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# The Motivations and Work-Life Balance of Paid Home-Based Caregivers of Clients Experiencing Dementia

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### Walden University

College of Psychology and Community Services

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Cheraire Lyons

has been found to be complete and satisfactory in all respects, and that any and all revisions required by the review committee have been made.

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Walden University 2023

#### Abstract

# The Motivations and Work-Life Balance of Paid Home-Based Caregivers of Clients Experiencing Dementia

by

Cheraire Lyons

MBA, University of Phoenix, 2017

BIS, Arizona State University, 2010

Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy

PhD Human and Social Services – Nonprofit Administration

Walden University

September 2023

#### Abstract

With an expected increase in demand for professional caregivers for the growing older adult and aging population, caregivers need balance in their lives so they can provide quality patient care. The purpose of this qualitative multiple case study was to explore what motivates paid, professional home-based caregivers of clients with dementia to maintain their work-life balance. The caregiver ambition framework was the guide for exploring home-based caregivers' work life issues along with caregivers' motivations for work-life enrichment. Interview data were collected from five interviews that were analyzed first manually by exploring the transcribed interviews for commonly seen words and phrases. Then, the ATLAS.ti software assisted with cross case content analysis. Ayre and McCaffery's reflexive thematic analysis was used to create categories and themes that described patterns of shared meanings. Four categories were identified that showed: (a) home-based caregivers were overly stressed with consistently challenging working conditions, (b) they maintained resiliency and a sense of fulfillment being able to help others while obtaining personal growth, (c) significant time and energy in supporting the family of the client with dementia, and (d) areas of opportunity for providing better upfront training to caregivers that will improve caregivers' and family members' confidence in the care being provided.. The study's findings reflect how the social determinants of health for professional caregivers are impacted by balancing work and life. This study contributes to social change by highlighting the needs of home-based caregivers for health care policy planning and supporting aging in place along with recommendations for future research.

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#### Dedication

This doctoral project is dedicated to my mother, Marie Viola Mitchell Brantley, my father, Steve Blake Mitchell, my husband, Robert Lyons, and our three boys, Roddres Williams, Cherod Williams, and Xavier Lyons. My family and close friends have been my support that has inspired me to continue on over the years and to continue on the path to completing this degree. My mother taught me to never give up, while my father taught me to believe in myself. My children gave me strength and my husband gave me the level of confidence and support to stay the course. Through all the support and help I received through this journey I will always be thankful to my family who supported me and encouraged me to never stop learning and striving for more. My sons you are my purpose and the reasons why I take each step in life, giving me the resiliency to keep going. My husband, you are my joy and light, and with our children, you have made me whole.

#### Acknowledgments

I would like to express great love and appreciation to the Lyons family, who have always shown me love and gave me encouragement. I would also like to express my love and appreciation to my brothers, sisters, Ceiarra, and close family members who supported me over the many years of pursuing my goals. This journey has been met with some obstacles, loss, and a lot of love, joy, and triumphs. I want to acknowledge my work families and those who stood beside me through this journey. I would also like to express a huge thank you to my committee chair, Dr. Barbara Benoliel. Your support and input were very insightful and helpful during this process. I would also like to express appreciation and thank you to my committee member Dr. Sarah Matthey. Your feedback and insights were helpful during this process.

Thank you to the participants who participated in this study and for being advocates and caregivers to our parents, grandparents, aunts, uncles, and loved ones. Your commitment to making a difference to individuals diagnosed with dementia is admirable and appreciated.

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#### Chapter 1: Introduction to the Study

#### Introduction

Professional caregiving, concerning medical/nursing tasks, is often more demanding for caregivers of older adults with dementia compared to older adults without dementia, which can challenge the caregivers' motivation to continue their career and balance the demands of their work and home life (Zahed et al., 2020). Older adults with dementia also have more comorbid conditions, including more mental health problems, neurologic disorders, cerebrovascular disease, diabetes, and injuries, which can make caring for them additionally demanding (Lee et al., 2019). Despite the complexity of care associated with older adults diagnosed with Alzheimer's disease and related dementias, many in-home paid caregivers receive little to no training in competent and compassionate care for older adults (Guerrero et al., 2019). The burden of caring for Alzheimer's patients may adversely affect caregiver health (Zahed et al., 2020). Exposure to stress cannot be overlooked by the caregivers themselves, the individuals impacted by the care being received, or by society (Zahed et al., 2020). This study examined the experiences of these professional home-based caregivers caring for older adults with dementia while balancing their work and homelife.

By 2030, it is expected that 20% of the U.S. population will be 65 years of age or older and likely need long-term care services (Shotwell et al., 2019). Traditionally, families took care of older family members, and the tendency was to have parents with dementia stay in their home settings rather than nursing homes (Dimakopoulou et al., 2020). However, people have different levels of personal resources to cope with the

demands of caregiving (Kayaalp et al., 2021). The same level of caregiving may create greater burdens for professional paid caregivers or family caregivers, and it may lead to greater conflict between work and family roles that require the same resources (Kayaalp et al., 2021).

Some family members lean toward using professional home-based caregivers (Reckrey et al., 2022). Because of the unknown factors related to caregiver stress, further research is needed to understand caregivers' mental status and related factors to improve their quality of life (Zahed et al., 2020). To explore the challenges that exist, along with positive outcomes caregivers see related to balancing being a professional caregiver and their personal lives, it is worthwhile to explore the unique experiences of these professional home-based caregivers.

#### **Problem Statement**

The number of people at risk for dementia is increasing, and individuals with dementia are relying on healthcare services. Dementia is a major public health concern with individual, social, and economic challenges (Larsen et al., 2019). With the expected 20% increase in the aging population, the demand for home healthcare workers will likely double (Shotwell et al., 2019). Older adults and policymakers prefer aging in place or staying within a community dwelling because of the shortage of healthcare professionals along with the increase in healthcare costs (van Boekel et al., 2019). In understanding the shortage of home-based professional caregivers, there will not be enough professional caregivers to meet the growing need of older adults experiencing dementia (Shotwell et al., 2019). Any negatively-seen trend that could create a turnover

of professional caregivers could create both dissatisfaction with and a decline in patient care and patient quality of life as home healthcare workers feel underpaid, undertrained, and overly stressed (Shotwell et al., 2019). When professional caregivers begin to experience caregiver burden, stress, or being undervalued as a result of working with people living with dementia, they have a significant impact on their mental and physical health (Zahed et al., 2020). Because older adults have more cognitive and physical limitations, compared with other older adults, people living with dementia have complex care management needs, and their well-being is dependent on their caregivers (Mahmoudi et al., 2022). When professional caregivers begin to sustain mental or physical health decline, this could result in caregivers not having a balance in their work and life and being unavailable to care for the growing population of individuals who live with dementia (Zahed et al., 2020).

The research problem that was addressed in the study is that there is little guidance or information about what motivates paid, professional home-based caregivers of clients with dementia to maintain their work-life balance. With the growing demand for professional caregivers for the aging population, there is a need to better understand the work-life balance of professional caregivers and the implications that exist that may have led to strain, caregiver burden, and mental and or physical health decline (Dimakopoulou et al., 2020). Further understanding is needed of what paid home-based caregivers do to create and maintain a balance between work and home that helps sustain a long-term commitment to their jobs (Kayaalp et al., 2021). Although the research regarding paid professional, nonrelated caregivers working in the home of older adults

with dementia and or memory impairment illuminates important findings, I found no qualitative studies in which the experiences and motivations of professional nonrelated home-based paid caregivers on their work—life balance were examined. In the study, I explored the experiences of home-based professional caregivers and their perceptions of working closely with families.

#### **Purpose Statement**

The purpose of the qualitative multiple case study was to explore what motivates paid, professional home-based caregivers of clients with dementia to maintain their work—life balance. I selected a sample of individual cases and explored how each caregiver finds a way to balance their work and home life to be able to sustain a balanced quality of life. This research attempted to fill the gap in understanding the experiences and motivations of paid, professional, home-based caregivers in balancing their work and home life while being a caregiver working within the home amongst the family of the older adult with dementia.

#### **Research Question**

The research question for the study is the following: What motivates paid, professional home-based caregivers of clients with dementia to maintain their work–life balance?

#### **Conceptual Framework**

Bear's (2019) caregiving ambition framework is one of the key constructs for the conceptual framework for the study. Bear developed this framework to understand an individual's aspirations and motives to nurture and care for others above and beyond any

obligation. Bear argued that people vary in their overall levels of caregiving ambition and motivation, specifically, in their aspiration to be the provider of care and to procure the provision of care. The caregiving ambition framework helped to guide this study about how the caregivers' motives concerning professional caregiving relate to how they prioritize their work and home life. This framework was used to seek out a richer examination of the caregivers' experiences, motivations, and how they believe they find a balance in their work and home lives and there is further discussion of the conceptual framework in Chapter 2.

#### **Nature of the Study**

A qualitative multiple-case study methodology following a design developed by Yin (2012) was used to address the research question in the study. A multiple-case study is an empirical inquiry that focuses on investigating a contemporary phenomenon in its real-life context (Yin, 2012, 2018). In using a qualitative approach, a small and purposively selected sample can be used that will most likely yield appropriate and useful information (Campbell et al., 2020). Yin described a multiple case study design as being aligned with replication logic as the investigator must choose each case carefully to be able to be replicated by other investigators. Literal replication predicts similar results or theoretical replication predicts contrasting results but for anticipatable reasons (Yin, 2018). In the study, a multiple case study design allowed for focusing on specific cases and the theoretical replication of the case study to explore the individual experiences and motivations of professional home-based caregivers of older adults with dementia and how they balance their work and personal lives.

I collected data via in-depth individual interviews with paid professional home-based caregivers of clients with dementia via Microsoft Teams. I created an interview guide with questions related to the conceptual framework and the literature with open-ended questions for data collection. In keeping with the case study design, participants may also present artifacts such as awards, certificates, or letters from clients or family members. I used data points created by the participants' narrative oral responses to the open-ended questions from the interviews being conducted along with data points of any artifact data presented by participants to analyze the answers obtained to the research question. Data were analyzed using manual and software assisted content analysis, following guidance from Saldaña (2014).

#### **Definition of Terms**

These definitions used in the study:

Dementia: Dementia is the result of a progressive or chronic disease of the brain that severely impairs its cortical functions (Bergmann et al., 2022). People living with dementia make up a diverse population of racially and ethnically individuals with various levels of cognitive loss, impaired ability to communicate, and manifestations of distress who receive care in varying care settings (Sefcik et al., 2022).

Direct care workers: Direct care workers are personal care aides, home health aides, and nursing assistants who provide the most hands-on care to persons living with dementia (Sefcik et al., 2022).

Formal caregiver: Caregivers who are paid to provide care at home or in a care setting (Kayaalp et al., 2021). Formal dementia caregivers of all disciplines are relied on

to use person-centered care for non-pharmacological approaches, including well-being support, promoting function, and using alternative approaches to medication (Sefcik et al., 2022).

Home health aides: The role of home health aide is to aid with patient activities of daily living and to provide support for managing chronic conditions, depending on their employer (Shotwell et al., 2019). Home health aides are subject to a variety of state-level regulations that are determinants of their pay, work hours, and scope of work. The term home health aide is often substituted for the caregiver (Shotwell et al., 2019).

*Respite care*: Respite care is a formal service that provides support to caregivers in the way of managing the people cared for (Wakefield, 2020). This service acts as a temporary cessation of providing services and relinquishing the task of being the formal care professional for a short period (Wakefield, 2020).

*Work–life balance*: The concept of satisfaction with work has been measured as a psychological construct that includes the process by which people perceive aspects of life to possess significance (Guillen, 2020).

#### Assumptions

Certain assumptions guided the study as assumptions are a necessary element in proposals because they are required to enable and conduct the study (Simon & Goes, 2013). I assumed the participants had the knowledge and experience to be able to respond to the interview questions. I assumed that the participants responded to the questions using good faith and solid judgment. I assumed that the participants added their perceptions of their individual experiences honestly and without restrictions. Last, I

assumed that the participants did not feel pressured to answer the interview questions and understood their rights before, during, and after their interviews.

#### **Scope and Delimitations**

This study's scope consists of participants from multiple case studies who meet the criteria demonstrated in the methodology section. The participation inclusion criteria consisted of professional nurses, aides, or individuals working in other human services-related professions, with either current or previous experience of providing formal care of at least 1 year to a nonrelated individual diagnosed with dementia or a form of Alzheimer disease. In addition, they must be providing care or have provided care in the homes of clients living in the United States. Professional caregivers who work in a hospital or care setting outside of the home, or those who work at home with clients who are not experiencing dementia or other cognitive impairment, were not included in this study.

#### Limitations

There were several potential limitations in the study. Within the chosen population of the professional home-based caregiver, there was the potential to have limited participation. The plan was to find professional caregivers through networking with various physician practices such as primary care, neurology, and pain management, along with professional home care agencies or professional health care or community organizations that allowed my flyers to be posted in their waiting areas or other designated areas. In addition, I posted on social media platforms aimed toward paid, professional, home-based caregivers of individuals living with dementia. There was the potential of limited participants who would be willing to be interviewed about their

personal experiences because of privacy concerns. Individuals potentially limited how much they were willing to share, which may have limited the amount of data for analysis.

Next, the chosen method of using a virtual meeting platform such as Microsoft Teams could have created barriers for participants who may not have been familiar with using a virtual meeting app. Individuals could have also experienced technical difficulties with delays that were outside of the control of the participants. With this limitation, participants were provided instructions on how to sign in and use the software to ensure the audio component was captured. Additional time was allotted for any connection or technological challenges.

Finally, as the researcher, I acknowledged biases stemming from being a previous informal caregiver. The bias limitation could have influenced the study outcomes. I addressed the limitation presented through removing the potential bias by transcribing the interviews using the participant's verbatim responses within the transcription provided within the Microsoft Teams application, as the instrument for the study bias was removed through the use of software and verbatim notetaking. Researchers who demonstrate that they understand their context and data show credibility, consistency, and lack of bias in data analysis, providing enough detail for possible replication (Ayre & McCaffery, 2022).

#### **Significance**

Findings from this study illuminated important aspects of professional caregivers' experiences and their abilities to balance their work and home life while working with a client with dementia. Existing literature reflected expected increases in demand for professional caregivers. The current research addressed the family's role as a caregiver

along with what potential caregivers' needs exist. However, there is little known about the experiences of professional paid home-based caregivers and what they are doing to balance their work and home life. I explored the experiences of professional, paid, caregivers and how they balance their work and home life to address this knowledge gap.

Study findings may have significance for key stakeholders, including professional caregivers who are working in the home of an older adult with dementia and or some form of memory impairment. In addition, findings from this study could be useful for home health agencies, long-term care agencies, and facilities, governmental programs aimed toward professional caregivers of the aging population, and senior living communities along with professional caregivers working with clients with various comorbidities. The study results may add new information to contribute to reducing professional caregiver burnout and furthering change for individuals working in the home.

The increasing prevalence of Alzheimer's disease in older adults, who constitute a vulnerable stratum of society, is a health and social concern (Zahed et al., 2020). With the projected increase and demand for professional home-based caregivers, there is an expected demand for more training and access to support and resources to aid in balancing professional caregivers' work and life. Findings from the study could provide positive social change by exemplifying the experiences of professional caregivers and bringing awareness to the factors that enable or disable this profession in balancing work and home life.

#### **Summary**

As the demand for professional home-based caregivers increases with the expected increase in the aging population, caregivers need to find a balance between caregiving and their personal lives to create their overall satisfaction with life. As more families are moving toward using home-based professional caregivers, it is worthwhile to examine what are the motives of the paid, professional, home-based caregivers and how these professional caregivers are balancing their work and home life. I used a multiple case study of a selected sample of this subgroup of professional caregivers to provide a deeper understanding of how they balance their work and life. In Chapter 2, I review the literature that informed the study and the conceptual framework for this study.

#### Chapter 2: Literature Review

#### Introduction

Demand for professional home-based caregivers continues to grow as the general population continues to age (Reckrey et al., 2022). The research problem that prompted the multiple case study is what motivates paid, professional home-based caregivers of clients with dementia to maintain their work-life balance. Paid professional caregivers in the home frequently provide both hands-on care and a wide variety of tasks that support the physical health and social and emotional well-being of those they care for (Reckrey et al., 2022). There is a gap in understanding the various factors that could impact caregivers' motivations, along with how they can find a balance between work and home life. In this chapter, I review the literature on the research problem, the framework that guided the study, and the need for further research in this important area.

#### **Literature Search Strategy**

Databases used to locate research for the literature review included PsycINFO, the Cumulative Index to Nursing and Allied Health Literature, Medline, ProQuest, Sage Journals Plus with full text, EBSCO-SocIndex, ProQuest Health with full text and Medical Collection, and Google Scholar. The following search terms were used: paid caregivers, dementia, memory loss, caregiver burnout, caregiver burden, experiences, formal caregivers, work-family conflict, the balance of work and life, caregiver stress, and home-based caregiving. Other key terms included caregiver training, factors contributing to caregiver strain, caregiver—life balance, compassion fatigue, caregiver quality of life, and caregiver motivation, as well as a combination of these search terms.

#### **Conceptual Framework**

I incorporated Bear's (2019) caregiving ambition theory in the study's conceptual framework to explore how professional home-based caregivers find a balance between their personal and work lives while staying motivated. Bear used Maslow's (1943) needs theory, Alderfer et al.'s (1974) existence relatedness and growth theory, and Deci and Ryan's (1985) self-determination theory to understand the drivers for people who engage in caregiving. Bear's framework has a logical connection to the planned multiple case studies on how the professional caregivers' motives relate to how they prioritize their work and home life while working in the home of the client experiencing dementia.

The caregiving ambition framework provided a lens through which to conceptualize aspirations for caregiving (Bear, 2019). Motivation and aspiration are terms used to describe ambitions in this study. Bear considered both the individual and social factors that influence caregiving and posited that people's ambitions or motives are shaped by their environments, which affects the work–life interface in terms of conflict and enrichment. For caregivers working as employees in healthcare organizations, Bear viewed the caregivers' ambitions as associated with a high level of work–life conflict that offered them little flexibility. At the same time, these ambitions could also be associated with a high level of work–life enrichment if resources at work make individuals better able to give care (Bear, 2019). Bear did not explore caregivers' ambitions outside of organizational settings. Some of the interview questions for this study explored the concepts Bear (2019) raised in identifying motives, aspirations, and ambitions which may help explain caregivers' ideals in the profession of caring for patients with dementia.

Sherman and Cohn (2019) raised an issue of professional caregiver identity. In creating a work life balance, an individual can maintain career ambition without the feeling of compromising too much of the caregiver's identity. Bear (2019) viewed the construct of self-determination as an identifier of three needs that people are motivated to fulfill for a satisfying life: autonomy, competence, and relatedness. Sherman and Cohn indicated that, in the caregiving ambition framework, caregivers can harness the caregiving identity as their ambition without feeling they are compromising opposing obligations, thus connecting ambition to identity that may be present outside of a workplace organization. The connection of professional identity to motivation and ambition stretches Bear's caregiving ambition framework and encourages rethinking when and why people experience work-life conflict versus enrichment, and how these experiences are bound (e.g., work–family, family–community, and work–community) to their commitments. In the study, applying Bear's framework to a home care environment where professional identity is experienced outside of a traditional workplace setting may stretch current knowledge of this framework's application. Interview questions for this study capture information to illuminate motivations related to professional identity.

I illustrated the home-based professional caregivers' motivations and how they connect to their ability to find a balance between being caregivers and their personal lives. Bear (2019) indicated that although motivation theories acknowledge the need for relatedness, relatedness has been primarily studied and operationalized in terms of the subjective sense of belonging. Furthermore, caregiving, a behavior integral to fulfilling

relatedness needs, is not typically examined in terms of motivations and ambitions (Bear, 2019).

#### **Caregiving Ambition Applied in Other Research**

Examining the connection between work and life and exploring work-life balance has been researched by various researchers. Several reviews of the caregiving ambition theory have been done to provide an understanding of how work and life roles compare to one another. Rothbard et al. (2021) indicated that caregiving ambition is seen in the experience when the employee finds enrichment when their family and work roles allow them to fulfill their desire to care for others. Individuals with high caring ambition could inherently be more likely to experience enrichment in engaging with family or as a caregiver without scarifying the work that comes with the role of a professional caregiver (Rothbard et al., 2021). Individuals with high levels of extrinsic motivation could deter the work-life balance by exerting energy, depleting ties, and resources, and feeling unfulfilled (Rothbard et al., 2021).

Ysseldyk et al. (2019) viewed the caregiving ambition theory as having two independent dimensions: to be the direct provider of care and to procure the indirect provision of care. Bear (2019) offered a way of blending two constructs of caregiving and ambition to broaden the scope of how each construct is conceptualized and blurs the boundaries between the constructs, along with creating a model for caregiving ambition and how it is formed, and in turn, impacting the nature of the work-life interface (Ysseldyk et al., 2019). More work-life theories are needed that recognize that an employee's well-being is further understood in further examination of the community and

society that the employee lives in, the employer they work for, and all the people whose lives intersect with their own to incorporate significant interdependencies across multiple levels (Ysseldyk et al., 2019).

Caregiving ambition is not only relevant to family or the intimate context but extends to individuals that aspire to care for colleagues, neighbors, friends, and people that are unknown to them (Chinchilla et al., 2023). Ambition is normally perceived in terms of work, individuals could have ambition in terms of relationship and care, and caregiving ambition is defined as an individual's aspirations to nurture and care for others above and beyond the sense of obligation (Chinchilla et al., 2023). Caregiving exists in two dimensions, the desire to provide care known as the "provider dimension," and the desire to provide resources known as the "provision dimension" (Chinchilla et al., 2023).

In summary, the concepts described by Bear (2019) and extended by Sherman and Cohn (2019) helped frame the study by drawing intrinsic and extrinsic motivation, ambition, professional identity into consideration for work life balance in a way that has not been used to explore caregivers who are working outside of workplace settings caring for patients experiencing dementia. Ysseldyk et al. (2019) added a component by identifying the importance of the community environment, in this case the patient's home and family, and Chinchilla's et al. (2023) focus on aspiration of actually providing care helps identify a key element of work satisfaction related to this current study. I have captured these concepts both in exploring the literature and in the interview questions that are seen in later chapters.

#### **Literature Review Related to Key Concepts**

#### **Increased Caregiver Demand**

Kayaalp et al. (2021) cited individuals diagnosed with some forms of a dementiarelated disease are expected to increase from an estimated 46,000,000 in 2016 to over
98,000,000 by 2060. In the United States, an estimated 1 in 10 adults aged 65 years and
older have dementia, and their numbers are expected to increase exponentially as the
baby boomer generation ages (Lee et al., 2019). Sefcik et al. (2022) indicated in the
United States, more than 6,000,000 people were living with dementia in 2021, and more
than 11,000,000 were known informal caregivers. The number of formal caregivers is
unknown as it is difficult to discern (Sefcik et al., 2022). In addition, there is an
increasing number of states that are allowing family members or relatives to be paid for
caring for older adults, in part to promote consumer direction and increase the supply of
caregivers who are publicly funded by home care programs in the United States
(Muramatsu & Yin, 2019).

Kataoka-Yahiro et al. (2019) cited the U.S. Supreme Court's landmark 1999 decision in Olmstead v. L.C. gave rise to the rapid growth of alternatives to nursing homes, which gave rights to individuals to receive care in the community instead of in institutions. By 2050, there will be an increase in the number of formal caregivers along with individuals receiving care in nursing homes, with an estimated 22% of older adults in nursing homes, private care, or community dwellings (Kalanlar & Kuru Alici, 2020). With the increasing number of dementia patients, existing outpatient programs for individuals with dementia are not able to provide sufficient care to meet the demand (Liu

et al., 2020). Individuals living with dementia require increasing levels of care, the care model has evolved, and the Centers for Medicare and Medicaid Services is transitioning long-term care services from institutions to home or community-based services (Gilson et al., 2022). Although home-care agencies are being positioned to handle this transition, there is a need for more innovative solutions to address the special challenges that exist for caring for persons living with dementia (Gilson et al., 2022). Moreover, for persons living with dementia to be able to live at home longer; these persons require support from formal caregivers, who lack knowledge of their personal histories and have a high turnover rate (Gilson et al., 2022). The current struggle represents a promising opportunity for formal care providers to have access to tools to enhance patient care (Gilson et al., 2022).

#### Family Caregivers' Work Versus Life Conflict

Life expectancy is globally increasing and is associated with the rising need to care for the aging population, while at the same time, the labor market expansion has led to a lack of available family members to provide this care (Murphy & Cross, 2021). Keeping a balance between work and the responsibilities of family caregiving can be highly demanding as doing so might require diverting personal resources such as energy, time, and finances from caregiving responsibilities (Kayaalp et al., 2021). Kayaalp et al. (2021) found that 69% of employed people who were also family members had to adjust their work schedules to meet their caregiving responsibilities.

Informal caregivers of older adults account for about half of the informal caregivers that have dual caregiving and working, with 69% of these individuals working

at least 35 hours per week outside of the home (Templeman et al., 2020). Individuals caring for family members with dementia have additional challenges (Rahman et al., 2019). Employed caregivers are subject to not only the stressors of emotional, physical, and financial strain but also secondary stressors that could occur in the workplace (Templeman et al., 2020). Working hours must be in balance with home life because of the work-life interference that is exacerbated as the employed caregivers' hours increase, leaving many employees wanting to reduce their hours to become part-time to balance their life role and well-being (Chernyak-Hai et al., 2021). Rahman et al. (2019) stated that almost 60% of U.S. family caregivers of people with dementia reported issues balancing their caregiving responsibilities with work, with two-thirds of the 60% reporting missing work, 8% turning down promotions, and 31% giving up work to attend to their caregiving responsibilities. All of these demands indicate the need for professional home caregiver relief for both personal and economic reasons.

#### The Professional Caregiver's Relationship With the Family in the Home

Professional caregivers can be required to take on a surrogate family role in their relationships with the patients and the families in the home. Professional caregivers often take on the tasks of care management, coordination, and direct care provisions in establishing relationships with healthcare professionals and are responsible for navigating communications with the healthcare team (Acquati et al., 2022). When efficient communication between caregivers and healthcare professionals exists, the caregivers feel more empowered and able to provide the best care and security to help them accomplish their responsibility (Sfeir et al., 2022). However, family members can feel

frustrated when there is a lack of communication with and information from members of the formal healthcare team (Falzarano et al., 2022). Coordination between healthcare professionals and family members has been associated with better outcomes for care recipients (Geddis-Regan et al., 2021).

Professional caregivers may feel that they are being left out of the decisionmaking process (Mason & Hodgkin, 2019). These caregivers can offer educational and skills training to family members' caregivers to help them understand dementia and the person's behavior (Quinn et al., 2019). According to Mason and Hodgkin (2019), increases in knowledge and confidence in leading complex decision-making, improvements in coping strategies, and reductions in uncertainty along with minimization of anxiety were seen among professional caregivers when they were involved in decision making and advanced care planning. Paid professional caregivers may directly impact the family caregiving experience and can alleviate some of the burden's family caregivers face, underscoring the importance of the relationship between paid professional caregivers and families of individuals with dementia (Reckrey et al., 2022). Families and care staff may overestimate the family's level of involvement in the care provided, which can create tension when the family is perceived to have invaded the professional care staff's domain (Omori et al., 2019). An emerging theme in Reckrey et al. (2022) was that family members must act in managerial roles specific to dementia-care tasks performed by either family members or professional home-based paid caregivers.

In a study on the relationship between the family and the caregiver, Shaw et al. (2021) found that hiring and orienting a home care worker created logistical challenges.

Further, trying to find a home care worker who fit both the patient's and the family's needs was stressful (Shaw et al., 2021). Mason and Hodgkin (2019) found that having home care workers allowed families to have greater intimacy levels as well as opportunities to express their values, which ameliorated burdens or role conflicts. In Shaw et al., more than a third of unpaid caregivers living in the homes of adults aged 50 years and older reported these patients also receiving care from professional paid homebased assistants, family caregivers, and home care workers, who often shared responsibilities for patient care. Continuity of care for people with dementia requires collaboration between formal caregivers and family members to ensure organizational competence and avoid role confusion (Larsen et al., 2019).

#### **Caregiver Burden**

The concept of caregiver burden is based on the feeling of responsibility for caring for relatives with dementia, which is difficult for caregivers to cope with (Seidel & Thyrian, 2019). Several researchers have examined the burden of caring for family members with dementia and have noted these caregivers suffer from social isolation, stress, and depression (Dimakopoulou et al., 2020). However, research on the burden, depression and dementia knowledge of professional paid caregivers is limited (Dimakopoulou et al., 2020). Common behavioral disorders seen in individuals living with dementia such as repetitive phenomena, sleep disorders, aggressive behaviors, roaming and getting lost, inappropriate behaviors, and bulimia and pathological collection behaviors have been identified as the biggest sources of stress for caregivers (Liu et al., 2020).

Many studies have been conducted to identify behavioral and emotional changes in people living with dementia. Managing these changes can be particularly difficult for professional caregivers and can result in emotional distress, conflict in prioritizing their needs over the needs of those they are taking care of, and difficulty providing care when they are emotionally drained (Mwendwa et al., 2021). Exposure to certain stress and some of the negative consequences of caregiving may adversely affect the health of professional caregivers and result in caregiver burden (Zahed et al., 2020).

Caregiver burden might apply to professional caregivers as well as to family caregivers. Professional caregiver burden can impact the quality of care the professional caregivers can provide. Yıldızhan et al. (2019) found that caregivers would remain engaged and be more supportive of the patient's recovery if the caregiver burden was reduced. Within the professional caregiver role, emotional support may be a strong predictor of depressive symptoms of caregivers of people living with Dementia, which can lead to a greater need for acceptance, understanding, and compassion for professional caregivers who do not receive compensation for the burden of care they bear (Sołtys & Tyburski, 2020). The consistency of the phenomenon of professional caregiver burden needs to be further explored and defined to be able to advance the science related to formal professional caregivers, resident-centered care, and nursing care of older adults (Kunkle et al., 2020).

#### **Caregiver Training**

Professional caregivers working with people living with dementia may lack expertise and care knowledge specific to this condition (Bergmann et al., 2022).

Bergmann et al., showed that healthcare providers and professional caregivers need more dementia-specific health and social competencies. The dementia care workforce, including professional caregivers, is unprepared to meet the ever-changing and complex needs of people living with the progression of dementia, resulting in many individuals receiving inadequate care (Sefcik et al., 2022). Many in-home paid caregivers have little to no training in the competent and compassionate care of older adults (Guerrero et al., 2019). Compassionate care is closely related to patient-centeredness, and showing empathy, and the act of caring is endorsed by medical educators, patients, and patient's families as being integral to good medical care (Chen et al., 2021). Competency is described by patients as individuals having technical care and nursing knowledge as well as being able to provide individualized and patient-focused care that is related to the person's needs that are receiving care (Ness et al., 2020).

Indicators of the quality of care provided to patients with dementia include dementia knowledge, experience with working with individuals living with dementia, and training on how to work with individuals living with dementia is received (Bru-Luna et al., 2022). Many people with dementia can no longer effectively express how they are feeling, which can make caregiving extremely difficult (Maskeliūnas et al., 2019). Professional caregivers of persons with dementia need to enhance their abilities to perceive communication signals, including improving their listening skills and their ability to pay attention (Maskeliūnas et al., 2019).

Training programs, preceptorships, and reflective practice knowledge could develop support for professional caregivers of people living with dementia (Attard et al.,

2020). Programs have been created to aid in training caregivers along with providing supportive measures. The Generation Connect platform was developed to support individuals living with dementia and their formal and informal caregivers to improve clinical outcomes, reduce health care costs, lower out-of-pocket costs for persons living with dementia, and receive care through home care agencies (Gilson et al., 2022). Inhome monitoring tools to support formal caregivers in the home of people with dementia's ability to detect small meaningful changes over time, monitor disease progression, and assist in predicting to preventing falls (Wrede et al., 2021).

#### **Home-Based Professional Caregiving**

The number of people being diagnosed with dementia is increasing, resulting in a heavier reliance on home healthcare services, which are less expensive than institutionalization (Larsen et al., 2019). Family caregivers may be unable to meet their loved ones' extensive care needs, resulting in using paid caregivers (Reckrey et al., 2019). Professional home-based care is a publicly funded service comprising individuals with various backgrounds such as registered nurses, auxiliary nurses, and nurse assistants who provide services to individuals with an illness or disability who are living at home and need professional services (Gulestø et al., 2022). Nationally, Medicaid long-term care dollars between both federal and state spending were \$146 billion in 2013, with \$75 billion spent on home and community-based services and \$71 billion for institutional long-term services and support as a result of the Olmstead Decision court case being upheld, allowing individuals to receive care in the community as opposed to an institution (Kataoka-Yahiro et al., 2019).

Many home health aides and formal caregivers work for managed long-term care organizations and are paid by patients or their families (Shotwell et al., 2019). More than 4,600,000 direct care workers in the United States assist with the basic and instrumental daily activities of persons living with dementia (Sefcik et al., 2022). An estimated 10% of persons living with dementia in their homes receive paid care (Reckrey et al., 2022) The percentage rises to 50% for persons with severe dementia (Reckrey et al., 2022). The authors added there is an increasing reliance on paid caregivers for persons living with dementia living at home. However, only 1 in 4 persons living with dementia receive paid care at home (Mueller et al., 2022).

Figueiredo et al. (2021) found home-based formal caregivers indicated that they performed other tasks in the house, such as doing laundry, general cleaning, and cooking for the family. The responsibility of caring for patients with dementia in their homes is seen as extremely demanding and exhausting (Liu et al., 2020). In a 2014 national survey, 69% of Americans aged 65 years or older strongly agreed that they preferred to age in place (Wienclaw, 2021). People in this age group are projected to represent 20% of the population by 2030 (Rahman et al., 2019). The growing workforce of paid caregivers is spending hours each day with patients with functional impairments along with chronic health needs. Continuous hands-on care is needed for changes in health status and psychosocial stressors (Reckrey et al., 2019). Individuals living with dementia have significantly more chronic conditions. Higher healthcare utilization along with conditions of cognitive impairment may limit the capacity for self-care in individuals living with

dementia, making caregivers responsible for managing comorbid conditions (Polenick et al., 2020).

## **Compassion Fatigue**

Compassion fatigue is defined as a state of exhaustion and dysfunction resulting from prolonged exposure to suffering and stress (Koller et al., 2022). Bru-Luna et al. (2022) found that professional caregivers experienced a significant increase in emotional stress, burnout, and mental health problems for each year spent in the profession, which can influence the quality of care they provide. Considering the general atmosphere of the workplace, or the emotional relationships with older patients, can result in professional caregivers of older people desiring to help more than care for themselves, leading to exhaustion, energy-draining stress, and burnout (Kalanlar & Kuru Alici, 2020).

Caregiving can be a 24-hr, 7-days-a-week responsibility for most caregivers. At the same time, many caregivers may work full-time jobs (Mwendwa et al., 2021).

Excess physical demands can take a toll on caregivers, which could lead to increased fatigue levels resulting in sleep deprivation and overload affecting caregiver health (Beydoun et al., 2019). Self-sacrificing caregivers are at greater risk for developing compassion fatigue as they are more likely to smoke, experience financial stress, and suffer from headaches and hypertension (Thorson-Olesen et al., 2019). Compassion fatigue also reduces a caregiver's ability to and interest in bearing the suffering of others (Hidalgo-Andrade & Martínez-Rodríguez, 2020). Caregivers with compassion fatigue may begin to suffer from a sense of hopelessness, confusion, and isolation rather than burnout (Hidalgo-Andrade & Martínez-Rodríguez, 2020).

Burnout and compassion fatigue are closely related and overlapping (Sweileh, 2020). Fatigue is described as a drop-in comfort and lack of energy or tiredness and is connected to anxiety or depression and is affected by stress (Sfeir et al., 2022). Compression fatigue is described as physical or psychological distress in caregivers or rescuers, which occur as a consequence of a continual snowballing effect in a demanding relationship with needy individuals, high responsibilities, and work demands (Sweileh, 2020). Compression fatigue results from an unknown source and in a caregiver role, the caregiver is unable to engage in a caring manner (Sweileh, 2020).

#### **Quality of Life**

Caregivers' abilities to cope with the demands of caring for individuals with dementia can impact patient care as well as caregivers' physical and emotional strain levels. The lack of coping abilities can create a negative impact on caregivers' health and mental well-being and performance and can result in their abandoning caregiving (Sarabia-Cobo & Sarriá, 2021). Disruptions in quality of life as the disease progresses and concerns over the future of the patient living with the disease can cause caregiver stress (Zahed et al., 2020). Takai et al. (2009) found that low quality of life was the most significant factor in caregiver burnout and depression. Caregivers may encounter stigmas that negatively impact their quality of life, increase caregiver burden, and lead to emotional and psychological problems, especially if they delay seeking help (Mehra et al., 2021). When there is a perceived lack of resources and energy this could create barriers for caregivers in accessing help (Stjernswärd & Hansson, 2020).

In research on dementia caregiving's impact on caregivers and facilitators, Wang et al. (2019) found that over two-thirds of caregivers in their study were physically inactive, and nearly 1 in 6 reported only eating two meals per day. These caregivers reported more financial difficulties than caregivers of people without dementia while also indicating they had less time to take care of their health because of being preoccupied with caring for the patient (Wang et al., 2019). Professional caregivers of people with dementia often have higher levels of stress and suffer from depression more frequently compared to caregivers of older adults with other health issues, which can affect their mood and health (Rahman et al., 2019). Paid professional caregivers of older adults are likely to witness significant health needs and new medical problems when chronic conditions are exacerbated or symptoms are uncontrolled, which are particularly common in homebound older adults (Reckrey et al., 2019). Providing care for a person with a disease, illness, disability, or problem related to age, along with the economic costs of caregiving, can be stressful for a care provider and impact one's quality of life (Ysseldyk et al., 2019).

In contrast, some caregivers in Kalanlar and Kuru Alici (2020) defined the quality of their life as appropriate and described humane physical working conditions with reasonable hours and opportunities for promotion along with financial incentives and job security. In Thorson-Olesen et al. (2019), individuals who were in caregiver roles for 5 years indicated experiencing emotional, physical, and financial issues. Poor health was seen as the most impactful negative outcome (Thorson-Olesen et al., 2019). Providers of care for patients with Alzheimer's disease have an inherent amount of stress that can

eventually lead to a decline in their mental, physical, and social well-being (Liu et al., 2020). The social stress of reduced social opportunities and lack of recreational activities, along with the inability to pursue hobbies or meet personal and interpersonal needs, can produce physiological stress resulting in lack of sleep, poor health, fatigue, loneliness, feelings of powerlessness, and depression (Liu et al., 2020). Internalizing stigma can lead to misinterpreting and devaluing themselves (e.g., self-stigma or internalized stigma; Velilla et al., 2022). Mehra et al. (2021) called for further research on stigma encountered by caregivers of individuals with dementia as only a few researchers have studied how caregiver stigma can impact their quality of life and increase caregiver burden, which could lead to more psychological and emotional problems.

## **Caregiver Motivation**

Caregivers may be motivated to provide care for various reasons, including feelings of duty and responsibility; guilt, love, and affection; a desire to reciprocate past help; and societal norms, along with altruism and egotistic motives (Zarzycki & Morrison, 2021). Given the challenging nature of dementia caregiving, it is important to understand what motivates people to become caregivers and why they continue in the caregiver role, despite the progressing needs of the individual living with dementia (Dombestein et al., 2021). Informal caregivers are more likely motivated by emotional ties and cultural, spiritual, and religious responsibilities while formal caregivers have financial incentive motivation (Zahed et al., 2020). Many people enter this field because they have empathetic attitudes toward people who are suffering as well as a strong desire to help others alleviate their difficulties by providing healing, encouragement, and

support (Thorson-Olesen et al., 2019). In the state of Illinois, it is allowed for relatives of older adults to become home care aides if they are hired by home care agencies that contract with the state to provide home care (Muramatsu & Yin, 2019).

Caregiver motivation may also reflect personal beliefs and biases that are influenced by societal values and expectations and create a sense of obligation in the individual (Zarzycki & Morrison, 2021). Motivation to care for others can be low when there are problems in the caregiver's interpersonal relationships and the psychological burden of caregiving is associated with negative feelings (Hidalgo-Andrade & Martínez-Rodríguez, 2020). When they are caring for older people, caregivers consistently remind themselves that one day they will also be alone, sick, and vulnerable (Kalanlar & Kuru Alici, 2020). Many caregivers do not develop high levels of psychopathological issues when motivated by a sense of satisfaction, which allows them to engage in meaningful interactions (Merlo et al., 2021).

#### **Caregiver Satisfaction**

Feelings of pleasure and satisfaction when helping others are known as compassion satisfaction (Thorson-Olesen et al., 2019). Caregivers who perceive their work purpose as working with people who need care exhibit greater satisfaction and a larger commitment to their work (Hidalgo-Andrade & Martínez-Rodríguez, 2020). Positive affection, effort, and dedication can help them communicate difficult issues more easily while providing more appropriate information to patients and feel more effective and secure in their interpersonal relationships with patients (Hidalgo-Andrade & Martínez-Rodríguez, 2020).

Caregiving is viewed as self-sacrificing in some cultures, and caring for older people may be regarded as a source of pride and status (Aman et al., 2020). Better working conditions, the payment and benefits received, the length of working hours, work demands, promotion, supervision, professional development, and participation in decision-making can empower caregivers and contribute to their perceptions of being supported, which can also create job satisfaction (Rong et al., 2022). Positive caregiving experiences can be seen in terms of psychosocial effects related to personal well-being and satisfaction with caring for another person, choosing to become a caregiver, keeping free time for oneself, and less need to vent emotions (García-Mochón et al., 2019). Taking care of individuals with dementia can be seen as rewarding and uplifting and lead to unexpected benefits such as more gratifying interpersonal connections along with recognizing one's strength of resilience, patience, and fortitude (Hu et al., 2022).

#### **Caregiver Grief**

Caregiver grief, defined as the behavioral reactions stemming from caregivers' emotional and cognitive recognition of significant personal loss, has emerged as a major stressor (Mwendwa et al., 2021). Caregiver preparedness has been connected to increased hope and reduced caregiver strain. In contrast, a lack of preparedness has been linked to the decline of the caregivers' physical and mental health along with creating complicated grief and a stressful caregiving experience (Mason & Hodgkin, 2019). Characteristics of caregiver grief include physical, emotional, and behavioral issues such as sadness, yearning, crying, changes in sleep and appetite, and trouble concentrating (Park & Galvin, 2021). Caregivers of people living with dementia may begin suffering from grief

long before the people they are caring for die. Anticipating the loss, despite the person with dementia still being physically present, can cause caregivers to become emotionally disconnected (Liew et al., 2020).

Rigby et al. (2021) found that grief increased as a direct reaction to the disease progressing, and the care recipient's functional decline increased. Prolonged grief is a clinical condition with specific grief reactions, including difficulty in accepting the loss and being able to move forward without the deceased. Symptoms associated with prolonged grief persisting for at least 6 months after the actual loss are more likely to result in adverse health conditions (Park & Galvin, 2021). Liew et al., identified the need to equip caregivers with skills for coping with caregiver grief, including providing upfront training on identifying grief.

## **Caregiver Needs**

In a systematic review, Mueller et al. (2022) analyzed 20 articles on the needs of caregivers of older adults with dementia. They found that understanding caregivers' needs across various care settings in the U.S. is essential for being able to better support the caregiving role (Mueller et al., 2022). A lack of appreciation and respect, excessive workload and conflicting expectations can lead to distress for formal caregivers (Kalanlar & Kuru Alici, 2020). Being criticized by others and being held up to others' expectations can create shame, depression, and fear of entrapment in the caregiving role (Avdikou et al., 2019). In a 2019 study, Reckrey et al. found low health literacy among paid caregivers. These caregivers were also seen as having minimal structured contact with other health providers, which may hinder appropriate communication about health needs.

Informal caregivers in Mason et al. (2022) who perceived gaps in their caregiving knowledge began seeking information to learn how to better care for their loved ones. When caregivers do not get the help they need, or if they try to do more than what they can do, physical or financial burnout can occur. Caregivers may also feel guilty when spending time caring for themselves rather than their ill or older loved ones (Mento et al., 2019). Respite care is a way to temporarily relieve caregiver burden and allow time for caregivers to rest and tend to basic everyday needs such as caring for themselves, going shopping, and having social interactions. Respite care workers can shoulder caregiving responsibilities and help minimize the incidence of caregiver burden among individuals caring for patients with dementia (Wakefield, 2020).

#### **Work-Life Balance**

The more professional caregivers are prepared, the lower the burden, strain, and mood disturbances. Lower levels in all of these areas can contribute to better self-care and improved outcomes, not only for the caregivers but also for patients (Pucciarelli et al., 2022). Caregivers who are performing double duty (e.g., caregiving and working outside of the home) can feel mental and physical pressure and have feelings of guilt and inadequacy when they lack the knowledge to provide certain aspects of care (Ladi, 2021). Without an immediate commitment to prepare the dementia care workforce, formal caregivers will be unprepared to meet the individual needs of persons living with dementia, which and may result in many persons living with dementia receiving inadequate care (Sefcik et al., 2022).

Formal caregivers with a prolonged lack of control to cope with work demands could suffer from psychological stress and burnout (Nieto et al., 2022). There need exists for balance between feelings of work–life conflict versus the enrichment of being a caregiver (Sherman & Cohn, 2019). Work–life balance across multiple roles, relationships between conflict and facilitation, and satisfaction and perceived control between the multiple roles can make it difficult to balance the complexities of life with one's environment, community, employer, geography, economics, personality, values, or information (Venkatesan, 2021). It is necessary to pay attention to workers who could have role conflicts when trying to manage work and care functions as these conflicts can lead to decreased work performance and worsening physical and mental health (Medeiros et al., 2022).

The lack of a sustainable work—life balance for caregivers can also impact employers in the forms of reduced productivity, poor employee morale, employee turnover, and higher overall stress. In the state of New York, there is a 13-hr rule under its managed long-term care program, allowing companies to mandate 24-hr shifts while only paying for 13 hr. of work (Shotwell et al., 2019). The number of years as a caregiver who feels low personal control and limited opportunities to modify their work environment exist could end up feeling helpless and suffer burnout (Nieto et al., 2022). These conditions could lead to caregivers taking a leave, reducing work hours, or quitting (Ding et al., 2021).

## **Summary and Conclusion**

In professional home-based caregiving, attempting to balance work and life can create additional burdens that can lead to further conflict with deciding between caregiving and caring for oneself. As the demand for professional home-based caregivers continues to increase, it is worthwhile to examine aspects of this work role, including how these caregivers manage to find a balance between work and life.

In Chapter 3, I discuss the methodology that I used to explore the aspects of professional home-based caregiving.

#### Chapter 3: Research Method

#### Introduction

Professional caregivers face demanding work roles, long working hours, and work overload as causes related to the work-family-caregiving conflict (Medeiros et al., 2022). The research question for the study is the following: What motivates paid, professional home-based caregivers of clients with dementia to maintain their work—life balance? This chapter includes the research design and approach to the planned study. I discuss using qualitative methodology to address the identified problem and how employing a multiple case study methodology yielded answers to the research question. Also, in this chapter are details on the interview setting and participant inclusion and exclusion criteria. I also describe the plan for ensuring the trustworthiness of the study findings and discuss ethical considerations for the study.

#### **Research Design and Rationale**

The design for the study is a qualitative multiple-case study. Yin (2012) indicated that multiple-case designs have a distinct advantage and are often considered more compelling, and overall regarded as being more robust. Case studies are defined as a systematic investigation of a case or phenomenon that has embedded and interacted within its real-life social context, and where the boundary between the case and its context is unclear and the investigation is conducted within a natural setting (Nilmanat & Kurniawan, 2021). I used a collection of five individual cases examining the personal experiences of a select sample of professional home-based caregivers who met the specific criteria for participation and had intimate firsthand knowledge of the problem

being addressed, working with clients with dementia. I analyzed the cases together in a cross-case analysis of the multiple cases to answer the research question. I examined individual stories of experiences and what each participant is doing to find a balance between being a professional caregiver and their personal lives as well similarities or differences between cases. The unit of analysis was the individual home-based professional caregiver working with clients experiencing dementia. I recruited a purposive sample of qualified participants with different experiences and motivations related to balancing their work and life.

I considered using phenomenology as the research design and determined a phenomenological approach not to be the most appropriate method for this study. Phenomenology typically seeks out a single and reasonably homogenous sample of participants who probably share a similar perspective of a phenomenon of interest to define the phenomenon (Larkin et al., 2019). Multiple case study methodology is used to answer how and why questions while developing a rich, in-depth understanding of the phenomenon of interest in its natural context (Czosnek et al., 2022). In this study, I hope to generate a new understanding of how professional caregivers balance caregiving and their personal lives and motivations to continue in their chosen career.

#### **Role of the Researcher**

In qualitative studies, the researcher is the primary data-gathering instrument. As an observer of the interviews conducted with open-ended questions to the study participants to examine what motivates paid, professional home-based caregivers of clients with dementia to maintain their work-life balance. As a previous informal

caregiver for a parent, it was important for me to recognize and address my personal biases during this study. I did reflexive journaling throughout the interviews and bracketing my ideas so as not to influence the analysis, following guidance from Baksh (2018). As a researcher using the case study method as the research methodology, I had no power over the participants as they were interviewed in a setting of their choosing and asked specific questions relating to experiences unique to them. In using a case study, how or why questions are being asked for a contemporary set of events, over which the investigator has little to no control (Yin, 2012).

When considering my personal experience as a caregiver the stories with the participants were explored, creating meaning within a context that transcend any of my preconceived notions of the phenomena, based on past experiences (Urcia, 2021). I was prepared to gather any artifacts, such as certificates from training, letters or notes from clients or families, photos, or other artifacts that they might have chosen to share with me that were related to the case. It was my goal to ensure the data being obtained used an approach that focused solely on the experiences of the paid, professional home-based caregivers of the interviewees.

#### Methodology

#### **Participant Selection**

Purposive sampling was used to recruit individuals who meet the inclusion criteria. Purposive sampling is a form of nonprobability sampling in which the participants are deliberately chosen (Bullard, 2022). I posted flyers at local nonprofit and community facilities and recruitment notices on social media platforms including

Facebook groups for professional caregivers, and healthcare offices serving the community of clients with dementia or cognitive impairment. The participants recruited were the units of analysis for the multiple case study, per Yin (2018). This method is appropriate because participants who have personal experiences with the specific phenomenon of working in the homes of individuals with dementia or who have a cognitive impairment and are paid, professional caregivers are needed for this study. Potential participants were asked questions by phone or email to determine if they qualify to participate. This process helped to narrow the potential candidates to a group of individuals who met all criteria for participation.

## **Participant Selection Criteria**

The participation inclusion criteria consisted of five individuals with either current or previous experience of providing formal care to nonrelated individuals diagnosed with dementia or cognitive impairment and receiving care in their homes. Yin (2018) referenced in using a multiple case study design the number of cases is irrelevant when the number of theoretical replications is considering each case similarities and differences. I vetted the participants and excluded individuals who did not have experience working in the home of the individual receiving care, the individual receiving care who did not have dementia or a cognitive impairment disorder, who choose to not participate in the study, who were related to the client, or who were not of a legal working age working within the United States with previous experience of providing formal care of at least 1 year to a nonrelated individual diagnosed with dementia or a form of Alzheimer disease. I targeted physician practices, and home care agencies, or

recruited via social media platforms such as Facebook, LinkedIn, or caregiver social forums. Participants were those who had cared for individuals with moderate or severe dementia or a form of cognitive impairment using professional caregivers in their homes. Participants were 18 years of age or older and were paid regardless of the source of payment.

#### **Data Collection**

For this multiple case studies, I collected narrative interview data from individual interviews conducted using internet technology programs such as TEAMS with the five participants selected for the study. This number of participants was chosen because using this sample size allowed me to recruit and interview in detail within a reasonable timeframe with only one researcher. In a simple multiple case design, the selection of two or more cases is believed to be literal replication (Yin, 2018). Participants were able to provide artifacts such as certificates from training, letters or notes from clients or families, photos, or other artifacts that are related to the case. However, no participant presented any artifact during the interviews. The goal is to collect rich thick data for each case as suggested by Yin (2018).

During data collection, care was taken to protect the confidentiality of the participant by not including any identifying details. The video camera feature was disabled, allowing for audio recording only. The duration of the interviews was 40 to 60 minutes, but if more time was needed, I allowed the participants to continue. Each study participants were provided a participant ID to protect their identity. The nomenclature of the participant ID started with "CG" caregiver, and the second half was a digit that was

based on when the researcher accepted to be a part of the study (i.e., 1, 2, etc.). I stored the data in a password-protected file on my laptop that is not shared.

#### **Instrumentation for Data Collection**

I was the data collection instrument, and I collected the data obtained for this study within a 30-day timeframe, with individual in-depth semi-structured interviews of selected participants who meet the inclusion criteria. I used an interview protocol created for this study, with the interview questions guided by the literature and reviewed by the committee chair for relevance to generating responses to answer the research question (Appendix A). Interview questions focused on the experiences and motivations of the participants in how they came to be in a workplace situation to need to balance work and home life while caring for patients with dementia in home settings, as well as their work environment. I used a virtual meeting platform such as Microsoft TEAMS to conduct the interviews.

#### **Data Analysis**

I conducted a narrative content analysis on the collected data, as detailed in Saldaña (2014) using descriptive coding. I uploaded the saved audio file transcribed to text using the TEAMS program from the interviews to ATLAS.ti software. The interviews were manually coded first to search for common words or phrases that were used as codes to code the data using the software. I used descriptive coding to search for trending phrases or words to assist with establishing categories and indexes (Saldaña, 2014). Saldaña (2014) referenced the descriptive coding process as useful in gathering summarized topics from studies such as interview transcripts, field notes, documents, and

visual materials such as photographs. Rigor was demonstrated through continual reflection, questioning, and awareness of my role in generating themes and sharing the ongoing analysis with a knowledgeable person (the chair), as suggested by Ayre and McCaffery (2022).

Once I completed the manual coding of the data, I used ATLAS.ti to organize the data and assist with analysis. ATLASTI are analysis software that sorts through the data, breaking it into parts, allowing for segmenting and retrieving sections using codes. During the coding section of the study, I decided to use ATLAS.ti over other QDA programs after I saw the quantity of data and the number of codes that came from the manual coding. The software, unlike statistical computation, does not analyze the data, but acts as a repository allowing for additional coding to reflect possible interrelationships that occurred in the content (Saldaña, 2014). The highlighted words from the manual coding were then placed as nodes in the software where the commonly seen words were searched within all conducted interviews. In addition, the ATLAS.ti AI component within the software allowed for additional codes to be seen and were then used to create additional nodes to be analyzed. The collected and organized nodes were then examined for creating categories, and the categories used explored the possible themes that cross cases. I used inquiry audits to examine the findings with my chair, who has experience in using the constant comparative method.

#### **Issues of Trustworthiness**

The term rigor instead of trustworthiness and the reconceptualization and continued use of the concepts of reliability and validity in qualitative research, which ensures rigor is built into the qualitative research process rather than evaluated only after the inquiry, and that the researcher is being proactive an taking responsibility in ensuring the rigor of the research study (Cypress, 2017).

#### Credibility

A credible study is one where the findings and conclusion accurately reflect and represent the population that was studied and has provided assurance that the researcher has properly collected and interpreted the data (Yin, 2018). As scholar-practitioner researchers, it is important to be adept in using self-techniques to improve research outcomes and provide credibility (Shufutinsky, 2020). However, it is also important for the researcher to recognize biases that they may allow for misinterpretation of the data being obtained. Using the verification and approval process enables the researcher to spend time repetitively going back and forth to obtain approval from the participant of the constructed data (Kekeya, 2021). I demonstrated credibility by citing related research, reviewing my references to ensure their accuracy and consistency, and corroborating the data with the study participants that have been confirmed for accuracy. Saldaña (2014) cited credibility can be established by validating all references are cited and are listed within the references or bibliography and specifying the method employed for data analysis is followed by the corroboration of the data with the participants themselves or through your description of data and findings were substantiated (e.g., "Data sources

included interview transcripts, participant observation field notes, and participant response journals to gather multiple perspectives about the phenomenon.")

The use of triangulation helped enhance the credibility of the study by administering the same research questions to different participants of the study, along with collecting data from different sources such as the participants and using different methods to affirm the case study being the most appropriate method. Researchers can use data triangulation interviews, focus groups, and observations to confirm the rigor of qualitative research findings (Bernstein et al., 2020). I used the method of triangulation, which assists researchers with the ability to collect comprehensive relevant information while also cross-checking the consistency of the collected data to enhance the robustness of the findings (Wahyuni, 2012). I used data triangulation involving looking at something from several angles, rather than looking at it in one way, which allows the data used to illustrate an authentic picture of a phenomenon under study (Kekeya, 2021).

#### **Transferability**

Qualitative research's purpose is to develop richness through data that is situated within a unique context (Czosnek et al., 2022). Transferability in research is being able to determine whether the findings are potentially applicable to another individual, population, time, context, or setting, and to evaluate the potential of transferability, concepts, and theories that have emerged from the original study will need to be decontextualized and abstracted (Langtree et al., 2019). Researchers can use detailed descriptions to show how the research study's findings can be applied to other contexts, circumstances, and situations (Pallipedia, n.d.). Transferability is facilitated when the

study provides a thick description necessary to enable someone interested in making a transfer to conclude whether there is a possibility of transfer can be contemplated and if the study's finding is useful for others while allowing them to make the judgments and transfer to other similar social environments (Kekeya, 2021). I ensured the study findings were transferable by illustrating the concepts and theories that were seen from the study and that the researchers discern is worthwhile to continue to examine this phenomenon.

## Dependability/Reliability

When researchers access multiple sources of evidence and apply replication logic to select cases, maintain a case study database, and develop logic models to establish causal pathways, enable the study to demonstrate reliability and validity of the study that also adds transparency and quality to the study (Czosnek et al., 2022). Establishing a chain of evidence or an audit trail will further increase the reliability of the data being collected (Yin, 2018). The study's findings have value, and other researchers can refer to similar situations which allow the study to demonstrate the study's findings, without doubt, can be relied upon (Kekeya, 2021). I ensured the study findings were dependable by establishing an audit trail for the data that I collected and how this data was used within the study.

#### Confirmability/Objectivity

The events and ideas emerging from qualitative research can represent the meanings given to real-world events by the people who live them, not the values, preconceptions, or meanings held by researchers (Yin, 2018). Confirmability is the term used to demonstrate the study's findings have been accurately and fairly presented

without bias following the required standards and requirements from the initial to final stages of the research study (Kekeya, 2021). Confirmability concerns itself with ensuring that the interpretation of the findings is not an artifact of the participants' imagination but is derived from lived experiences and is embedded in the data (Tuval-Mashiach, 2021). In qualitative case studies the researcher communicates the findings of the study to the participants to verify the meanings of interpreted data and confirm the data as a part of an audit process that is recorded and tracked in an ongoing process which leads to the conformation of the data (Kekeya, 2021).

#### **Research Ethics**

Before the interview were conducted with the professional home-based caregivers, I ensured approval was provided by Walden's University institutional review board (IRB) along with complying with Walden University's checklist regulations on appropriate procedures. Walden's IRB purpose requires compliance with federal regulations and university policies (e.g., protection of human rights, ethical partnerships with partner organizations, alignment with the University's social change mission, and appropriate usage of scholarly tools). I will identify willing partner organizations or sites. Data collected was from participants within the United States. The data collected was not obtained from my employer or any other partner organization. Study participants were not recruited from my subordinates (except for the use of anonymous surveys). Individuals were recruited using social media platforms such as Facebook, LinkedIn, and Twitter along with posting the IRB-approved flyer within the organization's office on their bulletin boards along with word-of-mouth.

I took additional measures to ensure confidentiality was taken as the priority of conducting the study. I provided participants with letters of informed consent including their rights to confidentiality before and after the interview. I did not offer any incentives to participate. To protect the privacy of the participants of this research study, I used both written and verbal informed consents that were approved by the IRB. All interviewees' identifiers were redacted, and the interviews were audio-only recordings the video component was disabled before conducting the interview. The interviewees were informed of any potential risks along with their not being any benefits to them. In addition, the interviewee was informed at the beginning and at any time during the interview, sensitive information is being shared and that their consent can be withdrawn at any time as their interview was voluntary. Throughout the interview, the interviewee was reminded of their rights and that they are volunteering to inform the study of their personal experiences. There is no ethical issue regarding where the study is conducted, as the interview was conducted using a virtual platform allowing the participant to choose where they want to join the virtual interview. I interviewed in a secure locked office and in a room where I did not have any interruptions. The data collected during the interview is stored in a locked file cabinet within my office. Walden faculty, IRB, and study participants will have access to the data collected. The data will be destroyed after 1-year preceding publication.

## **Summary**

Within Chapter 3, I have provided an outline of the methodology plan for the multiple case study to examine the challenges of balancing work and life, while also examining what successful strategies exist that create a meaningful balance allowing the caregiver to balance their roles. In this chapter, I discussed interviews with professional home-based caregivers that was conducted to illustrate what experiences and motivations of professional home-based paid were and did these experiences impact their ability to balance their work and personal lives while working with clients with dementia. The data that was obtained through the interviews from the case studies was analyzed to determine what themes are related to the primary research. In the following chapters, the findings from the analysis of the interviews may assist in providing further insight into how professional caregivers are finding a balance between work and life. In the last chapter, I discuss the interpretation and implications of the findings of this study.

#### Chapter 4: Results

#### Introduction

The purpose of this qualitative multiple case study was to explore what motivates paid, professional home-based caregivers of clients with dementia to maintain their work-life balance. I used the seminal work of Yin (2012, 2018) as a guide for the data analysis methodology of the study to focus on the real-life context of the phenomenon. I used an empirical inquiry to analyze multiple case studies of individuals with first-hand experience to understand their motivations to maintain a work-life balance for professional caregivers. The multiple case study was used to explore the connection between caregivers' work and life balance, their ambition or motivation, and what they were doing to fulfill their desire to find enrichment and balance in their work-life while working with clients with dementia keeping in line with, as suggested by Rothbard et al. (2021).

The findings were based on the analysis of data collected using semistructured individual interviews with a selected sample of professional, paid, home-based caregivers. I explored how each caregiver came into the field of caregiving and what brought them to working with patients experiencing dementia. I also explored the ways the caregivers were balancing work and life. In this chapter, I present the study's strengths and limitations.

#### **Research Setting**

This qualitative multiple case study was conducted in virtual meeting environments using Microsoft Teams. Each study participant was able to choose their

environment to take part in the virtual interview platform. No conditions were set outside of the participant's determined date, time, and agreement to use the virtual meeting place for the interviews. Each participant was able to provide their availability and reschedule the interview at any time. As a part of the inclusion criteria, each selected participant was required to have firsthand knowledge of providing care within their client's home.

#### **Demographics**

No participant demographics were collected, but the study participants were all female. In addition, the following information was noted for the participants as a part of the study criteria: (a) the participants' experiences ranged from 1 to 20 years of working as a paid professional caregiver who was also home-based with clients who experienced dementia, (b) each participant was 18 years or older and had cared for individuals with moderate or severe dementia or a form of cognitive impairment in their homes, and (c) participants were paid regardless of the source of payment. Each participant started out in a different career but wanted to do more to help a population that needed to be cared for. Each participant reflected a compassionate characteristic when speaking about their experiences and of their time as a caregiver. During the interviews, the caregivers each expressed how they felt this career was a calling, and they felt a need to continue to come back to caregiving to satisfy their own sense of purpose.

#### **Data Collection**

In this qualitative multiple case study, there were five participants from whom the data were collected. The five participants were interviewed separately using Microsoft Teams. The participants were interviewed once as all of the data were able to be obtained

during the single interview. The interview's duration was between 45 minutes to over an hour depending on the time spent on the participants' ability to provide details to a specific question. I was the data collection instrument, and I collected the data for this study with individual, in-depth, semistructured interviews of the selected participants who met the inclusion criteria.

I used the interview protocol created and approved for this study, with the interview questions guided by the literature to conduct the audio-recorded interviews. During the Microsoft Teams meeting, I informed the participants that the interview would be recorded as audio-only and I requested that the participants not turn on their camera. Once the participant understood and agreed to the condition of the virtual meeting, the meeting began to be recorded, and each interview was conducted using the plan described in Chapter 3 of this study. Within Chapter 3, the plan included that, during data collection, I protected the confidentiality of the participant by not including any identifying details. This was done by ensuring that the video camera feature was disabled, allowing for audio recording only.

Each study participant was provided a participant ID to protect their identity. The participant ID was also used for all note taking during the interviews, the journaling, and throughout the analysis of the data. The nomenclature of the participant ID started with "CG" as an acronym for the word caregiver, and the second half was a digit that was based on when I accepted the participant to be a part of the study (i.e., 1, 2, etc.). At the conclusion of each interview, I scanned the notes to the password-protected folder that was saved to my personal computer. The hard copies of the notes are stored in my locked

file cabinet. The audio recordings are saved to my OneDrive folder on my personal computer and are each labeled using the participant ID assigned at the time of being accepted into the study. The transcribed audio-files are also saved to my password-protected OneDrive folder in my personal computer.

#### **Data Analysis**

#### **Coding of the Data**

At the conclusion of the interview, the Microsoft Teams audio recording was transcribed using the virtual meeting platform transcription. The transcription was copied verbatim to a Word document, using a new document to save the transcription from each interview. After the five interviews were transcribed, I began to manually code each interview keeping in line with Saldaña's (2014) descriptive coding process. I reread each interview response multiple times and highlighted specific words or phrases that stood out in the response for each question and these words were seen repeatedly across interviews. During the first round of coding, I identified over 50 codes relevant to the research question. At this time, I saw the quantity of data and the number of codes that came from the manual coding and made the decision to use ATLAS.TI to further analyze the data and to ensure all codes and phrases were found. The interview transcriptions were uploaded into ATLAS.ti to enable the AI component to search for additional codes to further the analysis of data. The found words from the manual coding were then placed as codes in ATLAS.ti where the commonly seen words were searched within all data from the conducted interviews using the AI coding capacity in ATLAS.ti.

### **Categorization of the Codes**

Once the computer assisted coding was completed, I then manually grouped the coded words and phrases into clusters or categories that were similar in response to each interview question. Scholars can conduct searches or queries of coded passages to find where codes co-occur, overlap, appear in a sequence, or lie in proximity to each other, which enables the researcher to infer, make connections, identify patterns and relationships, and interpret and build theory (Saldaña, 2014). I began to axial code looking for connections between each code to create categories. The categorization of the codes resulted in identifying four categories: (a) a category of codes related to caregiver challenges leading to work life conflict, (b) a category of codes that related to motivates to maintain satisfaction and self-care, (c) a category of codes related to family involvement and direct care responsibilities, and (d) a category of codes related to training provided and areas of opportunity to improve a gap in training that had not been provided.

#### **Themes**

First, I reviewed categories from the five transcribed interviews to assist with creating a structured way to review the findings. Then, I manually analyzed each of the four categories looking for the key message that permeated across the data in that category. The four themes identified within the categories included the following: (a) unacceptable working conditions negative impactful to work life balance; (b) resiliency that contributes to ambition, motivation, and work life balance; (c) the education and care of the client's family as an additional burden and boundary issue; and (d) risks from

insufficient and inconsistent training illustrated the underlying meaning of the experiences of the professional caregivers.

#### **Evidence of Trustworthiness**

## Credibility

A credible study includes findings and conclusions that accurately reflect and represent the population that was studied, and the data obtained and interpreted were properly collected (Yin, 2018). During the collection of the data, I demonstrated credibility by citing related research relevant to answering the research question. Saldaña (2014) stated that credibility can be established by validating all references are cited and are listed within the references or bibliography. I corroborated the data by using transcriptions of the interviews that took verbatim responses from the participants. Saldaña indicated that specifying the method employed for data analysis is followed by the corroboration of the data with the participants themselves or through the researcher's description of data and findings. I cross-checked the consistency of the collected data to ensure that they represented a comprehensive collection of data for a robust study. Rigor was demonstrated through the use of triangulation; I collected data from different sources, such as the participants of the multiple interviews and through the use of the secondary research cited in Chapter 2. Langtree et al. (2019) cited that credibility is seen when the researcher acknowledges a wide range of primary and secondary sources that are used to develop and validate the researcher's interpretation. To support credibility, the data were reviewed from different data points, rather than looking at the data only considering a single perspective from the interviews, which allowed the data to illustrate

an authentic picture of what motivates paid, professional home-based caregivers of clients with dementia to maintain their work—life balance as suggested by (see Kekeya, 2021).

## **Transferability**

In the study, I provided detailed descriptions to show how the findings from the research can be applied to other contexts, circumstances, and situations. The study's findings illustrated categories and their emerging themes that could be useful in others making the decision to transfer the findings to other similar social environments as suggested by (Kekeya, 2021). The research findings are potentially applicable to other individuals, populations, times, contexts, or settings as indicated within Chapter 3. The findings can be transferable to other caregivers who have had difficulties concerning maintaining work-life balance. Overall, the study demonstrated a richness through the data that were situated within the unique context illustrated, as suggested by Czosnek et al. (2022).

## **Dependability**

The data can be deemed dependable, as I followed my data collection and analysis plan as presented in Chapter 3. According to Langtree et al. (2019), dependability is demonstrated by providing a comprehensive description of the study's design in the narrative giving a detailed account of the search strategy, analysis methodology, and how the researcher monitored biases. To ensure dependability, I established an audit trial by maintaining a journal throughout the data collection process which consisted of my notes and thoughts, as suggested by Yin (2018).

### **Confirmability**

The data obtained in this study were derived solely from the interviews of the participants who had firsthand knowledge of the research question. I demonstrated the confirmability of the study findings by accurately and fairly presenting the data I collected without bias that were derived from the experiences of the participants of the study. I was able to demonstrate confirmability by regularly reflecting through journaling. Langtree et al. (2019) stated that researchers need to examine how their own subjective, preconceived notions may be influencing the analysis; through reflection, researchers are then able to organize, critically evaluate, and reconceptualize their thinking, resulting in the generation of new insights and understanding.

## **Study Results**

The research question addressed in this multiple case qualitative study was the following: What motivates paid, professional home-based caregivers of clients with dementia to maintain their work—life balance? The study findings have been analyzed to determine how each caregiver found a way to balance their work and home life while sustaining a balanced quality of life. Responses from the participants during the individual interviews revealed that participants felt that they did not have a work-life balance, and they recognized that a balance is needed to be able to care for themselves. Furthermore, it was found that participants received limited training and more often obtained specialized training either while working on the job or through seeking it out on their own.

## Theme: Unacceptable Working Conditions Negatively Impact Work/Life Balance

From the categories that included all the challenges leading to work/life conflict, the theme was the unacceptable working conditions that negatively impact work/life balance. Most of the participants indicated that they found the general working conditions intolerable, with long workdays and challenges in receiving adequate relief during the day to allow for them to go home at the end of their shift to care for themselves and their family. Participant CG1 stated, "You do 12 hours, you 16 hours sometimes" and "I don't have enough time, I don't have no time." This theme was poignant, as it related to caregivers working in their clients' homes, the stress of constant care demands with clients experiencing dementia, and the need for relief and support that goes unheeded in private home settings. Participant CG2 stated, "If someone was coming in to stay for the overnight shift, a lot of time people call out like on a Friday or Saturday, and you are required to stay there until they find coverage." Most participants referenced that call-out and inconsistent call coverage was constantly a challenge.

## Theme 2: Resiliency That Contributes to Ambition Motivation and Work Life Balance

The theme I extracted from the categories illustrated that a sense of purpose was found to be the most prominent motivation of the professional caregivers, which was seen in the motivates to maintain satisfaction. Two of the participants left caregiving, but returned to the career based on caregiving provided a sense of purpose. Participant CG1 stated, "My major satisfaction is when you see your clients doing what they couldn't do before, when you see them improving daily... it's kind of gives me a sense of satisfaction

fulfillment as an individual." Participant CG5 stated, "Sometimes it's hard when you do have kids as young as I do and be able to make it to sporting events and try to balance your schedule." Participant CG1 stated, "What motivates me? I'll say definitely not the money.... because the money is not good. Okay, there is a passion that I have for the clients. I have that kind of challenge, but the passion motivates me." Through analysis of interview data, a common trend was that the participants worked between 18 to 20 years in the field, and that, regardless of the caregiver professional challenges that led to work-life conflict, caregivers were resilient and still chose to stay in the caregiver field. The emerging theme of resiliency was seen in their commitment and motivation to maintain satisfaction and self-care. Most of the participants referenced low pay, but felt caregiving was still their calling.

# Theme 3: The Education and Care of the Client's Family as an Additional Burden and Boundary Issue

In the categories that included the codes related to family involvement and direct care responsibilities, there was a key message about the need for collaboration amongst the professional caregivers, family members, and clients experiencing dementia. In addition, relationship building was seen as important while managing expectations of the family. Participant CG5 stated,

But just the safety aspect and the caregiver fatigue that comes with being in the home, that's like the biggest thing that I've noticed...And the fact that some family members don't know when too much is too much...And that's what you see a whole lot because it's definitely frustrating and no one wants to say this is

bothering me, I don't want to do it anymore and then feel guilty for not wanting to take care of their family members. But it is a lot that goes into taking care of someone who is demented and keeping them safe in their environment and being able to live and have a life outside of them is a very difficult thing to do.

Participant CG1 stated, "I teach the family about dementia, the different stages of it and what to expect actually when it is coming up to the end." The role and expectations for the professional caregivers to provide education and support to family members while continuing to care for the clients with dementia was seen as an unwelcome burden. The constant demands of family for additional care hours created a boundary problem, where families did not consider the work/life balance and personal needs of the professionals in the clients' homes.

## Theme 4: Risks From Insufficient and Inconsistent Training

The theme from the categories that included codes from data related to training, lack of training, and the need for training suggests that there are risks to the professionals and the clients from insufficient and inconsistent standards of training for the role of professional home caregiver. Within the category of training provided and areas of opportunity, the participants indicated that they went out on their own to obtain education and training on care specific to dementia, along with their employers and caregiving agencies providing support in means of training on noncompliant patients and CPR.

When participant CG1 was asked the interview question of what types of specialized training was received, Participant stated, "I did more it on my own by reading more" and I had that challenge and then by the time I worked with one to two, I got to know more."

Further analysis of the category illustrated the participants' perception of receiving limited training and how these perceptions were found to be an emerging theme of gaps in training as four of the five participants felt that they received some form of training but not nearly enough for them to be sufficient to do their job in the beginning. Participant CG2 stated, "when I first started, I was kind of like this is it, you know, like you're putting me in there and like I just had a manual and a quick little training." Participant CG1 stated, "the training was not really specialized" and "I did more of it on my own by reading" the training consisted of "three hours of training on how to care for patients with dementia" when being placed in the home.

Although training was offered, it was indicated that the participants obtained training through self-directed means, such as online education, reading on their own, or researching dementia care. The data in the categories of training provided areas of opportunity that illustrated there was a lack of availability to obtain additional training. Participants recalled experiences of wanting additional training and not being able to obtain the training because of the limited education on dementia and availability to receive additional training because of employer limitations. Most of the participants felt that there was a lack of support with the lack of availability to receive additional training. Participant CG1 stated "it would have been better if we do it consistently, maybe every six months do another one, because the training from before, when I first started the job is not enough to get me through the whole year" and do kind of a refresher course, it will help us a lot to help patients."

Although there were no discrepant cases, there were differences that were factored into the analysis as the participants' responses when compared to the other interviews within this study on work-life balance challenges. Although the participant answered the majority of questions similar to the other participants, this participant had 1 year of home-based caregiving experience and when asked the interview question: How do you feel about your preparedness for being a professional caregiver for an individual with dementia? The participant CG5 stated,

I'm very prepared, I feel like I'm like fully prepared, but I feel like I'm fully educated on the different types of dementia. You, know, there's always room for learning, but I do feel like I'm prepared enough to be able to handle my demented patients, to handle my family members of the demented patients and be able to recognize it in a community setting, whether they're my patients or not.

Although the other participants did not feel prepared when they first began working within the home of the client with dementia, they all indicated that, as they continued caregiving, they learned on the job to be what their client needed. In addition, this interview participant was the only participant who did not feel that their pay was too low, but when asked what others were says about caregivers pay, the participant CG5 stated,

I hear about the pay being so terrible and the hours being so long and you know the coverage not being consistent and not being able to leave when they need to leave because their coverage isn't coming and now their shift is turning into an overnight shift and I think that its lost on the family members because there's this need to care for their, their family member, but not realizing that the person coming into your home, they have a family too.

# **Summary**

Within Chapter 4, I examined the study results and provided the data analysis based on the research question of what motivates paid, professional home-based caregivers of clients with dementia to maintain their work—life balance. The participant responses for the multiple case study were examined to determine what the participants were doing to maintain a balance of work and life, while also answering the questions from the protocol interview guide. I analyzed the data using ATLAS.ti a qualitative database that provided a sense of necessary order and organization, while enhancing the cognitive grasp of the work demonstrating the codes and emerging themes Saldaña (2014).

The study revealed that the caregivers' satisfaction and ability to self-care provided enough motivation to continue working under challenging conditions. However, the training that was received did not prepare the caregivers to feel equipped and able to care for their clients who were experiencing dementia. In Chapter 5, I discuss in what ways the findings confirm what was discussed in Chapter 2. An in-depth analysis and interpretation of the findings and a review of limitations from Chapter 1, followed by recommendations for future research and any seen implications for social change for professional, paid home-based caregivers of clients experiencing dementia. Analysis of the data from the multiple case study provided a foundation for the study findings presented in this chapter and recommendations that I present in Chapter 5.

## Chapter 5: Discussion, Conclusions, and Recommendations

#### Introduction

The purpose of this study was to explore what motivates paid, professional home-based caregivers of clients with dementia to maintain their work—life balance.

Furthermore, the study's design allowed the data collected to determine the experiences and motivations of the participants in balancing their work and home life, while being a caregiver working within the home amongst the family of the older adult with dementia. In Chapter 4, I analyzed data collected from the semistructured interviews with the selected five professional caregivers and explored what caregivers were doing to find ways to balance their work and home life to sustain a balanced quality of life. In Chapter 5, I convey recommended solutions, an interpretation of the study's findings, and an overview of the study's seen implications that could potentially create a social change.

# **Interpretation of Findings**

Based on information I collected from the individual interviews, I was able to discover themes from the interview questions. Findings from the interviews were compared to the literature review in Chapter 2 with the intent to address the research gap of understanding the experiences and motivations of paid, professional, home-based caregivers in balancing their work and home life while being a caregiver working within the home amongst the family of the older adult with dementia.

In the data obtained during the semistructured interviews, the responses to the interview questions provided support that there is a work-life conflict seen across cases. The caregivers indicated that conflict was felt in their work schedules, and they

experienced limited training, a lack of time for themselves, being overwhelmed, and experiencing emotional exhaustion and stress. When compared with the literature review in Chapter 2, a balance in working hours must be in balance with home life, and when work-life has been exacerbated by increased hours, this leaves caregivers wanting to become part-time or leave the field to support their own well-being, as cited by Chernyak-Hai et al. (2021). Through the data analysis, I found that more understanding is needed on what motivates these caregivers to not only create but sustain a work-life balance when working 12-hour days, 6 days a week as reported by four of the five participants.

Although the participants provided coping mechanisms that they used to assist in creating a balance that motivates them to continue to care for their clients experiencing dementia, most of participants said that they felt caregiving was their calling and recognized the challenges that exist. However, the participants felt a sense of fulfillment when being able to demonstrate a helping, patient-centered behavior with compassion and personal growth. Participants' responses reflected that having a helping behavior contributed to caregiving satisfaction and feeling appreciated created a positive experience for most of the participants. Hidalgo-Andrade and Martínez-Rodríguez (2020) referenced that when there is a perception of the caregivers working with people who need care, work is seen as purposeful greater satisfaction and commitment to their work is demonstrated.

Three of the participants felt that they had developed a positive relationship with the family that created a bond. Additionally, when asked to what extent do they believed

the family plays in creating their working conditions, all five participants agreed that having a positive relationship was good for the client's ability to not resist the care they needed. One prominent work-life conflict that created professional challenges across cases was when patients were noncompliant. All five participants recalled experiences where the patient was resistant to receiving care because of memory loss and not remembering that they needed assistance with their care needs. When compared to the literature review in Chapter 2, the coordination of patient care that exists between the healthcare professionals and family members has been associated with better outcomes for care recipients (Geddis-Regan et al., 2021). Most of the participants indicated family involvement with collaboration as being significant and needed when providing in-home care. Two participants expressed that they provide support to not only their client, but also to the client's family, and they feel they need to manage expectations, which contributes to professional work-life challenges. As cited within the literature review in Chapter 2, Figueiredo et al. (2021) stated that home-based formal caregivers were found performing other tasks in the house, such as doing laundry, cleaning, and cooking for the family outside of caring for their client.

Participant responses obtained for the initial interview question of how did they become interested in becoming a professional caregiver yielded similar responses in motives and experiences with someone close to them who had a healthcare challenge and did not receive the care they needed and had the desire to provide help. All participants expressed a sense of purpose in becoming a caregiver and choosing to work with clients with dementia or cognitive impairment. Most participants indicated career fulfillment by

acknowledging personal sacrifice with the personal experiences in professional caregiving. When comparing the literature review in Chapter 2, Liu et al. (2020) stated that when social opportunities and a lack of recreational activities exist, a social stress creates an inability to pursue hobbies or meet personal and interpersonal needs that can create stress that has a direct effect on sleep, poor health, fatigue, loneliness, feeling of powerlessness, and depression.

Most participants felt that the training was limited and was self-directed in the beginning when working with clients with dementia. Most of the participants responded to the interview question how they felt about their preparedness for being a professional caregiver for an individual with dementia or cognitive impairment with the answer of feeling unprepared. Within the literature review in Chapter 2, Bergmann et al. (2022) claimed that professional caregivers working with people living with dementia may lack the specific care knowledge with an expertise specific to the condition.

The connection between the conceptual framework of caregivers' experiences, motivations, and how the participants believe a balance in work and life exists is seen in the themes I found through an analysis of data obtained through the interviews.

Participants' commonly seen motive to maintain a work-life balance was the sense of purpose and personal growth amongst all of the participants. Bear's (2019) caregiving ambition framework aligns with the study's findings. Bear's caregiving ambition is seen in the caregiver's experience of enrichment when their roles with their family and work lives allow them to fulfill their desire to care for others. The study findings indicated that the participants felt that when they were able to help others, they were able to feel a sense

of purpose and a feeling of being fulfilled. When considering Bear's caregiving ambition framework, ambition in terms of relationship and care, along with the caregiver's aspirations to nurture and care for others beyond their sense of obligation, the study theme of motivation and ambition aligned with the framework.

# **Limitations of the Study**

Various limitations may be present in this study that were indicated within Chapter 1. Amanfi (2019) stated limitations are factors that are out of the control of the researcher. For this study, five participants were interviewed to collect data. However, Campbell et al. (2020) stated that a purposively small sample can be used and would most likely yield appropriate and useful information.

Another limitation of the study involves the selection of participants. For this study, participants were limited to only female caregivers. This limitation provided a generalization of experiences from only a female perspective. It is important to point out that a male professional caregiver of clients experiencing dementia may have different experiences and motivations to maintain a work-life balance. To fully understand the gap of the experiences and motivations of paid, professional, home-based caregivers in balancing their work and home life while being a caregiver working within the home amongst the family of the older adult with dementia, more researcher will need to include professional, paid, and home-based caregivers who are male and female.

#### Recommendations

There is an anticipated increase in demand for professional caregivers that is fueled by the expected increase in the aging population living with dementia. This study

focused on the firsthand knowledge of professional, paid, home-based caregivers who work with clients experiencing dementia among their family. The study reflects the perspectives of five participants and their motivations to maintain a work-life balance with clients experiencing dementia.

#### **Recommendations Related to Work-Life Balance**

Participants who have worked within the home-based caregiving field for longer than 18 years admitted challenges in creating a work-life balance. Through this study, I found that participants felt that it was beneficial for caregivers to have passion for their career choice. The participants felt that the challenges that contributed to having worklife conflict did not change their motives to maintain the balance that they have created to allow for them to continue to be a caregiver. However, research provided within the literature review in Chapter 2 has shown that professional caregivers experience emotional stress, burnout, and mental health problems for each year spent in the profession significantly, which can influence the quality of care they provide (Bru-Luna et al., 2022). Sarabia-Cobo and Sarriá (2021) stated that when caregivers lack coping abilities, this can create a negative impact on the caregivers' health along with their mental well-being and performance and can result in their abandoning caregiving. The recommendation of adding self-care education prior to the beginning of care giving and at various work stages can aid in the prevention of emotional stress and burnout while assisting caregivers in maintaining a work-life balance.

All participants identified ways that they coped with challenges experienced while caring for others. It is recommended for future research that caregivers be provided with

resources and training on the various coping mechanisms to assist with creating and maintaining a work-life balance. Job satisfaction is created when better working conditions that include better payment and benefits, improved work demand that include length of working hours, with the opportunity for professional development, and participation in decision making can create empowerment, in which, contribute to their perceptions of being supported (Rong et al., 2022). While future research on creating resources focused on coping mechanisms, caregivers could develop skills to help overcome struggles or challenges to maintain mental and emotional well-being.

# **Recommendations Related to Professional Caregiving Training**

Amongst the participants, I found a gap in caregiving training specific to caring for clients who were experiencing dementia and the progression stages of this disease that has the potential to impact the professional caregiver's ability to provide quality care to this population. I reviewed the literature review in Chapter 2 to make connections with the participants' responses. The research illustrated that the dementia care workforce of professional caregivers is unprepared to meet the ever-changing and complex needs of people living with the progression of dementia, in which may result in many providing inadequate care (Sefcik et al., 2022). All participants indicated that they went out on their own to obtain the training they felt was needed to provide adequate care for their clients living with dementia. It has been suggested by the study's participants that training needs to be more specialized around care specific to dementia. Gilson et al. (2022) stated that formal caregivers need to have access to tools to enhance patient care and this deficiency creates a promising opportunity. Various training courses on emotional support to assist

with being able to manage the challenges were described in working with noncompliant patients. In addition, participant's responses indicated training on the varying stages of dementia and behavior modification training to understand the various ways to communicate with individuals experiencing dementia or cognitive impairment would be helpful. Furthermore, it has been suggested that trainings need to be more consistent and made available more frequently along with in-depth training provided at the beginning of working with clients with dementia.

The recommendation is to have certified, licensed, or registered nurses or previously trained healthcare professionals experienced in the specific training modality related to dementia care provide this training. The recommendation includes videos made publicly available that are vetted by the agency or employer of the professional caregivers to ensure that the training is specifically related to dementia care. It is also recommended that these materials are reviewed on an annual basis to ensure that the quality and content is still relevant and up to date to meet the current standards of medical care. These recommendations will provide professional caregivers the opportunity to further their knowledge, awareness, and understanding at the beginning of working with clients with dementia and as their conditions progress instead of the limited training being provided or the self-directed training being done by the caregiver. This training can also provide positive experiences that expand caregivers' motivations and ambitions to maintain their work-life balance and stay within the caregiver field.

This study focused on what motivates these caregivers to maintain a work-life balance. This study focused on the family involvement, satisfaction, challenges, and

work-life conflict that may impact the caregiver's ability to maintain a work-life balance.

A possible area to further the research is to include the perceptions of self-efficacy on the self-directed training versus the training offered by the caregiver agency and or employer. Professional caregivers pursue self-direct training, education, and knowledge may have a greater self-efficacy if they feel they have been offered similar training by their agency or employer and did not have to pursue this training on their own.

### **Recommendations for Future Research**

It is recommended that future research on professional caregivers working within the home of the client experiencing dementia examine the upfront training at the beginning and at varying intervals that is being offered and provide updated materials to ensure that the information is still relevant. As professional caregivers continue to be in demand, future research is warranted in order to provide society with professionals who are not only trained to work with dementia-specific clients but have the emotional and mental capacity to care for themselves. Professional caregivers' ability to create and maintain work-life balance is essential as parents, grandparents, and loved ones continue to age and be diagnosed with dementia. The study's findings have illustrated there is a need for future research on examining coping mechanism education, dementia-specific training that varies over the stages of dementia, and self-care resources to aid in emotional and mental health well-being and quality of help.

### **Recommendations Related to Social Change**

Based on the participants' responses, limited training had been offered and no dementia specific training to clients living with dementia had been received. The

participants found themselves unprepared to provide quality care which created work life conflict. This study's findings present a social change opportunity for employers and caregiving agencies with the ability to create caregiver preparedness for those who work with clients experiencing dementia. In addition, requiring professional caregivers of clients experiencing dementia to have dementia-specific knowledge and training before they can be assigned to provide homecare to clients experiencing dementia or cognitive impairment has the potential of creating preventative measures to help professional caregivers sustain a work-life balance.

# **Implications**

The potential for a positive social change is seen in the findings of this study. Through analyzing the qualitative multiple case studies, I gained a greater understanding of the professional caregivers' experiences with work-life balance to determine their perceived preparedness to effectively provide care to clients living with dementia. The results provided insights into the experiences and the motivations of professional caregivers of clients experiencing dementia to maintain their work-life balance.

Professional caregivers for this population said they tend to feel unprepared to meet the needs of their client. Mason and Hodgkin (2019) stated that, when there is a lack of preparedness, there is an increase in caregiver decline in physical and mental health.

Professional caregivers expressed their desire for more training that focuses on patient-centered dementia care, ways to manage stress relating to emotional exhaustion, and how to manage expectations of the family and client.

Although professional caregivers receive limited training that is focused on dementia care, research shows that there is a need to inform employers and the community of training needs to ensure they are focused on dementia-specific health and social competencies (Bergmann et al., 2022). Although home-care agencies are being positioned to handle this transition, the need exists for more innovative solutions to address the challenges that are unique for formal caregivers of persons living with dementia (Gilson et al., 2022). Through the results of this study, I hope that positive social change will occur through creating more understanding and awareness on the need for professional dementia care education for caregivers working with clients living with dementia at the beginning of providing care to patients living with dementia.

#### **Conclusions**

The study's aim was to inform professional caregivers and their employers of the challenges and barriers, along with satisfaction, experienced by professional caregivers as they attempt to find a balance between their work and life. The findings of the study provide the key stakeholders with improved understanding of the motives that professional caregivers have in coming into the field of caregiving and choosing to work with clients experiencing dementia. Furthermore, the study findings illustrated the gap in understanding relating to the limited training on dementia care, leaving caregivers feeling unprepared along with examples of motivations of professional caregivers of clients experiencing dementia to maintain a work-life balance. It is my hope that positive changes will occur with the recommendations and implications provided within this study for the professional caregivers working with clients experiencing dementia.

### References

- Acquati, C., Hibbard, J. H., Miller-Sonet, E., Zhang, A., & Ionescu, E. (2022). Patient activation and treatment decision-making in the context of cancer: Examining the contribution of informal caregivers' involvement. *Journal of Cancer Survivorship*, 16(5), 929–939. https://doi.org/10.1007/s11764-021-01085-9
- Alderfer, C. P., Kaplan, R. E., & Smith, K. K. (1974). The effect of variations in relatedness need satisfaction on relatedness desires. *Administrative Science Quarterly*, *19*(4), 507–532. https://doi.org/10.2307/2391808
- Aman, Z., Liew, S. M., Ramdzan, S., Philp, I., & Khoo, E. (2020). The impact of caregiving on caregivers of older persons and its associated factors: a cross-sectional study. *Singapore Medical Journal*, *61*(5), 238–245. https://doi.org/10.11622/smedj.2019100
- Amanfi, M. (2019). A step-by-step guide on writing the dissertation: Using the qualitative research methodology. (No Title).
- Attard, R., Sammut, R., & Scerri, A. (2020). Exploring the knowledge, attitudes, and perceived learning needs of formal carers of people with dementia. *Nursing Older People*, 32(3), 25–31. https://doi.org/10.7748/nop.2020.e1225
- Avdikou, K., Stefanatos, C., Tsatali, M., Gouva, M., & Tsolaki, M. (2019). The role of gender in shame, hostility, and aggression experienced by caregivers for patients with dementia. *American Journal of Alzheimer's Disease & Other Dementiasr*, 34(4), 231–235. https://doi.org/10.1177/1533317518802458
- Ayre, J., & McCaffery, K. J. (2022). Research note: Thematic analysis in qualitative

- research. *Journal of Physiotherapy*, *68*(1), 76–79. https://doi.org/10.1016/j.jphys.2021.11.002
- Baksh, B. (2018). To bracket or not to bracket: Reflections of a novice qualitative researcher. *Reflections: Narratives of Professional Helping*, 24(3), 45–55.
- Bear, J. B. (2019). The caregiving ambition framework. *Academy of Management Review*, 44(1), 99–125. https://doi.org/10.5465/amr.2016.0424
- Bergmann, S., Peper, J., & Bieber, A. (2022). The use of formal care for dementia from a professional perspective: A scoping review. *BMC Health Services Research*, 22(1). https://doi.org/10.1186/s12913-022-08229-2
- Bernstein, A., Merrilees, J., Dulaney, S., Harrison, K. L., Chiong, W., Ong, P., Heunis, J.,
  Choi, J., Walker, R., Feuer, J. E., Lee, K., Dohan, D., Bonasera, S. J., Miller, B.
  L., & Possin, K. L. (2020). Using care navigation to address caregiver burden in dementia: A qualitative case study analysis. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 6(1).
  https://doi.org/10.1002/trc2.12010
- Beydoun, J., Nasrallah, L., Sabrah, T., & Caboral-Stevens, M. (2019). Towards a definition of caregiver fatigue: A concept analysis. *Advances in Nursing Science*, 42(4), 297–306. https://doi.org/10.1097/ans.00000000000000262
- Bru-Luna, L. M., Martí-Vilar, M., Merino-Soto, C., Salinas-Escudero, G., & Toledano-Toledano, F. (2022). Variables impacting the quality of care provided by professional caregivers for people with mental illness: A systematic review.

  \*Healthcare\*, 10(7), 1225. https://doi.org/10.3390/healthcare10071225

- Bullard, E. (2022). Purposive sampling. Salem Press Encyclopedia.
- Campbell, S., Greenwood, M., Prior, S., Shearer, T., Walkem, K., Young, S., Bywaters, D., & Walker, K. (2020). Purposive sampling: complex or simple? Research case examples. *Journal of Research in Nursing*, 25(8), 652–661. https://doi.org/10.1177/1744987120927206
- Chen, A. Y., Kuper, A., & Whitehead, C. R. (2021). Competent to provide compassionate care? A critical discourse analysis of accreditation standards. *Medical Education*, 55(4), 530–540. https://doi.org/10.1111/medu.14428
- Chernyak-Hai, L., Fein, E. C., Skinner, N., Knox, A. J., & Brown, J. (2021). Unpaid professional work at home and work-life interference among employees with care responsibilities. *The Journal of Psychology*, *155*(3), 356–374. https://doi.org/10.1080/00223980.2021.1884825
- Chinchilla, N., Grau-Grau, M., & Kim, S. (2023). Integrating the decision-making process in the work- family field: An action-based approach. *Revista Empresa y Humanismo*, 26(1). https://doi.org/10.15581/015.XXVI.1.93-120
- Cypress, B. S. (2017). Rigor or reliability and validity in qualitative research:

  Perspectives, strategies, reconceptualization, and recommendations. *Dimensions o f Critical Care Nursing*, *36*(4), 253–263.

  https://journals.lww.com/dccnjournal/fulltext/2017/07000/rigor\_or\_reliability\_an d\_validity\_in\_qualitative.6.aspx
- Czosnek, L., Zopf, E. M., Cormie, P., Rosenbaum, S., Richards, J., & Rankin, N. M. (2022). Developing an implementation research logic model: using a multiple

- case study design to establish a worked exemplar. *Implementation Science Communications*, *3*(1). https://doi.org/10.1186/s43058-022-00337-8
- Deci, E. L., & Ryan, R. M. (1985). The general causality orientations scale: Self-determination in personality. *Journal of Research in Personality*, 19(2), 109-134. https://doi.org/10.1016/0092-6566(85)90023-6
- Dimakopoulou, E., Vamvakari, E., & Sakka, P. (2020). A profile of paid caregivers who assist older adults with dementia: A descriptive study. *International Journal of Caring Sciences*, 13(3), 1582–1588
- Ding, R., Dardas, A., Wang, L., & Williams, A. (2021). Improving the workplace experience of caregiver-employees: A time-series analysis of a workplace intervention. *Safety and Health at Work*, *12*(3), 296–303. https://doi.org/10.1016/j.shaw.2020.12.003
- Dombestein, H., Norheim, A., & Aase, K. (2021). How to stay motivated: A focus group study of Norwegian caregivers' experiences with community healthcare services to their parents with dementia. *Health & Social Care in the Community*, 30(1), 235-243. https://doi.org/10.1111/hsc.13396
- Falzarano, F., Cimarolli, V. R., Minahan, J., & Horowitz, A. (2022). Long-distance caregivers: What are their experiences with formal care providers? *Clinical Gerontologist*, 45(5), 1273–1284. https://doi.org/10.1080/07317115.2020.1783043
- Figueiredo, M. D. L. F., Gutierrez, D. M. D., Darder, J. J. T., Silva, R. F., & Carvalho, M. L. D. (2021). Formal caregivers of dependent elderly people in the home:

- challenges experienced. *Ciência & Saúde Coletiva*, 26(1), 37-46. https://doi.org/10.1590/1413-81232020261.32462020
- García-Mochón, L., Peña-Longobardo, L. M., D. Río-Lozano, M., Oliva-Moreno, J.,
   Larrañaga-Padilla, I., & García-Calvente, M. D. M. (2019). Determinants of
   Burden and Satisfaction in Informal Caregivers: Two Sides of the Same Coin?
   The CUIDAR-SE Study. *International Journal of Environmental Research and Public Health*, 16(22), 4378. https://doi.org/10.3390/ijerph16224378
- Geddis-Regan, A., Errington, L., Abley, C., Wassall, R., Exley, C., & Thomson, R. (2021). Enhancing shared and surrogate decision making for people living with dementia: A systematic review of the effectiveness of interventions. *Health Expectations*, 24(1), 19–32. https://doi.org/10.1111/hex.13167
- Gilson, A., Gassman, M., Dodds, D., Lombardo, R., Ford II, J. H., & Potteiger, M. (2022). Refining a digital therapeutic platform for home care agencies in dementia care to elicit stakeholder feedback: Focus group study with stakeholders. *JMIR Aging*, *5*(1), e32516. https://doi.org/10.2196/32516
- Guerrero, L. R., Shim, A., Gans, D., Schickedanz, H. B., & Tan, Z. S. (2019). Training for in-home supportive services caregivers in an underserved area. *Journal of Health Care for the Poor & Underserved*, 30(2), 739–748. https://doi.org/10.1353/hpu.2019.0053
- Guillen, M. (2020). Motivation in Organisations. https://doi.org/10.4324/9780429317293
- Gulestø, R., Lillekroken, D., Bjørge, H., & Halvorsrud, L. (2022). Interactions between healthcare personnel and family caregivers of people with dementia from minority

- ethnic backgrounds in home-based care—An explorative qualitative study. *Journal of Advanced Nursing*, 78(5), 1389–1401. https://doi.org/10.1111/jan.15101
- Hidalgo-Andrade, P., & Martínez-Rodríguez, S. (2020). Development of a cognitive-existential intervention to decrease compassion fatigue in formal caregivers.

  \*Revista de Psicologia y Ciencias Afines, 37(2), 239–251.

  https://doi.org/10.16888/interd.2020.37.2.15
- Hu, R., Lai, B., Ma, W., Zhang, Y., Deng, Y., Liu, L., Lv, Z., Chan, C., Zhang, F., & Tao, Q. (2022). How formal caregiver's BPSD knowledge influences positive aspects of caregiving: the mediating role of attitude and the moderating role of self-efficacy. *BMC geriatrics*, 22(1). https://doi.org/10.1186/s12877-022-03417-5
- Kalanlar, B., & Kuru Alici, N. (2020). The effect of care burden on formal caregiver's quality of work life: A mixed-methods study. *Scandinavian Journal of Caring Sciences*, *34*(4), 1001–1009. https://doi.org/10.1111/scs.12808
- Kataoka-Yahiro, M. R., Davis, J., Ka'opua, L. S., & Sy, A. (2019). Sociodemographic characteristics and preferences for family (informal) and formal caregiver help with ADLs. *Home Health Care Management & Practice*, 31(2), 120–127.
  https://doi.org/10.1177/1084822318801811
- Kayaalp, A., Page, K. J., & Rospenda, K. M. (2021). Caregiver burden, work-family conflict, family-work conflict, and mental health of caregivers: A mediational longitudinal study. Work & Stress, 35(3), 217–240.
  https://doi.org/10.1080/02678373.2020.1832609

- Kekeya, J. (2021). Qualitative case study research design: The commonalities and differences between collective, intrinsic, and instrumental case studies. *Contemporary PNG Studies*, *36*, 28–37.
- Koller, E. C., Abel, R. A., & Milton, L. E. (2022). Caring for the caregiver: A feasibility study of an online program that addresses compassion fatigue, burnout, and secondary trauma. *Open Journal of Occupational Therapy*, *10*(1), 1–14. https://doi.org/10.15453/2168-6408.1847
- Kunkle, R., Chaperon, C., & Hanna, K. M. (2020). Formal caregiver burden in nursing homes: A concept analysis. *Journal of Gerontological Nursing*, 46(9), 19–24. https://doi.org/10.3928/00989134-20200706-02
- Ladi, E. (2021). Placing additional burden on caregivers with a clinical background. *Gerontology and Geriatric Medicine*, 7, 233372142110573. https://doi.org/10.1177/23337214211057386
- Langtree, T., Birks, M., & Biedermann, N. (2019). Separating "fact" from fiction:

  Strategies to improve rigour in historical research. *Forum: Qualitative Social Research*, 20(2), 1–17. https://doi.org/10.17169/fqs-20.2.3196
- Larkin, M., Shaw, R., & Flowers, P. (2019). Multiperspectival designs and processes in interpretative phenomenological analysis research. *Qualitative Research in Psychology*, *16*(2), 182–198. https://doi.org/10.1080/14780887.2018.1540655
- Larsen, L. S., Normann, H. K., & Hamran, T. (2019). Continuity of home-based care for persons with dementia from formal and family caregivers'

- perspectives. *Dementia: The International Journal of Social Research and Practice*, 18(3), 846–863. https://doi.org/10.1177/1471301216682626
- Lee, M., Ryoo, J. H., Campbell, C., Hollen, P. J., & Williams, I. C. (2019). Exploring the challenges of medical/nursing tasks in home care experienced by caregivers of older adults with dementia: An integrative review. *Journal of Clinical Nursing*, 28(23–24), 4177–4189. https://doi.org/10.1111/jocn.15007
- Liew, T. M., Tai, B. C., Wee, S. L., Koh, G. C. H., & Yap, P. (2020). The longitudinal effects of caregiver grief in dementia and the modifying effects of social services:

  A prospective cohort study. *Journal of the American Geriatrics Society*, 68(10), 2348–2353.
- Liu, C.-C., Lee, C.-F., Chang, T., & Liao, J.-J. (2020). Exploring the relationship between the caregiver's stress load and dementia patient behavior: A case study of dementia specialist outpatient data from the Southern Medical Center of Taiwan. *International Journal of Environmental Research and Public Health*, 17(14). https://doi.org/10.3390/ijerph17144989
- Mahmoudi, E., Wu, W., Najarian, C., Aikens, J., Bynum, J., & Vydiswaran, V. G. V. (2022). Identifying caregiver availability using medical notes with rule-based natural language processing: Retrospective cohort study. *JMIR Aging*, *5*(3), 1–11. https://doi.org/10.2196/40241
- Maskeliūnas, R., Damaševičius, R., Lethin, C., Paulauskas, A., Esposito, A., Catena, M., & Aschettino, V. (2019). Serious game iDO: Towards better education in dementia care. *Information*, 10(11), 355. https://doi.org/10.3390/info10110355

- Maslow, A. H. (1943). A theory of human motivation. *Psychological Review*, 50(4), 370–396. https://doi.org/10.1037/h0054346
- Mason, N., & Hodgkin, S. (2019). Preparedness for caregiving: A phenomenological study of the experiences of rural Australian family palliative carers. *Health & Social Care in the Community*, 27(4), 926–935. https://doi.org/10.1111/hsc.12710
- Mason, N. F., Francis, D. B., & Pecchioni, L. L. (2022). Health information seeking as a coping strategy to reduce alzheimer's caregivers' stress. *Health Communication*, 37(2), 131–140. https://doi.org/10.1080/10410236.2020.1824665
- Medeiros, T. J., Barbosa, G. C., Alves, L. C. D. S., & Gratão, A. C. M. (2022). Work-family balance among caregivers of elderly people: A systematic review. *Cadernos Brasileiros de Terapia Ocupacional*, 30. https://doi.org/10.1590/2526-8910.ctoAR241831542
- Mehra, A., Parveen, S., Kumar, K., & Grover, S. (2021). A comparative study of caregiver burden and stigma among the caregivers of patients with dementia and schizophrenia. *Journal of Geriatric Mental Health*, 8(1), 15–19. https://doi.org/10.4103/jgmh.jgmh\_10\_21
- Mento, C., Rizzo, A., & Settineri, S. (2019). Caregivers help-seeking related to physical and mental burden. *Clinical Neuropsychiatry*, *16*(3), 135–139.
- Merlo, E. M., Sicari, F., Frisone, F., Alibrandi, A., & Settineri, S. (2021). Burden and professional quality of life of caregivers: The clinical role of suppression and resilience. *Life Span and Disability*, 24(1), 55–83.
- Mueller, A., Thao, L., Condon, O., Liebzeit, D., & Fields, B. (2022). A systematic review

- of the needs of dementia caregivers across care settings. *Home Health Care Management & Practice*, *34*(2), 133–147.

  https://doi.org/10.1177/10848223211056928
- Muramatsu, N., & Yin, L. (2019). Gentle physical activity intervention led by caregivers in a Medicaid home care program: Do outcomes differ between family and nonfamily caregiving dyads? *Innovation in Aging*, *3*(3), https://doi.org/10.1093/geroni/igz034
- Murphy, C., & Cross, C. (2021). Blurred lines: work, eldercare, and HRM. *International Journal of Human Resource Management*, *32*(7), 1460–1485. https://doi.org/10.1080/09585192.2018.1528470
- Mwendwa, P., Mutunga, E., Kroll, T., & De Brún, A. (2021). "It is stressful, almost every hour...": Experiences of caring for people living with dementia in Kenya—An interpretive phenomenological approach. *Dementia*, 20(8), 2916–2932. https://doi.org/10.1177/14713012211022989
- Ness, T. M., Söderberg, S., & Hellzèn, O. (2020). 'The same care providers over time who make individual adjustments and have competence' older South Sami people in Sweden's expectations of home nursing care. *Scandinavian Journal of Caring Sciences*, 34(1), 181–189. https://doi.org/10.1111/scs.12719
- Nieto, A., Contador, I., Palenzuela, D. L., Ruisoto, P., Ramos, F., & Fernández-Calvo, B. (2022). The distinctive role of grounded optimism and resilience for predicting burnout and work engagement: A study in professional caregivers of older adults. Archives of Gerontology and Geriatrics, 100.

- https://doi.org/10.1016/j.archger.2022.104657
- Nilmanat, K., & Kurniawan, T. (2021). The quest in case study research. *Pacific Rim International Journal of Nursing Research*, 25(1), 1–6.
- Omori, M., Baker, C., Jayasuriya, J., Savvas, S., Gardner, A., Dow, B., & Scherer, S. (2019). Maintenance of professional boundaries and family involvement in residential aged care. *Qualitative Health Research*, 29(11), 1611–1622. https://doi.org/10.1177/1049732319839363
- Pallipedia. (n.d.). The Free Online Palliative Care Directory. https://pallipedia
- Park, J., & Galvin, J. E. (2021). Pre-loss grief in caregivers of older adults with dementia with lewy bodies. *Journal of Alzheimer's Disease*, 82(4):1847-1859. https://doi: 10.3233/JAD-210616.
- Polenick, C. A., Min, L., & Kales, H. C. (2020, March 1). Medical comorbidities of dementia: Links to caregivers' emotional difficulties and gains. *Journal of the American Geriatrics Society*, 68(3), 609-613. https://doi.org/10.1111/jgs.16244
- Pucciarelli, G., Lyons, K. S., Petrizzo, A., Ambrosca, R., Simeone, S., Alvaro, R., Lee, C. S., & Vellone, E. (2022). Protective role of caregiver preparedness on the relationship between depression and quality of life in stroke dyads. *Stroke*, 53(1), 145–153. https://doi.org/10.1161/strokeaha.120.034029
- Quinn, C., Jones, I. R., Martyr, A., Nelis, S. M., Morris, R. G., & Clare, L. (2019).

  Caregivers' beliefs about dementia: findings from the IDEAL study. *Psychology*& *Health*, *34*(10), 1214–1230. https://doi.org/10.1080/08870446.2019.1597098
- Rahman, A., Anjum, R., & Sahakian, Y. (2019). Impact of caregiving for dementia

- patients on healthcare utilization of caregivers. *Pharmacy*, 7(4). 138. https://doi.org/10.3390/pharmacy7040138
- Reckrey, J. M., Tsui, E. K., Morrison, R. S., Geduldig, E. T., Stone, R. I., Ornstein, K. A., & Federman, A. D. (2019). Beyond functional support: the range of health-related tasks performed in the home by paid caregivers in New York. *Health Affairs*, 38(6), 927-933. <a href="https://doi.org/10.1377/hlthaff.2019.00004">https://doi.org/10.1377/hlthaff.2019.00004</a>
- Reckrey, J. M., Watman, D., Tsui, E. K., Franzosa, E., Perez, S., Fabius, C. D., & Ornstein, K. A. (2022). "I am the home care agency": The dementia family caregiver experience managing paid care in the home. *International Journal of Environmental Research and Public Health*, 19(3), 1311. https://doi.org/10.3390/ijerph19031311
- Rigby, T., Johnson, D. K., Taylor, A., & Galvin, J. E. (2021). Comparison of the caregiving experience of grief, burden, and quality of life in dementia with lewy bodies, A
- Alzheimer's disease, and Parkinson's disease dementia. *Journal of Alzheimer's Disease*, 80(1), 421–432. https://doi.org/10.3233/jad-201326
- Rong, X., Zhou, Z., & Su, Y. (2022). Factors affecting the job satisfaction of caregivers in a home-based elderly care program. *International Journal of Environmental Research and Public Health*, *19*(15), 9332. https://doi.org/10.3390/ijerph19159332
- Rothbard, N. P., Beetz, A. M., & Harari, D. (2021). Balancing the scales: A configurational approach to work-life balance. *Annual Review of Organizational*

- *Psychology and Organizational Behavior*, 8 (1), 73–103. https://doi.org/10.1146/annurev-orgpsych-012420-061833
- Saldaña, J. (2014). Coding and Analysis Strategies. *The Oxford Handbook of Qualitative Research*, (pp. 580-598). https://doi.org/10.1093/oxfordhb/9780199811755.013.001
- Sarabia-Cobo, C., & Sarriá, E. (2021). Satisfaction with caregiving among informal caregivers of elderly people with dementia based on the salutogenic model of health. *Applied Nursing Research*, 62, 151507. https://doi.org/10.1016/j.apnr.2021.151507
- Sefcik, J. S., Boltz, M., Dellapina, M., & Gitlin, L. N. (2022). Are Interventions for Formal Caregivers Effective in Improving Dementia Care? A Systematic Review of Systematic Reviews. *Innovation in Aging*, 6(2). https://doi.org/10.1093/geroni/igac005
- Seidel, D., & Thyrian, J. R. (2019). Burden of caring for people with dementia—comparing family caregivers and professional caregivers. A descriptive study. *Journal of Multidisciplinary Healthcare*, *Volume 12*, 655-663.https://doi.org/10.2147/jmdh.s209106
- Sfeir, M., Zeitoun, A., Hallit, S., & Obeid, S. (2022). Presence of a psychiatric patient at home and work fatigue in family caregivers: The moderating effect of spirituality. *Perspectives in Psychiatric Care*, 58(4), 2664–2675. https://doi.org/10.1111/ppc.13107
- Shaw, A. L., Riffin, C. A., Shalev, A., Kaur, H., & Sterling, M. R. (2021). Family

- caregiver perspectives on benefits and challenges of caring for older adults with paid caregivers. *Journal of Applied Gerontology*, *40*(12), 1778–1785. https://doi.org/10.1177/073346482095955
- Sherman, R. O., & Cohn, T. M. (2019, October 2). Leadership challenge: The role of timing in work and life. *American Nurse*. https://www.myamericannurse.com/leadership-challenge-the-role-of-timing-in-work-and-life/
- Shotwell, J. L., Wool, E., Kozikowski, A., Pekmezaris, R., Slaboda, J., Norman, G., Rhodes, K., & Smith, K. (2019). "We just get paid for 12 hours a day, but we work 24": home health aide restrictions and work-related stress. *BMC Health Services Research*, 19(1). https://doi.org/10.1186/s12913-019-4664-2
- Shufutinsky, A. (2020). Employing use of self for transparency, rigor, trustworthiness, and credibility in qualitative organizational research methods. *Organization Development Review*, 52(1), 50–58.
- Simon, M. K., & Goes, J. (2013). Assumptions, limitations, delimitations, and scope of the study. (*Doctoral dissertation, Dissertation and scholarly research: Recipes for success*). Seattle, WA (*Doctoral dissertation, Dissertation Success, LLC*).
- Sołtys, A., & Tyburski, E. (2020). Predictors of mental health problems in formal and informal caregivers of patients with Alzheimer's disease. *BMC Psychiatry*, 20. https://doi.org/10.1186/s12888-020-02822-7
- Stjernswärd, S., & Hansson, L. (2020). A qualitative study of caregivers' experiences, motivation and challenges using a web-based mindfulness

- intervention. *Community Mental Health Journal*, *56*(3), 416–425. https://doi.org/10.1007/s10597-019-00477-7
- Sweileh, M. W. (2020). Research trends and scientific analysis of publications on burnout and compassion fatigue among healthcare providers. *Journal of Occupational Medicine and Toxicology*, *15*(1), 1–10. https://doi.org/10.1186/s12995-020-00274-z
- Takai, M., Takahashi, M., Iwamitsu, Y., Ando, N., Okazaki, S., Nakajima, K., Oishi, S., & Miyaoka, H. (2009). The experience of burnout among home caregivers of patients with dementia: Relations to depression and quality of life. *Archives of Gerontology and Geriatrics*, 49(1), e1-e5.
  https://doi.org/10.1016/j.archger.2008.07.002
- Templeman, M. E., Badana, A. N. S., & Haley, W. E. (2020). The relationship of caregiving to work conflict and supervisor disclosure with emotional, physical, and financial strain in employed family caregivers. *Journal of Aging and Health*, 32(7/8), 698–707. https://doi.org/10.1177/0898264319848579
- Thorson-Olesen, S. J., Meinertz, N., & Eckert, S. (2019). Caring for aging populations: Examining compassion fatigue and satisfaction. *Journal of Adult Development*, 26(3), 232–240. https://doi.org/10.1007/s10804-018-9315-z
- Tuval-Mashiach, R. (2021). Is replication relevant for qualitative research? *Qualitative Psychology*, 8(3), 365–377. https://doi.org/10.1037/qup0000217
- Urcia, I. A. (2021). Comparisons of adaptations in grounded theory and phenomenology: Selecting the specific qualitative research methodology. *International Journal of*

- Qualitative Methods, 20, 160940692110454. https://doi.org/10.1177/16094069211045474
- van Boekel, L., Wouters, E., Grimberg, B., van der Meer, N., & Luijkx, K. (2019).

  Perspectives of stakeholders on technology use in the care of communityliving older adults with dementia: A systematic literature review. *Healthcare*,
  7(2), 73. https://doi.org/10.3390/healthcare7020073
- Velilla, L., Acosta-Baena, N., Allen, I., Lopera, F., & Kramer, J. (2022). Analysis of family stigma and socioeconomic factors impact among caregivers of patients with early- and late-onset Alzheimer's disease and frontotemporal dementia. *Scientific Reports*, 12(1). https://doi.org/10.1038/s41598-022-16400-2
- Venkatesan, R. (2021). Measuring work-life balance: Relationships with work-family conflict and family-work conflict. *Journal of Strategic Human Resource Management*, 10(2), 28–36.
- Wahyuni, D. (2012). The research design maze: Understanding paradigms, cases, methods, and methodologies. *Journal of Applied Management Accounting Research*, 10(1), 69–80.
- Wakefield, C. J. (2020). Community respite service utilisation and dementia care: A review of literature. *Australian Journal of Advanced Nursing*, *37*(2), 31–37. https://doi.org/10.37464/2020.372.94
- Wang, X. R., Liu, S. X., Robinson, K. M., Shawler, C., & Zhou, L. (2019). The impact of dementia caregiving on self-care management of caregivers and facilitators: a qualitative study. *Psychogeriatrics*, 19(1), 23–31.

- https://doi.org/10.1111/psyg.12354
- Wienclaw, R. A. (2021). Caring for the elderly in America. Salem Press Encyclopedia.
- Wrede, C., Braakman-Jansen, A., & van Gemert-Pijnen, L. (2021). Requirements for unobtrusive monitoring to support home-based dementia care: Qualitative study among formal and informal caregivers. *JMIR Aging*, 4(2), e26875. https://doi.org/10.2196/26875
- Yıldızhan, E., Ören, N., Erdoğan, A., & Bal, F. (2019). The burden of care and burnout in individuals caring for patients with Alzheimer's disease. *Community Mental Health Journal*, 55(2), 304–310. https://doi.org/10.1007/s10597-018-0276-2
- Yin, R. K. (2012). Case study methods. *APA handbook of research methods in*psychology, Vol 2: Research designs: Quantitative, qualitative,

  neuropsychological, and biological, 141–155. https://doi.org/10.1037/13620-009
- Yin, R. K. (2018). Case study research and applications. (6<sup>th</sup> ed). SAGE
- Ysseldyk, R., Kuran, N., Powell, S., & Villeneuve, P. J. (2019). Self-reported health impacts of caregiving by age and income among participants of the Canadian
  2012 General Social Survey. *Health Promotion and Chronic Disease Prevention in Canada*, 39(5), 169–177. https://doi.org/10.24095/hpcdp.39.5.01
- Zahed, S., Emami, M., Eslami, A. A., Barekatain, M., Hassanzadeh, A., & Zamani-Alavijeh, F. (2020). Stress as a challenge in promoting mental health among dementia caregivers. *Journal of Education and Health Promotion*, *9*(1), 65. https://doi.org/10.4103/jehp.jehp\_445\_19
- Zarzycki, M., & Morrison, V. (2021). Getting back or giving back: Understanding

caregiver motivations and willingness to provide informal care. Health

 ${\it Psychology and Behavioral Medicine}, 9 (1), 636-661.$ 

https://doi.org/10.1080/21642850.2021.1951737

# Appendix A: Interview Protocol

Researcher Interview Protocol
Date:
Time:
Location:
Participant ID:
Interviewer:
Data Collection Interviews
Introductory Protocol
Thank you for joining me here today. You have been selected to participate in this interview because you
have been identified as someone who has experience with working as a professional caregiver in the
home of clients with dementia or cognitive impairment and can speak to how you find a balance between
being a professional caregiver and your home life. I just want to confirm that is correct.
To assist in note taking and transcribing, I would like to use an audio virtual platform to record our
conversation from today. I will only be privy to the recordings that will be eventually destroyed after they
have been transcribed. I know you sent me back the confirmation of your consent to be in the study, can
I ask again do you understand the study and consent to participate? Do you have any questions before
we begin?
I just want to confirm (1) all information will be held confidential, (2) your participation is voluntary,
and you may stop at any time if you feel uncomfortable or wish to no longer participate.

Thank you for agreeing to participate.

I have planned for this interview to last no longer than one hour. During this interview, I have several questions that I would like to go over. To consider time constraints, it may come a time during the interview when I may need to request additional time if needed to complete this line of questioning.

### Demographic Information:

First can I ask how long have you worked as professional paid caregiver with clients who experience dementia? Now I would like to ask you some questions about your work.

- 1. How did you become interested in becoming a professional caregiver?
  - a. PROBE: What do you feel motivated you to want to work with clients with dementia or cognitive impairment?
- 2. Can you tell me what types of specialized training you have received with working with dementia or cognitive impairment?
  - a. PROBE: Please describe any training that you have received for any type of medical condition.
- 3. How do you feel about your preparedness for being a professional caregiver for an individual with dementia or cognitive impairment?
  - a. PROBE: What are some of the advantages and disadvantages that you gained from this training?
- 4. How would you describe your experience with working within the home and caring for an older adult with dementia?
  - a. PROBE: Do you feel that you received training or were given resources to support being able to balance being a caregiver and leaving time to tend to your personal life?
- 5. How do you balance your work schedule and your own care needs?
  - a. PROBE: To what extent do you believe the family plays a role in creating your working conditions?
- 6. How would you describe your ability to prioritize creating time for yourself outside of being a professional caregiver?
  - a. PROBE: How would you describe what a typical day is for you?
  - b. PROBE: Do you find yourself juggling being a caregiver and your personal life?

- 7. Please tell me about a time when you were working at the home of a client living with dementia and had a challenge balancing work and life.
  - a. PROBE: What advantages or disadvantages have you had while working within the home?
  - b. PROBE: Do you perform any other tasks other than direct care of the client living with dementia?
- 8. Can you tell me about any support you have from your agency?
  - a. PROBE: What advantages or disadvantages have you had while working within the home?
- 9. Can you tell me about any support you have from your employer or the family of the client living with dementia?
  - a. PROBE: Do you perform any other tasks other than direct care of the client living with dementia?
- 10. How would you describe resources or additional training provided by your employer or agency?
  - a. PROBE: How would you describe the resources that your employer or agency has provided you and do you feel they are adding value to your ability to not feel unprepared or feel ready to care for a client with dementia?
- 11. Can you describe any satisfaction you find in being a caregiver?
  - a. PROBE: What advantages or gratification have you received while being a home-based caregiver?
- 12. How might you describe any challenges or stress associated with caregiving that you think could make you feel overwhelmed?
  - a. PROBE: How would you describe how you have dealt with being able to manage your work and life conflicts?
  - b. PROBE: If you do not feel overwhelmed how would you describe your work life?
- 13. What things do you do to manage any stress or fatigue?
  - a. PROBE: How would you describe what activities you do that allow you to manage your stress or fatigue levels?
  - b. PROBE: Do you feel that you have time in your day to manage your level?

- 14. Are there any other family members in the home with the client? If yes, are you able to tell me about the relationship that you have with the adult family members that are living within the home?
  - a. PROBE: How would you describe the family dynamics?
  - b. PROBE: How would you describe your role while working within the home with the client living with dementia?
- 15. Can you describe the artifact that you are sharing? Ask only in the event the participant is showing a training certificate, thank you note/card, journal, book, or strategy they use to help manage their work-life balance.
  - a. PROBE: How do you believe this has helped you with creating or managing a work-life balance?

At the end of the interview

Thank you again for participating in the study. I will be able to provide you with a summary of the findings from the study and send that to your email address. Would that be ok with you? Please keep a copy of the consent form and my contact information if you have any questions after we finish today. Goodbye.

# Appendix B: Flyer



EDUCATION FOR GOOD"



Volunteers Needed!

# **Research Study Seeks Participants**

ARE YOU A PROFESSIONAL CAREGIVER WORKING IN THE HOME OF AN INDIVIDUAL LIVING WITH DEMENTIA OR A COGINTIVE IMPAIREMENT?



ARE YOU TRYING TO FIND A BALANCE BETWEEN YOUR WORK AND LIFE?



You may be eligible for this virtual interview for a research study.

# You May Qualify if You

- Are you 18 years or older
- Working within the home of an individual living with dementia or a cognitive impairment
- Are a professional non-related caregiver
- Are English speaking (Bilingual)

### FOR MORE INFORMATION

Please contact Cheraire Lyons at Cheraire.Lyons@waldenu.edu