A Phenomenological Study of Central Texas Caregivers' Experiences in Relation to Stress and Coping Mechanisms

Becky Olson
Department of Community Care and Counseling, Liberty University

A Dissertation Presented in Partial Fulfillment
Of the Requirements for the Degree
Doctor of Education

School of Behavioral Sciences
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Abstract

Long-term, publicly funded caregiver services in Texas have always focused on institution-based care, although informal caregiving makes up 8% of the country's long-term care. Informal caregivers provide care to their loved ones who demand support due to illness, disability, or frailty. Taking care of one's loved ones or family members is rewarding and demanding. Consequently, informal caregivers are known to encounter negative and positive psychological health effects and, therefore, should be provided with appropriate support. This is contributed by the fact many times, informal caregiving is unpaid, mentally and physically demanding, and often performed by individuals who are balancing their caregiving roles with other domestic duties and responsibilities. This phenomenological study explored stress and coping among informal caregivers from participants of Bell County in Central Texas. The research adopted a qualitative approach to assess caregiver demands, stress and burden, and caregiver mental and physical well-being. The study process included a screener survey, a demographics form, and recorded virtual interviews of 12 participants. The study findings indicated that caregiver stress and burden are directly related to the well-being of caregivers. Six themes were identified during the coding process which included caregiving, coping, day, experience, health, and stressors. Subthemes that were revealed included the definition and role of a caregiver, coping strategies, and resources and supports; a typical day, daily chores, and a difficult day; the caregiving experience, challenging experiences, and grief experiences; physical and mental health status; and stressors with full-time caregiver and stressful situations.

Keywords: informal caregiver, caregiver stress, caregiver burden, grief, caregiver coping, stressors

Dedication

I want to dedicate this dissertation to my family, friends, and anyone who serves in an informal caregiving role. Some of them are no longer with us, which is why I began the journey toward a Community Care and Counseling degree. In 2012, my brother, Steve Sandefur, passed away suddenly and unexpectedly at 41. My grandfather, Bobby Bridges, who passed away at the age of 92, was a one-of-a-kind, generous, and trusting man. My brother-in-law, Aaron Tilley, lost his short battle with lung cancer in 2021. A special feeling of gratitude to my sister, Sonia Sandefur Tilley, and my grandmother, Edna Penny Bridges, for helping me keep the secret of my doctoral work and cheering me on behind the scenes.

I also dedicate this work to my coworkers and the best team ever, who have encouraged me not to give up. A special shout out to my parents, Don and Linda Sandefur, who raised me with a grounded Christian foundation and support me no matter what I take on, even if I keep it a secret. Lastly, a special dedication of my dissertation work to my husband, Michael, for always believing in me and pushing me harder. He allows me to dream and always reach for the stars (not to mention picking up extra duties while I worked on schoolwork, listening to me cry, and reminding me of my "why.") I also dedicate this dissertation to my daughter, Kelsie, for inspiring me to be a better person and allowing me to advocate for her and others. These individuals believed in me and kept my spirits and motivation high during this process. I love each one of you.

Acknowledgments

Many people helped me along the way on this journey. Words cannot express my gratitude for my dissertation experience at Liberty University. To Dr. Milacci and Dr. Volk, thank you for having faith in my doctoral journey and placing me with a perfect match, the chair of my committee, Dr. Sharita Knobloch. Dr. Knobloch has provided me with invaluable feedback and encouragement along the way. She went above and beyond to help me reach my goal. She became my cheerleader and my rock. I also acknowledge my reader, Dr. Alysha Blagg, and proposal defense chair, Dr. Penny Boone. Additionally, this endeavor would not have been possible without the generous support from the Liberty University Community Care and Counseling Program staff. I would also like to sincerely thank my doctoral peers who traveled this journey alongside me and the friendships we developed through this virtual program. A big shout out and thanks should also go to the study participants and organizations who impacted and inspired me.

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List of Abbreviations

Activities of daily living (ADLs)

Centers for Disease Control and Prevention (CDC)

Institutional Review Board (IRB)

Posttraumatic stress disorder (PTSD)

Quality of life (QOL)

Chapter One: Introduction

Overview

The purpose of this phenomenological research study is to explore caregivers' experiences in relation to their stress and coping mechanisms. Informal caregivers provide care to their loved ones or significant others who demand support due to illness, disability, or frailty (Gérain & Zech, 2019). Taking care of a loved one or family member is rewarding and demanding (Gérain & Zech, 2019; May, 2021). This chapter will cover definitions of important key terms, the study's background, the research's theoretical contexts, the problem and purpose statement, the significance of the study, and research questions aimed at guiding the researcher.

Background

Caregiving is a journey that most people experience in their lifetime. For instance, parents play the role of caregiving to their children. In contrast, other parents extend these roles for a longer period when taking care of adult children living with a disability (May, 2021). Also, individuals may care for their sick or aging spouses, relatives, parents, and even friends (National Research Council, 2010). Gérain and Zech (2019) found that aging is intrinsic and universal, meaning all human beings will, at one point, undergo the phenomenon of aging. Aging is a chronological growth for all individuals without exception (May, 2021). The need for caregivers continues to grow as life expectancy has increased and improved worldwide due to technological advancements, higher levels of personal hygiene, and environmental sanitization (May, 2021).

Both internal and external factors influence aging in human beings (May, 2021). Different people undergo diverse aging processes determined by physiological aging that can affect them. For instance, toxic aging, associated with dangerous physical consequences, is affected by his or her psychological and physical deterioration that occurs (May, 2021). Friends, adult children, and close family members always provide informal caregiving to their loved ones, perform simple domestic activities, and provide help by supervising and organizing services. Services offered by caregivers include acquiring medical services, finding a nursing home, observing quality, organizing public services assistance, and managing funds (May, 2021).

Family Caregivers

Family caregivers provide emotional support services to their loved ones, information, and physical care (May, 2021). Informal family caregivers partly offer these services to honor their elderly adults and to maintain the quality and dignity of their lives (Parveen et al., 2013). In some cases, service delivery units include natural social networks and household units that consist of people who share dwellings and other services and may include children, spouses, and friends among other family members (Morton et al., 2015). Caregivers encounter diminishing interests in providing their services and exhaustion, according to May (2021), thus, requiring the support of other systems, such as respite services in the community, to support and strengthen family units.

Future Needs for Caregivers

The need for more caregivers will intensify in the near future with the continued expansion of general life expectancy, which increases growth in the population of older adults (Morton et al., 2015). Population experts noted that there is a likely increase in the size of the aging adult population attaining 85 years or older to over 18 million Americans by the year 2060 (U.S. Census Bureau, 2021). Similarly, other experts have also projected that the population of Americans 85 years and above will increase twofold from 18 million to 36 million. The U.S.

Census Bureau (2021) noted that 72,197 people were aged above 100 years in 2014, a 72% growth from 1990.

The caregiving demand is exacerbated by many older people remaining disabled for extended periods, requiring urgent and continued support services from caregivers. Morton et al. (2015) stated that apart from the rise in the population of older adults in societies, there is also a sharp rise in the number of people living with disabilities and medical health challenges such as cancer, schizophrenia, and posttraumatic stress disorder (PTSD), among others. These variations in society are consequential in that they require an increase in the number of caregivers. Other demographic variations include childbirth, marriages, reduced size of the family, or family structure and configuration modifications (Morton et al., 2015). The number of years caregivers, especially adult children, spend caring for their patients increases with improved long life for the elderly, compels even their offspring to take care of them. Effective strategies are more developed to address the challenges caregivers encounter while delivering care to their patients or loved ones. This includes developing health strategies that provide quality caregiving services while ensuring the health of the caregiver is not compromised (Morton et al., 2015).

Caregiver Stress and Coping

The patient’s condition can enable caregivers to encounter additional burdens and stress, including family conflicts, financial difficulties, challenging work activities, and recreation (Gérain & Zech, 2019). Caregivers in such environments can experience negative impacts, including physical, social, and psychological health concerns (Gérain & Zech, 2019). Subjective stress describes psychological reactions that caregivers experience in the form of sadness, shame, frustration, and other stressors when dealing with disruptive behavior (May, 2021).

The burden for caregivers is heavier when chronic disease onset happens at an early age, as it causes the caregiver to encounter stress and burnout that manifest in the forms of emotional expressions, personality dysfunction, and nonconstructive coping (Gérain & Zech, 2019). Caregivers express emotions through harsh speaking, hostility, isolating patients, and disrespecting patients, which influence recurring symptoms (Gérain & Zech, 2019). The physical and psychological stressors and burdens are associated with the caregivers coping mechanisms (May, 2021). Caregivers use various coping mechanisms and techniques that have a significant relationship with their level of burden. Implementing coping mechanisms can be done constructively or destructively by involving ego defense to protect themselves.

The Stress Adaptation Model is one of the adaptive mechanisms by Calysta Roy that explains that stimuli influence coping strategies (May, 2021). For instance, caregivers that take care of patients with schizophrenia receive stimuli from the symptoms of their patients, including environmental and health attitudes. The human system influences the process of a coping mechanism as formed behavior influences the emergence of control mechanisms in people. Such coping mechanisms have cognates and regulator subsystems comprising of four modes: self-concept, physiological, role function, and interdependence. Emotion-focused and problem-focused coping are the two primary coping mechanisms for caregivers caring for patients with schizophrenia in addition to other illnesses and disabilities. Stress in caregivers results from the patient's symptoms and the caregiver's use of coping mechanisms (May, 2021).

In order to improve one's relationship with stress, it is important to understand the process which reinforces it (Lazarus & Folkman, 1984), as well as explore how the relationship with stress impacts the ways individuals try to cope. The transactional model of stress and coping explores that the experiences of stress include a system composed of appraisal, response, and adaptation (Lazarus & Folkman, 1984), which will be explored in detail in Chapter Two.

Situation to Self

My family and I have been very close ever since I can remember. Growing up, I viewed my grandmother as a caregiver. Nine children were in her family, and her father was an alcoholic. Being one of the oldest girls, she took on the caregiving role. Growing up, she made sure her siblings bathed, were fed, and even took them to the store. She had one brother who was declared incompetent and helped raise and care for him until his passing.

My parents also cared for their siblings and aging parents in various ways. My mother was the oldest and while my grandmother was attending school, she helped care for her younger brothers. My dad was the baby of his family, but as his sister developed dementia, he continued to care for her. As his parents aged, he was often providing care to them until their passing.

I was raised in a loving and caring environment and grew to know how the adults in my family took on caregiving roles and always made sure their loved ones had what they needed. I feel that because of what I was around and exposed to, it just fell into my lap. My grandmother and grandfather were married at the age of 16, and in 2020, my grandfather became ill due to old age and diabetes, among other ailments. My grandmother, doing what she does best, cared for him at home and even continued this care at a nursing home during the COVID-19 pandemic. It was at this point that I learned so much more about the caregiving role. My family has been healthy for the most part. My brother-in-law was diagnosed with stage IV lung cancer in December of 2021. I was an active part of his care and walked the journey alongside my sister, who cared for him while working full-time. During these two specific instances, I observed caregiving in a different light in addition to anticipatory and experienced grief.

Another highly relevant experience with my caregiving journey involves my role as a parent. I gave birth to my daughter in 2005 after a long stint of infertility. By 2006, she had been through many blood tests, scans, x-rays, and doctor appointments. By the end of 2005, she was diagnosed with periventricular leukomalacia, cerebral palsy, and epilepsy. That was just the beginning of my caregiving journey. As a new mom, adjusting to married life, and working full-time, I learned so much about caring for an individual with special needs. There is much to process and handle when caring for a loved one, including all the emotions and maintaining one's composure while helping the person feel better and reassured. In addition, as a caregiver, one just wants the best for their loved one and will do anything at any cost to help make it easier for them. A caregiver must continually monitor their care recipient, take them to appointments, and administer all medications, just to name a few. Now that I have learned that she will have very little independence and I will have to take care of her for the rest of our lives, it has become a necessary part of my existence.

As I observed my grandmother, parents, sister, and myself with all their caregiving responsibilities, I learned how to adapt, manage, and remain calm under pressure. Although, I feel like nothing in life truly prepares you when you have to take on an informal caregiving role. But I also know that you just step up and take on the role without asking any questions at the time. Being blessed with my special needs daughter, every turn has been a new adventure waiting for us. I have had to learn to adapt to the situation at hand and manage that in order to give her the attention and care she needs. Given my life experience and how some of these situations impacted my family, these are some of the reasons I am pursuing my doctoral degree. I also discovered that having a profession is a fulfilling experience and that I enjoy being helpful. For many people, managing stress and other issues with caring is difficult. While caregiving and coping are often researched, some aspects, such as lived experiences, culture, and well-being are not addressed. One way to explore this problem is by sharing the lived experiences of individuals who are enduring this. I have thus focused my research on assisting caregivers in understanding their difficulties and coping mechanisms for stress.

Problem Statement

The problem is the gap in research surrounding caregiving burnout and stress encountered by caregivers. Caregiving has been shown to reduce work productivity and increase the likelihood of leaving the workplace (Watson Caring Science Institute, n.d.). Caring for a spouse, parent, or cohabitant contributes to physical, financial, or emotional health concerns. Caregivers suffer losses such as lost wages, reduced health benefits, decreased retirement savings, and may reduce their hours or even quit (Family Caregiver Alliance, 2016b). The Family Caregiver Alliance (2016b) stipulated that caregiver health worsens over time and that 35% of family caregivers consider their health fair to even poor. Individuals who may experience a higher physical strain on their health are those who provide care for longer than a year, are older caregivers (65 years and above), those with a higher level of burden, caregivers of patients with Alzheimer's or dementia, or finally, those who live with their care recipient. Research also shows that females report more stress than males as caregivers (Family Caregiver Alliance, 2016b).

Individuals who participate in activities of daily living (ADLs) tend to feel more physical stress on their health (Morton et al., 2015). Caregivers who are employed full-time say they experience poorer physical health than their noncaregiving counterparts (Family Caregiver Alliance, 2016b). Sixteen percent of full-time caregivers have a Physical Health Index score of 77.4%, which is noticeably lower than noncaregivers, which is 83.0% (Mayo Clinic Staff, 2022).

Up to 70% of caregivers suffer from clinically significant symptoms of depression, where 20% of them are females who are employed (Family Caregiver Alliance, 2016b). Caregivers who work full-time show the most prominent emotional and physical health deficits in caregivers. Reports indicate that there is a correlation between a caregiver's physical and mental health and income as well as their level of education (Family Caregiver Alliance, 2016a; Mayo Clinic Staff, 2022; Sigelman & Rider, 2015).

A core value for most caregivers is being there for a loved one when they need them. However, it is evident that a shift in roles and emotions is inevitable. As a caregiver, it is a familiar feeling to be angry, frustrated, exhausted, alone, or even sad (Mayo Clinic Staff, 2022). Caregiver stress is prevalent, including the caregiver's emotional, financial, and physical stress. Individuals who experience caregiver stress are vulnerable to changes in their health and are at risk for health factors (Wehei, 2018). Caregiver burnout is another example of how repeated exposure to stress can be detrimental to one's mental and physical health. Chronic stress can trigger a release of stress hormones in the body, leading to exhaustion, irritability, a weakened immune system, digestive difficulties, headaches, and weight gain (Mayo Clinic Staff, 2022). Caregivers must have resources available to them and outlets as well as reminders to make themselves a priority (Mayo Clinic Staff, 2022; Wehei, 2018).

The problem is that when an individual assumes the role of a caregiver, whether of their child, an aging parent or family member, or someone else, they go all in and focus on the job at hand, resulting in a daunting task that takes over the individual in an overwhelming way (May, 2021). For instance, Morten et al. (2015) noted that caregivers fail to take care of themselves, and their health is in jeopardy before one knows it. Family caregivers provide emotional support services. information, and physical care to their loved ones. Informal family caregivers partly offer these services to honor their elderly adults and to maintain the quality and dignity of their lives (Parveen et al., 2013).

Caregivers encounter diminishing interests in providing their services and exhaustion, according to May (2021), thus requiring the support of other systems, such as respite services in the community, to support and strengthen family units. As a result, this calls for more caregivers to intensify in the near future with the continued expansion of general life expectancy, which increases growth in the population of older adults (Morton et al., 2015).

Purpose Statement

This phenomenological study fills a gap in research regarding informal caregivers and understanding the principle of informal caregivers' lived experiences in relation to stress and coping behavior for caregivers in Central Texas. Caregiving was generally defined as the activity or profession of regularly looking after a child or a sick, elderly, or disabled person (Watson Caring Science Institute, n.d.). The theory that guided this study was the caregiver stress theory (Chari et al., 2015), as it illustrates that the social support of a caregiver reduces their perceived stress through changing cognitive appraisal of caregiving. From the theory perspective, depression and perceived caregiver stress are known as coping mechanisms, whereas depression is the emotional part of the subsystem as well as the immediate result of perceived caregiver stress (Watson Caring Science Institute, n.d.). The theory classifies and links depression with adaptive modes to different degrees.

Significance of the Study

This study is important due to the rise in the demand for caregivers across the United States and the world due to the population trends that depict a growing number of older adults (Chari et al., 2015). Therefore, this implies that the demand for caregivers rises exponentially to care for the increasing number of the elderly, people with disabilities, and those with chronic illnesses (Chari et al., 2015). Nevertheless, the problems that caregivers encounter while taking care of their loved ones are likely to discourage other people from becoming home-based informal caregivers. The shortage of informal caregivers will be exacerbated by the inability to provide informal caregivers with resources and services that reduce stress and the burdens associated with caregiving. Current study trends indicate that more caregivers will be required in the near future (Bauer & Sousa-Poza, 2015). However, only a few individuals are motivated to become informal caregivers (Watson Caring Science Institute, n.d.).

Home-based informal caregivers are essential as they reduce the need for proper health care facilities for the elderly and those with chronic diseases. As a result, seniors have access to their families and, therefore, live longer within their communities. Also, informal caregiving reduces the cost of health care, which has become a significant issue in the United States. Therefore, home-based caregiving provides a positive cost-efficiency balance as it reduces health care expenditures (Nemati et al., 2017). Therefore, the study is significant as it will encourage policymakers and health care professionals to appreciate home-based informal caregivers' challenges and determine ways of addressing them (Morton et al., 2015). As a result, informal caregivers will be able to provide adequate care for their loved ones and motivate more people to become caregivers in a society that is experiencing a growing number of older adults.

Research Questions

This phenomenological study aims to understand and describe the significance of lived experiences of informal caregivers.

Central Research Question

What are the lived experiences of informal caregivers in Central Texas in relation to coping and stress?

The central research question identifies and explores the challenges that informal caregivers experience in relation to stress and coping. Some of the potential stressors include financial strain, difficulties that they experience while navigating their caregiving roles, mental and physical struggles, and their lack of support to ease their struggles (Chari et al., 2015). Therefore, the question is foundational to understanding the many challenges that informal caregivers in Central Texas experience while providing care to their loved ones.

Subquestion 1

How do informal caregivers in Central Texas describe the effects of providing care on their well-being?

This question is intended to understand the detailed experience of informal caregivers in Central Texas. Specific questions were asked to support this research question, including information surrounding the person they care for, the length they have been engaged in informal caregiving, and possible positive and negative experiences during that time. This involves an exploration of the experience that informal care created in the lives of caregivers (Chari et al., 2015) in light of their overall well-being.

Subquestion 2

What are the key stressors of informal caregivers in Central Texas?

Subquestion 2 was selected to create a clear understanding of the different forms of stress and their impacts on caregivers. Some possible stressors based on previous literature include financial strain, difficulties while navigating their caregiving roles, mental and physical struggles, relationship conflicts, and their lack of support and resources (Chari et al., 2015; May, 2021). Ultimately, this question attempted to uncover the main sources of stress that caregivers in Central Texas experience during the interview process (Chari et al., 2015).

Subquestion 3

What coping methods do caregivers in Central Texas engage when they experience stress?

While caregivers experience stress when providing care to their loved ones, they attempt to repel the stressors to live a normal life (May, 2021). Therefore, this question is important as it attempts to uncover various ways that caregivers adapt to cope with stressors. While coping styles vary from person to person they are comprised of emotional, cognitive, and behavioral responses (Panicker & Ramesh, 2018). Some specific coping strategies include environmental support, social support religion and spirituality, and external resources (Central Texas Aging, Disability & Veterans Resource Center, 2022; Ong et al., 2018; Pargament, 2013; Sabata et al., 2005). Subquestion 3 is most closely related to the overall theoretical framework of this study, the Transactional Model of Stress and Coping (Lazarus & Folkman, 1984).

Subquestion 4

What internal or external resources do caregivers in Central Texas utilize to cope with stress?

Previous literature indicates that information caregivers may or may not have access to a variety of both internal and external resources. This includes local and state organizations and online support. In the Bell County area, there are several aging, disability, and independent living organizations and online supports (Central Texas Aging, Disability & Veterans Resource Center, 2022). This question is to help identify if caregivers in Central Texas have access to any resources that they use to help cope with their stressors and experiences (Watson Caring Science Institute, n.d.).

Definitions

1. *Aging/elderly* – Aging is the process of growing old. The term is also used interchangeably with *elderly* (May, 2021).
2. *Alzheimer's* – Alzheimer's is a brain disease that causes degeneration and is a common form of dementia (Sigelman & Rider, 2015).
3. *Anxiety* – Anxiety is an overwhelming sense of worry and fear that is usually presented with physical signs (Sigelman & Rider, 2015).
4. *Burden* – A burden is something that weighs heavily on the mind or is worrisome (Gérain & Zech, 2019; Liu et al., 2020).
5. *Caregivers* – A caregiver is a professional, family member, or paid helper who looks after a disabled person, elderly, sick, or child (Sigelman & Rider, 2015).
6. *Caregiving* – Caregiving is regularly looking after a child or a sick, elderly, or disabled person (Gérain & Zech, 2019).
7. *Coping* – Coping is the thoughts and behaviors set forth to manage internal and external stress (Algorani & Gupta, 2022; Folkman, 2013).
8. *Dementia* – Dementia is a progressive condition that affects cognitive deficits such as memory and behavior (American Psychiatric Association, 2013).
9. *Disability* – A disability is a physical, mental, cognitive, or developmental condition that limits a person's ability to participate in daily activities, interactions, or tasks (American Psychiatric Association, 2013).

10. *Emotion-focused coping* – A type of stress management that tries to decrease negative emotional responses that happen as a result to exposure to various stressors is referred to as emotion-focused coping (Lazarus & Folkman, 1984).
11. *Grief* – Grief is characterized by sadness or distress caused by a significant loss (Duke, 1998; Rogalla, 2018).
12. *Informal caregiver* – Informal means relaxed, friendly, or unofficial manner or nature (May, 2021). An informal caregiver is someone who assists a friend or family member with a health condition (Centers for Disease Control and Prevention [CDC], n.d.).
13. *Problem-focused coping* – A stress management coping method in which an individual faces a stressor in order to lesson or eliminate it is known as problem-focused coping (Lazarus & Folkman, 1984).
14. *Quality of life* – Quality of life (QOL) is referred to as the degree to which a person is healthy, comfortable, and able to enjoy daily living (Zarit et al., 1980).
15. *Special needs* – Special needs refers to the physical, emotional, behavioral, or learning disability or impairment that requires an individual to need specialized services or accommodations (May, 2021).
16. *Stress* – Stress is a physical, chemical, or emotional state that can cause bodily or mental tension (Pearlin et al., 1990).

Summary

This chapter has covered the background of the study, theoretical contexts of the research, problem and purpose statements, the significance of the study, research questions, and relevant definitions. The research explores the experiences of caregivers in relation to stress and coping mechanisms. Informal caregiving is rewarding as well as demanding. Caring for a spouse, parent, or cohabitant contributes to physical, financial, or emotional health concerns, thereby making caregivers experience losses such as lost wages, reduced health benefits, and decreased retirement savings, and they must quit their job or reduce their hours (May, 2021). This study is important due to the rise in the demand for caregivers across the United States due to population trends that depict a growing number of older adults (Pearlin et al., 1990). Therefore, this implies that the demand for caregivers rises exponentially to care for the growing number of elderly populations, individuals with disabilities, and those with chronic illnesses. The research will answer essential questions from the basis of the study, beginning with a thorough exploration of the existing literature.

Chapter Two: Literature Review

Overview

The previous lucid explanation of the topic, the purpose of the study, and the problem statement gave clarity for an understanding of the phenomenon under investigation in the subsequent chapters. This phenomenological study aims to describe and understand the essence of lived experiences of informal caregivers in relation to stress and coping mechanisms. In the previous chapter, the study introduced some of the problems caregivers encounter when dealing with older adults or patients with chronic diseases and persons with disabilities.

This chapter provides a comprehensive literature review that will serve as a framework for developing the study, organizing the data, and enhancing knowledge of previous studies on informal caregiving. The information discussed in this chapter includes an analysis of peer-reviewed and germinal literature on caregivers and their coping mechanisms, theoretical frameworks, and understanding of family caregiving. Also included in this chapter are an introduction to the literature review, consideration of the theoretical framework, analysis of informal caregivers, the prevalence of caregivers in the United States, characteristics of caregivers, the role of caregivers, American caregivers, and caregiver burden, impacts of caregiver stress and caregiver burden, anticipatory grief, caregiving, and role stress, caregiving and QOL, cultural and ethnic contribution, and coping strategies, research gaps, and limitations of the study.

Theoretical Framework

The theoretical framework for this study is Lazarus and Folkman’s (1984) transactional model of stress and coping. One of the critical factors in selecting this framework is that Lazarus and Folkman (1984) looked at personal factors and environmental challenges and how that plays a part in the coping process (Biggs et al., 2017). Several concepts of frameworks place the foundation around caregiver stress and how caregivers cope with stress. Understanding the frameworks helps bring clarity to the aspects of caregiving, which may include stressors, coping strategies, and how cultural values influence caregiving and caregiver stress. Models and theories explain how relationships and behavior contribute to conceptualizing social and caregiving interactions within communities or families (Hayden, 2013). Furthermore, theories and models are essential in helping to understand how relationships have assisted caregiving activities, including intervention mechanisms for specific caregiving challenges and improving the health of older adults and recipients of informal care.

Foundations of the Transactional Model of Stress and Coping

One of the most popular and influential models for exploring stress was the transactional model of stress and coping, developed by Lazarus and Folkman in 1966 (Lazarus & Folkman, 1984). Lazarus and Folkman defined stress as a disproportion between demands, resources, and coping that an individual perceives to tolerate or reduce the stressors (Biggs et al., 2017; Lazarus & Folkman, 1984). This model denotes the existence of a disparity in the resources and demands placed on caregivers, causing a stress reaction (Lazarus & Folkman, 1984). In addition, it distinguishes between primary and secondary stressors, where primary stressors are the caregiver perception and environment, while secondary stressors include coping methods and strategies to handle stress (Cooper & Quick, 2017; Lazarus & Folkman, 1984; Parveen et al., 2013). These coping categories they identified were known as problem-focused coping and emotion-focused coping (Biggs et al., 2017). Lazarus and Folkman (1984) describe coping as a dynamic process with cognitive and behavioral responses between a person and their environment to manage their stressors. The coping responses explored aim to manage or alter the problem one experiences and the emotional responses (Biggs et al., 2017).

Understanding some of the mechanisms underlying stress and how they affect people's coping mechanisms might help them better manage it. The transactional model of stress and coping can help people comprehend this. According to the transactional model of stress and coping, stress is ultimately a system of evaluation, reaction, and adaptation (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) noted that stressors are demands made by the external and internal environments that upset balance, thereby impacting psychological and physical well-being that will require action to restore body balance. Initially, stressors were considered transactional phenomena depending on the meaning of the perceiver's stimulus. Based on the explanation of Lazarus and Folkman (1984), the transactional model of stress and coping is a context or framework used to evaluate the process of coping with stressful events or experiences, which are person-environment transactions. The transactions are mediated by first the appraisal of the stressor by the person and second by the available social and cultural resources (Lazarus & Folkman, 1984).

The transactional model of stress and coping suggests that stress is viewed as an appraisal or evaluation of one's circumstances (Lazarus & Folkman, 1984; Parveen et al., 2013). The model proposes explicitly that before experiencing and reacting to stress, people go through two states of assessment. First, they assess the circumstance to see whether they pertain to them (Lazarus and Folkman, 1984), specifically if there is a chance for benefit or damage. If there is not, the individual will decide the situation is irrelevant (Cooper & Quick, 2017). If there is a chance for benefit or damage, they determine if the situation is advantageous or harmful (Biggs et al., 2017; Lazarus & Folkman, 1984). A secondary evaluation is then done if the individual perceives that the situation may be harmful (Biggs et al., 2017; Lazarus & Folkman, 1984). In these assessments, the individual determines if they can handle the events by balancing the demands of the circumstances, such as difficulty, uncertainties, risk, and ambiguity, with their perceived resources (Lazarus & Folkman, 1984). When needs exceed available resources, they feel under stress. At this moment, coping mechanisms were also being used (Parveen et al., 2013).

Founders of the Theory

Lazarus and Folkman (1984), the founders of the transactional model of stress and coping, thought that the way individuals respond or interpret an event can have a stronger effect on stress levels than the event itself. These two individuals developed a framework to help people deal with stressful situations using coping strategies. The model is one of the most popular and influential theories for exploring stress (Lazarus & Folkman, 1984). The two authors, in their model, defined stress as an imbalance between demands, resources, and coping that an individual perceives to tolerate or reduce the stressors (Biggs et al., 2017; Lazarus & Folkman, 1984).

Richard Lazarus

Richard Lazarus, an American psychologist, was born on March 3, 1922. He graduated with his undergraduate degree from City College of New York and later his master's from The University of Pittsburgh (Lazarus & Folkman, 1984). He was known for his theory of cognitive mediational theory within emotion. In 1959, he completed his doctorate and joined the University of California, faculty. As a professor there, he worked with a PhD student, Susan Folkman, in developing her thesis. Lazarus advocated that emotion and thought are said to be united like a marriage. Richard Lazarus died on November 24, 2002 (Folkman, 2013).

Susan Folkman

Susan Folkman was born on March 19, 1938. She is recognized as an American psychologist and author as well as emerita professor at the University of California at San Francisco. She obtained her Bachelor of Arts in History from Brandeis University and her Master of Education in counseling psychology from the University of Missouri St. Louis (Lazarus & Folkman, 1984). She obtained a PhD in educational psychology from the University of California at Berkeley. She focuses her research methods on conducting community-based studies.

Lazarus and Folkman co-authored a book, *Stress, Appraisal, and Coping*, in 1984. Folkman is recognized for coining the terms problem-focused and emotion-focused coping. This book is the most widely cited academic book in social sciences (Lazarus & Folkman, 1984). In their book, Lazarus and Folkman (1984) define stress as the body's internal response to any perceived harmful external stimulus. They document that stress occurs when you feel you are not in control. According to Lazarus & Folkman (1984), this could be anything from spilling a morning coffee to a life-altering event. Lazarus and Folkman (1984) found that a person's confidence level in handling a threat is directly related to the level of stress they experience. How we interpret or respond to an event can frequently significantly impact our stress level more than the event itself. The goals of the development of the framework were to assist individuals in coping with stressful situations through objective evaluation and coping mechanisms (Lazarus & Folkman, 1984).

Applications

Lazarus and Folkman's (1984) theory has been applied in various contexts. Since the early 1980s, stress research has multiplied, and many studies look at a variety of stressors and coping (Robinson, 2018). In a training simulation research study looking at the impact of different coping methods on posttraumatic stress disorder symptoms, stress reactions, and performance with recruits from the police force, avoidance coping was linked with beneficial short-term results, but negative long-term consequences (Biggs et al., 2017). A study focusing on the transactional model of stress and coping was done with mothers of children with a chronic disease and found that mothers interact with their children more and experience the highest impact of stressors (Asadi Shavaki et al., 2020).

A recent situation where researchers utilized Lazarus and Folkman's (1984) framework was the COVID-19 outbreak. During the COVID-19 pandemic, participants of one study shared similar frustrations and a wide range of stressful life events including the unknowns and concerns for loved ones (Jean-Baptiste et al., 2020). According to the transactional model of stress and coping, different people react differently to stressors they perceive in different situations (Lazarus & Folkman, 1984). Asadi Shavaki et al. (2020) noted that during the COVID-19 pandemic, the stressors that each individual and family encountered affected how they viewed stress. For example, families who had loved ones in nursing homes or medical facilities were unable to visit face to face. Special needs individuals who are cognitively impaired did not understand why they were unable to go to school, eat at places, or even shop. Towns and cities were empty and sad-looking, parents were unemployed and had to find alternative ways to bring in income. This pandemic took a toll on couples, marriages, families, and children, as well as those who were ill, aging, mentally, cognitively, and physically impaired (Asadi Shavaki et al., 2020).

The evaluation interaction can likewise be impacted by an individual's social and cultural foundation, as well as their prior encounters with similar circumstances (Biggs et al., 2017). In other words, how we perceive potential stresses depends on individual differences. The transactional model of stress and coping is advantageous because it takes into account individual variations in stress response. Stress is brough on by the cognitive evaluation of events (Biggs et al., 2017). Even though some situations are more likely to be viewed as stressful than others, an event only qualifies as such when it is deemed to be stressful (Kivak, 2020; Lazarus & Folkman, 1984). The transactional model of stress and coping, centers around how individuals see their environmental factors when they experience stress and make coping decisions (Lazarus & Folkman, 1984). The worldview fights those collaborations among people and their environment, instead of an external event, are what cause stressors (Biggs et al., 2017; Lazarus & Folkman, 1984). When people's available resources are insufficient to handle their needs, stress is the result (Kivak, 2020). This is how the recent pandemic has affected so many individuals.

In order to decide if a situation is stressful, individuals make use of the appraisal, also known as the self-evaluation process (Lazarus & Folkman, 1984). The term *coping* alludes to the mental and behavioral methodologies individuals use to deal with stress (Kivak, 2020). The transactional model of stress and coping has advanced the field of cognitive psychology, the study of how the mind functions (Kivak, 2020; Lazarus & Folkman, 1984). The model emphasizes how important the assessment is in determining a person's behavior and feelings (Asadi Shavaki et al., 2020; Kivak, 2020). From Lazarus and Folkman's (1984) view, a stressor cannot anticipate or initiate a disease, whether physical or mental illnesses. However, an individual's views determine how the stressor is assessed (Kivak, 2020). Therefore, further study into individual perspectives is required to ascertain how stress affects the development of solutions, and researchers should use an efficient model in this respect (Asadi Shavaki et al., 2020).

Theoretical Framework Coping Methods

Many caregivers encounter stressors that affect their life and health (Biggs et al., 2017). As a result, coping is one of the ways of overcoming their challenges and experiences since informal caregivers have little or no support (Chari et al., 2015; May, 2021). Coping methods in frameworks distinguish between primary and secondary stressors (Cooper & Quick, 2017; Lazarus & Folkman, 1984; Parveen et al., 2013). The coping categories identified are known as problem-focused coping and emotion-focused coping (Biggs et al., 2017). Focusing on one's problems is one way of accepting the existence of that challenge to cope with it. This includes asking for support from others, avoiding the problem, managing their time, as well as other possible ways.

Problem-Focused Coping

Problem-focused coping is defined as a technique of solving problems in which one addresses the stressors or the problem directly in an attempt to eliminate or alleviate it (Lazarus & Folkman, 1984). Problem-based coping typically employs action-oriented and practical strategies. When a situation is evaluated as stressful and requires efforts to manage or resolve the event, coping actions are sanctioned (Biggs et al., 2017). Making an action plan or delegating responsibilities are examples of this. Problem-focused coping techniques entail dealing with the problem and making it more tolerable. This active coping can be challenging and will lead to a genuine change in the situation if it is successful. Problem-focused demonstrates lower levels of emotional exhaustion (Biggs et al., 2017; Lazarus & Folkman, 1984).

The first strategy in problem-focused coping is time management (Biggs et al., 2017; Lazarus & Folkman, 1984). People regularly struggle to find the time to finish tasks or reach their goals and suffer stress. It is possible that they have too much to do or that stress is keeping them from finishing tasks as a result of caregiver stress and coping. In either scenario, utilizing time management techniques may aid individuals in minimizing and avoiding stressful situations. Avoidance is the second strategy in problem-focused coping (Biggs et al., 2017; Lazarus & Folkman, 1984). Stress is common, and it's difficult for people to make time for their responsibilities and or goals. This could be because they have too much to do or because they are too stressed out to finish things. People could thus ignore the issue and refrain from discussing it. Avoidance may be an unproductive coping strategy since the issue could not be solved until immediate action is made (Biggs et al., 2017; Lazarus & Folkman, 1984).

Another strategy for problem-focused coping is asking for support (Biggs et al., 2017; Lazarus & Folkman, 1984). People often ask for help or guidance from others to help them cope with problematic circumstances. Reaching out to family and friends, going to therapy, or getting counseling may all be part of asking for help. Also, trying to change the situation is another strategy of problem-focused coping. More often, people tend to directly address their problems by changing an event or situation that they believe is causing their stress. For example, someone who is stressed out with their employment or supervisor, may seek out a new position with their employer or apply for a new job elsewhere (Biggs et al., 2017; Lazarus & Folkman, 1984).

Emotion-Focused Coping

Emotion-focused coping entails altering our perception of the circumstances to lessen the tension it generates (Biggs et al., 2017; Lazarus & Folkman, 1984). Denial, avoidance, or changing the way one thinks about the experience or event can all be used in this coping method. While this does not alter the nature of the issue per se, it does alter how it affects people (Jean-Baptiste et al., 2020). Emotion-focused coping is linked with unfavorable outcomes such as increased anxiety, emotional exhaustion, and dissatisfaction (Biggs et al., 2017). Few studies permit assessments of coping effectiveness as they neglect to concurrently take into account the situation, personal characteristics, and outcomes (Biggs et al., 2017).

Positive coping strategies like taking ownership or finding emotional or moral support may be included in emotion-based strategies (Lazarus & Folkman, 1984). On the other hand, they may also contribute to an increase in undesirable behaviors like self-blame, avoidance, rage, and frustration (Biggs et al., 2017). Emotion-focused coping may be especially useful in circumstances that cannot be meaningfully changed and are often used as a maladaptive coping strategy (Biggs et al., 2017).

Reappraisal Within the Theory

The importance placed on appraisal in the transactional model of stress and coping underlines that it is the discernment that the event is stressful, rather than the actual event itself, that determines whether coping strategies are initiated and whether the stressors are ultimately settled (Biggs et al., 2017). Coping mechanisms and responses to stress are dynamic. Lazarus and Folkman (1984) describe two forms of appraisal: primary and secondary. The primary is the meaning of a specific matter and determines the significance of that situation to an individual's well-being (Biggs et al., 2017). When people attempt to deal adaptively or nonadaptively, they reassess going through the primary and secondary evaluation processes once again (Biggs et al., 2017). The system is transactional in this sense: based on their assessments, they respond in a way that modifies the circumstance or selves and, in turn, their assessments. These reevaluations may cause one to stop feeling stressed or alter their coping mechanisms (Biggs et al., 2017). Cognitive reappraisal is a process in which the situation is reassessed to determine if coping efforts have been effective or whether the situation has changed from stressful to unrelated or benignly positive (Lazarus & Folkman, 1984). This process is accompanied by new information from the environment. The following review of the literature was conducted based on the transactional model of stress and coping (Lazarus & Folkman, 1984).

Related Literature

Beyond the theoretical framework, there is also a significant amount of literature on informal caregivers and the relationship between stress and coping. The subsequent literature review will explore informal caregivers including the demographics, characteristics, and roles. There will be an expansion of caregiver QOL including stress and burden, grief, as well as historical context and cultural contributions.

The Demographic: Caregivers

Throughout their lifetimes, the majority of individuals encounter caring in various ways with parenting and providing for children as one of these methods (Nemati et al., 2017). As with caring for challenged children or individuals who have mobility issues brought on by a disability or injury, chronic illness, or the aging process, an individual's responsibility can be expanded (May, 2021). Additionally, individuals look out for their ailing or aging parents, spouses, siblings, and even acquaintances (Kivak, 2020).

Caregiving is an endeavor that affects all people (National Research Council, 2010). Although caregiving has been an essential part of the research, the topic is salient today due to the convergence of various factors, including the aging, longer life expectancy of baby boomers, who make up the largest population in the United States, and finally, the emergence of advanced medical technologies that allow people to live longer but with chronic illnesses and disabilities (National Research Council, 2010).

Even though many caregiving services remain informal, the public long-term caregiving system has shown institutional bias (National Research Council, 2010). As the population in the

United States continues to age, more programs in rural areas need to be developed that support caregivers. The profession is mentally and physically demanding, while caregivers are typically unpaid (National Research Council, 2010). Additionally, caregivers carry out the role while performing other domestic duties such as family and household responsibilities (Nemati et al., 2017). Therefore, it is important to conduct research that outlines the roles of caregivers, their prevalence in the country, characteristics, and caregiving stress and burnout, as well as strategies and requirements that will support their effort and well-being.

History of Caregiving

Caregiving was first recorded in the 19th century, according to Family Caregiver Alliance (2016b), which defined a caregiver as one who takes care of things, places, or a person; that is, one put in charge of anything. Women were naturally regarded as caretakers of children, families, and the community (Davies, 2012; Family Caregiver Alliance, 2016b). They were regarded as nurses or caregivers with the evolution of society. Before modern nursing and caregiving started, nuns and the military offered nursing-like services (Davies, 2012; Nemati et al., 2017). The Crimean War is significant in the development of caregiving where Florence Nightingale, an English nurse, offered caregiving service to wounded military service members before Queen Victoria ordered the construction of a hospital to train and offer nursing services (Davies, 2012). Modern nursing started in the 19th century in Britain and Germany before spreading worldwide in 1900. In the mid-19th century, nursing transformed into domestic caregiving to care for extended family members. From there on, strangers started hiring nurses to care for their loved ones at home (Davies, 2012).

Historical factors confronted by individuals influence their growth during life (Morton et al., 2015). The principle of lifespan perspective notes that the standards of care for older adults are influenced by situational factors that are in some way associated mutually with these factors. Gender, race, ethnicity, and other rural/urban residency setups identify differences in individual behavior as a reason for various situations due to intervention or growth (Morton et al., 2015).

Informal Caregiving

Definition of Informal Caregiving

Schultz and Tompkins (2010) and Nemati et al. (2017) define an informal caregiver, which is often a member of the family, as an individual that typically provides care without pay to people with whom they have personal relationships. Informal caregivers are also regarded as family caregivers, often providing home care services to their family members or loved ones, usually without pay (Nemati et al., 2017). Informal caregivers always offer care within a home environment for an aging, disabled, or sick parent, spouse, relative, or friend (Sigelman & Rider, 2015).

Informal caregiving is an important resource to the care recipient and a critical component of the health care system within the United States (Schultz & Tompkins, 2010). However, society still needs to appreciate the role and importance of caregiving. An informal caregiver, typically a family member, provides unpaid care to someone with whom they have a personal relationship (Schultz & Tompkins, 2010). Nemati et al. (2017) endeavored to figure out who informal caregivers are, their needs, their role in society, and the strategies and requirements to support their efforts. This research, therefore, seeks to provide and describe the prevalence of informal caregiving in a community by identifying caregivers, their roles and responsibilities, and challenges such as stress and burnout that they experience while coordinating care (Nemati et al., 2017).

Eleanor Rosalynn Carter, the spouse to former President Jimmy Carter, was known for her advocacy in mental health and caregiver issues and as the founder of The Carter Center (National Research Council, 2010). Rosalynn Carter, American writer and activist, noted that “there are only four types of people in the world: first, those who have been caregivers; second, those who are caregivers; third, those who will be caregivers; and finally, those who will need caregivers” (National Research Council, 2010, p. 118). Informal caregivers are in three distinct groups defined by the age of their care recipients (Sigelman & Rider, 2015). For instance, children with disability and chronic illnesses are cared for by their parents, adult children with illnesses such as mental health care are cared for by middle-aged parents, and finally, elderly care recipients are cared for by both their aged spouses and adult children (National Research Council, 2010). Numerous of these caregivers also hold full-time jobs and other duties, including caring for their families, volunteering and doing chores, and cleaning (Nemati et al., 2017).

Prevalence of Informal Caregivers

The number of people receiving unpaid care (care recipients) in the United States rose by 9.5 million between 2015 and 2020 to a total of 53 million people (May, 2021). This is nearly 17% of the country’s adult population. Caregivers that offer the service to care recipients such as family and relatives, such as spouses, are 89%. Seventy-five percent of informal caregivers are female, while 25% are males, and the average caregiver in the country is 50.1 years old. The marital status of family caregivers of adults above 50 years old significantly changed, with 60% of caregivers being married or in a long-term domestic partnership, and 23% being single individuals. The largest population, 34%, attended college or postsecondary education, while 25% are high school graduates, and 6% of informal caregivers did not complete high school education. The majority of informal caregivers (71%) have other jobs or are employed (May, 2021).

Characteristics of Informal Caregivers

Understanding the characteristics of informal caregivers and their challenges could inform the enactment and implementation of policies and improvements in support systems that could enhance both the health of a caregiver and that of a care recipient. Informal caregivers' needs are challenging to determine apart from those related to caring for their loved ones, especially terminally ill loved ones (Torelli, 2020). In most cases, the individual needs of informal caregivers are not tracked and provided for due to their day-to-day activities and responsibilities of care (Torelli, 2020). It is expected that at some point in one's life, one will serve as an informal caregiver (May, 2021). Caregivers come from any socio-economic group and of any age (Ramos, 2019). A classic caregiver in the United States is a female in their mid-40s with a college education, has a job outside the home, and provides at least 20 hours of care per week (May, 2021). According to May (2021), 66% of caregivers are women employed full-time or part-time.

Armstrong-Carter et al. (2021) noted that 24% of middle school students and 16% of high school students provide care to their families regularly whereas those receiving care are characteristically female (66%) and older than 50 (80%). In 12% of people who need care, the main presenting problem or illness is old age (Armstrong-Carter et al., 2021). Of this population, 10% suffer from Alzheimer's or dementia, 7% from cancer, 7% from psychological/emotional illnesses, and 5% from heart diseases. In comparison, the other 5% suffer from stroke. As for the young adult care recipients aged 18-49, 23% suffer from mental illnesses and depression as their primary health problems that call for care (Armstrong-Carter et al., 2021). Shepherd et al. (2018)

suggested that the main reason for providing care for children aged 18 or younger is due to the unique needs of the child, including autism spectrum disorder, uncommon diseases, as well as physical and mental disabilities.

The care provided by caregivers involves a varied range of daily living skills. For instance, 83% of their caregiving time involves helping with transportation, 75% doing domestic housework, 75% doing grocery errands, and 65% preparing and taking care of the care recipient's meals (Bryant, 2016; May, 2021). May (2021) notes that the average length of time for providing care, as reported by caregivers, is 4.6 years. Therefore, the life of an informal caregiver is stressful and full of symptoms such as financial, mental, and physical strain. While it is challenging to articulate informal caregivers' characteristics clearly, reviewing them is crucial to help identify appropriate support mechanisms required to support their well-being while caring for others and forgetting themselves (Torelli, 2020).

Roles of Caregivers

Biello et al. (2019) noted that people who provide informal care play a significant part in the United States health care system since they offer extra and unpaid support. May (2021) and Shin and Choi (2020) also note that informal caregivers take on this rewarding task without proper, cost-effective services and support. Caregivers must take up various roles to deliver real home-based health-related care (May, 2021). Providing informal care requires communication and negotiation between caregivers and family members concerning care decisions. Caregivers and care recipients must agree on how the care recipient will receive companionship and emotional support and how the caregiver will work with physicians and other health care providers regarding the patient's status and needs (Liu et al., 2020).

Other tasks that the caregiver performs and which should also be communicated and negotiated with the family include taking the patients to their appointments, housework, shopping, completing paperwork, managing finances, aiding with personal hygiene and care, lifting and directing the patient, assisting with difficult medical and nursing duties like tube feeding, infusion therapies and monitoring the patient's medication, and provide assistance with any additional daily living skills compelled by the health and care conditions of the recipient (Gérain & Zech, 2019). Caregivers are also required to coordinate services from health and human service agencies, make difficult decisions about patients' service needs, and figure out how the patients or care recipients can access the services they need. It is worth noting that all the tasks involved in caregiving pose a strain on the physical, cognitive, and emotional well-being of the caregiver (Gérain & Zech, 2019; May, 2021). However, May (2021) notes that older individuals with low income and suffering from disabilities or chronic diseases but playing the role of caregivers are highly likely to experience adverse outcomes.

A national survey conducted for children with special care needs indicated that 10% of family caregivers of children spend over 11 hours every week arranging, coordinating, and providing care (May, 2021). Twenty-four percent of those caregivers either quit or reduced their work hours, eventually creating financial challenges for their families (May, 2021). Some common assistance caregivers provide to children with special needs, as stipulated by May (2021), include monitoring the child's condition and ensuring that other people, such as teachers, are aware of the child's condition and how to manage the child's needs. Caregivers also advocate for the child to schools, other care providers, and government agencies (Flores, 2021; May, 2021). In addition, caregivers perform emotional or behavioral treatments or therapies on the child and administer their medication (Flores, 2021).

Cultural and Ethnic Contributions

Parveen et al. (2013) described familism as a cultural value that identifies and attaches individual and family feelings and loyalty, mutuality, and unity among family members' structure. The idea of a caregiver's readiness for caregiving is similar to familism in providing care, their attitudes towards caregiving and support, and the ability to identify whether the support required is a current or future need (Parveen et al., 2013). Caregivers express positive feelings regarding caring for their loved ones as a fulfillment of their cultural obligations, but they still experience caregiver stress and burden (Hennessey & John, 1996).

Walsh's (2003) theory, which defines family resilience as the ability of the family to endure and recover from adversity as a functioning system, demonstrates the existence of a correlation between family resilience and parenting stress within family systems (I. Kim et al., 2020). In the United States, about one fifth of the non-Hispanic White and African American ethnic groups provide informal care. The American Psychological Association (2011) found that approximately 18% of Asian Americans and 16% of Hispanic Americans provide caregiving services.

Many caregivers are from minority ethnic groups and undertake more activities, unlike their white counterparts, resulting in worse physical and mental health than white caregivers (American Psychological Association, 2011). African American caregivers do not demonstrate as much stress and depression but reap the rewards from caregiving compared to White caregivers. The American Psychological Associations (2011) also noted that American caregivers of Hispanic and Asian origin show more characteristics of depression than their white counterparts. Research also indicates that White caregivers generally get help from their spouses. In contrast, Hispanics get help from their adult children, and African Americans usually get caregiving from people who are not members of their families (American Psychological Association, 2011).

Literature advises that those providing care should have basic knowledge of ethnic mapping (Valle & Gait, 2014). This means that practitioners should be able to comprehend the cultural processes and put in writing the cultural-historical data of the ethnic groups within which they serve. Providers should understand language and communication and be able to access and understand interactional patterns. Providers need to acknowledge targeted group values, beliefs, and expectations, as well as identify the socio-economic status, impacts of discrimination, situations of low social status, and level of education, and have the ability to distinguish them and understand that they are not the things that describe the ethnic groups (Valle & Gait, 2014).

Caregiving Needs on the Rise

The majority of people in the United States who were informal caregivers provided substantial services through in-home and unpaid assistance to their family members and friends (CDC, n.d.). As the population of the United States continues to age, the need for informal caregivers continues to increase across the country. This implies that unpaid and informal caregiving in the United States occurs widely as part of the family (Schulz & Eden, 2016). CDC (n.d.) data show that 58% of the caregivers are women, and the majority are non-Hispanic white with the least college education, married, or living with a partner. Across the states, CDC (n.d.) reported that at least 19.2% of informal caregivers reported being in poor or fair health. Informal caregivers support their family members, friends, loved ones, and the country’s health care system while compromising their health and well-being (CDC, n.d.).

The National Alliance for Caregiving estimated that 5.7 million Americans would be caregivers for their sick or disabled relatives in 2020, while the CDC (n.d.) estimated 17.7

million would be caregivers (CDC, n.d.; May, 2021). As the population of the United States continues to age, the need for informal caregivers continues to increase across the country. According to data from the Behavioral and Risk Factor Surveillance System collected by the CDC (n.d.) between 2015 and 2017, one in five adults in the nation reported having provided informal care to a family member or loved one (May, 2021; Schulz & Eden, 2016). This suggests that unpaid and informal caregiving is a common occurrence in the United States (CDC, n.d; Schulz & Eden, 2016).

The American people will continue offering informal caregiving to their loved ones, including family and friends who need assistance due to increased caregiving services caused by their diminishing health or functional needs (Torelli, 2020). People continue stepping up to offer informal caregiving because of the diminishing health or functional needs due to increased caregiving services (May, 2021). This increase in prevalence may be due to an aging population comprising baby boomers that require more immediate care, limited or lack of health care sector workforce, or prolonged care services. Community-based and home services are also on the rise, according to May (2021). Americans have identified caregiving as their responsibility, personal daily activity, and the connection of all these trends (May, 2021).

The United States is facing a shortage of in-home caregiving aides and professionals that perform tasks such as helping the aging population who are unable to care for themselves at home due to a lack of family caregivers or supplementing family care (May, 2021). The shortage of caregivers in the country keeps increasing due to the rapid rise of the elderly and sick population in many states. At least 11,000 hours of personal care are unstaffed every week in each state. Every day, at least 100 people in the health care systems across the country cannot be discharged from hospitals due to a lack of a caregiver or posttreatment care at home (May, 2021). There is a dramatic rise in the need for home-based aid as most states in the country face a critical shortage of caregiving.

Lack of Research on the Caregiver Demographic

There needs to be more formal caregiving research and studies that limit the development of interventions to address the growing and unmet needs of informal caregivers. There is interest in determining and establishing priorities for studies in informal caregiving that require the input of experts (Sterckx et al., 2013). One of the research gaps is the lack of a consensus on a harmonious definition of caregiving that considers the scope and breadth of caregiving, dynamic caregiving changes, availability of economic and social resources to caregivers, and cultural and ethnic differences in the roles of caregiving. Second, research must clearly articulate the cost of caregiving to society and caregivers since the number of informal caregivers is unknown (Sterckx et al., 2013). This makes it difficult for scholars to understand how informal caregiving affects societies and how demographic changes affect informal caregiving.

A cross-national study that includes international data samples and harmonization efforts is required to identify ways different demographics, geographies, economic environments, and composition impacts the cost of caregiving (Wilkinson & McLeod, 2015). Also, previous studies have not been able to identify predictors of high-risk caregivers (Wilkinson & McLeod, 2015). Caregivers, in most instances, are women who always encounter mounting and ever-changing challenges. However, it has not been documented how caregiving affects their well-being and health, given that some individuals thrive while caregiving and others encounter stress and burnout (Smith, 2023). Therefore, intervention strategies can be determined if research identifies key predictors of high-risk caregiving to form interventions promoting the well-being and health of the informal caregivers and the community. Finally, caregiving needs are ever-changing among recipients suffering aggressive illnesses that create uncertainty among caregivers leading to unhealthy outcomes such as undue financial burdens (Wilkinson & McLeod, 2015). Research has not disseminated and developed evidence-based, community-based interventions for recipients and caregivers that will reduce the burden of caregiving (Smith, 2023).

Theoretical frameworks examined in the literature suggest that all caregivers provide equal physical and mental health benefits to the recipient (Ghasemi et al., 2020). The theories classify informal caregivers and the significant concepts associated with caregiving relationships, including familiarity, availability, preference, and motivation (Ghasemi et al., 2020; Schulz & Eden, 2016). Ghasemi et al. (2020) supported the analogy that social network theories do not specify whether these theories can be applied to psychological and physical support.

Schulz and Eden (2016) noted that the current research could be more extensive for various reasons. First, the authors believe that information about informal caregivers in many research studies is self-reported and likely influenced by recall bias and social desirability. Also, Schulz and Eden (2016) noted that most people perceived as informal caregivers might not identify themselves as so but think of their roles in family caregiving as a personal responsibility to their loved ones, thus underestimating the number of informal caregivers. Finally, the Behavioral and Risk Factor Surveillance System and other researchers, such as Schulz and Eden (2016), interview only one person per household. This renders family caregivers not participating in such studies undercounted and their views left out.

Caregiver Stress and Burden

Providing care to a loved one is frequently a long-term challenge (Smith, 2023). Current data exploring the long-term challenges of caregivers over the lifespan reveal a downward spiral of physical, mental, and emotional attrition resulting from having to provide care for someone over several years and even decades. Caregivers often feel like they are in over their heads. The psychological duress experienced by these individuals results in the perceptions of being consumed in an emotional vortex that ultimately leaves caregivers feeling like they are overwhelmed and mentally exhausted. Data have shown this type of bio-psycho-emotional malaise is especially true if there is no chance a family member will get well, or if their physical condition continues on a steady decline (Smith, 2023). Furthermore, data also underscores the myriad of services provided by caregivers who are deployed by health and human services agencies (Wilkinson & McLeod, 2015).

Wilkinson and McLeod (2015) list the following coordinated essential services provided by primary caregivers: coordinate services from health and human services agencies, make essential decisions about the recipient's needs, and evaluate the efficacy of how services are implemented, applied, and assessed. Other services caregivers partake in include shopping, scheduling and transporting the care recipient to appointments, managing finances, completing paperwork, and assisting with ADLs such as personal and hygiene assistance, monitoring medication, and feeding, among other roles that the health condition of the recipient necessitates (Wilkinson & McLeod, 2015). In addition, research regarding caregivers implies the misconception that people tend to perceive caregiver stress as situational or as an isolated phenomenon. However, Pearlin et al. (1990) revealed that caregiver stress is a combination of circumstances, experiences, and responses considerably varying among caregivers, affecting their physical and mental health, which is understandable according to the aforementioned list of informal caregiver responsibilities posited by Wilkinson & McLeod (2015).

The theoretical explanations of informal caregiver stress can be characterized according to their primary approach of the stress experience to include stress as an external stimulus, stress response, stress as an individual or environmental interaction, or stress as an individual or environmental transaction (Biggs et al., 2017). Hence, through these studies, it is ostensibly apparent that caregiver stress is not defined by a seminal isolated event, but rather an accumulation of a present and continuous set of circumstances in the lives of those providing care to a family member. Moreover, it is critical that research identifies these misleading and inaccurate interpretations in an effort to bolster the appropriate ancillary support and self-care services to caregivers who often internalize the physical and psycho-social-emotional stressors over extended periods.

Definition: Caregiver Stress

Research conducted by Wilkinson and McLeod (2015) articulated caregiver stress as a distinct shift from a caring and positive attitude to one of unconcern and negativity due to mental, physical, and emotional exhaustion. This ultimately leads to burnout and stress when caregiver roles fluctuate without getting the assistance they require and working on tasks that exhaust them mentally, physically, and financially (Sterckx et al., 2013; Wilkinson & McLeod, 2015). Moreover, Sterckx et al. (2013) revealed a causal relationship between domestic caregiving and stress. For instance, data indicated a pattern in the shift of the attitudes of individuals and family members regarding their roles and responsibilities once they had to take on a multidimensional caregiving role which entailed providing the patient with ADLs and emotional support (Ramos, 2019). The caregivers often must add new duties, leaving them with the sensation that they have a whole family and household (Sterckx et al., 2013).

Definition: Caregiver Burden

Caregiver burden can be defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member (Liu et al., 2020, p. 439). The caregiver burden is a multifaceted personal strain, often leading to the caregiver neglecting their own physical and mental health (Gérain & Zech, 2019; Liu et al., 2020). The long-term burden can cause disruptions in the caregiver's physical and psychological health, including anxiety, depression, heart disease, and hypertension (Gérain & Zech, 2019; Liu et al., 2020).

Liu et al. (2020) conducted a concept analysis by reviewing 33 articles regarding the definition of caregiver burden to clarify the concept. The data revealed that a clinically accepted definition accurately describing the term caregiver burden can be nebulous to define given the subjectivity of the emotions including the caregivers' feelings and objectives, and the psychological attachment associated with the meaning of a particular caregiving activity. In addition, this self-perception was identified as a defining attribute of caregiver strain, which varies from caregiver to caregiver (Liu et al., 2020).

A study by Northouse et al. (2012) illustrates another dichotomy in the variance when applying this term between gender. Results suggested that there is a higher caregiver burden among female caregivers than it is among their male counterparts. Within the workplace, caregivers consistently feel under pressure, lack recognition, and struggle with personal and work content (Czuba et al., 2019). In addition, QOL has been demonstrated to have an inverse relationship to the perceived level of burden, and reducing the caregiver's burden can significantly improve their QOL (Liu et al., 2020).

Negative Effects of Caregiver Stress and Burden

Caregivers devote a significant amount of time and energy to caring for their loved ones, and often significantly compromise or neglect appropriate and necessary self-care for themselves (Broxson & Feliciano, 2020; CDC, n.d.; Lou et al., 2022). Despite the variance in the functionality of each caregiver role, it is essential to note the potential negative outcomes associated with stress for a significant portion of the American population (CDC, n.d.). Broxson and Feliciano (2020) demonstrated that the chances of family caregivers experiencing physical and emotional health issues are higher than noncaregivers. The effect of the caregiver burden is accompanied by negative changes that can impact care and decrease QOL and physical and psychological health (Liu et al., 2020).

Broxson and Feliciano (2020) note that family caregivers under stress are at risk of dying young, and a study by Roth et al. (2015) found that over 55% of the caregivers who participated reported feeling overwhelmed by the care that their aging or chronically ill family member required. Research further identifies caregiver burden as an identified public health issue because of the biological, mental, and social impacts of the increased burden on the caregiver, which can also affect their ability to offer care to their loved ones (Broxson & Feliciano, 2020). A study by Irfan et al. (2017) points out that older people who care for others may be especially vulnerable because these caregivers may have to strain their physical and mental well-being as well as their immune systems. Ramos (2019) found that caregiving is demanding and places a lot of physical, emotional, and cognitive strain on the caregiver, putting their health at higher risk. Long chronic stress due to caregiving causes wear and tear in the body resulting in the development of physical, emotional, and behavioral symptoms (Lou et al., 2022; Wilkinson & McLeod, 2015). Caregivers in this category often sacrifice their wants and endure much stress and feel overlooked.

Studies show that the caregiver’s age, income, knowledge, and employment status can predict the quality of their lives, thus impacting their outcomes (Northouse et al., 2012; Wilborn-Lee, 2015). Wilborn-Lee (2015) noted an increasing need for homecare services that do not require formal training for baby boomers. Multiple studies also indicated that the more distress and burden perceived by the caregiver, the more negative changes the caregiver experienced regarding their health (Broxson & Feliciano, 2020; Northouse et al., 2012; Rumpold et al., 2016; Tuncay & Fertelli, 2019). Moreover, data strongly implies caregiving exhibits all the signs of chronic stress.

For example, long-term caregivers have inherently higher levels of vigilance, causing physical and psychological strain over extended periods. High degrees of unpredictability and uncontrollability make this worse, and it has the potential to lead to secondary stress in a number of areas of life, including relationships with family and at work (Schulz & Sherwood, 2008). Caregiving has the potential to serve as a model for exploring trends, themes, and patterns for researching the negative effects of chronic stress on health given its congruency in aligning with the chronic stress model. Factors related to the patient's condition determine the caregiver's well-being and individual characteristics of the caregiver, including relational, psychological, and demographic factors (Weitzner et al., 1999). Studies are replete with data highlighting a greater elevation of care regarding the needs of patients who have become more debilitated, thus increasing the demands of caregiving. Such caregiving demands include actual physical care that is needed, offering emotional support, changing the role of a caregiver in the family structure or system, and the increased need for financial support. When the needs of a care recipient increase, it adversely affects the sense of self-esteem of a caregiver, physical and mental health, finances, relationships, and a caregiver's schedule (Weitzner et al., 1999).

Physical Health Impacts. According to Lou et al. (2022), caregivers are particularly vulnerable to high-stress levels and are at an elevated risk of mortality, coronary heart disease, and stroke. Irfan et al. (2017) also noted that caregiver stress may aggravate already preexisting chronic health conditions of older caregivers exhibited in the reaction of physical symptoms being exhibited in the forms of body pain and aches, racing heart and chest pains, sleeping problems, exhaustion, dizziness, shaking, and high blood pressure. Other symptoms include muscle tension, digestive and stomach problems, and a weak immune system among others (Irfan et al., 2017). Furthermore, individuals who conduct their own ADLs such as meal preparation, toileting and personal hygiene, and dressing reported experiencing elevated levels of physical health stress than those who do not participate in ADLs (Morton et al., 2015). Caregivers who work full-time say they experience poorer physical health than their noncaregiving counterparts (Family Caregiver Alliance, 2016b; Morton et al., 2015). Data reveal that 16% of full-time caregivers have a physical health index score of 77.4%, which is significantly lower than 83% for noncaregivers (Family Caregiver Alliance, 2016b).

Another factor impacting caregiver stress is the physical stress absorbed via traumatic experiences one encounter while offering caregiving services (Wilkinson & McLeod, 2015). Adverse physiological and biological responses such as fatigue, substance abuse, and dietary stressors are some of the physical stressors that may impact informal caregivers (Sterckx et al., 2013; Wilkinson & McLeod, 2015).

Studies are consistent with data indicating that the perceived physical health of the caregiver is generally lower than that of the general population, and the perceived health of spouse caregivers is lower than that of parent caregivers (Roman et al., 2021). Many caregivers have reports of comorbidities such as hypercholesterolemia or high rates of cholesterol, hypertension, obesity, and depression (Roman et al., 2021). Broxson and Feliciano (2020) and Northouse et al. (2012) identified additional comorbidities and physical health problems associated with caregiver burden including heart problems or diseases, hyperglycemia, arthritis, high cholesterol, cortisol, and diabetes. Northouse et al. (2012) and Rumpold et al. (2016) also point out that caregivers are at an increased risk of developing mental health problems.

Mental Health Impacts. Current longitudinal and empirical studies consistently underscore and highlight the negative long-term effects of providing care which can be stressful and taxing (Schulz & Sherwood, 2008). Further exploration expounds on the caregiver burden resulting in mental and emotional problems characterized by irritability and anxiety, sadness, panic attacks, and depression (Rumpold et al., 2016; Schulz & Sherwood, 2008). There is a correlation between caregiving stress, depression, and economic and mental stress, which in turn impacts self-esteem (D. Kim, 2017). An overview of peer-reviewed publications examining the psychological well-being and emotional agony of family caregivers of cancer patients was conducted by Northouse et al. (2012). They found that the stress of caregiving takes the greatest toll on the caregiver's psychological well-being (Northouse et al., 2012).

In reviewing data from traditional points of view, studies consistently identify other forms of psychological stress including panic, anxiety, and feeling out of control (Sterckx et al., 2013; Wilkinson & McLeod, 2015). Additionally, studies have also indicated findings for anxiety and depression for informal caregivers in conjunction with findings for depression, PTSD, and substance abuse, which further validate the need for additional future studies to better understand these causal and correlative factors (Rumpold et al., 2016). Similarly, Northouse et al. (2012) found increased levels of anxiety and depression in caregivers when care recipients had increased distress from symptoms or poor physical functioning. The results of a study done by Rumpold et al., (2016), examining the presence of psychiatric conditions that were potentially present in informal caregivers, indicated that 18.7% of participants had a positive screening for PTSD and 11.3% had a positive screening for alcohol abuse.

Additional data also reflect secondary concerns germane to the mental well-being of caregivers such as financial problems, shortage of time, sleep problems, and other health issues, which increased their stress levels (Nemati et al., 2017). In addition, caregivers exhibited low emotional well-being, high anxiety levels, and depression (Wilkinson & McLeod, 2015). Rumpold et al. (2016) agree that compared to noncaregivers of the same age, informal caregivers show higher levels of depression, anxiety, and perceived stress and exhibit lower well-being. In addition, 34.1% of participants had a positive score for anxiety, and 42.6% had a positive or borderline screening for depression. Up to 70% of caregivers suffer from clinically significant symptoms of depression, where 20% of them are females who are employed (Family Caregiver Alliance, 2016b).

Emotional Health Impacts. Another key component in evaluating caregiver stress is accurately categorizing emotional characteristics resulting from psychological stress. Various researchers have not only identified emotional characteristics of stress, but have highlighted external behaviors such as fear, resentment, sadness, frustration, anger, attachment, and resistance (Santos-García et al., 2022; Sterckx et al., 2013; Wilkinson & McLeod, 2015). Moreover, these emotions often manifest when one takes over the job of caregiving whether by default or willingly (Santos-García et al., 2022). Studies also indicated that these feelings of emotional overload can occur instantly, however, it is important to note that other symptoms may be more progressive in nature, thus taking longer to manifest over time (Santos-García et al., 2022).

Another condition resulting from caregiver stress is a term called ambivalence, which is conflicting feelings of compassion (wanting and willingness of wanting to perform the role of caregiver) and a feeling of resentment and dread (feeling burdened and angry; Biello et al., 2019). This dilemma results in great emotional angst with caregivers expressing feeling abandoned and isolated during those tumultuous and turbulent periods, yet conversely expressing feelings of joy and rejuvenation when they view their role as a gift to the care recipient (Biello et al., 2019). A second feature is anger, which develops as the frustration of being around the care recipient (Santos-García et al., 2022). Other symptoms of emotional overload include anxiety, boredom, fear, sadness, embarrassment, guilt, grief, resentment, loneliness, and sadness.

An additional emotional impact that informal caregivers may experience is anticipatory grief (Clukey, 2008). Anticipatory grief is a term invented by Erich Lindemann in 1944 to elucidate the grief reactions he witnessed among people who were not bereaved (Duke, 1998; Rogalla, 2018). In Clukey's (2008) qualitative study examining anticipatory mourning using nine participants who had all provided care to a terminally ill family member, he found that anticipatory grief consisted of a set of dynamic processes such as sadness, anger, disbelief, numbness, relief, and guilt. A literature review of texts from 1990 to 2015 identified themes around the family experience of anticipatory grief to include death anticipation, emotional distress, intrapsychic and interpersonal protection, hope, exclusive focus on the patient care, personal losses, relational losses, ambivalence, end-of-life relational tasks, and transition (Coelho & Barbosa, 2017). The anticipation of death distinguishes anticipatory grief from traditional grief (Coelho & Barbosa, 2017). Victims of anticipatory grief commonly question God's existence while having trouble connecting with others emotionally (Shore et al., 2016). Unfortunately, anticipatory grief rarely or does not ameliorate or eliminate the grief that a person experiences after the actual death of their loved one. Palliative care providers need to identify families and patients experiencing anticipatory grief to enable them to assess and determine their complications, provide the necessary support, and nurture effective intervention strategies to help them cope (Shore et al., 2016).

Social and Relationship Strain. The burden of informal caregiving responsibilities is strongly associated with social isolation (Sterckx et al., 2013). Informal caregivers often experience psychosocial stress, which occurs when they encounter problems in their relationships and partnerships due to their caregiving role (Wilkinson & McLeod, 2015). This includes marriage and relationship difficulties such as problems with siblings, partners, employers, and coworkers. A lack of social support, loss of loved ones, and isolation are depictions of psychosocial stress (Sterckx et al., 2013; Wilkinson & McLeod, 2015).

Another negative outcome of the social and relationship experience of informal caregivers is eventual relationship difficulty is characterized by increased feelings of resentment, loss of desire, and loss of interest in personal needs (Shore et al., 2016; Sterckx et al., 2013). This occurs when a caregiver loses interest in the recipient of care (Shore et al., 2016). Increased feelings of resentment and hatred towards a care recipient or family is a common phenomenon in caregiving that illustrates the caregiver burden. (Shore et al., 2013).

The impacts of social networks are distinct based on the support (Ghasemi et al., 2020). The current literature focuses on using analytical methods to understand hypotheses that examine the relationship after the adjustment of variables. The shortcoming of this study is that it is majorly used to estimate the independent impacts of disability or illnesses on the dependent variable, which is the health of a caregiver (Ghasemi et al., 2020; Shore et al., 2016; Stercks et al., 2013).

Financial Impacts. Another component of caregiver stress is financial strain. Research identifies the internal friction and pushback exhibited towards caregivers by patients who were the primary managers of their finances and are now confronted with relinquishing that responsibility (Sterckx et al., 2013). Even though caregiving roles are emotionally, physically, and cognitively demanding, individuals subjected to caregiving roles likely have no income making them vulnerable to adverse financial consequences (Wilkinson and McLeod, 2015).

The National Research Council (2010) shows that being a caregiver reduces one's work productivity and increases their chances of leaving the workplace. Informal caregiving often causes the caregivers to take time off work, thus, leading to financial strain (Sterckx et al., 2013). The responsibilities of informal caregivers are placed along a continuum, and the varying hours can impact the amount of income or lack thereof (National Research Council, 2010). Caregivers without outside work provide approximately 29 hours of care each week, while those who work outside of the home engage in about 20 hours of providing caregiving tasks (Flores, 2021; Walker, 2022). While working outside the home and being immersed in a work role can positively impact stress levels in some caregivers (Bainbridge et al., 2006; Wilborn-Lee, 2015), the need to balance their time or fluctuating levels of income can also be stressful for informal caregivers.

Poor Overall QOL. Consistent with previous research, caregivers often carry a heavy burden that hinders them from keeping up with their daily lives, leading to increased isolation (Cavers et al., 2012). A literature review conducted by Wilkinson and McLeod (2015) examined the QOL of informal caregivers and found that apart from their inability to maintain everyday life, caregivers also experienced a significant burden of responsibility, which was associated with a lower QOL compared to that of the general population. Although poor QOL is not a clinical diagnosis (Zarit et al., 1980), it is a concern for informal caregivers. QOL is the extent to which caregiving has impacted the life of a caregiver negatively concerning emotions and financial, social, spiritual, and physical well-being (Martin et al., 2021; Zarit et al., 1980). This is one of the widely used definitions and measures of QOL. However, the measure and definition of QOL have changed to include specific conditions, including the type of illness of the care receiver and positive appraisals such as perceived benefits of caregiving (Martin et al., 2021; Zarit et al., 1980). Researchers focus on determining the QOL based on strains and burdens, including stress and a caregiver's experience (Martin et al., 2021).

In a study done with hospice family caregivers, caregivers' QOL was lower than their noncaregiving compatriots (Parveen et al., 2013). Caregivers of more debilitated patients had inferior QOL, especially concerning their physical health. Data from Weitzner et al. (1999) support the above findings that caregivers to patients under palliative care have the lowest QOL score. The QOL score has much to do with the physical demand of caregiving, the stage under which a care receiver's illness is, and the role and functions a caregiver undertakes, including domestic responsibilities for the family (Weitzner et al., 1999). Caregivers experience role strain and role change after the death of their loved one (Duke, 1998). They go from doing the caring to needing the caring. They go from being with their spouse to now being alone. While they were once creating memories, they are now in a stage of remembering (Duke, 1998). Parents and caregivers adapt to challenging roles while others struggle to adjust. Contextual factors like socioeconomic status, child factors, behavior, the severity of a disability, intrapsychic issues, coping strategies, and social supports impact informal caregivers' mental and physical outcomes (Raina et al., 2004).

Wilkinson and McLeod (2015) agree that caregivers find the demand to take multiple roles to deliver effective health-related home care. To varying degrees, they are required to communicate and negotiate with other family members regarding care decisions, provision of emotional support, care decisions, companionship, and interaction with health care providers such as nurses and physicians regarding the status and needs of the patient (Wilkinson & McLeod, 2015). Individuals providing care to their spouses, parents, or cohabitants face challenges regarding their physical and emotional health and financial situations (May, 2021; National Research Council, 2010). As caregiving moves from institutional to home-based care, the incidence and burden on individuals participating in a caregiver role will increase (Armstrong-Carter et al., 2021), leading to a greater need for resources and effective coping mechanisms, as will be outlined in the next section.

Caregivers and Coping

Monteiro et al. (2018) defined coping strategies as particular behavioral and psychological attempts to manage or lessen stressful experiences. The results of coping mechanisms might be good, unpleasant, or unresolved (Biggs et al., 2017). Positive feelings are evoked when stressors are successfully resolved, whereas distressing or unfavorable resolutions cause the person to seek more coping mechanisms in an effort to effectively address the stressor (Biggs et al., 2017). Various psychosocial and pharmacological interventions have shown some effectiveness in decreasing caregiver stress (Adelman et al., 2014). Adelman et al. (2014) and Biggs et al. (2017), point out that just like the care recipients, caregivers should also be given support for their well-being. Coping styles vary, but they all comprise emotional, cognitive, and behavioral responses that the individual encounters in a challenging situation (Panicker & Ramesh, 2018).

Applying models that align with theory is essential in guiding interventions (Douglas, 2017). Bravo-Benítez et al. (2021) and Savundranayagam and Orange (2011) noted that intervention programs are essential to target caregivers' feelings to monitor grief. It is essential to design interventions to lessen the burden and test their efficacy because caregiver burden affects caregiving in such a significant way (Gräßel & Adabbo, 2011). There should be as many caregivers as possible who can access effective interventions. “The usefulness of an intervention is the multiplication of effectiveness and usage” (Gräßel & Adabbo, 2011, p. 151). Therefore, it is necessary to develop interventions and to find ways to improve and strengthen the awareness and use of these interventions (Gräßel & Adabbo, 2011).

Transactional Model of Stress and Coping Applied to Caregivers

Within the transactional model of stress and coping theory, Lazarus and Folkman (1984) state that coping strategies either directly control the stressor or regulate the emotions or feelings that arise as a stressful outcome is encountered (Biggs et al., 2017). There are three steps in the transactional model of stress and coping. The primary appraisal is the first step, which looks at how relevant the event is to one’s well-being (Lazarus & Folkman, 1984). During this phase, the event involves one of the following: irrelevant, stressing, and benign-positive (Lazarus & Folkman, 1984). The event did not affect one’s well-being if they were in the irrelevant category. If the event positively affects one’s well-being, it is placed in the benign-positive category. The third class is stressing, implying that it will include mischief or misstructure and will challenge individuals (Lazarus & Folkman, 1984).

The next step in the transactional model of stress and coping is a secondary appraisal, which assesses assuming an individual has the assets accessible to adapt to the circumstance or occasion (Lazarus & Folkman, 1984). Strategies for coping are the third step (Lazarus & Folkman, 1984). In other words, an individual’s coping strategy determines how well they handle the stressor or situation (Lazarus & Folkman, 1984).

As mentioned in the theoretical framework section, the transactional model of stress and coping includes two types of coping: problem-focused and emotion-focused (Lazarus & Folkman, 1984). Emotion-focused is when the individual tries to lessen the emotional discomfort, typically seen as avoidance. One sees this often when stressful situations are uncontrollable (McCleary & Blaine, 2013). Conversely, problem-focused is changing a situation using effort whenever possible.

The theory has been applied to caregivers in a number of studies. A longitudinal study by Santos-García et al. (2022) indicates that problem-focused and emotion-focused coping mechanisms moderate the relationship between primary stressors, decreasing caregiver depression with time. There are three broad categories for caregivers under which coping strategies are divided (McCleary & Blaine, 2013; Vaillant, 2022). They include danger response coping strategies, social support mobilization, and involuntary approaches (Vaillant, 2022).

Methods of Coping for Caregivers

Coping is the continuous cognitive change and behavioral adaptation when facing external and internal demands that are judged as something that exceeds the person's resources (Folkman, 2013). In addition to several deliberate cognitive and behavioral actions, coping is a dynamic process involving reciprocal responses. It allows for interaction and impact between the individual and their environment. In addition to controlling the surroundings, managing stressful situations might involve limiting, evading, enduring, and accepting stressful circumstances. Theoretically, coping mechanisms may be a significant and modifiable factor of psychological illness. As a result, they comprise all the intellectual, emotional, and behavioral actions a person takes in response to internal or external stressors though to be greater than what is usually without the power to handle (Folkman, 2013).

Monteiro et al. (2018) outline three types of coping mechanisms: dysfunctional (disengaging from the demanding circumstance or feelings), problem-focused (taking real-world efforts to eliminate or lessen the demands), and emotion-focused (controlling how one emotionally responds to stress). There have been controversies in the results that different studies have produced regarding the best coping mechanisms for caregivers. Some coping strategies help to manage symptoms, situations, and the meaning to manage expectations (Papastavrou et al., 2011). It is helpful to develop favorable comparisons and understand the big picture of the situation (Papastavrou et al., 2011). A coping method connects internal and environmental factors, such as difficulties and threats (internal or external, such as illnesses or earthquakes), and individual resources (both internal and external, such as a seemingly high self-efficacy and social environment with rich resources) are seen as interconnected elements (Monteiro et al., 2018).

Environmental Supports. While changing jobs or moving is not always the best route to take, changing things in the environment one is surrounded by can be done (Sabata et al., 2005). Although sometimes disregarded in discussions of caregiver support, the home environment has a substantial impact on caregivers' abilities to offer aid (Sabata et al., 2005). The house, whether that of the care receiver or the caregiver, typically serves as the location where services are provided (Nemati et al., 2017; Sabata et al., 2005; Sigelman & Rider, 2015). Care recipients frequently require caregivers to perform physically difficult chores, such as lifting and turning, and assisting someone to the bathroom (Chari et al., 2015; Sabata et al., 2005). To help with caregiving, family carers require enough room and comfort in their homes, especially when looking after care recipients (Sabata et al., 2005). According to research, when the home environment is changed to be more supportive, carers are less disturbed by the behaviors of the care recipient and are better able to meet functional demands. The physical demands on caregivers are lessened by home modifications and assistive technology or devices. For instance, night lights can assist in directing a person down a hallway to a bathroom in the darkness. Challenges arise in the realm of environmental coping if families lack knowledge of or resources to create safety and ease the family and caregivers' concerns (Sabata et al., 2005).

Social Supports. Ong et al. (2018) looked at perceived social support as a possible factor of burden among caregivers, finding that resilience and social support reduce physical and psychological effects on the caregiver burden (Ong et al., 2018). Caregivers need more support from agencies and more education on caregiving training alongside public education regarding caregiver burden and roles (Bialon & Coke, 2011). It is essential for health care professionals, specifically those who provide services to assist caregivers, to promote and identify supportive family and friend networks that may help address the caregiver burden (Ong et al., 2018). Community interventions in the public health system are significant, especially if they promote social support and coping mechanisms (Mendoza et al., 2020). It is also important to take measures that help reduce caregivers' care burden through education and support programs. This helps improve their family functioning and QOL (Ghasemi et al., 2020).

Religion and Spirituality. About 80% of Americans say they practice some form of religion, while nearly 20% say they do not engage in some type of religion (Pargament, 2013). Individuals who have little resources and are dealing with the most difficult issues often find comfort in religion and spirituality as a coping mechanism. There are several variations of religious coping, some of which are more successful than others. Many different religious and spiritual activities are available to people, and these practices have been associated with better crisis coping (Pargament, 2013). Life transitions may be made easier by God or a higher power, spiritual forgiveness, support from a religious institution, and reinterpreting a tumultuous event are some examples of these helpful religious coping techniques (Ahmadi et al., 2018; Pargament, 2013).

Ahmadi et al. (2018) shared that one study's most intriguing findings regarding coping was that several participants said they relied on God. Stressful events in life, such as informal caregiving, can cause people to become spiritually shaken and broken, as well as mentally, socially, and physically (Pargament, 2013). This occurs when a caregiver who believes that his or her spirituality can help them as a coping mechanism falls short of their expectations. In many instances, caregivers who believe that their religion or faith in God can help them heal or adapt to their current status quo drop or question their religion whenever they fail to overcome their stressors. Caregivers may experience spiritual worries related to their perception of God, issues within themselves, or personal and social relationships. A growing number of caregiving studies have associated these spiritual conflicts with more severe psychological distress, poorer physical health, and even a greater mortality risk (Ahmadi et al., 2018; Pargament, 2013).

External Resources and Online Support. Each demographic area has organizations and resources available to help individuals with coping. In the Central Texas area, some of the local organizations are the Area Agency on Aging, the Texas Department of Health and Human Services, and an Aging and Disability Resource Center. More exclusively to the local area are the Heart of Central Texas Independent Living Center, the Children's Special Needs Network, Baylor Scott and White Support Services, and the University of Mary Hardin Baylor Life Community Center. In addition to these local supports, there are also national and statewide supports such as workplace support, respite, and care services, and websites with links for resources for family caregivers and community resources (Central Texas Aging, Disability & Veterans Resource Center, 2022).

Summary

This phenomenological research study aimed to describe and understand the essence of lived experiences of informal caregivers in relation to stress and their coping mechanisms. Understanding the perceptions and experiences of informal caregivers offers much-needed insight into potential pathways for alleviation and support of the burden of future caregivers. It is important to acknowledge that not having enough informal caregivers to support the high number of elderly and sick population in the United States, families and employees will continue encountering challenges in caring for their loved ones within their communities (Morton et al., 2015).

Therefore, it is important to think of coping mechanisms as actions that lessen undesirable results while enhancing desirable ones. The coping taxonomy, which has had a significant impact on the larger coping literature, challenges the theoretical difference between problem focus and emotion focus. However, taxonomy of dual coping has come under fire for both theoretical and methodological shortcomings (Biggs et al., 2017).

According to Lazarus and Folkman's transactional model of stress and coping, one can adopt a problem-focused or emotion-focused coping style. In addition, stress management tools include disclaiming, evading responsibility or blame, admitting blame, practicing self-control of thoughts and behaviors connected to the circumstance, and participating in positive reappraisal. If coping mechanisms assist in long-term stress management, they are categorized as adaptive coping mechanisms. For instance, changing the problem or focusing on the good in a situation regarding stress management (Lazarus & Folkman, 1984). Maladaptive coping strategies, on the other hand, shorten the duration of our stress experience but do not assist or worsen the situation over time (Biggs et al., 2017).

Long-term caregiving is a chronic stressor that results in adverse mental, psychological, and physical health outcomes among caregivers (Gérain & Zech, 2019; Liu et al., 2020; National Research Council, 2010). As a result, caregiving is a complex endeavor that research seeks to capture (Biggs et al., 2017; Gérain & Zech, 2019). The outcomes dynamics of caregiving are always associated with the care recipient and the caregiver characteristics (Family Caregiver Alliance, 2016b; Gérain & Zech, 2019). Caregiver outcomes are also shown to depend on gender, age, kinship, and other roles and responsibilities of the caregiver, such as family, work, financial burdens, the health of the care recipient, physical and cognitive functioning, and supportive interventions, among others (Gérain & Zech, 2019). The literature review portion of this study has assessed informal caregiving, characteristics of informal caregivers, caregiver role stress, caregiving, QOL, and coping strategies. Various caregiver factors are examined to identify the level to which different characteristics of caregivers may determine or contribute to the relationship between caregiving demands and caregiver stress (Liu et al., 2020). Interventions and coping strategies to moderate caregiver burden have also been examined. Research has sought to use qualitative analysis to determine caregiving experiences and help illustrate the differences between caregivers while illuminating the impact of caregiver roles on stress, burnout, and motivation (Morton et al., 2015).

Finding a support system and informal network is crucial (Sun et al., 2012). Other interventions such as psychoeducation incorporated with technology, mindfulness, online interventions such as websites, email support with coaches, and chat room groups have been found to reduce caregiver stress (Gallagher-Thompson et al., 2010; Ploeg et al., 2018). Counseling and cognitive-behavioral approaches help reduce depressive symptoms (Wiegelmann et al., 2021). Providers should be aware of cultural considerations, including religious and spiritual coping methods (Ahmadi et al., 2018). The methodology that was used in this study to fill a gap in the literature will be discussed in detail in the next chapter.

Chapter Three: Methods

Overview

This phenomenological research study aimed to describe and understand the essence of lived experiences of informal caregivers in Central Texas, including how their experiences and perceptions of caregiving impacted their well-being and the ability to provide care services to their loved ones. The following chapter will cover the study's methodology, including research design, data collection methods, participants, data analysis techniques and storage methods, setting, the role of the researcher, and ethical considerations, among other critical issues to the research. The chapter is designed to ensure that the research provided credibility, trustworthiness, and dependable outcomes. Therefore, the methodology adopted for this research interviewed participant caregivers about their stress experiences, coping strategies, and interventions, which enabled the researcher to bridge the gap in the knowledge of managing experiences and strategies in the existing literature on informal caregivers.

Design

This study was based on a qualitative phenomenological research design. According to Wehei (2018), qualitative phenomenological research explores the researcher's perception as an obvious occurrence and digs deeper into reality to uncover ordinary life experiences. Furthermore, the approach enabled the researcher to perceive the phenomenon under study from a fresh perspective that led to the exploration of in-depth events (Wehei, 2018). Phenomenology uses inductive research approaches to understand commonly shared experiences (van Manen, 1990; Wehei, 2018). Phenomenological scholar van Manen (1990) examined and interpreted experiences encountered to identify fundamental themes, and when these themes are combined, the meaning of the experience emerges (Nemati et al., 2017; van Manen, 1990).

Phenomenology is a Western cultural philosophy resulting from reacting to the idea that scientific methods can control human behavior (Nemati et al., 2017). Since the behavior of human beings cannot always be predicted to terms and data that are quantifiable, the phenomenological approach was adopted to achieve a comprehensive understanding of human experience (Schumacher, 2010). Traditional techniques have fallen short in grasping the subjective nature of human experience since each experience is unique from one person to another (Schumacher, 2010). The research process included finding eligible and accessible respondents following ethical guidelines for the research and staying to the objectives, goals, and philosophy of the researcher's profession through scientific methods (Nemati et al., 2017; Schumacher, 2010). The researcher heard and saw beyond the written words to interpret lived experiences to ensure they encompassed the grammatical and psychological axes (Nemati et al., 2017).

This qualitative research aimed to determine caregivers' shared experiences concerning stress and coping mechanisms when caring for their loved ones and family members in Central Texas. Applying a qualitative phenomenological study design enabled the researcher to explore themes that best described lived experiences of caregivers in the area of Bell County, Texas, and their coping mechanisms. Creswell and Poth (2017) suggested that it is difficult to determine and identify variables in a phenomenological research design.

Research Questions

The following are the relevant research questions to phenomenological research from the expectancy theory regarding coping strategies for caregivers that experience stress taking care of their loved ones:

Central Research Question

What are the lived experiences of informal caregivers in Central Texas in relation to coping and stress?

Subquestion 1

How do informal caregivers in Central Texas describe the effects of providing care on their well-being?

Subquestion 2

What are the key stressors of informal caregivers in Central Texas?

Subquestion 3

What coping methods do caregivers in Central Texas engage when they experience stress?

Subquestion 4

What internal or external resources do caregivers in Central Texas utilize to cope with stress?

Setting

For this study, purposeful sampling was employed, where participants were chosen based on their involvement with the phenomena of caregiving. The study involved people who care for their loved ones or family members with various health care needs and illnesses in Bell County, Central Texas. Bell County comprises 12 surrounding cities: Belton, Fort Hood, Harker Heights, Killeen, Little River-Academy, Moody, Morgan's Point Resort, Nolanville, Rogers, Salado, Temple, and Troy. Individuals who qualified for the study were those that provided care for a loved one with a disability or illness for a minimum of 6 months. The care recipient was required to be an individual with a permanent illness or disability that affected their daily life. Some of these diagnoses included persons with dementia or Alzheimer's, special needs (such as a cognitive, physical, or mental disability), cancer, aging-related issues that require help with daily living tasks, or a chronic disease or illness that required care (such as heart disease, pulmonary diseases, cystic fibrosis, diabetes, inflammatory bowel diseases, muscular sclerosis, Lou Gehrig's disease, epilepsy, among others).

The study was conducted online utilizing a screener to determine participant eligibility for the study, informed consent, a short demographic survey to gather basic participant information and a virtual interview. All screeners and surveys were filled out through Google Forms (see Appendices F and H). The interview took place through a video conferencing platform, Zoom. The interview was conducted in the researcher's home and in a private location to ensure confidentiality and that the conversation not be heard. The study participant was able to choose their location and time in order to remain available for caring for their care recipient as well as be in a quiet and confidential area. Participants were primary or secondary caregivers whom they helped with legal issues and financial or health decisions in their daily care functions.

Participants

Finding participants for a research study can be challenging due to organizational culture and established protocols (Creswell & Poth, 2017). The maximum number of subjects for this study was 30 participants. This allowed for attrition or if a participant's circumstances changed and they could not participate in the study. Interviews were conducted until data saturation was reached. Data saturation was achieved after 12 interviews.

The sample population identified for the study included caregivers based in Bell County, Central Texas. The research consisted of three male and nine female participants at least 18 years of age. The participants were required to be adults to ensure no ethical issues arose. Details gathered from participants via a demographic survey included careers, employment, educational background, culture, race, and religion.

Texts defined an informal caregiver, often a family member, as an individual that typically provided care without pay to people with whom they had personal relationships with (Nemati et al., 2017; Schultz & Tompkins, 2010). To be eligible for the study, participants had to have provided informal care to a family member, friend, neighbor, relative, sibling, child, etc. for a minimum of six months. The care recipients were required to have had a terminal or permanent illness such as those with a cognitive, mental, or physical disability that affected their daily lives, aging individuals, cancer, or chronic disease or illness that required care. Some examples included heart disease, pulmonary diseases, cystic fibrosis, diabetes, inflammatory bowel diseases, muscular sclerosis, Lou Gehrig’s disease, and epilepsy. Participants were recruited through personal and public Facebook, Twitter, Instagram, other social media platforms, and personal acquaintances.

Procedures

After a thorough review of preexisting literature, the researcher reviewed Liberty University’s regulations and guidelines and sought approval from the Institutional Review Board (IRB) at Liberty University to conduct the study. The IRB is the authority that ensured ethical standards in a human research study as stipulated by the American Education Research Association (Creswell & Poth, 2017). The purpose of needing approval was to provide evidence that the research study followed an ethical design (Creswell & Poth, 2017). Once approval of the study was received (see Appendix A for IRB Approval Letter), the researcher began recruiting potential participants.

A verbal conversation was held (Appendix C) with potential participants with whom the researcher was acquainted and had expressed an interest in being a part of the study. Through this initial contact, four participants agreed. Since the researcher needed more participants, a social media post was made on the researcher's personal Facebook account (Appendix B) to gain more subjects. This post brought three more individuals who were possibly interested in the study. At this point, information was being spread, and individuals reached out to the researcher through acquaintances of the researcher. Three additional subjects were introduced to the study. Since the study still needed more participants for data saturation and collection purposes, the researcher contacted several acquaintances via telephone (Appendix C) to inquire about interest in participating. At that time, four more participants expressed interest. Additional recruitment follow-up documents were emailed after participants responded to the study request or if they expressed an interest (Appendices D and E). Once the participants were recruited, study screening documents were sent out to be completed.

It was important to make sure the researcher allowed for flexibility as well as confidentiality. With that said, the researcher chose to collect initial screener data through an online survey platform. This also allowed for a quicker response and ease for the potential participant. The first document sent out to be completed was a screener survey. An email was sent to interested participants with a link to a Google Forms screener survey (Appendix F). The screener included simple yes and no questions to determine if the potential participant was eligible for the study. If the interested individual answered yes to every question, they qualified to participate in the study. Individuals were ineligible for the study if they did not meet the study requirements, answered no for at least one of the screener questions, or if they were unable to participate in the data collection process, including recorded interviews. In addition to meeting the study criteria, interested participants were required to have the ability to complete screening and demographic surveys via Google Forms. They also needed the ability to utilize the Zoom platform to complete the virtual interview. Also, potential participants were not eligible if they provided care for a recipient with a short-term or temporary illness, impairment, injury, or disability such as surgery, medical treatments, broken bones, allergies, cold, flu, headaches, and other common illnesses.

After the screener results were received and eligible participants were verified, participants were sent a copy of the study consent (Appendix G). Informed consent was obtained from participants regarding the intent and purpose of the study and their role as contributors. The consent outlined the objective of the study, potential risks between the researcher and participants, and their right to participate or withdraw from the study. This document also assured them of their rights to terminate cooperation if or when they felt uncomfortable or unable to continue for any reason known best to them.

Once informed consent was signed and received from the participants, a demographics survey link was emailed (Appendix H). The cost and convenience of an online survey ensured that the survey had a high response rate. Furthermore, an online survey was fundamental in the study as it ensured the privacy of respondents. The web-based method was the most trusted online or internet research where participants received emails containing a link. Clicking the link took the participant to a secure online survey form where they filled the survey out confidentially.

Upon submission of the demographics survey, an interview was scheduled with the participant. The interviews were conducted via Zoom, a communication platform. The researcher adopted interviews as the most appropriate method of collecting data in this study. The interviews took place virtually so the researcher as well as the participant would not have to travel or take time off from paid employment or caregiving responsibilities. One of the important skills adopted in this research crucial in the development of the interview procedure was the ability to ask questions (Schumacher, 2010). Participants indicated respective suitable dates and times for the interview. The researcher set up an interview date and time and the participant were notified of their interview status participation via a Zoom meeting invite that included the date and time.

The interviews were designed in a way that enabled participants to describe their lived experiences of caregiving to their loved ones (Rubin & Rubin, 2005). To ensure confidentiality and that the conversation was not overheard, the interview took place in a quiet area of the researcher's home, and notes were taken using pseudonyms. The interviews were scheduled in advance with participants and each meeting ranged from 38 to 57 minutes. Other crucial methods of data collection congruent with the phenomenological study included observation and audio/video recording where data was reviewed as the study progressed (Rubin & Rubin, 2005). During and after each interview, the researcher reflected on the interview as well as the participant (Appendix K). At the conclusion of the interview, the researcher thanked the participant for taking the time to volunteer and be a part of this study. Participants were asked if they would like a list of local resources in the area (Appendix J), and a copy was emailed to them if they wanted one. The interviews were transcribed then reviewed by the researcher and uploaded into NVivo, a qualitative data storage and retrieval program used to facilitate qualitative analysis. The auto-coding option was used to code the interview transcripts thematically which involved familiarization with the data, identifying thematic frameworks, indexing, charting, mapping, and interpreting. Data analysis of recorded and transcribed dialogues entailed groping similar statements or themes into groups and calculating the number of declarations of items falling into the defined categories.

The Researcher's Role

The research was conducted by Becky Olson, a doctoral student passionate about higher education and assisting with coping strategies for those who experience stressful situations. The researcher chose this topic on caregiver stressors and experiences due to personal experiences dealing with emotions and stressors from raising a special needs daughter. The primary role of the researcher in the study was to act as the vital instrument for data gathering and analysis, to collect, evaluate, organize, and deduce the information (Rubin & Rubin, 2005). Some materials utilized during data collection included an audio recorder, pen, laptop, and mobile phone. The researcher gathered data from participants' replies and interactions to read their nonverbal cues. The research considered a suitable setting and environment for the study that was free from unnecessary distractions and noise (Schumacher, 2010). The goal of evaluating data was to learn how caregivers care for their loved ones and family daily while managing stress and utilizing coping mechanisms. Such coping strategies or mechanisms were worth sharing and understanding with caregivers in other capacities.

To eliminate researcher bias, the researcher addressed ethical norms. One way the researcher ensured this was by guaranteeing no personal link with any of the respondents or subjects and evaluating self and personal beliefs by making a list of what the researcher wanted to achieve as a result of this study. Before and after conducting interviews, the researcher journaled her thoughts to relieve personal stressors or biases that could have affected the outcome. Other ways to remove bias included creating a thorough research plan and asking general questions before specifying and summarizing answers using the original context. The researcher ensured that the questions asked were not formed by personal, cultural, and emotional responses but were geared directly to the research. Respondents from social media recruitment such as Facebook, Twitter, and Instagram as well as personal acquaintances were selected. Participants were assured of their rights to terminate as well as cooperation if they felt uncomfortable continuing or for any reason best known to them.

Data Collection

Data collection techniques congruent with phenomenological methods were adopted in this research and included a screener survey, consent form, demographic information, and a recorded audio and video virtual interview (Christensen et al., 2013). Once a potential participant expressed an interest in the study, a screener survey was emailed. The initial screener survey took no more than two minutes to complete. The survey included a name and email and asked the potential participant if they met the study criteria of age, location, and caregiving requirements (Appendix F). Those yes and no questions inquired if the participant was at least 18 years old, had resided in Bell County, provided informal care for a loved one with a lifelong illness or disability, have provided care for at least six months, and if they were willing to fill out a demographics form for data collection and participate in a recorded interview. After the Google Form was complete and the researcher verified that the participant met all eligible criteria, consent information was sent as an email attachment.

The consent form took no more than seven minutes to review and sign. The consent form included the purpose of the study and identifiable risks and benefits (Appendix G). It also included information to protect identity as well as consent to be audio and video recorded. There was also contact information should they have any questions. Participants were asked to save a copy of the form and print, sign, or type their name and return it to the researcher via email or text. Once submitted and the researcher verified eligibility from the survey and consent form, a link to the demographics survey form was emailed.

The demographic survey questions included the participant's name, email address, age, religion, race, education, employment, and questions regarding the care recipient. The demographics form included multiple answers for the participant to choose from (Appendix H). Upon completion of the consent and demographic form, an interview was set up via Zoom.

The virtual interview was the principal data collection method, with the interviews lasting from 38 to 57 minutes. The interview process focused on gaining entry into each participant's inner world of personal experience regarding the phenomenon of caregiving. An important skill crucial to developing the interview procedures was the ability to ask questions. An interview template with open-ended questions was created to enhance an in-depth interview for the study participants. Data was tape-recorded and reviewed as the study progressed until data saturation was achieved or when a notion of closure yielded redundant information (Merriam & Tisdell, 2016). The data collection process continued until the researcher believed that the quality, completeness, and amount of information collected from respondents was enough for the research.

Participants could be identified by their email communication and the audio and video recording from the virtual interview conducted via Zoom (Rubin & Rubin, 2005). In order to prevent this from happening, all recordings were stored on a password-protected computer with current versions of programs and antivirus software. Email communication was in a multifactor authentication school email system. Any potentially identifiable data was only accessible by the researcher, who was the only one with access to any online documents. The interviews began with an introduction from the researcher followed by questions to get to know the participant and the care recipient. The questions then went deeper into situations and experiences the participant may have dealt with and how they responded to various situations.

The interview was concluded by inquiring about the participant's well-being and any additional information they wanted to share. All participants were given a pseudonym to ensure confidentiality. All responses and video recordings were stored on a password-protected personal computer, and data was analyzed qualitatively through a password-protected software program, NVivo. All individuals were disguised in written reports to protect any identifying information. All Bluetooth and remote devices were disabled to ensure wireless devices could not access data and network systems. When applicable, the researcher ensured that any data was appropriately destroyed.

Interviews discovered information to provide a profound understanding of the phenomenon (van Manen, 1990). Participants were asked to respond to relevant research questions for the phenomenological study from the expectancy theory regarding coping strategies for caregivers that experience stress taking care of their loved ones. This phenomenological study aimed to understand and describe the significance of lived experiences of informal caregivers. The main research question was: What are the lived experiences of informal caregivers in relation to stress and coping mechanisms? Other specific questions that are central to the main research questions are included in the paper's appendix section (Appendix I).

The open-ended interview questions were as follows:

1. Introduction by the researcher.
2. Tell me about the person whom you provide care for.
3. Tell me about your role in the person's life prior to becoming their caregiver.

4. Explain what a typical day looks like.
5. Describe for me your emotions (thoughts and feelings) when you found out the diagnosis of your loved one.
6. Take a few moments to think about a challenging situation or a difficult day. Describe that to me.
7. How did you feel during that moment?
8. How did you cope with those difficult days?
9. Is there a specific coping strategy that you have found that works best?
10. How do you feel that your well-being and upbringing impacted your coping during stressful times?
11. What would you have done differently?
12. What do you think it means to be a caregiver?
13. What do you attribute to how you responded to the caregiving role?
14. How do you feel that providing care to your loved one has impacted your well-being?
15. Describe your current mental and physical status.
16. Tell me about the support you have as you stepped into the role of a caregiver.
17. Are there any resources or support that you feel would be beneficial to one taking on a caregiver role?
18. Reflecting on your own experience, what advice would you give someone entering the role of a caregiver?
19. What additional information can you share with me about your caregiving experience?

Question one was an icebreaker and introduced the researcher to the participant being interviewed. This was important in encouraging participants to feel comfortable sharing their experiences and the researcher's knowledge (Rubin & Rubin, 2005). This first conversation was to share personal experiences of the phenomenon and establish a rapport with the participant (Marshall & Rossman, 2015). Questions two through four were informational questions to learn more about the caregivers and the care recipient. Questions five through seven dove into the emotional parts of the caregiver and the caregiving experience. Questions eight and nine looked into coping strategies as well as resources that one utilized. Question 10 reflected on the caregivers and their upbringing rolling into Question 11 asking if there was anything they would have changed or done differently. Question 12 asked the caregivers to define caregiving in their own words. Questions 13 and 14 looked at the participant's well-being and upbringing and how it may have impacted their caregiving role. Question 15 asked the participant about their mental and physical health status and reflected on if they sought medical support or even counseling. Questions 16 and 17 discussed the support and resources that the participants had as well as what would be helpful to individuals that may be new in the caregiving role. Question 18 allowed the caregivers to provide advice to someone just entering the caregiving role. Lastly, the interview was concluded with Question 19, which allowed the participants to address anything else that would offer an understanding of the phenomenon being studied (Patton, 2015).

The above interview questions were important in the study as they addressed the way through which the relationships between caregivers and their families are affected by caregiving dynamics and experiences. The significance of the interview questions helped the study to determine what happens to prior caregiving responsibilities and are recipients are affected when a caregiver experiences stressors such as a decline in financial stabilities, health, or functioning status. Also, the interview questions allowed for differentiation among various caregivers by evaluating the quality of stress that was related to the care they deliver. At a minimum, some of the questions sought to determine, quantify, and gather information on the number of family caregivers and their relationship to the care recipient. The questions were well designed to achieve a more comprehensive explanation of caregiver networks and their effects on caregiver stress experiences and coping phenomena. Furthermore, the questions developed interventions that count and support care providers such as training, and trainer-inspired educational interventions that extend knowledge gained to care recipients and other family members.

Data Analysis

Demographic information was analyzed using tables and graphs. Qualitative data analysis involved describing captured information and determining themes (Wehei, 2018). The objective was to interpret correctly and distill the data to determine subjects. Through the identification of themes, data gathered contributed to the body of knowledge on the perceptions and experiences of caregivers. Such information was added to the rich information about caregiving skills for current and future caregivers. Data analysis within this inquiry focused on understanding the general essence of caregiving as lived by the caregivers and essential patterns among the caregiver’s experiences.

Data analysis also included exploring how the phenomenon is experienced consciously, suspending judgment, and interpreting the event’s meaning from the participants’ perspective (Merriam & Tisdell, 2016). Since the behavior of human beings cannot always be predicted to terms and data that are quantifiable, a phenomenological method was adopted for this study to achieve a comprehensive understanding of human experience. Traditional techniques fell short in grasping the subjective nature of human experience since it is unique from one person to another (Schumacher, 2010). This qualitative research determined the shared experiences of caregivers concerning stress and coping mechanisms when caring for their loved ones and or family members. Applying a qualitative phenomenological study design allowed the researcher to explore themes that best describe lived experiences of many caregivers in Bell County, Texas, and their mechanisms of coping. All responses and video recordings were stored on a password-protected personal computer, and data was collected qualitatively through a password-protected software program, NVivo.

NVivo is a program designed for qualitative researchers to organize, analyze and find common themes of qualitative data. NVivo helps qualitative researchers to collect, analyze and find insights in unstructured or qualitative data like interviews, open-ended survey responses, journal articles, social media, and web content, where deep levels of analysis on small or large volumes of data are required like open-ended interviews. After the initial read-through, the researcher reread the interview notes, refining the prior codes and creating new, emergent codes. On the third read-through, the researcher combined codes into themes. Data analysis in this qualitative research also involved synthesizing, which determined everyday occurrences and variations of the phenomenon and study participants.

Comprehension means an understanding of the data collected. Theorizing entails a systematic sorting that reveals alternative explanations of the phenomenon (Vitaliano et al., 2003). Audio-taped interviews were transcribed and subjected to content analysis by coding data arranged into categories from which themes were identified (Vitaliano et al., 2003). A technique known as bracketing was used to set aside various assumptions and beliefs about caregiving to assess how the participant perceived caregiving. Data analysis of audiotaped and transcribed discussions involved identifying and compiling groups of identical statements or themes and counting the quantity of declaration of items in the designated categories. Themes were grouped on a summary table labeled with core themes and subthemes of the experiences of family caregivers, which are presented in detail in the results found in Chapter Four.

Trustworthiness

Qualitative research is uniquely positioned to offer research with storied, narrated, process-based data that is related closely to human experience (Christensen et al., 2013; Stenfors et al., 2020). People learn significantly from the experience of others even though the degree of trust one has in another is attributed to the story (Sutton & Austin, 2015). Similarly, building trust is imperative in qualitative phenomenological research to convey truthful findings to the study readers and consumers (Stahl & King, 2020; Sutton & Austin, 2015). This section presents various ways the researcher intended to justify the factuality and accuracy of the research process, and findings passed on the principle of trustworthiness.

The researcher acquired the principle of trustworthiness for this qualitative investigation due to her honesty and the need to be truthful to avoid bias. Another way that the researcher attained trustworthiness in this research was by determining and excluding materials and substances considered less important for the study while explaining their unsuitability.

Christensen et al. (2013) underlined the veracity of qualitative research by stating several conditions that may aid in discovering the truth. Efforts were taken to establish credibility, transferability, dependability, and confirmability by Crowe and Sheppard (2011)'s four criteria for improving the trustworthiness of a qualitative study. In qualitative research, trustworthiness demonstrates the capacity of the researcher to assure rigor and quality (Sutton & Austin, 2015). Therefore, trustworthiness included transferability (generalizability or external validity), credibility (internal validity), dependability (reliability), and confirmability (construct validity or objectivity).

Credibility

Credibility is the quality of being trusted, believed, and convinced (Stenfors et al., 2020). Creswell and Poth (2017) suggested that validation refers to credibility in a qualitative investigation. The form of validation that was adopted was triangulation (Creswell & Poth, 2017). Triangulation is using multiple methods or data sources in qualitative research to understand phenomena (Bialon & Coke, 2011) comprehensively. According to Lincoln and Guba (1985), triangulating means using several sources of information or procedure from the field to repeatedly establish identifiable patterns.

The authenticity of the study was reflected by the fair description and honesty of the respondents regarding their social life. Bialon and Coke (2011) note that the conclusion made based on the researcher's ideas and lack of rigor is one of the main critiques of qualitative research. Therefore, it was important to undertake various activities to guarantee that the study was robust, accurate, and legitimate (Merriam & Tisdell, 2016).

Credibility or internal validity was ensured through direct engagement in the data-collecting phase of this study. Using this strategy and attitude as the primary data collection tool ensured that the researcher was not prone to misinterpretation and concept distortion (Creswell & Poth, 2017). The credibility of the interview questions was reviewed and re-evaluated to ensure they answered the study questions. The research used inclusion and exclusion criteria to ensure accurate data was collected. The inclusion criteria included people with experience in caregiving and 18 years of age and above. The interaction with respondents was audio-taped and repeatedly replayed to ensure the right message was obtained. Bracketing, which involves removing personal biases, prejudices, misunderstandings, or personal beliefs, prevents these values from influencing the study (Bialon & Coke, 2011). For these reasons, the data was transcribed verbatim to convey the participants' experiences as they reported them.

Dependability

Peer debriefing verified the study's dependability and reliability (Bialon & Coke, 2011). The researcher sought the services of peers to ensure quality and rigor as well as to examine and offer input on the transcripts, interpretations, methodology, and final report. The use of overlapping methods, which included in-depth methodological explanations, allowed for the study to be reproduced, further ensuring dependability (Bialon & Coke, 2011). Aside from triangulation to limit the influence of investigator bias, participatory methods provided confirmability by allowing other researchers to see the project design and review the interpretations and findings (Bialon & Coke, 2011; Stenfors et al., 2020).

Transferability

Patterns and descriptions of the research context apply to similar research studies (Stenfors et al., 2020). The research found it productive to seek understanding from other systematic qualitative inquiries by analyzing literature sources (Stenfors et al., 2020). Also, to ensure the trustworthiness of the research, lessons from one study, such as that of the student experience in a community, were transferred to the research as references. Transferability was established by providing evidence that these findings apply to other contexts, findings, and situations (Stenfors et al., 2020; Sutton & Austin, 2015).

Confirmability

This is the degree to which others could confirm or corroborate the results (Stenfors et al., 2020). In this study, the researcher documented enough procedures that can be used to check and recheck data in the research and its findings (Crowe & Sheppard, 2011). In addition, the researcher took a neutral reading of what was seen and heard putting subjectivism views aside. The findings in this study are solely based on the participant's words and not the researcher's biases.

Ethical Considerations

Respondents participating in this research were all volunteers with no compensation or tangible incentive. Before launching the process or engaging with participants, they self-identified to determine if they fit the required criteria, including their age, a minimum of 18 years old. Informed consent was provided to every participant that clearly outlined both advantages and the risks of participating in the research study. Additionally, the informed consent explained why the research is being performed and the potential challenges with confidentiality. Finally, collected data, including personal information, remained confidential information that the researcher kept in a safe location with limited or no access for intruders. This included encryption and a password-protected flash disk.

Summary

The study design and other analytic methodologies are described for uncovering facts from the acquired data. The study employed a phenomenological paradigm, with purposive sampling to recruit survey participants. In-depth, open-ended interviews were used as the principal data-gathering strategy through Zoom. Additional supportive methods included journaling and Google Form surveys. To grasp the experiences of participants, a qualitative phenomenological design was adopted (Creswell & Poth, 2017). The methodology developed by Wehei (2018) was utilized to guide data reduction, presentation and conclusion drafting, and data verification. Ethical problems affecting confidentiality and participant safety were considered to establish dependability. Complete results from this study are presented in the following chapter.

Chapter Four: Findings

Overview

Chapter Four presents the discoveries made by the researcher during the study including results. This chapter also provides a table containing participant information and a brief introduction of the 12 participants in the study. The information in this section informs readers of the interview process, the research, and the analysis process. This phenomenological study was designed to explore if and how lived experiences of informal caregivers impacted their well-being. The participants in this study were identified based on criterion sampling including their age, location, and caregiving role, as well as their ability to participate and willingness to share their personal lived experiences. The data collection included open-ended interviews which were audio and video recorded. Data collection ended when there were no new themes emerged and data saturation was achieved. Findings from the interviews are analyzed using the development of themes. The participant's experience and well-being are examined as to how that may impact their caregiving attributes. The chapter includes responses to the research questions and is concluded with a summary of the findings.

Participants

The study included 12 participants who met the minimum requirement of age 18 and older, as all participants were 23 years old and above. There were nine females and three males that participated in the study. Participants ranged from mid-20s to late 60s and represented caregiving for those with a variety of disabilities and illnesses. Each participant was informed of the study details and criteria and completed a screener to determine if they met the study criteria. Criterion sampling involved creating pre-established criteria which are important to the research, in which the sample participants used to qualify for the study. Eligibility requirements for the study included age 18 or older, living in the Bell County area of Central Texas, provided informal care to a loved one, had been a caregiver for at least six months to someone with a permanent or lifelong disability or illness, and willing to fill out demographic information as well as participate in an audio-video recorded interview. The researcher recruited participants through personal acquaintances on the researcher's personal social media page. There was a total of 14 potential participants that completed the screener survey and 12 of those met the criteria for the study. A follow-up email with the consent form attached was sent to the participants who qualified. All 12 of the participants signed the consent and returned it via email. All 12 also completed the demographics form and participated in the virtual interview.

Description of Participants

Table 1 in this section provides an overview of participant demographic data. The inclusion criteria for the study were that the participant lives in the Bell County area of Central Texas and is at least 18 years old. The study required that the participant provide informal care to a loved one for a minimum of six months. The care recipient must be an individual with a permanent illness or disability that affects their daily life. Some of these diagnoses may include persons with dementia or Alzheimer's, special needs (such as a cognitive, physical, or mental disability), cancer, aging individuals that require help with daily living tasks, or a chronic disease or illness that will require care such as heart disease, pulmonary diseases, cystic fibrosis, diabetes, inflammatory bowel diseases, muscular sclerosis, Lou Gehrig's disease, epilepsy, among others.

Each participant chosen for the study was actively providing unpaid, informal care to a loved one. All participants completed a consent to participate in the study (Appendix G), and a screener survey (Appendix F). The screener was analyzed by the researcher to determine if they met the criteria to participate in the study. All participants used the link sent via email to complete the demographics questionnaire through Google Forms (Appendix H) and set up an audio-video recorded interview through the Zoom platform. Pseudonyms were assigned to participants to preserve anonymity using the following aliases: Cecilia, Tammy, Sandra, James, Josh, Kristi, Amber, Monique, Randall, Tina, Melissa, and Renee. Participants selected for the study were residents in the Bell County area of Central Texas in the cities of Belton, Temple, Morgan's Point Resort, Moffat, Little River Academy, and Holland.

Table 1

Participant Demographic Data

Participant	Gender	Age	Profession	Years as caregiver	Patient condition	Patient relationship
Cecilia	Female	23–29	Paraprofessional/ college student	1–5	Stroke	Stepfather
Tina	Female	40–49	Occupational therapist	1–5	Stroke	Mother
Renee	Female	40–49	Teacher	>1	Multiple sclerosis	Ex-Spouse
Kristi	Female	40–49	Homemaker	11–20	Special needs	Son
James	Male	40–49	Unemployed	11–20	Special needs	Daughter
Josh	Male	40–49	Engineer	>1	Cancer	Spouse
Sandra	Female	50–59	Accountant	>1	Cancer	Spouse
Randall	Male	60–69	Retired	1–5	Aging	Mother
Amber	Female	40–49	Security	11–20	Diabetes/ special needs	Son
Melissa	Female	40–49	Medical coder	11–20	Special needs	Son
Tammy	Female	23–29	Teacher/barista	>1	Cancer	Father
Monique	Female	50–59	Unstable jobs	1–5	Mental disorder	Mother

Cecilia

Cecilia is a young Hispanic woman in her early 20s who is going to school online full-time to pursue a college degree. In addition, she works full-time in the public education sector. She has two young boys and is planning a summer wedding. She provides care to her stepdad, who had a stroke while on duty as a public officer. Cecilia previously quit her job to care for him three years ago so that his former wife (Cecilia's mother) could continue to work and help with their special needs daughter. During the rehabilitation phase of his recovery, he and his wife began arguing and having marital issues, which eventually led to divorce. While they were separated, Cecilia continued to help provide care for him. Once he became able to do things for himself without a lot of support, Cecilia moved into her own place but continues to go over to his house several times a week to help him. Some of her activities she helps in includes household maintenance things like changing lights, sweeping, mopping, taking out the trash, making sure his meds are prepped for the week, and making plans for any upcoming appointments.

Cecilia's care recipient is the only father she ever knew. He raised her since she was eight years old when he and her mom got together. Cecilia reflects on her life prior to caregiving:

> Before his stroke, I was just a daughter and mother. I did not take care of him in that role. He provided and cared for himself, and his wife (my mom). I would visit him and my mom often with his grandkids. They also had a special needs daughter and I helped with her some.

Tammy

Tammy is a young Caucasian female in her late 20s. She is recently divorced and lives with her parents. Her divorce came shortly after only being married for a couple of years. Tammy and her spouse were going through fertility treatments and trying to conceive. The stress of infertility, obtaining her master's degree, starting a teaching job, and her dad becoming sick, took a toll on their marriage. While going through her divorce, she moved into her residence with her pets.

Over eight months ago, when her dad was diagnosed with pancreatic cancer, she would travel about 30 minutes to her parent's home to help care for her father. "It's my dad and I would do anything for him. I am daddy's little girl." While seeing his health deteriorate, she decided to move in with her parents so she could provide care and support to her mother as well. She recently graduated with her master's degree and works two jobs. She is a full-time teacher and works part-time in the evenings and weekends as a barista. Tammy is the one who is up at the hospital with her dad when he is admitted for cancer and other health-related issues. She has been providing care for him for almost a year. When discussing her emotional state during these difficult times, she said, "I snap quickly and get mad very easily. I feel that I cannot focus on things, and I am emotionally a wreck."

Sandra

Sandra is a middle-aged Caucasian Christian woman in her 50s who has been caring for her husband for almost a year. She has a bachelor's degree and works full-time as an accountant. Sandra is in her second marriage and together, they have four kids all over the age of 16. While she continues to work full-time, her husband had to quit his job for 20 years due to his stage four lung cancer progression. Sandra takes off work to take him to his appointments and works extra time to make up for the work she misses. This is usually by not taking a lunch break, working late, and even working in the evenings.

In the past, they used to always share in the daily household chores. They enjoyed cooking together and even did laundry together. Her care recipient usually cleaned the house, did the maintenance and upkeep, as well as maintaining the outside of the house. He was also a barbeque pitmaster and was very active in the disc golf community. When he was first diagnosed, he tried to continue his interests and hobbies as well as help as much as he could. His health quickly declined, and he became more fatigued. Just getting up to use the restroom and take a shower became difficult for him. Sandra now provides care for him in addition to all the household responsibilities and parenting roles. When Sandra was asked how she felt after hearing the diagnosis, she said, “I wanted to know what I could do to help him. That changed as time went on to what can I do to make him feel comfortable and I just want to be there for him.”

James

James is a middle-aged Caucasian male in his late 40s who is unemployed. He completed trade/technical school in the public service sector. He has not had steady employment for the past eight years and helps provide care to his 18-year-old daughter with special needs. For over 10 years, his wife was the primary caregiver to their child while he worked as a firefighter and paramedic. James suffered debilitating migraines as well as extensive knee surgery which put him out of full-duty work as a firefighter. This setback caused him to lose his job and ultimately stay at home. Since he was not working, James and his wife decided that he should be the main caregiver to their daughter.

His daily activities include taking her to school, picking her up, and taking her to any therapies and appointments. This has been his responsibility for the last eight years. James’s daughter has physical and cognitive delays as well as an extensive medical list of diagnoses and a rare disease. She has incontinence issues, so he must help with toileting needs. When asked how he feels in the moment of a difficult day, James responded, “I don’t feel anything in that moment because I don’t have needs or wants. I have one responsibility to do.” He reflects that his response to stress, as well as his current situation, could partially be related to his line of work and training as a firefighter and paramedic.

Josh

Josh is a middle-aged Caucasian male in his late 40s who works from home in engineering. He and his wife have four children, two of whom are still living at home in school. One of their sons is a high schooler with special needs but is relatively independent, yet still requires supervision and monitoring as they do not like to leave him alone. Josh has been providing care for the last eight months to his wife who has colon cancer. His wife previously worked full-time in education as a teacher. Due to her extensive health issues as well as appointments including chemotherapy and other treatments, she had to decrease her hours. Josh's wife now teaches part-time but has decided to not teach for the next school year due to her health. Josh reflected on his wife's independence and made the following comment:

> Seeing her not be able to do things she enjoys was difficult for me. She was always so active and enjoyed sewing and doing crafts. Just walking to the next room and sitting for a few minutes takes a toll on her body.

Kristi

Kristi is a middle-aged Caucasian female in her 40s who cares for her special needs son. Her husband has always worked full-time in the business and health care industry. She would work odd jobs here in there as she is hearing impaired and finding employment is a challenge. Kristi and her husband have two children. Their firstborn son is off at college and is very intelligent and independent. Their other son, whom Kristi provides care for, is on the severe end of the autism spectrum. His disability affects his speech, mental health, cognitive ability, and daily living skills such as feeding, dressing, and hygiene. Kristi is currently a homemaker and stays home to care for him. Their son recently graduated high school, so he does not have a regular school routine since graduation. Kristi is a petite woman and her care recipient is a tall, strong, nonverbal young man. This makes her daily responsibilities difficult physically, mentally, and emotionally. When asked about how she felt when she got the diagnosis, she said,

> Devastated. I was heartbroken. There was still a lot to learn about autism and there was not much in regards to support in the area we lived in. My family and friends struggled to be able to handle him and I cried a lot. I questioned my faith and my purpose.

Amber

Amber is a middle-aged Caucasian female in her late 40s. She works evenings and nights in security while her husband works days. Amber and her husband have a teenager with special needs who is 17. He not only has a rare genetic disease that affects his speech and cognition, but he was also recently diagnosed with type 1 diabetes and put on insulin. Their son is a very picky eater, and it has been a struggle to change his eating habits to meet his dietary needs. Their son is still in high school and rides the bus to and from school. Amber’s mother-in-law has always helped care for their son. Now that he is getting older, and prefers to stay at home, ensuring that he has the proper care has been a priority. Amber and her husband’s current work schedule is not the typical schedule for every couple, but it works for them. With their alternating schedules, someone is always home to monitor their son, especially his diabetic care. Amber reflects on caregiving and her son’s diagnosis.

> Just when you think you feel like you are smooth sailing and everything is going great, there is a bomb dropped on everything and you have to revamp everything you are doing. At that point sometimes you just want to crawl in a hole.

Monique

Monique is a middle-aged multiracial single woman in her 50s. Monique was raised by her parents and became independent at a young age. She has been in several relationships and has children of her own. Throughout the last several years, Monique’s mom was diagnosed with a mental disorder. She recently learned that her mom was in and out of facilities when she was growing up. It has come to the point where her mom requires additional support to help monitor her mental health. Monique has recently moved back in with her mom and works part-time. At the time of the interview, she is working as a long-term substitute at a local school district. Monique’s mom has a formal diagnosis of schizophrenia. She has not had steady jobs due to having to care for her mom as well as herself. “When she [my mom] is experiencing one of her schizophrenia episodes, it makes it difficult. While I know the difference between her states, she is unable to distinguish the reality. I try to remind myself of that daily.”

Randall

Randall is an older aged male in his late 60s who is a retired professional. Randall is the youngest of three children. His older brother is deceased and his sister lives in the same town as their mother. However, Randall does not live in the same town as his mother but does reside in Bell County. Randall is the caregiver to his aging mother who lost her husband of 75 years a few years ago during the COVID-19 pandemic. Since Randall does not live in the same town as his mother, he must travel to provide care for her. A few of his daily activities include taking her to appointments, going to the grocery store for her, and making sure finances and bills are handled.

His mother has also developed early stages of dementia due to her aging and declining health. Her dementia has caused her mental state to be altered. Due to this, she will only allow him to care for and do things for her and does not acknowledge other family members or anyone else to be able to care for her. Randall is solely bearing all caregiving responsibilities. Randall enjoys traveling with his partner and often has to put trips on hold to make sure her needs are met. He discusses situations such as when he tried to convince her to go into an assisted living facility and she wanted to go to her own house with her things. He finally convinced her to get some home health support through an agency that comes to her home. Randall recalled, “I think the most challenging thing was her wanting to become independent.” Randall noted that while there are some things she could probably do on her own, due to her age of 95, she continues to just need some extra support for safety.

Tina

Tina is a female in her 40s who is married with two teenagers. Her husband owns his own company, and she works as an occupational therapist. Tina’s boys are very active in selective sports outside of what they participate in with school athletics. As a family, they often travel to tournaments and trips. Tina and her sister were raised by their single mom. Her mom remarried over 10 years ago and was a nurse until she retired several years ago. Tina’s mom lives in a different town and was always coming to see her grandkids or would take them for the weekend. With no warning, Tina’s mom had a stroke which resulted in a week-long hospital stay.

Once released, she was moved to a care facility about 45 minutes away. Being the oldest sibling, and most responsible to take on such a role, Tina took on the caregiving role to her mom. While in the care facility, the damage of the stroke was assessed, and it was determined that Tina’s mom had developed some memory loss and was developing the early stages of dementia. Tina recalled a difficult time when her mom started using her cell phone to call friends and family at all hours of the day. She would even call random numbers which eventually became a problem, as she would tell those on the other end of the phone things that did not make sense or were not true. For several months, Tina traveled to the care facility while her mom was healing. After Tina’s mom was released and moved back home, Tina continued the caregiving role and goes over nearly every day to check on her. When Tina learned of her mom’s health, she just “wanted to do what was best for her and help get her well.”

Melissa

Melissa is a Caucasian female in her 40s who is divorced and remarried. Melissa and her current husband have been married for over 10 years. Her current husband works from home in the technology field and Melissa works from home full-time as a medical coder. She and her first husband have a son with a rare condition which affects his cognitive function, and he experiences many behavior episodes. At a young age, he also had seizures and other medical concerns. Melissa has been providing care for him since he was born, and he is now a junior in high school. For over 15 years, she has been the primary caregiver. While the road has not been easy for Melissa, she reflects on when she knew something was not right with her child:

> I had come to terms with my son not being “typical” long before we had any diagnosis. I was scared for his future and mine. I was sad that we wouldn’t get to have the life I saw for us. I immediately started researching medical journals and books to understand what we would be facing. I wanted to arm myself with all the knowledge to help my son have a happy and balanced life. If anything, his diagnosis gave me more insight into my son.

Renee

Renee is a Caucasian female in her 40s who is recently divorced. Renee has always worked full-time jobs off and on while attending college and taking classes toward her bachelor’s degree. She recently went to work full-time as an educator. Renee and her ex-husband have two children: a son and a daughter. As a family, they were active in theater, cosplay, and being outside. Renee reflected on those previous experiences.

> We were a very close family that did everything together. I mean everything. We traveled, did theater, played dress up, and we were just living life and having fun. I was going back to school to become a teacher and I did photography on the side because it was a passion of mine.

About eight months ago, her ex-husband became ill with multiple sclerosis. Muscular sclerosis impairs many body systems including muscular, pain, mood, speech, mental, and cognition. Since their son was in middle school and their daughter was off at college, trying to navigate the disability and their rocky marriage was difficult. Their marriage and careers were compromised and even though he has his son every other weekend, Renee now helps out by going to her ex-husband's house a few days a week to help with any tasks.

Interviews

Participant interviews were conducted May 2023. The researcher's role was explained to each participant before the interview. The researcher reviewed the reason for the study and the qualifying criteria for participation, the purpose, procedures, risks, benefits, duration, and confidentiality. Information regarding the informed consent that was signed by the participant was reviewed to verify that the participant understood the purpose and their role in the study. The participant was also reminded that the study was voluntary and that they could stop the study at any time. Interviews were recorded using Zoom, a video-conferencing platform. Participants were sent a Zoom meeting invitation link to begin the interview process and they were informed when the audio recording began. The interviews were limited to questions and discussions around the research topic. Observations of facial expressions and body language were noted during the video interview. The interviews began with a brief introduction of the researcher followed by semi-structured questions. Additional questions were asked if clarification was needed or if there was a need to expand on the participant's answers. After the interviews, the researcher reviewed the transcription for inaccuracies. Any words misheard by the transcription application were corrected. Conducting the research through a video conferencing platform was important in assisting the researcher to remain objective.

Results

This study investigated the lived experiences of informal caregivers by exploring the participant's perceptions to further understand factors that impact their well-being. Participant demographics were collected to understand how they might influence the participant's views and responses. Participants completed a screening survey and were contacted via email if they met the study criteria requirements (Appendix F). Two individuals completed the screening questionnaire but were excluded as they did not meet the study's criteria. One participant did not live in Bell County, but her care recipient did. The individual lived an hour away in another city/county. This potential participant was excluded for that reason. The other potential participant was not currently providing informal care. This individual previously provided informal care, but the care recipient passed away. Since the criteria stated that the caregiver must be actively providing informal care, this individual was excluded from the study. Participants recruited were familiar with the researcher based on prior contact and acquaintances.

Three-quarters (75%) of the participants were employed full-time or part-time. Education levels differed, as 66.7% held a postsecondary degree such as a bachelor's or master's degree, while 25% had some college, completed a certificate, or had trade school training. All but one participant reported having some level of post-secondary experience.

By exploring the lived experiences of informal caregivers, the researcher discovered thoughts and feelings as well as their overall well-being by being in a caregiver role. The results of this study were developed from analyzing the following data collection methods: participant screener, participant demographics form, and semistructured one-on-one audio and video recorded interviews. The screener and demographics form were for study participation criteria and to gather supplemental information about the participants. The forms were created in a Google Form platform with a hyperlink emailed for access to the survey. The interview was conducted via Zoom and was recorded for transcription purposes. After each interview, the researcher read through the transcripts for accuracy. Corrections were made as needed. Upon completion of the interview, the researcher imported the file through the NVivo software program and then used the auto-code feature to assist in coding. As new themes emerged, the researcher clustered similar codes together and subthemes began to form.

At the time of the interviews, nine participants were employed while three were unemployed, a homemaker, or retired. Interviews also revealed that most participants were of Christianity religion denominations, while three stated they followed no religion in particular. Two participants revealed they were atheists, agnostics, or other. Ten of the 12 participants reported Caucasian as their race. The remaining two individuals identified as Hispanic and Multi-racial. Less than half (33%) of the caregiver participants shared their caregiving experience from caring for their child. The remaining participants care for a parent (42%) or spouse (25%). Of those being cared for, 25% needed care due to cancer, 8.3% needed care due to aging, and 41.7% needed care due to special needs such as those with a cognitive or developmental disability. The remaining 25% had a variety of other needs.

Five out of 12 participants care for a parent. Of those five, three care for their mother while the other two care for a father. One of the mothers is aging and has developed dementia along with other health concerns. Another mother suffered a stroke and developed dementia as a side effect. The other mother has a mental diagnosis of schizophrenia and experiences other mental health issues. Of the two male care recipients who were parents, one has cancer and the other suffered a stroke. Three of the 12 participants care for a spouse. Two participants care for their husbands and one of them has a diagnosis of cancer and the other one has a diagnosis of multiple sclerosis. The third participant cares for his wife who has cancer. Four of the participants provide care for a child. This included three sons and one daughter. All of the children have a cognitive disability. However, one of the sons also has a diagnosis of type 1 diabetes, which requires extensive care and monitoring.

Randall lives in a different location from his ailing mother, who is developing early symptoms of dementia. He is the only caregiver providing care for an aging parent. Josh, Tammy, and Sandra are the three caregivers who provide care for a loved one with cancer. James, Kristi, Amber, and Melissa are the individuals providing care to their special needs children that includes three boys and one girl. Renee, on the other hand, provides care to her ex-husband that is diagnosed with multiple sclerosis, while Amber is a mother providing caregiving services to her special needs son who has diabetes. Monique provides care to her mother who has a mental illness, and Cecilia and Tina are caregivers who provide care to a parent who had a stroke (refer to Table 1).

Theme Development

Participant responses were coded by following the steps taken in the phenomenological approach which included labeling and organizing texts into codes and is vital for accuracy during the development of themes. After reviewing the documents for errors, the transcripts were reread to identify the emergent themes. Emergent theme clusters were identified by the researcher and noted. The themes were placed in an outline form for ease of comprehension and interpretation.

Data was uploaded into NVivo and the auto-coding function was used for analyzing the interviews. During analysis, early themes were discovered from participant perspectives. Early themes revealed that most participants just took on the role of caregiving with no thought or hesitation. The following section of the chapter presents the themes as well as words and phrases that were commonly used by participants. The themes are presented beginning with those having the most recurrent participant responses to those having the least recurrent participant responses. The data revealed six themes and 15 subthemes (Table 2).

Table 2

Thematic Presentation of Findings

Theme	Subthemes
Caregiving	Definition of a caregiver
	Role of a caregiver
Coping	Coping Strategies
	Coping resources and supports
Day	Typical day
	Difficult day
	Daily chores
Experience	Caregiving experiences
	Experienced grief
	Challenging experiences and situations
Health	Mental health
	Physical health
Stressors	Full-time caregiver
	Stressful times

Theme One: Caregiving

The central research question asked respondents to describe their experiences as caregivers in relation to stress and coping mechanisms in Central Texas. For many caregivers, the role of caregiving is stressful and challenging. All 12 participants expressed that they did not give any second thoughts to taking on the caregiving role. However, despite Tammy taking on the role of caring for her father, she still finds it stressful. Tammy shares that she is daddy’s little girl and would do anything for her dad. She moved in with her parents when her father's health deteriorated in addition to providing support for her mother as well. Similarly, Cecilia provided care for her stepdad recalling that he was the only father figure she had growing up. Even though he was not her real dad, she expressed that she loved him and would do anything for him. Cecilia expressed, "I would do anything even if it meant teaching him how to eat, walk, and talk again." According to Tammy, "I snap quickly and get mad very easily. I feel that I cannot focus on things and I am an emotional wreck." Similarly, despite Monique always wanting to know how to help her mother, the feeling changed as time went on to how can she live and adapt to what she has been dealt. James and Amber both align in their answers in that they would rather care for their own children than someone who does not know them. These are just a few experiences caregivers encountered.

Definition of Caregiving

All participants defined caregiving in similar words and connotations. The common theme for defining caregiving is making sure that a loved one's needs are met in any way possible. Sandra and Josh reflected on their wedding vows that they took, and Josh said,

> I vowed to love my spouse for better or worse, or sickness and in health. This is exactly what I promised to her in front of God and our family and friends. Therefore, this is what I am supposed to do.

Monique shared that caregiving to her means "You just suck it up and do what you have to do to take care of your loved ones. You know they will get better care than in most institutions or facilities." Tammy and Kristi had similar responses in saying that you give up your own time or yourself to provide support for your loved one and make sure their needs are met. In contrast to these responses, Renee shared from her perspective that "You have to want to be a caregiver.

Other than our basic caregiving instincts like being a mom, you have to want to take on that additional role.” Cecilia responded, “To me, being a caregiver is helping somebody who can no longer help themselves or somebody with limited ability to do things for themselves such as cook, clean, shower, etc.”

Caregiving Role

The caregiving role varied among all participants. Nine of the 12 participants live with their care recipient. The remaining individuals (Tina, Randall, and Cecilia) did not live under the same roof as their care recipient but do visit them daily or several times a week. All of the participants said they did not think twice about taking on the role and just did it, although many of them did not fully understand what it would entail. Cecilia even said, “I would do it again in a heartbeat.” Just knowing that a loved one is getting the care and support they need is important. The participants expressed a variety of emotions both verbally and with body language and tone. Some of the emotions mentioned were love, compassion, overwhelm, and frustration. Limitations on one’s personal life constitute a key cause of stress for carers according to May (2021). Frequently, the caregiver will need to coordinate his or her hectic daily schedule as a parent and employee, as well as manage the care receiver’s calendar. For example, when asked about her role as a caregiver, Tammy said:

> Being a caretaker is demanding and draining on all sorts of levels including the physical, emotional, and mental aspects. It is very rewarding and yet very stressful. Make sure you have supports in place to help you along the way.

Melissa expressed that for her the caregiving role is “Supporting and loving the ones you care for. Being an advocate for those that cannot.”

Theme Two: Coping

This theme identified the coping used by participants during stressful and difficult times. As stated in research, coping styles vary from person to person and they include emotional, cognitive, and behavioral responses (Panicker & Ramesh, 2018). Some specific coping strategies include environmental support, social support, religion and spirituality, and external resources. Kristi noted that her family and friends struggled to be able to handle her son. “I cried a lot. I questioned my faith and my purpose.” Josh shared that “I just pray and do what I can for her. I don’t really need to cope.” Where in Tammy’s situation, she expressed, “Well, I cry. I get wrapped up in my work. I have recently started seeing a therapist and have been put on medication. I feel that has been the best thing for me.” As Kristi reflected on her support and coping, she shared,

> To be honest, I didn’t know what I had. I don’t like to ask for help. But through the years, my sisters have stepped up. I have family that reaches out and tells me about events and things that are available.

Amber noted, “Just when you think you feel like you are smooth sailing and everything is going great, there is a bomb dropped on everything and you have to revamp everything you are doing.”

Coping Strategies

Strategies for coping with stress and uncomfortable emotions are called coping mechanisms or coping skills. Whether one is aware of it or not, an individual frequently employs coping strategies. The common coping skills and strategies that were repeatedly mentioned were friends, family, and prayer. There were a few other strategies mentioned such as yoga, counseling, journaling, and devotionals.

Cecilia shared that “One coping mechanism I do is yoga every night to calm my body down and try to relax as much as possible.” Two participants noted that at the initial diagnosis, they did whatever they could to start finding ways to help their care recipient. This was looking for answers, finding alternative medical professionals, and praying it was a dream. Sandra and Josh noted that they used Google and the internet to look up treatments and prognoses for their spouses. Other participants such as Melissa, James, and Amber shared that they used social media and the internet to read more about the diagnosis of their loved one. Melissa even reached out to organizations to find information that could help her son.

Three of the 12 participants mentioned their faith in helping them throughout the caregiving journey. Those same three, as well as one other participant, shared that a coping strategy that worked for them was prayer. Sandra shared, “We were raised to be strong and that helped me get through each day. That and being a Christian helps. I just don’t see how people do it when they don’t have that belief.” Josh said, “I have learned to overcome it with the help of prayers and blessings of God.” Similarly, Kristi shared,

> If I did not have the strong foundation of faith growing up, I don’t know that I could do it. And I still don’t know how I do it. My family is very supportive of each other and they are my foundation.

Four of the 12 caregivers shared that family and friends were an important part of their caregiving journey. One of the four specifically mentioned her sister, who has experience with individuals with autism as well as other special needs. She shared that she was a huge blessing and support when it came to helping care for her son. Some other coping strategies that varied were turning to food, television, and just crying to let all the frustration and anger out. Sandra shared that devotionals were a strategy that seemed to work well for her, even though it took her a while to find that strategy. Cecilia said that yoga and journaling were the best strategies for her. She stated, “Being able to get my feelings out on paper without talking to someone took a huge weight off my shoulders. I feel like I can just breathe easier.”

Resources and Supports

Coping resources and supports that caregivers identified as an area of need that were mentioned were support groups, counseling for families, a resource of numbers and contacts, or one person to talk to who can answer your questions or refer you to someone. Ten of the 12 participants mentioned that medical professionals should have resources available to give to family members when a loved one is diagnosed with a long-term illness or disability. Amber noted, “I wish there was information that was given to families when their loved one was diagnosed with a disability.” In addition, several participants felt like counseling services should be provided to everyone involved in the caregiving role. Tina suggested, “They should assign a counselor to families to help deal with the illness and process for rehabilitation.” Randall stated,

> I wish there was an assisted living facility that could take in aging individuals to assess them and see if they are truly capable of living independently, living alone with supports such as home health, or if they continue to need assistance throughout their day-to-day lives.

Along this same theme, as Monique discussed her mother’s mental disease and the treatment she receives, she shared,

> It seems like individuals with mental health problems get sent from an emergency room to a temporary or short-term mental health facility. From there, they are regulated and treated and then released. Then, when my mom has another one of her schizophrenia episodes, we go through the same process all over. I wish there was a long-term or

> significantly stricter program to assist and help individuals like her. At least that is what it is like in this area.

Melissa, who cares for her special needs son, expressed “I wish there was easier access to individual and state services and supports.” During her interview, she said with frustration, “It seems like people who have services get access to them so easily and those who truly need access to services have to wait years and go through evaluation processes just to get what they need.”

Theme Three: Daily Experiences

This theme was broken into subthemes such as typical days, difficult days, and daily chores. This study reflected on a summary of a typical day with caregivers. In addition, many of the participants recounted a typical day while they also reported difficult days. For instance, Monique noted that she tries to reflect on her mother’s condition every day, “When she [her mom] is in one of her schizophrenia episodes, it makes it difficult. While I know the difference between her states, she is unable to distinguish the reality. I try to remind myself of that daily.” Similarly, Melanie shares that when she gets frustrated with her son, she often has to take a step back and remember that he is not like a regular teenager. In contrast, James explains that when his daughter is having a difficult day, he knows that it will affect his wife. “I have to remain calm and strong for both of them. It is not about me at this point.” Tammy and Tina noted that they are emotionally damaged by the daily encounters and having so much to take care of in addition to their full-time employment and other obligations.

Daily Chores

Daily chores for many participants included making sure medications were being administered or set out for ease of remembering to take them. Only a few participants mentioned having to help with showering, toileting, and dressing. The majority of participants expressed that they have to help cook, prepare meals, as well as do laundry and other household chores. Transportation is another chore that participants mentioned. This is mostly to take their care recipient to and from appointments, school, or to run errands. Josh shared that some days he felt like he did not get much work done because he was having to take the kids to school and extracurricular activities and his wife to appointments. During Tina's interview, she informed the researcher that she needed to be done in time to get to her mom's and then make it to one of her teen boys' sports activities. James noted that he has all his attention on taking care of his special needs daughter, which is his priority.

Typical Day

All participants mentioned part of their typical day was making sure their care recipient had their medications, meals, and transportation to appointments. The caregiver participants all mentioned that having to take on additional roles of chores such as laundry, paying bills, cleaning, cooking, and even household upkeep was a burden on them. Randall shared that "I go back and forth with her about her medications, doctor appointments, and bills." Cecilia, James, Kristi, Sandra, and Renee all share that their day begins with getting their care recipient up, making sure they are dressed, have medications, and breakfast before beginning their day. Kristi shared that with her autistic son,

> He doesn't sleep through the night, so our days just vary. But typically, we get up and work on getting dressed. I feed him breakfast and get him ready for the day. During school, the bus picks him up and then I have the day to myself, unless the school calls, we have therapy or appointments, or something else going on. When he gets home, we have dinner and then get ready for bed.

Difficult Day

While difficult days varied for each participant, it is noted that some difficulty was just seeing the individual not have their independence. This may include the care recipient no longer having the ability to enjoy a previous hobby or the need to take away keys to the car or cell phone privileges. The participants who care for their children, especially Kristi and Melissa, express that a difficult day is usually when their child becomes frustrated, distressed, or has behavior outbursts. Some of these outbursts happen in public and around friends or in social situations which makes punishment and redirection a little difficult. Melissa stated, "I just try to remain calm, but it upsets me. Sometimes I feel embarrassed. I am sad that I can't help him understand that his behavior can't be controlled."

Kristi teared up as she reflects on a difficult day: "Just when I thought something was challenging, we had another obstacle to endure." Josh and Sandra share that it makes the caregiving role more difficult when their spouse is unable to do things they once could. Sandra said, "To see him not be able to get up to go to the bathroom on his own is heartbreaking." Monique casually said in response to her difficult days, "I just deal with and go with the flow."

Theme Four: Experiences Related to Caregiving

This theme analyzed caregiving experiences to help illustrate the differences between caregivers while also evaluating the impact of caregiver roles on stress, burnout, and motivation (Morton et al., 2015). The individual caregiving experiences shared some similarities across all participants yet were also very different based on whom they provide care. Individuals such as Cecilia, Tina, Tammy, Randall, and Monique, who care for their parents had a lot of similar responses versus those who care for a spouse or child. Melissa took the opportunity of caring for her son with a rare condition to learn more about the experience and how to care for him.

> I had to come to terms with my son not being "typical" long before we had any diagnosis. I was scared for his future and mine. I was sad that we wouldn't get to have the life I saw for us. I immediately started researching medical journals and books to understand what we would be facing. I wanted to arm myself with all the knowledge to help my son have a happy and balanced life. If anything, his diagnosis gave me more insight into my son.

Similarly, Kristi shared, "I have learned the long and hard way that this is the journey God gave me. He chose me for this opportunity. It is very hard, but so rewarding too."

Caregiving Experiences

Not only were all of the participants providing informal care, but their experiences were also similar in regard to stopping what they were doing in their personal lives to provide care and ensure that their loved one was having their needs met. While the illness and disabilities varied, they all had to pick up similar chores whether they were daily living skills, household chores, or financial responsibilities. Tammy noted that "Caregiving is not for the weak." Melissa added later in her interview, "Take it one day at a time. It will feel overwhelming at times, but there are good days."

Challenging Experiences

Many caregivers usually adapt to their caregiving role while others tend to struggle (Raina et al., 2004). In addition, the challenging experiences that were described varied as well. Many factors come into play in this section due to age, level of severity of illness, and employment factors. Two participants, Tina and Randall, shared that the most challenging experience for them was having to tell their moms that they could no longer do something. In most cases, one requires to coordinate a busy day of activities as a study, parent, or employee when managing their care recipients. Tammy responded on her experience as a caregiver noting that "Being a caretaker is demanding and draining on all levels including physical, emotional, and mental." When Tina had to take away her mother's cell phone and tell her she was not able to call her friends, this was a very difficult experience for her.

> My mom would call me at all hours. Her conversations didn't make sense. She would also call random people on her cell phone. I had to make the decision to take her phone away and her car keys. This is taking away someone's independence and when you do that, especially as a daughter, you have some guilt.

Participants taking care of a parent expressed that as a child, one does not want to disobey their parents or talk back to them. Both of these caregivers had to step up and take on the role of the adult while their care recipient was not in the proper mental state.

The caregiving experience in the realm of challenges shifted in the perspective of Sandra, who cares for her spouse with cancer.

> One of the most challenging ones was when he was in the hospital for two weeks. I had a job, we had a son living at home still, and we had bills and needs that had to be met. All of the older kids had moved out. It was difficult to go to work because you wonder if they are being cared for by the nurses and medical staff. You were worried you might miss something. He was still in his right mind, but he was unable to go to the bathroom himself.

Renee shared that getting the diagnosis was challenging in itself. She said,

> I think I was just numb. I thought it was a cop-out for him in response to life in general. I was mad and didn't understand why I had to take care of him now. Then both of us became frustrated. This was a cycle from being told his diagnosis to getting answers and figuring out what to do next.

Experienced Grief

Along with these emotions and feelings that the participants shared, the experience of grief was evident in the majority of participants. If not in the early diagnosis stage, throughout the caregiving process. While death has not been on the forefront of any participant's mind at this stage in their individual caregiving journey, death anticipation, emotional distress, intrapsychic and interpersonal protection, hope, exclusive focus on the patient care, personal losses, relational losses, ambivalence, end-of-life relational tasks, and the transition (Coelho & Barbosa, 2017) is evident from the interviews.

Kristi said, "I am weak and tired. I know I experienced grief and depression in a roller coaster fashion. I am not at all who I once was." Kristi experiences difficult days with her autistic child who has developed various complications. She noted that when her son was diagnosed with autism, there was still so much to learn about the disability. It was not common at the time in the area she lived in, especially in regard to support and the development effects Her family and friends found it difficult to handle her son and she expressed that she cried often. It was at this time that Kristi questioned her faith.

As Sandra reflected on her experience as a caregiver, she shared,

> I wouldn't trade it for anything in the world. Do I wish sometimes maybe life wasn't there so I could spend more time doing things with him, of course? But there are lots of things he is unable to do now.

Theme Five: Health

Caregiver health is known to worsen over time (Family Caregiver Alliance, 2016b). Individuals who provide care for over a year, or those who are older caregivers report higher levels of stress and burden. Eight out of the 12 caregiver participants have provided care for longer than a year. Of those eight participants, five of them (Cecilia, Melissa, Amber, James, and Kristi) noted significant changes in their health after taking on the caregiving role. Three of the 12 participants fall in the age category of 50 or older. Of these three, Sandra reported a higher level of burden and stress while Monique reported some moderate changes in her health. In contrast, Randall, who fell in the older caregiver age category and is a male reported no additional stress or burden. Kristi shared, “My physical status is not active at all. I am weak and tired and sometimes unable to find motivation to get up some days. I experience depression and fatigue, and I cry often and question a lot.” In contrast, Josh shared, “I feel like I am in a good place, I mean I could always work out a little more or eat healthier, but I am good.”

State/Status

The caregivers noted that they all seemed to be in pretty good health before taking on the caregiving role and would now define their health in a fair to poor state. Three of the 12 participants stated they experienced no change in their physical or mental health. Notably, these participants were males. Four of the participants experienced a change in one category or another, while five felt that both their physical and mental health were compromised. The nine females experienced some type of physical or mental health issues. Renee noted, “My physical health hasn’t changed. My mental health has. Friends and family think I have turned my back and did the wrong thing.” Cecilia said that since she is no longer living with her care recipient, “I feel that I am in a better place now. My dad is able to do more things independently and my son is in school. This has helped relieve some of the stress.”

Physical Health

Sandra mentioned that prior to becoming a caregiver, she would find time to walk at work. If she was unable to walk at work, she would walk in the evenings at home. Once becoming a caregiver, if she was not at work, she did not walk. However, since she was missing work due to caring for her husband, her physical activity significantly decreased. In addition, her mental health has impacted her motivation to find time for physical activity. Melissa shared similar sentiments in the realm of her physical activity.

> I am not as physically active as I once was. I think a lot of it is I am just exhausted some days and want to curl up on the couch and watch TV or scroll through Facebook. I try to work out some days, but it has become a chore and a challenge now.

Mental Health

Tammy mentioned that she has become an emotional wreck. She has found herself snapping at her coworkers and friends. She also stated, "I cry at the drop of a hat." Tammy shared that one thing she does not regret is seeking help. She started seeing a therapist as well as being put on medications has helped her quite a bit during the caregiving role and the depression that is associated with it. While this may not be the preferred method for everyone, it is a supplemental way to help with coping and mental health. Renee and Kristi both share that their mental health has been affected due to the change in their roles. James expressed in regard to his special needs daughter, "Emotionally I have lost a lot of emotion. Well, that's not what I am trying to say. She has made me more emotional, and I don't know how to go about that."

Theme Six: Stressors

The majority of caregivers encounter stressors at some point during their journey (May, 2021). Some of these primary and secondary stressors can have a physical or mental impact, financial burden, and employment difficulties. In addition, due to the lack of support and the relationship strain that caregivers feel can put additional stressors on the individual.

All 12 caregivers shared that at some point they experienced stressful times throughout the caregiving journey. Tammy shared that she does not feel that caregiving is for the weak and that it takes a strong person to be able to take on the role. Kristi shares her personal story,

> It became a lot for me when he [her son] became violent since he was stronger and bigger than me. I am his primary caregiver, and he is a big boy. It is stressful maneuvering him and dealing with those situations.

Stressors that each individual encountered affected how they viewed stress and coped with it.

Caregiving Stressors

Those who provide caregiving in a full-time capacity documented less stress than those who are employed with a family while caregiving in conjunction with those roles. Cecilia and Kristi mentioned that their care recipient was much bigger and stronger than them, which made the caregiving role more difficult. This was especially true when the care recipient was in a distressed mood or frustrated. The individuals who provide care for their children with special needs expressed that their role becomes stressful when their child becomes distressed and does not understand, does not listen, or has emotional and verbal outbursts.

Josh and Sandra reflected on their role and share that when their spouse, who was their care recipient, was hospitalized for their cancer treatment or care or was down due to the side effects of the chemotherapy or the cancer itself. Josh and Sandra said having to manage their spouse in the hospital or at home in addition to working full-time as well as caring for their kids and keeping up with the household chores had an impact on their stress. As Amber discussed her caregiving role, she also shared,

> You give up your life and yourself to care for your loved one and that is an internal battle that you fight. Especially if you have to provide care long-term. You find your new normal, but it is very stressful.

Stressful Times

What one individual expressed as a stressful time was not the same as another. One thing did remain in common and that is that all 12 participants endured a stressful time at least once while taking on the caregiving role. Some individuals reflect that every day there is some sort of stressful situation that occurs. This varies from daily hygiene duties to eating, and even toward the care recipient feeling that they can do things independently when it is not always a good choice for them. Sandra shared, “When you know they are in their right mind, but can’t do simple things such as shower or use the restroom independently, it becomes hard on both you as the caregiver and your loved one.” Renee expressed that “Just trying to figure out what we need to do is very stressful and overwhelming.” Melissa reflected on how overwhelming the caregiving role can be and that frustration often occurs. However, she reminds herself and others, “There are good days.”

Research Question Responses

Research questions in the study aimed to assess the caregivers and their lived experiences with stress and coping. One central research question asked about the experiences of caregivers as well as four research subquestions which assessed a caregiver’s well-being, coping, and stressors followed by resources that would help them guide this phenomenological study. The participants answered questions regarding the person to whom they provide care, which included parents, spouses, and children.

Central Research Question: What are the lived experiences of informal caregivers in Central Texas in relation to coping and stress?

This research question addressed all six themes of caregiving, coping, day, experience, health, and stressors. All participants expressed their experience with caregiving as well as the challenges they faced. In addition, they shared their stressors and the coping strategies in which they utilize. For many caregivers, the role of caregiving was a stressful experience as participants talked about the time they spent with their loved ones as frustrating, and difficult, yet filled with love. Even while providing care for another person is a loving and selfless act in and of itself, for some participants, love played a significant role in their caregiving experience.

For several participants, taking care of their spouses, children, parents, and partners came naturally as a result of their bond and commitment. In a similar manner, a child helping a parent was paying back the years their parents spent taking care of them. For instance, despite frustrations and difficulties taking care of a patient with a stroke, Cecilia noted that “I am young and I just want to live life and have fun. I have a family and kids to care for. But, when I see him suffering constantly, what I want just vanishes.”

Tammy said that because her father had always done so much for her and her siblings, she treated him with affection. “After spending so much time being so attentive to [my siblings and me], it would feel awful to entrust his care to a complete stranger.” She claimed despite working two jobs, she would never feel the need to entrust her father’s care to a third party. “I have headaches and pain in my body, but, when I see him suffering each moment, all of my pain is forgotten.”

Stress is an inherent experience that caregivers encounter. Ten of the 12 participants said that providing care was stressful in some manner. These individuals believed that providing care was fundamentally stressful. Despite their best efforts to care for their care recipients, several participants described how heartbreaking it was to watch their loved ones suffer. Some participants had to consider other choices, including placing their care receivers in a facility or hiring outside support, because the demands of their care recipients grew to be too significant.

The lives of the caregivers did not stop just because someone else needed their attention as many participants' care recipients need around-the-clock attention. They had to continue to fulfill their own obligations while also taking on another person. According to Sandra, "When my husband is well, I feel all right. But, when he has very bad days or has pain, I feel disturbed. The worst thing is to see him suffering with pain." The most difficult aspect of caregiving, according to Josh, was juggling his wife's needs, the son who requires special needs, the rest of the family, and his own family obligations as well as work. He believed that because he had to care for his wife, son, and other kids, he was unable to give each work his whole attention. He also has frustration towards his family, but he lacks a means of letting it out. Despite doing his best, he said he still feels that his efforts are insufficient. Josh said,

> Because most of the time I am with my ill wife and our kids, I do not make time to care for myself. I spend most of my time with them, so why should I care about my appearance or wants and needs? I do not care about myself as much as my wife's and kids' well-being.

Subquestion 1: How do informal caregivers in Central Texas describe the effects of the provision of care on their well-being?

According to previous research, factors related to the patient's condition can determine the caregiver's well-being and individual characteristics of the caregiver (Weitzner et al., 1999). Therefore, this question addressed the themes of coping, stressors, day, and health. Kristi explained her feelings and emotions on her health and day-to-day as “experiencing grief and depression in a roller coaster fashion.” Tammy shared that she started seeing a therapist for her depression and mental health was put on medication as well. Kristi and Renee shared that their physical activity has not been impacted, however, their mental health has. Melissa and Sandra both shared that they were physically active prior to the caregiving role, but have now become stagnant in their physical activity. Melissa shared, “I get frustrated and overwhelmed often, which makes me not want to do anything.” Sandra noted, “When I get home from work and have to check on our son as well as work on dinner and other household chores, I don’t have the time or energy to do anything else.” The three males, Randall, Josh, and James, all share that their well-being hasn’t really been impacted due to taking on the caregiving role.

Subquestion 1: What are caregivers in Central Texas’ main coping methods when they experience stress?

This question addressed the themes of coping. The participants shared a variety of coping strategies. Four of the 12 study participants mentioned their faith, prayer, or religion in their interview. Kristi said, “I lean on my faith. I also lean on those who I knew would help.” Monique noted, “I pray and talk to my friends.” Monique, Sandra, and Kristi discussed that they often use prayer as a coping mechanism.

While some of the participants utilize prayer as a way of coping, some found other outlets. This included yoga, devotionals, journaling, watching television, and scrolling through social media. Cecilia shared that she does yoga every night to help her release stressors. Sandra noted, “I have found devotionals that have helped me at different steps along this journey.” Melissa shared, “I tend to bury myself in food or social media when I am frustrated.” Randall, James, and Josh were a select few individuals who expressed that they do not cope since they do not feel any additional stressors. Josh casually stated, “I don’t really need to cope. I just pray and do what I can for her.” James replied simply with “I don’t” in regards to coping. Alternatively, Tammy and Renee put their time and energy into their work. Tammy shared, “I get wrapped up in my work. I have recently started seeing a therapist and have been put on medication. This has been the best therapy for me.”

Subquestion 3: What are some of the key stressors for caregivers in Central Texas?

This question addressed the themes of stressors, experiences, and day. When the needs of a care recipient increase, it adversely affects the sense of self-esteem of a caregiver, physical health, finances, and a caregiver’s schedule (Weitzner et al., 1999). Many of the caregivers reported that their days became challenging when the care recipient demanded that they were independent and could do certain tasks. This was most common in the older care recipients such as the ones who were spouses or parents of the caregiver. The participants who cared for children expressed behavior exhibited by the care recipient as having the biggest effect on their stress and difficult days. Amber shared, “When his diabetes gets out of whack and it causes his behavior and sleep to be impacted, we struggle.” Kristi noted that when her son started getting stronger and bigger than her, just the daily tasks impacted her.

Subquestion 4: What resources could help one while being in a caregiver role?

This question addressed stressors and coping. Several of the caregivers reported that having a central hub to be able to access information would be beneficial. The examples given by Amber were “a phone number to call to ask questions, help with appointments, and find support.” Josh suggested, “Find who you can seek out for support, and don’t just Google.” Sandra said that she wishes there were resources out there because “I would go looking for something and I wouldn’t even know where to start.” Another popular resource requested was a counseling or therapist that could come and help the families of the care recipient including the caregiver, spouse, siblings, parents, etc. Lastly, another resource requested was support groups. It seems there are several support groups for grief after losing a loved one, widows, autism, and other specific topics. However, there was not any focus on informal caregiving or caregivers having to see their loved one decline slowly or rapidly with their illness. Jokingly, Tammy quickly responded with,

> A life coach, LOL. No, on a serious note, how great would it be to have someone who can say, “Wait Tammy, take a step back, take a break, or we need to do something different?” Also, someone who can help you manage everything you need including appointments, and daily chores, and even help you find the resources you need.

The central research question as well as the subquestions were addressed in this study. Caregiver participants reported that they took on the caregiving role because it is their job to do so. For spouses, they expressed that when they said their vows to each other they promised to care for one another for better or worse, and sickness and health. They vowed to help care for their spouse and they never thought twice about it. The individuals who care for their parents shared that their parents provided care to them growing up and now it was their turn to care for their parents. Lastly, those who provide care to their children expressed that when they decided to have children, they knew all that came with that role and even though they may have additional needs than most children, as a parent, it was their responsibility.

Summary

Chapter Four presented the lived experiences of informal caregivers in the Bell County area of Central Texas. The participants ranged in age, ethnicity, and education level. The 12 participants’ experiences were examined through their interviews, words, expressions, and ideas that described the themes. The information from the interviews revealed that participants just take on the role of caregiving without giving it a thought and not knowing what it will entail. Information gathered also revealed that participants view their upbringing and home life as having an impact on their caregiving role. All participants shared they did not have any support or resources before taking on the caregiving role. They reported that family was the primary support they leaned on. They were all in significantly good health before taking on the caregiving role while now over 90% experience some sort of physical, mental, or emotional strain. All participants did verbalize and display some negativity towards caregiving. However, each participant did speak highly regarding their role toward their care recipient.

The data gathered from the interviews was used to answer the central research question: What are the lived experiences of informal caregivers in Central Texas in relation to coping and stress? The main themes of caregiving, coping, day, experience, health, and stressors give answers to the question. Caregiving roles differed among caregivers with eight living with their care recipients and four not living in the same. Emotions like love, compassion, and frustration were expressed by caregivers. Caregivers experienced grief while their physical and mental health was also affected, including difficulty focusing on work and having emotional outbursts. Finally, caregivers encountered stressful times and additional stressors related to the caregiving role. This was particularly so for the parents of the care recipient, or the spouses who also had additional children in the home which added more responsibilities to the caregiver. The next section discusses the study findings in this chapter in relation to the empirical and theoretical literature reviewed in earlier chapters.

Chapter Five: Conclusion

Overview

The purpose of this phenomenological study was to understand and evaluate the lived experiences of informal caregivers and how their culture, upbringing, and other demographics impact their stress and coping. Evidence from research on caregiving examined in this study revealed that a large number of aging individuals, persons with disability, and those with chronic illnesses are looked after in their own homes by family members (May, 2021; National Research Council, 2010; Wilkinson & McLeod, 2015). Aligned with research, these family carers see informal care as stressful or demanding (Wilkinson & McLeod, 2015). According to studies on family care, informal care has negative effects on family caregivers (Wilkinson & McLeod, 2015), which was affirmed by the results from this study. These negative consequences include mental health problems, caregiver well-being, the demand of daily chores, coping, employment, and caring results, as well as other social and economic factors (May, 2021; National Research Council, 2010; Watson Caring Science Institute, n.d.; Wilkinson & McLeod, 2015). Delimitations and limitations of the study are also offered within this chapter. Finally, recommendations for future research based on the study's findings will be presented followed by a summary of Chapter Five.

Summary of Findings

The research presented a phenomenological analysis of the lived experiences of participants that live in the Bell County area of Central Texas. The study revealed six major themes during the interviews. These themes were: caregiving, coping, day, experiences, health, and stressors. The themes revealed key concerns and the participant responses addressed the research questions as well as revealed opportunities for future research. From the findings of this study, it is reasonable to infer that providing family care might harm the health and QOL of informal caregivers given the negative impacts of informal caregiving identified. The negative outcomes are perceived on a variety of levels. This includes the caregiver strain that is felt when assistance is missing. According to May (2021), the pressure of caregiving can affect well-being, exacerbate concerns, increase social isolation, and modify interactions between the caregiver and care recipient. Informal caregivers in this study supplemented the existing research by offering insight into their personal environment and perspectives. Participants expanded existing literature by providing a deeper understanding of the lived experiences including coping and stress regarding informal caregiving.

Theme One: Caregiving

Informal caregivers are in three distinct groups defined by their care recipients: Children with disability and chronic illnesses are cared for by their parents, adult children with illnesses such as mental health care are cared for by middle-aged parents, and finally, elderly care recipients are cared for by both their aged spouses and adult children (National Research Council, 2010; Sigelman & Rider, 2015). In this study, four of the participants provide care to their children, one middle-aged caregiver provides mental health care to her mother, three caregivers provide care to their spouse or ex-spouse, and four caregivers provide care to a parent. While majority of the caregivers did not give jumping into the caregiving role a second thought, others such as Randall tried to get other providers in to help with the role.

Numerous caregivers also hold full-time jobs and other duties, including caring for their families, volunteering and doing chores, and cleaning (Nemati et al., 2017). Cecilia, Sandra, Tammy, Josh, Amber, Tina, Melissa, and Renee all have full-time jobs and/or other children in the home they provide care for. James, Krisit, Monique, and Randall are not employed or work part-time in order to be available for their care recipient. In other words, all participants had to pick up additional duties when taking on the caregiving role.

Participants defined caregiving in similar words and connotations as making sure that a loved one's needs are met in any way possible. While a majority of the caregiving participants (nine) live with their care recipient, others (three) do not live under the same roof as the care recipient but do visit them daily or several times a week.

Theme Two: Coping

As stated in previous literature, coping styles vary from person to person and can include emotional, cognitive, and behavioral responses (Panicker & Ramesh, 2018). Some specific coping strategies include environmental support, social support, religion and spirituality, and external resources (Central Texas Aging, Disability & Veterans Resource Center, 2022; Ong et al., 2018; Pargament, 2013; Sabata et al., 2005). Contrary to this, one participant, James said he does not cope. However, he did note that caring for his special needs daughter has affected his emotions. Feelings that go along with the caregiving experience include anxiety, boredom, fear, embarrassment, guilt, grief, resentment, loneliness, and sadness (Santos-García et al., 2022). Many of the female caregivers expressed feelings of anxiety, grief, frustration, embarrassment, and being overwhelmed. The male caregivers did not express much emotion or feelings in regard to their coping and caregiving experience. Under this theme, the common coping skills and strategies that were found were friends, family, prayer, yoga, counseling, and devotionals. Different caregivers preferred different combinations. For example, Josh said, "I have learned to overcome it with the help of prayers and blessings of God."

Theme Three: Day

The day-to-day activities and responsibilities of informal caregivers are rarely tracked since they vary from individual to individual (Torelli, 2020). Under this theme, subthemes were created that include daily chores, difficult days, and typical days. All participants mentioned part of their typical day was making sure their care recipient had their meds, meals, and transportation to appointments. Therefore, having to take on additional roles of chores such as laundry, paying bills, cleaning, cooking, and even household upkeep was a health, social, and/or economic burden. Sandra and Josh both mentioned that in addition to their full-time jobs, they also had to be responsible for the household chores such as cooking, cleaning, and laundry in addition to taking their children, who were still living at home, to school, appointments, and events or activities. In addition, while Josh's wife resigned from her teaching position, Sandra said,

> He had to quit his job of over 20 years as an air conditioner service technician. This caused a drastic reduction in our income and financial stability. This all happened during the COVID-19 pandemic, so it was difficult for everyone.

Theme Four: Experiences

The individual needs of informal caregivers are not tracked and provided for due to their day-to-day activities and responsibilities of care (Torelli, 2020). Researchers have focused on determining the QOL based on strains and burdens, including stress and a caregiver's experience (Martin et al., 2021). The caregiving experience has many similarities yet also differed based on for whom they provide care for. Caregivers that care for their parents had a lot of similar responses versus those who care for a spouse or child. In addition, the challenging experiences that were described varied as well. Many factors come into play in this section due to age, level of severity of illness, and employment factors.

Along with these experiences, the experience of grief was evident in the majority of participants. If not in the early diagnosis stage, throughout the caregiving process. Individuals who experience these grief-related experiences commonly question God's existence or question their faith (Shore et al., 2016), which three of the participants expressed in their interview. Kristi noted, "I have experienced grief and depression in a roller coaster fashion." The individuals who provide care for cancer patients described how they were devastated to hear the news, but Sandra said, "I just wanted to do anything we could to help with his prognosis." As her care recipient's health deteriorated, Josh's situation was slightly different. He shared, "I had faith we would get through it. I just go with the flow, and we take it all day by day."

Theme Five: Health

While theoretical frameworks suggest that caregivers provide physical and mental health benefits to the care recipient (Ghasemi et al., 2020), data also reports that informal caregivers experience poor to fair health of their own (CDC, n.d.). Informal caregivers support their care recipients as well as the country's health care system while compromising their own health and well-being (CDC, n.d.).

Some of the health challenges that caregivers encounter includes physical and mental health as they defined their health in a fair to poor state. Two of the 12 participants stated they experienced no change in their physical or mental health and they were males. Five of the participants experienced a change in one category or another, while six felt that both their physical and mental health was compromised. In comparison to what the Family Caregiver

Alliance (2016b) stated, nine of the 12 participants work full time in addition to their caregiving role, and seven of them expressed poorer or decreased physical and mental health.

Theme Six: Stressors

The caregiving role can cause stress and burden on an individual (Gérain & Zech, 2019). The care recipient's condition as well as other factors, can aid in additional burdens and stress including family conflicts, financial difficulties, and relationship strains (Gérain & Zech, 2019). Caregivers can experience a variety of stressors such as reactions of sadness, shame, and frustration (Gérain & Zech, 2019; May, 2021). Tammy shared that "Caregiving is not for the weak."

In alignment with research from the Family Caregiver Alliance (2016b), this study found that all 12 participants either live with their care recipient (Cecilia, Tammy, Renee, Kristi, James, Josh, Sandra, Amber, Melissa, and Monique), provided care for longer than a year (Cecilia, Tina, Kristi, James, Randall, Amber, Melissa, and Monique), are older caregivers (Randall), and experienced a higher level of burden. Seven of the nine females versus none of the three males reported an increase in stress with the caregiving role, which coincides with research showing that female caregivers report more stress than male caregivers (Family Caregiver Alliance, 2016b).

At least all respondents suggested that they experienced stressful times throughout the caregiving journey. It was evident that full-time caregivers had less stress compared to those employed and working different shifts while also taking care of their loved ones. Although participants listed a variety of caring experiences, participants shared that it was stressful to play the position of a caregiver. Taking care of an aging family member or a family member with a chronic illness exhibited some amount of stress (May, 2021; Nemati et al., 2017). Some people found it upsetting to witness their parents or other loved ones in pain. Others were concerned that they would have to either place their care recipient in a facility or employ outside aid because their care recipient's requirements had grown too great, and they lacked the money to provide for them according to CDC (n.d.).

Sometimes, the care recipient's health makes it difficult for the caregiver to leave him or her to do other, equally necessary tasks. Caregiving obligations, especially for daughters, cause them to lose their privacy. Compared to their colleagues in the broader public, caregivers under these circumstances have fewer opportunities to maintain an active social life. In addition to their duties as carers of sick, aging relatives or acquaintances, the majority of caregivers also play several other roles. Middle-aged caregivers who regularly serve as parents, housekeepers, employees, and primary carers for aging or ill relatives are at a higher risk for role conflict. Participants contend that family carers may be disproportionately sensitive to different physiological, psychological, and financial stresses when providing informal care services (Biggs et al., 2017).

Furthermore, each participant's experience providing care was unique. The majority of participants either had direct, easy access to a health care provider who was willing to assist them in providing care or were themselves health care providers, typically family members. Participants with health care expertise did, however, indicate higher levels of stress related to caring for their loved ones; they also expressed less doubt about the medical system in general and made fewer mistakes at the beginning of caring for others. Some caring tasks were perceived by participants to be psychologically and physically draining. The participants were frequently asked to do tasks for which they felt unprepared.

Discussion

The discussion section describes how this study supports and contributes to existing literature. It also reflects on the experiences participants disclosed during the interview process. It examines how lived experiences (Creswell & Poth, 2017) of participants reflect on their coping and stressors as related to informal caregiving. The theoretical framework that guided the study was Lazarus and Folkman's (1984) transactional model of stress and coping. This theoretical framework is a process that includes the product of a stressor by the environment and the individual's response to the stressor. This section discusses the interpretation of findings including implications, limitations, and delimitations, as well as recommendations for future research.

According to May (2021), providing care for a family member can have a significant negative influence on mental health. These effects can include depression, emotional issues, increased levels of anxiety, and cognitive issues (National Research Council, 2010). According to Lou et al. (2022), gender has some relationships with the outcomes of family caregiving. Additionally, women who care for others have worse coping skills than men when it comes to managing higher levels of depression or mental health concerns, unsatisfactory levels of personal well-being, and poor QOL (Lou et al., 2022). This was affirmed in this study as the three male participants did not report major changes to their physical or mental health, but the women mentioned significant difficulties in these areas. Although providing care is stressful, none of the participants reported losing their sense of self as a result of the experience.

While employment provided the caregiver with a source of money, it also competed with the care that was given to care recipients (Armstrong-Carter et al., 2021). Many individuals lamented having to change their work patterns since their job performance had declined. Most of the care recipients were unable to work and had to resign from their jobs, thus leaving a financial burden on their household responsibilities. In addition, some caregivers such as Kristi, James, Cecilia, and Monique had to decrease their hours or even quit their jobs in order to take on the demanding role of their care recipient. This took the two-income families down to one income and required lifestyle adjustment to the decreased income. According to the results of other studies (Armstrong-Carter et al., 2021), caregivers may suffer negative effects if they combine family caring with full-time paid employment.

The number of hours a family member spends caring for the care recipient is one of the caregiving factors evaluated by the Caregiver Burden Inventory (National Research Council, 2010). According to May (2021), time spent providing care might, for a while, put a temporal constraint on the caregiver. These time constraints have an impact on the family caregiver’s ability to understand their suffering (May, 2021). During Tina’s interview, she made it clear that she needed to leave in order to go check on her mom as well as get to her son’s extracurricular activity. Sandra discussed how she had to work and then rush home to check on her husband, as well as cook dinner, and other household chores while making sure he had what he needed to be comfortable. Amber shared that her care seems like it is around the clock because they are always having to check his blood sugar levels and administer insulin.

Whether one is aware of it or not, an individual frequently employs coping strategies. These behaviors can either be beneficial or harmful depending on the situation (Sutton & Austin, 2015; Vaillant, 2022). Survival strategies assist with diminishing the results of pressure. The “flight or fight” function within the nervous system starts the stress response (Mayo Clinic Staff, 2022 Wehei, 2018). This causes changes in the body to help one prepare to run away from or face potential danger head-on. The stress response can have several side effects (Monteiro et al., 2018; Vaillant, 2022). While not verbally mentioned, as the participants were discussing their caregiving role and their care recipient, the researcher could sense a change in their heart rate, breathing, body posture, and facial expressions. There is a possibility that they may have experienced a rise in blood pressure. The participants were observed to have adjusted their position and some even stretched out their necks and backs. However, their purpose is also temporary. Additionally, chronic stress can result in issues such as difficulty sleeping, changes in appetite, aches, and pains as well as a loss of interest in activities (Lou et al., 2022) which each participant mentioned in their interview.

A source of caregiver participation, behavior, and stress is the living situation between the informal caregiver and the care recipient (Sutton & Austin, 2015). To accommodate their care recipient, the majority of participants change their living arrangements. These adjustments included moving into their care recipients' homes, having their care recipients move into their homes, or asking a relative to visit their care recipients' homes and keep an eye on them. While the participants' time was heavily consumed by caring, obligations to their loved ones also forced them to alter other aspects of their life.

In many cases, caregivers transfer their care recipients or other family members to make sure they can provide their loved ones with the care they need. Whether they move in with their care recipients or the care recipients move in with them, for many caregivers, this represents a change in their way of life. Some caregivers renovate their homes to ensure safety and accessibility for older, chronically ill, or disabled residents. Other times, care receivers express a desire to remain in and near their homes (Armstrong-Carter et al., 2021). Being closer to the care recipient enables the caregiver to plan and oversee services for the recipient. According to Sutton and Austin (2015), a house plays a significant role in the lives of many people in need of help since it is a location where they feel comfortable and secure and where life is generally unchanging. Despite the costs to their personal security and emotional and physical health, some care recipients insist on staying in their current homes to receive family care (Merriam & Tisdell, 2016). Monique firmly agrees by saying that she knows her mother will get better care at home with family than being in an institution or long-term facility.

Implications

This study has shown that informal caregivers have numerous responsibilities. According to the findings of the study, there are a variety of stressors that caregivers deal with. Financial constraints and hardships were some of the stressors since providing care requires additional resources. Other issues mentioned in this study include physical and mental health challenges that caregivers encounter among others. The theoretical, empirical, and practical implications of this study are addressed in the following sections.

Theoretical Implications

Lazarus and Folkman's (1984) transactional model of stress and coping entail concepts of frameworks that place the foundation around caregiver stress and how caregivers cope with stress. The data from the 12 participants and the findings of the study validated that this theory was an appropriate theoretical framework for this study. The framework has been utilized to help bring clarity to the aspects of caregiving, which includes stressors, coping strategies, and how cultural values influence caregiving and caregiver stress, making it a fitting framework for this research. The theory relates with the findings of the study that while informal caregivers encounter various stressors, there are ways through which they can cope and influence their behavior to conceptualize social and caregiving interactions (Merriam & Tisdell, 2016).

This study also found that a variety of stressors lead caregivers to utilize problem- and emotion-focused coping strategies. Lazarus and Folkman (1984) emphasized that problem-focused coping leads individuals to manage self-directed and environmental changes. Participants in this study adopted problem-focused coping responses by utilizing social support systems. Pursuing activities such as interacting on social media, and yoga served as means for coping with stressors. According to Lazarus and Folkman (1984), emotion-focused coping occurs when a person perceives a lack of control and may be apt to seek emotional support from a family member or loved one. Participants reported coping through prayer, reaching out to family and friends, and meeting with a counselor or therapist. By reflecting on their lived experiences, participants shared valuable insight into how to cope with the caregiving role.

Empirical Implications

In this study of caregiver burden and coping mechanisms, the outcomes indicate that the majority of caregivers encounter several stressors including physical and mental health, financial burdens, and difficulties coping with their work (Chari et al., 2015; Gérain & Zech, 2019; May, 2021). Therefore, it follows that informal caregivers go through stressful experiences when taking care of their loved ones and find it difficult to relate positively to their work and other responsibilities. Despite embracing different coping mechanisms such as prayer, counseling, yoga, devotions, family members, and friends, many informal caregivers have not fully and successfully coped with their role (May, 2021).

Practical Implications

It is evident from the study that participants noted that caregiving has practical implications for them that include feelings of uncertainty, and reduced levels of self-esteem (Chari et al., 2015). Many caregivers have low levels of self-acceptance with less control over their lives (Gérain & Zech, 2019). The study found that informal caregiving has consequential impacts on caregivers including a decline in their physical and mental health, decreased QOL, and high financial costs. Therefore, administrators and policymakers should implement strategies and offer resources required by caregivers to cope with and counter their challenges. This includes meal delivery programs, medical and adult daycare programs, home health care, caregiver training, a sense of hope, durable medical equipment and home modifications for patient care needs, and transport services.

Long-Term Care

Long-term care is a system for providing personal, social, and health care services over an extended time to enable people with disabilities or functional impairments, who are limited in their ability, to operate at near optimum levels (Armstrong-Carter et al., 2021). The services are important for care receivers, particularly for those with mental challenges or chronic problems. Results from this study supported the claims in the literature surrounding the importance of long-term care programs.

Monique shared that she wished there was a policy in place for those like her mother with a mental illness that they spend time in a long-term facility rather than a temporary one to get the mental patient stabilized and then sending them home within one week. Similarly, Randall expressed that he wished the medical professionals would discharge his mother to an evaluation facility such as assisted living to determine their living abilities and needs. In these cases, professionals in the health care sector including physicians, nurses, family, and social workers provide long-term care services. Resources and medications can be put in place upon dismissal. Volunteers both in the public and/or private sectors are another source of long-term care services (Armstrong-Carter et al., 2021).

Respite and Daycare Services

This is a nursing intervention and the provision of short-term relief, planned emergency provisions to relieve caregivers from their everyday endeavors in caregiving and the pressure and stress that comes with it (Armstrong-Carter et al., 2021; Merriam & Tisdell, 2016). While the participants did not mention someone skilled in coming and providing care to their loved ones so they could have a break, it was sensed in their answers they wish there was someone to give them a break.

Tammy shared that she feels that she is the only one who will give her dad the care he needs and that is why she chose to become his caregiver rather than a stranger. Her only break is while she is at work, however, she is constantly checking on him and worried when she is not around him. Monique brought up that she knew that she was giving her mother what she needed, and she chose that care. Randall encouraged home health services to help relieve some of his daily duties, which he shared has been helpful during his role as a caregiver.

Respite care includes a variety of services and can be provided in or outside of the home (Merriam & Tisdell, 2016). Services like respite care and adult day care are especially important for helping informal carers. Family carers can take a break from their caring duties sometimes with the aid of respite care. Particularly in community settings, adult daycare programs provide a scheduled bundle of services throughout the day. Randall, who lives in a different town from his care recipient, discusses how he tried to convince her to be admitted to an assisted living facility and she was adamant that she wanted to go to her own house with her own things. He finally convinced her to get some home health support through a nursing agency that comes to her home a few hours a week. According to Merriam and Tisdell (2016), these environments relieve unpaid caretakers so they may go to work and make a living.

Family carers should get beneficial support that includes evidence-based caregiver interventions and respite care (Borneman et al., 2002). A systematic review was performed by May (2021) to examine the effectiveness of various forms of respite care in assisting family carers of patients with chronic diseases. The results showed that adult daycare services help ease the stress on caregivers. Other research endorsed the advantages of day program attendance and claimed that the advantages increase thoroughly as day program attendance becomes more dependable (Sutton & Austin, 2015). Particularly, people who consistently attended daycare services had a decreased likelihood of being institutionalized as older individuals. For instance, Monique recently learned that her mom was in and out of facilities when she was growing up. It has now come to the point where her mom requires additional support to help monitor her mental health.

Support Systems and Resources

Biggs et al. (2017) noted that before modern caregiving, formal aid from community relief programs like adult day centers, in-home support, and short-term stays at home were all recognized as ways to assist carers. Randall mentioned that “back in the good ol’ days hospitals and care facilities would make sure you were fit to go home before sending you home.” He also mentioned that they made sure you had all the pertinent information you needed prior to leaving. This may be home health companies, medical equipment companies, or other resources. When his mother was released to go home, he had to find the resources on his own. More resources are required to support family carers (Crowe & Sheppard, 2011).

Second, carers are frequently friends or other family members who have an interest in the care recipient’s wellbeing. This is difficult for caregivers like Monique and her mother’s mental health needs. It is also hard to find someone to watch those care recipients who have special needs as it requires a special person to take on that role. They might not take on responsibility for the care recipient, unlike the primary caregiver (Merriam & Tisdell, 2016). Resources that would be beneficial to caregivers include financial aid, such as insurance compensating family caregivers when institutional arrangements can be avoided, and businesses should create more sensible family-friendly policies.

Melissa and James mentioned that social media outlets and support groups were helpful to them. In addition, individuals with disabilities must struggle to obtain better-integrated care that extends beyond the single-family caregiver and includes informal care networks. Such networks with several in-built carers would be very advantageous. Participants such as Sandra, Tammy, and Josh said it would be helpful to have a single person such as a social worker to reach out to in regard to treatment, appointments, etc. when dealing with their care recipients diagnosed with cancer. It was even suggested by several participants that a list of resources and phone numbers would be helpful in dealing with their care recipient. It would extend the caregiving activities to more people inside the family and outside such as church-based assistants, friends, or community health advisers, so lowering the tensions and enhancing health benefits (Biggs et al., 2017).

Caregiver Training

Caregivers should be offered educational classes that teach them about the illnesses that older individuals experience as well as how to handle care-related issues (May, 2021). Melissa shared that when she first learned the diagnosis of her son, she started looking for answers “all over the place.” Josh wanted future caregivers to not just Google the answers, but to look to the specialists. Sandra also expressed that she wanted to help her husband and find the best hospitals, the best care, and the best treatment for him, but she was just unsure where to even start.

The Geriatrics Workforce Enhancement Program is a key innovation for enhancing education, clinical treatment, and training initiatives that may respond to regional, local, and national needs for people in need (Busby-Whitehead et al., 2016). Programs such as the Geriatrics Workforce Enhancement Program address workforce shortage issues and train a diverse and inter-professional array of health providers to assess recipients' needs in the community, among other things (Busby-Whitehead et al., 2016). Assisting families to cope with symptoms such as incontinence and behavioral disturbances that have been identified as triggering influences in the decision to institutionalize a care recipient, education, counseling, and training programs must also be developed (Armstrong-Carter et al., 2021). Melissa was at a loss when her son began exhibiting some behavioral outbursts and she did not know how to help him or how to get him to understand the outbursts. In agreeance with the participant's answers, studies agree that providers need to identify families and patients experiencing anticipatory grief to enable them to assess and determine their complications, provide the necessary support, and nurture effective intervention strategies to help them cope (Shore et al., 2016).

Sense of Hope

According to Lincoln and Guba (1985), family caregivers of patients with chronic conditions like Alzheimer's disease experience similar degrees of misery as the elderly patient they are caring for. The sense of hope is a crucial psychological resource for informal caregivers to deal with their caregiving experiences. For example, Sandra mentioned that she held on to hope: hope for the future, and hope for a cure for her husband's lung cancer. According to one definition, hope is a multidimensional active life force characterized by a specific but unidentified expectation of achieving future good, which is indubitably attainable and important to the individual who is hoping (Bialon & Coke, 2011). According to research on family carers for people with terminal cancer, hope was essential in helping them deal with challenging caregiving situations (Borneman et al., 2002). Sandra, James, and Tammy all expressed a sense of hope in the healing and recovery of their loved ones and their cancer diagnoses. “I wanted to know what I could do to help him. That changed as time went on to what can I do to make him feel comfortable and I just want to be there for him,” Sandra noted.

Delimitations and Limitations

This study was subject to delimitations and some unavoidable limitations. The design selected was a phenomenological study. The researcher thought this was the best design to explore stress and coping through the perceptions of informal caregivers in the Bell County area of Central Texas. Using this design provided a deep description of the experience of the participants. Interviewing 12 participants offered multiple perceptions of informal caregiving.

Delimitations

Delimitations are intentional choices made by the researcher to control or outline the boundaries of their study (Morton et al., 2015). One of the delimitations of the study is that the researcher was guided by a set of research questions and one central research question that asked respondents to describe their experiences as caregivers in relation to stress and coping in Central Texas to prevent the study from going beyond the required set boundary. Also, the research was guided by clear objectives which limited the scope of the study.

The population target of the study was the Bell County area of Central Texas. This is where the researcher resides and wanted to collect data in this area. As a result, the researcher was able to base the study on one common geographical location which was significant in understanding the experiences of informal caregivers in the region.

The researcher chose to include participants in the study to include those who have provided care for at least six months. This allowed for caregivers to fully take on the caregiving role and be able to discuss their experiences. In addition, to get a wide variety of data, those who had been providing long-term care were included to gather data on the long-term effects of caregiving. This was a purposeful choice as those who lived through the phenomenon could recall a more detailed and robust account of their experiences. Individuals who may have only provided care temporarily or for less than six months may not have experienced the same stressors that others who have taken on the long-term role may have endured.

Limitations

Limitations of this study consisted of the study's gender representation, racial factors, participant ages, and number of participants from a geographical location. Gender, race, ethnicity, and other rural/urban residency setups identify differences within the study and can affect this study's outcome as well (Morton et al., 2015). No controls were implemented for gender, level of education, religion, employment status, or residence (living with the care recipient). The mentioned demographics were not regulated as they would be too restrictive, limiting the sample size further and complicating the study.

May (2021) noted that 75% of informal caregivers are female while 25% are males, and the participant gender proportions in this study (nine females and three males) aligns with those percentages. However, since each gender regarded the caregiving role differently, interviewing more male participants in the study than female participants may have produced different results. In the future, research should include an equal representation of genders, or focusing on one gender at a time.

The result of this research was influenced by racial factors. The majority of the respondents in this study were Caucasian, which means that focusing on other races in the research is likely to give different accounts of their caregiving experiences. According to American Psychological Association (2011), about one fifth (20%) of White Americans and African American ethnic groups are informal caregivers while 16% of Hispanic Americans and 18% of Asian Americans provide caregiving services. With this in mind, the high number of Caucasian participants gave a narrower view of caregiver experiences from a cultural standpoint.

An additional limitation consisted of the recruitment of participants between 23 and 69 years of age and living in the specific area of Bell County in Central Texas. The participants were all high school graduates or above, though this was not a requirement of the study. Research notes that the average caregiver in the country is 50.1 years old (May, 2021). Seven of the 12 participants in this study were aged 40–49 while two others were 50–59. This supports May (2021) in that nine of the 12 participants fell in the average age range, but also limits the application of these study results to those falling outside of this age range.

A considerable limitation of the study was the number of participants from a specific geographical location, Bell County in Central Texas. Due to the area’s nature, community resources, and demographics, the makeup of the participants was somewhat similar. Because all participants were chosen from a single county in Texas, the geographically constrained region from which they were drawn was also made clear as a second constraint. The results’ applicability to different contexts may be impacted by the use of goal-directed sampling while recruiting individuals. Focusing on one region in the country is not a representation of the entire country’s or State’s population for various reasons. First, the availability of resources is not uniform across the country, implying that the results are likely to be different in other parts of the country. Furthermore, economic disparities in the United States are not uniform across States, thereby implying that States with higher or lower income or economic prosperity compared to Texas are likely to give accounts of caregiving experiences.

Although every attempt was made to foster a climate in which participants felt comfortable answering honestly and concisely, the sincerity, accuracy, and integrity of the replies of those who participated are likely to limit the reliability of the data. Similar to how unnecessary interpretation of the data was avoided at all costs, researcher bias might affect how well people understood the data.

Recommendations for Future Research

The recommendations for the direction of future research consider the study's findings as well as limitations and delimitations. Recommendations for future research expand this study exploring the lived experiences of informal caregivers across various regions in Texas or the United States. Participants could be recruited from various rural or urban areas to incorporate more cultures and diverse samples. This would also allow for the exploration of differences among a variety of racial and ethnic groups as well as their caregiving roles and coping strategies.

Another recommendation includes exploring why caregivers choose the informal caregiving route and when is the decision ultimately made. Four of the participants care for their children which they made the decision to care for them when they became a parent. The three caregivers who provide care to a spouse again jumped into the role but did not think about the implications it would have on their family and how much it would take away from their own lives. Finally, the five adult children who provided care to their parents took on the role as their parent's health started to decline and it became too much for their spouse to fulfill.

The years of informal caregiving experience were equal in that one third of them have provided care for 6-12 months, one third of the participants had 1-5 years, and one third had 11-20 years of informal caregiving experience. Therefore, future research could focus on caregivers who have under 5 years or over 10 years of experience. To further this topic, research could describe caregivers structures and needs in addition to how these change over time or as the care recipient's illness declines or deteriorates.

Although it is reported that women are primarily caregivers (May, 2021), the number of males taking on the caregiving role is increasing. One side of this would be to look at why males are becoming primary informal caregivers. Literature also suggests that females tend to report more stressors than male caregivers (Northouse et al., 2012), which suggests that men manage stress differently as noted in this specific study. While social and cultural explanations could be plausible, further research could be evaluated to identify the extent to which male caregivers are impacted by stress in relation to caring for an individual with a chronic illness. Comparing and contrasting the various coping mechanisms between male and female informal caregivers is also recommended. Future researchers may also consider exploring a variety of theoretical frameworks beyond Lazarus and Folkman's (1984) transactional model of stress and coping.

Summary

This study focused on individuals who provide caregiving to shed light on a phenomenon lacking representation in existing research. It was discovered that informal caregiving is associated with a lack of knowledge of resources, education, and training (Chari et al., 2015; Sterckx et al., 2013; Wilkinson & McLeod, 2015), social and relationship difficulties (Schulz & Sherwood, 2008), and financial struggles (Gérain & Zech, 2019). Long-term informal caregiving has impacted the physical, emotional, and mental health of those who take on the caregiving role

(Gérain & Zech, 2019; May, 2021). There should be a variety of resources and coping strategies for caregivers to have access to for coping and reducing the stressors they experience (Central Texas Aging, Disability & Veterans Resource Center, 2022; Watson Caring Science Institute, n.d.).

The findings in this study addressed a research gap in current literature that explored a part of informal caregiving that has not sufficiently been discussed. In addition, this study aligns with Lazarus and Folkman's (1984) transactional model of stress and coping. Six themes emerged from the 12 interviewed participants in this qualitative, phenomenological study: caregiving, coping, day, experiences, health, and stressors. It is notable from this study that creating personal time is important for caregivers as one way of relieving stress and overcoming the challenges and experiences encountered during caregiving moments. Lack of adequate rest and time out creates burnout which includes mental, physical, and psychological implications. Finding healthy and effective ways for informal caregivers to cope with their stress and promoting caregiver well-being could prove to be effective for all individuals involved (Morton et al., 2015; Shin & Choi, 2020; Shore et al., 2016).

As this study evolved from a personal to a professional need to understand the lived experiences of caregivers, it was evident that an individual's upbringing, including culture, religion, and even family life and relationships, impacted their well-being in addition to taking on the caregiving role. This phenomenology method was chosen as the research method to allow a discovery within the context of the experiences of caregivers. Each participant willingly and eagerly shared their personal lived experiences, which were true and different. In van Manen's (1990) work, "care" is described in many languages where the word care and worry are synonymous. Participants expressed worry as a typical response in taking on caregiving. Each caregiver shared that they took on the role of caregiver to give their loved one the support, care, and love that they felt they needed. In addition, the participants who took on the role of caregiving were willing to give up themselves, take on any additional roles needed, and deal with the stressors that they may endure to ensure their loved ones were cared for unconditionally.

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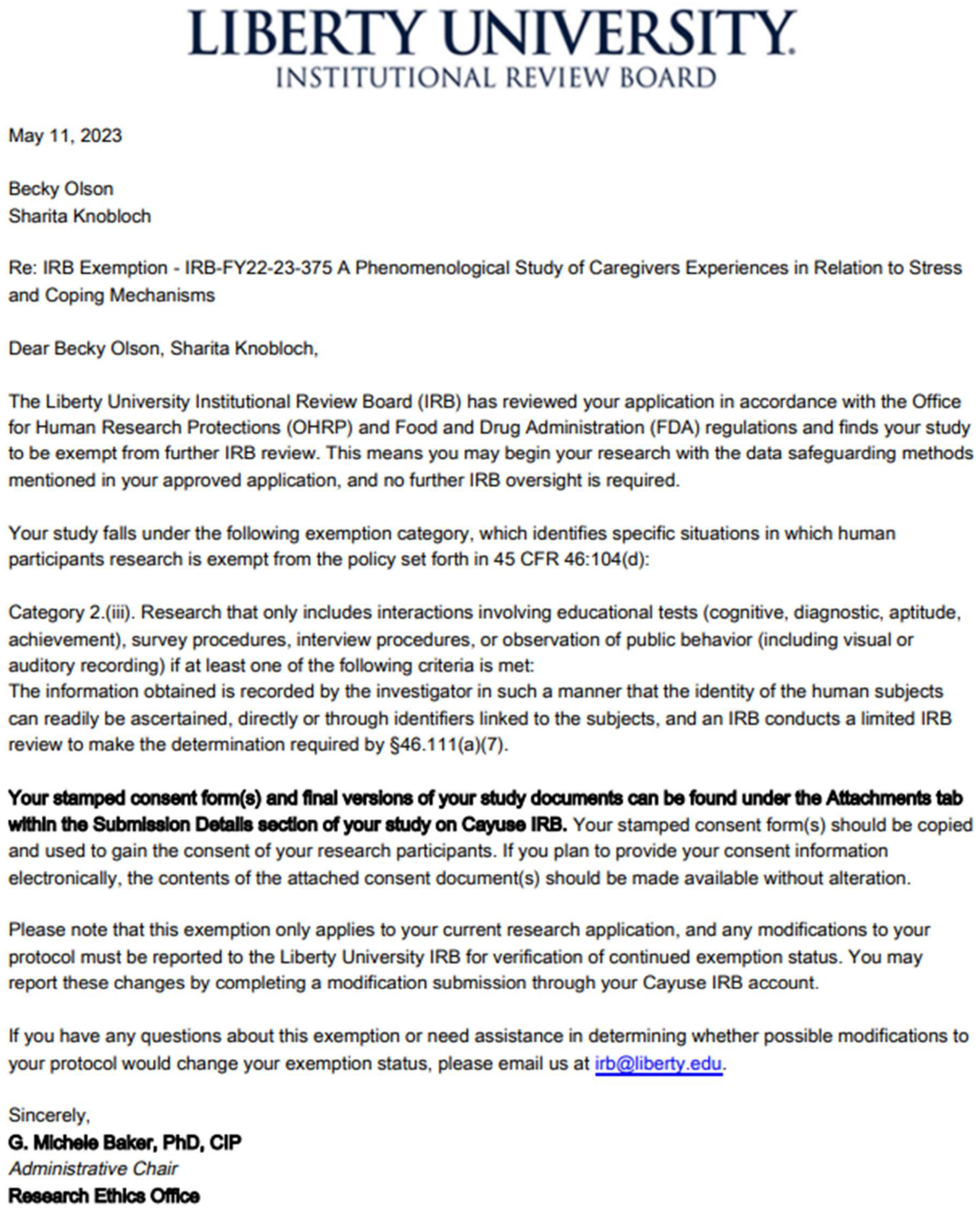
Appendix A: IRB Approval Letter



LIBERTY UNIVERSITY.
INSTITUTIONAL REVIEW BOARD

May 11, 2023

Becky Olson
Sharita Knobloch

Re: IRB Exemption - IRB-FY22-23-375 A Phenomenological Study of Caregivers Experiences in Relation to Stress and Coping Mechanisms

Dear Becky Olson, Sharita Knobloch,

The Liberty University Institutional Review Board (IRB) has reviewed your application in accordance with the Office for Human Research Protections (OHRP) and Food and Drug Administration (FDA) regulations and finds your study to be exempt from further IRB review. This means you may begin your research with the data safeguarding methods mentioned in your approved application, and no further IRB oversight is required.

Your study falls under the following exemption category, which identifies specific situations in which human participants research is exempt from the policy set forth in 45 CFR 46:104(d):

Category 2.(iii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:
The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by §46.111(a)(7).

Your stamped consent form(s) and final versions of your study documents can be found under the Attachments tab within the Submission Details section of your study on Cayuse IRB. Your stamped consent form(s) should be copied and used to gain the consent of your research participants. If you plan to provide your consent information electronically, the contents of the attached consent document(s) should be made available without alteration.

Please note that this exemption only applies to your current research application, and any modifications to your protocol must be reported to the Liberty University IRB for verification of continued exemption status. You may report these changes by completing a modification submission through your Cayuse IRB account.

If you have any questions about this exemption or need assistance in determining whether possible modifications to your protocol would change your exemption status, please email us at irb@liberty.edu.

Sincerely,
G. Michele Baker, PhD, CIP
Administrative Chair
Research Ethics Office

Appendix B: Recruitment for Social Media

Facebook

I am conducting research as part of the requirements for Community Care and Counselling at Liberty University. My study aims to understand the principle of informal caregivers' lived experiences in relation to stress and coping behavior. To be eligible to participate, you must:

- be 18 years of age or older,
- reside in Bell County,
- primary caregiver to persons with characteristics such as those with a terminal or permanent illness, dementia or Alzheimer's, special needs (those with cognitive, mental, or physical disabilities that affect their daily lives), aging individuals that require help with daily living tasks, cancer, or a chronic disease or illness that will require care such as heart disease, pulmonary diseases, cystic fibrosis, diabetes, inflammatory bowel diseases, muscular sclerosis, Lou Gehrig's disease, epilepsy, among others,
- be able and willing to participate in a screener, general demographics survey, and an open-ended virtual interview session for approximately 45-60 minutes.

If you want to participate and meet the study criteria, please direct message me or contact me at [redacted] for more information or complete the screening survey. Once the survey is sent and the requirements are met, an email with a consent form and demographics survey will be sent.

Twitter

Are you at least 18 years old?
Do you live in Bell County?
Do you provide care to a loved one?

If you answered **yes,** please get in touch with me to complete a screening survey to determine eligibility. Once received and the criteria are met, an email with a consent form and demographics survey will be sent. Please get in touch with Becky Olson at [redacted] for any additional questions.

Appendix C: Recruitment Verbal Script (Phone or In Person)

Hello Potential Participant,
As a graduate student in the School of Behavioral Sciences at Liberty University, I am researching to understand better the principle of informal caregivers' lived experiences concerning stress and coping behavior. My research aims to discuss the impacts of stress from caring for loved ones at home by describing caregivers' experiences when offering care services to their loved ones. If you meet my participant criteria and are interested, I invite you to join my study.

Participant criteria are that the participant must:

- reside in the Bell County area of Central Texas
- be 18 years old or older
- provide informal care to a family member, friend, neighbor, relative, sibling, etc.
- care recipients must have a terminal or permanent illness, dementia or Alzheimer's, special needs (those with cognitive, mental, or physical disabilities that affect their daily lives), aging individuals that require help with daily living tasks, cancer, or a chronic disease or illness that will require care such as heart disease, pulmonary diseases, cystic fibrosis, diabetes, inflammatory bowel diseases, muscular sclerosis, Lou Gehrig's disease, epilepsy, among others.
- participants must have provided care for at least 6 months.

Participation will be confidential, and names and other identifying information will be requested as part of this study, but the information will remain confidential.

Would you like to participate? If Yes. Fantastic. Could I get your email address so I can send you the link to the screener survey? Can we set up a time for an interview? If No, I understand. Thank you for your time.

Thank you for your time. Do you have any questions?

Appendix D: Recruitment Follow Up

Dear Recipient

As a graduate student in the School of Behavioral Sciences at Liberty University, I am researching to understand caregivers' stressors and experiences better. A week ago, you stated that you would like to participate in my research study. This follow-up email is being sent to remind you to complete the screening survey. The deadline for participation is XX/XX/XXXX.

If able and willing, participants will be asked to participate in a virtual interview. It should take approximately 45-60 minutes to complete. Participation will be confidential, and other identifying information requested as part of this study will remain confidential.

To participate, please complete the link to the screening survey provided above; contact me at [redacted] or [redacted] for more information and to schedule an interview.

Sincerely,

Becky Olson
Principal Investigator
Doctoral Candidate

Appendix E: Participant Response Email

Dear potential participant,

Thank you for expressing interest in my study on caregivers and their lived experiences. I have received your screening and survey, and you meet the requirements for the research study. In order to get started with the process, please do the following:

- ✓ Complete the Consent Form
  The consent form contains additional information about my research. If you choose to participate, you must sign the consent document and return it to me before the interview. Doing so will indicate that you have read the consent information and would like to participate in the study.
  <u>Please fill in your name and date on the consent form and return the form to me via email or text.</u>
- ✓ Complete the Demographic Survey
- ✓ Contact me to schedule the virtual interview

If you have any questions, please do not hesitate to reach out and ask.
I look forward to hearing from you soon.

Becky Olson
Principal Investigator
Doctoral Candidate

Appendix F: Screening Form

Name:

Email:

Are you at least 18 years of age?

○ Yes

○ No

Do you reside in Bell County?

○ Yes

○ No

Do you provide informal care for a loved one (parent, child, spouse, sibling, relative, neighbor, or friend)?

○ Yes

○ No

Does your care recipient have a diagnosis of a permanent or lifelong illness or disability? Does this include dementia or Alzheimer’s, cancer, special needs (cognitive, mental, or physical), aging, long-term illness, or chronic disease?

○ Yes

○ No

Have you been a caregiver for at least 6 months?

○ Yes

○ No

Are you available and willing to fill out an online form collecting general demographic information?

○ Yes

○ No

Are you able and willing to participate in an audio- and video-recorded virtual 45-60-minute interview about your caregiving experiences?

○ Yes

○ No

Appendix G: Study Consent Form

Title of the Project: A Phenomenological Study of Caregiver Experience in Relation to Stress and Coping Mechanisms
Principal Investigator: Becky Olson, Doctoral Candidate, Liberty University

Invitation to be part of a Research Study

You are invited to participate in a qualitative research study. To participate, you must be 18 years of age or older, live in Bell County, and be a primary caregiver to a loved one for at least 6 months. The care recipient must be an individual with a permanent illness or disability that affects their daily life. Some of these diagnoses may include persons with dementia or Alzheimer's, special needs (such as a cognitive, physical, or mental disability), cancer, aging individuals that require help with daily living tasks, or a chronic disease or illness that will require care such as heart disease, pulmonary diseases, cystic fibrosis, diabetes, inflammatory bowel diseases, muscular sclerosis, Lou Gehrig's disease, epilepsy, among others. Taking part in this research project is voluntary.

Important Information about the Research Study

Things you should know:

- The study aims to understand the principle of informal caregivers' lived experiences concerning stress and coping behavior. You will be asked to participate in a demographic survey and an open-ended interview if you choose to participate. This will take approximately one hour.
- Risks or discomforts from this research include taking more time and being influenced by the researchers.
- Taking part in this research project is voluntary. You do not have to participate, and you can stop at any time.

Please read this entire form and ask questions before deciding whether to participate in this research project.

What is the study about, and why is it being done?

The study aims to enhance the provision of home-based informal caregiving services, which is essential for older adults and individuals with disabilities and chronic illnesses.

What will happen if you take part in this study?

If you agree to be in this study, I will ask you to do the following:

1. Fill out a screener survey
2. Fill out a survey questionnaire with personal details and information
3. Participate in a 45-60-minute interview which will be recorded

Participants should not expect a direct benefit from participating in this study.

What risks might you experience from being in this study?

The expected risks from participating in this study are minimal, which means they are equal to the risks you would encounter in everyday life.

How will personal information be protected?

The records of this study will be kept private. Published reports will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the researcher can access the documents.

- Participant responses will be kept confidential by replacing names with pseudonyms. Information collected as part of this research could be used or distributed to another investigator for future research without additional informed consent from you or your legally authorized representative. If your information is used or distributed, identifiers are removed. After three years, all electronic records will be deleted, and all hardcopy records will be shredded.

Is study participation voluntary?

Participation in this study is voluntary. Your participation will not affect your current or future relations with Liberty University. If you decide to participate, you are free not to answer any question or withdraw at any time without affecting those relationships.

What should you do if you decide to withdraw from the study?

If you choose to withdraw from the study, please get in touch with Becky Olson at the email address/phone number in the next paragraph. Should you decide to withdraw, data collected from you will be destroyed immediately and will not be included in this study.

Whom do you contact if you have questions or concerns about the study?

The researcher conducting this study is Becky Olson. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact: Becky Olson at [redacted] or [redacted] or Sharita Knobloch at [redacted]

Whom do you contact if you have questions about your rights as a research participant?

If you have any questions or concerns regarding this study and want to talk to someone other than the researcher, **you are encouraged** to contact the IRB. Our physical address is Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA, 24515; our phone number is 434-592-5530, and our email address is irb@liberty.edu.

Disclaimer: The Institutional Review Board (IRB) ensures that human subjects research will be conducted ethically as defined and required by federal regulations. The topics covered, and viewpoints expressed or alluded to by student and faculty researchers are those of the researchers and do not necessarily reflect the official policies or positions of Liberty University.

Your Consent

By signing this document, you agree to be in this study. Make sure you understand what the study is about before you sign. You will be given a copy of this document for your records. The researchers will keep a copy of the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

☐ The researcher has my permission to record me as part of my participation in this study.

Printed Subject Name	Signature & Date

Appendix H: Demographics Survey

Name:

Email:

What is your born sex?

○ Male

○ Female

○ Other

What is your race?

○ Caucasian

○ Hispanic

○ African American

○ Asian

○ American Indian

○ Hawaiian or Pacific Islander

○ Multi-racial

What is your age group?

○ 18-22

○ 23-29

○ 30-39

○ 40-49

○ 50-59

○ 60-69

○ 70+

What is your preferred religion?

○ Christian- Catholic

○ Christian- Protestant

○ Christian- Orthodox

○ No religion in particular

○ Atheist or Agnostic

○ Other

○ Prefer not to say

What is the highest education you have completed?

○ Did not complete high school

○ High School/GED

○ Some College

○ Bachelor’s Degree

○ Master’s Degree

○ Doctorate Degree

○ Certificate or Trade/Technical School

What is your current employment situation?

○ Employed Full-Time

○ Employed Part-Time

○ Student

○ Unemployed

○ Homemaker (Stay-at-home, etc.)

What is your relationship with your care recipient?

○ Parent

○ Sibling

○ Child

○ Spouse

○ Friend or Neighbor

○ Relative

How long have you been a caregiver?

○ 6 months to a year

○ 1-5 years

○ 6-10 years

○ 11-20 years

○ 21+ years

What is the primary diagnosis of your care recipient?

○ Dementia or Alzheimer's

○ Cancer

○ Special Needs (Cognitive, Mental, or Physical Disability)

○ Aging

○ Long-term illness

○ Other

Appendix I: Interview Questions/Guide

1. Introduction by the researcher: “As a reminder, this interview will be recorded for data collection purposes only. It will allow me as the researcher to verify that I translate your answers verbatim as well as be able to note other things I may observe during the interview. First of all, I want to thank you so much for volunteering to participate in this study. A little about me, as you know I am a doctoral student at Liberty University. This topic of informal caregiving is important to me as I have a special needs daughter to whom I am the primary caregiver. To reassure you, I have put all of my emotions and challenges aside to focus on you and your responses during this interview. Do you have any questions for me before we get started?”
2. Tell me about the person whom you provide care for.
3. Tell me about your role in the person’s life prior to becoming their caregiver.
4. Explain what a typical day looks like.
5. Describe for me your emotions (thoughts and feelings) when you found out the diagnosis of your loved one.
6. Take a few moments to think about a challenging situation or a difficult day. Describe that to me.
7. How did you feel during that moment?
8. How did you cope with those difficult days?
9. Is there a specific coping strategy that you have found that works best?
10. How do you feel that your well-being and upbringing impacted your coping during stressful times?
11. What would you have done differently?

12. What do you think it means to be a caregiver?
13. What do you attribute to how you responded to the caregiving role?
14. How do you feel that providing care to your loved one has impacted your well-being?
15. Describe your current mental and physical status.
16. Tell me about the support you have as you stepped into the role of a caregiver.
17. Are there any resources or support that you feel would be beneficial to one taking on a caregiver role?
18. Reflecting on your own experience, what advice would you give someone entering the role of a caregiver?
19. What additional information can you share with me about your caregiving experience?

Appendix J: Participant Resources

UMHB Life Community Center
Community Life Counseling - Cru Community Clinic (umhb.edu)
(254-295-5531 or email communitylife@umhb.edu)

Baylor Scott and White Cancer Support Services
Cancer Support | Baylor Scott & White Health (bswhealth.com)

Area Agency on Aging
Area Agency on Aging (AAA)
(800-252-9240)

Health and Human Services
Health and Human Services Commission
(855-937-2372 toll-free)

Aging and Disability Resource Center
Aging and Disability Resource Center (ADRC)
(855-937-2372 toll-free)

Workplace Support
Supporting Caregivers in the Workplace

Respite and Care Services
Take Time Texas
(512-424-6500)

Additional Resources:
Community Resource Finder
National Resources for Family Caregivers
Heart of Central Texas Independent Living Center (HOCTIL)

Appendix K: Reflection Journal

Cecilia

Cecilia seemed very frazzled when she came to the interview. She was dressed, but had just got off of work and picked up her kids. She had checked on her stepdad and then went home to get ready for the interview. She was very energetic. Her voice changed in some discussions during the interviews, but I noticed this more when she would refer to her mom doing her thing, while she provided care to her step-dad. I sensed frustration during that time. Other than that, she seems to be in a good place.

Cecilia's story made me feel sad because I can't see how a wife would do that to her husband. I wanted to tell Cecilia how proud I was of her.

Tammy

Tammy started the interview late. She looked like she just had not had time to breathe. She had an energy drink in her hand and a coffee. She just completed teaching students and was also texting on her phone. The interview started with her being strong and speaking very intelligently. As the interview went on and discussions about her dad (the care recipient) continued, she teared up and began to get emotional. Her body language changed as well as her facial expressions. I also noticed she was not looking at the computer and making eye contact as often. Tammy did not hold back any emotions. She cried and laughed as she talked.

This interview had my anxiety at an all-time high. I wondered how she could help with her parents, and teach when she was all over the place. I also wonder if her laughter was a sense of coping when she begins to get stressed. I did sympathize with her in that as a daddy's little girl, I could see myself in her shoes. I am also in education so I know as an educator we try to keep busy by burying ourselves in our work while wanting the best for our parents.

Sandra

Sandra was sitting on the couch when we began the interview. She was sitting up tall and seemed to be focused on the interview. At some point, she changed positions because I noticed she was slouching as if her feet were up on the couch beside her. She was also wrapped up in a blanket. As she reflected on the questions asked, specifically challenging situations, she looked away and I sensed some tears, but she never let them out during our interview. She paused on the more difficult and specific questions about health, the care recipient, and emotions. It felt as if she had not told her story to very many people if anyone at all. She was reliving some very sensitive emotions. Sandra spoke a lot about prayer, her faith, and the church foundation. I am curious if this is a newfound faith since her husband's diagnosis, or if she has always been that way.

When she mentioned stage 4 lung cancer, my gut went to the worse about not having long to live. During Sandra's interviews, she never mentioned a shortened life, or even life expectancy for that matter. A part of me sits back and wonders if she is even taking time to make memories or discuss the inevitable with the kids and her husband. I feel she is living in the present and has a lot of hope for his healing.

James

James was relaxed sitting on his couch. His body language represented that he was comfortable and in a good place. He did not seem to be uptight or frustrated like some of the other participants. His response to the questions came across in a stern, masculine way. In other words, it seemed like he was having to be strong. Maybe this is his personality, but I did not see the personable side of him or his sincerity. He was focused on having to be strong for his wife and daughter. I am not sure if this is due to his career choice or upbringing.

I wonder if James has emotion or shares it often. I felt like due to his previous career role, he was used to remaining calm when others are in distress. I do question if he was being completely honest during his interview. James made me uncomfortable at times with his answers that came across as “cocky” to me. There were also times that I wanted to talk to his wife to see her side of the story. I just felt like he was trying to sound the like the hero of the story.

Josh

Josh was in an office setting. He was casually dressed and seemed very calm. His answers to questions were very short and sweet and he did not willingly elaborate. I found that I had to ask follow-up questions if I needed him to be more specific. He seemed to be quiet and shy.

Josh spoke very highly of his wife and I sense that she is the social one. This has to be frustrating for him when she is down and unable to do things she has always done. I wonder if he has some battles he is facing and may need to release those. I feel that he would benefit from some type of support group or counseling.

Kristi

Kristi was difficult to understand due to her being hearing impaired. Several questions had to be asked repetitively. She was sitting at a kitchen table. I felt like there was a sense of peace around her. Maybe it was her first time that day being alone. She spoke softly and answered questions. As she answered, her volume tapered off so it became more difficult to hear on my end. Her emotions were very high and she teared up several times during the interview.

Kristi’s crying did make me uncomfortable at times. I felt like she cried over everything. Having a special needs child, I too get emotional at times, but as long as I have been on this special needs journey, I feel like I have accepted that this is my life and I embrace it. She has been caring for her son for so long and has a pretty good family support system that I don’t feel the emotions should be that high. I am wondering how much help her husband provides and maybe she feels some relationship strain through her situation.

Amber

Amber was drowsy during her interview. She works nights, so she had been asleep prior to the interview. Her eye contact was very limited and she seemed all over the place. She spoke fast and was often sidetracked by her son walking through the room. He would try to see what she was doing and would talk to her. This caused her to become distracted and have side conversations. I had to repeat myself often. At one point, she had to pause the interview because her son wanted something to eat and she had to calculate the carbs and administer insulin to him. I did not feel that she was one hundred percent present in the interview. She did not get emotional during the interview, but you could sense frustration when she was interrupted by him.

Amber did not make much eye contact and she seemed to be all over the place. I wonder how much of her story is true or if it is exaggerated. It bothers me that she sleeps the majority of the day and works at night leaving her husband and mother-in-law to help care for her son. As a mother, I feel that you should work a schedule that is reasonable for you and your child. Especially while they are in school, needing appointments, etc. I felt some frustration as I listened to Amber's story.

Monique

Monique was in the car during her interview. I am sure this is the best place she was able to find to be quiet and comfortable. She stated she had just finished working a substitute role for high schoolers. She is a very bold lady and spoke very strongly. She did not show any emotion during the interview. However, it seems like she does demonstrate some frustration when finding out the diagnosis of her mother. She comes across as a very strong woman who holds it together well. She spoke often of God and prayer and church, which led me to believe she is a strong Christian woman.

Monique was very well-spoken and excited to tell her story. I am sure she has become strong through her experiences with her mom. I bet it was hard for her when she was younger, but now that she is older, and able to manage what comes her way, she has remained calm and strong for her mother.

Randall

Randall was at home during his interview. He was very casual and seemed relaxed. He had just spent the day with his mother running errands and taking care of financial things. Given the knowledge of his career in the business industry, he handled himself just as that. He was professional and clear and concise in his responses. While he did not elaborate, he gave short answers, but they were just enough information to answer the questions and there was no need to ask follow-up questions.

Randall did not show much emotion during the interview. It came across just as the other males in the interview, but you did sense a bit of confusion or uneasiness in the words when he spoke about some of the situations he has had to be put in. I feel that there is some pain in the caregiving role and that he is the only one.

Tina

Tina was in her office at work during the interview. She did say that she needed to leave by a certain time in order to check on her mom and then get to one of her kid's events. You could tell she wanted to answer the questions without giving elaborate details, but she did share some stories. There were times that she would laugh or giggle when explaining situations or typical days, but it may either be funny now or just her way of coping.

Being in the medical field, Tina has experienced a wide range of illnesses and disabilities. I am sure she felt emotional when her mom was first hospitalized, but she expressed more frustration when she talked about being the only one that could handle this. I am sure she keeps busy with her teenage boys, work, and caring for her mom that there isn’t much time to reflect on the caregiving role.

Melissa
Melissa was in her home office at the time of the interview. She stated that she wanted to do it while her son was at school because when he got home, she would not have any quiet time. She started the interview very relaxed as she and I know each other from our kids being in school together. As she talked about a stressful time, her voice and tone changed. I even noticed that she adjusted her position in her chair during that conversation. Since she has been providing care for a long time, asking about emotions during the diagnosis stage, she paused often. I am not sure if this is because she was reliving it or trying to remember those feelings. She looked tired by the end of the interview.

Melissa does not hide emotions well. Her face, body language, and overall demeanor were very evident. I could tell when she was trying to shut down at times as well as becoming frustrated. I know this was not towards me, but towards her son, her life, and just the overall special needs journey she has been on. I hope she wasn’t trying to be strong because I am a special needs mom too. I hope she knows it is okay to cry and show emotion.

Renee
Renee is full of energy and bubbly. She was in her classroom at school for the interview and it was her conference period. As she talked about her care recipient, which was her spouse at first and is now her ex-husband, I got mixed feelings. I wasn’t sure if she was happy that he was diagnosed or upset. It was almost as if their marriage was rocky and then he got sick, so they just decided to divorce easier. There seems to be a lot of confusion with her and the responses somewhat reflect that. At times, they were difficult to follow and I had so many other questions to ask.

Renee seemed unfocused and not fully into the caregiving role. I think it is more what her family and kids expect her to do. I don’t think she really wants to provide the care for him and will probably back off before too long. I am sure there is some grief that has not been dealt with in regards to her marriage, her divorce, and her ex-husband.