

Molloy University

DigitalCommons@Molloy

Theses & Dissertations

11-17-2023

Family Caregivers: From Invisible to Visible Within the Healthcare Continuum

Tara Anglim

Follow this and additional works at: <https://digitalcommons.molloy.edu/etd>



Part of the [Education Commons](#)



This work is licensed under a [Creative Commons Attribution 4.0 International License](#).

[DigitalCommons@Molloy Feedback](#)

Recommended Citation

Anglim, Tara, "Family Caregivers: From Invisible to Visible Within the Healthcare Continuum" (2023).
Theses & Dissertations. 167.

<https://digitalcommons.molloy.edu/etd/167>

This Dissertation is brought to you for free and open access by DigitalCommons@Molloy. It has been accepted for inclusion in Theses & Dissertations by an authorized administrator of DigitalCommons@Molloy. For permissions, please contact the author(s) at the email addresses listed above. If there are no email addresses listed or for more information, please contact tochter@molloy.edu.

**FAMILY CAREGIVERS:
FROM INVISIBLE TO VISIBLE WITHIN THE HEALTHCARE CONTINUUM**

A Dissertation Submitted to Molloy University
The School of Education and Human Services
Education Doctorate

In Partial Fulfillment
of the Requirements for the Degree

Doctor of Education

by

TARA ANGLIM
Dr. Allison Roda, Dissertation Chairperson

NOVEMBER 2023

Copyright by TARA ANGLIM

All Rights Reserved

2023



**MOLLOY
UNIVERSITY**

SCHOOL OF EDUCATION AND HUMAN SERVICES

The dissertation of Tara Anglim entitled: *Family Caregiver: From Invisible to Visible Within the Healthcare Continuum*, in partial fulfillment of the requirements for the degree of Doctor of Education in the School of Education and Human Services has been read and approved by the Committee:

Allison Roda, Ph.D.
Associate Professor, School of Education and Human Services
Molloy University

Maureen Carey, Ph.D.
Professor Emerita of Social Work, School of Education and Human Services
Molloy University

Laurie Maldonado, Ph.D.
Assistant Professor, School of Education and Human Services
Molloy University

Joanne O'Brien, Ed.D.
Dean, School of Education and Human Services
Molloy University

Date: November 17, 2023

ABSTRACT

As the United States' aging population rapidly grows, the prevalence of adults with chronic illness or disabilities who require intermittent or long-term caregiving from family members also increases. Despite the prevalence of caregiving, the role of the family caregiver is a label that lacks a clear description, definition, or societal understanding. The inability to identify family caregivers creates negative ramifications, including diminished recognition and support throughout the healthcare continuum. Drawing from caregiver identity theory, this qualitative phenomenological study aimed to describe the experiences of family caregivers to promote a deeper understanding of how they became aware of their caregiver identity and role in the healthcare system. The data included semi-structured interviews with a diverse group of 12 family caregivers currently caring for parents, grandparents, siblings and significant others over the age of 65. As suggested in the caregiver identity theory, the findings in this study confirmed that identity as a family caregiver is a complex change process. Additionally, this study found that awareness and acceptance of one's family caregiver role/identity are not synonymous, but are shaped/influenced by previous experiences within their family or work life, cultural norms, prior relationships with their loved one, and the external labeling process. These findings indicate that identifying as a caregiver is not always a simple or automatic process of acknowledging that what they are doing is family caregiving, with some participants actively rejecting or feeling ambivalent about the caregiver label. Implications of this research supports the need for education for healthcare professionals, patients and family caregivers to ensure caregivers are routinely identified throughout the healthcare continuum, and their needs are assessed and supported as a standard of practice in delivering family-centered healthcare.

ACKNOWLEDGMENTS

I am grateful to my husband, Kevin, and children, Kevin Jr., Sean, and Kate, for their love, support, and encouragement. You never doubted I could do this, even when I did not think I could.

Carol, aka Nanny, your unconditional loving motivation was constant from the start; “you chose to either sink or swim.” I am lucky.

One of the most beautiful parts about this journey has been the reminder that we can do hard things. I am grateful my mom, Janis, who instilled that strength in me early on.

I am grateful to my family and friends for your understanding, patience, and love. I had to miss out on many moments over the last four years, but you kept loving me and my family through the thick of it, especially during the pandemic, when your caring was appreciated beyond words.

My deep gratitude to Dr. Amy Loeb and my PBMC family, who constantly inspire and remind me that the impossible is possible.

I want to thank my dissertation chair, Dr. Allison Roda, and my dissertation committee, Dr. Maureen Carey and Dr. Laurie Maldonado, and Dr. Andrea Silverstein, for their guidance, invaluable advice, and constant support.

I was blessed to learn from Dr. Maureen Carey, Dr. Lois Carey, and Dr. Ray Fox early in my professional journey. They shaped so much of who I am. I carry all that they have taught me to all that I do. I would not be the social worker or researcher I am without them.

I want to thank Cohort 6 and the Ed.D. faculty who never let me lose my way. “Geese fly together.” Dr. Kathleen Quinn and Dr. Alana Thomas, I am so grateful for our friendship. We did it!

I began this journey to elevate the voices and stories of family caregivers. My deepest gratitude goes to the 12 family caregivers in my study who trusted their stories and experiences with me. You are seen.

TABLE OF CONTENTS

ABSTRACT.....	i
ACKNOWLEDGMENTS.....	ii
CHAPTER 1: INTRODUCTION	1
PROBLEM STATEMENT.....	3
THEORETICAL FRAMEWORK.....	4
CONTEXT OF THE STUDY	5
PURPOSE OF THE STUDY	6
RESEARCH QUESTIONS	7
RESEARCH DESIGN AND METHODS.....	7
DATA COLLECTION.....	8
LIMITATIONS	8
DEFINITIONS OF KEY TERMS	10
CONCLUSION	11
CHAPTER 2: LITERATURE REVIEW	13
INTRODUCTION.....	13
THEORETICAL FRAMEWORK.....	15
THEMES IN THE LITERATURE	16
WHERE WE COME FROM: FAMILY, CULTURE, ETHNIC, AND GENDER ROLES	19
BECOMING A CAREGIVER: CHANGING IDENTITIES.....	20
LOSS OF SELF IDENTITY AND ROLE ENGAGEMENT	22
UNDERUTILIZATION OF SUPPORT SERVICES.....	24
CALL FOR EDUCATION AND SKILL BUILDING.....	25
CONCLUSION	26
CHAPTER 3: METHODOLOGY	28
INTRODUCTION.....	28
ROLE OF THE RESEARCHER.....	30
METHODS	33
POPULATION, SAMPLE, SETTING, AND SAMPLING.....	34
DATA COLLECTION PROCEDURES.....	35
DATA ANALYSIS PROCEDURES.....	37
TRUSTWORTHINESS	38
ETHICAL CONCERNS.....	39
CONCLUSION	40
CHAPTER 4: RESULTS.....	42
INTRODUCTION.....	42
PARTICIPANTS.....	43
<i>Berry Smith</i>	46

<i>Lola Vaughn</i>	46
<i>Stella White</i>	47
<i>Katherine Sharp</i>	47
<i>Sarah Washington</i>	48
<i>Bob Swan</i>	49
<i>KC McKenna</i>	49
<i>Rose Hanes</i>	50
<i>Cookie Rossi</i>	50
<i>Heather Davis</i>	51
<i>Ted Gunner</i>	51
<i>Ramona Files</i>	52
FINDINGS.....	53
<i>Theme 1: Awareness/ Acceptance of the Caregiver Role</i>	54
<i>Theme 2: You Before Me</i>	63
<i>Theme 3: Changing Roles and Relationships</i>	69
<i>Theme 4: Qualifications for Caregivers</i>	77
CONCLUSION.....	84
CHAPTER 5: DISCUSSION	87
DISCUSSION OF FINDINGS	88
AWARENESS AND ACCEPTANCE OF THE CAREGIVER ROLE.....	89
CHANGING ROLES AND RELATIONSHIPS.....	92
YOU BEFORE ME.....	93
EXPERIENCE OF LOSS AND GRIEF	94
QUALIFICATIONS FOR THE CAREGIVER ROLE	95
UNEXPECTED FINDINGS.....	96
RECOMMENDATIONS.....	98
PARTICIPANTS' RECOMMENDATIONS TO HEALTHCARE SYSTEMS AND PROFESSIONALS.....	99
RESEARCHER'S RECOMMENDATIONS FOR PRACTICE/HEALTHCARE PROFESSIONALS.....	101
RECOMMENDATIONS FOR FUTURE RESEARCH	102
CONCLUSION	103
REFERENCES	106
APPENDICES	114
APPENDIX A: IRB EXEMPT LETTER.....	114
APPENDIX B: INTERVIEW PROTOCOL.....	116
APPENDIX C: FOCUS GROUP PROTOCOL.....	119

LIST OF TABLES

TABLE 1: CAREGIVER DEMOGRAPHIC SUMMARY	44
TABLE 2: PARTICIPANT DEMOGRAPHIC TABLE	45

LIST OF FIGURES

FIGURE 1: DEVELOPED THEMES LAYOUT.....	54
FIGURE 2: FAMILY CAREGIVER EXPERIENCE AND FINDINGS MAP	85

CHAPTER 1: INTRODUCTION

The United States' aging population is rapidly growing; by 2050, the number of Americans 85 and older will more than triple (U.S. Census, 2019). As the population ages, the prevalence of people with chronic illness or disabilities who require intermittent or long-term caregiving from family members also increases. Over 53 million adults have reported the need to provide caregiving to an adult family member with health or functional needs in the last 12 months (AARP, 2020; The Federal Register, 2022). Of that 53 million, 11 million or 20% of family members reported needing to provide unpaid care, known as *caregiving*, to a family member over the age of 65 living with dementia (Alzheimer's Association, 2021). The Alzheimer's Association's (2021) *Special Report on Alzheimer's in America* projects the number of adults over 65 living with dementia in the United States will more than double by 2050. Much of this increase is attributed to the aging Baby Boomer generation, which is made up of 76 million people born between 1946-1964. The Baby Boomers' aging contributes significantly to an alarming age demographic shift in the U.S., with citizens over the age of 65 more than doubling by 2060 (Henderson et al., 2017).

This rapid increase in the aging population combined with a decrease in birth rates is termed a *silver tsunami*. This impending *silver tsunami* is a crisis for which the United States has not planned well, considering the impact it will have on the already declining healthcare and aging support systems. Besides this *silver tsunami*, there has been a dramatic change within healthcare delivery and health insurance models in the United States over the last two decades to enact policies, regulations, and incentives to reduce hospitalizations, re-admissions, and lengths of stay (AARP Public Policy Institute, 2019; Semere et al., 2022). Therefore, family members must provide complex medical care at home for prolonged periods with little or no medical training or support.

While the need for caregiving is growing rapidly as the Baby Boomers age, the share of family members to provide caregiving is shrinking (Wolff et al., 2016). U.S. Census data show that the

availability of family members to assume caregiving roles is threatened by smaller and more geographically dispersed families and an increase in working women (Wolff et al., 2016). In addition, an increasing population of adults who have never been married and higher rates of divorce among Baby Boomers are trends that contribute to the shrinking pool of in-place family members to care for sick, ill, or disabled loved ones.

The CDC estimates that 1 in 4 adults are living with some form of disability, with rates increasing for adults over the age of 65 (CMS Health Equity Report, 2022). For the first time in history, by 2040, we will have more people over the age of 65 than those under 18 in the United States. According to the National Alliance of Caregiving's report on *Addressing Family Caregiving as a National Public Health Issue* (2018), 90% of Americans over 65 will live with one or more chronic and advancing health conditions. The availability of family members to be readily accessible and prepared to care for their aging, ill, or disabled loved ones is a severe public health crisis.

Current estimates in the United States show that family caregivers provide over 500 billion dollars annually of unpaid care to an adult family member with cognitive, health, or physical needs/disabilities (Reinhard et al., 2023; Shillam, 2022). Family caregivers who have historically assisted with household tasks and personal care are now called on to provide complex medical care home, which traditionally was performed by nurses (ACL, 2019; Reinhard et al., 2023; Wolff et al., 2016). Moreover, because this work is unpaid, most caregivers are taking on these caregiving responsibilities while carrying on their own personal, professional, and familial responsibilities. Historically, U.S. healthcare systems focus singularly on the identified patients without considering and recognizing the health and well-being of millions of family caregivers in front of their eyes.

Research shows that providing care for a chronically ill loved one can have negative physical, mental, and emotional consequences for the family caregiver (AARP, 2020; ACL, 2019; Reinhard et al., 2019). Higher levels of stress, anxiety, depression and other mental health effects are noted among

family members who are caregiving for an older relative or friend (Rodenbach, 2019; Roth et al., 2015). Lapses of medical and preventive screenings among family caregivers, often because so much of their focus, energy and time is needed on their loved one who requires caregiving, may be a negative contributor to the family caregivers' increased risk to their well-being. Too often self-care of the caregiver is put off or ignored (Oliveira et al., 2019). Preparation and support for caregiving has been found to reduce stress if it is introduced before it reaches a crisis point (Ingersoll-Dayton et al., 2003).

Low rates of family caregiver identification within the health systems (AARP Public Policy Institute, 2019) suggest that more emphasis on understanding the experiences of family caregivers within the healthcare continuum is necessary. Although recent laws such as the CARE Act in 2016 and the RAISE Act in 2017, as well as federal initiatives, have been put in place to recognize and support family caregivers throughout healthcare systems in the United States, the responsibility falls on the care recipient (identified patient) to identify their family caregiver to their healthcare professionals when accessing healthcare. In situations where the care recipient (identified patient) is too sick, experiencing altered mental status, incapacitated or unable to communicate, a family member must identify themselves as the family caregiver. The expectation that our aging ill and disabled population identifies their family caregiver is not only a barrier but an inequity. Exploring family caregivers' perceptions about how, why, and when they chose to identify within healthcare systems is crucial to uncovering opportunities to support identification. Therefore, the purpose of this phenomenological study was to gain a deeper understanding of the lived experiences of family caregivers and understand how they experience the realization and acceptance of their caregiver role/identity within the continuum of care.

Problem Statement

One critical problem is that there is no consistent definition which universally describes caregiving or a family caregiver. The National Committee on Family Caregiving for Older Adults, enacted by Congress in 2014, stated in their summary (2016), "the vocabulary of caregiving is

challenging. Many fundamental terms in caregiving literature lack consistent definition. Much of what has been known about family caregivers is derived from population-based surveys" (pp. 2-3). Missing across the literature is a universally used definition for caregiver and caregiving. The term *caregiver* describes many other roles outside of family caregiving within American society. This insight gains support from the work of Carney et al. (2023) who suggest that "family and other social relationships almost always predate the need for care, and our labels [healthcare providers] of patient and caregiver may not be labels that families identify with personally" (p 11). The absence of language to understand, recognize, and identify family caregiving is a health literacy gap. There has been little progress or change within the healthcare systems and continuum to bridge this gap and connect family members to vital resources, education, and support.

There is also a lack of qualitative data to understand the experience of assuming the role of family caregiver. The experiences of becoming and recognizing oneself as a family caregiver must be more deeply understood. The absence of shared language to describe the role of caregiver is a twofold problem. First, healthcare professionals must be educated regarding what it means to be a family caregiver. Second, healthcare systems should provide a universal language that is generally understood and resonates with family caregivers to support the recognition and identification of this new role.

Theoretical Framework

For my study, I chose family caregiver identity as a lens to examine caregivers' experiences and how they come to recognize and identify as a caregiver, or not. In addition, this lens was used to look deeper at the lived experience of family caregivers who were actively caregiving. Montgomery et al.'s (2007) caregiver identity theory suggests that caregivers are in a constant situation of change. As caregiving responsibilities increase and they provide more care to their loved ones, their traditional or familiar role begins to shift, moving them from their role of origin to a changing role as a caregiver (Montgomery & Kosloski, 2009). Caregiver identity theory asserts that caregiving is an active process

of change (Montgomery et al., 2007). As caregiving activities increase, it transforms the familial role into a caregiver role. Over time, the caregiving needs of the care recipient change and intensify. As caregiving progresses with an increase in tasks and activities, there comes the point where they cross over a role threshold where what they are responsible for is no longer consistent with their original familial role but instead changes to a distinctly different role; becoming the caregiver.

Context of the Study

The term *family caregiver* does not have a universal definition. The varying definitions and descriptions across the literature are in relation to the specifics of the care recipient requiring family caregiving. The descriptive language specific to the care recipient, such as elderly, veteran, disabled, or disease-specific diagnosis, i.e., congestive heart failure, diabetes, ALS, metastatic lung cancer, or Dementia/Alzheimer's disease, contributes to varying family caregiving descriptions. For the purpose of this study, I use an inclusive definition of *family caregiver* that allows for varying caregiving scenarios, "an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation" (ACL.gov, 2020).

The sample of participants for this study was drawn from a population of adults who were recently, within the last 36 months, referred to a Caregiver Support Center (pseudonym) in a medical center in the Northeastern United States. The Caregiver Support Center is located in a 160-bed community hospital that sits among suburban and rural communities. The Caregiver Support Center is a place for family caregivers to be connected to free programs and services to support them in their caregiving role.

The Caregiver Support Center serves as a central hub for family caregivers in the surrounding communities, regardless if their loved one has received care at the medical center. As the researcher in this study, it is critical to disclose that I am very familiar with the Caregiver Support Center and

programs, as I founded the support programs and led the creation of the center in 2018. A full-time designated social worker runs the Caregiver Support Center and programs. Family caregivers are referred to the center in multiple ways, such as self-referral, an outside referral from a community partner such as a primary care physician, or an internal referral by a healthcare professional that can occur anytime during the hospitalization of their loved one. Primarily, family caregivers are referred to the center by healthcare professionals treating the identified patient, the care recipient, who is experiencing a healthcare crisis and requires emergency care or hospitalization. Once referred, caregivers voluntarily participate in any or all of the free programs and services offered. Family caregivers may decide to discontinue participating in any programs at any time.

Purpose of the Study

In this phenomenological study, I sought to gain a deeper understanding of the lived experiences of family caregivers, and how they come to recognize and identify themselves as caregivers internally to themselves and externally to healthcare professionals within the continuum of care. This research examined the phenomenon of family caregiving and made meaning of the process by which recognition, acceptance, and identification of family caregiver identity occurred, or not. How or why things happen and what individuals think or feel in situations offer valuable data and can lead to insights into how we make sense or meaning out of our experiences (Mertler, 2019). This study is necessary to understand how caregivers' experience realization and acceptance of their caregiver identity and move to self-identification, which is needed to access and receive support within healthcare systems.

Family caregivers must navigate through a wide range of healthcare providers throughout the continuum of care in order to accomplish the responsibilities and tasks of caregiving (National Academies of Sciences, Engineering, and Medicine, 2016). Although the focus with healthcare providers is on the needs of the their loved one, the family caregiver can be experiencing their own negative physical, mental, and emotional consequences as a result of caregiving. They are often

invisible in their role as family caregivers and instead identified by healthcare professionals in their familial roles. Being identified in only their familial role does not capture the breadth and depth of responsibilities and tasks they have had to assume for their ill, disabled, aging loved ones. Furthermore, by not identifying caregivers, it does not allow for the healthcare professionals to recognize and consider any needs to support the well-being and health of the family caregiver. Healthcare professionals need to understand how to recognize and identify family caregivers to make their role visible and ensure they receive support, education, and resources to support their well-being, which benefits their ability to provide care to their loved ones. This research offers potential benefits to healthcare professionals in understanding caregiver identity through caregivers' lived experiences.

Research Questions

The following research questions guided my study:

Overarching Research Question: How do family caregivers describe their experience of how they came to identify as family caregivers?

Research Question 1: What experiences shape how family caregivers see themselves and their role in relation to their family member requiring care?

Research Question 2: What external and internal influences contributed to their awareness of themselves as a caregiver?

Research Question 3: How do they describe their caregiving journey and the skills they have developed over time?

Research Design and Methods

My study utilized a qualitative research design to study the lived experiences of family caregivers and gain a deeper understanding of how they came to acknowledge their new identity and identify. After exploring different qualitative methods, a phenomenological approach aligned best with my inquiry to make meaning of caregivers' experiences. It provided an opportunity to examine human

experiences as it was occurring. Phenomenological methods such as in-depth interviewing offered a unique opportunity to capture and make meaning of the experiences as participants understood them without the influence of hindsight or reflective views (Van Manen, 2014).

Data Collection

For this research study, participants were actively providing unpaid care for a loved one over the age of 65 who was living with disability and advanced illness (i.e., ALS, COPD, CHF, Alzheimer's/dementia, Metastatic Cancer). A community hospital-based caregiver program referred participants for the study. Twelve participants were enrolled in the study. Data were collected until saturation was achieved.

The methods of inquiry include phenomenological reflection on data provided through open-ended inquiry in individual interviews and focus group session with family caregivers to make meaning of their lived experiences. Individual 60-minute semi-structured interviews were conducted in person with each participant. Follow up discussions were used to clarify participants detailed descriptions accurately. Participants completed the initial interview before enrolling in the focus group. The focus group was conducted to allow for participants to build off of each other's experiences to gain greater depth and identify similar experiences that may only resonate among fellow caregivers. Interviews and the focus group were audio recorded and transcribed. Triangulation was achieved between the caregivers' interview data, the focus group data, and my field notes to further explore the phenomenon of becoming and identifying as a family caregiver.

Limitations

There were three main limitations to this study. First, the findings drawn from the data were taken at a specific moment in time and are cross-sectional in a specific location with a specific set of participants. Therefore, this study is just a snapshot in the life of family caregivers. The study, as is true

for all qualitative studies, does not allow for generalizability but does, however, advance and deepen the understanding of the phenomenon of family caregiving.

A second limitation is related to diverse perspectives in terms of both role representation and demographics. Although the study provided the perspective of the family caregivers, it did not examine valuable perspectives from other key roles such as the care recipients [family member receiving caregiving] or the health care professionals working with family caregivers and their care recipients. The absence of these perspectives should be seen as a limitation of this study, as the findings were developed only through the lens of the family caregiver participants.

Although this study did seek a diverse demographic sample in terms of age, race, socio-economic background, and family roles of participants who met the study criteria to uncover the themes of family caregiving across a wide range of experiences, the study did not have representation across all demographic groups which is a limitation to the caregiving experience examined.

Thirdly, the Caregiver Support Center as the site for recruiting participants was a limitation as it is located in a rural and suburban area with limited infrastructure resources, such as healthcare, community centers, transportation, etc. Therefore, the study may have had different findings if conducted in or was able to include participants in urban areas. Additionally, the site could have limitations to the findings as participants were already aware of the caregiver center, services, and supports, which are not a standard of care or services across healthcare systems or communities. The Caregiver Support Center is an innovation and not a standard model.

Therefore, participants recruited from the Caregiver Support Center may have had a different experience than if the study was conducted in an area without a caregiver support center and programs. The influence of participants having caregiver support and access to education may have impacted the participants' lived experiences as family caregivers versus family caregivers from another geography that did not offer caregiver support programs. The participants in this study may have been more

informed to their identity as a caregiver. Therefore, they may have had different experiences than if the study was conducted in an area without caregiver support centers and programs.

Family caregivers can experience stress at any time due to a health crisis of their loved one. Therefore, finding caregivers willing to participate in a qualitative study was identified as a challenge because caregiving fluctuates and is unpredictable. The Caregiver Support Center was the chosen site for recruiting as it gave access to a large population of family caregivers with a wide range of demographics, all meeting the study's criteria and allowing them to participate in research. Recruiting and maintaining family caregivers in a phenomenological study may have been a challenge as the nature of family caregiving is that it is not stable and is unpredictable. The pressing responsibilities of caregiving may not be stable, which was identified to possibly impact participants' ability to commit to this study or to complete the study timeline. Therefore, the invitation extended to participants was clear and allowed each participant to decline to participate at any time. Twelve participants were enrolled and completed the study, therefore the site for the study was a strength.

Definitions of Key Terms

The following key terms ensure understanding for the reader throughout the dissertation.

Family caregiver refers to an unpaid family member or friend who provides a broad range of assistance to an individual with a chronic illness or other health conditions, disability, or functional limitations (ACL.gov, 2020).

Care recipient refers to an adult with a chronic illness or other health conditions or an older person with disability, functional limitations who needs ongoing assistance with everyday tasks to function daily (Family Caregiver Alliance, retrieved on October 8, 2022).

Continuum of Care refers to the range of healthcare services needed for individuals with chronic or advancing illnesses, disabilities, or functional limitations. Services cover a broad range inclusive of preventive measures, acute medical treatments, rehabilitative and supportive care, and social services. It

describes a series of continuing and concluding care events that result when the patient seeks providers in one or more environments within the healthcare system. (Stedmen, 2012).

CARE Act refers to The Caregiver Advise, Record, Enable (CARE) Act is state-based legislation that, to date, has been adopted in 40 states. The law requires that patients are given an opportunity to designate and identify their family caregiver and expects that healthcare facilitates must notify family caregivers before the care recipient's discharge. Additionally, it requires healthcare professionals to provide education and instructions directly to the family caregiver regarding the patient's needs, including caregiving tasks and self-care activities they will need to assist or provide for their loved one when they return home (AARP, 2022).

RAISE Act refers to the RAISE Recognize, Assist, Include, Support, and Engage Family Caregivers Act, signed into federal law on 1/22/2018. The law mandated the creation of an advisory council which examined and created recommendations and goals for a national caregiver strategy.

Conclusion

This chapter has introduced the problem and purpose of this study, as well as why it is necessary to understand how family members experience awareness and acceptance of their caregiver identity and move to self-identification within the healthcare continuum. In the chapters that follow, I will explain in more detail the pertinent literature regarding the research design and methodology, my findings, recommendations and conclusions. In Chapter 2, I present a summation of the existing literature directly related to my study, including caregiver identity theory as the theoretical framework (Montgomery & Kosloski, 2007). Chapter 3 describes in greater detail the elements of the qualitative research design and phenomenological methodology chosen for this study. Chapter 4 presents the descriptive narratives provided by the 12 participants in this study. The narratives are organized into four themes and 14 sub-themes which answers each of the research questions. In the final chapter, I discuss the findings in connection with the existing literature and theoretical framework. It uncovers several unexpected

findings and concludes with powerful testimony by caregivers who offer meaningful, concrete recommendations for healthcare professionals and the healthcare delivery system.

Discoveries in this research highlight that greater regularity of family caregivers' identification is needed to increase interventions to assess their needs and elevate practices in delivering family-centered healthcare. This study is necessary to understand how family members experience awareness and acceptance of their caregiver identity and move to self-identification within the healthcare continuum.

CHAPTER 2: LITERATURE REVIEW

“There are only four kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

Rosalynn Carter, First Lady

Introduction

Family caregiving often begins as a series of linked events that occur due to serious illness or disability of a loved one. Despite the prevalence of family caregiving and an increase in societal awareness, few family members anticipate managing the reality of caregiving at the point in which it occurs. A caregiving episode can be defined both in terms of duration and intensity, the number of hours spent daily, weekly, or monthly to provide needed care to a loved one (AARP, 2020). As these events increase in intensity the demands in caregiving take on a life of their own, with severe implications for the caregiver (Chiaraluce, 2018). Caregiving involves a wide range of activities, from running errands and coordinating healthcare appointments to administering medications and activities to completing hands-on personal daily hygiene care such as assisting with dressing, showering and toileting. With the widening range of responsibilities thrust upon them it is not a surprising that family caregiving itself is a risk factor, regardless of sociodemographic factors, for poorer health, reduced quality of life, and fewer preventive health behaviors (Hoffman & Wallace, 2018).

In this chapter, I review the literature on family caregiving, caregiver identity theory, current laws pertaining to family caregiving in the U.S., and six emerging themes found in examining the existing research on this topic. The review of literature on caregiving identified the absence of common terminology and widely understood definitions of *family caregiver* and *family caregiving* to increase caregiver identification within healthcare models (O'Connor, 2007; Reinhard et al., 2015, 2019; Wolff et al., 2016). In addition, multiple studies suggest that the inability to identify family caregivers is a barrier to connecting them to the supports and resources they need (ACL, 2019; Dobrof & Ebenstein, 2004;

O'Connor; Ugalde et al., 2012). Within healthcare systems, the responsibility of caregiver identification falls on the patient as directed in the CARE Act (AARP, 2020; ACL; 2019 Coleman, 2016). In the absence of the patient's ability to identify their caregiver, which can occur easily within healthcare settings due to circumstances such as exacerbated illness or acute health occurrence such as a stroke, heart attack, or respiratory distress, the family member themselves must identify openly as the *family caregiver* to receive information, education, and supports designated by new laws for their central role. Healthcare models in the United States rely on family members of origin or choice to readily accept responsibility for providing caregiving tasks to their ill and disabled loved ones without instruction, compensation, or even an assessment of their health needs. Despite their crucial role in healthcare delivery and recent changes to policies and laws such as the CARE Act, family caregivers are not routinely identified and remain invisible within the traditional healthcare model despite (AARP, 2020; Coleman, 2016).

As people live longer with chronic illnesses, Americans face the reality of either needing or providing caregiving. Rosalynn Carter (Carter & Golant, 2013) has done much to shed light on the phenomenon of family caregiving through her own experience as a caregiver. She suggested that although caregivers often do not self-identify, they do, in fact, function in a distinct and different role than that of a family member. Through self-narrative of her experience, Carter sheds insight into the experience of caregiving. She, and countless caregivers, has led much of the informal rally call to shed light on this phenomenon of becoming a caregiver. Examining what caregivers think or feel in situations as well as understanding their experiences offers valuable data and can lead to insights into how we make sense or meaning of the role of family caregiver (Mertler, 2019). Qualitative research on family caregivers' lived experiences allows for the possibility of uncovering or seeing something that may answer questions and allow for generalizations.

The question that emerges from the review of the literature in this chapter is that, while family caregivers are the backbone to the healthcare delivery model in the U.S., how and why do they remain often unidentified and invisible throughout healthcare systems and the healthcare continuum is misunderstood? Understanding what may be impelling them to reject or deny the realization and acceptance that they have transformed into a new distinct role as the caregiver needs closer examination. Equally important is exploring what external factors may be helpful for family caregivers to accept their emerging role and ultimately self-identify to healthcare professionals. The question healthcare needs to consider is how to best prepare family caregivers for their new role and offer support to meet the unique needs of caregiving. Understanding the struggles and supports family caregivers experience specific to accepting their caregiver identity may uncover new and critical markers in the process of caregiver identification and shed light on opportunities for healthcare systems to tailor support to meet the needs of family caregivers and their loved ones.

Theoretical Framework

I utilized the caregiver identity theory (Eifert et al., 2015; Montgomery & Kosloski, 2009; Skaff & Pearlin, 1992) as the theoretical framework and lens to examine family caregiving and make meaning of the experiences of family caregivers. In this theory, the term *caregiver* began as a practical or functional concept that labeled a role specific to the unpaid tasks they performed for their ill, disabled loved one and which evolves into a distinct identity with behavioral, cognitive, and emotional characteristics (Montgomery & Kosloski, 2009). Skaff and Pearlin (1992) introduced the idea of caregiver identity in 1992. They hypothesize that the caregiver identity develops because of the loss of self and role engulfment experienced due to the intensity and demand of caregiving tasks and responsibilities (Skaff & Pearlin, 1992). Montgomery and Kosloski (2009) described the sense of self related to the care recipient as a primary effect of the caregiver identity theory. According to the theory, a transformation occurs over time as the care recipient's needs change and increase due to declining

health or functional status increase in quantity and intensity, requiring a change in the relationship of origin between the family caregiver and the care recipient. This shift causes the caregiver to reorganize how they see themselves and make new meaning of their role in relation to the care recipient.

The theory is grounded in the significant observation that there is no typical caregiver role or description and is developed around three key concepts. First, the caregiving role is acquired by a series of events and occurs systematically. Second, caregiving is a fluid process that is continually changing. Third, as caregivers increase and intensify their responsibilities to provide care for the care recipient, they experience a change in their relationship and familiar role with the care recipient, creating a change in their identity (Montgomery & Kosloski, 2009, p. 134).

Eifert et al. (2015) expanded on this examining the loss of their primary identity as a caregiver role becomes dominant as caregiving increases, taking over and overshadowing any other important identity. Eifert et al. described a process where the individual experiences a complete change in their identity in both the self and social constructs as a result of caregiving. The caregiver identity supersedes all former identities emerging as the master identity (Eifert et al., 2015). My research utilized the overarching themes of caregiver identity theory to examine how caregivers experience the realization of their new role and how and why they step towards outwardly identifying as the family caregiver for their loved one within healthcare systems.

Themes in the Literature

A review of the literature uncovered several common themes in family caregiving as it related to caregiver identity and role acceptance, such as caregiver stress/burden, lack of recognition from the external world, struggle with the loss of life as it was for themselves and the care recipient, and loss of self/role engulfment (Lynch et al., 2018; Ugalde et al., 2012). In addition, multiple studies highlighted the family caregiver's struggle to acknowledge and accept the new role and identity as a critical reason why they do not receive referrals or utilize available support services (AARP, 2020; Dobrof &

Ebenstein, 2004; O'Connor, 1999; Ugalde et al., 2012). The inability of healthcare professionals to identify family caregivers is a barrier to connecting them with the support and resources they need (Eifert et al., 2015; Reinhard et al., 2015; Ugalde et al.). Missing across the literature is a universally used definition for caregiver or caregiving. As noted, the role of the family caregiver can differ dramatically and is described or defined most often in relation to the care recipient's needs which can also widely differ from one person to another (Dobrof & Ebenstein, 2004; Montgomery & Kosloski, 2009; O'Connor, 2007; Skaff & Pearlin, 1992; Ugalde et al. 2012; Wolff et al., 2016).

O'Connor (1999, 2007) found to a large extent, that what is written in the research about the term *caregiver*, and what most of the literature supports, describes the term as a distinct entity that one would expect to be clearly recognizable and easy to identify. However, this is an illusion both conceptually and pragmatically that occurred across much of the literature (AARP, 2020; Dobrof & Ebenstein, 2004; Montgomery & Kosloski, 2009; O'Connor; Skaff & Pearlin, 1992; Ugalde et al., 2012; Wolff et al., 2016). AARP conducted the Caregiver Identification Study (2001) finding that family members often do not acknowledge they have assumed the distinct role until they are immersed in caregiving tasks and their responsibilities far exceed the objective standards of what is most commonly described as caregiving (O'Connor). Eifert (2015) suggests that acknowledging the identity of the *caregiver* forces the family member to recognize that their traditional role as a daughter, son, grandchild, husband, wife, partner, or significant other has changed (Eifert et al., 2015).

Themes were identified throughout the review of the literature and categorized to help synthesize the research and include: (1) Caregiver Stress and Burden, (2) Where We Come From; Family, Culture, Ethnic and Gender Roles, (3) Becoming a Caregiver; Changing Identity, (4) Loss of Self Identity and Role Engulfment, (5) Underutilization of Support Services, and (6) Call for Education and Skill Building.

Caregiver Stress and Burden

Assuming the role of a family caregiver occurs as an unexpected or unprepared event at the outset it is considered a chronic stressor. The stress and burden associated with caregiving are prominent in the literature with adverse effects on caregivers' mental and physical health (Hoffman & Wallace, 2018; Montgomery & Kosloski, 2009; Rodenbach, 2019; Sorrell, 2014). The quality of life for family caregivers appears to be shaped not only by accepting the quality of care but also by their level of distress and other quality of life factors (Rodenbach, 2019; Savundranayagam et al., 2011). Despite increased research on family caregiving, studies on stress and quality of life within subsets of the caregiving population continue to be limited (ACL, 2019; Aranda & Knight, 1997; Hoffman & Wallace, 2018; Liu et al., 2021; Montgomery & Kosloski, 2009; Reinhard et al., 2019; Rodenbach, 2019).

It has come to be commonplace in the literature that family caregivers experience numerous stressful events that occur concurrently and increase over time (AARP, 2020; ACL, 2019; Reinhard et al., 2019; Rodenbach, 2019). Family caregivers enter into a new role, often unprepared and ill-equipped for the stress and strain, jeopardizing their own physical and mental well-being. Providing intense levels of caregiving increases the likelihood that the family caregiver will forgo self-care or neglect their health and emotional needs as they perceive the care recipients' needs to be of greater priority (AARP, 2020; Oliveira et al., 2019).

Aranda and Knight (1997) examined the role ethnicity and cultural identity play in caregiver stress and coping and found that caregivers across ethnicities experience high-stress burdens. However, what caregivers perceive as stressful and burdensome may differ significantly. The research highlighted the pressing need for cross-cultural research on caregiving to examine other ethnic and cultural differences related to the appraisal of stress, coping behaviors, and utilization of support systems in moderating caregiver stress (Aranda & Knight; Brewster et al., 2020; Liu et al., 2021; Pinquart & Sorensen, 2005). Attention to the varying needs of different demographic populations of family

caregivers is critical to developing effective, evidence-based programs and interventions designed to reduce the potentially damaging impacts of caregiving (Cohen et al., 2019). Understanding the needs of caregivers specific to what will support them to feel better prepared has a significant benefit in reducing stress and burden. The more caregivers feel well-prepared, the higher their quality of life (Sullivan, 2015; Zale, 2018).

Where We Come From: Family, Culture, Ethnic, and Gender Roles

Who we are in the context of our family, culture and community has an incredible influence on our values, norms and self-identity, forming how we see ourselves in relation to others around us. Understanding how family caregiving may challenge or support those values and norms is significant. Chiaraluce's (2018) narrative research provides insight into the struggle, explaining that family is not simply a biological, cultural, or physical entity. "Family roles are highly emotional and reside deep within our subconscious, our self-identities, and our hopes and visions for the future" (Chiaraluce, 2018, p. 2887). Self-identification as a caregiver requires acknowledging a change in the family role and accepting themselves and their loved ones in a new light.

The need for caregiving often occurs suddenly, thrusting a family member into the new role because of a loved one's sudden illness or decline. Family caregiving is morally commendable but it can often demand caregivers sacrifice themselves to exceed the call of love or obligation. Multiple studies examined whether a family member had a choice in taking on a caregiving role, with nearly half reporting they felt they had no choice (AARP, 2020; Brewster et al., 2020; Reinhard et al., 2012; Schulz et al., 2012). Gender also plays a factor, as females make up more than 60% of all caregivers in the U.S., with daughters twice as likely than sons to provide care to parents (AARP, 2020; Grigoryeva, 2017). The increased likelihood of females assuming the role may be related specifically to the personal care tasks often required in caregiving. Family caregivers are increasingly performing tasks that nurses typically perform (AARP, 2020; ACL, 2019; Reinhard et al., 2019). Many caregivers, regardless of

gender, readily admit they do not possess skills or know how to accomplish the multiple tasks and duties they face in caring for their care recipient regardless of gender (AARP, 2020; Rodenbach, 2019).

Recent studies (AARP, 2020; Brewster et al., 2020; Fabius et al., 2021; Liu et al., 2021) report that differences exist in perceptions of psychological and physical well-being as well as characteristics and experiences between families of color and non-Hispanic white family caregivers. Research suggests that a more positive outlook on the caregiving role connects with higher value placed on religiosity and familism among African Americans (Brewster et al., 2020; Liu et al., 2021; Pinquart & Sorensen, 2005). Although literature was found specific to African American and Hispanic/Latino caregivers, the literature was minimal on examining racially and ethnically diverse populations beyond those caring for a loved one specifically with developmental disabilities or dementia/Alzheimer's specific (Aranda & Knight, 1997; Brewster et al., 2020; Pinquart & Sorensen, 2005; Liu et al., 2021). Researchers highlight that quantitative studies attempts to capture the impact of caregiving for a loved one with dementia/Alzheimer's may not be sensitive to racial differences in the perception or acknowledgement of burden related to caregiving (Brewster et al., 2020; Liu et al., 2021).

Becoming a Caregiver: Changing Identities

For acceptance of the caregiver identity, there must be an acknowledgment of the significant changes in their life due to caregiving. Montgomery and Kosloski (2009) described these various changes in family systems, social systems, socio-emotional, behavioral, sexual, professional, financial, health, and educational as a significant part of the emerging caregiver identity. Montgomery and Kosloski mark a crucial piece of the "transformation of existing role relationship" in what is often the most significant relationship in their lives (p. 48). According to the caregiver identity theory role transformation happens in five stages. The first stage begins when the unexpected need for caregiving arises. The second stage begins with the caregiver taking on tasks or demands that were not part of their existing relationship. The third stage is a crossing over where the care recipient is dependent, and the

level of caregiving tasks is beyond what the caregiver is prepared for in their preexisting roles. The fourth stage begins with the fear and realization that the growing needs of the care recipient may soon exceed what the caregiver can safely and realistically provide. The final stage occurs when the caregiver can no longer provide care, and professional care providers such as hospice or skilled long-term care facilities are utilized to meet the intense care needs of the care recipient. Throughout all stages, there is increasing stress and burden and diminishing quality of life for the caregiver.

Identifying in the role of the *caregiver* requires a self-definition separate and distinct from the relational role in the family. O'Connor (2007) identified a critical gap between family members recognizing themselves in a new and distinct role as caregivers. "Recognition of oneself as a caregiver is produced primarily through interactions with others; without external influence, family members will often see the work they are doing as simply an extension of their relational role" (O'Connor, 2007, p. 166). She highlighted that the construct of the caregiver identity largely begins with initiating from an external source, friend, or healthcare professional. Labeling from the external source often initiates the internal recognition process of a distinct and different role. Furthermore, she found a correlation between caregiver identity and willingness to utilize support services (O'Connor, 2007). This finding supported earlier research by Dobrof and Ebenstein (2004) that suggested that caregivers may not take advantage of services that would help them and the care recipient in the absence of self-identity.

Taking on this new and ambiguous identity also requires acceptance regarding a change in the relationship as it was, thus, adding further complexity to self-identification (McLeod, 1999). Acceptance often requires letting go of so much of what a caregiver wishes would be different. McLeod states, "to become a caregiver, we must cross a threshold whose other side is unexplored and often threatening" (p. 22). Moving past wishing the changes were not happening and that the reality of what is, compared to what was or what they had hoped it could be, must be reconciled internally for each caregiver. Multiple studies highlight the need for future research to examine how earlier self-identification of the caregiver

role can be best supported among healthcare professionals (Dobrof & Ebenstein, 2004; O'Connor, 2007; Ugalde et al., 2012; Wolff et al., 2016).

Hernandez et al. (2019) examined the lived experience of caregiving spouses. They found the identity as a couple is a vital element and function of life together, which the caregiver often struggles to maintain or protect, despite the reality of changes to the relationship roles or norms as it once was. The mental and physical health of caregivers and their ill loved ones are interrelated, and caregivers' stress often worsens as their care recipient declines in functional status and health (Hernandez et al., 2019). This significant physical and emotional stress experienced by family caregivers can have adverse consequences, including a severe decline in physical health, an increase in sleep disturbances, clinical depression and anxiety, financial strain, and overall poor quality of life (Hoffman & Wallace, 2018; Rodenbach, 2019; Zale, 2018).

Loss of Self Identity and Role Engagement

The refusal to accept the new reality and acknowledge the caregiver identity outwardly carried through several research studies (Eifert et al., 2015; Montgomery & Kosloski, 2009; O'Connor, 2007; Skaff & Pearlin, 1992; Ugalde et al., 2012). Loss of self and role engulfment occur incrementally as caregiving demands increase, eventually becoming all-consuming with the sole focus on the care recipient's needs. Caregivers put aside their own interests, routines, behaviors, and social interactions that were vital to their self-identity prior to caregiving (Eifert et al., 2015). Themes of role engulfment and loss of self-identity are recurring throughout the literature, with caregivers commonly describing themselves as no longer separate from their care recipient but extending them and their relationship (Ugalde et al., 2012).

A key element of the caregiver identity theory is that family caregivers have a preexisting defined relationship with their care recipient established prior to the need for caregiving. This preceding identity is based on a primary relationship which often defines who they are in the context of the

relationship. For example, caregiving spouses are part of a couple that has a shared identity, *us* (Eifert et al., 2015, p. 361). This shared identity is often referred to throughout the literature on spousal or adult child caregivers as dyadic. A dyadic identity is dependent on the other person; a parent must have a child, a spouse, a husband or wife. Unique to the increase of family caregiving demands is that it often results in changes in how one sees themselves in the context of that shared family relationship. In a shared or dyadic identity, how one sees themselves in relation to the other person who is declining and needing greater levels of caregiving forces an acknowledgement that the relationship is changed. (Eifert et al., 2015).

The caregiver identity theory suggests that over time the needs of the care recipient increase in quantity and intensity, yielding a change in the relationship between the caregiver and the care recipient (Eifert et al., 2015; Montgomery & Kosloski, 2009). Caregivers go through a metamorphosis, changing not only their daily activities and behaviors, thoughts, and feelings but the way they see themselves in relation to the care recipient and their own identity and role. The literature supports this change in role identity as caregivers experience a change in their everyday lives and become consumed by their caregiving responsibilities (Eifert et al.; Montgomery & Kosloski; Skaff & Pearlin, 1992; Ugalde et al., 2012).

This change can clash with their existing social and familial roles and classifications commonly used to describe themselves (Eifert et al., 2015). The contrast between how family members describe and perceive their identity prior to needing to provide caregiving versus their distinctly different identity as a caregiver is critical to understanding the unique, complex experiences and quality of life of family caregivers. Despite the commonality of some themes in the literature, it is essential to note that each caregiver's experience is unique and has significant variability across caregivers. There is no such thing as an *average* caregiver (Montgomery & Kosloski, 2009; O'Connor, 2007).

Underutilization of Support Services

There has been a growing number of resources, organizations, and supports created for caregivers over the last two decades; however, they are underutilized (AARP, 2020). Washington et al., (2011) highlighted that all family caregivers are a crucial part of the care team for patients within healthcare models often are not receiving support, information, and education regarding the care recipients' specific needs and illnesses. Several studies call for further examination for healthcare and social service providers to have a better understanding of what is involved in crossing the threshold to self-identification as a caregiver and what types of programs and services can best support caregivers (Carbone & Gugliucci, 2015; Chiaraluce, 2018; Coleman, 2016; Dobrof & Ebenstein, 2004; Eifert et al., 2015; Rodenbach, 2019; Wolff et al., 2016). Healthcare providers often lack an understanding of the complexities of the identity and needs of family caregivers.

Dobrof and Ebenstein (2004) highlight that the lack of self-identification among caregivers is a critical gap that requires further examination. In the absence of healthcare systems and providers recognizing the caregiver's role and responsibilities, there is a breakdown of information sharing and referrals to support services. Dobrof and Ebenstein suggested that caregivers may not take advantage of services that would help them and the care recipient in the absence of self-identity.

Based on Dobrof and Ebenstein's (2004) work, healthcare systems need to consider how to best recognize family caregivers and partner with them in the care plan. This supported earlier research by Dobrof and Ebenstein suggested that in the absence of self-identity, caregivers may not take advantage of services that would help them and the care recipient. Despite the increase and availability of caregiver directed resources from federal, state, local agencies, and non-profit organizations, family caregivers continue to underutilize support services designed to support them in their role (Eifert et al., 2015). Studies suggest that a primary barrier to why family caregivers underutilize support services is that

many family caregivers do not necessarily self-identify as caregivers (Coleman, 2016; Eifert et al., 2015; Rodenbach, 2019; Wolff et al., 2016).

Family caregivers are not inclined to seek supportive services available to them if accepting the services in some way is perceived to impact the care recipient negatively. Moore and Gillespie (2014) explored the idea of the *caregiving bind*, where the caregiver feels compelled to hide the increased stress and burden that they experience due to the growing intensity of the care recipient's needs. This shielding is intended to protect the care recipient; however, the consequence is a diminished external awareness that the caregiver needs to support their developing caregiver identity.

Call for Education and Skill Building

Across the literature, scholars suggest support services such as education and health literacy are needed interventions to reduce stress and support efficacy in navigating complex health systems, insurances, physicians, and community resources for the growing number of family caregivers ill-prepared for their role (Carbone & Gugliucci, 2015; Coleman, 2016; Harvath et al., 2022; Reinhard et al., 2012; Rodenbach, 2019; Ugalde et al., 2012). Family members are unprepared in assuming the role as a family caregiver. Caregivers want and need primary education, including improving their health literacy (Coleman, 2016). This raises critical questions about gaps in the patient care delivery model and its role in caregiver utilization of support services.

Rodenbach (2019) suggested that care teams need to spend time attending to the caregiver's individual needs as well as the patient's. According to Zale (2018), when caregivers feel well-prepared, their quality of life is higher. The importance of tending to unique caregivers' emotional experiences and partnering with caregivers to understand the care recipients' needs has not translated into a standard of practice in healthcare. Multiple studies identified the need to provide education and skill-building to family caregivers finding preparedness for caregiving predicts caregiver stress and burden, mental and

emotional health, and caregivers' own medical health outcomes (Coleman, 2016; Sullivan & Miller, 2015; Zale).

The Family Caregivers Providing Complex Care Study (Reinhard et al., 2012) found that many family caregivers perform critical and complex medical and nursing tasks without adequate instruction, with more than 60% of caregivers reported needing to learn how to manage medications for the care recipient on their own, and 47% reported never receiving training from any source. Caregivers are unprepared and forced to seek out information and learn tasks without any healthcare professional teaching or guidance, causing increased stress and fear of causing harm to the care recipient by novice mistakes or unintentional errors (Reinhard et al., 2012). Carbone and Gugliucci's (2015) study highlighted that education is a needed intervention as they are ill-prepared for their role with the absence of specific education or training from healthcare professionals. Roth et al. (2015) recommended that family caregivers' recognition and partnering from healthcare professionals early in their caregiving journey can reduce stress and aid in preparation for their role. Harvath et al. (2022) called for healthcare professionals understand the lived experiences of family caregivers and provide education and support to the critical role they play in the care of patients. Missing from the research is from whom and how caregivers want to receive education and the best methods to increase their self-efficacy and reduce stress.

Conclusion

A review of the existing literature on caregiving and caregiver identity offers a gap in the literature as to understanding how family caregivers recognize they are in a caregiving role, how they define and describe their role, and what, if any, external prompts support or interfere with accepting their caregiver identity and acknowledging it outwardly with healthcare professionals. The literature reveals the need for further examination to understand why caregivers either do or do not self-identify to healthcare professionals, especially during crises such as acute hospitalizations. Is the caregiver

uncomfortable with accepting their new role, are they in denial, or are they rejecting to accept the role as it is labeled and what it means in the context of their identity?

My phenomenological study looked to gain a deeper understanding of the lived experiences of caregivers and the process by which acceptance of caregiver identity occurs. It further sought to gain insight into the role crisis intervention has on family caregiver identity, external identification of the role, and caregivers' utilization of supports and services. My study explored these identified gaps in the research as they provide healthcare and social service professionals with a more detailed understanding into the process by which caregivers decided to identify their role outwardly. Through in-depth qualitative interviews, my study was able to better understand and uncover opportunities for healthcare and social service professionals to connect and support family caregivers. My study is necessary to understand how caregivers experienced acceptance of their caregiver identity and moved to self-identification or not.

This research aimed to uncover opportunities to identify caregivers within healthcare models and connect caregivers to essential information, education and support. The valuable interview data and analysis was structured to aid healthcare professionals, administrators and policy makers in developing appropriate interventions to assist caregivers. It provided insight into understanding how caregivers identify during crises in order to reduce feelings of isolation, stress, and caregiver burden. The findings from this study provide ways to shape practices to support caregiver identification within the healthcare continuum to ensure their needs are assessed and supported as a standard of practice in delivering family-centered healthcare.

CHAPTER 3: METHODOLOGY

Introduction

This chapter will describe the research methodology that I utilized in my dissertation study. As described in previous chapters, the purpose of this study was to gain a deeper understanding of family caregivers' lived experiences of becoming caregivers and how they came to acknowledge their new identity internally and externally. Often, caregivers do not recognize they are immersed in a caregiving role, even when carrying out all of the tasks and responsibilities of what is commonly described as caregiving (O'Connor, 1999). In addition, acknowledging the identity of the *caregiver* forces the family member to recognize that their traditional role as spouse, significant other, child, or grandchild has changed (Eifert et al., 2015; O'Conner, 2007). This study is necessary to understand how caregivers experience acceptance of their caregiver identity and move to self-identification. As described in Chapter 2, my research study drew from the theoretical framework of family caregiver identity.

I chose to use a qualitative research design to gain a deeper understanding of family caregivers' lived experiences of becoming caregivers and how they came to realize and accept their role and identify. A qualitative research design was chosen for this study as it is characterized by observations in naturally occurring settings, allowing for rich descriptions, focuses on how and why things occur, utilizes inductive reasoning, and looks to understand how people make meaning of their daily lives (Mertler, 2019).

After exploring different qualitative methods, I concluded a phenomenological approach aligned best with my inquiry to make meaning of caregivers' experiences. Learning about phenomenological inquiry and methods, it best provided the opportunity for examining lived experiences as they occurred, life as it was happening. Padgett (2017) emphasized, "no other approach seeks to ensure that readers feel as if they have walked a mile in the shoes of study participants" (p.42). Phenomenological methods included in-depth individual and focus group interviewing which offered a unique opportunity to

capture and make meaning of the experiences as participants understood them before interpreting them with time and influence from reflective views (Van Maren, 2014).

Overarching Research Question: How do family caregivers describe how they came to identify as caregivers?

Research Question 1: What experiences shape how caregivers see themselves and their role in relation to their family member requiring care?

Research Question 2: What external and internal influences contributed to their awareness of themselves as a caregiver?

Research Question 3: How do they describe their caregiving journey and the skills they have developed over time?

My research aimed to expand understanding of the lived experiences of family caregivers and how they experience the realization and acceptance or not of the role as caregiver and identify themselves. Discoveries in this study uncover opportunities to support family caregiver identification within healthcare models and connect caregivers earlier in their role to essential information, education and support. In addition, the valuable individual interview and focus group data and analysis aids healthcare professionals in uncovering opportunities for appropriate interventions and intersections to assist caregivers in identifying. Identification of family caregivers is necessary to connect them to resources, support, and education to reduce of isolation, stress, and caregiver burden.

The balance of this chapter describes the research design methods and elements chosen and provides context to my choices as the researcher. I will describe my researcher's worldview and role in this study. The remainder of this chapter will detail and discuss the elements and protocols of the study, beginning with the description of the chosen location, the identified population, the study participant criteria, process for participant selection, consent, and enrollment in the study. In addition, I will detail the research data collection procedures, including the use of technology to record, transcribe, store, and

ensure data safety. I will describe the data analysis procedures, including methods used to support coding and sorting the data. I will discuss trustworthiness and my researcher choices which ensured that inquiry included phenomenological reflection.

I will discuss ethical concerns and what safeguards were implemented in the study. In addition, I will identify limitations to the study that could not be mitigated and detail steps taken to address limitations. This chapter will conclude with the study's purpose, significance, and alignment with qualitative research design.

Role of the Researcher

Although their role is vital, caregivers often do not self-identify and remain invisible within the traditional healthcare models. The personal experiences caregivers have shared with me have profoundly impacted my worldview and ultimately influenced my interest in research on family caregivers. I acknowledge pivotal moments in my life that presented me with the grace of *being seen* by someone and what that did in terms of my life's trajectory. Early childhood experiences shaped who I am and my self-identity. My family of origin was constricted by violence, divorce, poverty, mental illness, addiction, and caregiving, all of which informed and shaped what I knew about myself and what I understood about the world. Social workers were involved at key points throughout my early life experiences, and I identified them in a common way; they saw me.

The validation of being seen shaped how I saw myself. Each social worker briefly or more substantially acknowledged and validated that they saw me, reframing for me that I was not my circumstances. They helped to support and strengthen a belief that the challenges in my life could fuel my motivation, self-determination, empathy, grit, and resiliency. They each contributed to this growth mindset, whether knowingly or unknowingly. For me, social workers are the seers, the helpers, and the ones who bear witness to the invisible. As a social worker for over 25 years, I have worked hard to not

only see but shed light on those who are too often unseen, disenfranchised, discarded, underrepresented, and marginalized among the majority.

My constructivist worldview and philosophy as a researcher have been shaped and influenced by my early life experiences, my lens as a social worker as well as by those I have had the privilege to see and hold space with their lived experiences (Creswell & Creswell, 2018). As one of my favorite researchers, Brene Brown, stated, "We are hardwired to connect with others, it is what gives purpose and meaning to our lives, and without it there is suffering"(2018, p. 25). The people and families I have worked with have been my greatest teachers and have proven to me countless times that listening to their stories and experiences is an act of healing.

Unexpectedly, ten years ago, my career took a new path when I began to work in healthcare. The change in my career path was significant and required me to move from a micro approach to helping and advocating for people to a more mezzo and macro approach. My mindset moved from how I can best support this person to how I can best change the processes and create opportunities to help more people who are traditionally vulnerable, marginalized, disenfranchised, or invisible within my healthcare organization.

This pivotal shift intertwined a constructivist worldview with a newly informed transformative philosophy. This intertwined worldview fuels my passion for examining and understanding how to engage with historically overlooked populations within the traditional healthcare models. There is a specific need to engage and support family caregivers caring for people with disabilities who historically underutilize support, including the elderly, the poor, persons of color, LGBTQ communities, and veterans. The how or why things happen and what individuals think or feel in situations offer valuable data and can lead to insights into how we make sense or meaning out of our experiences (Mertler, 2019).

My lived experience and work with families have shown me that caregiving exists in more spaces than we choose to acknowledge or admit. I have often witnessed that in times of crisis and need, we show up for the people we care about in incredible ways to help get them back to baseline. It is interesting how life comes full circle. When I was an adolescent, I never thought of myself as a caregiver helping to care for my mother during her bouts of depression and for my grandfather through the stages of Alzheimer's disease, as he lived across the street and was not capable of caring for himself. Even as I write this, I am surprised at the emotions that resurface—ambivalence, vulnerability, grief, and embarrassment. I wonder if disclosing this about myself in my research somehow uncovers the vulnerabilities of people I love. Alternatively, maybe because my identity as a caregiver has always been invisible outside of my close friends and family, it makes me feel uncomfortable, as though I am sharing something meant to be kept secret. I know that uncovering this is essential to my research as I am the instrument, and this information is important to share to strengthen my reflexivity as the researcher.

The value of lived experiences and human perspectives found in qualitative research speaks to my personal and professional beliefs. The human perspective in qualitative research provides a clear benefit as it helps to learn and discover a more profound understanding of why and how something is happening. My hope as I take on this new identity as a researcher is to incorporate my social work abilities of advocacy and activism to transform how family caregivers are seen and supported within healthcare models and systems. My research topic is a social justice matter. The growing number of people requiring caregiving, paired with the enormous burden on families to provide, find or afford care, is felt more significant across the intersections of race, gender, class, religion, education, and abilities. My passion and lived experience both as a caregiver and a social worker provides authenticity to this research and provided me a deeper understanding of the lived experience of caregivers and how they come to accept and acknowledge their caregiver identity.

In this phenomenological study, I immersed myself in family caregivers' experiences as they described how they came to identify, internally and/or externally as caregivers. In small ways, I am native researcher as I work in the hospital and community where I conducted my research. My insider status was magnified by acknowledging that I have been a youth and an adult family caregiver, although my research participants did not know this information. I developed the programs and led the creation of the Caregivers Support Center where the study was conducted. My insider status as a researcher aided me to see and intentionally seek marginalized groups in my research and give them a voice.

My research created an opportunity for family caregivers to describe their experience of realization and acceptance of their caregiver identity both internally and externally. My study is significant as it makes meaning of the process of caregiver identity recognition, acceptance, or resistance and provides insights into the external and internal influences that contributed to or negatively impacted their awareness of themselves as family caregivers. This research sheds light on ways healthcare professionals can best aid and support family caregiver identification, acceptance, and acknowledgment to ensure connection to support and resources, it elevates the voices of family caregivers, and offers opportunities for future research.

Methods

My study gained a deeper understanding of family caregivers' lived experiences of becoming caregivers and how they came to acknowledge their new identity both internally and externally. This study was necessary to understand how caregivers experience their caregiver identity and move to self-identification. My research study drew from the family caregiver identity theoretical frameworks. I have used a qualitative research design to gain a deeper understanding of family caregivers' lived experiences of becoming caregivers and how they come to acknowledge their new identity both internally and externally.

Population, Sample, Setting, and Sampling

The population in this study engaged in making meaning of family caregivers. The term *family caregiver* does not have one universal definition. The varying definitions and descriptions across the literature are often connected to the specifics of the care recipient that requires family caregiving, veterans, elderly, and disease-specific definitions such as ALS or Dementia/Alzheimer's disease. For this study, I utilized an inclusive definition of family caregiver, allowing for varying caregiving scenarios. The sample was drawn from a population of people who have been referred to a caregiver support program and were recently, within the last 36 months, identified as family caregivers using this definition, "an adult family member or other individual who has a significant relationship with, and who provides a broad range of assistance to, an individual with a chronic or other health condition, disability, or functional limitation" (ACL.gov, 2020).

The Caregiver Support Center is the setting for this research study. The Caregiver Support Center is centrally located in the main lobby of a community medical center in the Northeast of the United States. The 150-bed hospital, nearing its 75th year, sits among a mixture of suburban and rural communities. The Caregiver Support Center is a place for family caregivers to be connected to free programs and services to support them in their caregiving role. The Caregiver Support Center opened in 2018 and was the first of its kind in the region, modeled after the Ken Hamilton Caregivers Center, which opened in 2006 in Mount Kisco, New York.

The Caregiver Support Center is a central hub for all caregivers in the surrounding communities, regardless of whether their loved one has received care at the medical center. Family caregivers are referred to the center in multiple ways, such as self-referral, an outside referral from a community partner or primary care physician, or an internal referral by a healthcare professional anytime during the hospitalization of their loved one. Primarily, family caregivers are referred to the center by healthcare professionals treating the identified patient. Once referred, caregivers voluntarily participate in any or all

of the free programs and services offered. Family caregivers can also choose to discontinue participating at any time. A flyer with a brief overview and criteria of the study was circulated at the caregiver support center to recruit participants for this study. The utilizing the Caregiver Support Center as the setting for the study required the Institutional Review Boards of the university and the healthcare system to approve the study design and protocols before beginning the research.

The participants were all recruited through the Caregiver Support Center. The study recruitment flyers were circulated and available in the Caregiver Support Center to increase awareness and seek participants for the study. Fourteen interested persons had initial interest in participating in the study. One was not able to participate as they did not meet the age criteria since their care recipient was younger than 65 year old, and one other prospective participant was not available due to the intensity of their caregiving responsibilities. The remaining made up the diverse sample of 12 participants for this study. The inclusion criteria for recruiting participants included individuals who were: (1) age 18 years or over, (2) English speaking, (3) currently providing family caregiving to a loved one over 65, (4) have been referred to the family caregiver support program within the last 36 months, and (5) willing to participate in the research study.

Data Collection Procedures

Data collection was obtained through in person individual interviews, focus group, and my researcher's field notes and memos. Data were collected from multiple participants until saturation was achieved. Molloy University and the healthcare system where the Caregiver Support Center is located granted IRB approval before enrolling any participants in the study. I began data collection in March of 2023, and the data collection period concluded in July 2023 lasting 4 months. Each participant in the study provided informed consent, agreeing to the interview process. The interviews focused on gaining the participants' lived experience of becoming a caregiver and how they came to internally and externally accept and acknowledge their caregiver identity. The initial interviews range from 50 to 70

minutes in length. When necessary, a follow-up interview was conducted with participants within two weeks from the initial interview to gain greater understanding regarding information in their initial interview.

Each study participant chose where they preferred to be interviewed in person. Majority of participants (9) chose the caregiver support center as the location for their interview, with two others choosing their own homes, and one choosing a local community location near their home. During each interview, I kept detailed fieldnotes, capturing what the participants physically looked like, where they sat in relation to myself for the interview, their emotional expressions during the interview, and my feelings and thoughts during the interview. After each interview I immediately recorded a memo capturing my researcher's reflexivity and non-verbal data from the interview which I wanted to capture. In addition to the individual interviews, participants were asked to voluntarily participate in a focus group. Interviews and the focus group were recorded using Rev Recorder and Call Recorder and then transcribed utilizing the fee-based premium transcription option within the recorder applications.

The focus group was used in this study as a method of collecting data from group interactions and discussions which allowed for different types of data that may not otherwise be uncovered in individual interviews (Merriam & Tisdell, 2016). The focus group created opportunity for participants who did not know each other to share their caregiving experience and insights together. The focus group was powerful as all of the participants started as strangers at the outset, but through sharing their stories, struggles and triumphs in caregiving they created a safe space. This experience allowed them to share things they had never shared, crying at each other's moments of loss and worry, and laughing when one participant used humor to describe what it felt like when she got two hours to herself. Providing participants, the opportunity to further share and discuss their experiences of family caregiving together allowed for socially constructed data on the phenomenon. Peoples (2021) suggested that the use of focus groups with participants who have experienced similar sensitive situations, such as caring for an ill

loved one, can aid participants in feeling more supported and therefore encourages participants willingness to discuss details that they may not have felt comfortable discussing in individual interviews alone.

The focus group participants were all enrolled in the study and had completed their initial interviews prior to the focus group. The focus group was in person and lasted 90 minutes long. The focus group participation was offered to all participants who had completed their individual interviews. Focus group size included 6 participants, all of whom were women. Detailed researcher fieldnotes were taken throughout the focus group, capturing the shared unspoken emotions and body language of each participant, as well as my thoughts and feelings throughout the focus group discussion.

For in-person interviews and focus group, any current COVID-19 safety precautions recommended by the Department of Health were in place and utilized to protect both the participant and the researcher. These precautions included, hand sanitizing, symptom monitoring, and social distancing. Mask were available for participants who chose to wear one.

Data Analysis Procedures

Data analysis within this study focused on exploring the phenomenon of how becoming a caregiver is experienced internally and externally. The goal was to suspend judgment and bias to interpret the meaning of the lived experiences of family caregivers as they identify how they came to accept and acknowledge their caregiver identity (Merriam & Tisdall, 2016). Data were gathered by capturing participants' expressed descriptions, perceptions, and experiences to add richness and make meaning of how caregivers acknowledge their new and unique identity as family caregivers.

Data analysis of audiotaped and transcribed discussions with participants both in the individual interviews and the focus group explored patterns and themes among caregivers' experiences. The transcriptions were initially read through and checked for significant errors or omissions. Once transcriptions were checked for accuracy, I began to use Dedoose software to organize and code the

transcriptions based on common categories and themes identified throughout the interview phase. Initial codes included, first acknowledgment of caregiver identity, internal awareness, external awareness, inner conflict, intervention, crisis, denial, acceptance, stigma, hope, loss/anticipatory grief, role engulfment, and loss of self.

A codebook was created, including memos on each code with clear description for each code. The codebook was utilized throughout the coding process to reduce errors. I began coding the data into chunks first electronically, utilizing the Dedoose software to assist and support coding, sorting, and storing data (Merriam & Tisdall, 2016). In addition to electronically coding the transcriptions, I also hand-coded by reading through printed versions of transcriptions and manually hand-coded by utilizing color-assigned highlighter markers and sticky notes for initial codes. The use of hand coding allowed me to have intimacy with the data, which would otherwise be hard to achieve with software alone. I utilized the hand and software coding to ensure the best opportunity for inductive and deductive coding.

Three distinct rounds of coding were utilized to examine and make sense of the data from the participant's responses. First, I completed a full read-through of each transcription using hand coding and some initial preliminary codes to begin chunking and winnowing the data (Merriam & Tisdall, 2016). Second, I read transcriptions again, utilizing the Dedoose software to code the data. At this read through I also drew from my field notes and memos to further examine and winnow the data to deepen my ability to identify new and emerging codes. The third read-through I looked to further synthesize, hand coding and collapsing sub themes to further move to thematic analysis. Four themes were uncovered: Awareness/Acceptance of the Caregiver Role, You Before Me, Changing Roles and Relationships, Qualifications for Caregivers.

Trustworthiness

To ensure the accuracy and trustworthiness of the findings in this study, I employed multiple internal procedures, including triangulation, member checking, the use of detailed and rich descriptions

of the participants' lived experiences, reflexivity notes, researcher journaling throughout the study, and peer debriefing. Triangulation was achieved in this study by using multiple data sources to add to the validity. The transcribed data from individual interviews, focus group, and researcher field notes were examined to draw themes.

Member checking is a necessary procedure for accuracy, which was accomplished by using the focus group session as well as follow-up interviews with participants which provided an opportunity for them to comment on findings. Field notes and memos were utilized in this study to capture my observations, self-reflections, thoughts, feelings, and insights to ensure honesty and transparency throughout data collection and analysis. To further secure validity in this study, I asked a fellow doctoral student unfamiliar with family caregiving to act as a peer debriefer.

Reliability in terms of the accuracy of the data collected was addressed by paying for premium transcriptions of all recorded interviews and focus groups. This more expensive transcription service is widely used by qualitative researchers and was recommended by my chair as it increases accuracy and reduces mistakes. In addition, I included a multiple read-through process for each transcription. Each transcription was read by myself three times through the coding process, which provided another opportunity to further find errors in the transcriptions, in addition I utilized going back to the recorded interviews to clarify key themes. Finally, reliability was further strengthened by the use of a codebook which was created to capture meaning of codes clearly. The code book was utilized in this study to ensure that clear descriptions and rationale of codes were captured and recorded.

Ethical Concerns

As a social worker and researcher, the respect, dignity, and rights of all the participants in this study are of paramount concern. Having worked with family caregivers over the last two decades, I am well aware of the heightened stress they can experience at any time due to a health crisis of their loved one. It was essential that the invitation extended to participants was clear and empowered each

individual to choose to decline to participate. I understood that the potential participant's caregiving responsibilities may not have been in a stable situation to allow for the time necessary to commit to the study interviews or focus groups.

Once participants agreed to participate, I provided a detailed review of each line of the informed consent in addition to providing them a physical copy to review. The entire informed consent was clearly reviewed with each participant to ensure they were fully informed before deciding to consent. The informed consent included the explanation of the study, the participant's role in the study, information confirming participants' confidentiality, and details clarifying any potential risk to the participants in the study. Informed consent is necessary for all participants to ensure ethical research practices and that all participants are provided the detailed information before choosing to take part in the research. Participants received a copy of the signed informed consent forms.

In addition, participants' privacy for themselves and their loved ones was safeguarded as all person identifiers were removed from data entry and replaced with pseudonyms chosen by each participant to support confidentiality for both the family caregiver and their loved one. I created a composite representation of participants using their chosen pseudonyms to be able to share their exact quotes and descriptors in a meaningful way while protecting their confidentiality. All participants were offered an opportunity to read their transcribed interview data to ensure that any identifying information was extracted before the coding process.

Conclusion

In order to answer the research questions posed in this study, the qualitative, phenomenological method was clearly best suited to gain insights into the lived experiences of family caregivers. Careful attention was paid to my own role as the researcher; reducing bias was paramount. Similarly, attention was paid to the outreach method to recruit potential participants and determine eligibility criteria for being in the study, designing appropriate interview questions, and keeping accurate field notes. After

completion of four months of data collection, the data analysis process utilized the audiotaped and transcribed discussions to determine patterns and themes among the caregivers' lived experiences. The initial analysis yielded 13 themes later collapsed into four major themes. To ensure the accuracy and trustworthiness of the findings in this study, I employed multiple internal procedures, and was guided by ethical standards throughout the entire process.

CHAPTER 4: RESULTS

Introduction

In this study, I sought to make meaning of the lived experience of family caregivers by examining in detail how they come to the realization and acceptance of their caregiver role and their identification within the healthcare continuum. The lived experiences of 12 adults who are actively caregiving for a loved one over 65 were examined through in-depth semi-structured interviews. Individual vignettes represent each participant, including their descriptive demographic characteristics and unique narratives.

The qualitative phenomenological approach was best aligned with this inquiry to make meaning of caregivers' current experiences as it provided the researcher with opportunity to examine the life of the participants as it was happening. My study drew from the theoretical framework of family caregiver identity theory (Montgomery & Kosloski, 2007). Montgomery and Kosloski (2007) discovered that a process of transformation of identity occurs over time as the caregiver experiences a change in the relationship with the care recipient due to their declining health or functional status which increase and intensify their care needs. Participants were recruited through a caregiver support center where I am employed within a community medical center. The Caregiver Support Center provides free programs and services to support family caregivers at any point in their caregiving journey. The center serves as a hub for family caregivers in the surrounding communities, regardless if their loved one has received care at the medical center.

In this chapter I present the participants demographic data including break down by age, gender, race/ethnicity, years of caregiving and relationship to their care recipient. The individual vignettes then represent each participant, including their descriptive demographic characteristics and unique narratives which added depth to understanding who they are and their rich lived experiences. Next, I report the findings and describe the central themes uncovered through thematic analysis. Throughout the chapter, I

present direct quotes from the participants to give meaning to the lived experience of family caregivers in their own words. In closing, I summarize the chapter in relation to the findings.

Participants

All 12 participants met the criteria for the study, which included the following: 1) over 18 years old and, 2) at the time of the study, were actively caregiving for a loved one over 65 years old. All caregiver participants and their care recipients were given pseudonyms to protect confidentiality. The participants chose their own first and last name pseudonyms to represent them in this research study. Participant-selected pseudonyms allowed each participant to maintain confidentiality, while still maintaining the ability to control the name that represented their story. Each participant was very thoughtful about the name they chose as their pseudonym.

As shown in Tables 1 and 2, the sample is predominantly female, with two male and 10 female participants. Half of the participants were caring for a male loved one and the other half were caring for a female. The participant's relationships with their care recipients included five daughters (42%) caring for their mothers, four wives (33%) caring for their husbands, and the remaining three participants (25%) of the sample included one son caring for both parents, one brother caring for his brother, and one granddaughter caring for her grandmother.

The number of years of family caregiving for their care recipient ranged from 2 to 27 years with five participants (42%) caregiving for their loved one for over 11 years, and the remaining seven participants (58%) caregiving between 2 to 6 years. The mean score for years of caregiving in this sample was 11 years of caregiving for the care recipient. Most of the participants (N=9) lived with their loved one needing care with the remaining three participants living nearby. Sixty-seven percent, or eight of the participants were White, 25% or three were Black, and one participant was Hispanic. The age of participants ranged from 26 to 85 years old, with half of participants over 65 years old.

Of the participants, only 33% worked full-time (N=4). In contrast, two participants explained they had to leave the workforce because of caregiving responsibilities, and the remaining six either stopped working or retired before needing to care for their loved ones. One participant who works full-time is also a part-time college student. Although socio-economic background questions were not included in the demographic questions posed to participants, 25% or three of the participants shared that their care recipient was enrolled in community Medicaid. The remaining eight participants were not asked nor disclosed any socio-economic background information. Almost all of the participants (ten out of twelve) shared that there was a financial burden to caregiving which they all worried about, e.g., financial insecurity, needing to work while caregiving, lost wages due to caregiving responsibilities, high cost to privately pay for either aides or nursing assistants to help in the home, or ability to pay for skilled nursing level of care if and when needed. Lastly, half of the participants shared that this was not their first experience of needing to provide caregiving for a family member and had other caregiving experiences prior to caring for the current care recipient.

Table 1
Caregiver Demographic Summary

Demographic	n-value
Relationship	
Adult Child/Parent	6
Wife-Husband	4
Siblings	1
Granddaughter/Grandparent	1
Gender	
Female	10
Male	2
Race/Ethnicity	
White	8
Black	3
Hispanic	1
Years of Caregiving	
2-6 years	7
7-11 years	1
Over 12 years	4

Table 2
Participant Demographic Table

Participant	Age	Care Recipient Relationship to Participant	Resides with Care Recipient	Years Caregiving	Race/ Ethnicity	Work Status
Berry Smith (Daughter)	61	Mother	Yes	18	White	Retired due to caregiving
Lola Vaugh (Daughter)	66	Mother	Yes	5	White	Retired
Stella White (Daughter)	49	Mother	Yes	25	White	Working Fulltime
Katherine Sharp (Daughter)	56	Mother	Yes	5	Hispanic	Retired
Sarah Washington (Daughter)	49	Mother	Yes	27	Black	Working Fulltime
Bob Swan (Son)	54	Both Parents	No/lives in same town	6	Black	Working Fulltime
KC McKenna (Wife)	73	Husband	Yes	13	White	Retired
Rose Hanes (Wife)	65	Husband	Yes	6	White	Retired due to caregiving
Cookie Rossi (Wife)	85	Husband	Yes	2	White	Retired
Heather Davies (Wife)	70	Husband	No /lives in nursing home	11	White	Retired/ runs own business
Ted Gunner (Brother)	73	Brother	No/ lives next door	4	White	Retired/ owns small business
Ramona Files (Granddaughter)	26	Grandmother	Yes	5	Black	Working Fulltime

There are 12 vignettes below which provide context to each of the participants and their caregiver situation. In the following vignettes I provide the caregiver's age, education experience,

relationship to their care recipient, and some historical background of how they became a caregiver for their loved one. A brief family and social context of participants is provided as well as the interview location. Please see Appendix G for full vignettes of the participants.

Berry Smith

Berry is a 61-year-old White female with a bachelor's degree in education. She is the primary and only family caregiver for her mother, Susan, who is in her late eighties. Berry has lived with her mother since 2005 when her father died. Her father had been her mother's primary family caregiver before his passing. Berry has been caregiving with increasing intensity over the past 18 years for her mother. She is solely responsible for her mother's caregiving needs. Berry believes she was always a caregiver beginning as a child between 6-8 years old when she began doing some caregiving tasks for her grandmother, who lived with her. Berry has never been married and does not have any children. At the time of this interview, Susan is in the intensive care unit after having a critical event overnight. When asked if she would prefer to cancel or postpone the interview, Berry stated, "This will be good for me, a helpful distraction." The interview took place in the family area of the intensive care unit room.

Lola Vaughn

Lola is a 66-years old White female and has a bachelor's degree in business. She is outgoing, with a warm and humorous demeanor. Lola is married with two adult children living independently outside the home. She is family caregiving for her mother, Estelle, who is in her early 90s and widowed for over 20 years. Lola and her sister, Michelle, share caregiving responsibilities. They have transitioned their mother between their homes over the last two years and three months. In recent months, Estelle has been living full-time with Lola as she has become increasingly frail, and her medical conditions have intensified, thus requiring a greater level of caregiving.

At the time of the interview, Lola's mother had been hospitalized for more than a week and was preparing to discharge to Lola's home. Lola has been at her mother's bedside daily from early morning until evening. The interview took place at the hospital in the Caregiver Support Center.

Stella White

Stella is a 49-year-old White female and is a high school graduate. Stella maintains a certification as a nurse's aide and works full time. Stella is a single mother of two teenage sons, often needing to work two to three jobs to provide for her family's needs financially. Stella shared she has been a family caregiver for her mother, Denise, for 25 years. The need to provide family caregiving began intermittently due to her mother's fluctuating mental health condition, which limited her mother's ability to care for herself. Stella shares that she always felt a reversal in her relationship with her mother as she often took on a parental role.

Stella's parents divorced when she and her two sisters were very young. She explained that other than financial support, their interactions with their father were minimal while they were growing up. Stella explained that her siblings often helped to care for their mother when she could travel and reside with them for short periods in different states; however, in recent years, they have withdrawn their interactions and become alienated from their mother, leaving Stella solely responsible for their mother's emotional, financial and physical needs. In recent years, Denise, who is 73, has also begun having medical issues that have increased her need for more consistent and intensive caregiving. Stella is currently the sole family caregiver for her mother, who resides with her. The interview took place at the hospital in the Caregiver Support Center.

Katherine Sharp

Katherine is a 56-year-old White woman. She is a high school graduate, divorced, with four adult children. Katherine is family caregiving for her mother, who is 78-years old, and her younger brother Anthony who is 51 years old and has Autism and a seizure disorder. Katherine immigrated to

the U.S. with her parents over 50 years ago. Neither of her parents ever learned English fluently; her mother's primary language is Spanish. Katherine began caregiving for her mother five years ago after she had her first medical emergency requiring surgery. Three years ago, Katherine moved her mother in with her during the COVID-19 pandemic, as the distance between their homes was too far to be able to respond quickly to an emergency. Katherine credits her children for helping her accept she had taken on the role of her mother's caregiver and encouraging her to bring her mother to live with her to reduce the stress of going back and forth to care for her. Katherine is the primary caregiver for her mother, with help from her adult children when they can.

Katherine reflected that being a family caregiver is part of her identity. She acknowledged that she became a family caregiver first for her brother, with Autism, long before she needed to care for her mother. The interview took place in the hospital's Caregiver Support Center, as Katherine preferred.

Sarah Washington

Sarah is a 49-year-old Black female with a master's degree in social work and is pursuing her Doctorate. She works full-time as an executive for a consulting firm. She is outgoing, confident, and vibrant. Sarah is not married but has been in a committed same-sex loving relationship for several years and describes her partner as someone who is always there for her. Sarah has two younger adult twin siblings with whom she has a close relationship. Sarah is the primary family caregiver for her mother, who has an advanced Multiple Sclerosis and is wheelchair-bound. Sarah's mother, Kim, is in her early 70s and has been a widow for many years, as Sarah's father died when she was only 14. She has been her mother's family caregiver for the last 27 years. Sarah has lived full-time with her mother, Kim, since she finished college because she required a greater level of caregiving. Sarah's younger siblings, a brother and sister, recently have been assisting her with the increasing caregiving needs and responsibilities for their mother. The interview took place at a local coffee shop close to Sarah's home in case she needed to return quickly.

Bob Swan

Bob is a 54-year-old Black male with an associate's degree. He is single, never married, and describes his nieces and nephews as his children as he never had children. Bob owns his own home. He works full-time for a non-profit that provides programs and residential settings for adults with developmental disabilities. He is friendly, kind, and helpful. Bob is very connected to his community and his church. Bob has been family caregiving for his parents over the last six years. His mother, Florence, is 80, and his father, Lee, is 86. Lee has been residing in a skilled nursing facility for the last two years after a significant stroke which left him unable to walk or care for himself.

Florence remains in the home she and her husband of 60 years built, where they raised their four children. Florence has diabetes and has been experiencing memory impairment which became more noticeable to her children once her husband moved in to the nursing facility. Bob lives separately from his mother, but he stays over her home 3 to 4 nights a week to provide caregiving and ensure she is safe. His sister lives locally, and his nephew help with caregiving responsibilities. The interview took place at the hospital in the Caregiver Support Center.

KC McKenna

KC is a 73- years old White female. She has been married to her husband, Robert, for over 45 years. They have no children. She has retired since the age of 60, having worked in the same industry since she was 18. KC shares that she experienced family caregiving three times in her life, first as an adolescent when her grandmother with dementia came to live with them, then as a young woman in her 20s when her mother was diagnosed and died from cancer, and now for her husband. KC has been family caregiving for her husband, Robert, for 13 years. Robert's motorcycle accident left him with a severe spinal cord injury. KC states that his accident was life-changing, leaving him functionally paralyzed from his torso down. Following the accident, Robert could push himself up to stand with a walker and move around in their home a little bit, but as time passed, he needed a wheelchair, and now

he cannot walk or stand at all. KC is solely responsible for her husband's caregiving needs. The interview took place at the hospital in the Caregiver Support Center.

Rose Hanes

Rose is a 65-year-old White female with a master's degree in social work. She has been married to Bill for the last 17 years; this is their second marriage. Each has adult children from their first marriage. Rose is a proud grandmother and enjoys spending anytime she can with family. Rose has been the primary family caregiver for her husband, who is 72-years old, for the last six years. She is petite, with a warm smile and friendly demeanor. Rose retired a few years ago due to her inability to balance her husband's growing caregiving needs and work. Her career as a social worker helping others was something that brought her great pride and satisfaction. Rose shares that as her husband first became ill with cancer and then COPD, he has progressively "pulled in and retreated within himself." She explained that as his health declined and he progressed with more mounting health issues, he needed more significant caregiving. The interview took place in the Caregiver Support Center.

Cookie Rossi

Cookie is an 85-year-old White female, and a high school graduate. She retired in her sixties after working as an administrative assistant for a large cosmetic firm. Cookie demonstrates a genuine warmth, caring nature, and a quick sense of humor. She is petite in height and build. She presents as younger than her stated age. She and her husband, Anthony, have been married for 65 years; they have three adult sons, 10 grandchildren, and 14 great-grandchildren. Anthony is 89 years old. They live in a one-story home within a senior community which they moved to over two decades ago after selling their large home. A little over two years ago, Anthony was diagnosed with dementia. Before this diagnosis, Cookie reported Anthony had been very healthy and active. Cookie began family caregiving for her husband, which has increased in intensity and duration over the last two years as his memory and ability to care for himself have significantly declined.

The interview took place in their home so that Cookie can be available for her husband. She shared she has been unable to leave her husband alone or unsupervised for even a small amount of time in the last few months because of his increased confusion, anxiety, and new heightened risk for falls or wandering. Their home is clean, bright and well furnished with many framed family photographs hung on the walls.

Heather Davis

Heather is a 70-year-old White female with a master's degree in business administration. She has been married to her husband, Stephen, for 17 years. He is 77 years old. This is Heather's first marriage. She shares she put off marriage earlier in her life as she was focused on her career and had great enjoyment and success from her work. With her marriage, Heather gained a family which included her four adult stepchildren, whom she lovingly refers to as her kids. Their family has grown, and she loves being a grandma to her 11 grandchildren.

Heather has been her husband's family caregiver for 11 years. Heather states she retired from her corporate career 15 years ago, but continues to work, running a small business she and her husband had built together. At the time of this interview, Heather's husband resides in a skilled nursing facility close to their home. The interview took place in their home, as preferred by Heather. Their home is small, neat, and nicely decorated with several pieces of antique furniture.

Ted Gunner

Ted Gunner is a 73-year-old White male with a master's degree in engineering. He has been married for 47 years with two adult daughters and four grandchildren. He described himself as a family man and his relationships with his wife and daughters as very close. He had a successful career working for a large company for over 25 years in leadership, allowing him to retire when he was 60. He currently runs his own small business, which he began after he retired. Ted is confident, outgoing, and engaging.

Ted is the primary family caregiver for his brother Jim who is 67. Jim has multiple advancing illnesses and has progressively needed greater caregiving over the last decade since his wife died.

Ted assumed the role of primary caregiver for his brother after their mother died four years ago at 89 years old. She had been her son Jim's family caregiver despite her lung cancer diagnosis until the final months of her life. Ted always knew he would become his brother's caregiver as he had been the only one in their family to care for first their father and then their mother at the end of their lives in their home. Ted shares that as Jim's advancing illnesses and his situation of needing care progressed, it became impossible for him to interact without caregiving for him. He believes that if he did not step up to care for him, Jim would need to live in a nursing home, which he knows his brother and mother would never have wanted. The interview took place in the hospital's Caregiver Support Center, as Ted preferred.

Ramona Files

Ramona is a 26-year-old Black female, a college student completing an associate's degree. In addition to attending college, she works full-time in a hospital as a nursing assistant. Ramona plans to pursue a bachelor's degree in nursing. She is single and lives with her grandmother. Ramona is friendly, outgoing, and articulate. She is engaging and has a warm smile. She is family caregiving for her maternal grandmother, Anna, who is in her 70's and widowed. Ramona and her mother, Ginny, share caregiving responsibilities.

Ramona began caregiving for her grandmother five years ago after Anna had a medical emergency requiring heart surgery, which left her needing more care and support for her advancing health conditions. She explained that her relationship with her grandmother has always been close because her grandparents helped to raise her as her mother was a young mom. The interview took place at the hospital in the Caregiver Support Center.

Findings

This section begins with the research questions that were used to guide the study and which the findings seek to answer.

Overarching Research Question: How do caregivers describe their experience of how they came to identify as caregivers?

Research Question 1: What experiences shape how caregivers see themselves and their role in relation to their family member requiring care?

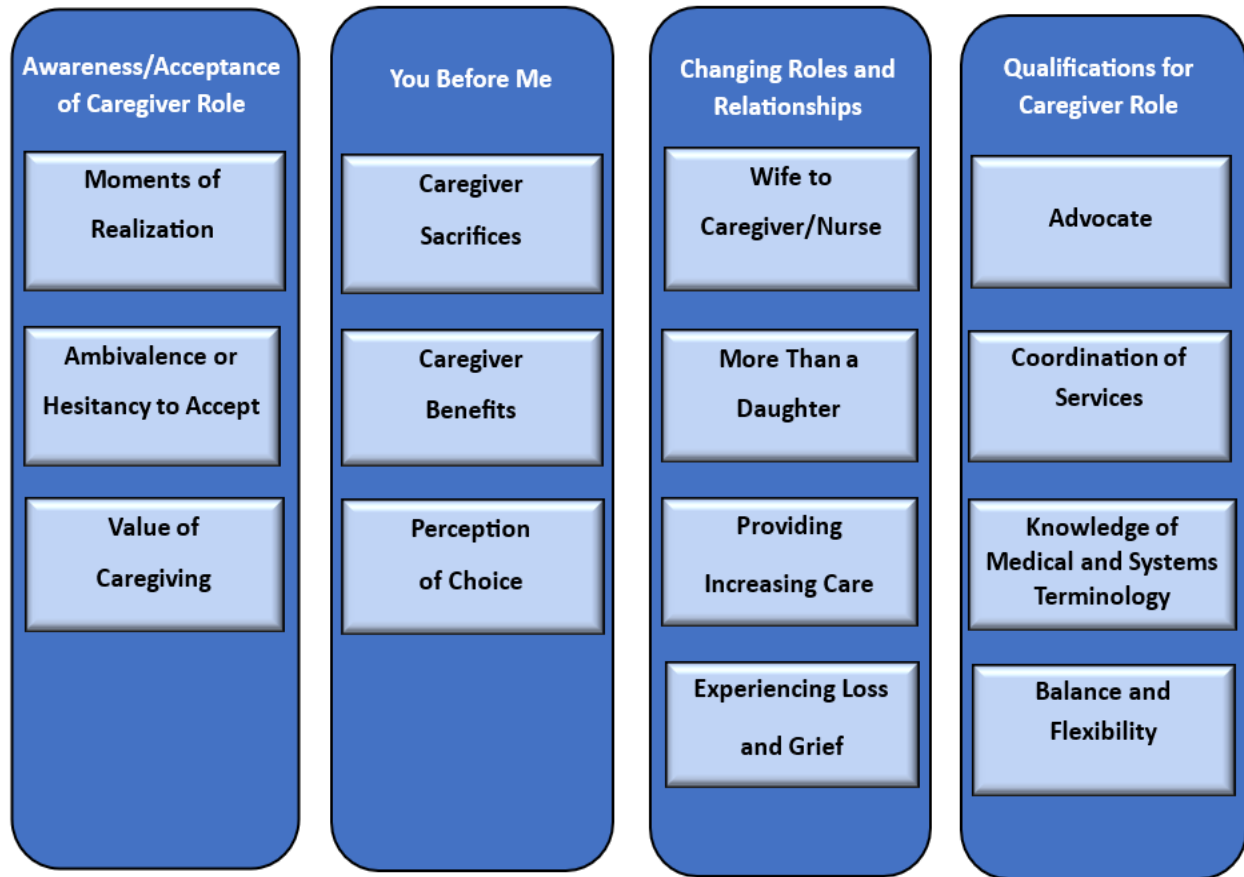
Research Question 2: What external and internal influences contributed to their awareness of themselves as a caregiver?

Research Question 3: How do they describe their caregiving journey and the skills they have developed over time?

The major findings have been organized into four central themes. As depicted in Figure 1, analysis of the data also yielded three or four subthemes for each of the four themes. Although presented in Figure 1 as four distinct themes, each with distinct subthemes, these themes in the data were not fully distinct as some elements were overlapping one with the other. Yet each of the themes and subthemes offered unique emphasis worthy of separate attention. However, for the purpose of data presentation they have been organized as follows.

Figure 1

Developed Themes Layout



Theme 1: Awareness/ Acceptance of the Caregiver Role

The participants were asked to describe what it means to be a family caregiver and describe how realization of their caregiver role began. Interview questions sought to understand how self-realization of their caregiving role/identity occurred. A series of prompts during the interview process allowed participants to deepen their own self-understanding of their acceptance or hesitation to accept the caregiver role and identity.

All participants had an awareness that they were performing caregiving tasks and responsibilities for their loved one. Yet, awareness of their caregiving activities for the care recipient did not guarantee

they accepted and identified themselves as a family caregiver. Eight out of the 12 participants identified as a family caregiver, however four were more hesitant/ambivalent to accept the term family caregiver due mostly to family norms or cultural reasons. The level of acceptance to the change in their loved one's needs played a key factor in their ability or willingness to self-identify as a family caregiver. The value of caring for another person was a perspective that was shared by eight of the participants who shared earlier life experiences where they witnessed or participated in which influenced and informed their awareness and accept of their own caregiver role. Three themes emerged from this category: 1) Moments of Realization, 2) Ambivalence/Hesitancy to Accept, and 3) Value of Caregiving.

Moments of Realization. Most participants shared varying degrees of acknowledgement that their loved one had changed due to illness or disability and required caregiving tasks. Of the eight participants who identified as a caregiver, their acceptance of their family caregiver identity ranged from immediate to over several years depending on the severity and progression of the illness, as well as when others would acknowledge their role. For example, Cookie Rossi experienced a realization over time when her husband's forgetfulness turned into a diagnosis of dementia. "At first, I noticed him losing his memory a little and I thought of it as we're just getting older; that happens to old people. But then as it went on, I realized it was more than that." For Cookie, this illness progression was also an acknowledgement that her husband would not be cured or recover what abilities he had lost. Her moment of realization was when she knew she needed to be his caregiver. These *moments of realization* played an important role in how the participants described their acceptance of their caregiver role/identity.

Alternatively, KC McKenna's moment of realization happened suddenly when her husband had an accident. It was a life changing event that did not allow for any hesitancy to accept that she would be his caregiver. "What made me accept that I was his caregiver...Well, oh gosh? I mean there was no decision. I realized it. I realized it." As KC shared, in the beginning months after her husband's accident

she tried to hold on to hope that he could recover. But that never happened and KC had no choice but to accept that their life and their relationship were changed forever.

Similar to KC, Ramona File's moment of realization of her caregiver role occurred when her grandmother had a sudden cardiac event and she could no longer care for herself independently. Ramona had immediate awareness during this hospitalization that this change in her grandmother's health would require family caregiving for the remainder of her life:

When my grandma had to come to the hospital and get a cardiac cath. She came and it was very bad. They saw changes in her EKG. They rushed her here [hospital] and she went for a cardiac catheterization that day. That was the day I was like, okay, this is getting a little more serious than I expected... So, when I got the call from her cardiologist, that's when everything changed. I knew I needed to step up because my other family have no medical knowledge, other than me and my mom. So, we were the only people who actually understood what was going on. So, that was honestly when everything changed for me. When she had surgery and she couldn't care for herself anymore that was the biggest thing.

Katherine Sharp explained that her acceptance came when she realized she needed to bring her mother to live with her and could no longer manage her caregiving needs from a distance, particularly during the pandemic when it was difficult to travel:

A little bit into the pandemic, I realized that she wasn't, or she didn't really understand that she was at a higher risk and that I had to guide her and provide for her because she no longer could do it on her own.... I needed to bring her to live with me so I could take care of her.

Katherine had been providing caregiving intermittently for her mother from a distance up until

the COVID -19 pandemic. The recognition that she needed to move her mother into her household was the moment of realization of her caregiver identity. Similarly, three other participants also expressed the pandemic was a challenging time for them as family caregivers as they experienced greater difficulty such as limited access to medical providers and supplies, greater isolation to reduce risk to their health comprised loved ones, and an inability to be present as their caregiver when they were hospitalized.

For some participants, like Heather Davis the realization happened when other people confirmed her caregiver identity. She recalled her moment of realization was not when her husband was first diagnosed with Parkinson's Disease 13 years ago, but instead it came two years later unexpectedly while she and her husband were on a cruise. As Heather explained,

He [my husband] had a long bucket list, he wanted to travel, take cruises, so we were trying to get everything in, but I didn't realize that at the time I was his caregiver. When we were away this woman came up to me on the river boat cruises and she goes 'I have to tell you, you are blessed. You're going to go to heaven. The way you take care of your husband is absolutely wonderful' and at the time I didn't even realize all that I was needing to do for him at the time, but that's when the awareness started, 11 years ago.

Heather did not realize she was her husband's caregiver until it was brought to her awareness by someone witnessing her caregiving activities.

Similarly, Sarah Washington's *moment of realization* of her caregiving role was brought on by a hospital social worker labeling her as her mother's caregiver. She recalled that moment by saying,

I know exactly when it had happened. We were about three years in, I came back in '96, and this was in late '99. My mother experienced a pretty significant exacerbation. She has progressive MS, so this was one of those points when she had a flare up and it progressed her symptoms. And I remember it hit me, because I think it was the social worker, who was like, 'Oh, okay. You're the caregiver'. And I distinctly remember I had never

referred to myself in that way, this is my mother and this is what she needed. But that's when it really hit me when that social worker was like, 'Oh, okay. You're the caregiver.' Because up until then, I had only associated that word with professionals, not necessarily with myself... I'm her daughter, why do I need another label?

In summation, these *moments of realization*, are significant as they mark the beginning to their acceptance of their caregiver role and identity. These moments of clarity occur in various forms, i.e.; an emergent medical event, a new diagnosis, recognition from an observer or healthcare professional or the pandemic lockdown. The *moments of realization* played a significant role in how the participants began to accept the change in their role and identity.

Ambivalence/Hesitancy to Request. Four of the participants were ambivalent or hesitant to accept their caregiver identity. The *Ambivalence/Hesitancy to Accept* subtheme must be understood in the context of the relationship between caregiver and care recipient, the identity of the care recipient, and past experiences with caregiving in the family. In order for one to take on the new role of caregiver, there must be a letting go of what was and a new acceptance of what is regarding the new relationship.

For example, Lola Vaughn expressed feeling uncomfortable with accepting she is her mother's family caregiver. She described that the title of family caregiver feels "formal" and that she perceived caring for her mother as more natural: "It's so organic. It just is like, you need me, I'm there." Lola does acknowledge that what she currently needs to do for her mother in terms of her caregiving responsibilities supersedes what the term *daughter* encompasses. However, Lola explains her hesitancy towards accepting the term family caregiver is that it reflects negatively on her mother, as it implies a description of her mother as being needy or in need of care, which is counter to the strong independent image of her mother which Lola wants to maintain and protect; "She's not needy. She wants to do it herself. But at 94, it's really hard to say I can't do this anymore." Lola's hesitancy to accept and identify

as a family caregiver is more understood as an act of protecting her mother's identity as independent and how her mother is seen or perceived by others.

Bob Swan had a similar ambivalence to self-identify as a family caregiver as he also felt a distinct term does not feel normal in his family. He recalled experiencing his parents, grandparents, and aunts and uncles caring for family members as they aged and became ill. His ambivalence has more to do with what is expected or the norm in his family, instead of protecting the identity of the care recipient like Lola's case. Bob shared that in his family for generations there was not a term family caregiver:

I just don't look at it as that [caregiver]. No, I just see it as being family. I was just like, 'Do what you're supposed to do, we're family.' I'm a family guy, and my family is first. And my faith, which they [parents] brought me to know. That's the center. It's just plug in, and do what you've seen your family always been doing. That's it. Yeah, just do what you've been raised to do. Do what your parents did, and their parents.....just do it, and it's going to work out.

For Sarah Washington the enormity of taking on the role as family caregiver in her 20's added to her initial ambivalence and hesitation as she did not have peers her age who she knew that we're caring for their loved ones as she was, nor was the term family caregiver familiar to her. She explained her early ambivalence to accept her caregiver identity as an act of pushing back or resisting the enormous responsibility she had been bestowed:

First of all, it wasn't a term that we used. And up until then, like I said, I was just like, Okay, this is just what I do. I'm the first born. But it was always that expectation that this is just what I do. And I never really complained about it but it wasn't until she was hospitalized that it really hit me. And I don't know if resentful is the right word, maybe it is and I'm just resisting it. But for a little while after that, I did have some resistance to identifying as the caregiver....I'm just taking care of my mother. That's what we do'. I

wasn't in that phase for too long but I do remember just going through that, like, 'This isn't my identity'. Even though it certainly was.

KC McKenna shared her awareness to her caregiver role for her husband was immediate after his accident, but her acceptance to the new identity/role took time, acknowledgement from a healthcare professional and validation from other family caregivers to occur:

Well, I guess after meeting with Deidre [her husband's Nurse Practitioner] all those times, I became more aware that I was [caregiving]. I mean, I didn't think it would be where it is now. I had hope that things would turn around somewhat, but they never did. But like I said, from coming here [CSC] because they had a caregiver's group. And when I heard all the stories, it's saying, 'I'm not alone. I'm not alone at all.'

In summation, the *Ambivalence/Hesitancy to Accept* subtheme is understood in the context of the caregiver not ready to accept nor wanting to accept a changed and new relationship with their loved one. There is a resistance of letting go of their original role. The relationship between caregiver and care recipient, the identity before the illness of the care recipient, and past experiences with caregiving in the family all influenced perceptions of what the caregiver role/identity means to them, their care recipient, and their family.

Value of Caregiving. In this subtheme the feeling of caring for another person is inherent in understanding the role of the caregiver. Participants described their earlier experiences of caregiving as informing their understanding of the caregiving role. Family caregiving is perceived as not only as needed and helpful but more so it is understood by the participants as a moral good. Seven of the participants witnessed caregiving in their families before, such as their parents caring for their ill or dying grandparents. For other participants, they had earlier caregiving relationships for other loved ones. It was not only a connection to an experience or caregiving history but it was additionally tied to a sense of duty or marital vow that shaped how they understood or thought about the value of caregiving.

More than half (8 out of 12) of the participants talked about valuing the concept of family caregiving as something that was seen as doing the right thing. Participants attributed positive personality traits and personal values such as compassion, love and caring to family caregiving. For some it aligned to a sense of purpose in their life. Sarah Washington explained that being the family caregiver for her mother connects with her personal values of being there for the people she loves when they need her. She clarified that this commitment to care for her mother is taken with a sense of honor, rather than an obligation or with an expectation of something in return:

I am very committed to family, chosen and biological family. And for me, it also makes a distinction between those who do it professionally, who are heroes themselves, but it makes a distinction that I'm not doing this for compensation, that I'm doing it because in my case, this is my mother and I'm caring for her in ways that she needs.

The majority (5 out of 6) of adult children participants' caregiving for a parent felt it was their core value to care for others which they saw modeled by their parents (care recipient) as they were growing up. Ramona Files described an expectation that caring for ill or aging family members was a family value and norm that she feels reflects the closeness of her family:

We've always been very close. I mean, my family is very tight-knit, so if someone needs something we always lean on each other. So, it's always been a one call away type of thing.

Although Ramona could not predict she would need to take on the role as family caregiver for her grandmother, she was ready and committed to filling that need for her.

She needs me. So, I need to be there for her. She's cared for me more than I can even ask for. So, I feel like giving back is the best thing I can do. I may not be able to do everything she's asking of me, but I do my best to make her happy.

Ramona also expressed feeling proud to be able to take on that role of caregiver for her grandmother, and admitted that although she did not initially see herself as a family caregiver, she believes the role has been rewarding to her personally.

I gained so much love. There's nothing like the love that your family can give to you. And that's something I really take pride in. My mom has had me at a young, young age, so my family always, my grandparents have been the ones to always step in for me. So, I see them also as parent figures to me. So, it's like losing a parent or it's like your parent is really sick. And it has just given me so much joy. Honestly, it's amazing. I never saw myself as being a family caregiver personally. I never thought it'd be me, but at the same time it had to be someone.

The presence of former family caregiving experiences with a different care recipient contributed positively to developing a positive value to caregiving. Many participants (7 out of 12) had prior family caregiving experiences which they felt contributed to their current awareness and acceptance of a caregiver role for the current care recipient. Sarah Washington described that while she was growing up, she watched as her mother was instilling a value of caregiving in her in all she did for others:

My mother was a caregiver in all the many ways there is... Even when her mother was alive, my mother has always had this matriarchal energy. My mother was the one who took care of others... My mom was the one who literally would pay other people's bills. She was the one who made food for people... And I come from a family that's like that, I come from a family of folks who worked primarily in healthcare and human services, with a few exceptions, and people who were very giving. You just did stuff, you helped people and you supported your community. That especially [influenced participant's value of caregiving] in terms of needing to help my mom... I'm going to step up. It

certainly has not been all sunshine and glitter but that's what always grounds me. It is just what she did.

Sarah expressed feeling proud to be there for her mother as her caregiver as she feels her mother always set an example for her that caring for others in need was a value in their family that was important and something to aspire to. Participants recounted clear examples of seeing the value in action during their childhood within their family of origin.

Ted Gunner had a similar experience and shared that he watched his mother care for others his whole life. He described her willingness and dedication to show up for those she cared about when they needed help due to illness, disability or aging. Ted shared that his mother set a high expectation on him to do the same for those he cared about:

Well, my mom.... had the gene where she always wanted to take care of everybody. And she took care of not only my grandmother, but two aunts, one of which was institutionalized for a long, long time... And she would step in and be the caregiver... So she always had that gene. And even around here, she would visit elderly women that were alone that she had befriended and so on and so forth... And then when my brother needed the support, she was right there.

Watching his mother caregiving for others instilled in him that it was the “right thing to do.” He acknowledged that doing the right thing is not always the thing you want to do, but it is the thing he feels he has to do. Participants who had seen caregiving within their families previously attributed value to caregiving.

Theme 2: You Before Me

Participants experienced varying levels of putting the needs of their care recipient in front of their own. Regardless of whether they perceive this prioritizing of their loved one's needs and wants over their own as positive or negative, all participants acknowledged having to give up or sacrifice some

or all of their own needs and wants to be able to take on the needs and responsibilities of their loved one. Caregiving is consuming. Family caregivers have to constantly make decisions about where to place their own needs on a growing list of responsibilities and needs for their ill or disabled loved ones. A common theme across participants was a perception that the needs of their loved one was of greater importance than their own needs. Family caregivers put their needs last as they perceive the care recipient's needs as paramount over theirs, creating a chain of You Before Me priorities. Three subthemes emerged within this category: 1) Caregiver Sacrifices, 2) Caregiver Benefits, and 3) Perception of Choice.

Caregiver Sacrifices. Family caregivers are making hard choices each day about what they can and cannot do in order to meet the needs and responsibilities of their ill or disabled loved ones. All voiced what they had to give up, put off or sacrifice for themselves due to their family caregiver role and responsibilities for their loved ones. Some talked about sacrificing relationships with others (friends and family) that was important in their life before their caregiving role. For others it was the financial sacrifices that were required either due to loss of earnings, loss of financial savings, due to costs of care, such as medications or supplies for care recipient. For several participants, the sacrifice was one of time for their own wellbeing or self-care.

Almost half of the participants expressed frustration and resentment for what they have had to sacrifice in caring for their loved one. Katherine Sharp reflected on what she has had to give up to take on the responsibility of being the family caregiver for her mother and her brother; her freedom, the ability to be spontaneous, time for relationships, traveling and most importantly time for herself; "Not having enough time for me... not being able to enjoy the things that a normal 50 something year old, empty nester would do." She explained that even when she is not actually there with her mother her caregiving role does not stop as she is in a constant state of readiness waiting for a call that her mother has another health emergency:

I'm so emotional all the time and worried. I carry my feelings. So, in Spanish we say 'a flor de piel', meaning it's like right on my skin, you can smell it, you can feel it, you can sense it. I'm always on high alert because I don't know when I'm going to get a phone call saying [you are needed] ... you are just on guard for something. It's something that a lot of people don't understand unless they've been in similar shoes.

Ramona Files also recognized she has had to sacrifice things and make difficult choices in order to care for her grandmother. She concedes she may not have made the same decisions if she were not family caregiving. These decisions include where she works, where she attends college, her schedule, her living arrangement, her friendships. She described what she has to give up in taking on the role of family caregiver:

I don't want to say give up life, but I'd say I've had to give up just being my own person, living my own life, going out to things or just vacations or anything like that. I feel like you adjust. You may lose out on some, but I gain in so many other ways by just caring for somebody. Because I think sometimes, we give so much of ourselves, we forget that we have other things that we might need to get done or that we need to be focusing on.

Working full-time, being a full-time student, and being a caregiver, it took a toll.

Ramona shared her insights in to some of the challenges and barriers she has faced as a family caregiver. She disclosed how financially challenging it is to balance family caregiving and working, while also trying to financially take care of your loved ones needs;

Financially to support someone else, trying to support myself, trying to grow in life. It is difficult. It sets you back a little, especially when you don't come from a family of wealth or a lot of money and you all just work very hard.

All participants spoke about the sacrifices they have had to make in order to meet the caregiving responsibilities of their loved ones. In short, these caregiver sacrifices were part of the experience for all

participants and ranged from minimal to profoundly impacting them either-or all-in terms of their financial, professional, relational, social, physical, emotional or existential wellbeing.

Caregiver Benefits. While there were many sacrifices, participants also spoke about what they have gained for themselves as a result of taking on the caregiver role for their loved one. Benefits included more compassion and empathy, a closer relationship with their care recipient, a deeper understanding of themselves, as well as increased skills and knowledge. These benefits expressed by all of the participants speak to the positive and rewarding components found in accepting the family caregiver role. Katherine Sharp feels she has gained so much personally in becoming a caregiver:

I've gained more empathy and caring. It has also helped me to learn.... I've learned what it is to be scared for someone, but I've also learned to be strong in those moments and just take it head on and just be very, very in touch with my faith.

Sarah Washington shared in Katherine's experience as she feels caregiving for her mother has expanded her capacity for empathy as a result of seeing up close the struggle with her illness:

I have taken empathy to another level, because I don't have MS, and I'll never know what that's like but I've seen her become a prisoner in her own body.... The empathy that I feel is just tremendous ... I've learned I don't have to go through that to understand what you're going through.

Ramona Files expressed that she gained a deeper closeness and understanding of who her grandmother is due to their caregiving relationship. She felt it gave her more personal one to one time with her that she is grateful for as she feels it has made her more compassionate:

I feel like it has actually brought us closer together.... So it has allowed us to get a better relationship, allowed me to actually understand who she is as a person herself. So I really understand now who she is and what she wants out of life.

It's changed me. I feel like it's [caregiving relationship] given me a better outlook....

And it has made me a more compassionate person.

Ramona also attributed her family caregiving experience as confirming for her choice to pursue nursing as a profession, "It showed me that I can do more. I can give back more and maybe I can make a career out of something like this."

A few participants noted they gained knowledge from their caregiving role. Rose Hanes described; "I have gained a lot of knowledge. I've gained knowledge about medical stuff... elder law and estate planning.... reiki I really have learned so much and I'm going to continue to." The ongoing learning and increased knowledge caregivers reported are seen as benefits to their caregiving role.

It was demonstrated by all participants that there are various benefits they attributed directly to their caregiving role and experiences. Participants identified what they gained in terms of becoming a family caregiver for their loved one and illustrated the positive and rewarding components found in their family caregiver role.

Perception of Choice. Participants either saw the caregiver role as a choice that they needed to embrace or that there was no choice and acceptance came with a heavy sense of obligation. This is an important distinction. The *Perception of Choice* for participants ranged on a spectrum. Some participants proactively embraced choosing to put their loved one's needs before their own while others perceived they had no choice but to prioritize their loved ones needs. Four participants had a positive perception of choice, while eight had conflicted feelings that they had no choice in prioritizing the needs of their loved one.

Four participants explained that putting the care recipients needs before their own was a choice they viewed positively with pride. As Bob Swan shared prioritizing his parent's needs over his own is something he feels honored and proud to do "Just knowing that they're the priority now. Putting their needs first". He also acknowledged that shift of prioritizing their needs over his own took time for him to adjust.

You're not just going to get up and go and do whatever. You got to make sure everything is in order. You don't just go. So, that was something that I had to deal with, because I'm involved with a lot of different things. So, they are my priority, and I had to get ahold of that, took me a little bit to get a hold of that.

Eight participants, expressed that putting the care recipient's needs before their own was not a choice but a necessity as they perceived their loved one was reliant on them to do so. They worry about what will happen to their loved one if they [the caregiver] cannot do their caregiving tasks anymore. Rose shared that the feelings of worry, stress and a constant watchfulness of prioritizing her husband's needs are always on her mind. "Stress is a big deal, and caregiving is stressful". She struggled with prioritizing her husband's needs over her own last year when her own health began to suffer.

I felt like taking care of my husband was starting to affect my health. So, I got scared ...

Don't forget yourself. Self-care. Self-care, you need it in order to be a caregiver. I can't take care of him if I'm not well... Sometimes you have to really think about how do I cope?

KC explained that prioritizing her husband means there often is no time for her own needs. "Well, sometimes I feel like I don't have a life. My life seems to have evolved around taking care of him and that's hard". She explains that acknowledging her own needs feels wrong when her husband had been the one who lost his ability to be independent. KC became teary speaking about Robert;

I feel bad for him. Here was a man who always did for everybody and now people have to do for him. It's a hard pill to swallow for him... [KC begins to cry]. Sometimes I worry about if something were to happen to me, because I've heard stories and I experienced it with people in the support groups with me who have died before the person they are caring for. I don't dwell on it, but I think 'how long can I do this' I've had my own health issues too. Robert says 'you didn't ask for this' and I say nobody asks for this.

Cookie Rossi described how from the moment she wakes up until she is able to fall asleep, her day is centered on meeting her husband's expressed and unexpressed needs. She explained that she saw no choice other than taking the role as family caregiver as her husband's illness progressed, he became reliant on her to take on more caregiving tasks and responsibilities. Cookie explains:

A family caregiver is someone who takes care of a person who can't take care of themselves... I do everything for him. He depends on me for everything. So I have a big job.

Understanding that variations occurred in how participants perceived whether they had any choice in prioritizing the needs of their loved one is important. The majority of participants' who felt they had no choice but to prioritize their loved ones needs perceived their caregiving responsibilities as all consuming. Whereas the remaining four described choosing their loved ones needs before their own as a choice which was viewed positively with pride.

Theme 3: Changing Roles and Relationships

When the norms or routine interactions between the care recipient and the family caregiver start to change due to declining ability/independence. It alters the existing relationship. The initial role as child, significant other, or sibling shifts. As described in the first theme, this change in relationship roles as described by participants can occur suddenly or gradually over time depending on the increasing

needs of the care recipient. Participants experience taking on roles that they perceive as reversed, in the case of an adult child and their parent, or more in line with a professional healthcare role when they conduct caregiving tasks, i.e., nurse, therapist, home health aide.

Family members have roles, and these roles can be ones we are born into such as a child, sibling or grandchild role, or they can be roles we choose such as spouse, partner or close friend. These roles are the origin relationships or starting roles with a loved one who may eventually need caregiving. In other words, a relationship of origin will predate the caregiver/care recipient relationship. These origin relationships (mother to son, husband to wife, granddaughter to grandmother, brother to brother) have norms and routines. As Ramona Files explained, “It's an adjustment. Just trying to adapt to the change and to know that it is a part of life, unfortunately. And I think sometimes it's just the unexpectedness that happens that makes it even harder.”

Participants describe that this relationship change is present in their current family caregiving relationships. This change in relationship shape how caregivers see themselves and their role in relation to their family member requiring care. The Changing Roles and Relationships theme is comprised of 4 subthemes; 1) Wife to Caregiver/Nurse, 2) More than a Daughter, 3) Providing Increasing Level of Care, and 4) Experiencing Grief and Loss.

Wife to Caregiver/Nurse. When the four wives in this study took on caregiving responsibilities for their husbands it was perceived as almost a shock because it changed their relationship and identity. Their primary role as wife changed in the relationship. Participants described how a marriage is dependent on two people both agreeing to assume a role in a marital partnership. The role of wife comes with it a set identity that is connected to the relationship. There is an expected level of intimacy and partnership that is expected in the marital relationship. When a couple's relationship is altered, the partnership and intimacy that they had before changes to the wife feeling like a healthcare professional,

such as a nurse or nurse's aide then a romantic partner. Heather Davies described how her role and relationship with her husband changed due to caregiving:

I'm not really a wife anymore, I'm a nurse. There's no intimacy now. To be honest, seeing a man in diapers and needing to care for him is very hard to get turned on. I still love him dearly. I want to take care of him. I want to make sure he has everything he needs.

Heather explained that the increased caregiving tasks she assumed for her husband combined with loss of independence made her feel more like his nurse than his spouse.

Rose Hanes explained that accepting that she is her husband's caregiver meant also acknowledging a significant shift in their roles in relation to each other, "I am his caregiver. I feel like I don't have a partner. I feel like I'm his home health aide." In addition, Rose describes a change in how she saw herself, "I don't feel I'm as light, spontaneous, or as fun, as I was because caregiving is heavy". This highlights the reality of letting go i.e.; relationship, intimacy, choices to go out and certain freedom of being which is inherent in the change of relationship for wives in this study. The realization that Rose was her husband's family caregiver didn't happen immediately, but instead "it's developed over the years". As she took on more caregiving tasks and responsibilities it changed how she perceived herself and her identity in relation to her husband.

More than a Daughter. When the six adult children and grandchildren step into the role of family caregiver for their parent or grandparent there is a shift or a reversal in roles which was expressed by more than half of the participants. Katherine Sharp described her relationship with her mother prior to becoming her family caregiver as close and very good. They continue to maintain a close relationship; however, Katherine recognized the relationship has changed and she has assumed a more parental position in their relationship:

It has changed tremendously because I've become more of the parent to her [my mother]. Now I advise her on how to take better care of herself. I provide for her when it was the other way around for so many years. But yeah, it's not a bad thing, but sometimes I resent it because she was a very, well, still is in some ways, but she was a very strong woman. And I knew that when I needed help, she would always be there and be the strong person for me. But now the roles have switched and it's so hard, and sometimes I wish we could go back.

Bob Swan also described how he perceived a reversal in his relationship with his parents when he began his role as their family caregiver:

It's really funny. It feels like how they were with me, now I am, to them. It's like the roles reversed, and it's kind of weird sometimes, but it makes me... Because I don't have any children, so a lot of times I think, 'Wow'.

When the parental figure required caregiving there was a shift or reversal in roles that was clearly experienced by the adult child or grandchild who took on the role of family caregiver. The participants described their caregiving role as a dramatic change from their origin relationship with their parent and a more paternal responsibility to their loved one.

Providing Increasing Level of Care. Throughout participant interviews were stories of intense caregiving needs of their care recipient. Caregiving tasks ranged broadly across the participants in complexity, but they all shared that caregiving needs of their loved ones increase over time. For Cookie Rossi at 85 years old, the increasing level of care is a concern as she tries to be able to do all that her husband needs. Cookie shared, "I know that it's a progressive disease [Dementia and Parkinson's Disease], and I don't know what's ahead. I hope I can be healthy enough to cope with it." She explained that what started out first as needing some direction and supervision now is involved in her providing hands on care with activities of daily living:

He's left-handed, and the Parkinson's affected his left hand. So it's a problem. He can't eat properly. He tries to use his right hand. Sometimes I cut up all his food for him, otherwise he wouldn't be able to eat. I have to dress him. Now I've got another job now. I shave him, because his dominant hand is dead and the right hand isn't as strong. So he wasn't shaving properly, so I shave him now. I dress him... he can't do any of that. So that's my job.

Heather Davies shared that as her husband's disease progressed, he had more falls and increased confusion which required more from her as his caregiver:

The nights became so hard as he would be up all night. He was confused and would be crying or screaming in the middle of the night. One night I had to call the police because he fell and I couldn't get him up that time on my own. It was the disease progressing....I felt very helpless and very frustrated, and I think a lot of my tears were tears of frustration because I do love him and I want to take care of him...but what I'm doing it's not enough.

Rose Hanes described her husband's dependency on her and the increased level of caregiving that is required as his disease has progressed:

I am taking care of him more and more. And now I shower him, help dress him and put on his shoes... He can't bend over and he gets out of breath and needs his oxygen on more and more. Now I have to be there for anything he needs.

And finally, for Berry Smith caring for her mother through her cancer treatments was something that she was not prepared for:

She had to go through chemo. And I expected the nausea, but I never expected the amount of diarrhea which is a side effect... I had to literally bathe my mother because

she was so severely weak. I wanted to get her in the shower and just try to hose her off to be honest with you, but she was too weak.

Berry shared how the intense level of caregiving her mother needed was emotionally challenging, “I can remember...I walked into my bathroom and I just started crying because this was not what I expected it to be like.”

Several participants shared that they have been taught or advised by healthcare professionals to provide tasks that are very medically involved. Some shared they had to teach themselves as they were not offered or provided any guidance or instruction from any healthcare providers. For example, KC McKenna described that her husband’s accident was life changing, leaving him functionally paralyzed from his torso down:

The type of injury he had... it was very overwhelming for me. I thought I was going to have a nervous breakdown. I remember when he was in the hospital, then he went to acute rehab and then he went to subacute rehab. All the things they [healthcare professionals] were teaching me I was like ‘I don’t know whether I can do this’. I doubted myself. I was like, ‘I don’t know whether I can do this’. I learned over the years how many things I had to learn to do like, cathing, giving him shots in the stomach, changing bandages, caring for wounds, how to get him dressed, moving him out of bed, cleaning him, hooking up his IV antibiotics into his port... I always doubted if I could do it. I still do. On any given day, I can feel overwhelmed and saying ‘Am I going to get all this done’?

KC explained that she was responsible to learn how to perform medical tasks, many of which are typically associated with nursing care. KC talked about the doubt and fear she experiences regarding whether she can do what is required to care for her husband as his complex needs increase. Many of the

caregiving tasks she discussed such as giving injection, performing wound care, and inserting a catheter can have negative impact to a patient if not done correctly.

All participants echoed the same sentiment: caregiving tasks continually increased in time intensity. Although their stories conveyed their caregiving tasks ranged broadly in intensity and complexity, they all discussed that caregiving needs and tasks increased over time. This is an important part in understanding how caregiving alters the relationship and changes how the participants viewed their loved one needing care and themselves as the caregiver.

Experiencing Grief and Loss. Grief and loss are woven into the caregiving experience. For many participants, grief or loss is related to the prior relationship they had with their loved one. Several participants described an ongoing experience of loss and sorrow about what was, and what will never be again, i.e.; independence, financial security, activities, hobbies, relationships, traveling, etc. All participants became emotional and tearful when talking about their insights of loss and grief connected to their caregiving experience. Ramona Files shared the difficulty watching her grandmothers' transition from a strong independent person to someone who is so dependent on others:

When the transition happened where she needed full-time care, I was also watching her lose her independence, so it was a struggle. I was trying to make sure she still had all the independence she could, even though it was very limited. So it was sad and challenging.

The sadness expressed by Ramona was echoed in Katherine Sharp's experience with her mother:

You feel like it's happening to you, even though you may not be experiencing everything that they're experiencing. But it is hard to watch someone lose everything or not be the person they once were... It really makes you sad. It is really sad. It hurt me because I knew it wasn't something that she was doing to herself.

Katherine expressed experiencing the loss of who her mother was and will never be again.

Participants had similar observations where they recognized that their loved one will never be able to reverse or go back to what was. Family caregivers are experiencing an ongoing series of losses.

Rose Hanes smiled while she described the relationship prior to her husband's need for caregiving; "We loved going out with friends, dancing, laughing, just a lot of joy". Rose says words that would describe their relationship then were 'fun', 'active' and 'a partnership'. Rose shares that as her husband first became ill with cancer and then COPD he progressively "pulled in and retreated within himself". She describes that as his health declined and he progressed with more mounting health issues he began to need greater level of caregiving, "I lost my partner, sometimes I feel like I lost my friend, it's difficult" She shares she had to give up some of herself, freedom, her partner in life. "I gave up some of me. I did. I gave up some freedom. I did. Sometimes I gave up my partner, of doing things together."

Rose shares that she and her husband go through many of the same feelings but at different times.

The feelings are anger, grief, and fear, on both our parts... We both grieved, who he was and who we were and still are. We grieve this healthy spontaneous energetic guy.

Grieving a loss that I still have him but yet I've lost him. I've lost him and he has lost him. So that's a big deal the whole grieving and loss piece.

She explained further that grief and loss happens continually for her and her husband throughout his advancing illness.

There are many ways to lose... The grieving is such a big thing. And the grieving of the normal life or what was typical in your life, and it's hard, that grieving thing. A lot of people think that when someone dies, you grieve. There's dying all along the way.

There's loss all along the way. I think that's a big thing, and I think that people need to be aware of that.

Heather Davies becomes emotional as she reflected on being his caregiver and seeing him decline year over year. "I've lost my husband already, he's not the man that I married. It doesn't make me love him any less. It is like slowly losing someone." Heather's expression of grief due to the dramatic change in her husband caused by his illness was shared by many participants.

Grief and loss while caregiving was a shared experience among participants. Although the anticipatory grief related to the inevitable death of their loved one was present it was not as pronounced as the existential loss that participants spoke about, loss of self, loss of who their loved one had been, or loss of hope that it could change. These perpetual experiences of loss are part of caregivers lived experience.

Theme 4: Qualifications for Caregivers

There are certain caregiving skills that participants expressed as crucial to learn. Some participants, who came to the role as caregiver already possessing any of these skills through previous education, job related training, and lived experience, acknowledged how their previous experiences benefited them now as a family caregiver. Participants described four common skills that are crucial to develop in order to feel effective in the role as a family caregiver: advocacy, coordination of services, knowledge of medical and system terminology, and flexibility and balance. Sarah Washington urged that family caregivers need to be better prepared when they enter into to this challenging role. "There's so much that you really need to know and learn....I have learned by making mistakes or just not doing something, not asking the right questions." She suggests creating an onboarding for caregivers with what they need to know. "Sometimes I joke and say, I wish there was an orientation for family caregivers." This insight was shared by all participants.

Participants shared situations where they relied on one or several of these key skills in order to get through caregiving challenges. All participants expressed that family caregiving is wrought with challenges, barriers and crisis points that require specific skills to get through them. These skills make up their recommended qualifications for family caregivers.

Advocacy. Family caregivers are often navigating through multiple systems such as insurance, healthcare, supplies, and financials simultaneously. These systems were not designed to be person- or family-centered but rather process-centered. The complex needs of aging, ill or disabled adults are not naturally provided for people in our current healthcare delivery system. The ability to speak up, press, question, champion, and in many of the participants experiences, argue or fight for what their loved one needs, requires the ability to advocate.

Heather Davies described the skill to advocate as essential for caregivers: “An advocate, that’s the word that really describes it. You have to be there for your loved one and make sure that you know what’s going on and that everything is done and handled correctly”. Heather attributes her strong abilities to advocate for her husband to her years working in business. KC McKenna explained that advocating for what her husband’s needs is a huge part of her responsibility as his family caregiver:

You have to be an advocate, and you have to fight. And is it easy? No, because, like I said, a lot of times, you're on the phone. You want to speak to a supervisor. They're at a meeting. Some people get back to you. Other people don't.....So you have to be willing to get on the phone and fight, fight, fight. And is it exhausting? Yes, it is exhausting.

KC shared that constantly needing to argue for what her husband needs is extremely time consuming but necessary. “You have to be an advocate, and you have to fight to get what you need”. She shared that she spends hours per week on the phone advocating for his insurance to cover medical supplies that her husband needs. Even when she wins one round, she knows that there’s a list of others she needs to move on to:

Is it easy? No! A lot of times you're on the phone for an hour just trying to speak to a supervisor who either doesn't want to speak with you or won't call you back...It seems like it's ongoing...especially when you're on Medicare.... It seems like there's more fight that you have to be prepared to do to get what you need. Yes, it is exhausting. KC has strengthened her ability as her husband's advocate over years of practice and learning from other family caregivers.

Ted Gunner agreed that to become a good advocate for his brother he has had to often get guidance and advice from trusted healthcare professionals and legal counsel; "I definitely had to learn. Oh, definitely." Across all participants there was a clear theme that advocating is a primary skill needed as a family caregiver.

Rose Hanes recalled a time she had to advocate and speak up during a hospitalization when her husband was administered a wrong medication. She advocated her complaint in the large medical center to the Chief physician:

And he [physician] looked at me, saw how frustrated and scared I was... And he said 'I'm going to tell you, you have to question, speak up and be your own best advocate'... so I figured if the chief of medicine at one of the best hospitals tells me that....I'm going to make sure that I advocate for him [husband] and that he gets the best care.

Rose's experience confirmed her belief that she needed to be vigilant as an advocate for her husband. She feels she has had to develop her voice as an advocate to be able to be listened to by health care professionals.

Sarah shared that advocating on behalf of her mother is more than a fulltime job that never shuts off or has a break or vacation. "I'm always having to advocate for her". She feels that teaching family caregivers at the onset of their role would make a positive impact on their effectiveness in advocating. She urges teaching; "This is how you advocate. This is a sample

script of speaking with your loved one's healthcare providers. Something instead of just winging it." Sarah believes basic advocacy skills should be taught to all family caregivers in order to help them effectively to ensure their loved one gets what they need.

Coordination of Services. Healthcare is solution driven. If you have a problem, healthcare providers are trained to assess, diagnose, treat and recommend a plan of care. There are endless number of problems patients with complex needs and multiple diagnoses can have. What is often forgotten is who is responsible for bringing that plan to action and reality are family caregivers through coordination of care and services for their loved one. This may sound as though this should be easy, but participants shared that coordinating multiple care and services is a complex skill, and one they have had to learn in the role while providing care to their loved one. For some, barriers to coordinating services may result in not achieving the goal that the healthcare provider has set.

Stella White said that even with her experience of working within healthcare has had challenges coordinating the recommended services for her mother. "I think that healthcare providers should understand that certain goals can be met and sometimes goals are not able to be met because there's too many obstacles in the way." Stella expanded that she feels healthcare professionals have to try to put themselves in the shoes of the family caregiver to understand all that they are expecting them to be able to do successfully without any support or training.

They [healthcare professionals] have to understand what is required to get all that done, and when they're like, 'Well, you got to do this....you got to do that....you got to go on this appointment.....and you have to get this done.....you got to get that done.' You [healthcare professionals] have to understand that there's somebody behind that little curtain that's working, running around.... taking care of this one individual, and that person [family caregiver] has a life too, and has to work, and now run all around and take

care of all of that stuff [healthcare professional's recommendations, orders, or care plans].

KC McKenna has had to learn over years how to coordinate multiple complex care needs and services all while being her husband's fulltime caregiver. She explained just learning the process to get authorization for a new medication is one step of the coordination but then locating the medication and getting it in time to administer it to her husband is another step of coordination of care. In the absence of being able to coordinate the care and services needed there is a gap between what the physician and care team is recommending and what can actually be done:

One of Robert's medications, our pharmacy didn't have it in stock, and the nurse practitioner went to see if another pharmacy had it. They didn't have it either. And then I called up another pharmacy, and they were able to provide it for me, but they were only authorized to give me a 30-day supply because our insurance wouldn't allow for a 90-day because they said it wasn't a participating pharmacy. And I'm saying, 'But if you can't find it at a participating pharmacy, what am I supposed to do?

KC's frustration was about the ability to schedule or obtain what she needs when she needs it to meet Robert's needs. Her experiences were echoed by several participants. Heather Davies agreed with how challenging coordinating services can be, but shared that her work experience as a businesswomen prepared her for coordinating her husband's care and services. "Well thank God I am a business woman because otherwise, I wouldn't be able to do it." She spoke about coordinating between multiple complex systems such as insurance, healthcare providers, medical supplies, pharmacies, legal, and financial can be a fulltime job.

Knowledge of Medical and System Terminology. The jargon of healthcare, legal, financial, and insurance systems are complex and meant to be understood only by their insiders. Similar to visiting foreign countries that have their own language and dialytic it can be challenging if not impossible for

those who are not native to that region to understand. Lola Vaughn emphasized that the language that healthcare providers use is difficult to understand for both she and her mother:

The language healthcare professionals use is Swahili. It's Swahili unless you're from there you just don't understand it. You need someone to interpret. It like a subway train.

It's going past you fast, fast and someone has to dissect the jargon.

Lola's point emphasizes that complex language and jargon can make caregivers feel inadequate.

Gaining knowledge of medical terms and jargon can help caregivers feel more competent;

"Knowledge is power." Ramona Files explained that even with working in healthcare, she too says it can be a lot to decipher; "It's also hard, I'm sure, for other people who aren't as knowledgeable in the healthcare, when you hear all these different words and meanings, it just brings up all these concerns."

Berry Smith agreed feeling that after being her mother's caregiver for 18 years she has developed a wealth of medical and system terminology knowledge. She doesn't just recognize much of the complex medical language, but has come to understand much of it and be able to talk with healthcare providers in their language; "Let's say you're a healthcare professional, I can speak to you on your level whereas someone who may have just started as becoming a caregiver may not have all of the knowledge." Berry concedes that for caregivers that cannot decipher medical terminology they may be at a disadvantage; "So they're sitting there and they might not understand everything. I'm blessed to have developed that knowledge." She feels expanding her knowledge of medical terminology and jargon is helpful on two fronts; "It helps the family caregiver where you're getting and understanding as much information as possible. And at the same time, it cuts down the time the doctor has to explain things so they can go on to somebody else." Caregivers emphasized that learning the *insider* language and terminology most commonly used within healthcare and the coordinating systems is critically important for their effectiveness as a caregiver in order to decipher and provide information.

Balance and Flexibility. Caregiving requires the skill to balance two often competing or opposing things at the same time. Participants shared that they work at balancing not just responsibilities but also their perceptions, expectations and feelings. They had to balance self-perceptions and feelings which can be paradoxes: competence as a caregiver and inadequacy, feeling overwhelmed and grounded in purpose, expectations from others/care recipient and themselves, and striving for perfection and simply settling for good enough. Katherine Sharp stated that she has to continually work to find balance for her own needs and her loved ones needs. “I balance it out. I don't take too much time for myself, but just enough on a weekly basis to be happy to do what I do for them.” Caregivers simultaneously must look to learn and strengthen their willingness to compromise, let go of the small stuff and be open to change. Their ability to be flexible is necessary as caregiving is full of things that they cannot change. For example, Katherine shared that rigidity is a caregiver's enemy, because every day is completely new with different concerns or issues to work through:

So I've learned that...even if something bad happens, that's what was set for me and for my family and for me to work around it and not just sit there and say, ‘Why me?’ But just look at it as, Okay, this is part of the process and I have to accept it and learn from it and move on.

Katherine has learned to be less rigid and allow herself to adapt where she can to make situations less stressful for herself and her mother.

KC McKenna reflected on what skill she has had to strengthen the most over her 13 years of caregiving for her husband, which was her ability to be flexible especially when things get tough. She credits her ability to bend and adapt helps her through the hardest moments of caregiving. “I think my mantra is being flexible, because I never know when things are going to change for him.”

Ramona Files admits she has had to become less rigid for both her and her grandmother; “I just know that we are stubborn people sometimes and we like what we want and we may not want to change

our ways, even though things may be changing. So just trying to adjust. It seems like each day is an adjustment”. Learning to be more accepting and flexible has helped Ramona reduce her stress as a caregiver.

Stella White shared that as a caregiver being flexible is an important characteristic. Stella has had to change employment settings to ensure she has flexibility to take off or attend medical appointments with her mother when she needs to. Stella feels at times this has limited her earning ability but that it is necessary that her employer is supportive and understanding that she is a family caregiver and at times may need flexibility to her work schedule.

Despite the challenges, barriers and problems all family caregivers faced, their commitment to do the best they can for their loved one prompted them to learn and develop necessary skills. The participants identified the skills needed to feel effective in the role as a family caregiver. These skills make up the qualifications for caregivers that consisted of four skills which are crucial to develop in order to feel effective in the role as a family caregiver. The skills include advocacy, coordination of services, knowledge of medical and systems terminology, flexibility and balancing. Being a family caregiver should not have to be so hard, but learning foundational skills needed for the role may help them feel more prepared.

Conclusion

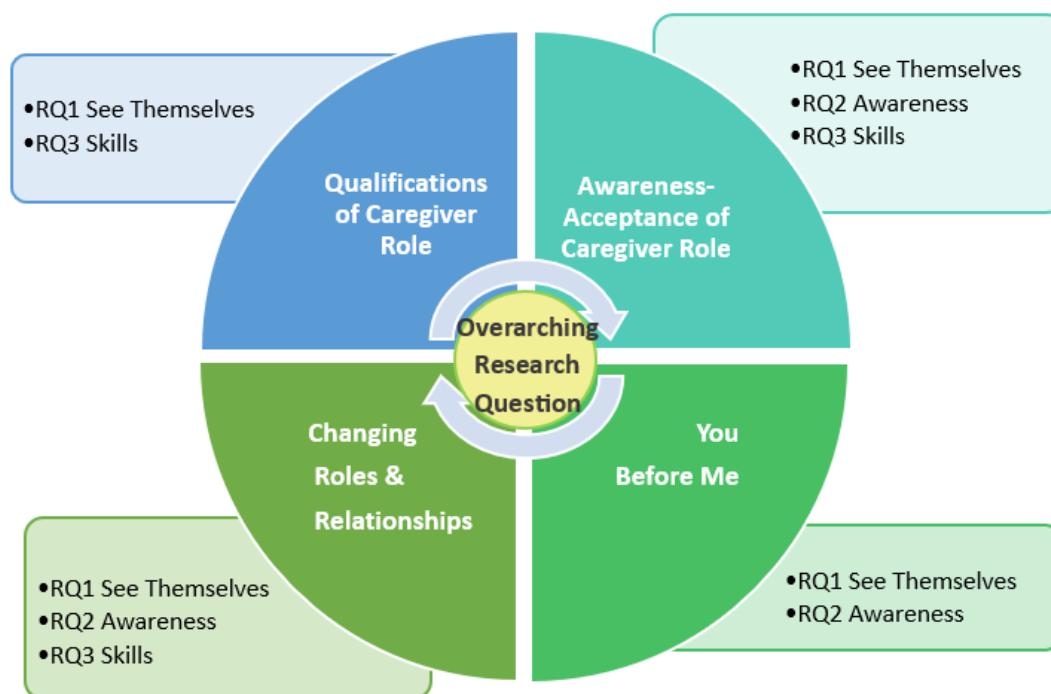
The findings presented in this chapter provide an understanding not only of the inner life but of the daily joys and struggles of family caregivers. It begins to paint a picture of the complex interactions, role changes, deep struggles and loss that are intricate parts to the family caregiver’s role/identity.

As shown in Figure 2, the four major themes of, Caregiver Awareness and Acceptance, You Before Me, Changing Roles and Relationships, and Qualifications for Caregiving Role-- each provided understanding to RQ 1 by describing the experiences that shaped how family caregivers saw themselves and their role in relation to their loved one needing care. The moments of realization either immediately

or progressively over time as the illness progressed are an important part in how family caregivers see themselves in their role as caring for their loved one. Past experiences of caregiving as seen in their families or work contributed to their awareness of their caregiver identity.

Figure 2

Family Caregiver Experience and Findings Map



Themes 1, 2, and 3 Caregiver Awareness and Acceptance, You Before Me, Changing Roles and Relationships provided insights into RQ 2 and explained the external and internal influences that have contributed to or negatively impacted the participant’s awareness of themselves as family caregivers. Many of the participants felt they had to prioritize their loved ones needs before their own, yet they also explained that caregiving comes with many benefits as well.

Themes 1 (Caregiver Awareness and Acceptance), 3 (Changing Roles and Relationships) and 4 (Qualifications for Caregiving Role) gave insights into to RQ 3 and explained skills they developed over

time. All participants expressed key qualifications for the caregiver role, which included advocacy, coordination of services, knowledge of medical and systems terminology, and flexibility and balance.

Therefore, regarding the overarching research question the main finding is that an acknowledgement of changed roles/relationship is needed for family caregivers to accept and identify their role as caregiver. This finding is supported through the four central themes and subthemes depicted in Figure 2. The findings presented in this chapter will be further discussed in Chapter 5 in the context of the extant literature and in connection with recommendations for family caregivers, researchers and health care professionals.

CHAPTER 5: DISCUSSION

My qualitative study examined the phenomenon of family caregivers caring for their aging loved one and how they experienced awareness and acceptance of their role within the healthcare continuum. It sought to make meaning of this changing role that many caregivers take on in response to illness or disability of an aging loved one. Interviews were conducted with 12 participants to answer the overarching question regarding how they developed an awareness and acceptance of the caregiver identity.

There is a growing need within the American healthcare continuum for family members to assume the role of family caregiver for their aging ill or disabled loved ones. As more healthcare models are designed to push care away from inpatient facility care, such as hospitals and skilled nursing care, more of the daily assistance and personal care needed for the aging ill and disabled adults falls on their family members. Despite the prevalence of caregiving, the role of the family caregiver is a label that, throughout literature, lacked a clear description, definition, or societal understanding which can have negative ramifications such as diminished recognition and support by healthcare systems (Beatie et al., 2021; Dobrof & Ebenstein, 2003; Eifert et al., 2015; O'Connor, 2007; Semere et al., 2022; Ugalde et al., 2012; Wolff et al., 2016).

The phenomenological design of this study drew from the theoretical framework of family caregiver identity theory (Montgomery & Kosloski, 2007) to capture and make meaning of family caregivers' lived experiences. This study was conducted between March 2023 and July 2023. Participants were recruited through a Caregiver Support Center within a community medical center, which provides free programs and services to support family caregivers at any point in their caregiving journey. The criteria for the participants in the study included that they were over 18 years old and actively family caregiving for a loved one over the age of 65 at the time of participation.

Drawing on caregiver identity theory (Montgomery & Kosloski, 2007), my study sought to answer the following research questions: How is it that caregivers describe their experience of developing an identity as a family caregiver? What experiences shaped this identity as a family caregiver and what external/internal influences contributed to their awareness? Were they able to describe their caregiving journey and the skills they developed over time? Twelve participants agreed to be in the study and provided deeper insight into what it means to be a family caregiver.

A deep exploration of the complex interactions, role changes, deep struggles, and experiences of loss that are an essential part of the role/identity of family caregivers was undertaken through rich interactive interviews and focus group follow ups. Participants were open, eager to talk, and at times emotional as they shared what they viewed as the essential parts of the role/identity of a family caregiver. One striking example is Rose who held back tears as she described what she experienced in taking on the caregiving role for her husband; “I gave up some of me.”

Discussion of Findings

The findings in this study suggest that the process of identifying as a caregiver is not always a simple or automatic (parsimonious) process of acknowledging or recognizing that what you are doing is family caregiving. Identification for family caregivers in this study connected to so much more as it involved accepting a label that is not yet universally constructed within family systems or American society. Yet it is a label that has been created and assigned by healthcare and policy makers to identify a role connected to an identified patient or person in need. Findings in my study support that identity and identification as a family caregiver is a complex change process, as explained in caregiver identity theory (Montgomery & Kosloski, 2007) and the literature (Eifert et al., 2015; Beatie et al., 2021; O’Connor, 2007).

Yet in this current study, my interview data and analysis also provided new insights into how realization, acceptance, and identification occurred over time. This study supported the literature

(Montgomery & Kosloski, 2007, 2009; O'Connor, 2007; Hernandez et al., 2019; McLeod, 1999) that an acknowledgment of the changed roles/relationship between the caregiver and care recipient is needed for family caregivers to accept and identify their role as caregivers. However, this study found that awareness and acceptance were not synonymous. Often participants described an awareness that what they were doing for their loved one met a description of caregiving but there was a hesitation or ambivalence to accept the label and identify as a caregiver. Acceptance is crucial as it leads to utilization of vital resources and supports sooner in the caregiving journey (AARP, 2001, 2020; Dobrof & Ebenstein, 2003; O'Connor, 2007; Beatie et al., 2021).

In addition to an awareness and acceptance that their loved one had changed; the interview data analysis provided new insights into other factors that contribute to their ability to accept their caregiving role/identity. They included the *moments of realization* of their caregiving role, the prioritization of their care recipient's needs over their own, and the nature of the unrelenting experience of loss and grief. Although all of the participants experienced challenges, sacrifices, and loss as part of their caregiving story, they also were able to identify positive aspects or benefits they gained in taking on the role/identity of caregiver. This paradoxical (incongruent) experience, which participants described, is vital in understanding family caregiving.

Awareness and Acceptance of the Caregiver Role

Participants described that in order for them to identify as family caregivers, they first had to recognize that they were experiencing the new role. As shared in Chapter 2, the role of a family caregiver is described or defined most often in terms of the tasks/responsibilities that they assume or take on for their loved one in need of care and measured most often in the frequency of hours spent caregiving (Dobrof & Ebenstein, 2003; Montgomery & Kosloski, 2009; O'Connor, 2007; Ugalde et al., 2012; Wolff et al., 2016). However, I also found that the label caregiver can be met with resistance, as shared by four participants (two of whom were people of color) who did not feel comfortable

identifying as a caregiver. For example, Bob struggled to identify as a caregiver because that term was not used within his own family experiences witnessing his parents' caregiving for family elders as they aged and became sick.

Although the term and role of family caregiver is a label that has meaning in the context of healthcare delivery models and policy (Herron et al., 2019; Wolff et al., 2016), my study found that the label was not universally accepted or did not align for all persons carrying out the caregiving needs and tasks for their ill, disabled, or aging loved ones. Four of the 12 participants did not readily identify as family caregivers. This reluctance to identify as a family caregiver is notable and worthy of further investigation. As two of the four were persons of color, there may be cultural norms or other variables that interact or contribute with delayed acceptance. Clearly a much larger sample that specifically explores other aspects of differentiation among caregivers' cultural, religious and social backgrounds may provide more nuanced understanding of this label reluctance used within current policy and legislative action (CARE Act, 2016; RAISE Act, 2018).

The caregiver identity theory (Montgomery & Kosloski, 2007) suggested that the caregiver role/identity was acquired through a series of events and occurred systematically. The *moments of realization* finding as described in my study did not present systematically for all 12 participants, but rather randomly occurred at different points within the caregiving journey. For example, Sarah and Heather were caregiving for more than two years before their *moment of realization* of their caregiver roles/identity occurred. In contrast, KC and Ramona's *moments of realization* were more immediate; occurring within the first month of taking on caregiving tasks due to the severity and progression of illness of their loved ones. This finding in my study underscores that available supports and resources may be underutilized because of diminished awareness and or delayed acceptance of the family caregiver role. Awareness and acceptance did not occur either simultaneously nor systematically.

My study found that the caregiver identity and label was not yet universally accepted or aligned for all participants. Sarah recalled her pivotal moment of realization was the first time she was labeled *family caregiver* by a hospital social worker during her mother's hospitalization. KC's moment occurred during her husband's post-surgery rehabilitation care when the doctor's told her she had to learn how to care for him. This external recognition and labeling of the role which participants identified assisted them in their awareness and acceptance of their new role, mirroring the critical gap that O'Connor (2007) explained in the literature. O'Connor discovered that labeling of the role from external sources such as a healthcare professional, friend, or observer initiated the internal recognition process thereby closing the gap between external acknowledgement of role and internal realization/awareness (2007). My current findings add to the understanding of this concept of external labeling which participants described as scenarios that prompted the start of their realization of themselves a family caregiver.

Most participants eventually accepted their identity as a caregiver, with some feeling proud or understanding personal value of their new role. However, as mentioned, a few rejected the caregiver label because they saw caregiving as part and parcel of their familial role. This hesitation or ambivalence to accept the label of caregiver as described by four of the participants is important. External labeling is critical to the identification of those in the role in order to connect them to resources and supports. The finding highlights that the label does not fully resonate with all those that are caregiving. Greater discourse is needed to embed the term across American society. Yet, to bring this full circle, a two-pronged approach may be most effective: (1) Greater research is needed to explore why caregivers are reluctant/ambivalent/hesitant to internalize this identification and (2) more systematic educational efforts (to the public and to healthcare professionals) are needed to increase familiarity with and understanding of caregiving and its vital role in our common life.

Changing Roles and Relationships

Caregiving is a fluid process that is always changing which is established in the literature (Montgomery & Kosloski, 2007, 2009; Eifert et al., 2015; O'Connor, 2007; Beatie et al., 2021). This concept was mirrored in this study by all participants who described the constant state of change they experience in the role of a caregiver. Overall, participants described the flexibility needed to allow them to manage the stress and function as a caregiver.

Montgomery and Kosloski (2007) explained that the caregiver identity results when the caregiving responsibilities increase and intensify. This intensification prompts the realization that their relationship and familiar role with their care recipient has changed, thus creating a change in their identity. My study findings supported this concept and further explores the complexities which are separate from the increase and intensity in caregiving responsibilities.

In addition, the findings in this study add to the research and understanding of how caregivers realize, accept, and identify with the role (Montgomery & Kosloski, 2007; O'Connor, 2007; Dobrof & Ebenstein, 2003; Beatie et al, 2021). The findings presented in Chapter 4 suggest that expanding the knowledge of the caregiver identity theory to include self-identification as part of the process may add value. Beatie et al.'s (2021) study, although specific to caregivers caring for someone with mild cognitive impairment, found that despite taking on the tasks and responsibilities, only a minority of participants self-identified as a caregiver, with the majority describing themselves "in-between" roles/identity.

Beatie et al., (2021) suggested that for the minority of participants their prior caregiving history or witnessed experiences shaped and assisted them in accepting their caregiver identity. In my study participants all shared their earlier experiences with caregiving, which shaped their understanding of the role identity. The four participants in my study who described hesitancy or ambivalence in self-identifying as a caregiver all recalled previous exposure or prior experience to caregiving yet it did not

influence an acceptance self-identifying. Counter to what Beatie et al. (2021) found, none of the four had a discrepancy in acknowledging that what they needed to do for their loved one met the description of family caregiving; however, their hesitation or resistance was specific to accepting and using the label as a family caregiver. For two of the four participants, it meant that if they accepted the label, their loved one would also be labeled as in need of caregiving. This supports what was reflected in the literature by Beatie et al., (2021), O'Connor (2007) and McAllum et al., (2021). Participants shared that they perceived that acceptance of the label would change how their loved one (care recipient) was seen/labeled.

For two other participants, the distinct and separate label from their family role was not understood in their family or social communities. I noted that these two participants, each of historically marginalized groups- African American and Latinx, both shared that the label of family caregiver was never used within their family and social systems until they introduced it. My study did not explore culture as a factor, yet this finding, though limited by sample size should be explored further as suggested in some of the literature (Brewster et al., 2020; Lui et al.; Pinqart & Sorensen, 2005; Chiaraluce, 2018). They suggest that who we are in the context of our family, culture, religious, and community systems has significant influence in how we make meaning of family caregiver and of our identity in relation to others around us.

You Before Me

The “You Before Me” theme in this current exploration introduced various dimensions of prioritizing the needs of the loved one over their own needs. This theme, though clearly identified in my study, was largely absent in the existing literature on family caregiver identity. Instead, a large body of the literature examined related areas such as caregiver burden and stress, role engulfment and enmeshment to care recipient (Skaff & Pearlin, 1992; Ugalde, 2012; Montgomery & Kosloski, 2007; Montgomery & Kosloski, 2009; Eifert, 2015).

This experience of prioritizing loved one needs over their own was shared by all participants. For example, for Lola her prioritization of her mother was perceived as a choice and reflection of her devotion to her mother. For Ramona, putting her grandmother's needs as a priority was something that she felt honored to do but also overwhelmed her. And for Stella putting her husband's needs ahead of her own was part of her marital vow which they made to each other, as she remarked: "that's what we do. I devote my whole life to him now. I miss being able to do some things for me."

The burden or sacrifices associated with caregiving is well established in the literature (ACL, 2019; Hoffman & Wallace, 2018; Montgomery & Kosloski, 2009; Reinhard et al., 2019; Rodenbach, 2019; Sorrell, 2014). The phenomenological focus in this study provided rich and important perspectives regarding the recognition of shifting priorities and what it "costs" the caregiver. However, benefits to caregiving were also mentioned by many participants. For example, Heather shared that being a caregiver for her husband taught her a lot about herself and affirmed her own strength. For Bob and Lola caregiving for their parent provided them an opportunity to have more time with them individually. Lola and Bob each felt caregiving afforded them an opportunity to get to know their parent on a deeper level. The gains and loss experienced by caregivers in the study were intricately wrapped together in their stories.

Experience of Loss and Grief

The exploration of loss and grief in relation specific to acceptance of the caregiver identity was largely absent in the literature. Loss in terms of loss of self is mentioned prominently throughout the literature in regard to caregiver stress and burden. Kepic et al., (2019) mentioned the need for counselors to address loss and grief with family caregiver as they are experiencing compounding loss. Nielsen's systemic review of studies during bereavement and end of life caregiving found that anticipatory grief is experienced by caregivers but it does not explore it in relation to role acceptance or caregiver identity.

The literature instead suggests anticipatory grief is experienced by caregivers well before expected death of the care recipient or after the loss of the loved one (Garand, 2012; Nielsen et al., 2016). My study's findings suggest that loss and grief is experienced continually along the caregiver's journey (Kepic et al., 2019). As the participants in my study described, their caregiving experience is wrought with ongoing losses. Loss for many of them was described in terms of what they gave up in order to take on the role of caregiver, loss in terms of seeing their loved one change due to illness, disability or aging, loss in terms of dreams or hopes, loss of what was. Heather provides insight: "I have lost my husband already because he's not the man that I married. It doesn't make me love him any less. It is like slowly losing someone."

KC explained further:

There is a lot of loss. So much you [caregiver] have to let go of. Letting go is the hardest part I think. I had to let go of the life I thought we would have together. I was younger when the accident happened and now I am older. I have lost those years to caregiving. I have to accept that.

My study expands the awareness that from the moment the caregiver assumed the role and identity, there is loss.

Qualifications for the Caregiver Role

Studies highlighted the need for access to education and training for family caregivers (Carbon & Gulucci, 2015; Roth et al., 2015; Zale, 2018; Sullivan, 2015). My study aligns with these findings that family caregivers must receive education for their role. For example, Berry described a learning curve that caregivers experience where they must work hard in the beginning to acquire the knowledge and skill to be successful in caring for their loved one. The participants in this study spoke with energy to describe what education and skill development areas are needed to feel better prepared for the role.

My study supports Dobrof and Ebenstein's findings (2003) which called for healthcare providers to be educated and understand the complexities of being a family caregiver. Understanding the needs of family caregivers was echoed in Coleman's (2004) call for education in health literacy. All felt that education is a crucial need for all caregivers and learning although hardest in the beginning as Stella and Heather both shared, is still ongoing through the caregivers' journey as the needs of the care recipient changes. Missing from the literature was what and how caregivers want to receive education.

Unexpected Findings

As presented in Chapter 4, identification as a family caregiver is not automatic; it first requires awareness and acceptance of their new role. An unexpected finding was how the participants experienced various stages of awareness and acceptance of their caregiver role/identity. These *moments of realization* for the majority of the participants involved the external recognition of a healthcare professional, family member, or observer labeling their caregiver role, which in turn helped them to process and understand what they were doing for their loved one. They were able to see that it was a distinct and separate role from their family or originating role. The importance that the participants placed on the external recognition and labeling was a strikingly powerful catalyst to solidifying their own awareness and acceptance of the caregiver role. This unexpected finding suggests that the use of the word "caregiver" needs greater usage in the public square in order to have the impact and lead to greater utilization of necessary resources and supports sooner.

Another unexpected finding was that more than 80% of the participants had been in their caregiving role/relationship for over six years and ranged from 2 to 27 years. And since these participants were interviewed as "active caregivers", the actual length of time may even be longer than these data suggest. This is important because it suggests that the years in actively caregiving for a loved one may be a longer trajectory than expected, which was the experience for the majority of participants in this study. When asked in the focus group if any of the participants had expected to be family

caregiving for the length of time they had been, they all adamantly said they had not. This study suggests family caregivers need to be informed at the onset or even prior to taking on the caregiver role that actively caregiving can have a long timeline and is more of a marathon than a sprint.

A third unanticipated finding relates to the onset time of grief and the type of grief experienced by caregivers. While there is abundant literature on anticipatory grief related to impending death of loved ones, this study uncovered that grief and loss is pervasive throughout the caregiving experience. Caregiver grief is experienced beyond the traditional boundaries of loss as in death or anticipation of death. It is occurring all the time. It encompasses multilevel types of losses. Participants described a journey of ongoing loss; perceived by this researcher as drip by drip, or bit by bit. For example, in response to the researcher's prompt:

Researcher: You are both having losses, some are shared and some are different. Is that right?

Rose: Yeah, because he lost himself as well. I lost him, he's lost him. That's how I feel.

Another example from Rose further clarifies how pervasive the experience of loss can be:

The feelings are anger, grief and fear on both our parts.....We both grieved who he was and who we were and still are. We grieve this healthy spontaneous energetic guy.

Grieving a loss that I still have him but yet I've lost him. I've lost him and he has lost him. So that's a big deal the whole grieving and loss piece. There're many ways to lose. I think people need to understand that caregiving is a process. It's a real process. And at the start it involves grieving. Grieving the normal life or what was typical in your life, and that's hard. A lot of people think that grief only happens when someone dies, but there's grief all along the way [caregiving journey]. There's loss all along the way for caregivers.

Participants in this study all shared experiences of loss, with some having insight that they were grieving that loss while others did not.

Recommendations

In this section I share recommendations based on the interview and focus group data from participants. Recommendations from participants to family caregivers new to the role include making a commitment to self-care, self-compassion, patience, and connection to supports, resources and other caregivers early in their caregiving journey. These recommendations from those with lived experience of family caregiving illuminate the benefit which peer support can provide. The participants in this study hope that their shared insights can help those new to the role.

Katherine urges family caregivers not to forget about caring for themselves. She highlights that self-care is vitally important to being able to care for someone else:

At the end of last year, I began to experience burnout. I had to stop and start to figure out where to incorporate self-care because my own health was struggling. I had to set some boundaries and I had to let go of the guilt I felt when I took time for me.

She recommends that family caregivers build relationships and create their own “little network” with the doctors, specialists, and social workers who are caring for their loved one. Self-care was a common recommendation among more than half of this studies participants.

Bob’s advices caregivers to have self-compassion and remind themselves that they are not alone in caregiving:

Get around people who've been through it. And again, just patience, you have to be patient [with yourself]. Remember you are human, and that there are going to be times where you don't think you're going to be able to do it, but you're going to be okay.

Because at first, you're like, ‘Oh my God’. But remind yourself you're not the first to do this. It's going to be okay.

Cookie's implores family caregivers to "be patient, be compassionate [self], and just accept it for what it is." She suggests the innate urge to get angry, to deny or refuse to accept the situation is real, but she beseeches caregivers to resist those feelings. They did not serve her well, as she had to adapt and take on the challenges as they presented.

In summary there was an almost universal recognition of the many stresses and strains that result from caregiving. Many provided a supportive wisdom to those new to the process that encouraged self-care and a realistic recognition that "doing it all" all the time impossible. These lessons learned were generously shared as a way of "paying it forward."

Participants' Recommendations to Healthcare Systems and Professionals

Berry recommends greater access to social workers who can provide support like therapy and support groups to help caregivers. Her caregiving journey has taught her that social workers are vital as they have the skills to provide support to caregivers at all points of their caregiving journey.

All caregivers need that bridge for the duration of their time caregiving because you're stressed in the beginning, you're stressed in the middle, you're stressed in the end. And there are times you just need to speak to somebody who understands what you're going through.

Bob recommends that healthcare professionals maintain a compassionate family centered approach, especially at pivotal moments in the caregiving journey:

To not make people feel that you're just a number. You're not just a number. Like I was saying, that's my dad, and you're just rattling off, and you're going through this like whatever. And I understand that's your job, but just remember there are people that, this is their everything. And for you just to, "And this is going to happen, and in this many days left." I'm like, "Well, wait a minute. No."

So, just to realize you're talking to people....So, just talk to us with love, and compassion.

Cookie's cautions healthcare professionals to slow down, be present, attentive and actively listen to family caregivers:

Well, they should be a little more attentive, not in and out of the office in five minutes, and give the caregiver a chance to ask questions. And if they have something that they feel the caregiver should know, they should tell them. They shouldn't be rushed. They should take their time talking. I know they are very busy, and you don't want to take up a lot of their time, but on the other hand, you need them to give you advice, you know?

Heather recommends that health care systems need to dedicate people who can provide family caregivers with guidance and bridge gaps in understanding and knowledge. "I think family caregivers need a lot of guidance. They need to have somebody who they can ask questions to and get answers that they need to help them either deal with the situation or accept the situation".

And lastly, Ramona implores healthcare professionals to "walk a mile in my shoes":

I would say my biggest advice to healthcare professionals is imagine you are that family member. I think sometimes we forget, as healthcare professionals, this could be you one day.... And to put yourself in someone else's shoes to just try and understand why they could be as frantic or scared, even though it may not be a fearful situation, but it's scary for them.

These insider insights hold deep value. They clearly highlight the need to move toward a family-centered approach in care delivery. There was a call from the participants to health care providers to listen and be attentive to family caregivers by treating them as partners in their mutual investment in the well-being and care of the loved one. Many identified the need for greater support in navigating multiple

complex systems as outsiders. The word “bridge” was used to explain the need they felt for a more caregiver-inclusive integration of care.

Researcher’s Recommendations for Practice/Healthcare Professionals

As a result of the findings, I recommend healthcare professionals need to be trained to ask open-ended and probing questions to identify family caregivers. Healthcare professionals need to look intentionally for the signs of the caregiver role even when the caregiver does not respond to the label. For example, targeted questions posed to the patient [care recipient] and family member to uncover who has assumed the tasks and responsibilities the person now needs assistance with. The family member may more easily identify to the tasks of caregiving, as seen in this study, without accepting the label of caregiver. Also, the care recipient, the person in need of caregiving, does not necessarily view the caregiver as the caregiver. They can tend to minimize the role their loved one plays in their health and wellbeing.

Therefore, including the care recipient in the conversation can help to educate them to the role and encourage them to identify their family caregiver within the healthcare continuum. Again, it is essential to ask questions beyond just the label to identify the family caregivers assisting them. Also, healthcare professionals need to be educated to better understand the realities and challenges of family caregivers. Doctors, nurses and social workers working within the healthcare continuum need to understand that family caregivers prioritize the needs of their ill, aging, and disabled family members over their own, including health needs, which places them at greater risk for declined health than a non-caregiver. Healthcare professionals need to actively listen and assess the family caregiver’s needs to ensure they have what is needed to carry out complex patient care plans.

Finally, the US healthcare delivery system must recognize the vital function family caregivers assume and provide funding to support them in their role. Funding is necessary for innovative programs such as the hospital-based caregiver support center which typically exists due to philanthropy. Caregiver

Support Centers, often led by social workers, can serve as central hubs and access points bridging family-centered interventions and practices to support, provide needed education and fortify family caregivers at any point along their caregiving journey. In addition, it is essential to provide an environment that can foster communities of learning for family caregivers to teach and support each other.

Recommendations for Future Research

This study provided an understanding of family caregivers' unseen and invisible lives. It gave a valuable description of how realization, acceptance, and identification of the caregiver role/identity occurred. This study adds to the body of literature on the complex phenomenon of family caregiving and calls for future research in specific areas. Based on this study, further research should examine how the label of family caregiver is socially constructed and understood across race, culture, religion, and family norms. My research suggests that more needs to be examined and understood by researcher regarding the acceptance of the label of family caregiver, specifically across historically marginalized groups, to ensure the label itself is more recognized and accepted.

In addition, future research needs to examine how and when to prepare and educate those entering into the family caregiver role to ensure they are given access to support and increase utilization of existing services. The external acknowledgment and labeling of family caregivers by healthcare professionals may be essential to encourage and support the family caregiver's realization, acceptance, and self-identification. Therefore, there needs to be serious acknowledgement in the importance language has in conveying meaning. There should be much greater consistency using the term *family caregiver* by all healthcare professionals and systems in the US, embedding the term throughout the continuum of healthcare and by extension to wider public.

In addition, it is important to examine how best to educate current and future patients [care recipients] regarding identifying their family caregiver. This education must include language and

description to the role of a family caregiver and the importance in the patient's life living with illness or disability. The descriptive language will assist and support them to identify their family caregivers. The valuable perspectives from other key roles, such as the care recipients [family member receiving caregiving], or the health care professionals working with family caregivers and their care recipients, should be considered for future studies. The inclusion of these perspectives may allow for a more expanded understanding of the problem of identifying family caregivers.

Additionally, future studies are needed that focus on similarities and differences in culture, race, age, socio-economic status, and gender in relationship to caregiver identity/identification. Future research must examine how families and communities construct and give context to the label of family caregiver to best support acceptance of the label and identification within the healthcare continuum.

This two-pronged effort mentioned earlier requires both advocates for family caregivers and researchers to continue their efforts on both the micro and macro level. Greater research at the micro level should continue to examine the complexities of family caregiving and its place in our society. More specifically the studies should continue to explore role identification in terms of reluctance/ambivalence/hesitation of caregivers to accept this role. Simultaneously we must also continue to better integrate systematic educational programs across all age groups that advance familiarity with and understanding of family caregiving and its vital role in our common life.

Conclusion

This chapter presented my study's findings in relation to the literature, the unexpected findings, recommendations for family caregivers, health care professionals, and future research. The participants in this study provided their voices, insights, perceptions, and experiences to make more visible the role/identity of family caregivers and how they come to realization, acceptance, and identification. The timeliness and relevance of their lived experiences are never more needed, as the current models of healthcare delivery are ill-prepared for the *silver tsunami*, which results in the most significant historic

shift in the population of people over 65 and older in the US, consequently pulling with it the prevalence of family caregiving. The ability to assess and support the needs of the family caregivers throughout the healthcare continuum will be critical to ensuring they have the skills, education and supports they will need to meet the care needs of their aging ill or disabled loved ones.

My study found that: (1) family caregivers' acknowledgment of changed roles/relationships is needed for family caregivers to accept and identify their role as caregivers, (2) awareness and acceptance of one's family caregiver role and identity are shaped/influenced by previous experiences of seeing family caregiving within their family or work life, (3) external influences contributed to awareness of themselves as a caregiver, and (4) family caregivers either learn/develop or strengthen/hone a specific skill set which includes advocacy, coordination of services, knowledge of terminology, and flexibility and balance to make them more effective in their role. My study's findings provided a more profound understanding and added depth to Montgomery and Kosloski's (2007) caregiver identity theory.

This examination of the phenomenon of family caregivers and how they come to realize, accept, and identify within the healthcare continuum is significant as the findings in this study advances the literature. In addition, the participants provided specific recommendations for healthcare providers and systems on what would be most helpful to support them in their role. My hope is that the findings encourage and shape best practices within the healthcare continuum by influencing healthcare professionals to routinely externally label family caregivers, making them visible throughout the healthcare continuum, to more swiftly provide them with the resources and supports needed to reduce stress and burden associated with the role.

The participants in this study provided their voices and shared the inner workings of being a family caregiver with the sole hope that it may assist someone else who is new to the caregiver role. "It shouldn't have to be this hard" Ramona shared; "there are millions of us; we shouldn't feel like we have

to create the wheel.” Rose explained, “I hope this [research study] can help other caregivers get connected earlier to the resources they need to feel better about caring for their loved one.” This study was necessary to understand how caregivers experience acceptance of their caregiver identity and move to self-identification for the purpose of connecting them to essential resources and supports for their role. These findings propel future examination of family caregiver identity and recognition by engaging diverse populations and employing various research methods. Elevating the lived experiences of these 12 participants makes their stories visible and their role and identity as family caregivers seen. This study is an act of advocacy and activism for family caregivers, helping to move them from invisible to visible within the healthcare continuum.

REFERENCES

- Alzheimer's Association (2021). 2021 Alzheimer's disease facts and figures. *Alzheimer's & dementia: the journal of the Alzheimer's Association*, 17(3), 327–406. <https://doi.org/10.1002/alz.12328>
- Administration on Aging. (2021). *2020 Profile of Older Americans*. ACL.gov
- Administration for Community Living (ACL)(2019). *Brief ACL supports for family caregivers across the lifespan*. <https://agid.acl.gov>
- Aranda, M., & Knight, B. (1997). The influence of ethnicity and culture on the caregiver stress and coping process: A sociocultural review and analysis. *The Gerontologist*, 37(3), 342-354. doi:10.1093/geront/37.3.342
- AARP and National Alliance for Caregiving. (2020). *Caregiving in the United States 2020*. AARP. <https://doi.org/10.26419/ppi.00103.001>
- AARP and National Alliance for Caregiving. (2020). *The “typical” African American caregiver*. [The “Typical” African American Caregiver – AARP Fact Sheet](#)
- Beatie, B. E., Mackenzie, C. S., Funk, L., Davidson, D., Koven, L., & Reynolds, K. A. (2021). Caregiver identity in care partners of persons living with mild cognitive impairment. *Dementia*, 20(7), 2323–2339. <https://doi.org/10.1177/1471301221994317>
- Brewster, G. S., Bonds, K., McLennon, S., Moss, K. O., Epps, F., & Lopez, R. P. (2020). Missing the Mark: The Complexity of African American Dementia Family Caregiving. *Journal of family nursing*, 26(4), 294–301. <https://doi.org/10.1177/1074840720945329>
- Brown, B. (2018). *Dare to lead. Tough conversations. Whole hearts*. Random House
- Carbone, K., & Gugliucci, R. (2015). Delirium and the family caregiver: The need for evidence-based education interventions. *The Gerontologist*, 55, 345–352. doi:10.1093/geront/gnu035

- Carney, M.T., Gieniusz, M., Burns, E. (2023). Caregiving (in the Twenty-First Century). In: Wasserman, M., Bakerjian, D., Linnebur, S., Brangman, S., Mims, A., Johnson, J.C. (eds) *Geriatric Medicine*. Springer. https://doi.org/10.1007/978-3-030-01782-8_107-1
- Carter, R., & Golant, S. (2013). *Helping yourself help others: A book for caregivers*. Three Rivers.
- Census.gov. (2019). *Aging population in the U.S. ACS 2011-2015*.
<https://www.census.gov/topics/population/older-aging.html>
- Center for Medicare & Medicaid Services CMS Health Equity 2022-2032. (2022)
<https://www.cms.gov/files/document/cms-framework-health-equity.pdf> Accessed on October 4th, 2022.
- Chiaraluce, C. (2018). Narratives on the autism journey: “Doing family” and redefining the caregiver self. *Journal of Family Issues*, 39(10), 2883–2905. <https://doi.org/10.1177/0192513X18765048>
- Cohen, S., Sabik, N., Cook, S., Azzoli, A., & Mendez-Luck, C. (2019). Differences within differences: Gender inequalities in caregiving intensity vary by race and ethnicity in informal caregivers. *Journal of Cross-Cultural Gerontology*, 34(3), 245-263.
<http://dx.doi.org.molloy.idm.oclc.org/10.1007/s10823-019-09381-9>
- Coleman, E. (2016). Family caregivers as partners in care transitions: The caregiver advise record and enable act. *Journal of Hospital Medicine*, 11, 883–885. 10.1002/jhm.2637
- Dobbins, J. F. (2009). Voicing care: Discourse, identity and making of family caregivers. ProQuest
- Dobrof, J., & Ebenstein, H. (2004). Family caregiver self-identification: Implications for healthcare and social service professionals. *Generations*, 27(4), 33–38.
- Eifert, E., Adams, R., Dudley, W., & Perko, M. (2015). Family caregiver identity: A literature review. *American Journal of Health Education*, 46(6), 357–367.
[doi/10.1080/19325037.2015.1099482](https://doi.org/10.1080/19325037.2015.1099482)

- Fabius, C. D., Wolff, J. L., & Kasper, J. D. (2020). Race Differences in Characteristics and Experiences of Black and White Caregivers of Older Americans. *The Gerontologist*, 60(7), 1244–1253.
<https://doi.org/10.1093/geront/gnaa042>
- Grigoryeva, A. (2017). Own gender, sibling's gender, parent's gender: The division of elderly parent care among adult children. *American Sociological Review*, 82(6), 116-146.
doi.org/10.1177/0003122416686521
- Harvath, M. J., Sexson, K., & Bettega, K. (2022). Development of competencies to strengthen support for caregivers and enhance their capacity to provide care. *Gerontology & Geriatrics Education*, ahead-of-print(ahead-of-print), 1–5. <https://doi.org/10.1080/02701960.2022.2083117>
- Henderson, L., Maniam, B., & Leavell, H. (2017). The silver tsunami: Evaluating the impact of population aging in the U.S. *Journal of Business and Behavioral Sciences*, 29(2), 153-169.
<https://molloy.idm.oclc.org/login?url=https://www-proquest-com.molloy.idm.oclc.org/scholarly-journals/silver-tsunami-evaluating-impact-population-aging/docview/2070913293/se-2>
- Hernandez, E., Spencer, B., Ingersoll-Dayton, B., Faber, A., & Ewert, A. (2019). We are a team: Couple identity and memory loss. *Dementia*, 18(3), 1166–1180.
[doi./10.1177/1471301217709604](https://doi.org/10.1177/1471301217709604)
- Herron, R. V., Funk, L. M., & Spencer, D. (2019). Responding the “Wrong Way”: The emotion work of caring for a family member with dementia. *The Gerontologist*, 59(5), e470–e478.
<https://doi.org/10.1093/geront/gnz047>
- Hoffman, J., & Wallace, P. (2018). The cost of caring: Economic vulnerability, serious emotional distress, and poor health behaviors among paid and unpaid family and friend caregivers. *Research on Aging*, 40(8), 791–809. <https://doi.org/10.1177/0164027517742430>
- Kepic, M., Randolph, A., & Hermann, K. (2019). Care for caregivers: Understanding the need for caregiver support. *Adultspan Journal*, 18(1), 40-51. <https://mds.marshall.edu/adsp/vol18/iss1/4>

- Liu, C., Badana, A. N. S., Burgdorf, J., Fabius, C. D., Roth, D. L., & Haley, W. E. (2020). Systematic review and meta-analysis of racial and ethnic differences in dementia caregivers' well-being. *The Gerontologist*, 61(5), e228–e243. <https://doi.org/10.1093/geront/gnaa028>
- Manen, M. (2014). *Phenomenology of practice: meaning-giving methods in phenomenological research and writing*. Left Coast Press.
- Marino, V. R., Badana, A. N. S., & Haley, W. E. (2020). Care demands and well-being of primary and secondary non-spousal caregivers of aging adults. *Clinical Gerontologist*, 43(5), 558–571. <https://doi.org/10.1080/07317115.2020.1759748>
- Mather, M., Jacobsen, L. A., & Pollard, K. M. (2015, December). *Aging in the United States*. Population Reference Bureau, 70(2), 1-19. Retrieved from <http://www.prb.org/pdf16/aging-us-population-bulletin.pdf>
- McAllum, K., Simpson, M. L., Unson, C., Fox, S., & Kilpatrick, K. (2021). The socialization of unpaid family caregivers: A scoping review. *Research on Aging*, 43(7-8), 263–273. <https://doi.org/10.1177/01640275211005092>
- McLeod, B. (1999). *Caregiving: The spiritual journey of love, loss, and renewal*. John Wiley & Sons.
- Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation*. John Wiley & Sons.
- Mertler, C. (2019). *Introduction to educational research* (2nd ed.). Sage.
- Montgomery, R. J., Rowe, J. M., & Kosloski, K. (2007). Family caregiving. *Handbook of gerontology: Evidence-based approaches to theory, practice, and policy*, 426-454.
- Montgomery, V., & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. *Generations*, 33(1), 47-52.

- Moore, H., & Gillespie, A. (2014). The caregiving bind: Concealing the demand of informal care can undermine the caregiving identity. *Social Science & Medicine*, 116(2), 102-109.
doi.org/10.1016/j.socscimed.2014.06.038
- National Alliance for Caregiving. (2015). Caregiving in the US 2015. *NAC and the AARP Public Institute*. https://www.caregiving.org/wp-content/uploads/2020/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf
- National Alliance for Caregiving. (2018). *From insight to advocacy: Addressing family caregiving as a national public health issue*.
- Nielsen, K., Neergaard, A., Jensen, B., Bro, F., & Guldin, B. (2016). Do we need to change our understanding of anticipatory grief in caregivers? A systematic review of caregiver studies during end-of-life caregiving and bereavement. *Clinical Psychology Review*, 44, 75-93.
- O'Connor, D. (1999). Living with a memory impaired spouse: Recognizing the experience. *Canadian Journal on Aging*, 18
- O'Connor, D. L. (2007). Self-identifying as a caregiver: Exploring the positioning process. *Journal of Aging Studies*, 21(2), 165–174. doi.org/10.1016/j.jaging.2006.06.002.
- Oliveira, D., Zarit, S. H., & Orrell, M. (2019). Health-Promoting self-care in family caregivers of people with dementia: The views of multiple stakeholders. *The Gerontologist*, 59(5), e501–e511.
<https://doi.org/10.1093/geront/gnz029>
- Older Americans Act Reauthorization Act of 2016, 42 U.S.C. § 3002 (2018).
<https://www.law.cornell.edu/uscode/text/42/3002>
- Padgett, D. (2017). *Qualitative methods in social work research* (Third edition). Sage.
- Peoples, K., (2021). *How to write a phenomenological dissertation: A step by step guide*. Sage.

- Pinquart, & Sörensen, S. (2006). Gender Differences in Caregiver Stressors, Social Resources, and Health: An Updated Meta-Analysis. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 61(1), P33–P45. <https://doi.org/10.1093/geronb/61.1.P33>
- Raise Family Caregiving Advisory Council. (2021). “recognize, assist, include & engage (RAISE) family care act initial report to congress. Retrieved 2022, March 14
<https://acl.gov/programs/supports-caregivers/raise-family-caregiving-advisory-council>
- Reinhard, S. C., Young, H. M., Ryan, E., & Choula, R. B. (2019). *The CARE Act implementation: Progress and promise*. Washington, DC: AARP Public Policy Institute.
- Reinhard, S., Feinberg, L., Choula, R. & Houser, A. (2015). *Valuing the invaluable: 2015 Update*. AARP Public Policy Institute. <https://www.aarp.org/content/dam/aarp/ppi/2015/valuing-the-invaluable-2015-update-new.pdf>
- Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019). *Valuing the invaluable 2019 update: Charting a path forward*. AARP Public Policy Institute, 146, 1-32.
- Reinhard, S. C., Caldera, S., Houser, A., Choula, R., & Evans, M. (2023). *Valuing the invaluable: 2023 update strengthening supports for family caregivers*. AARP Public Policy Institute, 1-32.
- Reinhard, S., Levine, C., & Samis, S. (2012). *Home alone: Family caregivers providing complex chronic care*. AARP Public Policy Institute & United Hospital Fund.
- Rodenbach, R. (2019). When chemotherapy fails: Emotionally charged experiences faced by family caregivers of patients with advanced cancer. *Patient Education and Counseling*, 102, 909-915.
doi.org/10.1016/j.pec.2018.12.014
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal caregiving and its impact on health: a reappraisal from population-based studies. *The Gerontologist*, 55(2), 309–319.
<https://doi.org/10.1093/geront/gnu177>

- Savundranayagam, M. Y., Montgomery, M. V., & Kosloski, K. (2011). A dimensional analysis of caregiver burden among spouses and adult children. *Gerontologist*, 51(3), 321-331.
doi.org/10.1093/geront/gnq102
- Schulz, R., & Eden, J., National Committee on Family Caregiving for Older Adults In National Academies of Sciences, Engineering, and Medicine (U.S.). (2016). *Families caring for an aging America*. The National Academies Press.
- Schulz, R., Mendelsohn, A., Haley, W., Mahoney, D., Allen, R., Zhang, S., Thompson, L., Belle, S., Resources for Enhancing Alzheimer's Caregiver Health Investigators (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine*, 349(20), 1936–1942. doi.org/10.1056/NEJMsa035373
- Semere, W., Cemballi, A. G., Schillinger, D., Casillas, A., Lemberg, M., & Lyles, C. R. (2022). “We need to bring them out from the shadows:” A qualitative study of safety net physician leaders’ perspectives on caregivers. *Patient Education and Counseling*, 105(6), 1663–1670.
<https://doi.org/10.1016/j.pec.2021.10.019>
- Shillam, C. R. (2022). Congressional laws provide resources to support family caregivers. *Journal of Gerontological Nursing*, 48(9), 5-7.
- Skaff, M., & Pearlin, L. (1992). Caregiving: Role engulfment and loss of self. *Gerontologist*, 32(2), 656-664. doi.org/10.1037/0882-7974.11.2.247
- Sorrell, M. (2014). Moving beyond caregiver burden: Identifying helpful interventions for family caregivers. *Journal of Psychosocial Nursing and Mental Health Services*, 52(3), 15-18.
- Stall, N.M., Campbell, A., Reddy, M., & Rochon, P.A. (2019). Words matter: The language of family caregiving. *Journal of American Geriatric Society*, 67, 2008-2010.
<https://doi.org/10.1111/jgs.15988>

- Stedman, V. (2012). *Stedman's medical dictionary for the health professions and nursing*. (Illustrated 7th ed.). Lippincott Williams & Wilkins.
- Sullivan, A., & Miller, D. (2015). Who is taking care of the caregiver? *Journal of Patient Experience*, 2(1), 7–12. doi:10.1177/237437431500200103
- Ugalde, A., Krishnasamy, M., & Schofield, P. (2012). Role recognition and changes to self-identity in family caregivers of people with advanced cancer: A qualitative study. *Supportive Care in Cancer*, 20(6), 1175–81. doi.org/10.1007/s00520-011-1194-9
- Van Manen, M. (2014). *Phenomenology of practice: Meaning-giving methods in phenomenological research and writing*. Routledge.
- Washington, K., Meadows, S., Elliott, S., & Koopman, R. (2011). Information needs of informal caregivers of older adults with chronic health conditions. *Patient Education and Counseling*, 83(1), 37–44. doi.10.1016/j.pec.2010.04.017
- Wolff, J. L., Feder, J., & Schulz, R. (2016). Supporting family caregivers of older Americans. *New England Journal of Medicine*, 375(26), 2513-2515.
- Wolff, J.L., Spillman, C., Freedman, A., & Kasper, D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine*, 176, 372-379.
- Zale, E. (2018). Resiliency is independently associated with greater quality of life among informal caregivers to neuroscience intensive care unit patients. *General Hospital Psychiatry*, 52, 27-33. doi:10.1016/j.genhosppsych.2018.02.012
- 2022 National Strategy to Support Family Caregivers Available for Public Comments. (2022). In The Federal Register / FIND (Vol. 87, Issue 193, p. 60684–). Federal Information & News Dispatch, LLC.

APPENDICES

APPENDIX A: IRB EXEMPT LETTER



**MOLLOY
UNIVERSITY**

1000 Hempstead Ave., PO Box 5002, Rockville Center, NY 11571-5002

www.molloy.edu

Patricia A. Eckardt, PhD, RN, FAAN

Chair, Molloy University Institutional Review Board

Professor, Barbara H. Hagan School of Nursing and Health Sciences

E: peckardt@molloy.edu

T: 516.323.3711

DATE: January 30, 2023

TO: Tara Anglim, MSW, BSW

FROM: Molloy University IRB

PROJECT TITLE: [1997843-1] Family Caregivers: From Invisible to Visible
Within the
Healthcare Continuum

REFERENCE #:

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS

DECISION DATE: January 30, 2023

REVIEW Exemption category # 2

CATEGORY:

Thank you for your submission of New Project materials for this project. The Molloy University IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations. However, exempt research activities are subject to the same human subject protections and ethical standards as outlined in the Belmont Report.

You may proceed with your project.

This acknowledgement expires within three years- unless there is a change to the protocol.

Though this protocol does not require annual IRB review, the IRB requires an annual report of your exempt protocol (Expedited and Exempt Research Protocol Annual Report Form) which is available on the IRB webpage.

If there is a proposed change to the protocol, it is the responsibility of the Principal Investigator to inform the Molloy University IRB of any requested changes before implementation. A change in the research may change the project from EXEMPT status and requires prior communication with the IRB.

We will retain a copy of this correspondence within our records.

If you have any questions, please contact Patricia Eckardt at 516-323-3711 or peckardt@molloy.edu. Please include your project title and reference number in all correspondence with this committee.

Sincerely,

Patricia Eckardt, Ph.D., RN, FAAN

Chair, Molloy University Institutional Review Board

This letter has been issued in accordance with all applicable regulations, and a copy is retained within Molloy University IRB's records.

APPENDIX B: INTERVIEW PROTOCOL

For all Participants: The study will be explained in detail to the participant by the researcher, during the informed consent discussion and review of forms. At that time any questions that the participant has regarding the interview process will be answered. The confidentiality of the participant will be explained.

The following semi structured interview sample questions may be changed as the research progresses.

Sample Interview Questions for Family Caregiver:

Intro:

1. Tell me about why you were referred to the Family Support Center.

Probe: How long have you cared for your family member?

Probe: Who referred you and why?

2. Can you talk a little about the relationship you had with your loved one before you became a caregiver?

Probe:

Internal Caregiver Identity:

(1) How would you currently describe your identity as a caregiver for your loved one?

Probe:

(2) How is your caregiver identity different from how you saw yourself before becoming a caregiver?

Probe:

(3) What experiences have shaped how you see yourself as a caregiver in relation to your loved one?

Probe: Does your loved one see you as a caregiver, why or why not?

(4) Do you feel there was a pivotal moment where you recall that your role shifted in relation to your loved one? Possible clarifying question: Was there a specific situation where you had to

acknowledge that your role as child/spouse/partner/sibling/friend had changed? Can you tell me about that?

- (5) Can you share your story of how you came to identify yourself as a family caregiver for the first time?*

External Caregiver Identity:

- (1) Do healthcare professionals within the continuum of care consider you a caregiver? Explain.*
- (2) As a family caregiver, tell me about a time that you had to advocate for your loved one and what was the response.*
- (3) What supports or resources from the healthcare center or healthcare system would make the caregiver's job easier?*

Caregiver Acceptance:

- (1) What do you feel occurred that helped you in accepting and acknowledging you were a caregiver?*
- (2) What do you feel occurred that made it more challenging or complicated to accept or recognize yourself as a caregiver?*
- (4) What did you gain or give up in terms of accepting the caregiver role?*
- Probes: job, freedom, travel, etc.*
- (5) At what point did you realize you were caregiving? What do you feel prompted this realization?*
- Probes: Was there a specific event or person that you recall contributed to the realization?*
- (6) What are some ways you feel healthcare professionals can best support those in a new family caregiver role to accept and acknowledge their new identity?*

Grand Tour Questions:

- (1) What advice would you give to other caregivers who are new to this role?*

- (2) *What advice would you give to healthcare professionals in regards to how they can be most helpful in supporting family caregivers?*
- (3) *Is there anything I should have asked that I didn't ask? Is there anything you want to add to anything you said?*

APPENDIX C: FOCUS GROUP PROTOCOL

For all Participants: After a participant complete the initial interview they will be asked if they wish to participate in a focus group to further discuss their experiences of becoming family caregivers. The following semi structured interview sample questions may be changed as the research progresses.

Sample Focus Group Questions for Family Caregivers:

- (1) How would you describe what it means to be a family caregiver?*
- (2) What descriptions or terms of family caregiving do you dislike and why?*
- (3) How is your caregiver identity different from how you saw yourself before your loved one needed care?*
- (4) Who remembers a specific situation where you had to acknowledge that your role as child/spouse/partner/sibling/friend had changed to that of caregiver? Can you tell me about that?*
- (5) Why do you think family caregivers do not self-identify?*
 - (a) How can we change that?*
- (6) Can you recall the first time you were referred to as a caregiver by someone other than yourself? Can you share who acknowledged you that way and the circumstances surrounding it?*
- (7) What supports have you utilized to strengthen you in your caregiver role and how were you connected to those resources?*
- (8) What do you feel healthcare professionals need to understand to better support you in your family caregiver role?*