions, and compassion, as well as the impact nurses exhibit within communities, rural areas, and in the lives of patients and their families, are unparalleled. It is imperative for the United States to match supply with demand for nursing or significant unfavorable consequences will cause patient suffering and caregiver breakdown (Snavely, 2016).

### **Limitations**

The researcher in this study used naturalistic methods of inquiry. This method

dealt with the issue of human involvedness by exploring it directly. Naturalistic ethnologies emphasize the complexity of human beings, their ability to shape and create their own experiences, and the idea that truth merges from the authenticities (Polit & Beck, 2008). Polit and Beck (2008) noted a limitation of the naturalistic model in that “it reduces human experience to only the few concepts under investigation, and those concepts are defined in advance by the researcher rather than emerging from the experiences of those under study” (p. 17). A further limitation was the comparatively small group that may be under study. Consequently, the generalizability of research from the naturalistic model was occasionally called into question (Polit & Beck, 2008).

### **Implications for Practice**

Rural communities often do not have resources for caregivers, and elderly caregivers are in danger of being isolated in their homes with lack of knowledge to care for their loved ones and for themselves. Practical implications that would be supportive to this population are numerous. The themes of this study designate that caregivers experience high stress and anxiety. This study indicates a need for community health practitioners to provide stress-reduction or stress-management interventions and education. As mentioned earlier, caring for self is imperative. This study supports the need for community health practitioners to provide education on the need for caregivers to care for themselves, which may include increased respite sessions for caregivers to allow them time to recoup and rest and to give them time to care for themselves.

The importance of psychosocial education on dealing with resentment and frustration that is experienced by caregivers is central. It is important to train them in the knowledge that they are natural feelings and to giving them tools to address these feelings. In addition to practical implications are the necessary resources for caregivers.

This includes education about caregiving in general and in-home sessions on specific tasks. Moreover, provision of aides and assistants and other resources that may be of help. This may also help to ease the stress associated with caregiving.

### **Recommendations for Further Research**

Statistics indicate in the study the elderly population is living longer, and the volunteer caregivers are managing their diseases. The population is growing, and the number of health-care providers is not. Further research on this topic is recommended by the practitioner's level of practice and the implications of the study's findings.

Recommendations include that more indepth investigations be done to find solutions for the elderly and caregivers to support the process of providing care. Educating future practitioners in the practice of supporting caregivers is a recommendation for further research. A research study that shows the percentage of medical schools and nursing schools supporting indepth stand-alone gerontology courses instead of just integrating short summations in each area of study.

Additional areas of importance for researchers to investigate include getting resources and education to the rural population. It is important to discover the opportunity for research on how to acquire elderly folks in rural locations the help and resources they need. Transformed types of research is recommended, such as quantitative studies, to examine the connections between the factors that are found in this study and if they have causal relationships in a quantitative study. Recommendations for health practitioners would be a catalyst for change in the older adult population. The medical profession needs to think outside the box and be part of the solution for the many older adults who will need care. Based on the findings, health practitioners have a unique opportunity that could be directed at those who work with caregivers and the caregivers themselves.

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Appendix  
Interview Protocol

## Interview Protocol

**Project:** Lived Experiences of Older Adult Caregivers and their Debilitated Chronically Ill Relatives in a Rural Southern County

**Date:** \_\_\_\_\_

**Time:** \_\_\_\_\_

**Location:** \_\_\_\_\_

**Interviewer:** \_\_\_\_\_

**Interviewee:** \_\_\_\_\_

**Release form signed?** \_\_\_\_\_

**Beginning script:** It is so good to meet you. My name is Nancy Dameron. Thank you so very much for volunteering to help me in my study. I believe your input will be valuable to the research and to future caregivers and health-care professionals. Confidentiality is guaranteed, this should take no more than an hour or we can stop at any time you would like.

**Purpose of research:** The purpose of the research is to enable me to better understand experiences elderly caregivers have in caring for their loved one. It is like, the elderly caring for the elderly and the challenges this situation will have on the elderly individuals. This research will be able to give a voice to the caregiver's and make known the loved one's feelings during this time. This research will also investigate the upsurge of the older adult populations who are living longer and the shortage of health-care provider for the older adult.

### Central Research Questions with Supporting Research Questions

Research Questions	Possible Pertinent Research Questions (not limited to only these questions)
<b>Central RQ1:</b> What are the lived experiences of the older adults who are caring for their chronically ill relatives?	Tell me about a typical day in your life.  Tell me about a typical day in your relative's life.
<b>Support RQ2:</b> How have older adult caregivers created and adapted to daily routines and coping strategies for their ill relative and the caregiver?	Tell me about times when you relax.  Do you feel any stress? If so, tell me what you do about the stress.
<b>Support RQ3:</b> How have chronically ill, older adult patients created and adapted to daily routines and coping strategies for their ill relative and the caregiver?	Tell me about your loved one.  Are you able to see the affect the daily routine and illness has on your loved one?  In what way does your loved one express these affects?
<b>Support RQ4:</b> What teaching and training strategies do older adult individuals, both caregiver and ill relative, feel would be helpful in their circumstances?	How do you and your loved one feel about having help from the community?  Are there people or families that help you? If so, how often and what do they do?  What would be most helpful for you and your loved one in regard to help?

Field Notes: