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Coping Strategies of Dual-Role Informal Caregivers

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Walden University
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Abstract

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by

Lorilee Maldonado

MA, University of Phoenix, 2011

BS, University of Phoenix, 2009

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

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Abstract

There are nearly 43.5 million informal caregivers (ICGs) in the United States, and this number will nearly double by 2030. Trying to fulfill the needs of an aging family member and commitments to work, home, and other relationships create a constant state of stress that may result in either leaving the workforce or placing the care recipient in a facility. Finding strategies that support both roles is economically and socially critical. This study explored the strategies that some ICGs have acquired that enable them to cope with these pressures. Work-family conflict theory, focusing on the conflict between work and family that can arise in elder care, was used to frame this study. This study used the interpretative phenomenological approach (IPA) to explore what coping strategies ICGs use to manage time, stress, and behavior conflicts between both work and caring. Face-to-face interviews were conducted with 11 working ICGs taking care of a family member over the age of 71 residing in the same household. The IPA method of descriptive, linguistic, and conceptual data analysis was conducted revealing three themes. Findings indicated that dual-role ICGs employed a combination of passive coping techniques (acceding to the care recipient's demands, calling up positive memories, and viewing caring as an investment that will pay off in the future) and commanding coping techniques (use of technology, planning ahead, and asserting boundaries with the care recipient). In addition, they relied on support from family and friends, as well as internal support from self-help aids and religious faith. This study shows despite the lack of assistance from the strain of care and work, dual-role ICGs have developed their own coping strategies to remain in both roles. This study may be a catalyst for improving the quality of care and health outcomes for both ICGs and care recipients by providing applicable coping and resource management strategies.

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Dedication

This study is dedicated to my husband, Jaime Maldonado for his encouragement, patience, support, and prayers. Now that this study is complete, I look forward to the next chapter of our lives. I also would like to dedicate this research to all the informal caregivers committed to the task of caring and working. You are the unsung heroes of our aging society.

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I humbly acknowledge the Lord Jesus Christ who strengthened me through this entire process. I would like to express my deepest gratitude to my dear husband, my Sweet Baboo, who silently waited in the wings to get his wife back. Thank you to my daughter, Angel for your prayers and to my grandchildren who have only known grandma as a student, I look forward to making fun memories. To my grandson William, you thought college textbooks were nursery rhymes, one day you'll understand why you know so much about health care administration! A special thank you to my daughter Carolee for being my sounding board, you were invaluable throughout the conceptualization process. I must also acknowledge the blessing of my sons-in-law; Ryan and Raul who have been readily available every time I needed help, thanks for keeping the house from falling down around me. A special thank you to my mother, my own care recipient; I made it mom because you always told me I could do anything I set my mind to. I extend a debt of gratitude to each participant in this study who took the time to share their stories. I wish to express my appreciation to my chair, Dr. Harold Griffin. I was not always gracious, yet you did not give up on me. I would also like to thank my co-chair, Dr. Kimberly Dixon-Lawson whose encouragement in qualitative studies helped me believe I could do this. There are many others who accompanied me on this journey; your support and prayers remind me I did not do this on my own. It takes a village to complete a PhD.

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Chapter 1: Introduction to the Study

This study explored the strategies that some informal caregivers (ICGs) have acquired that enable them to cope with the pressures of managing their dual roles of work and caregiving. In 2015, 40.4 million unpaid caregivers were providing elder care in the United States, of which 61% were employed outside of the home (Bureau of Labor Statistics [BLS], 2019). One in six employees is providing care while employed (National Alliance for Caregiving [NAC], 2020). By 2050, the demand for ICGs is expected to double (BLS, 2019). The pressures associated with work and informal caregiving have been linked to decisions to reduce work hours, quit employment, take early retirement, or put the care recipient into a long-term care facility (Altomonte, 2016). This study has the potential to enable more ICGs to continue in the roles of caring and working by exploring strategies that help them to cope with the conflicts; this improved coping may improve the quality of care for the recipients.

Chapter 1 provides the background for this study through a brief review of the literature on stress factors that ICGs cope with at work and in the caregiving role. The importance of addressing their stress and the need to retain ICGs in both capacities is discussed in the problem statement. The research questions focus on three constructs associated with caregiver strain in order to explore how ICGs overcome them. These constructs are outlined in the work-family conflict theory that frames this study. The use of qualitative methodology to explore the lived experiences of ICGs is justified by the nature of the study. Terms specific to the subject of informal caregiving are listed, and the study's scope and limitations are discussed. Lastly, issues of bias, assumptions, and validity as well as transferability of this study are discussed.

Background of the Study

The aging population in the United States is expected to double over the next 30 years as the largest portion of society, the baby boomers, move into retirement (BLS, 2019; NAC, 2020). Caring for the needs of an aging family member concurrently with commitments to work, home, and other relationships puts ICGs in a constant state of stress (Kohl et al., 2018; Longacre et al., 2016). ICGs experience financial pressures, health issues, strained relationships, and work conflicts. When ICGs are depleted emotionally, physically, psychologically, and financially, the result is a reduction of the quality of care for the receiver. The strain of managing the roles of working and caregiving may eventually lead to the carer leaving the workforce or placing the recipient in a long-term care facility (Betini et al., 2017; Merla et al., 2018).

Recent studies have discussed effects of stress on ICGs' health, including obesity, chronic fatigue, headaches, acid reflux, chronic anxiety, and depression (Sadavoy et al., 2021; Schulz & Eden, 2016; Suryavanshi, 2020). The strain of informal caregiving is magnified when another role, such as work, is added (Clancy et al., 2019; Oldenkamp et al., 2017; Sadavoy et al., 2021). Numerous studies have examined the conflicts between work and informal caregiving (Abramowska-Kmon, 2017; Burch et al., 2018; Harris et al., 2020) Research shows that ICGs experience elevated levels of stress from trying to juggle their multiple roles (Longacre et al., 2016; Wang et al., 2020). ICGs' work performance suffers from late arrivals, missed days, sudden departures, and frequent interruptions by phone calls from or about the care recipient (Dich et al., 2016; Hopps et al., 2017; Longacre et al., 2016).

The effects of elder care on work performance are magnified by employers' attitudes. Employment policies are based on stereotypes about and ignorance of the ICG role (Burke, 2017; Hopps et al., 2017; Oldenkamp et al., 2017). Employers grant time for childcare obligations but have little tolerance for absenteeism due to elder care (Burke, 2017). Many ICGs do not inform their workplace of their status for fear of repercussions (Clancy et al., 2019; U.S. Department of Labor [DOL], 2016). The stress of dual-role informal caregiving (i.e., caring and working) and the lack of support in the workforce cause many to quit work, retire early, or reduce employment to part time (Burke, 2017; Clancy et al., 2019; Longacre et al., 2016). A growing need exists to examine strategies in the workplace, community, and home that can help ICGs manage both caregiving and employment (Burch et al., 2018; Mortensen et al., 2017; Moussa, 2019).

In a public policy report, Reinhard et al. (2019) stated that "progress has resulted from decades of research and advocacy calling attention to the essential, but often overlooked, role of the family in long term services and supports and healthcare," but that "strengthening support systems must continue" (p. 1). After conducting a study on 1,015 ICGs, the NAC and the American Association of Retired Persons (AARP) recommended more support for caregivers in the workplace (NAC, 2020). However, studies have been inconclusive and inconsistent regarding the best interventions and coping strategies for support (DePasquale et al., 2017; Gérain & Zech, 2019; Suryavanshi, 2020).

Significant barriers exist to identifying such interventions. Multiple studies have shown variations in the mental status and physical conditions of care recipients, as well as differences in living arrangements and culture, all of which produce distinct types of conflict for ICGs. These variations make it difficult to find best practices for coping; there is no one-size-fits-all solution (Gérain & Zech, 2019; Rodríguez-Pérez et al., 2017; Vandepitte et al., 2016). Studies that do offer recommendations for managing ICGs' burdens fall short in validating effectiveness or application (Araujo et al., 2015; Rodríguez-Pérez et al., 2017). Some research suggests that social activities alleviate strain (Cohen et al., 2015; Kelley et al., 2017). Other articles in the literature indicate that demands on the carer's time are a major contributor to ICGs' burden, and that the problem is magnified for dual-role ICGs (Andersson et al., 2019; Gérain & Zech, 2019; Prevo et al., 2017). Dixe et al. (2019) suggested that greater preparedness for informal caregiving alleviates burden; however, research shows that informal caregiving is usually a sudden event caused by a crisis in the care recipient's life, leaving little time to prepare for the role (Schulz & Eden, 2016; Strommen et al., 2018). Chen (2016) wrote that "although significant effort has been devoted to developing effective interventions for caregivers, most studies have found that these interventions provide little measurable benefit" (para. 4).

Despite the current lack of successful interventions, there is evidence in the literature of real satisfaction in caregiving. Kajiwara et al. (2015) found that a positive view of informal caregiving resulted in the continuation of care (ß = 0.20, $p < .001$); however, the researchers did not study what factors contributed to a positive appraisal. Araujo et al. (2015) reported that in-home training for ICGs of stroke patients can be beneficial in reducing strain by aiding ICGs in preparedness. The research results, however, were not included to support the assertion. Jellema et al. (2018) concluded that maintaining valued activities is paramount to staying engaged, interested, and productive in life. While the authors of these studies made excellent suggestions, none showed how to apply them, and most recommendations did not reflect consideration of the conflicts associated with working responsibilities. Studies applicable to managing ICGs' burden while remaining in the workforce are scarce, with even fewer from the perspectives of dual-role ICGs sharing their personal experiences. As the need for ICGs continues to increase, so does the need to find strategies that enable them to remain in both the workforce and the informal caregiving role. This study addresses the identified gap by exploring best practices in coping with the role of ICG.

Problem Statement

There are nearly 43.5 million ICGs in the United States providing $470 billion a year in health care services (NAC, 2020). Conflicts between informal caregiving and working often result in choosing one over the other (Andersson et al., 2019; Burke, 2017; Clancy et al., 2019; NAC, 2020). Approximately 61% of ICGs fill both positions, working a full- or part-time job while spending 40 hours or more in the ICG role (NAC, 2020). As the population ages, the need for ICGs will increase. The number of people over 65 years old is expected to double by 2030 to 71 million. Currently, there are seven ICGs per adult; by 2030, that number is expected to drop to four ICGs per adult (NAC, 2020). Trying to fulfill both the needs of an aging family member and commitments to work, home, and other relationships creates a constant state of stress (Socci et al., 2019). Conflicts associated with balancing work and caregiving responsibilities force many ICGs to reduce hours, quit work, or take early retirement (Sadavoy et al., 2021) The resulting average loss totals $24,044 in lifetime earnings and $25.2 billion a year in reduced corporate earnings (Family Caregiver Alliance [FCA], 2019). Over the next 30 years, the number of those over 65 years of age will increase by 67.7%, while the number of those under 55 years will increase by only 8.4%, resulting in a sharp rise in the dependency ratio and ultimately negatively affecting the economy (BLS, 2019). Workforce retention of ICGs will no longer be merely a corporate problem, but a societal issue.

Numerous studies have addressed emotional, physical, and financial factors affecting ICGs (Burke, 2017; Cohen et al., 2015; Koyanagi et al., 2018). Some researchers have explored the conflict between work and informal caregiving (Harris et al., 2020; Hawken et al., 2018;

Pearson et al., 2019). However, there is a growing urgency to discover coping strategies to manage both roles (DePasquale et al., 2017; Sadavoy et al., 2021). Stress and strain associated with informal caregiving contribute to poor health outcomes for those delivering care to another (Bom et al., 2018; Hawken et al., 2018; Riedel et al., 2016). Gérain and Zech (2019) pointed out the gap in the literature associated with strategies and support needed to effectively manage the dual role of caregiving and working: "Investigation of the coping strategies used when actually experiencing the situation—e.g., through ecological momentary assessment—would allow us to understand if they are effective responses to the stress caregivers face" (p. 6).

Purpose of the Study

The purpose of this study was to examine the lived experiences of ICGs in order to ascertain the coping strategies that are the most beneficial while filling the dual role of employee and ICG to an aging family member. ICGs are increasing in number, making up 35% of the U.S. workforce and providing $449 billion a year in healthcare value (FCA, 2019). As the baby boomer population ages, the requirement for more ICGs will continue to rise (BLS, 2019; FCA, 2019). By 2050, one out of five people will be over the age of 65, with many requiring an ICG (U.S. DOL, 2016). Finding strategies that support both roles is economically and socially critical (Administration for Community Living [ACL], 2020; DOL, 2016; FCA, 2019). Caregiving is divided in the literature by age category; 14% of care recipients are 18 to 49 years, 39% are 50 to 74 years, and 47% are 75 years and older (NAC, 2020). Due to the many differences in these populations, the scope of this study was limited to the largest population of care recipients: ICGs providing care to an aging family member over 71 years of age residing with the caregiver. Our study was conducted in the metropolis of Dallas, Texas.

Research Questions

RQ1. Based on lived experiences, what coping strategies do informal caregivers apply to manage time conflicts associated with their dual roles as a caregiver to an aged family member and as an employee?

RQ2. Based on lived experiences, what coping strategies do informal caregivers apply to manage stress conflicts associated with their dual roles as a caregiver to an aged family member and as an employee?

RQ3. Based on lived experiences, what coping strategies do informal caregivers apply to manage behavioral conflicts associated with their dual roles as a caregiver to an aged family member and as an employee?

Theoretical Framework

The theoretical basis for this study was work-family conflict theory. Work-family conflict exists when the roles of work and family collide, resulting in an incompatible state (Greenhaus & Beutell, 1985). Work-family conflict theory (WFC) emerged from Robert L. Kahn’s theory of role conflict, which developed within the confines of industry (Kahn, 1964). Kahn observed that clashes occurred when demands between different obligations created pressure. Greenhaus and Beutell (1985) developed the theory of WFC from Kahn’s role conflict theory. Work can cause conflict with family commitments, or family obligations can cause problems with fulfilling work responsibilities (Greenhaus & Powell, 2006). The conflict can be bidirectional, with greater conflict occurring when the more valued role comes into conflict with a lesser valued role (Madsen & Hammond, 2005). For example, if a work assignment is perceived to have greater value than attending a family dinner, then the family event creates more significant stress than the obligation of the work assignment.

I selected work-family conflict theory because other related theories used in work and family conflict research are less relevant to the specifics of the topic under study. Role theory was rejected because it originated from research on roles in corporate settings with an emphasis on inner work-related conflicts (Kahn, 1964). Even though role theory addresses conflicts of work and family, it is commonly used in research on conflicts that arise between interoffice roles or interfamily roles such as parent and spouse (Madsen & Hammond, 2005). This study was out of the scope of role theory because it was an examination of the nuances of the working ICG. Spillover theory was initially considered; spillover theory, however, is not used as often as work-family conflict theory in ICG research and is more often referred to in studies that focus on ICG burden. Because the study's focus was strategies for coping with burden rather than burden itself, spillover theory was rejected as a theoretical framework to keep the research centered on the primary purpose.

Work-family conflict theory is relevant to elder care when conflicts arise between work responsibilities and caring (Clancy et al., 2019; Kohl et al., 2018). Barriers to managing both roles include time, stress, and behavior (Greenhaus & Beutell, 1985). Time conflicts arise when caring interferes with work obligations; the outcomes include absenteeism, poor job performance, and job loss (Andersson et al., 2019; Sadavoy et al., 2021). Stress-induced conflict may occur when work responsibilities interfere with informal caregiving duties; the resulting stress can lead to outcomes such as health problems, fractured relationships, and inadequate care (Lin, 2020; Rigby et al., 2019). When the conflict becomes severe enough, ICGs quit employment, reduce work hours, or take early retirement (Longacre et al., 2016). Behavioral disputes between caring and work occur when ICG strain builds to an agitated emotional state expressed by inappropriate reactions such as outbursts, depression, and elder abuse (Merla et al., 2018; Orfila et al., 2018).

The three constructs of work-family conflict theory—time, stress, and behavior—frame the contributing factors that cause conflict in the ICG role (Clancy et al., 2019; Kohl et al., 2018; Longacre et al., 2016; Moon et al., 2016). These constructs guided the study via classification of the emerging coping strategies that ICGs apply to overcome time, stress, and behavioral clashes in each role. These constructs guided the research; I used each to (a) determine what strategies that ICGs applied in their daily lives to manage time conflicts between their job and caring role, (b) examine how they coped with the effects of stress, and (c) determine what strategies they used to control behavioral conflicts that arose. Chapter 2 provides more detail regarding how work-family conflict theory addresses the issues experienced by dual-role ICGs (Clancy et al., 2019) and how the three constructs (time, strain, and behavior) frame the barriers faced by ICGs (Kohl et al., 2018).

Nature of the Study

The method selected to achieve an in-depth exploration of the phenomenon was the interpretive phenomenological approach (IPA). The IPA concentrates on an experience that has become meaningful in a person’s life (Smith et al., 2009). In this study, the experience under consideration was the dual role of the ICG. Central to this study was the IPA feature of exploring the personal meaning that people apply to a specific experience and how they make sense of it (Smith et al., 2009). Particular to IPA is performing analysis of individual accounts while exploring the similarities and differences across cases (Smith et al., 2009). People experience phenomena differently; the reality of each subject’s experience is therefore that subject’s truth and may not be true for another (Mackenzie & Knipe, 2006). Each study participant experiences his or her reality concerning time, stress, and behavioral conflicts, and each may be different, but the totality of the experiences sharing the central phenomenon leads to a consensus of truth. This method provided an opportunity to explore ICGs' strategies and garner a deeper understanding of the struggles that they face daily. The IPA's focus on rich details of individual experiences makes it possible to create resources that minimize work-family conflict and improve management of the roles of work and caregiving.

The IPA requires in-depth data gathered from participants who share their experiences, and semi structured interviewing is recommended to achieve this purpose (Smith et al., 2009). To acquire a sufficient sample size, I used various methods of recruitment, such as flyer distribution, gatekeeper assistance, Facebook, and referral sampling. A short screening questionnaire was given to candidates to ensure that all criteria for participation were met. Smith et al. (2009) recommended that an inexperienced interviewer use a set of predeveloped open-ended questions to initiate conversation and keep the conversation on topic; I therefore developed an interview guide to elicit meaningful conversation pertinent to the research questions.

I conducted face-to-face interviews with ICGs caring for an elderly family member residing in the same household. The interviews were recorded on a digital voice recorder, then transcribed verbatim to ensure that all data were captured for later analysis. I also took field notes to record any nonverbal cues that gave a deeper understanding of the recorded interviews (Creswell, 2009). ICGs often experience unplanned care needs; contingencies for this were built into the study. If an interview was cut short, a follow-up meeting was arranged to complete the interview within 2 weeks of the original interview. If a face-to-face interview was not possible, I suggested arrangements to continue through Skype or Facetime. Once completed and transcribed, interview data were analyzed individually using a four-step process: (a) rereading; (b) taking notes; (c) coding using descriptive, linguistic, and conceptual processes; and (d) finding connections between the codes to create themes (Smith et al., 2009). Once this was done with each case, all cases were analyzed for common themes. I used the NVivo software program to aide in organizing the data.

Definitions

Activities of daily living (ADLs): Functions of everyday life such as eating, grooming, dressing, getting in and out of bed, toileting, showering, and meal preparation (FCA, 2019).

Caregiver burden: The psychological, physical, emotional, and social response of the caregiver to the strain caused by the disproportionate demands on resources associated with trying to fulfill multiple roles (Gérain & Zech, 2019).

Dual-role informal caregiver: A person simultaneously operating in a workforce and a caregiver capacity (Kohl et al., 2018).

Informal caregiver (ICG): A person aiding with daily living activities of another without compensation (FCA, 2019).

Instrumental activities of daily living (IADLs): Household duties such as paying bills, laundry, light housecleaning, shopping, and transportation (FCA, 2019).

Assumptions

To ensure that studies are replicable, it is vital for researchers to clearly present the assumptions underlying a study. Analysis of the data is dependent on the information shared by the participants; it is therefore a methodological assumption that they will share openly and honestly (Fekete et al., 2017). I assumed that the questions in the study were sufficiently clear and concise to elicit responses pertinent to the purpose of the study, and that the information provided was rich and detailed to provide enough data for reflective analysis of the relevant phenomena (Smith et al., 2009). The sample size of 12 participants was assumed to satisfactorily represent the population within the limits of the study. It was further assumed the instrument chosen, face-to-face interviews, captured the essence of the phenomena and provided meaningful results (Adhabi & Anozie, 2017). Finally, I assume that the theoretical framework, work-family conflict, accurately reflected the experiences of dual-role ICGs (Korstjens & Moser, 2018).

Scope and Delimitations

The existence of ICG strain is well established, and while burden has been discussed, there is scant discussion of coping strategies for the stress that occurs when a person is employed while also caring for a person in the home (Kohl et al., 2018; Longacre et al., 2016). Although research shows that more women than men are ICGs (BLS, 2019; NAC, 2020), neither gender was excluded from this study because the literature indicates that both sexes experience caregiver strain (Burke, 2017; Reyes et al., 2020). Race and ethnicity were not an exclusion factor because studies have supported the conclusion that all ICGs share common burdens associated with the stress of dual-role caregiving (Plaisier et al., 2015; Reinhard et al., 2019; Wolff et al., 2016). Although participation in the study was open to all races and ethnic groups, participants had to be fluent in written and spoken English in order to complete interviews, participate in member checks, and read study-related documentation such as the screening questionnaire and consent forms. This study was limited to exploring coping strategies that ICGs use to continue working while caring. To ensure that participants had enough knowledge to share, participants with less than 1 year of experience as a dual-role ICG were excluded. In addition, participants had to be legal adults and over 20 years of age to ensure that all subjects in the study had experience acting independently in the role of an adult ICG. Furthermore, only those caring for in-home family members over the age of 70 were allowed to participate, because research has shown that this group produces the greatest degree of ICG burden (Clancy et al., 2019; Gérain & Zech, 2019; Wolff et al., 2016). Because the study explored coping strategies associated with working and caring, all subjects were employed. Data were collected in face-to-face interviews; study subjects were therefore restricted to a 50-mile radius of my location in Dallas, Texas.

Informal caregiving is a broad term, and each population of ICGs experience strain unique to the type of care administered, such as long-distance caring, disabled care, or childcare (Plaisier et al., 2015; Reinhard et al., 2019). These other types of ICGs were not included in this study in order to limit the scope of the research to a homogenous sample sharing similar lived experiences.

This study was limited to the population of ICGs who live within a 50-mile radius of Dallas, Texas; however, because the literature has established that ICG strain is universal and that six out of ten ICGs are in the workforce, the results of this study may be transferred to other populations experiencing the same work-family conflicts associated with the dual role as caregiver and employee (Burch et al., 2018; Kohl et al., 2018; Longacre et al., 2016; Oldenkamp et al., 2017)

Limitations

Qualitative research by nature presents a host of limitations: Strategies replace rules, inquiries replace formulas, and people replace statistics (Patton, 2002)**.** Although qualitative methods do not produce numerical values, the results provide greater understanding of human nature (Patton, 2002). Bias is the most significant limitation that must be addressed in qualitative research to ensure that study results are not skewed (Creswell, 2009; Patton, 2002; Smith et al., 2009). Various forms of bias could have posed a threat to this study. Respondent bias as a result of the research design could have posed a threat, such as if interview questions were misunderstood. To address this possibility, the interview guide was evaluated by a panel of experts for clarity and relevance. Another way to avoid this type of bias is to listen to the interviewee's language and word questions in a similar manner (McGrath et al., 2019). Sponsor bias can be introduced when the interviewee begins asking the interviewer questions and aligns answers with the interviewer's point of view (McGrath et al., 2019). To avoid this type of bias, I refrained from answering questions related to the study and redirected the interviews when necessary to focus on participant responses.

Researcher bias can affect results through leading questions, premature assumptions, and influencing responses through the order of questioning (Schade, 2017). As the sole researcher and an ICG, I carefully considered personal bias and built tools into the study to ensure trustworthiness, credibility, and dependability while reducing bias (Creswell, 2009). The following are various ways that potential researcher bias was addressed.

Design

The IPA seeks rich data to ensure dependability (Smith et al., 2009). The sample size of 12 could have been a limitation to gathering enough data to establish patterns, making it necessary to add more participants. I allowed time in the original research plan to add participants if necessary. The richness of the data was also contingent on the quality of the interview; researcher inexperience and lack of interviewing skills could have affected the study results (Patton, 2002). I used an interview guide to keep the conversation focused on the purpose of the study and used tools such as artful listening, meaningful silence, and observation of nonverbal communication to derive insights from my subjects' communication (Smith et al., 2009). I employed a two-column field note system, with one column to document interactions and the other to document my thoughts during the interviews, in order to recall both events and my reaction to them (Patton, 2002). I applied reflective analysis to reduce the risk of researcher bias, stepping away from the data after the initial interpretation of findings, then returning to review it again (Patton, 2002). I kept a journal throughout to document reflections (Smith et al., 2009).

The IPA design captures a snapshot of the lives of dual role ICGs; analysis is limited to viewing the phenomena from a single frame of time (Patton, 2002; Smith et al., 2009). This research thus does not capture how participants' views of their situation or coping skills change over time. As the researcher and an ICG, I was able to understand the phenomenon on multiple levels and establish trust with subjects, allowing them to more readily share their personal experiences on a deeper level in a single interview. Finally, only ICGs were questioned; this limited the study to viewing the phenomena solely through their perception.

Internal Validity

Phenomenological research is often undertaken by researchers with personal experience with the phenomenon; while advantageous, this experience can limit the study outcome by introducing bias (Creswell, 2009). As the sole researcher in this study and a dual-role ICG, I incorporated several methods proven to reduce bias into the design: namely, member checking, peer debriefing, and interview question order. These aided in establishing the trustworthiness of the study results.

Member Checking

Patton (2002) referred to member checking as "analytical triangulation" (p. 560). Member checking offered accuracy and impartiality to the study findings. Validity was achieved by allowing the study subjects to review the analysis of their interview, offering new insight (Patton, 2002). Additional triangulation occurred when data based on shared themes found in the perspectives of the participants (Creswell, 2009) were triangulated with my observations and field notes taken during the interviews.

Peer Debriefing

A peer reviewed the interview transcripts and analysis, provided feedback, and helped me avoid interjecting bias into the study results. The peer reviewer (PR) who was selected to perform these tasks is employed as a journal peer reviewer at an accredited university. To assist the PR, the research protocol and code book were provided as a guide for the study analysis (Creswell, 2009).

Order of Questioning

Bias is a risk if questions are asked in a leading manner, priming the interviewee using wording that may elicit responses to fit the researcher's preconceived hypothesis (Schade, 2017). To avoid this, general questions were asked before more specific ones, only neutral words without a positive or negative connotation were used, and no prompts were given to elicit answers. The interview guide was evaluated by a panel of experts, and an online pilot test of ICGs was conducted to ensure that the instrument elicited responses pertinent to the research questions. I administered three mock interviews to practice effective interviewing skills and avoid bias.

External Validity

Qualitative research relies on effective study design to support reliability and integrity, with an emphasis on reflection, assessment, and plausible interpretation of the participants' lived experiences (Carcary, 2009). Validity is proven by how well the researcher demonstrates understanding of the data and transparency in their analysis and interpretation (Carcary, 2009). This study used member checking to ensure full comprehension of the data shared by the participants.

While participant responses may vary in their individual details, transferability is present if ICGs outside the study can associate their own experiences with the findings (Korstjens & Moser, 2018). According to Carcary (2009), “the researcher needs to provide detailed descriptions of context and phenomena so as to enable others to assess the findings’ transferability” (p. 15). For this purpose, a detailed research audit trail is included in Appendix L.

Significance of Study

This study uniquely addressed the support needed by ICGs who are balancing work and caregiving responsibilities through a thorough examination of the personal experiences of those informally caring for an aging family member. This study may positively affect society by focusing attention on the accommodations needed by ICGs to meet the growing holistic healthcare requirements of the elderly segment of the population. Stress affects the health of both ICGs and care recipients (Kelley et al., 2017). This study may be a catalyst for improving the quality of care and health outcomes for both ICGs and care recipients by providing applicable coping and resource management strategies. The findings might also improve workplace retention by providing insights that could spur the development of more employee-friendly policies that make it easier for ICGs to fulfill their dual roles as ICG and employee. The findings from this study may also lead to the development of publicly funded or philanthropically supported programs designed to help ICGs and their care recipients. It is hoped that this study will lay the foundation for future scholarly inquiry with regard to support strategies necessary to improve ICG effectiveness and the health outcomes of their care recipients within the United States and globally.

Summary

Currently, 40.4 million ICGs spend an average of 25.8 hours per week providing care for an aging family member while working full time (BLS, 2019). The barriers that these individuals encounter are causing them to leave the workforce prematurely (Phillips et al., 2016). The majority of the current literature is focused on the needs of care recipients or the stress of ICGs (Cohen et al., 2015; Koyanagi et al., 2018; National Academies of Sciences, Engineering, and Medicine, 2018) but scarcely includes discussion of successful coping strategies to manage both roles (Bangerter et al., 2017; Hawken et al., 2018). Today, one in six employees is an ICG (NAC, 2020); it is thus vital to discover mechanisms to keep these individuals in both roles (Jellema et al., 2018; Vandepitte et al., 2016). This study explored the perceptions, attitudes, and personal experiences of 12 dual-role ICGs in Dallas, Texas who had successfully managed to remain caregivers and employed. The study examined coping strategies that ICGs apply to effectively manage (a) time, (b) stress, and (c) behavioral conflicts associated with their dual role, using an interpretive phenomenological approach. ICG burden is established in the literature; subjects were willing and eager to share their experiences of trying to manage the strain of both caregiving and work. Previous research shows that ICGs of live-in care recipients suffer a high degree of anxiety, especially if the care recipient is an aging family member (Gérain & Zech, 2019; Wolff et al., 2016). For this reason, the study was limited to this population. The literature indicates similar burdens associated with time, stress, and behavioral conflicts for the entirety of this population; therefore, the results of this study should be beneficial to ICGs in locations outside the study site. Transferability of this study’s results is supported with thick description of the research process, including a detailed audit trail of the data collection protocol.

Chapter 2 is an assessment of the literature that reviews the stress that ICGs experience and its impact on caregiving and employment. The scarcity of research specific to coping strategies for dual-role ICGs is discussed. Chapter 2 also addresses research conducted on work-family conflict in relation to this population, supporting the significance of this study.

Chapter 2: Literature Review

Juggling caring for the needs of an aging family member and commitments to work, home, and other relationships puts ICGs in a constant state of stress (Andersson et al., 2019; Reinhard, 2019). With over 48 million caregivers providing 29% of elder care in the United States valued at $449 billion dollars, the risk of reduction in dual-role ICGs creates a dilemma both economically and socially (BLS, 2019; FCA, 2019). The burden of multiple roles causes many ICGs to either leave the workforce or relinquish their caregiving role and place their relative in a long-term care facility (Boucher et al., 2019; Kokorelias et al., 2021; Merla et al., 2018). ICG strain leads to an increase in health problems such as hypertension, obesity, loss of sleep, and depression (Andreakou et al., 2016; Clancy et al., 2019; Strommen et al., 2018), as well as financial struggles (Andreakou et al., 2016; Phillips et al., 2016) and manifestations of anger, depression, and abuse (Lin, 2020; Orfila et al., 2018; World Health Organization [WHO], 2016). Interventions for managing ICG stress are limited. Most relevant sources recommend support groups, behavior modification techniques, and religious affiliations (Cohen et al., 2015; Kelley et al., 2017; Vandepitte et al., 2016); very few provide coping recommendations for dual-role ICGs (Dich et al., 2016; Fekete et al., 2017; Peng et al., 2019).

The aging of the U.S. population, along with decreases in government support for healthcare services for seniors, is increasing the demand for ICGs (NAC, 2020). As the baby boomer generation ages, the number of those over 65 is expected to double by 2030, increasing the need for ICGs from one in six to one in four working adults (FCA, 2019). These trends indicate a need to address the strain of ICG burden (Gautun & Bratt, 2016; Kayaalp et al., 2020; NAC, 2020). The purpose of this study was to examine the lived experiences of ICGs to ascertain the coping strategies that they use that are the most beneficial.

This chapter contains a synthesis of current literature on ICG strain and the effects of caregiver burden on self, work, family, and care recipients. A description of the literature search strategy with a listing of the databases and terms used is provided for replication and future reference. Application of work-family conflict theory in prior research is discussed, as well as how the constructs framed this study. The chapter concludes with a summary of the major conclusions in the literature, as well as how this study explored the gap in coping strategies specific to the needs of dual-role ICGs.

Literature Search Strategy

A comprehensive literature search was conducted. Two hundred seventy-six articles about ICG burden and dual-role informal caregiving were retrieved from Walden databases: Academic Search Complete, Sage Premier, Science Direct, ProQuest, PsycINFO, PsycARTICLES, PubMed, and Ebscohost. Google Scholar databases included Researchgate, Oxford Journals, and Wiley online library. Statistical and demographic data specific to aging and caregiving were retrieved directly from the primary sources referenced in the literature: Aging Care, FCA, Families and Work Institute, NAC, and The National Association of States United for Aging and Disabilities. The U.S. Census Bureau and the U.S. Department of Health and Human Services also provided demographic data. Articles about formal caregiving were excluded from the review, leaving a remainder of 121 articles. Of the articles selected, 111 were published within the last 5 years, and 10 articles from 2015 were retained for their value of longitudinal research in the field of aging. Keywords used to search for articles related to the effects of caregiver stress on dual-role ICGs included *informal caregivers, elder care, aging, caregiver burden, caregiver stress,* and *caregiver strain.* More defined searches were conducted using combinations of *informal caregiver* with *caregivers and employment, caregivers and* *employed*, *dual-role caregivers*, *informal caregivers and work*, *caregivers and work stress*, and *caregivers and work burden*. Key terms used to find articles about coping strategies included *caregiver coping*, *caregiver strategies*, and *caregiver interventions*. Search parameters were limited to elderly care, family care, and living at home. The term *caretaker* was also interchanged with all search combinations. The term *carer* was substituted for *caretaker* in an international article search. Search terms for articles using work-family conflict theory as a theoretical framework included *work-family conflict* and *role conflict theory* combined with *informal caregiver*, *work*, *caregiver burden*, *and caregiver stress.* These keywords were used to search Sage Knowledge, Sage Premier, and Sage Handbooks for books on work-family conflict theory. Journals contributing a significant portion of articles included *Journal of Family Issues*, *Clinical Gerontologist*, *Journal of Applied Gerontology*, *Journal of Family Economic Issues*, *Health Psychology*, and *Quality of Life Research.*

The studies in this review, in which the researchers used quantitative methods for comparative analysis of caregivers to noncaregivers, focused on topics such as the workplace, health, and conflict. Studies in which the researchers used qualitative methodologies covered topics such as physical, cognitive, and behavioral effects of ICG burden. No mixed-methods studies were found in the date range for this review. Dissertations about caregiving, the elderly, and aging were not used in this review to avoid the risk of bias. Newspaper and trade magazine articles were excluded to ensure accurate articles.

Theoretical Framework

Studies on the dynamics of work and family have been popular in literature since the turn of the century, when industrialization began affecting traditional views of work and family (Lavassani & Movahedi, 2014). Voydanoff (2013) suggested that the separation of the family following the shift from home-centered work such as farming to men going to work in factories and offices while women stayed home initiated work-family conflict. As Reb and Atkins (2015) noted, early studies focused on attempts to balance the conflicting roles of work and family.

The industrial revolution initiated a process of redefining wage earners and homemakers (Lavassani & Movahedi, 2014). The differentiation between responsibilities created conflict (Kahn, 1964). Kahn (1964) conducted a series of studies within numerous large corporations in which he developed his theory on role conflict within the context of organizational role expectations and behavior. Kahn observed conflicts that arose between positions, when demands from one task put pressure on the individual's ability to fulfill other responsibilities (Kahn, 1964). The occupation of simultaneous roles created pressures as obligations competed for priority, causing incompatibility between the roles (Clancy et al., 2019b; Longacre et al., 2016; Socci et al., 2019). Kahn hypothesized that the development of large corporations created a need for conformity within organizations (Kahn, 1964). For a business to function successfully, each person within the company must perform within a given role (Kahn, 1964). Behavior is modified to conform to the dictates of the assigned position. When change is introduced, conflict and ambiguity of tasks create problems of role identity and strain (Kahn, 1964; Socci et al., 2019).

Greenhaus and Beutell (1985) developed the theory of work-family conflict (WFC) based on Kahn's role conflict theory. WFC theory is confined to conflicts that arise from pressures specifically caused by incompatibility between work and family obligations (Chang et al., 2017; Greenhaus & Beutell, 1985). Kossek and Turner (2017) explained that WFC occurs when two or more purposes that had been compatible begin to compete for resources when an additional demand is added. Numerous theories have been developed based on WFC. For example, boundary theory treats family and work as separate entities and focuses on understanding how one influences the other (Lavassani & Movahedi, 2014). Boundary theory excludes the overlapping demands on time experienced by dual-role ICGs, making it inapplicable to this study. The term “spillover” began to be used with work-family conflict research in the early 1980s, with researchers proposing that both positive and negative events at work have an effect on family (Madsen & Hammond, 2005). Spillover theory was originally developed by Wilensky (1962) in reference to the positive influence of leisure on work and vice versa. By the 1990s, researchers began using the term “spillover theory” interchangeably with “work-family conflict theory.” Although spillover theory and WFC theory are similar, they are not identical. Spillover theory pertains more specifically to the effect that events have on work and family, whereas WFC addresses conflicts that arise between roles of work and family. I used WFC theory as the theoretical framework for this study.

Many researchers have used WFC theory as a framework to support their studies in caregiving. Halinski et al. (2019) applied WFC theory in a study to evaluate whether flexible work options for dual-role ICGs would diminish conflict. Clancy et al. (2019) used WFC to establish a correlation between elder caregiving strain and work-related factors. Additionally, Longacre et al. (2016) explored absenteeism at work related to WFC among dual-role ICGs. Kossek and Turner (2017) also used WFC to determine the effect that caregiving has on job and family demands.

WFC theory supported the focus of this research study. The additional task of caregiving requires adaptations to meet the demand to fulfill multiple responsibilities, increasing the level of conflict between obligations (Mortensen et al., 2017). The theory is bidirectional; when participation in the work role is made more difficult because of family obligations, or when family responsibilities cause difficulties in fulfilling work obligations, work-family conflict is the result (DePasquale et al., 2017; Greenhaus & Beutell, 1985). The more valued role determines which role creates the most conflict; a high commitment to job performance is strained when the added pressures of informal caregiving require more investment in the family role (Abramowska-Kmon, 2017; Burke, 2017). On the other hand, when one receives a deeper satisfaction from family responsibilities than from work responsibilities, then work satisfaction is threatened, and work interferes with the perceived need to invest more into caregiving (Betini et al., 2017; Clancy et al., 2019). The NAC-AARP 2020 report states that 60% of employed ICGs experienced greater work-related stress than nonworking ICGs (NAC, 2020). In other studies, the opposite was found to be the case (Dich et al., 2016; Kohl et al., 2018). In a study of 1,991 employed ICGs, Plaisier et al. (2015) found that female caregivers working full-time experienced a 1.5% higher degree of well-being than nonworking female caregivers (Plaisier et al., 2015). Plaisier et al.'s study examined these bidirectional conflicts as they relate to the three WFC constructs of time, strain, and behavior. These conflicts typically operate in a cascading effect, starting with time conflict, which produces a strain that affects behavior (Socci et al., 2019)

Time

Time-based conflicts occur when two or more roles compete for a person's time (Kossek & Turner, 2017). Time given to activities of one role reduces the amount of time that can be given to other roles. Time-based conflict can occur in two ways: (a) the total amount of time devoted to one task may not leave enough time to fulfill other obligations (Mortensen et al., 2017; Peng et al., 2019), or (b) preoccupation with one role may drain the attention needed to focus on another (Altomonte, 2016; Chang et al., 2017; Orfila et al., 2018). The second conflict of time results in loss of quality time (Andersson et al., 2019; Kayaalp et al., 2020; Peng et al, 2019). ICGs suffer time conflicts as they struggle to meet the obligations of both work and caregiving; the average full-time ICG spends an additional 25 hours a week performing care-related duties, resulting in a 65-hour work week (FCA, 2019). Inevitably, time conflicts between work and caregiving result in absenteeism, lost wages, and compromised care (Andersson et al., 2019; Kayaalp et al., 2020; Wang et al., 2020).

Strain

When the stress from one role affects a person's performance in another, strain-based conflicts occur (Kossek & Turner, 2017). The roles become incompatible when the strain experienced in one position makes it difficult to fulfill the duties in the other, resulting in the psychological experience of stress (Boumans & Dorant, 2020; Halinski et al., 2019; Longacre et al., 2016). For example, when pressures at work produce anxiety, tension, and fatigue, the strain may exhibit itself through lack of participation in family events, resulting in strain-based conflicts between the roles of work and family (Kossek & Turner, 2017). Less time to meet all of the obligations of work, family, and caregiving leads to strain (Jimenez et al., 2017; Reinhard et al., 2019). Studies show that the constant strain induced from the multiple demands placed on ICGs frequently leads to health, emotional, and mental issues (Kayaalp et al., 2020; Kim et al., 2018; Ramos-Campos et al., 2020).

Behavior Conflict

Behavior conflict occurs when the behavioral expectations of one role are incompatible with the expected or acceptable behavior in the other role (Greenhaus & Beutell, 1985; Kossek & Turner, 2017). For example, a female ICG may hold a managerial role at work that requires a woman to be assertive, objective, and aggressive; however, in the role of mother, she is expected to be gentle, warm, and nurturing. When the expected behavior of one identity invades the other, conflicts ensue. ICGs often experience a role reversal from that of child to guardian, health advocate, and financial manage (Moon, 2016). Many ICGs thus experience resistance and resentment from the care recipient. The ICG is often unprepared both emotionally and intellectually to assume these duties, and the backlash can lead to feelings of resentment, frustration, anger, and depression (Moon, 2016; Peng et al., 2019).

The three constructs in WFC theory can operate independently, in tandem, or sequentially (Kossek & Turner, 2017). While work-family conflicts may stem from one central conflict, more often the conflict is a sequential cycle (Kossek & Turner, 2017). Time-based conflicts lead to strain-based conflict; as the stress builds, the ability to manage behavior deteriorates, resulting in behavior-based conflict (Kossek & Turner, 2017; Strommen et al., 2018). Studies on ICGs suffering from WFC indicate a progression of time conflicts leading to strain that may result in behavioral problems (Moon et al., 2016; Peng et al., 2019).

Dual-Role Time Conflict

Studies show that ICGs experience time conflict in a variety of forms (Gautun & Bratt, 2016; Longacre et al., 2016). Caregivers spend an average of 34 hours a week in caregiving duties; this is equivalent to a second full-time job (NAC, 2020). Rigid scheduling policies at work contribute to work-family conflict; according to a 2015 NAC-AARP study, 34% of ICGs left the workforce due to inflexible work hours (Holzapfel et al., 2015). Other studies have indicated that ICGs were more prone to absenteeism and reduced productivity than their noncaregiving coworkers (Clancy et al., 2019; Hopps et al., 2017; Oldenkamp et al., 2017; Sadavoy et al., 2021). The 2015 NAC-AARP study found that the working ICGs in the study made 70% more adjustments to their work schedules due to time conflicts compared to their noncaregiver coworkers (Lee & Tang, 2015). In a comparison study of 3,057 working ICGs and noncaregivers, Lee and Tang (2015) found that women caregivers were more likely to leave or not even enter the workforce due to the additional demands associated with caring (OR .49, CI .24, 1.00, $p < 0.5$; Lee & Tang, 2015). The NAC-AARP 2015 study of 794 ICGs reported that 61% of the participants experienced some form of negative effect on work due to caring (Feinberg, 2016). The study also reported 49% of ICGs going in late, leaving early, or taking time off (Feinberg, 2016).

Even when they are at work, ICGs may feel distracted, suffer from poor concentration, and not have enough time to complete tasks (Hopps et al., 2017). This phenomenon is referred to as *presenteeism*, which means "reduced productivity while at work due to providing care" (Coumoundouros et al., 2019, p. e268). Hopps et al.'s (2017) study found that ICGs were 27.4% more likely to arrive late, leave early, and experience presenteeism. Andersson et al.'s (2019) study of 642 ICGs revealed that the percentage of work-related absenteeism and presenteeism was linked to lack of support for the needs of the ICG. Those who experienced high levels of support were 16.87% less likely to have work interruptions.

The globalization of the employment market over the last decade has increased competition in the job market, resulting in increased work hours and workload for many current employees (Burke, 2017; Yeandle et al., 2017). These demands in the employment sector have increased work-family conflict; those who are already suffering time constraints from the dual role of caregiving feel the greatest strain (Burke, 2017; Yeandle et al., 2017). Longacre et al. (2016) reported that over 39.8% of the ICGs they interviewed had quit or retired due to caregiving demands. In the same study, more than half stated that caregiving interfered with their job (Longacre et al., 2016).

Time conflict is intensified among ICGs when caregiving responsibilities increase (Gérain & Zech, 2019; Schulz & Eden, 2016). Unlike childcare, where responsibilities decrease as children grow older, eldercare demands increase over time as the care recipient becomes more debilitated and care dependent (Gérain & Zech, 2019; Schulz & Eden, 2016). ICG employees are unprepared for changes that may occur suddenly and require an abrupt departure from work (Andersson et al., 2019). Employers require advance notification for a leave of absence, typically 2 weeks or more (Reinhard et al., 2019). Events in eldercare such as a health-related episode happen abruptly and without warning, requiring a sudden leave of absence. There is very little support in the employment sector for ICGs (Sadavoy et al., 2021). While parents have an established array of support to share childcare, such as school, daycare, and sports activities, ICG support to relieve time demands is scarce (Gautun & Bratt, 2016). Employers hold misperceptions regarding the ICG role; the majority of ICGs thus do not divulge their time conflicts to supervisors out of fear of reprisal (Clancy et al., 2019). Employers accept the demands of childcare and absenteeism related to it; however, eldercare is a lesser known, newer issue in the workplace and is viewed as less demanding and time consuming, resulting in less tolerance for missed work (Holzapfel et al., 2015). In a Canadian study, owners of 114 companies were asked what policies they had in place for the one third of their workforce who were ICGs; they were surprised, as "they knew that caregiving was happening, but not at such a high level" (Employer Panel for Caregivers, 2015, p. 12).

Time Conflict Intervention

ICGs, whether employed or not, feel a loss of control over time (Altomonte, 2016). In a qualitative study conducted by Altomonte (2016), ICGs expressed their inability to control their schedules and make plans due to the constant demands of caring. For dual-role caregivers, time became frenzied; each day was filled with pressure to complete all the tasks of multiple roles, leaving little to no time for self-care (Kayaalp et al., 2020). Many working ICGs use their sick or vacation days to manage caregiving-related conflicts (Oldenkamp et al., 2017). Discrimination and unequal treatment between eldercare and childcare are prevalent (DOL, 2016; Wiggins, 2018). In the case *Robinson v. T-Mobile*, Rachel Robinson took family leave for pregnancy and was promoted when she went back to work. The next year she requested leave to care for her ailing mother and was denied and told she could take only intermittent leave (Wiggins, 2018).

Flexible work schedules are often suggested as a solution to reconciling dual-role time constraints (Halinski et al., 2019; Holzapfel et al., 2015). However, flextime is contingent on implementation by the employer, company dynamics, and job description (DOL, 2016; Employer Panel for Caregivers, 2015). These limitations may make flextime an inaccessible coping solution for most ICGs to manage time conflicts between work and their caregiving role (Andersson et al., 2019).

These strategies are poor substitutes for resolving time conflicts between work and care; rather than relieving stress, these methods of coping may increase work-family conflict because they do not provide a respite from caregiver burden. Due to the multitude of variations in ICG demographics, such as ethnicity, income, culture, and age, there is no one answer to resolving the problem of time constraints for dual-role ICGs (Chang et al., 2017; Halinski et al., 2019; Kayaalp et al., 2020).

Dual-Role Strain Conflict

The extra role of caregiving results in higher degrees of work-family stress than that experienced by noncaregivers who also experience work-family conflict (Abramowska-Kmon, 2017; Sadavoy et al., 2021; Wolff et al., 2016). Strain induced by ICG burden is manifested in a variety of ways. ICGs may exhibit signs and symptoms of stress in one, several, or all areas affected by caregiver burden (Gérain & Zech, 2019; Kossek & Turner, 2017).

Manifestations of Strain

ICG strain is manifested physically, emotionally, and socially (Bertilsson et al., 2016; Gérain & Zech, 2019; O'Donnell, 2016). The lack of time and energy and limited access to relief lead to neglect of self-care. ICGs are at high risk for developing hypertension, obesity, sleep deprivation, digestive problems, and slowing of cognitive function (Koyanagi et al., 2018). These risks are highest in dual-role ICGs, and even more so in ICGs with in-home care recipients (Chang et al., 2017).

Physical

Health status is compromised by the strain of dual roles (Bom et al., 2018; Dich et al., 2016). Caregiver stress can weaken the immune system, lead to chronic health problems, and accelerate aging (Scommegna, 2016). At least one-third of ICGs report chronic fatigue (Hopps et al., 2017; Koyanagi et al., 2018). In Mortenson et al.'s (2017) pooled analysis study of 1,396 ICGs, long-term caregivers had the highest risk of coronary vascular disease (6.17, 95% CI: 1.73; 22.1). Participants in Altomonte's (2016) phenomenological study of 19 family caregivers complained of worsening health conditions due to a lack of time to care for themselves. Several participants stated that they had no time for leisure to reduce stress. In a literature review synthesizing 17 articles, Bom et al. (2018) found a strong correlation between poor health and caregiving. Not all studies support the theory of greater health disparities in ICGs compared to noncaregivers. However, Dich et al. (2016) note that many studies make no distinction between working and nonworking caregivers. This is an important distinction, since dual-role caregivers typically report less time to seek care for themselves (Altomonte, 2016; Andreakou et al., 2016). A possible contradiction to this assertion is a study by Dich et al. (2016) that suggested employment may improve physical health in ICGs if social support in the workplace is high.

Although the effect of dual-role caregiving on physical health status is disputed in the studies, most agree that it negatively affects emotional status (Hopps et al., 2017; Kohl et al., 2018; Suryavanshi, 2020).

Emotional

The emotional strain of caregiving was found to have a significant effect on dual-role employees, leading to difficulty making decisions, poor concentration, and burnout (Andersson et al., 2019; Strommen et al., 2018). The emotional toll of caregiving burden is expressed by many as a cycle of frustration and anger followed by guilt and feelings of inadequacy (Herron et al., 2019; Riedel et al., 2016). Hopps et al. (2017) linked the loss of work productivity in dual-role caregivers to depression and anxiety. Holzapfel et al. (2015) stated that "today's employee caregiver faces a work-care conflict that has the potential to grow more at odds each day. They can face rigid scheduling policies at work, stressful distractions at home, and see their health decline" (p. 97). Other researchers have argued that it is not the stress of employment, but rather inability to cope with the strain of caregiving, that interferes with work performance (Kayaalp et al., 2020). In direct contrast, Clancy et al. (2019) found that the interference of work with caregiving was more emotionally disruptive then caring was to work. This claim supports the bidirectional element of work-family conflict theory; when the role of caregiving has greater value, work interference creates a greater emotional strain, and when work has a greater value, caregiving interference causes emotional strain (Greenhaus & Beutell, 1985). The family-work direction, however, is complicated by the psychological effects of guilt and remorse imposed by societal expectations of family value (Øydgard, 2017). Society dictates that caregivers should value caring over employment. This leads to internal emotional conflicts and social strain (Broese van Groenou & De Boer, 2016; Li & Lee, 2020).

Social

Conflicting emotions lead to feelings of isolation and loneliness, as caregivers are reluctant to express their feelings (Øydgard, 2017). Many dual-role ICGs give up social time simply because they are too busy with work and caregiving (Kong et al., 2021) . The average ICG spends 34 hours a week performing routine caregiver duties. That time increases if the care recipient needs acute care services (FCA, 2019). Acute care recipients require additional assistance for average daily living (ADL) tasks. Acute ADL recipients may require as much as 62 hours a week of care time (NAC, 2020). These hours are in addition to a full-time 34- to 40-hour work week (FCA, 2019). The consumption of hours committed to work and care leaves little to no time for social activities or leisure time (Sadavoy et al., 2021). Leisure and socialization are two factors that alleviate emotional and health problems and going without them can lead to feelings of isolation (Hawken et al., 2018). In a qualitative study conducted by Rigby et al. (2019), participants described the difficulties associated with socializing. Typically, the care recipient cannot be left alone for any length of time, which restricts social activities. Taking the recipient to gatherings requires additional time and planning. Rather than a reprieve, it is exhausting and additionally stressful for the caregiver (Rigby et al., 2019).

Vandepitte et al. (2016) conducted a systematic review of 53 papers investigating the effectiveness of support strategies for ICGs. The review concluded that "stating which intervention type works best for all caregivers and also indirectly benefits recipients is still impossible due to the complex nature of supporting strategies" (p. 961). The strain of managing both roles, compounded by feelings of isolation, cause approximately 10% of ICGs to leave the workforce entirely (NAC, 2020). Leaving the workforce, reducing hours, or taking less stressful jobs at lower pay are coping strategies that lead to financial stress, another contributor to work-family conflict (Cohen et al., 2015; Holzapfel et al., 2015; Phillips et al., 2016).

Financial

Financial burdens are associated with the cost of care and loss of income (Koyanagi et al., 2018; Phillips et al., 2016). Nearly 23% of ICGs report financial hardship as a result of caring (Cohen et al., 2015). ICGs commonly pay for care recipient expenses including medical supplies, transportation, prescriptions, and living assistance, most of which is not covered by Medicare or insurance (Schulz & Eden, 2016). Studies reported a higher level of caregiver burden when the level of financial cost is greater (Cohen et al., 2015; Koyanagi et al., 2018). Over 40% of ICGs consider the cost of caring for a recipient an immense financial burden (Phillips et al., 2016). Working ICGs are not exempt from financial stress, as studies indicate there is a greater expectation for employed caregivers to bear the costs of care for the recipient (Coumoundouros et al., 2019; National Academies of Sciences, Engineering, and Medicine, 2018; Schulz & Eden, 2016). The financial burden is compounded when the effects of stress lead to hour reductions, missed promotions, or job loss (Holzapfel et al., 2015; Longacre et al., 2016). Job reduction or termination not only add to the financial burden of care, but also have long-term ramifications, costing the average caregiver $300K-$600K in lifetime earnings and retirement funds (FCA, 2019). Wiggin (2018) points out the discrimination older ICGs face in the workforce: “Leaving the workforce to care for a family member creates distinct financial risks for these women because age discrimination often bars them from jobs when they later wish to return to work and resume making an income” (p. 164). Employers also suffer financial loss as a result of work-family conflict among ICG employees (Burke, 2017). Higher rates of health issues in ICGs cost employers approximately 8% more in health provision plans than they would otherwise pay

(FCA, 2019). Employers also pay over $25.2 billion a year in lost productivity from working ICGs' absenteeism (FCA, 2019).

Respite From Stress and Strain

Although the dual role of work and family creates greater stress for ICGs, some studies show that work is also beneficial for many ICGs (Clancy et al., 2019). Work provides respite from daily care and support from coworkers, bolsters self-esteem, offers social networks, and relieves financial strain (Murphy & Cross, 2018). The positive effects of work are contingent on ICGs learning to balance both roles. In a qualitative study of 25 caregivers, Murphy and Cross (2018) found they balanced the roles of care and work by viewing work as a "place of escape" (p. 1472). In a longitudinal study of 146 participants, Socci et al. (2019) discovered that working caregivers who did not reduce their hours of care had better health then those who did reduce hours to provide care, possibly because work provided a mental and physical reprieve from care (Socci et al., 2019).

ICGs state that lack of knowledge of health conditions, inadequate training for care-specific tasks, and not knowing where to obtain information adds to caregiver burden (Moon, 2016; Strang et al., 2019). Several studies recommended that employers create programs to provide assistance and information to caregivers (Jimenez et al., 2017; Phillips et al., 2016; Reinhard et al., 2019). The majority of employers do not have support programs in place. A brief by the United States Department of labor states that "our workplace and public policies have not evolved to meet the needs of the growing army of unpaid, mostly family, caregivers who also work outside the home" (DOL, 2016, p. 8). Public organizations appear to be more willing than the private sector to develop policies to help ICGs, but research shows that implementation is limited by company size and resources, with cost and lack of resources being the two main deterrents (Holzapfel et al., 2015; Ireson et al., 2016). Many caregivers are reluctant to use services when they are made available for fear of reprisal (Murphy & Cross, 2018). The perceived stigma associated with severe cognitive impairment in care recipients causes many ICGs to avoid services that may expose them (Herrmann et al., 2018).

Research on coping strategies for stress associated with caregiving and work is sparse. Morimoto et al. (2017) conducted a quantitative study of 456 working ICGs to determine the effect of coping strategies for work-family conflict in ICGs; however, the study was limited to effects of coping and did not evaluate specific strategies (Morimoto et al., 2017). Vos et al. (2021) conducted a qualitative study of 25 working caregivers to gain insight into support needs. The study identified six areas of need; however, no additional research was conducted to assess what strategies could address those needs (Vos et al., 2021).

Lastly, several studies suggested that religion is a coping resource for many ICGs (Coluccia et al., 2017; Jellema et al., 2018; Machado et al., 2018; Mehta & Leng, 2017). ICGs who are actively involved in a religious organization have a stronger social network (Machado et al., 2018; Mehta & Leng, 2017) Studies also indicated that religious caregivers have a more positive perspective of the caregiving role, which in turn lowers caregiver burden (Machado et al., 2018; Mehta & Leng, 2017). Numerous participants in Mehta and Leng’s interviews indicated that their faith was integral in coping with caregiving demands (Mehta & Leng, 2017). Aside from these few studies, there is scarce literature on coping strategies specific to dual-role ICGs.

Dual-Role Behavioral Conflict

Time and strain conflicts are often manifested in behavior (Longacre et al., 2016; Plaisier et al., 2015). Behavior that is acceptable or even necessary in the caregiving relationship, such as assuming an authoritarian role, may be inappropriate at work, and vice versa. Behavior that is a result of strain, such as exhibitions of frustration or anger, may also spill over into the work environment with negative repercussions (Vos et al., 2021).

The perception by caregivers that there is a lack of choice in providing care creates a sense of loss of control, resulting in negativity towards the role of caregiving (Li & Lee, 2020; O'Donnell, 2016). The concept of choice is associated with feelings of well-being; when the freedom to choose seems restricted, feelings of well-being are replaced with emotional, physical, and mental strain (Al-Janabi et al., 2017) . The loss of choice is exacerbated in dual-role ICGs who already feel a loss of control over time and are suffering from multiple stressors (Coumoundouros et al., 2019; Vos et al., 2021).

A major factor contributing to the perception of lack of choice is poor preparedness (Moon, 2016). Since the early 1990s, studies have produced data documenting the increase of informal caregiving on a global scale (Clancy et al., 2019; Moon et al., 2016). Projections estimate that one in four adult children will become ICGs by 2030 due to longer lifespans, higher costs of formal care, shortage of caregivers, and smaller families (BLS, 2019). Despite these forecasts, few families are prepared for the role of caring for an aging loved one (Moon, 2016; Schulz & Eden, 2016). Typically, the role of caregiving is suddenly assumed after a major health event that leaves the care recipient with diminished capacity to live independently (Boucher et al., 2020). Often both the caregiver and recipient perceive the arrangement as temporary, but that is seldom the case (Al-Janabi et al., 2017; Schulz & Eden, 2016). The aging process is a progressive deterioration; when an elder reaches the degree of needing assistance, there is no going back (Dich et al., 2016; Fekete et al., 2017). Lack of preparedness affects roles at work and in the family (Moon, 2016). Wang et al. (2020) conducted a study of 214 working ICGs to determine how job demands and caregiving influence quality of life. Study results indicated that participants who had higher levels of preparedness had better quality of life (Wang et al., 2020). In a study by Rigby et al. (2019) using an online survey, 415 participants expressed feelings of resentment because of lack of self-care time, lack of support from other family members, and loss of friendships (Rigby et al, 2019). In some studies, ICGs expressed resentment towards the medical community for lack of assistance in and information about providing adequate care (Moon, 2016). Frustration was also expressed by ICGs towards employers and coworkers for lack of understanding and support in the caregiver role (Vos et al., 2021).

Depression in ICGs is associated with feelings of failure, hopelessness, resentment, and anger (Taati et al., 2016). Many ICGs have difficulty articulating how they feel and fear their feelings will not be validated (Chen, 2016). Internalizing feelings of helplessness, aloneness, and being lost can lead to depression (Riedel et al., 2016). Depression manifests in a variety of behaviors: withdrawal, hostility, anger, and aggression (Lin, 2020; Taati et al., 2016). The strain of trying to balance the roles of work, family, friendships, and caregiving can put a negative focus on the caregiving role, developing into resentment and depression. Caregiving becomes a state of agitation; the demands on time and interferences with roles lead to intolerance, being easily bothered, and outbursts of anger (Vos et al., 2021). Continual exposure to strain in caregivers increases the chance of emotional reactions, and seemingly incidental provocations can provoke an outburst of anger towards the care recipient, family members, coworkers, and supervisors (Herron et al., 2019). The ramifications of uncontrolled displays of anger in the workplace can lead to disciplinary action or termination, creating a cycle of greater caregiver burden and more manifestations of dysfunctional behavior with greater work-family conflict (Andersson et al., 2019; Rodríguez-Pérez et al., 2017).

Anger towards the care recipient can lead to abuse (Jackson & Hafemeister, 2016; Roberto, 2016). Studies showed that care recipients with diminished cognition, such as dementia and Alzheimer's patients, are a greater burden on caregivers due to behavioral dysfunction in the care recipients (Kokorelias et al., 2021; Lin, 2020; Taati et al., 2016). Daily exposure to volatile behavior deteriorates ICG mental and physical health, which increases the risk of abuse (Lin, 2020; Storey, 2020). Studies on caregiving characteristics showed a greater risk of abuse in new ICGs, with a marked decline after 1 year of caregiving; this is thought to be attributed to greater adjustment to multiple roles in the first year of caring (Storey, 2020). Abuse is not always violent; more frequently it is manifested in the form of neglect (Lin, 2020). Intentional neglect because of anger, frustration, and resentment results in poor nutrition, unmanaged pain, urinary incontinence, poor hygiene, and falls. Unintentional neglect may be the result of depression or poor understanding of care (Lin, 2020; Tao & McRoy, 2015). Tao and McRoy (2015) found that ICGs suffering from depression were more prone to forget to administer medication and lacked the energy to perform daily tasks such as bathing, feeding, and toileting the care recipient. Dual-role caregivers are at greater risk of negligence because of exhaustion from trying to manage work and care (Orfila et al., 2018). Neglect may also spill into work duties, as ICGs fail to meet project deadlines, leave unfinished work, and skip meetings (Reizer & Hetsroni, 2015). Neglect has a great impact on early withdrawal from the workforce or long-term care placement when left unchecked (Andersson et al., 2019; Burke, 2017). In a study on organizational citizenship behavior (OCB), Reizer and Hetsroni (2015) found poor performance among ICGs suffering high caregiver burden. OCB consists of five characteristics: (1) altruism, (2) civic virtue, (3) conscientiousness, (4) courtesy, and (5) sportsmanship (Reizer & Hetsroni, 2015). ICGs scored particularly low in courtesy, lacking the initiative to provide personal assistance (Reizer &

Hetsroni, 2015). This was attributed to the lack of empathy ICGs sensed in the workplace from coworkers and supervisors (Reizer & Hetsroni, 2015).

Behavioral Conflict Interventions and Sources of Support

When support is not available on a formal organizational level, it often comes from coworkers and supervisors (Murphy & Cross, 2018; Rofcanin et al., 2019). When ICGs feel that they are valued in the workplace, work-family conflict decreases (Plaisier et al., 2015). Supervisor support, whether expressed as concern or tangible assistance, results in a higher degree of relief than coworker support (Rofcanin et al., 2019). The perception of empathy and a tangible effort to relieve caregiver strain from the organization enhances a sense of individual worth (Kohl et al., 2018). Increased perceptions of self-worth replenish resources depleted by the caregiver role and bolster resources needed for work (Kohl et al., 2018; Plaisier et al., 2015).

Coworker support is also beneficial in the workplace, providing interpersonal relationships and offsetting social isolation (Gérain & Zech, 2019; Plaisier et al., 2015). While work may provide some relief from work-family conflict for ICGs, it does not eliminate caregiver burden (Hilbrecht et al., 2016). Much of the stress induced by caregiving cannot be alleviated by a family-friendly work culture (Boumans & Dorant, 2020).

Many studies in the literature review recommended social interventions (Andersson et al., 2016; Dam et al., 2017; Taati et al., 2016). Joining support groups or getting counseling is the recommended strategy to manage social isolation (Dam et al., 2017). A study using a private-invitation Facebook platform was conducted with 58 participants (Benson et al., 2020). Overall, the study results indicated that Internet sites provided ICGs easy access to information without having to leave home or find substitute care for the recipient. Exit interviews revealed that while the online model provided some emotional relief, there was a higher need for face-to-face contact with other ICGs whether in person or virtually to reduce feelings of isolation (Benson et al., 2020).

A review of 53 studies using various support modalities (Vandepitte et al., 2016) indicated inconsistent results using telephone-based counseling programs. While some studies showed improvement in reducing depression, the same study showed no improvement in quality-of-life outcomes. The reviewer concluded, “Stating which intervention type works best for all caregivers and also indirectly benefits recipients is still impossible due to the complex nature of supporting strategies” (Vandepitte et al., 2016, p. 961). Another controlled intervention was conducted with patients receiving inpatient palliative care (Kühnel et al., 2020). Two studies were conducted using existential behavioral therapy for ICGs of palliative patients. The original study by Fegg et al. (2013) required participants to attend six sessions, and they showed improved quality of life and decreased stress levels (Fegg et al., 2013). However, the study results were skewed due to a significant dropout rate of participants. The second study (Kühnel et al., 2020) required only two sessions, resulting in higher participation and significant caregiver relief.

The caregiver role is physically demanding, emotionally draining, and mentally challenging (Jellema et al., 2018). A literature review of 662 studies, of which 30 were extracted for the study, showed that loss of activities valued by ICGs resulted in poor mental health, yet none of the studies suggested interventions (Jellama et al., 2018). Chen’s (2016) presentation of a case study referred to inner reserves as “grit” (para. 4), which enables a caregiver to cope with the stressors of caring. The author argued that some individuals have grit naturally, and those who lack it can undergo cognitive-behavioral therapy (CBT) to develop it (Chen, 2016). Chen asserted that acquiring and using grit is the key to successful coping strategies (Chen, 2016).

Although the study suggests potential for CBT as a successful coping strategy, there are no studies in the literature supporting such results.

A study by Fekete at el. (2017) supported the importance of positivity as the primary quality linking tensions and rewards of caregiving. While study participants expressed emotions of frustration, resentment, and anger, they also shared satisfaction in caring when they focused on the positive aspects. The authors recommended interventions targeting mental health aimed at positivity strategies (Fekete et al., 2017). A personal bond with the care recipient is the coping strategy most used by adult children (Betini et al., 2017). Adult children report the highest levels of caregiver strain, yet they are also the least likely to put the care recipient in a long-term care facility (Boucher et al., 2020; Cohen et al., 2015). One study showed that ICGs who focused on the positive aspects of caring showed less caregiver burden (Fekete et al., 2017). Another study found that ICGs who participated in social activities managed stress better (Cohen et al., 2015). Rodríguez-Pérez et al. (2017) proposed that caregiver quality of life (QOL) is related to coping strategies. Avoidance-type coping worsens QOL, while active, emotion-focused coping and socially supported coping improve QOL (Rodríguez-Pérez et al., 2017). Although the study was limited to only two types of coping strategies, it does provide some insight into coping strategies for ICGs.

The studies presented in this chapter indicate that the dual roles ICGs experience may result in a greater degree of time conflict, strain, and behavioral conflicts attributed to the additional burden of managing both work and caregiving (DOL, 2016). Numerous studies analyzed the additional stress factors of this dual role, such as work interruptions, caregiving demands, and depression (Altomonte, 2016; Gautun & Bratt, 2016; Lee & Tang, 2015). In a qualitative study by Altomonte (2016) of 19 caregivers, all the working ICGs interviewed reported struggling with maintaining a balance between their own needs and those of the patient, with little or no respite. One ICG summed it up: “Sometimes you can plan ahead, making reservations and all that stuff, but then sometimes that just doesn’t work. Just when you think you got things handled, there’s always something else that comes up that smacks you in the head” (p. 652).

While the information in the literature is revealing, it lacks solutions. Cohen et al. (2015) performed an exploratory factor analysis on data from the 2011 National Study of Caregiving to determine factors associated with caregiver burden. The study contributed to understanding the psychosocial factors of caregiver burden to develop interventions, but no interventions were forthcoming (Cohen et al., 2015). After analyzing data from the Health and Retirement Study (HRS), Lee and Tang (2015) determined that a lack of organizational support and social change has left ICGs on their own to find a way to balance caring and work responsibilities. Studies that presented suggestions or recommendations for interventions emphasized social change. However, further research is needed to evaluate the effectiveness of such interventions. Qualls (2016) supports that need, stating:

> Appraisals of the burdens of caregiving are powerful mediators of mental health outcomes, as are coping styles, perceived mastery, and informal social support. However, little is known about the processes by which family caregivers select a coping style, develop mastery, and negotiate support. Models used in research often treat a response style as existing or not (e.g., problem-focused coping) without inquiry into the processes by which one strategy or another is selected, revised, or discarded. (p. 288)

While proposals for social change are necessary, change has been slow, and as the current literature reveals, programs and regulations have failed in providing support to ICGs on any significant level.

Summary

Dual-role informal caregiving is a significant social issue; one in six employees in today's workforce are ICGs (FCA, 2019). The literature summarized in this chapter establishes the conflicts associated with managing both roles of caring and work (NAC, 2020). Dual-role ICGs experience severe time conflicts when trying to balance the multiple roles of family, work, social responsibilities, and caregiving (Andersson et al., 2019). Time conflicts typically lead to strain that then leads to health problems and emotional and social conflict (Kossek & Turner, 2017). The strain associated with ICG burden often spills into behavioral conflicts such as resentment, outbursts, depression, and isolation (Schulz & Eden, 2016). Research further indicates that most work, social, and government interventions are inadequate in addressing dual-role ICG burden (Broese van Groenou & De Boer, 2016; Cohen et al., 2015; Reinhard et al., 2019). Future policy to address the needs of ICGs remains abstract; ICGs need plausible strategies that provide tangible relief to make the dual roles more manageable (Vandepitte et al., 2016). This study explores the lived experiences of ICGs to ascertain how they manage their dual roles in order to remain in both the workforce and caregiving. These findings may serve as a catalyst for improving the quality of care and health outcomes for both the caregiver and care recipient by providing applicable management strategies. The findings might also improve workforce retention by providing insights that could spur the development of more employee-friendly policies that make it easier for ICGs to fulfill their dual role. This study contributes to future scholarly inquiry, giving insight from the lived experiences of ICGs about support strategies to improve caregiver retention in the workforce and caregiving fields.

The following chapter is a detailed account of the research methodology for this study. Most studies on informal caregiving have been quantitative. While the studies reviewed in this chapter assist in understanding the complexity of conflicts with which ICGs must cope, they repeatedly concluded that additional research is necessary to identify coping strategies from lived experiences of ICGs (Cohen et al, 2015; Martinez & Anantharaman, 2016). Chapter 3 below describes a qualitative methodology using a phenomenological approach to examine the lived experiences of dual-role ICGs.

Chapter 3: Research Method

The purpose of this study was to examine the lived experiences of ICGs to ascertain the coping strategies applied that are most beneficial to those filling the dual role of employee and caregiver to an aging family member. This chapter provides a detailed explanation of how the study's purpose was fulfilled. The research design and methodology are discussed, along with the study population and recruiting plan. The process of data collection using face-to-face interviews and how the data were analyzed are described, as well as how the information has been stored to meet the requirements of the Institutional Review Board (IRB). Procedures to confirm trustworthiness are outlined. This chapter concludes with ethical considerations encountered and how I addressed them.

Research Design and Rationale

Interview questions in the IPA method focus on people's understandings of their experience. The questions are exploratory, not explanatory (Smith et al., 2009). In alignment with IPA, the research questions for this study reflect the coping process that ICGs go through to manage the stressors associated with caring while working, not just the outcome of dual-role caregiving (Smith et al., 2009).

RQ1. Based on lived experience, what coping strategies do informal caregivers use to manage time conflicts associated with their dual roles as employees and caregivers to an aged family member?

RQ2. Based on lived experience, what coping strategies do informal caregivers use to manage stress conflicts associated with their dual roles as employees and caregivers to an aged family member?

RQ3. Based on lived experiences, what coping strategies do informal caregivers use to manage behavioral conflicts associated with their dual roles as employees and caregivers to an aged family member?

The study explored how ICGs manage dual roles—what strategies ICGs apply as effective coping skills to function as caregivers and employees. The qualitative methodology focuses on the meaning of experience (Moustakas, 1994), providing a detailed understanding of a phenomenon (Creswell, 2013). Because human experience cannot be measured by numbers (Moustakas, 1994), qualitative research finds meaning in experience rather than measurement. Meaningful data gathered from the study participants are best understood through reflective analysis, in which the parts make up the whole (Moustakas, 1994). Quantitative research provides statistical data warranting a qualitative study of ICGs (Collinson & De La Torre, 2017). Quantitative study results have revealed the increasing need for ICGs and the alarming rates at which they are leaving the workforce (DOL, 2016; NAC, 2020; Reinhard et al., 2019). Qualitative research makes it possible to understand how and why ICGs remain in both the workforce and caregiving (Halinski et al., 2019). Some recent qualitative research has provided recommendations for coping with informal caregiving (Chen, 2016; Dam et al., 2017); however, few studies have been done from the perspective of ICGs who share strategies from their own experience. The IPA approach was selected for this purpose. This approach incorporates personal expertise with interpretive reflection, producing a phenomenological and hermeneutic analysis of the data (Smith et al., 2009). With IPA, data are gathered from each person’s description of the phenomenon from their perspective and collectively analyzed to extract the commonality in the experience (Moustakas, 1994). In that perceptions are regarded as the primary source of knowledge and examined from every angle, every perspective adds to understanding

(Moustakas, 1994). Research indicates that ICG strain from caring and working varies according to the specifics of the phenomenon; coping strategies therefore vary as well (Dich et al., 2016; Gérain & Zech, 2019; Kokorelias et al., 2021). Using IPA allows for individual differences while simultaneously exploring the common threads that run through all of these experiences.

Role of Researcher

Smith et al. (2009) pointed out that the researcher is both a participant and an observer when using IPA. The researcher is a participant who experiences phenomena as a fellow human being, and as an observer trying to understand the experience through the subject's perspective (Smith et al., 2009). My role as a participant had even greater significance than implied by Smith et al.'s (2009) definition, in that I was not only the researcher, but also an ICG. In phenomenology, the researcher typically has a personal interest in and is intimately connected to the study (Smith et al., 2009). From this perspective, my familiarity with the phenomenon helped me develop a rapport with the study subjects and elicit greater depth in the interviews. However, my personal experience also presented a risk of bias to the study; I therefore employed several strategies to put aside my preconceptions, such as bracketing, peer review, and member checking. Dörfler and Stierand (2020) recommended the use of bracketing to minimize the risk of personal influence and add reflexivity. Bracketing can be achieved using various techniques, such as reflective journaling and field notes. I kept a diary of my thoughts, feelings, and perceptions; this helped to bring any biases to consciousness during this study (Dörfler & Stierand, 2020). Two more methods of bracketing recommended by Tofford and Newman (2010) are field notes and bracketing interviews. During interviews, I made memos of my reflections to facilitate an unbiased analysis process. Preparing a semi structured interview guide also helped to reduce bias by keeping the conversation focused on the research questions and not straying toward leading questions (Dörfler & Stierand, 2020). I reviewed my initial analysis of each interview with a peer who had research experience to expose any unconscious bias and preconceptions that may have been interjected (Tofford & Newman, 2010). To further guard against prejudice and give validity to the method, I used member checking after the analysis, requesting that the participant check for any misinterpretations of their responses (Castleberry & Nolen, 2018).

Research indicates that a small remuneration for the time and inconvenience of study participation is appropriate if it is commensurate with the time and effort of subject involvement (Committee for Protection of Human Subjects, 2017). A study by Largent and Lynch (2017) found a general consensus that a small amount of compensation for time and travel is permissible as long as it is not enough to coerce or impede informed consent. In a national study of investigators and IRB chairpersons, participant inconvenience was considered the primary factor warranting compensation (Ripley et al., 2010). Largent and Lynch (2017) found that 94% of the IRB and research ethics professionals agreed that offering money for time and inconvenience was acceptable. Because dual-role ICGs consented to give up their time to participate in this study, and time demands contribute toward caregiver strain (Altomonte, 2016), each participant was given a $25 gift card at the conclusion of the interview. The amount was sufficient to cover time and travel, yet not enough of an incentive to bias subject responses (Andersson, 2019; Cheff & Roche, 2018; Committee for Protection of Human Subjects, 2017; Nyangulu et al., 2019). Aside from my close association with the phenomenon, I did not have any relationships with the study participants. All participants were recruited from organizations with which I had no professional or personal association; therefore, no conflict of interest was present in this study.

Methodology

Population

There are 40 million ICGs in the United States who work outside the home and care for an aging person over 65 (NAC, 2020). Studies indicate that the most significant strain experienced by ICGs affects those caring for a family member over the age of 70 living in the same household (NAC, 2020). Based on these statistics, this study targeted working men and women caring for a family member in their own home for a minimum of 1 year. One year allows for a transitional period to establish some coping strategies (LaManna et al., 2020; Moon, 2016) Using purposive sampling, I collected data in face-to-face interviews; the population pool encompassed a geographic radius of 50 miles within the Dallas metroplex. I used IPA, an analysis method based on a small, homogeneous sample, with an emphasis on experience, not population, making purposive sampling the most appropriate strategy (Smith et al., 2009). Smith et al. (2009) recommended three to six participants; however, the study objectives dictate the size of the sample. This study sample target size was slightly larger in case all participants did not experience conflicts in all three construct areas of time, stress, and behavior. A more significant sample increased the possibilities of thorough data collection to cover all three research questions.

Sample size in qualitative research focuses on saturation, not generalization (Patton, 2002). Korstjens and Moser (2018) stated that the sample size is driven by the research, which is centered on attaining an in-depth understanding of the phenomenon. Because the point of phenomenological analysis is to gather rich data, a small sample size is recommended to avoid thinning the data (Miles et al., 2014). Experts in qualitative research suggest a range of four to 10 for a phenomenological approach (Creswell, 2013; Miles et al., 2014; Smith et al., 2009). Several studies of sample sizing have revealed that an average of 11-20 interviews achieves sufficient saturation (Marshall et al., 2013; Mason, 2010). Marshall et al. (2013) cited a study that used a statistical analysis of the dataset from 60 interviews in a phenomenological study. Using Cronbach's alpha to measure the reliability of code frequency distribution, they found that saturation was achieved at 12 interviews and steadily decreased with more interviews (Marshall et al., 2013). Using IPA's method of coding, I coded and searched for emergent themes in each interview after I transcribed the data. Based on the recommendation of experts in the field, prior studies using the phenomenological approach (Braun & Clarke, 2013), and the results of the statistical analysis, the sample size for this study was a minimum of 12 interview participants, with the contingency to increase the sample size until saturation was achieved. Using IPA methods, I coded each interview individually in three ways: descriptive coding, which focuses on the participant's meaning; linguistic coding, which conveys how the experience was communicated; and conceptual coding, which indicates what the data reveal (Braun & Clarke, 2013). Once the interviews were coded, all of the codes were reviewed to see what patterns developed; in IPA, this is equivalent to categorizing the data (Smith et al., 2009). The categories were then developed into themes that emerged. This process was conducted on each interview; once the interviews stopped producing any new information, indicated by no new codes or patterns, I determined that saturation was achieved. At this point, all of the themes were compared across the entire data set to determine the themes for the final analysis process (Braun & Clarke, 2013).

A purposive sampling strategy was used to ensure a homogeneous model in IPA, keeping the research narrowed down to a specific subpopulation of ICGs (i.e., working ICGs caring for an elderly family member over the age of 70 living in the same household for a minimum of 1 year). Prospective candidates who answered in the affirmative to these four questions met the study criteria:

1. Do you care for a family member over the age of 70?
2. Do you work outside the home?
3. Does the care recipient reside with you and if so, has he/she lived with you for at least 1 year?
4. Are you available to meet for at least a 90-minute face-to-face interview?

Participants also had to agree to the recording of conversations for data analysis purposes, as well as peer reviewer access to the redacted interview transcripts. Further qualification for participation required the completion of a short demographic questionnaire that asked for more details for verification of eligibility, such as the age of the care recipient, occupation, and hours worked per week. The questionnaire was included in the participation packet that was emailed to potentially eligible subjects to be returned via email. A final proof of eligibility in the form of the care recipient’s ID was required before commencing the interview.

Recruitment

Previous researchers have recommended using several methods of recruitment to obtain a sufficient sample (Kubicek & Robles, 2016; Whitaker et al., 2017). This study used flyer distribution, gatekeeper assistance, Facebook, and referrals from participants and agencies working with the aged. The average response ratio to flyer distribution is 1%-3% (“Flyer Distribution,” n.d.; University of California San Francisco, 2018); therefore, approximately 1,000 flyers were distributed in locations frequented by ICGs, such as geriatric physician waiting rooms, home healthcare agencies, caregiver support groups, and a social media website for caregivers within a 50-mile radius of Dallas, Texas. Facebook advertising has a higher response rate than flyers. Published studies have demonstrated that Facebook advertising is a successful recruiting tool, superior to most other social media methods (Whitaker et al., 2017). Permission to distribute was obtained in writing and logged in the study appendix. The flyer (Appendix A) explained that I was looking for people to interview for a doctoral research study about strategies that caregivers use to manage caregiving while working. The ad outlined the participant criteria: informal (not paid) caregiver working outside the home while caring for an elderly person over the age of 70 living in in the same household. Contact information was provided, including email and phone number. Gatekeeper assistance was used to distribute an electronic flyer through a personal home care agency that provided in-home private care workers for the elderly; the owner agreed to distribute the flyer at a monthly interagency meeting for caregiving. The last method of recruitment was referral sampling, which involved requesting study participants to encourage others who would qualify for the study to contact me.

Every respondent who initially met eligibility requirements and agreed to participate received a packet (Appendix D) by email. The documents included a description of the study, a consent form, and a demographic questionnaire to collect socioeconomic information, additional data to confirm eligibility, and a signed agreement that all information was true and accurate. Instructions to complete, sign, and return the consent form and questionnaire were included. Once the consent form and questionnaire were returned, confirming eligibility, the recruit was contacted by phone or email to schedule an interview. The participant was asked to bring documentation of study eligibility to the interview in the form of a valid ID, proof of employment, and a document such as a Medicare card with Part A effective 2014 or earlier, or an insurance receipt showing proof of the care recipient’s age and address.

Instrumentation

The instrument for this study was face-to-face interviewing using a semi structured interview guide to collect coping strategy data from the subjects. Interviews were recorded using an Olympus W-853 digital voice recorder. As an experienced transcriptionist, I personally transcribed all of the recorded interviews within 7 days of each interview; this increased the confidentiality of the data. Semistructured interview questions were developed from the literature review for each research question. A panel of seven experts reviewed the interview questions to evaluate their relevance. These experts were pooled from several organizations in the field of aging: AGE of Central Texas and North Central Texas on Aging. In addition, the panel included an author and public speaker on aging and a professor. The panel consisted of people who worked with caregivers and aging, which was the subject matter of this study. A list of the panelists' titles and qualifications is included in Appendix H. The panelists were instructed to rate on a scale of 1-3 (with 1 being *most relevant* and 3 being *not at all relevant*) how well the wording of each interview question would elicit responses about the appropriate research question. The results were evaluated using Lawshe's (1975) one-tailed test using n_r for the number of most relevant responses and N_2 for the total number of panelists divided by 2 to determine the content validity ratio (CVR) for each question:

$$CVR = \frac{n_r - N_2}{N_2}$$

A separate CVR was calculated for each question. The average of all CVRs gave the content validity index (CVI) for the entire instrument. Schipper's table of CVR values for Lawshe's one-tailed test (Lawshe, 1975) was used to determine the minimum acceptable value for each question. The mean of the CVRs was used to calculate the content validity index (CVI) of all of the questions to give the estimated Cronbach's alpha of the complete interview guide to determine the reliability of the instrument. A suggestion section was included to comment on any questions with a rating of 2 or 3. Based on the ratings and suggestions from the panel, the revised questionnaire guide underwent an online pilot test of ICGs to determine its effectiveness.

Field notes were another source of data collection used in this study. Field notes help provide understanding of a phenomenon (Creswell, 2013; Miles et al., 2014; Patton, 2002). During the interviewing process, I kept a journal, making memos of observations such as emotions, expressions, impressions, thoughts, and insights made during the interview. Notations of the date and time were made beside the memos to ensure that they were linked to the proper content of the interview.

Lack of interview experience and skills can significantly affect the quality of data in a phenomenological study (Seidman, 2013). To gain experience and calculate the length of time an interview requires, I performed mock interviews with three former ICGs. These individuals were no longer ICGs and did not qualify for the study; the data from these interviews were not included in the results. These interviews were solely for practice.

Pilot Testing

Once it was determined that the interview questions adequately corresponded to the research questions, a pilot test was conducted online using ICGs to test the interview questions for effective data collection. Responses to the pilot test aided in correcting any ambiguity and leading questions and ensured that the instrument was user-friendly. The pilot test was conducted through the FCA research registry (https://www.caregiver.org/resource/research-registry/). The FCA allows graduate students to post research questions and surveys at no charge on their website and in their e-newsletters for a 3-month period. This website has a nationwide audience of caregivers. The interview guide was revised based on results to elicit rich data from the interviews. The information from the pilot test was not used in the research results; the pilot test was for the sole purpose of testing the instrument to ensure that the nature of the questions was clear and easily understood to retrieve useful information. A sample of the pilot test is included in Appendix J for audit trail purposes.

Data Collection

As the sole researcher of this study, I collected data using face-to-face, semi structured interviews. The recommended allotment of time for interviewing is typically 90 minutes (Seidman, 2013). Research indicates that ICGs are a difficult population to recruit (Hansen et al., 2016). A meeting room was prearranged in locations close to the interviewee, such as a local library. To successfully acquire an adequate sample size, Seidman (2013) suggested the location should be equitable. Numerous researchers recommend that a home setting offers the best environment for intimacy and friendliness, especially on sensitive subjects (Hansen et al., 2016). I suggested a home setting or a neutral prearranged location when the interview was scheduled. However, it was negotiable if the interviewee was unable to meet at the suggested location.

The goal was to schedule at least one interview a week. At the rate of one interview a week, data collection would have been completed within 20 weeks. The extended time frame allowed for cancellations, no-shows, and rescheduled encounters. If recruitment methods did not yield enough participants, an additional 6 weeks would be added to data collection. Prior to commencing the interview, I reviewed the requested documents to verify eligibility and reiterated voluntary participation in the study, including the right to withdraw at any time without reason or repercussion. The participant was asked if he or she had any questions or needed clarification. The subject was assured verbally and in writing (via the consent form) that all information was confidential. All identifying information was expunged from the material;

each person was assigned an alphanumeric identifier. The interview transcripts were kept on my computer hard drive with password protection. At the completion of the study, all digital information was moved to an encrypted flash drive and will be stored with all hard-copy data for a minimum of 5 years in a combination-locked safe at my residence for which only I have the code. If the interview was progressing well and I determined that more than the allotted 90 minutes would be beneficial, I asked the interviewee for permission to continue. In the event that a meeting was cut short due to an unforeseen emergency, I made every effort to reschedule a face-to-face continuation within 2 weeks, or at least within a month. If another in-person interview was not likely, arrangements were suggested to continue using Skype or Facetime to retain a face-to-face experience in which verbal cues and expressions could still be observed. If the interview could not be continued, I had to determine if there were sufficient data to answer any of the research questions. A notation of partial data collection from the interview was noted in the data results. If the data were entirely insufficient, they were excluded from the study.

All conversations were recorded using an Olympus W-853 digital voice recorder. As a trained, certified medical transcriptionist, having worked in the field for several years, I transcribed the recordings verbatim. During the interview, I kept a journal and made memos of observations such as emotions or expressions displayed during the conversation, marking the recorded time to link it to the proper content. I also made notations of any personal reflections prompted by the interview, to share with the peer reviewer. The journal peer reviewer is employed at a regionally accredited university in the northeastern United States. Notes were recorded in a designated tabbed binder. Once the interview was complete, each subject was given additional instructions on how to complete the member check of the analyzed copy and return it by email within 7 days. I also obtained permission to contact the interviewee by phone if any follow-up information was necessary. Each person was thanked for their time and given a $25 gift cared for time and inconvenience, along with an information sheet of resources for ICGs (included in Appendix E).

Data Analysis Plan

Each interview was transcribed by me, then read in its entirety. The transcribing process is integral to the accuracy of the data. Poor, incorrect, or omitted data can significantly affect the analysis (Korstjens & Moser, 2018). Transcribing the interviews personally guaranteed that the transcripts were verbatim and confidential, and allowed an extra layer of reflection (McGrath et al., 2019). After a process of reading and rereading, I analyzed each interview in the context of the research questions to ensure that all research questions had been answered (Saldana, 2016). Comparing the data obtained in the interview to the research questions verified the neutrality of the questioning, adding another safeguard against bias. In the first cycle of analysis, each interview was coded using descriptive, linguistic, and conceptual analysis (Braun & Clarke, 2013). In the second cycle of analysis, the coded data were categorized into themes that emerged from the patterns in the codes (Smith et al., 2009). I scheduled interviews far enough apart to focus on the reflective process while analyzing each interview. Using Nivo12 software, I developed a codebook to assist the peer reviewer. Analytic memoing was conducted throughout analysis using Nivo12 to reflect on the process and aid in bracketing researcher bias (Saldana, 2016). Each transcript was coded individually, then added to the Nvivo12 data matrix (Miles et al., 2014). All results, including those that did not fall within the determined categories, are discussed in the Results chapter of this study; these outliers may add value as coping strategies for unique situations (Maxwell, 2013). Nvivo 12 Pro software was used in the analysis process to help keep the data organized (Dollah et al., 2017).

Trustworthiness

Credibility

Qualitative research credibility is the equivalent of internal validity in quantitative research; a credible qualitative study adequately answers the research questions. Four principles are necessary to establish credibility: sensitivity to context, rigor, transparency, and impact (Yardley, 2000, cited in Smith et al., 2009). This study exhibits sensitivity to the context of the data through the voices of the study participants using verbatim text (Smith et al., 2009). As the researcher, I "bracketed" any preconceptions and experiences by keeping a reflective journal (Rodham et al., 2015). Recording reflections immediately after an interview helped to clear my mind of any personal conclusions before starting the analysis process (Rodham et al., 2015). Rigor was ensured through in-depth interviewing, the use of interpretive coding, and rich data to substantiate the results (Smith et al., 2009).

A peer reviewer was used in this research project to review the coding analysis and give insight into any coding that could have been skewed by researcher bias. The peer reviewer selected holds a Ph.D., has published numerous papers in peer-reviewed journals, is experienced in qualitative research, and is employed at Eastern University as a peer reviewer for the International Journal of Multicultural Education. Mason (2010, cited in Rodham et al., 2015) suggested that transparency is established when accuracy in data collection, recording, and analysis is well indicated. This additional level of independent review of my data analysis added rigor to the study. Peer reviewer audits were recorded in the audit log to support study conclusions. A participant log has been included (Appendix K) and archived with the research to substantiate the study upon request. Member checking also supports the credibility of the study. Moustakas (1994) asserts that data are best validated by the interviewee. To this end, once an interview had been analyzed, it was sent back to the participant by email for feedback on the analysis of their interview. Member checking of the data is another method of ensuring validity and safeguarding it from researcher bias (McGaha & D'Urso, 2019). Yardley's (2000) fourth principle, importance, is shown by the contribution this study will make in caregiver research and the assistance it will provide to ICGs.

Transferability

Transferability in qualitative research is equivalent to validity in quantitative research. Transferability is present when the content describes the subjects' behavior and experiences to the extent that it becomes "meaningful to the outsider" (Korstjens & Moser, 2018, p. 121). Rich, detailed data in the participants' own words are included in the Results chapter, allowing readers to compare their own experiences. This study's transferability is based on the shared experiences of ICGs undergoing similar experiences associated with work and caregiving. A thick description of the subjects' own stories contributes to transferability of the data through commonality among ICGs (Shenton, 2004). Even though all ICGs do not have the same degree of caregiving burden, it is well established that all ICGs experience burden (Collinson & De La Torre, 2017; NAC, 2020; Reinhard et al., 2019); this study's findings on coping strategies are thus readily transferable to other ICGs.

Dependability

Dependability in qualitative research is equated to reliability in quantitative analysis. Although the research results cannot be duplicated exactly due to the human variation involved in the study, the method does employ some strategies to ensure dependability (Moustakas, 1994; Smith et al., 2009). Shenton (2004) suggests that the study process should be reported in detail, allowing another researcher to repeat the process, but not necessarily obtain the same results.

This study used an audit trail that documents all the operations of the study; it is included in Appendix L. The validity testing of the open-ended interview guide showing the CVR and CVI are included in Appendix I as well as the details of the pilot test and results in Appendix J. Every phase of the sample selection, interviewing, data collection, and analysis was recorded, and a sample is included in Appendix M. The recruitment flyer, demographic questionnaire, and resource handout are included in the appendices. A detailed spreadsheet of the coding and analysis in the form of a codebook appears in Appendix N. By providing meticulous detail, this study presents itself as a possible prototype for other researchers hoping to conduct similar studies of this nature (Cope, 2014; Shenton, 2004).

Confirmability

Although similar to dependability, confirmability focuses on researcher objectivity (Shenton, 2004). Confirmability is reinforced through evidence of the research findings as a result of careful analysis of the data themselves and not interjected researcher bias. To this end, intrarater reliability—stepping away from the analyzed data for a few days, then reviewing the analysis afresh—provides new objectivity. Complete transparency of any related experience of the researcher must be revealed to ensure study results (Tofford & Newman, 2010). As explained earlier, I too am a dual-role ICG. To safeguard against any interjections of bias, I kept a reflective journal and a detailed audit trail of the processes of this study (Smith et al., 2009; Tofford & Newman, 2010). Also, a peer reviewer experienced in research reviewed the redacted data and analysis to ensure that the findings are void of bias. Rich quotes from the subjects are included in the Results and Discussion chapters to illustrate the findings (Korstjens & Moser, 2018). Member checks also demonstrate the actions taken to avoid researcher bias in the study results (McGaha & D'Urso, 2019).

Ethics

To recruit participants, I obtained permission to distribute flyers in locations where this population is prevalent. Each facility was given a request form to sign (Appendix B) granting distribution of flyers for this study. Once the document was signed by the authorized personnel, the flyers were circulated. The signed forms are kept on file with the study documents. All advertising for the study included explicit instructions not to leave identifying information with the initial inquiry, but to use only the first name. Responders were advised to contact the researcher via email, phone call, or text message. Only my Walden email was used for responders to ensure privacy; no work or personal email was linked to this account. At the time of initial contact, the candidate was asked only questions to verify they met the study criteria; no identifying information was required at this point, but they were asked to bring documentation of eligibility to the interview. These documents were viewed by me, and no copies were made. If the candidate did not meet the study criteria, he or she was informed why and thanked for responding. When it was determined that the respondent was eligible and agreed to the terms of the study, contact information including name, phone number, address, and email address was obtained for the express purpose of emailing the consent form and information on the study, and scheduling an interview. This information was recorded in a participant log and secured on my password-protected computer; any hard copy was kept in a safe at my residence. An identifying alphanumeric code was assigned to the participant; all identifying data on any forms included in the study appendix have been redacted and replaced with the alphanumeric code. I have kept a secure log cross-linking the identification of the subject with the code. This log is in a locked safe at my residence, to which only I have access. Participants were informed verbally and in writing (included in the consent form) of the steps taken to protect their privacy and that the signed consent forms are locked in the safe.

Data for this study were obtained through face-to-face interviews. The interviews were recorded; I identified each subject with the alphanumeric code at the start of the interview and reminded the subject not to use identifying information during the recorded interview. Although I was not interacting with elderly care recipients, information regarding this vulnerable population was discussed in the study. Care was taken to ensure that all care recipients stayed anonymous. To ensure that no identifying data were recorded, the consent form specified that if any identifiers were mentioned during the interview, the researcher would stop recording, remind the participant not to use identifiers, and erase it from the recording. If an identifier was discovered during transcription, it was omitted from the transcribed record. Since the researcher was also the transcriptionist, anonymity was guaranteed. A peer reviewer had access to reproduced data and analysis with the consent of the participants. No identifying data were provided to the peer reviewer; all information was already redacted. A written agreement between the peer reviewer and the researcher outlined the terms and the specific role and limitations of the peer reviewer. As part of the agreement, the peer reviewer agreed to make no attempts to identify or contact any of the subjects.

The subject of this research elicited stressful emotions. Participants were fully informed of the study purpose, and the risk that discussing this issue might cause distress. Before beginning, the interviewee was instructed that if any question caused discomfort, they could elect not to answer. Furthermore, they could terminate the interview at any time without giving cause. If it appeared that a subject was becoming upset, I reworded the question or offered to conclude the discussion. A significant concern was the potential revelation of elder abuse; if, during an interview, elder abuse was suspected, it would have been reported to adult social services. This disclosure was stated in writing and verbally before the start of each interview. An information sheet obtained from adult social services defining elder abuse was included in the participation packet.

The exit plan for each participant included instructions on how to review and provide feedback on the analyzed case data, a $25 gift card to compensate for time and inconvenience (Largent & Lynch, 2017), and a resource sheet that included support groups, counseling facilities, care assistance, and aid programs (Appendix E). So as not to be interpreted as payment or coercion, the $25 gift card was given to every person at the end of the interview, even if the interview was stopped or the analyzed data were not returned (Largent & Lynch, 2017).

During the study, data were stored and password-protected on my laptop. At the completion of the dissertation program, all data will be transferred to a flash drive and secured in a locked safe in my home along with all hard copy documents for 5 years. After 5 years, hard copies will be cross-cut shredded, and the flash drive will be erased; this will be verified by reopening the drive to confirm it is empty.

Summary

This chapter gave a full description of how this study was conducted. The interpretive phenomenological approach was explained, along with why it was chosen as the approach for this study. The role of the researcher, also a dual-role ICG, was revealed. The instrumentation was provided in detail, showing alignment with the research questions asking how ICGs cope with conflicts between work and caregiving within the constructs of time, stress, and behavior. An explanation of study participant criteria and the sample size of 12 was supported, along with recruitment modes via flyer distribution, social media, gatekeepers, and referrals.

Instrumentation using face-to-face interviews with a semi structured interview guide was discussed. Testing of the instrument by an expert panel and pilot testing was provided. Data analysis with open coding and the use of a peer reviewer was explained. Transferability was indicated through the collection of rich data from the shared experiences of ICGs. Dependability was substantiated with an exhaustive audit trail and the collaborative results of a peer reviewer. Confirmability was supported through member checks, rich data, and the peer reviewer. A thorough discussion followed on the ethical issues this study may have had to address. Assurance of confidentiality by redacting identifying information and the securing of documents in a locked safe was presented. This chapter described how the study was conducted; Chapter 4 below will present the results.

Chapter 4: Results

The purpose of the study was to explore the strategies that some ICGs have developed that enable them to cope with the pressures of managing both work and caregiving. Of the 40.4 million unpaid caregivers in the United States, 61% are employed outside the home (BLS, 2019). By 2030, the number of ICGs is expected to double (BLS, 2019). Studies have been conducted on conflict associated with working and caregiving, as well as the stress and strain associated with the role of caring (Boumans & Dorant, 2020; Peng et al., 2019). However, there is a lack of literature specific to the coping strategies that ICGs actually use to remain in both roles. This qualitative, phenomenological study used face-to-face interviews with dual-role ICGs to explore what strategies they applied to keep working and caring. The IPA was used. Based on the literature review, three main stressors associated with both roles were explored in the research questions:

RQ1. Based on lived experiences, what coping strategies do informal caregivers use to manage time conflicts associated with their dual role as an employee and caregiver to an aged family member?

RQ2. Based on lived experiences, what coping strategies do informal caregivers use to manage stress conflicts associated with their dual roles as employee and caregiver to an aged family member?

RQ3. Based on lived experiences, what coping strategies do informal caregivers use to manage behavioral conflicts associated with their dual roles as an employee and caregiver to an aged family member?

In this chapter, I describe the findings of this study. A detailed description of the processes that were used in the development of the instrument and pilot study is presented. The recruitment and data collection methods are described, as well as the criteria for participation and how subjects were screened for qualification. I further explain the transcription, coding, and analysis process that led to the results of this study. The actions taken to safeguard against bias and ensure trustworthiness are also discussed.

Pilot Study

I elected to conduct an online pilot study to test the interview questions for effective data collection. The responses to the online questions were used to aid in correcting any ambiguity in my questions and ensure that my instrument was user-friendly. The pilot study was conducted through the FCA research registry using Survey Monkey as the data collection instrument. The registry allows a study to be posted for 90 days; however, for unknown reasons, the study was actually accessible for 4 months before they closed it. The research registry linked participants to Survey Monkey, where I had created my instrument guide in a 10-question online interview that coincided with the interview guide that I had developed for the face-to-face interviews that I would conduct for the research study. The pilot test was for the sole purpose of testing the instrument to ensure that the questions were clear and easily understood to retrieve useful information. The test was conducted with 16 participants, whose responses indicated that the instrument questions were clear and extracted data in response to the study’s purpose of exploring dual-role coping strategies. The pilot study results thus indicated that the interview guide was ready to be used in face-to-face interviews for the research study.

Setting

There were no personal or organizational conditions that might have influenced the participants or interpretation of this study. All subjects of the study were recruited according to methods approved by the IRB. Subjects responded to the IRB-approved methods of recruitment: flyers, social media, and participant referrals. The study provided an outlet for the participants, who willingly and eagerly shared their experiences as dual-role ICGs.

Demographics

To adhere to a purposive sampling strategy for the homogeneous model in the IPA, I limited the demographics to dual-role ICGs over the age of 21 who were working outside the home while caring for a person over the age of 70 residing in the same household. On the recommendation of my committee chair, I was able to conduct limited stratification in the study to analyze any differences in coping strategies based on the age of caregivers. For this purpose, I divided the caregivers into four age groups separated by decades to reflect stages of life and maturity. For example, 30- to 40-year-olds are often raising young children, while 41- to 50-year-olds often have teenagers and are focused on careers. Adults between 51 and 60 years old are transitioning to empty-nest status, while those over 61 years are looking toward retirement. Each decade involves various factors in life that contribute to stress and the conflicts of caring and working (Campbell et al., 2015; Kim et al., 2018). The four age groups of participants were nearly equal: three were 30-40, two were 41-50, four were 51-60, and three were over the age of 61. The age groups provided an opportunity to analyze whether there were age-related differences in coping strategies.

In addition, it was determined that care recipient health was an influencing factor in caregiver burden (Betini et al., 2017). The care recipients were aged from 73-91 ($M = 83$; $SD = 5.79$), with varying degrees of health status contingent on health conditions. The health status of each care recipient and condition are recorded in Table 1 for a better understanding of the care recipients' state of health. This is an important distinction; various health conditions create different levels of stress (Altomonte, 2016; Betini et al., 2017). Because the research was conducted using face-to-face interviews, I limited the study to a 50-mile radius around Dallas, Texas. A summary of relevant patient demographics is provided in Table 1.

Table 1

Participant Demographics

Participant	Age	Care recipient age	Health status	Condition
1	67	88	Fair	Ambulatory with assist
2	55	87	Fair	Moderate dementia
3	57	80	Poor	Advanced dementia
4	48	73	Good	Ambulatory
5	60	82	Fair	Emphysema
6	62	91	Good	Mild senility
7	32	84	Good	Mild dementia
8	40	72	Poor	Alzheimer’s
9	31	83	Good	Moderate senility
10	60	82, 83	Excellent	Minimal health issues
11	47	84	Poor	Cancer
12	62	91	Good	Mild senility

Data Collection

Data collection began with the first interview taking place on April 27, 2019 and concluded with the last interview on March 20, 2020. Although the literature stated that data collection from ICGs is a challenge due to time constraints, it proved to be much more difficult than initially anticipated (Hansen et al., 2016). Originally, I estimated conducting one interview a week, resulting in completing the data collection in 20 weeks. However, it proved to be challenging to recruit ICGs who had time for interviews. Ultimately, it took a total of 47 weeks to recruit participants and complete all of the interviews. The first two responses were through my flyer distribution. Afterward, one participant gave me a referral. Three more candidates were a result of flyer placement in a medical office, which led to two referrals. A Facebook post resulted in six more responses. A caregiver support group yielded one participant, and the final candidate was referred through a hospice agency employee.

Each applicant was phone screened or emailed a set of questions asking for age, number of years as a caregiver, whether the care recipient resided in same house, whether the candidate was working, age of the care recipient, and whether the candidate would consent to having the interview recorded. If all answers were affirmative, the candidate met the study requirements. Three responders did not meet the requirements; one was not working, and two did not reside in the same household as the care recipient; therefore, these candidates were thanked for their interest and dismissed. In the end, this process led to 12 qualified participants. Each of the qualified participants was then scheduled for a face-to-face interview either by text message, email, or phone. The consent form was emailed for review, and I had each participant sign a copy at the interview. I informed each candidate prior to the interview that I would need verification of the care recipient’s age. I suggested that a snapshot of their Medicare card would be sufficient. All participants were compliant with this request.

The location of the interview proved to be pivotal for participation because dual-role caregivers are so pressed for time. I suggested a neutral location, such as the public library, but allowed each person to select a location most convenient to them as long as we could conduct a recorded interview without interruptions. Various settings were used to accommodate the interviewees (Heath et al., 2018). Three interviews were conducted in the subjects’ offices after work hours, one was conducted in my home office, one was conducted in my work office, three were conducted in the interviewees’ homes, two were conducted in public libraries, one was conducted in a school, and one was conducted at a coffeeshop. The only location that proved challenging was the coffeeshop, which had limited seating and was noisy. In spite of these obstacles, the interview went well; the recording was satisfactory because the recorder was equipped with an excellent noise filter.

I began the interview by reminding the participant that the interview would be recorded, asking them not to use any identifiers about the care recipient, and reminding them that if they did, the identifying information would be redacted from the transcripts. I also assured them that if at any time they wished to end the interview, they were free to do so by simply asking me to turn off the recorder. A handheld Olympus WS-852 recorder was used; however, on one occasion, the recorder malfunctioned, and I used a recording application on my cell phone. Toward the end of the agreed-upon time of 60 minutes, if the interview was still going well, I reminded the interviewee of the time and asked if they would like to continue or needed to wrap it up. Some interviews did not take a full 60 minutes. A total of 12 interviews between 40 minutes and 120 minutes in duration were completed (*M* =75; *SD* = 5.29).

Once the interviews were complete, one participant withdrew from the study due to the sudden death of the care recipient. Because this participant requested to not be a part of the research, the interview data were destroyed, leaving a remaining 11 interviews for analysis.

Data Analysis

Data analysis was conducted using the IPA. As a certified transcriptionist, I personally transcribed each recorded interview into a typed transcript within 7 days of the interview. Per IPA protocol, each transcription was initially analyzed independently. The transcript was first read in its entirety; this provided an overview of the data in their own context. This did not involve any note-taking; I did this simply to immerse myself in the participant's story. I then returned to the transcript a second time, usually 1 to 2 days later, and printed out the transcript. I read the printed transcript again, this time making handwritten comments in the margins as the data provoked thoughts and questions. For example, on one interview, I noted “see it getting worse” and “doesn’t trust others to do, yet worries she can’t?” This process was still done using a broad lens, which Smith et al. (2009) referred to as “free textual analysis” (p. 83). This process was conducted on each interview after each transcription.

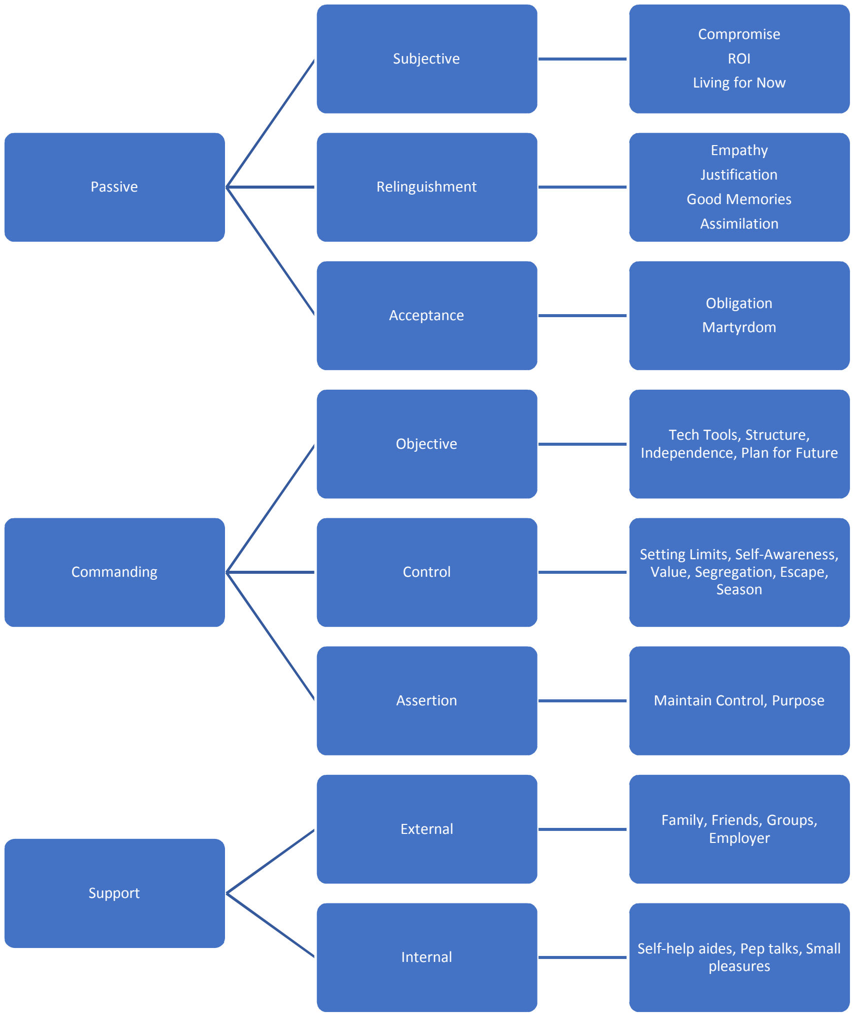
Once all of the interviews were complete, transcribed, and notated, a three-step analysis was applied to each set of data. Each transcript was imported from its Word document into NVivo 12, and the corresponding handwritten notes were manually keyed into the memo section on each transcript. I then conducted a descriptive analysis on each data set, notating keywords, phrases, and emotions that the participant used to describe the experiences of caregiving and working. Smith et al. (2009) referred to this first level of analysis as “taking things at face value” (p. 84). Notations such as “regret, frustrated, escape, started crying” were coded in NVivo 12 and color-coded to identify them as descriptive codes.

I conducted a second analysis on each transcript using a linguistic approach, identifying what type of language was used to describe the experience, such as pronouns, repetition of words, tone, and what elements were focal to the caregiver, including words such as “lost myself,” “no control,” and “always about her.” Notations were also made of expressions and cues such as hesitation, sudden loss of emotion, and drifting off. Again, these were listed and color-coded under the category of linguistics.

The third and final analysis involved a conceptual approach; this was the most time-consuming. Each transcript required taking a step back from the data and reviewing the story reflectively, ruminating on what meaning was within the story told. I looked at all of the codes and data sets from a conceptual perspective to gain an overall understanding of the phenomenon: what was being said or not said, but somehow conveyed between the lines, and what emotion or lack of emotion was expressed in these stories. Concepts such as justification, compromise, and personalization were noted. The patterns that emerged through this process were coded with a third color to represent conceptual. Once this was done, I had a completed code book, color-coded to each type of analysis. I then read through all of the transcripts collectively. After doing so, I reviewed all of the codes and began to move them into categories as patterns emerged, grouping the codes that were similar. I then stepped away from the entire process for several days to distance myself from the data. I came back after about 3 days and read through the transcripts once again as a collective set. I then reflected on the categories of codes and made some adjustments. I continued this process for about 2 weeks, reviewing the categories, rearranging codes, and relabeling categories for better definition. Once I felt that I had exhausted this process and no new insights emerged, I again stepped away for a couple of days. When I returned to the data and believed the categories to be complete, I started the process of analyzing the categories into major themes. I moved the process to pen and paper, making it easier to create new lists without losing the former. I listed all of the codes under each category, then looked at each category to determine whether there was a common thread. This process took several weeks as I moved the data around on paper. Eventually, two overarching themes emerged from the data: passive coping and commanding coping. I then reread all of the transcripts with the two themes in mind to determine whether the data were in alignment with the themes. A coping strategy emerged as a subtheme, which I labeled “support.” This was placed separately because I discovered that support, externally and internally, is a coping strategy exclusive of the two main methods of coping. Figure 1 shows the codes, categories, and themes for each research question.

Figure 1

Themes, Categories, Codes



Evidence of Trustworthiness

Credibility

In accordance with the criteria outlined in Chapter 3, I followed three key principles to establish credibility: sensitivity to context, rigor, and transparency. Smith et al. (2009) suggested that sensitivity to the data be accomplished through the voices of the research participants by including their experiences verbatim in the text. As a dual-role ICG, I found that the participants quickly became comfortable sharing their stories. In order to maintain credibility and safeguard against bias, I kept a reflective journal during and after the interviews (Rodham et al., 2015). This helped to bracket any preconceptions and clear my mind of any personal conclusions before I started analysis of any of the interviews.

The second principle of rigor was followed through the in-depth interviewing process. A majority of the interviews lasted over the agreed-upon time of 60 minutes, as subjects wanted to share their experiences in depth. The interview guide aided in establishing rigor, as it enabled me to keep the subjects on task answering questions pertinent to the research questions. The purposive sample was set at 12 for face-to-face interviews. Even though one participant withdrew from the study and a second participant's experience was minimal, the remaining interviews yielded rich data that addressed all three of the research questions. Using the three-step IPA approach to analysis—descriptive, linguistic, and conceptual—resulted in a thorough analysis of the data.

As recommended by Moustakas (1994), after each interview was transcribed and the first analysis was complete, a copy was sent to the subject for feedback. I requested that each subject provide feedback on the analysis of their interview in the context of coping skills they apply to remain in both roles of working and caregiving (Braun & Clarke, 2013). I sent out three requests by email, voice mail, and text for the return of each document. Even though I emphasized the importance of this process both before and at the conclusion of each interview, I obtained a very poor response rate of six out of 11. Participants provided minimal feedback; most stated that they agreed with the analysis and had nothing more to add, and only one person provided additional insight to the data. Although this was a disappointing outcome, I am confident that the other methods incorporated into the study established rigor.

My final process to add rigor was the use of a peer reviewer. This additional level of independent review was very important to ensure that I had not added any of my own bias (Mason, 2010, cited in Rodham et al., 2015). After I completed my analysis of all the data, I sent a copy of all the transcripts, my analysis, and the code book. I explained my own experience as a dual-role caregiver and requested an objective review to determine if any personal bias had been interjected into the study. After a thorough review of all the transcripts, the analysis, and the code book, the peer reviewer determined overall that my analysis was well-reasoned, objective, and clearly based on the research data. A few suggestions were made in regard to some ambiguity in the interpretation of my codes into categories, and she also pointed out some redundancy in coding, noting that by combining some of my codes I could reduce the number of categories and come to a clearer conclusion for my themes by creating "support" as a subtheme of "coping."

Transferability

According to Korstjens and Moser (2018), transferability is present when the description of behavior and experiences sufficiently conveys meaning to the reader. The interviews of all the subjects portrayed a common thread of shared burden by all ICGs. The commonality among caregivers, as evidenced in the subjects' own words, indicates transferability of the study (Smith et al., 2009). Each interview conducted provided rich, meaningful data, as the subjects readily shared their experiences in relation to each research question. The purpose of the study was to explore coping strategies caregivers apply to manage both roles of caring and working. Reading about experiences in the participants' own words provides an awareness of coping strategies for other dual-role caregivers. The abundance of compiled data established that all ICGs experience caregiver burden and use a matrix of coping strategies to remain in both roles of caring and work, making the results of this study readily transferable to other ICGs.

Dependability

To establish dependability, I documented the study process with sufficient detail to be used as a prototype by other researchers to conduct similar studies of this nature (Cope, 2014; Shenton, 2004). The proposed study protocol was followed and recorded using an audit log (Appendix L), and the process of this research has been explained in detail. Additionally, all forms used for recruitment, screening, and interviewing are in the appendix, as well as the demographic criteria for participants.

A validity test was conducted prior to the research to evaluate how well the interview guide questions correlated to the research questions. Inquiries were sent by email to 17 persons deemed experts in the field of aging, yielding responses from four. Of these four, two worked with the North Central Texas Area Agency on Aging, one is a program director of a caregiver resource agency, and the fourth is a public speaker and author of several books on caring for aging loved ones. The interview guide questions were sent to these individuals, with instructions to rate each question on a scale of 1-3 for relevancy to each research question, with 1 being the most relevant. The same scale was then applied to each question to determine clarity, with 1 being the clearest. The results were evaluated using Lawshe's (1975) one-tailed test, resulting in a CVR of 0.99 for relevancy, a CVR 0.78 for clarity, and a CVI of 0.96 for the instrument. According to Gilbert and Prion (2016), a CVI over 0.78 by three or more experts is considered good content validity.

The pilot test was conducted as an additional measure to ensure the interview guide's effectiveness; a sample has been provided in Appendix J. A detailed explanation of the coding and analysis process has been provided in the data analysis. Because the research process and materials used are fully disclosed, this study can be used as a prototype by other researchers to conduct similar studies (Korstjens & Moser, 2018).

Confirmability

Confirmability of this study was established in several ways. Intrarater reliability was accomplished in the analysis by stepping away from the data for a few days after each interview was transcribed and between each phase of coding. Complete transparency was established, as I informed participants and the peer reviewer of my role as a caregiver. In addition, I kept a reflective journal and an audit trail during the interviews and analysis to safeguard against bias (Smith et al., 2009).

Using direct quotes from the participants not only validates the study's findings but also reveals the thought process behind them (Smith et al., 2020). Rich quotes from multiple interviews have been used to illustrate the findings of this study and validate the results (Heath et al., 2018).

Member checks to avoid bias were only partially successful due to the poor response rate. The six participants who did return their documents confirmed that the analysis reflected their personal experiences as dual-role caregivers.

Results

Overall, two types of coping strategies emerged from the data in all three research questions: passive and commanding. A subtheme of support also emerged. The term "passive" in this analysis is used in the context of the dictionary definition, "accepting or allowing what happens or what others do, without active response or resistance" (Lexico, "Passive," n.d.). This is not referring to personality types, although a passive response is often related to a passive personality (Winch, 2015). In the terms of this study, I discovered that even more aggressive personalities applied passive methods in particular areas of coping. The term “commanding” means “to have authority, control or restraint of oneself or feelings” (Lexico, “Commanding,” n.d.). My research found that regardless of personality type, all ICGs used a mixture of these two methods of coping unrelated to their own personality type. The ICGs did not necessarily demonstrate solely passive or commanding strategies, but rather they mixed methods. For example, an ICG would use commanding methods when dealing with time constraints, then switch to passive methods to cope with stress.

Research Question 1

Based on lived experiences, what coping strategies do informal caregivers use to manage time conflicts associated with their dual roles as an employee and caregiver to an aged family member?

Passive: Subjective

To manage time, respondents used the passive method in a subjective form. Coping was based on feelings, moods, and attitudes, sometimes generated by the caregiver, other times influenced by the care recipient. The passive response focused on the caregiving role more than the work role. Through using these methods, subjects aimed to keep a balance between the CR and the ICG that was manageable for the ICG emotionally by making the CR’s happiness a priority; the perception is that less resistance makes tasks easier (Winch, 2015).

Compromise. Compromise was one of the subjective strategies used to manage the stress of time. The focus was on what was emotionally less stressful rather than what was the most time-efficient. Although it would appear that taking more time-consuming approaches to tasks would add stress, the value of emotional relief was a higher priority; therefore, it alleviated the time stress factor. For example, rather than get a good night's rest, this ICG compromised by sitting with her mother:

> I was active before and moving. I go and sit 9 hours at work and then come home, have dinner with her for a half hour, and then she wants me to sit in her bedroom with her. Half the time she falls asleep, and then she gets mad when I get up and leave at 9 every night. I've been doing that for 5 years and I'm exhausted. There are good days and bad days.

Several participants expressed passive subjectivity when discussing mealtime, such as P8:

> When I am fixing meals, I make one for her and one for me because I try to do keto, and she wants certain things like very basic meat, potatoes, and vegetables. So I end up cooking two meals to make sure she's satisfied.

Another participant stated that "I tried to change my eating habits to match her eating habits because she eats her meals at lunch and at night she only eats fruit, so I've started doing that too." P9 shared struggles with family time, stating that "now her schedule is my schedule." One participant conveyed frustration when talking about tasks such as grocery shopping, but still demonstrated the passive response:

> I'm not as picky as she is but I don't really want (other) people to pick out my produce either. But I'm kind of at the point where if I have a bruise on an apple I'd rather have that and spend time with my daughter.

Return on Investment. Compromise was usually accompanied with the thought that although it is difficult right now, ultimately it will be worth the sacrifice. I termed this form of thinking "return on investment." This coping strategy was evident in nearly every passive method, possibly because it made the stress more bearable to think there would ultimately be a reward. Frequent comments were made such as “hopefully my kids will take care of me if I ever need them” and “you do what you have to do, and I hope my kids will do the same thing for me if necessary.” Two participants in particular expressed this sentiment throughout the interview. P5, who struggled with her mother’s demanding control over her, stated “I know there’s a lot of sacrifice, but I know in the end I’ll be happy that I did what I’ve done”; and P8, whose mother has Alzheimer’s, stated “My thought is I’ve done a lot. I have sacrificed a lot; I have given a lot. I have done my best; I just have to give myself a break.”

Living in the Now. When asking if the coping strategies currently being applied would be effective in the future to maintain both roles, I was surprised to discover most of the ICGs had not made plans for the future. On the surface this may not appear to be a coping strategy; however, denial is a method commonly used to deal with the unpredictable (Chen, 2016). Caregiving involves a great deal of unpredictability (van Wijngaarden et al., 2018). A working caregiver never knows when they come home from work how the situation may have suddenly changed. The care recipient may have had a health episode that requires immediate care. The caregiving arrangements may quickly change while the ICG is at work; for instance, paid care may get sick or quit. There is the constant uncertainty of change (Altomonte, 2016). To cope with this, many ICGs focus on the present because they do not have enough in their mental reserve to manage coping with the future (Wang et al., 2020). When subjects were asked in the interview “How do you see things looking down the road, do you see anything changing? What if she takes a turn for the worse? Have you thought about what’s going to happen if he requires more care?” the responses were very similar, regardless of the care recipient’s current health issues or age. The ICG with a fairly healthy 91-year-old mother responded “No, I haven’t really thought about that.” Even the caregiver whose mother has Alzheimer’s stated:

> I think mentally I feel like I walk around on the verge of depression and anxiety at all times. This is not the life I saw for myself and there's no end in sight and you can't plan for the future.

Other participants responded similarly: "Right now, it's working. I don't know, there's a lot of balls up in the air. We'll just have to see." "I'll deal with that when the time comes." "I cannot make that lifelong decision with what's happening right now." "Right now, it's manageable. I can foresee a time where she needs to be picked up physically [and] she's not going to let me. I don't know what I'm going to do." "I think I can handle it for now; you just have to take it one day at a time."

Commanding: Objective

The commanding methods of coping with time involved more of an objective perspective. Decision-making was more logic-based, detached, and void of emotion. There was a greater focus on developing methods to make time constraints easier on the ICG while still caring for the CR; emotional comfort was not a motivating factor, but rather the subject sought efficient ways to cope with time constraints experienced in both roles. Some of the tools were structural applications such as the use of technology or making a schedule of every task and planning ahead.

Technology Tools. Technology can be a beneficial aide in time management (Block et al., 2020). Simple use of a Google calendar, lists on a smartphone, installing web cameras, and online shopping allow greater flexibility to multitask. This was a particularly useful coping strategy for P8, whose mother had Alzheimer's:

> If she's been there by herself I check in. I have cameras so I can look at [the house] on my phone and check in and make sure, you know, everything is good. I just bought an

> [Amazon Alexa virtual assistant]. Yes, technology tools... working outside the house and having those cameras has been another technology tool [I use]. I'm a very bad time management person; what's been most helpful [is] I mark all of her appointments; any outings, anything she has, I have them on my calendar; I carry my Google calendar on my phone."

P4 uses local online shopping: "I set up a Walmart [online] account…. I've talked to my mama about the groceries coming [to the house], about ordering online." P2 travels for work, and stated:

> I use Amazon to order nearly all of her products. It is a huge time-saver. I can order her diapers online, and things like that so I don't have to spend time going out to the store, not finding what I need, or waiting in line.

Structure. To minimize conflict when work is a high priority, having a schedule, creating structure, and planning ahead were major coping strategies to keep time constraints manageable. These ICGs were very specific when they shared their time management strategies; they had detailed time schedules. For example, P3 was able to explain the care routine step-by-step:

> It starts off with that coffee (laughs) and then I make sure she's bathed and dressed. She does wear adult diapers, so I make sure we have fresh ones. Then I mix a good protein [shake]... evening time about 5 we have a routine where I put on *Family Feud* because she loves to try to guess the answer.

Other examples include "My grandma and I just kind of came up with the work schedule so I can do what I need to do at home to leave at a certain time." "I help her with her coffee, meds, and TV. I'll ask her if she needs anything [else] before I leave [for work]." "I call her before I go home and tell her I'm picking up dinner." "We make chili and put it in freezer containers, so she can just pull it out of the fridge (when I'm at work)." P6 indicated the importance of organization for coping, stating:

> I just schedule the things that I need to get done. I try to do some things in the evening if there are things like grocery shopping; I'll go Thursday evenings and I have house cleaning in the morning. I clean on Saturday morning, and generally during the week I just pick up here and there and do a quick vacuum and that sort of thing.

P4, who is a teacher, described how important structure is to help her cope, stating she was already planning for the following school year:

> I've already talked to [the CR] and told her I cannot leave before 3:00 pm for doctor appointments, there's just no way during school. So as long as she knows if I have to be there she can make the appointment at 4:30 pm, which would be even better because that would give me a cushion. I won't be able to leave until definitely 3:00 pm and then I have to park my car somewhere different so I can get out of there at 3:00 pm.

Passive and commanding methods were sometimes used interchangeably. One subject demonstrated passive methods of acceptance and compromise throughout the interview until she discussed her work schedule, then applied commanding coping strategies. "When she gets put in the hospital, I will use my catastrophic hours. I have 400 catastrophic hours and I have 12 weeks of family medical leave; I'll just try to balance it." The caregiver was matter-of-fact about the inevitability of her mother, who has advanced emphysema, being hospitalized, and she has already planned her work schedule and finances.

Maintain Independence. Another commanding coping strategy for time management was to maintain as much independence in the CR as possible and to prioritize real needs. A common trait ICGs fall into is enabling the ICG, doing things for them that they can actually do for themselves. This pattern can eventually lead to a loss of function when done in excess (Bursack, 2020). By encouraging independence, the ICG limits the number of tasks they have to perform, thereby saving time. Two good examples of this coping strategy were “we would like to maintain her independence even if it is not on the surface that was keeping her stable and not progressing is letting her still do for herself.” P4 also applies this strategy:

> Sometimes I try to push her to do more because I don’t want her to lose it...trying to convince her to get groceries where I can put them up during the week because that would save me 2 hours on the weekend. I want my mom to do as much as possible for the independence thing...like the other day she called me and couldn’t even open a can of soup and I said “Mom, it’s a pop top, you can do this, get a fork.”

Planning for the Future. In contrast to the passive response discussed earlier, several caregivers took a commanding approach to cope with the uncertainty of future care. These ICGs were more realistic in their thinking and accepted the fact that the care recipient would require more care with aging. P7, who cares for her grandmother, stated, “We’re hoping within a year or two, she’s still stable enough to stay home, but if she’s not then we plan on selling her house and moving her in with my mother.” P8 stated:

> I’m going to end up needing to have some help. I’m going to have to bring in someone at some point. I was actually talking to a recruiter this week at a full-time work-at-home job, and it’s still not necessarily a dream [job], it’s just a job. But it is full-time work at home, and it would have benefits.

This expectation of a future decline in health was also expressed by P4:

> My mom is financially stable, but we know that one sickness can wipe it out very quickly. I told her I don’t mind working to pay for her medical bills if needed or to hire if we need a full-time nurse. I don’t mind working for that if she needed me too, if she went through her money. I don’t think she will, but if she did, I wouldn’t mind hiring full-time medical people so she could stay at home. She wouldn’t have me [caring for her] all the time. I’m not a nurse, tech person, I don’t think I could be that every 24/7.

Research Question 2

Based on lived experiences, what coping strategies do informal caregivers use to manage stress conflicts associated with their dual roles as an employee and caregiver to an aged family member?

Passive adaptation to the stress associated with caregiving and working was accomplished through relinquishment and assimilation, whereas in the commanding method, more aggressive strategies involved control and segregation.

Passive Relinquishment

The passive response of relinquishment was not giving up or giving in, but rather focusing on the care recipient instead of the ICG’s own needs or feelings. Common methods were empathy, justification, good memories, assimilation, empathy, and viewing caregiving as a season in life.

Justification. One subject’s mother moved in with her 5 years ago and took over the house. She narrated many instances of how critical and condescending her mother is towards her, but when asked “Have you found any techniques that help you deal with the frustration, anger, and lashing out?” she replied “I know my mom well enough to know she’s not mean like that. Although sometimes I would take it like that.” This caregiver could cope with the strain of her mother's verbal outbursts and criticism directed at her by telling herself that her mother does not really mean what she says and therefore it should not be taken to heart. Another subject justified her mother's difficult behavior as acceptable by blaming herself as the cause of it, and concluding that she has to accept it: "I think they need some space because I'm sure as caregivers we do a lot of things that are dysfunctional and sometimes frustrating to the person that we're taking care of." P7 justifies the strain of personal neglect while caring by reminding herself that it is okay since she is young: "There's never a time when someone just says '[name redacted], do you need something?' and that's hard for me, but that's okay because I'm capable, I'm young, I don't have any health issues."

A different way of using justification came by means of apologies to justify outbursts. One caregiver can cope as long as she can allow herself to slip up. She responded to the question saying, "Wine [laughs] and liquor! I mean, I guess I'm still working on it. It still happens quite often. Of course I feel bad at the end, and I go apologize to her and the kids, but I'm still working on that" (P9).

Empathy. Caregivers also demonstrated relinquishment of their own feelings in order to cope through empathy for the care recipient's condition:

> Just her personality itself has added to how my caregiver role has changed as well. She is more sensitive now, where she used to be this independent person. I've noticed how her attitude has changed a lot. She's more sensitive to the fact that she is more dependent, so I have to skirt around it to make her feel like she is capable.

P5 struggles with her mother's overbearing personality, yet she expressed empathy:

> I know she struggles with not being in her own home and not having her own space. She felt like there was nothing left in life. Although she does not express she has nothing to

> live for, she just sits in her room all day and I try to pull her out to break the boredom. She struggles getting in the car because she can't breathe. Her chest tightens up and it's hard to get her to go anywhere.

When P5 takes some time to herself, she quickly returns to her mother's room because it causes more stress to have time to herself then the sacrifice of giving her time to her mother: "Does she think I'm ostracizing her? Does she think I'm ignoring her? Which I don't want her to think!"

P8's empathy for her mother's condition allows her to cope with her own frustration about not having the job she wants or living where she desires:

> I could get a better job up there [another city mentioned] but I'm not going to uproot somebody with Alzheimer's from their life, their surroundings, and what little sense of routine they have. She would be in an unfamiliar environment, and it would be really challenging and uncomfortable for her.

One subject experiences her stress as chronic fatigue, but copes with the stress through empathy: "She already feels like she's outlived her usefulness; not useful to society and nobody has time for her. But she wants to feel love and I'm already tired, but I do it anyway." Additionally, P4 demonstrated empathy by acknowledging how her mother feels: "She feels bad asking sometimes and then I get kind of like, 'Ugh!' because she asks a lot of things and then I know she feels bad because she still wants to be independent." P6 became very emotional when she shared her empathy for her mother's decline:

> Maybe the hardest thing is watching her do things. I kind of watch and clean up after her because she was always very clean when she was young, but I think sometimes she doesn't realize that she is dropping things, or she can't feel very well with her hands so she can't feel that things are sticky. I kind of have to go behind her sometimes and clean

> because she doesn't realize that she had something on her hands, and she touches things and leaves it sticky and I'm trying not to stress her out about it. I go behind her when she is not watching and clean those things, so she doesn't get upset with herself and feel bad.

Good Memories. A more subtle passive response to stress was to focus on good memories and turn negative feelings into a positive perspective. Calling up good memories of the relationship and what the care recipient was like in the past helps to cope with the present. Examples of this coping method were expressed by P3:

> She used to make these stretchy bracelets and we hid them, like remember, the painted rocks? it started off like that—I said, "let's go start hiding them" and so we hid them for like 2 years around the community and people would find them and post on her Facebook page and say "look, I found one."

P4 talked about her mother making her home welcoming in her childhood:

> She knows my mom [talking about her best friend], not as well as I do, but almost. She's been around since eighth grade and would come to our house and in high school she would spend the night with me probably three to five nights a week.... My mom cooked, and we all sat around the table as a family.

P7 shared childhood memories about her grandmother:

> She's my only living grandparent, she's like a second mom to me and if I have to choose between staying at work or going to the hospital I'm going to go to the hospital because I can't tell you how many times she went to the hospital for me as a kid or to the doctor with me as a kid.

P6 expressed her indebtedness:

> I think probably the secret for me is maybe that I have always been so thankful for my mother. She gave up a lot for my sister and I as a young woman [so] I feel like I owe it to her to take care of her because she's always been there for me. So I think that just gets me through doing what I feel like I need to do because she deserves the attention now because she always gave me the attention and always put my sister and I first above herself.

In addition to good memories, a common technique was turning negative feelings into a positive response. One participant talked about the activities she used to participate in and coping with no longer being able to go do those things. "I didn't mind giving up a lot of those things because I didn't really want to do them anymore anyway, so it just fell [i.e., taking care of her] at the right time." P9 turned the negative of no longer being able to go out into a positive because she finds joy in caregiving: "I think being able to do it for her, it's just meant to be, it gives me joy to help her." She goes on to discuss the need to fix up her grandmother's house, which needed repair:

> It's rewarding sometimes too, I'm also redoing her entire house, that's rewarding but then I go and lay down and I'm exhausted, and I can't believe I just did all this by myself, just things like that. Things that I do and that I would never think I would be doing 5 years ago.

Although this ICG puts in a lot of hours at work, she uses the coping strategy of turning the negative, having to now take care of the house, into a positive; learning to do more things. P10 discovered that she could turn the strain of caring into a positive at work: "I relate to my patients better because of my parents and my in-laws." Rather than resent the fact that she had to go back to work, she responded that "it's been good going back full-time because it put me in a routine again because I was getting lazy.” P7 viewed caring for her grandmother as a coping mechanism to deal with the loss of her husband: “I think that we were both dependent on each other, I had just lost my husband, she was a welcome distraction at that point.” Another participant expressed significant emotional stress throughout the interview; she copes by making a mental decision to see the positive:

> I’m blessed that I have my mother in my home. We talk about work and that gets her mind off other stuff and that helps me. She is wise on some things, or she’ll laugh about something that happened. I try to bring out the positive.

P6 elects to see changing her eating habits to accommodate her mother as a positive:

> When I was by myself I went the other way, maybe…it was out of boredom. I was stress-eating. Since she’s been with me I’ve lost some weight; I’ve been more conscious of [eating habits]. Changing my eating habits has actually helped me because since she’s come to the house, her eating habits are different so that’s been a bit of a plus for me.

P1 concludes, “it’s a sacrifice and it’s good...she actually inspires me.”

Assimilation. Assimilation occurred when the caregiving role became the primary identity. These ICGs coped by making the role a part of their identity and seeing the CR’s identity as more important than their own. The ICGs accepted the role with minimal resistance to the sacrifice. This was accomplished through a sense of obligation, making the CR’s happiness a priority and also through empathy with the CR’s feelings over their own. An example was exhibited by one participant as she shared that she had been a difficult child, causing her to cope through a sense of obligation: “I was not a good kid growing up, especially in my teens. My mom supported me through it all. She never left me behind and I’m never going to leave her behind.”

P9 also used this strategy: “It can be rewarding sometimes because it gives you a feeling of knowing that she’s my grandmother and she took care of me for so long. It gives me a chance to do it for her, now it’s my turn.” P10 shared:

> My husband’s an only child and we talked about [caregiving]. She [the CR] said “I can’t believe you’re doing this; I hope I didn’t push him into this” and I said “no, this is something we talked about before we got married.” We’ve been married 40 years, we discussed this before we got married. I don’t think it’s somebody else’s job to take care of my in-laws, it’s my job.

P5, whose mother has created a great deal of stress for her by taking over her home, stated:

> I know nobody else will step up and do anything. I told my mom that I love her and I would be there for her. She came in and I gave her my master bedroom, master bath, and another bedroom of my daughter’s. She’s been wanting to move from there to the living room and basically take over my home. I don’t want to hurt her feelings.

By suppressing their own needs and focusing on the CR, these ICGs were able to cope with the stress by taking the focus off themselves and focusing on the CR’s happiness instead. One couple had already sold their home and purchased a boat to live on and were planning to retire in the Caribbean. When they decided his parents needed care, they purchased a home again in order to have a home for the care recipients:

> A lot of the reason we picked the area we did is because we’re close enough to church so they can get involved with the community and make some new friends. They were living in an all-adult complex before and they had a huge social life and then they moved over here. They don’t have friends here at this time, so we probably don’t go out as much; we don’t have as many people over at this point.

Rather than taking her own vacation, P5 offered to take her mother:

> I told my mom I'm going to take this week off so we can do something. If you want me to drive you somewhere so you can see your sister I will be happy to do that. If you want to stay there I'll stay with you.

Even though her mother won't remember going out, P8 still gives up her own time to take her mother out: "Because she's an Alzheimer's patient I try to do very well at getting her out of the house and things like that." This was also demonstrated by P2 when he spoke about giving up his own home: "I had a nice place of my own that I had to give up and move into her home because she needed more help, she was falling."

Commanding Control

Control was an essential coping strategy in the commanding methods of managing stress. The ICGs kept the relationship and tasks within their realm of control. Some of the characteristics of control were exhibited even in the more passive ICGs in order to cope. Control was most often exhibited through structure. A sense of order was imperative to alleviate stress.

Structure. P4 schedules all appointments and time off work before her job as a schoolteacher starts for the new year. "I've already got 4 days in my calendar out of 10 I'm going to be gone." P7 stated that the only way she could cope was scheduling her family members to help: "We kind of all rotate on shifts." P3's daily routine was so precise that she was able to share it in detail:

> It starts off with that coffee [laughs] and then I make sure she's bathed and...then I mix a good protein breakfast.... she puts beads on the stretchy wire so every morning I set it up for her... And of course, we do lunch. it's just a daily routine. In the afternoon she likes to

> sit outside on the patio, and it has a fan, and the dog goes out there with her... Evening time about 5 we have a routine where I put on *Family Feud*. She's usually in bed by 8.

P8 uses the flexibility her job gives her to keep a schedule of checking in on her mother. "The job is 5 minutes from my house so I can run home on my lunch break and still be back in time. I come in a little later because I deal with her in the morning, and they've been pretty flexible." P10 also stated that her work schedule was flexible: "I work 12-hour shifts so I'm home 4 days a week, so I'm around when I have to drive them to the doctor." Another participant described the importance of structure to cope:

> I have to schedule everything ahead of time to get it done. I clean on Saturday morning and generally during the week I just pick up here and there and do quick vacuum and that sort of thing because of the dogs. I cook on the weekends.

Setting Limits. This was also a commanding method used, even by the more passive personalities. For example, P5 allowed her mother to move in and take over her home, but when the stress became too much, she set limits: "I finally had to say, 'no, you have those two rooms, and the rest of the house is mine.'" She also shared how she is developing the ability to set limits:

> I've told my mom, "You need to respect my wishes." She'll say, "don't you want to watch this movie with me?" and I'll say, "No, I don't want to watch any TV." Another time she didn't want me to go to the store and I said, "I AM [capitalized for emphasis] going to the store."

A similar situation was expressed by P1:

> I'm having to learn boundaries in this caregiving and learn my mother needs to learn to respect me and my needs too, as I'm trying to help her so I need to learn to not be afraid

> to say "I'd love to get to that as soon as I can," but it's okay to say "not now, I need rest" or even say "I have other plans and we'll do something later."

Self-Awareness. Control can also be accomplished through self-awareness. ICGs suffer a great deal of stress through self-imposed guilt; becoming self-aware proved to be a very liberating strategy (Prevo et al., 2017). P9 stated "I've learned that you can't do everything. I was always the one trying to do everything, and I learned that I just can't." This was also expressed by P7:

> I figured out I could not give from an empty cup. I couldn't pour from an empty cup, there was no way, so I made it a priority. I had to quit my second job. I finished school, and once that was done I made it a priority that all the extra time that I was having to figure out how to get all that done, I was going to focus on myself. I can feel it building back up again and I have triggers—I know when it is coming. I can tell when my anxiety is getting out of control.

P8 also uses self-awareness to cope:

> I've been doing this for so long because I dealt with my grandmother too, so I know there are certain things that get me through, like you can't win an argument with somebody with Alzheimer's, so when you find yourself going down that road you just stop. You know it's not worth the time.

Other caregivers shared similar stories. P1 shared:

> Coming home, you're tired. You just want to lay down. It's been a long day; then you find yourself irritable. I know I'm being irritable, I have to monitor, try to control that. It's a natural thing and I told myself, as the Lord helps me, I'm only a human being so be nice to yourself.

P4 stated:

> I live with the guilt and then I become negative and then I become in a bad mood and that affects my family and that's not fair to them. So, I'm making strategies. I found a new person, Doctor [redacted]. She is a Christian lady. I'm reading her book; it's about putting together brain and science we know to renew our mind.

Value. A more subtle sense of control was exhibited through the idea of giving value to the CR. It was much easier to cope with the stress when the CR offered value to the ICG's life. P1 shared:

> I want her to feel that she is valuable because she is. She deserves the respect that she raised us as kids. We all go through pain. I can learn from her, her struggles; the surgery she has gone through, and sticking herself with needles every day. I don't want to do that! She actually inspires me, her strength to go through this.

P9 expressed the value of comfort her grandmother instills: "when I'm mad [at work] I'll call her and ask, 'are you okay?' and she'll say, 'yeah, I'm okay' and just hearing that she's okay makes me feel better and she loves that it helps me." P6 expresses value directly to her mother: "I try and tell her 'You're not a burden at all.' She tries to come in and help me if I'm cooking on the weekends." Even though P5 shared how difficult her mother can be, she discovered that giving value provides relief. "We talk about work and that gets her mind off other stuff and that helps me. She's wise on some things or she'll laugh about something that happened." Other caregivers such as P10 have found positivity and value as primary coping strategies:

> It's different living in the same household. This isn't my home, it's pretty much our home. We purchased the home together so it's in our name because they didn't really want it in their name, but they helped with the down payment. They are both good about

> picking up after themselves, so when I come home they usually have dinner taken care of.

P3 expressed a similar idea:

> She used to work in that little cubicle [at my office], and she'd come every day for lunch, and she would do my lecture note copies, but she can't do that now. Now I'm trying to simplify it; I do the copies and tell her to staple them, but now she doesn't understand how to staple. She's doing okay with the three-hole punch—it makes her feel important.

Segregation. An alternative method of coping that was very popular within the commanding method was practiced by segregating the roles: seeing each as a separate role, not related to the other. This was exhibited through tactics such as impersonalizing the caregiving role when caregivers used third-person or universal terms. P8 shared her frustration with her sister not helping to care for her mother who has Alzheimer's, but rather adding to her stress. She dispels it through making it impersonal: "I find that is the case with most caregiving situations: It falls on one person. I know very few situations where everyone rallies together to take care of mom or dad. It usually falls on one person." P1 spoke in third-person phrases often when speaking of her stress:

> You want to love and care for them, but they feel they're being a burden and you feel like they're a burden and you just have to work that out because it's just human. So much is impersonal. As a caregiver you kind of know this up close and personal more than other people.

All the ICGs interviewed agreed that caregiving was a greater burden of stress then work. However, the commanding method used work as a reprieve. P1 not only finds a reprieve in work, but also indicates that her stress is alleviated by work because it gives her value:

> I'll tell you the truth about my relationship. Going to work gives me relief because there is too much of the interpersonal struggles going on and when caregiving is mixed in there's the psychological stressors, you know, that drain you and drain your loved one. You don't know when to let go, you say things and do things, they'd rather be by themselves. So, I feel sorry for people who can't leave, that have to be there constantly. Work gives me another perspective, a change of pace. I'm learning new things. My work is valuable.

Similarly, work is where P3 gets her satisfaction: "[work] is my fun." Again, this was expressed by other caregivers, such as P2: "Now that I'm working again I find the break from caring gives me the relief I need." P10 stated that "I work at a plant nursery part-time. That's my true escape." P4 also copes this way. "When I'm at school I'm not even thinking about my family, I'm pretty focused at work." I noticed throughout the interview that P5 did not even speak of work in the same context as her caregiving role. One comment gave insight as to why: "My home becomes a prison."

Escape. The commanding method also uses escape in order to obtain time apart from the role of caring (Prevo et al., 2017). P3 converted her greenhouse into a place of reprieve:

> My greenhouse is now a "she-cave" and I do a lot of crafts and I go out there. It is situated in a part of my yard, so she [mother] doesn't ever go in there. I'll set her up outside with her cup of coffee and her word search puzzle and I'll go in there. I love listening to Christian music, and I just jam that stuff and do my arts.

One participant sneaks off to have some time to herself:

> She believes I'm going to church. I will drive, and most of the time I do go to church, but lately I don't. I just have to go sit in a parking lot and de-stress. Sometimes I just

> want to go somewhere and talk to a friend or just get out of the house. The best coping mechanism is to get out of the house away from the situation, rethink things, go do something fun. I went to Alaska for 2 weeks. So that's the way I cope, is to get away. I go up to see my kids for 3 days. When it's unbearable, I go on vacation.

P8 shared that "I've managed to retain some level of travel, because I've always loved to travel, and it keeps me sane." In order to have time with her husband, P4 takes little trips:

> Even though we only spent one night, we didn't come home till late Wednesday night, and we were able to reconnect again. We will be able to do that in December with a business trip, even though it's for business... we'll be able to have a few hours a day, like on the beach or taking a nap.

P3 also takes time with her husband: "We have a motorcycle and then we bought a Jeep, and there are times that he and I go out and just ride in the country."

Season. Relief was found in viewing the caregiving role as a "season" in life, indicating that this role would not last forever, unlike other roles such as spouse or parent. P7 spoke of future plans: "At some point we know it's going to get to the point where she is going to have to move in with my mom, and we've already designated my mom as the person." P5 frequently used the term "season":

> I have to hit the reset button and tell myself this is a season and when she's gone she's gone for good. I have to be constantly resetting myself with a lot of prayer and go back and say this is a season.

Several other caregivers also expressed this as a coping mechanism. P8 stated: "Eventually you realize, this is not necessarily the life I plan for myself, but I keep telling myself it's a season, you know." P1 said "It's not forever and I'll be glad I did when she passes [away] that I was there for her." And P4 stated "I'm just saying if I had to do it longer, being a teacher, I could not do it. But knowing that there is an end, there is light at the end of the tunnel."

Research Question 3

Based on lived experiences, what coping strategies do informal caregivers use to manage behavioral conflicts associated with their dual roles as an employee and a caregiver to an aged family member?

To cope with behavioral stress, the passive method applied acceptance as opposed to maintaining control. ICGs resigned themselves to the stress associated with the roles of caring and work; by accepting the burden of the two roles they were relieved from the strain and turmoil that comes with resistance to the tasks that are required.

Resignation

Acceptance through resignation was demonstrated by a strong commitment to the role of caregiving. P3 expressed this, stating: "I refuse to put her in a nursing home, and I know we talk about the need to get a home care nurse and I've tried it but nobody's going to take care of Mama the way you do."

Other participants expressed similar feelings: "I don't mind doing this. I would never have taken her in if I felt it was an issue. She's my mom and I would do anything for her," "I don't want to see anybody else take care of her," and "Because of who I am, I'll be here; I was for my grandma, and I am my mom's caregiver." P2 expressed the idea that "I have to figure out what I can still do. There isn't the time to think about me or my needs. I've sacrificed a lot."

Obligation

Many caregivers’ commitment is rooted in a sense of obligation, which enables them to accept their role (Øydgard, 2017). They view it not as a choice but as a moral obligation. One caregiver expressed it very clearly:

> Because I was not a good kid growing up, especially in my teens; my mom supported me through it all. She never left me behind and I’m never going to leave her behind. Growing up she was that *Leave It to Beaver* mom who was always home. Our house was the house that all the kids came to. She was that kind of a mom. She deserves someone taking care of her like this—she’s earned her right.

Several other caregivers shared similar sentiments: “My husband’s an only child and we talked about [caring for his parents]” and “It can be rewarding sometimes as well, because it gives you a feeling of knowing that she’s my grandmother and she took care of me for so long.” P6 stated:

> I think probably the secret for me is maybe that I have always been so thankful for my mother. She gave up a lot for my sister and I as a young woman that I feel like I owe it to her to take care of her because she’s always been there for me.

Martyrdom

Since caring is an obligation that these caregivers are proud of, they have a sense of pride in the caregiving role that reduces stress, which in turn reduces behavioral issues. Pride in their accomplishments as caregivers is often exhibited as martyrdom and the ability to tolerate any difficult behavior in the care recipient. P1 displayed martyrdom:

> You feel guilty and you try to make amends...you try to fix it. I’m such a pleaser, I want to make everything all better, and if I don’t know what the problem is then I can’t make it better. Oh my goodness, I apologize when I know I haven’t spoken in love, not that she

> ever apologizes to me, not that she ever sees what she's done. But you have that conscious[ness], and you know you have to for the relationship, to try to make it all better and just say "I'm sorry." It's about honoring our parents; God is noticing. It's the right thing [to do and] it makes me better. I think I would be full of myself if I weren't doing this right now—it's a learning lesson.

Other caregivers also demonstrated moments of martyrdom: "I have a bad habit of taking care of everybody, I've always put everyone else ahead of myself" and "I've been doing this for a long time; I've taken care of two people with Alzheimer's, two! It's the hardest thing I've ever done in my life with no help."

Growth Opportunity

Similar to turning a negative into a positive, many passive ICGs view the ICG role as a personal growth opportunity in order to divert negative emotional responses. This coping strategy reduces guilt, thereby reducing stress. P1 shared a good example:

> I'm being strengthened by it. I see myself getting stronger and stronger through what the Lord is doing in me, through the work of caring for my mom, doing things that bring life to her, taking care of the yard, the flowers. It wears me out but yet it gives me life. I'm proud and glad of that, so I think God blesses all of that and is going to bless me. I find myself being more resilient, more than I thought I could be. It has brought out stressors. It has brought out blessings as well… things that needed to be resolved in my heart. I'm learning from this experience how to take care of myself.

Similarly, P9 stated:

> It's definitely given me a bigger picture of life. When you're younger you feel like life is so far away, and in reality it's like today and tomorrow. You have an 83-year-old

> grandma, and she has lived this long life and you know that tomorrow is not promised…even though it's been 83 years and I've only had 31 years. It's kind of given me a different perspective of life and not to take a whole lot for granted. When you're younger you don't think about those things until you get older. Taking care of her, it's definitely changed my outlook on life for sure.

Additionally, P5 stated "I have these emotions, these feelings of wanting to have time to myself, and I'm thinking God paid the ultimate price and gave everything and here I am complaining." P10 said "It makes me think more about my mother who is almost 90, so I relate to my patients better because of my parents and my in-laws."

Commanding Assertion

The commanding method to manage stress-induced behavioral issues was demonstrated by asserting control and giving the care recipient purpose.

Maintain Control. ICGs assert control by understanding their own limitations and setting boundaries to keep from being pushed beyond those limits (Chen, 2016). P8 knows she does not have the energy necessary to develop a romantic relationship:

> I dated a guy here last year and he was understanding. He would come over and be nice to my mom. We're still friends but it didn't work out…. It's not a priority as far as romantic relationships. I mean I have too much other stressing—too many other things to deal with. When I was younger and in my twenties, going out at 10:00 was normal, but now it's okay. I'll fix a drink at home and watch TV.

P1 understands she must manage her physical limitations:

> I have to tell her I've got to go lay down and not to feel guilty about it. she's not going to understand, because I heard from somebody, they say older people lose their perspective

> on things, their logic about things. I just be honest with her and say, "It's been really tough, I'm going to go lay down now, don't get your feelings hurt, I have to lay down, just understand that I can't be your support right now."

P4 knows her limits as a caregiver and asserts herself to stay within those boundaries:

> I don't do overwhelming very well, unfortunately. I wish I had more grace. I wouldn't mind hiring full-time medical people so she could stay at home, but in that she wouldn't have me all the time. But then I'm not a nurse-tech type person, I don't think I could be doing it every 24/7, I just don't think I have it. We've had conversations—her maid does come once a month, because I told her when we move I was going to have a family and I would be working, and I would not be able to clean.

P3 is very aware of her triggers and copes by removing herself: "It's hard because you don't want to get mad at the patient, at your mom, but sometimes you just get so angry you just have to walk away, go outside and scream." She also has discovered she needs to control the level of stress induced at work. "I've already removed three students, it's just when they start interrupting too much it just gets to be too much for me when I have to go home and deal with stress too," P10 explains, "I'm around people and noise all day long. I like quiet and time to myself, so when the weather is nice I'm outside." P2 voiced how work helps him keep control:

> I am less tolerant of people being stupid! But I think I am more patient with my mom and less patient with the world. Now that I'm working again I find the break from caring gives me the relief I need. That's working for now. Sometimes in my hotel room I do yoga and that helps.

Purpose. Another commanding method to maintain control was accomplished through assigning purpose to the CR. Doing so redirected the stress towards a productive outlet. P10 assigns purpose through the lens of friendship:

> Just try to do things that are fun, spending time with them doing things with them like playing cards with them. We talk a lot. We usually have dinner together every night, and as the weather gets nice my mother-in-law likes to garden. [That is] something we can do together—doing things that make us both feel good, put the house together and things, always try to include them.

Even though her mother has advanced dementia, P3 chooses to see her mother as a participant in her own care as much as possible. “I tried caregivers that come and check her pulse and blood pressure morning and afternoon and just keep a log on her, and then they’ll sit on their phone and I’m like, ‘I could do—you’re not involving my mom.’” P8’s mother has Alzheimer’s, but she still insists that her mother’s days are purposeful:

> I try to do very well at getting her out of the house, but we could go to Six Flags, church, the mall, and out to eat and get home at 7 at night and she won’t remember that she did any of it, so there’s a frustration of that. Even when you are taking her out you know she’s not going to remember that you took her.

Although she accurately expressed her frustration, she also indicated the emotional relief derived from continuing to maintain activities that simulate a relationship with her mother, which is a positive outlet for behavioral stress. Even though P5 is stressed over feeling obligated to sit and watch TV with her mother, she maintains control of her emotions by seeing the role as companionship:

> I have to sit there and think, "she sits there all day long by herself doing nothing, so when I get home she wants to come spend time with me." We don't even say much to each other. We just go watch TV. Just that I'm sitting there with her brings her comfort, and I'm more like "can't we talk about stuff" and I'm like "there's nothing going on in my life." I'll ask her about when she was younger and stuff like that and that's been interesting.

P7's grandmother has early dementia; however, she is given responsibilities she can still manage, which gives her purpose. "We have two dogs at home, and they keep her active. She likes to let them out and she brings them back and she feeds them. It gives her something to do."

Role Support

In both methods, caregivers sought support through external and internal means to cope with their dual roles.

External

External sources of support were sought through family, friends, groups, and employers.

Family. Family was the primary source of support. P7 stated that she can only manage both roles because of her family help:

> We have a lot of family who help us. I don't do it all by myself; my mom is her daughter, and she helps, especially on the weekends. So I know I can count on my mom to be with her on the weekends, so that helps me a lot. I feel like I get a break when family members step in to take over.

P1 not only relies on her family for assistance with caring, but also for emotional support:

> I have brothers and sisters, so that's a great blessing. Other people are a strength; they come on board and help support. [They] help you the most when they can take her to the

> doctor when I have to work. When I can call them and ask, "how's it going?" and they're there, it relieves my anxiousness because they're with her and supporting her and she gets along better with some of the siblings then with me. When I get together with my sisters and we're talking and I'm talking about her, it hurts me, but I need to air. I need to air the frustration of caring and how frustrating it is.

P4 tells how helpful and supportive her children are, as well as her spouse. "He does all the work of the pool, and he fixes things. He's always been really supportive. I don't have any siblings, but my kids are really good. My family support is really fabulous." P3 also relies on her spouse for support: "I do all the diapers and my husband does her laundry. He's always going in and checking on her and stuff, like when I go work out it gives me time because I'm the main caregiver." P6 has a sister who helps: "I have a sister who sometimes takes her to some of her appointments." P2 stated that his nephew is a big help with taking care of his mother.

Friends. Some did not have any family but used outside sources for support. For instance, P8's mother's friend gives her a reprieve: "My mom's best friend lives in the same suburb as us and she takes my mom to church every Sunday." This caregiver has also found agencies to help support her role:

> I was able to get grant help through an area agency on aging for respite. For two months she went to adult daycare, so she was able to go there all day while I was at work. It took so much off of my back. I ended up getting a senior companion from another agency. It's a senior volunteer who comes to the house for a couple hours and they sit with her and take her out and hang out with her, so I've got that.

Groups. Additionally, P8 uses a support group for emotional assistance. "You feel that you're the only one, but in a support group you find out how other moms yell at them too. It's a really interesting dynamic to be around other people who are going through it.” Although P1 expressed that she gets a lot of support from her family, she also mentioned a boarder who has turned into a supporter: “The woman that is living with us now helps because she’s renting a room and that takes a load, because I know she’s there from time to time. “ P4 mentioned outside help even though she stated that her family is very supportive: “She has a friend from [town redacted] that has taken her to the doctor in the spring and summer when I’m really busy. If I really need her I can call her.” Some outside support provided a diversion for the care recipient, thereby giving the ICG a break. “My in-laws come over, they love my mom, so they’ll see her,” and “I have good neighbors and they’re always watching her.”

Employment. In addition, some found support through work. P9 expressed that her main support comes through her job:

> I have a lot of support at work, not only [from my boss] but with my coworkers. My coworkers are big supporters; [they are] very cool coworkers.” [My boss is] very understanding—we don’t have a lot of employers like that. His mom is in his home, so he understands more personally how that goes. When I tell him sometimes I have to go because of her, he understands. He never gives me a hard time about it.

Other participants also described work as a support structure: “My boss has been wonderful, you know, all I have to say is ‘my mother has a doctor’s appointment.’” Another subject commented “my students know about my mom. It’s amazing how understanding they are. Sometimes they’ll hug me.” P4 said “My principals that I’ve had during this time have been really good about letting me go from work a little bit early.” P8 says that at work “they are flexible. I don’t have a micromanager that’s over my shoulder all the time, so I’ve had freedom.”

Internal

Support for the role was also found internally. Self-help methods such as pep talks, capitalizing on small pleasures, and self-help aides were often used by the participants.

Pep Talks. ICGs found that self-supporting methods such as mental "pep talks" enabled them to handle stress. P9 frequently gives herself a pep talk:

> I just say "suck it up" and I keep going. Sometimes I want to give up; sometimes I feel like I just want to say "grandma, I'm done, I don't want to work anymore, I don't want to be mom anymore," I don't want to take care of her anymore, I just want to go. But in reality I can't do that, and I have felt like that plenty of times, so I just have to talk myself out of it and keep going.

P8 similarly stated, "I just have to snap out of it and give myself a break."

Self-Help Aides. Self-help aides are also employed to help caregivers cope. P8 used breathing techniques: "I've learned to just breathe, just remember that it's just what I have to do. At work I just have to go outside for a fresh breath of air." P8 stated, "I just have to force myself to go out and socialize and [be] around other people. You just got to be intentional about forcing yourself to do it." P4 found that a self-help book was beneficial: "a book teaching you to switch your brain, just stop and renew my mind and try a little reconnect trick."

Small Pleasures. An interesting strategy that appeared to be quite effective was finding pleasure in the little things. This seemed to enable the ICG to mentally change gears and ward off stress: Subjects commented "Usually on my day off I like I take the dog for a walk or go to the park" and "Taking care of the yard, the flowers. Take a hot shower in the morning, try to get enough rest. I like to stay up and read a book or watch a movie." P8 shared that "I went to the bookstore and sat on the floor. I looked through a book and I was like 'I don't have to rush home.'" Other obvious methods of self-help are found through exercise, developing healthy habits, and faith. These are all well-documented techniques to relieve stress, and when employed by ICGs, they appear to be very effective. Relevant comments included "I'm a runner, I like to run to clear my head" and "I would go to the gym and I made it a point to do for myself what I was doing for her on a daily basis, to make sure I was okay, and I lost weight and I got back on track." P2 also finds relief in yoga: "I do yoga and that helps." Many of the participants shared that developing a healthier lifestyle was helpful to relieve stress. "I try to work out, I try to work out the stress. I work with a nutrition partner, and he keeps telling me take time." "I take herbs and try to get enough rest." "At night she only eats fruit, so I've started doing that and I don't eat a heavy meal at night."

Faith. The final self-help strategy that was very effective was a strong personal faith. The ICGs who expressed faith that a higher being then themselves gave them strength to cope. Strategies included "reading the daily inspiration every day and a whole lot of prayers" and "spending more time reading my Bible lately." P5 stated "I pray and ask God to help me and then I go back up with a better attitude. She might say something else which upsets me, but I walk away, and I ask God to help." P1 relies heavily on her faith: "I cannot overemphasize faith and prayer in the Lord, because He has our life. He is the reason that we love when we hurt, when we do more than we think we can do."

Summary

Two central themes emerged from the coping strategies IGCs used to manage conflicts that arise from their dual roles: passive and commanding strategies. In addition, a subtheme of support emerged involving both internal and external avenues of coping.

Research Question 1

The first research question asked what coping strategies ICGs use to manage time conflicts that arise. Passive methods were based in an emotional perspective, subjective to feelings, moods, and attitudes. The ICG focused more on the caregiving role then work. As long as conflict was resolved in one role, conflict in the other was manageable. Mechanisms used included compromise, return on investment, and living in the now. Compromise involved keeping the care recipient content even if it took more time; the time strain was manageable when there was less emotional conflict. Return on investment gave hope that others would provide the same care if needed, which made the current extra work worth the time. Some ICGs thought only about getting through one day at a time and did not think about the future, stating they would deal with future problems when they came.

The commanding theme was based in a more objective perspective: logic-based, detached, and often void of emotion. Relevant methods applied technology, structure, independence, and planning for the future. Technology was often used as an aide to manage tasks and save time. Structure provided relief by allowing the ICG to use time efficiently. These ICGs pushed the care recipient to maintain as much independence as possible to reduce the time spent in caregiving. Almost the opposite of passive coping, commanding strategies involved planning for the future. Having a plan in place for future occurrences provided reassurance that they could handle matters.

Research Question 2

In relation to the second research question, how ICGs manage conflicts that arise from stress, I found that they used passive adaptation through relinquishment and assimilation and commanding methods involving control and segregation. Passive relinquishment strategies involved empathy, justification, good memories, and assimilation. These methods focused on the care recipient's well-being, which resolved stress conflict through the sacrifice of the ICG's own needs and desires.

Commanding strategies involved multiple methods. Control was essential to managing stress. ICGs kept the relationship and tasks within their own control, which reduced their stress. Control was often accomplished through self-awareness: a reflectiveness that allowed the ICG to evaluate whether stress was the result of self-imposed guilt. An interesting strategy was one I termed "value": control was exercised through attributing value to the care recipient, which resolved some conflict in the relationship. Segregation was accomplished by compartmentalizing roles, mentally viewing each as separate from the other. Most commanding ICGs had a place or time of escape to relieve stress, and also viewed the caregiving role as only a season in their life that would end. Viewing the stress as temporary enabled them to cope.

Research Question 3

The third research question asked what coping strategies are used to manage behavioral conflict that arises from both roles. Passive methods involved acceptance, resignation, obligation, martyrdom, and viewing the role as a growth opportunity. The commanding method, on the other hand, involved maintaining control and assigning purpose.

The use of acceptance and resignation to the two roles of caregiving and work relieved stress and resolved behavioral conflict through resignation rather than engaging in the conflict. The deep-rooted feeling of obligation to the caregiving role eased behavior conflict through seeing the care recipient as deserving and having a right to the care they receive. Obligation was often accompanied by martyrdom, as the caregivers had a sense of pride in managing their roles as caregivers. Pride in their roles gave satisfaction, which reduced behavioral conflicts.

Commanding methods used control to set boundaries, which prevented the ICG from being pushed beyond coping. This strategy enabled the ICG to stop behavioral conflicts from getting out of control. Caregivers also resolved conflicts through assigning purpose to the care recipient, thereby redirecting stress into a productive and positive outlet.

Coping through the use of support was also found in all three areas of stress. Support took both internal and external forms. External modes of support were obvious in the form of family, friends, groups, and employers. More subtle forms of support were internal, using self-help aides, pep talks, focus on small pleasures, and personal faith. Both internal and external support were coping strategies that all caregivers used to manage conflict in both the workplace and the caregiving role.

Conclusion

This chapter described research conducted to answer three questions: how ICGs manage the conflicts of time, stress, and behavior that arise in the roles of work and caring. The process of data collection and analysis was explained in detail for the purpose of establishing the trustworthiness of this study. A comprehensive analysis of the interview results was presented according to each research question.

In Chapter 5, interpretation of these results will be presented within the framework of work conflict theory. The study findings will be compared to the current literature presented in Chapter 2, and I will discuss how this study may provide additional insight to the field of dual-role informal caregiving.

Chapter 5: Discussion, Conclusions, and Recommendations

I conducted this study to examine coping strategies that dual-role ICGs use to remain in both the workforce and the caregiving role. There are nearly 43.2 million ICGs in the United States, of which 69% are working while caring (NAC, 2020). By 2050, the demand for ICGs is expected to double (BLS, 2019). The pressures associated with work and informal caregiving have been linked to decisions to reduce work hours, quit employment, take early retirement, or put the care recipient into a long-term facility (Phillips et al., 2016). The largest segment of U.S. working society, the baby boomers, are retiring; this, coupled with the increased need for ICGs, will result in a sharp rise in the dependency ratio, negatively affecting the economy (BLS, 2019). Many studies have been conducted to determine the effects of caring and working on ICGs (Feinberg, 2016; Gautun & Bratt, 2016; Hilbrecht et al., 2016). Some studies have suggested methods to manage both roles (Andersson et al., 2016; Bertilsson et al., 2016; Chen, 2016). However, there is a scarcity of literature examining this phenomenon through the experiences of ICGs themselves.

This study was conducted to explore the lived experiences of ICGs in order to ascertain the coping strategies they apply that are most beneficial to remain in both roles. The literature review indicated that working ICGs experience conflict in three main areas: time, stress, and behavior (Altomonte, 2016; DePasquale et al., 2017; Mortensen et al., 2017; Oldenkamp et al., 2017; Sadavoy et al., 2021). These conflicts therefore became the research focus of my qualitative study. The interpretative phenomenological approach was selected because it concentrates on the experiences that have meaning in a person’s life (Smith et al., 2009). Semi structured interviews allowed the collection of rich, detailed dialogues of individual experiences, which collectively revealed patterns of similar coping strategies used to minimize work-family conflict while managing the strain of both roles.

I discovered two central methods of coping: passive and commanding. In the context of this research, the term “passive” refers to acceptance, without active response or resistance (Lexico, “Passive,” n.d.). Passive coping was displayed subjectively, based on feelings, moods, and attitudes. Passive strategies used compromise, living in the moment, and viewing caring as an investment in others caring for oneself someday, a mental strategy I referred to as “return on investment.” The term “commanding” is used to indicate authoritative and self-controlled strategies (Lexico, “Commanding,” n.d.). Commanding methods of coping were generally objective and less emotional, and they tended to involve logic-based decision-making. These included structure, planning, and using technology as an aid.

In addition to the two central methods of coping, I found that all ICGs sought support through internal and external means. External support came through the obvious channels of family, friends, employment, and groups. Internal support was less obvious, involving self-administered pep talks, self-help aids, enjoying small pleasures, and faith. These internal methods were as effective as external support and were used more often because they were not dependent on other sources.

The findings in this study indicate that ICGs use many coping strategies, employing passive and commanding strategies interchangeably along with external and internal support to manage the conflicts that arise in their dual roles.

Interpretation of the Findings

Current literature focuses on the effect that caregiving has in the areas of time, strain, and behavioral conflicts (Altomonte, 2016; Feinberg, 2016; NAC, 2020). Studies have shown that working caregivers suffer the most in these areas due to conflicts that arise from the demands of both roles (DePasquale et al., 2017; Gérain & Zech, 2019; NAC, 2020). Literature suggests that the strain of trying to fulfill the expectations of multiple roles and cope with conflicting obligations produces a burden, resulting in ICGs either leaving the workforce or relinquishing their caregiver role to long-term placement in a facility (Betini et al., 2017; Boucher et al., 2019; DePasquale et al., 2017). My interpretation of my findings is presented as a contribution to the literature from the perspective of the lived experiences of ICGs.

Time Conflict

In several studies, ICGs have expressed their inability to control their schedules and make plans due to the constant demands of caregiving. Time is described as frenzied, with each day filled with pressure to complete all the tasks of multiple roles, leaving little to no time for self-care. My research found this to be very accurate. Every caregiver interviewed expressed the same frustration about time constraints (Jellema et al., 2018; Lindeza et al., 2020; Prevo et al., 2017). The most often cited solution was flextime to manage work and caring. However, studies showed that this was an inconsistent solution, as it was contingent on the employer, company dynamics, and job description (Longacre et al., 2016; Oldenkamp et al., 2017). The literature also shows that workforce discrimination contributes to time conflicts; examples of bias toward ICGs were found in leave denial, disciplinary action for taking personal days, and termination for taking time off, making time conflict between work and caregiving so significant that ICGs eventually leave the workforce (Clancy et al., 2019; Oldenkamp et al., 2017; U.S. DOL, 2016).

I discovered that ICGs who are taking care of an aging person in their home while working experience an added measure of stress due to managing the demands of work and caring. The most significant time conflict originates with caregiving responsibilities causing the caregiver to be late for work, to need to leave early for a caregiving emergency, or to take days off to take the care recipient to appointments. These issues are mentioned in the literature (Holzapfel et al., 2015; Longacre et al., 2016; Øydgard, 2017) and were supported by the ICGs I interviewed. However, my research indicated that the demands of caregiving were more of a contributing factor to time conflict than work; most of the ICGs interviewed stated that their employers were supportive of their caregiving responsibilities and allowed them to make small adjustments to their time when possible, which supports the suggestion that flextime on a limited basis is in fact an effective solution to alleviate time conflict. While this informal flextime is not a major adjustment to dual-role ICGs' schedules, it does appear to alleviate time conflicts enough that they can continue to operate in both roles. Flextime alone cannot remedy the complex issue of time management for dual-role ICGs; additional strategies are necessary to cope. ICGs supplemented informal flextime with both passive and commanding methods. Passive methods involved an emotional perspective, using subjective tools such as compromise, viewing time stress as an investment that would bring returns, and limiting the strain by thinking only of the present and choosing to deal with the future when it happened. Commanding methods involved more objective strategies such as technology and structuring time, as well as maintaining one's independence and planning for the future.

Strain Conflict

Burnout is common in ICGs (Gérain & Zech, 2019). Lack of time, energy, and access to relief lead to health problems such as high blood pressure, chronic fatigue, weight gain, and depression (Bangerter et al., 2017; Bom et al., 2018). The emotional strain of caregiving results in an increase in work-related injuries due to poor concentration and distractions at work (U.S. DOL, 2016). Some studies have indicated that it is not the stress of employment, but rather the inability to cope with the strain of caregiving, that interferes with work performance (Andersson et al., 2019; Clancy et al., 2019). The ICG is often caught in a cycle of frustration and anger followed by guilt and feelings of inadequacy (Andersson et al., 2017). Studies have shown that ICG strain is also manifested socially (Bertilsson et al., 2016; O'Donnell, 2016). Conflicting emotions lead to feelings of isolation and loneliness (Boucher et al., 2019; Smith et al., 2020). Many caregivers give up social and leisure time because they are too busy with work and caring (Jellema et al., 2018; Rigby et al., 2019). Literature results suggest that care networks are instrumental in alleviating caregiver burden through family sharing (Reyes et al., 2020). My research did not support this as a reliable coping strategy. Most ICGs I interviewed stated that they did not have much, if any, family support due to a lack of family in the area or unreliable family members. Often, ICGs asserted that their family felt that because the care recipient was taken care of, they were "off the hook" from helping out. Family support thus would have been welcome but was rarely available.

Although the dual role of work and caring creates greater stress for ICGs, some studies show that work is beneficial, providing a form of respite (Dombestein et al., 2019; Lindeza et al., 2020). This view was strongly supported in my study. The ICGs I interviewed expressed that although work created conflict, it provided respite from daily care, support from coworkers, and relief from financial strain.

Behavioral Conflict

Behavioral conflict often develops over time, as the stress and strain of the two roles of caring and working take their toll both physically and emotionally. Exhibitions of frustration, anger, and depression may spill into the workplace or be manifested in the form of elder abuse (Lin, 2020; Orfila et al., 2018). The pervasive feeling of a lack of choice in providing care creates a sense of loss of control, resulting in negativity toward the role of caregiving (O'Donnell, 2016). The loss of choice is exacerbated in dual-role ICGs who already feel a loss of control over time and are subject to multiple stressors (Lindeza et al., 2020). The major contributing factor to the perception of lack of choice is poor preparedness (Moon et al., 2016; Strommen et al., 2018). Few family members are prepared to take on the role of caregiving, and even fewer are prepared to be dual-role caregivers. Typically, the role is suddenly assumed after a major health event that leaves the care recipient with diminished capacity to live independently (Moon et al., 2016).

Lack of preparedness affects work and family roles; the sudden stress leads to behavioral conflicts (Araujo et al., 2016). Studies have shown that ICGs express resentment because of financial strain, lack of family support, and loss of friendships (Andreakou et al., 2016; National Academies of Sciences, Engineering, and Medicine, 2018). Studies have also shown that care recipients with diminished cognition, such as those with dementia and Alzheimer's, are a greater burden on caregivers due to behavioral dysfunction (Andreakou et al., 2016). Daily exposure to volatile behavior deteriorates ICGs' mental and physical health, which increases the risk of depression and abuse (Orfila et al., 2018). Dual-role ICGs are at greater risk of negligence due to exhaustion from managing work and care (Lin, 2020). Many studies in the literature have indicated that support for behavioral conflict is derived from work, often coming from coworkers and supervisors (Rofcanin et al., 2019; Socci et al., 2019). However, work can only partially aid the ICG suffering from depression, anger, and resentment; studies in the literature thus support recommendations for support groups or counseling (Berwig et al., 2017; Navab et al., 2016). However, my research found that ICGs did not have the extra time to pursue these methods, as time was already lacking.

A study by Fekete et al. (2017) supported the importance of positivity as the primary quality linking tensions and rewards of caregiving. While study participants expressed emotions of frustration, resentment, and anger, they also shared satisfaction in caring when they focused on its positive aspects. The authors recommended interventions targeting mental health focused on positivity strategies (Fekete et al., 2017). However, the study failed to explain how ICGs suffering from the strain of care could maintain a positive perspective. In my study, participants exhibited high emotional resilience through the use of passive and commanding strategies. Passive strategies involved acceptance, expressed through resignation to the role, operating on a sense of obligation, and pride bolstered by a sense of martyrdom. Commanding methods involved asserting control. Behavioral conflicts were best managed by all participants using these strategies. In addition, coping was enabled by external support from family, friends, coworkers, and supervisors, as indicated in the literature (Greenhaus & Beutell, 1985).

Theoretical Framework

Work-family conflict theory indicates that conflict is created when the demands of one role interfere with the demands of another role (Greenhaus & Beutell, 1985). The interference of work with caregiving was more emotionally disruptive than caring was to work. This disparity supports the bidirectional element of work-family conflict theory: When the role of caregiving has greater value, work interference creates a greater emotional strain, and when work has greater value, caregiving interferences create a greater emotional strain (Greenhaus & Beutell, 1985). The work-family conflict is further complicated by societal expectations of family value (Øydgard, 2017). Society dictates that caregivers should value caring over employment; this contributes to emotional conflict and social strain (Broese van Groenou & De Boer, 2016; Yeandle et al., 2017). In my research, I discovered that caregiving was the primary source of stress, but work contributed indirectly simply because of the hours and being physically removed from the caregiving role. ICGs expressed conflict from being at work and worrying about the care recipient, interruptions regarding care while at work, and having to leave work due to care recipient needs. The conflict was perceived as caring interfering with work rather than the other way around. The subjects interviewed conveyed a strong desire to remain in the workforce; it appeared that work was a reprieve. However, none of the ICGs indicated that they would give up working for caring or vice versa. It was evident in my research that these caregivers had developed passive and commanding strategies both consciously and unconsciously to cope with the stress imposed by both roles, enabling them to remain dual-role ICGs.

Limitations

In preparing for this study, I considered limitations. The use of qualitative methods is by nature a limitation, involving the threat of bias. Bias can be a threat to trustworthiness of the research results by skewing the results. Numerous processes were included in the preparation for this study to safeguard against bias. The greatest potential cause of bias was the fact that I am an ICG. I knew that this could be an asset or a limitation to this study. The interview guide was instrumental to protect against bias, keeping me within a script so that I did not introduce bias into the interview through the type or order of questions. To ensure that the interview guide could safeguard against bias, I had it reviewed by a panel of experts to evaluate its clarity. Next, it was posted online in the form of a pilot study to determine if it would extract data relevant to the research questions. The interview guide was limited by the interview process; face-to-face interviewing invites responses that require questions beyond the scope of the guide, so it was important to safeguard against leading the participant. IPA was chosen for this reason. IPA uses personal experience as a tool to extract meaningful data through alignment with the subjects while bracketing personal bias (Smith et al., 2009).

The use of member checking and peer debriefing was essential to the internal validity of the study results. After each interview was completed and underwent initial analysis, the results were sent to each member for feedback. A limitation in this process was the poor response rate by the participants; not all participants sent feedback, and those who did provided only minimal responses. In addition to member checking, peer review was also a part of ensuring the internal validity of the study. The data analysis with a codebook and all transcribed interviews along with an explanation of my role as an ICG were sent to be reviewed by a peer. Although communication between the peer reviewer and myself was minimal, peer review served to benefit the study and support internal validity.

The method of phenomenological qualitative research typically uses small sample sizes for the purpose of seeking rich data that establish patterns. The limitation of a small sample size could result in not finding emerging patterns. This study involved 12 participants, but one withdrew from the study. In spite of this, the data proved to be well saturated with emerging patterns and yielded results that not only confirmed much of the literature, but also added valuable insights regarding coping strategies used by dual-role caregivers.

Recommendations

The majority of the literature on informal caregiving is focused on the effect that caring has on the caregiver (Bangerter et al., 2017; Bom et al., 2018; Dombestein et al., 2019; Gérain & Zech, 2019; Jellema et al., 2018; Lindeza et al., 2020). This study was conducted to illuminate how dual-role caregivers cope; it served as a voice for ICGs who had developed coping strategies to manage the stress of caring and remain in the workforce. Keeping caregivers in the workforce is quickly becoming a crucial issue, as the largest segment of society, the baby boomers, continue to age into retirement. Society is facing not only a work shortage, but also a caregiver shortage. Economically and socially, it is imperative to find coping strategies that will enable dual-role caregivers to remain in both roles (BLS, 2019; United Nations Economic Commission for Europe [UNECE], 2019).

In this study, I was able to conduct limited stratification to examine how different age groups cope. I discovered that age did not appear to affect how ICGs coped; methods were universal, not contingent on age. There was a distinct difference, however, in what problem the age groups found to be the most challenging to manage. Younger ICGs expressed a more difficult time with time management, and older ICGs struggled more with behavioral strain. While younger ICGs focused on social isolation, the older ICGs were more reflective and struggled with issues such as exhaustion and depression. Further studies within this scope would be of value, as more younger caregivers will be required to care for the baby boomers.

These results of this phenomenological study are based on the lived experiences of the participants during one point in time. A longitudinal study would be beneficial to determine how dual-role caregiving strategies change as the caring role changes with length of caring, the care recipient’s condition, and the aging of the caregiver.

There are many more studies that could be conducted that would add value to this field of study, such as studies on how differences in financial status affect coping, gender differences in coping, and the role ethnic diversity has in coping. Future researchers may use the methods in this study to make additional contributions to knowledge in this area of study.

Implications

Today there are over 40.4 million ICGs, of which 82% are dual-role caregivers (BLS, 2019). These statistics indicate a looming crisis in our country, as the strain of caring and working removes more ICGs from the workforce. Research is abundant on the effect caregiving has on the ICG (Altomonte, 2016; Chen, 2016; Hawken et al., 2018; Lindeza et al., 2020). However, there is scarce literature on successful coping strategies to remain in the workforce and provide care. This study presents coping strategies ICGs are using to successfully manage both roles. The outcome of this study may have a positive social effect as a resource for caregiver support groups. The data in this study would be especially helpful to individuals who are just becoming caregivers; studies show that the first year of caregiving is the most difficult adjustment period to managing both roles (Lindeza et al., 2020). The strategies in this study are learned tactics of ICGs who have been in the role for a year or more. The strategies shared by these ICGs have been tried and proven to help them through the difficult first year.

On a larger scale, it is my hope that the information in this study will have a positive effect on employers, to be used as a resource made available by HR to management and employees.

It is my intent to submit the outcome of this research to area agencies on aging that I contacted through the expert panel I used for my interview guide and who expressed an interest in the subject. Agencies such these may extract useful data toward legislative support for policies that will aide dual-role ICGs.

Methodological, Theoretical, and Empirical Implications

The qualitative method of research, using the IPA, linked the data that were gathered to answer the questions posed in the research study. IPA is a thought-provoking method to approaching data; the process of multiple stages of analysis allows for much reflection and viewing the data from various perspectives. By exploring the lived experiences of individual caregivers, I was able to gain an understanding of how these ICGs cope with both roles. The data collected through this method were insightful, revealing how ICGs apply passive and controlling strategies to manage time constraints, stress, and behavioral challenges. The use of qualitative interviewing would prove equally beneficial in future research that focuses on the dynamics of dual-role informal caregiving, as well as expanding the field of research on broader issues surrounding caregiving.

The results of this study support the theory of work-family conflict (Greenhaus & Beutell, 1985). Conflicts were described by the participants when they discussed their frustrations and feeling that there was not enough time to complete all the demands on them. They shared how the constant strain of working and caring took a toll on them physically, emotionally, and financially. Madsen and Hammon (2005) assert that conflict could be bidirectional, with greater conflict occurring in correlation to the more highly valued role. Results of this study indicate that the role of caregiving held a greater value, indicated by subjects' response that they would choose caring for their loved one over remaining in the workforce. Caregivers experienced a greater conflict from caregiving, as it interfered with work responsibilities, yet suffered more guilt and feelings of inadequacy in their role as a caregiver due to work obligations.

This study's results contribute to the literature on ICGs, specifically contributing to the little-researched topic of how dual-role ICGs cope with the strain of both roles. The results of this study indicate that caregivers use both passive and controlling strategies to cope with both their roles, which enables them to manage working and caregiving. This conclusion is based on responses by the participants, who shared in depth how they cope with time, stress, and behavioral challenges.

Recommendations for Practice

The research conducted on informal caregiving primarily concentrates on the effect caregiving has on the caregiver. Studies that addressed work and caregiving focused on the affect caregiving has on work (Boumans & Dorant, 2020; Clancy et al., 2019; DePasquale et al., 2017). This study's outcomes indicate a need to expand the field of research. The caregivers in this study were committed to remaining in both roles; however, they also revealed the lack of support they have to do so. As the population ages, the need for ICGs will increase by 2030 to one out of every four adults (FCA, 2019). As the baby boomers age and the demand for informal care increases, the majority will be working (Reinhard et al., 2019). More research is needed that explores ways to provide tangible support to all parties: the caregiver, recipient, and employer. There is an urgent, growing need for research that identifies employment practices and social policies that will offer relief from the pressure of work and care.

Conclusion

In summary, I discovered that ICGs who are taking care of an aging person in their home while working experience an added measure of stress due to managing the demands of work and caring. This research study examined how ICGs manage the conflicts caused by time constraints, stress, and behavior. These men and women sacrifice their time, health, finances, and relationships to care for those who can no longer care for themselves. Unfortunately, the struggles associated with providing care while working go unheralded, and support to remain in both roles is virtually nonexistent. There is little employer- or government-provided respite from the strain. Dual-role ICGs have developed their own methods in the absence of assistance. Two main types of coping methods are used, passive and commanding. Passive methods focus on the caregiving role more than the work role. This method aims to keep a balance between the care recipient and the ICG that is manageable for the ICG emotionally. On the other hand, commanding methods involve authority, compartmentalizing, and restraint of feelings. Analysis of the data reveal that ICGs use both passive and commanding strategies interchangeably in order to cope with the stress of both roles. These methods have been developed through lived experiences of ICGs. However, as the demand for working ICGs escalates and the demographics broaden, the time to adapt as a caregiver will shorten. The risk of losing ICGs to either role before they are able to evolve becomes greater. This is no longer a private, family concern; it is a looming societal and economic crisis (BLS, 2019). This study has made an initial contribution to describing the unique coping strategies ICGs use to manage work and caregiving; it is my hope that the initiative started here will be furthered in the field of research on this critical issue to stem the rising threat of ICG shortages in the near future.

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Appendix A: Study Recruitment Flyer

INFORMAL CAREGIVER RESEARCH STUDY

****Are you an informal (not paid) caregiver 21 years or older of an elderly person over the age of 71 living in your home while you continue to work? ***

***I am looking for people to interview for a doctoral research study of how caregivers manage caregiving while working ***

I want to hear how you manage working and caring

You will take part in a face-to-face interview lasting approximately 90 minutes.

For more information, please contact:
Lorilee Maldonado
Lorilee.Maldonado@WaldenU.edu
Call or text: 972-352-8416
(Doing so does not obligate you to participate)

Appendix B: Recruitment Distribution Request

I am a doctoral student at Walden University conducting a research study on Informal caregiving. This study is a requirement for my degree and is not for profit. I am requesting permission to distribute the attached flyer in your facility.

This is a study of voluntary participants. No contacts or requests will be made outside the scope of this study. All personal information will be kept confidential, no identifying markers will be included in the study.

Please sign authorization below to distribute this flyer. Thank you very much for your assistance.

Name of Facility: ____

I give permission to Lorilee Maldonado to distribute a flyer for a doctoral research study:

____
Authorized Personnel/title (Please print)

____
Signature/Date

Appendix C: Participating Recruitment Locations

NAME OF FACILITY	DATE	PERMISSION SIGNED	METHOD	RESPONSES
Medical practice, Dallas, TX	3/2019	Physician	In person	0
Medical practice, Plano, TX	3/2019	Manager	In person	0
Formal caregiver service (owner distributed to network of eldercare agencies)	5/2019	Owner	Electronic/in person	0
Caregiver support groups	6/2019	N/A	Posted on Facebook	1
Medical practice, Dallas, TX	10/2019	Manager	In Person	2

Appendix D: Qualifying/Demographic Questionnaire

1. Do you take care of a person over 71 years in your own home? ______
2. Are you over the age of 21? __________
3. Do you also work outside the home? _________
4. Are you willing to have a face-to-face interview for approximately 90 min? _____
5. Your ID will be kept completely confidential, but I need to record the interview, will you allow me to record? ___

<u>If all these questions are yes, proceed to contact information</u>:

Name: ____
Assigned ID: ____
Preferred method of contact: ____
____
Interview Date: ____
Location: ____

<u>At Interview</u>:
Age: _______ Sex: M ___F ____
Of adults (other than CR in home): _____ # of dependents (other the CR): _____
of CR in home: _____
Work: FT ___PT ____Hrs per wk: ___ Job Role: ___________________
Combined household income: 25-45K ____ 45-65K ____ 75-95 over 95K_______
Age of CR: ______ General Health CR: poor ___fair ___good ___excellent____
Ambulatory ___partial wheelchair ____full wheelchair ___bed-bound_____
Age of CR: ______ General health CR: poor ___fair ___good ___excellent____
Ambulatory: ___partial wheelchair ____full wheelchair ___ bed-bound_____

Appendix E: Resources for Assistance

Support Groups: Facebook support group: Dementia Warriors (also meet in person)
Methodist hospital, Colorado Blvd. every third Saturday morning.
Elder options of Texas: https://www.elderoptionsoftexas.com/

(a) Hotlines: The senior helpline phone number is 855-241-1699 for information on senior care services. The Institute on Aging has a support number—very helpful: 800-971-0016

Websites: The Texas-area agencies on aging are broken into 28 regions; you can find the local office in your area by going to their website: https://txregionalcouncil.org/regional-programs/health-and-human-services/area-agencies-on-aging/
Great online resource: Family Care Alliance: www.caregiver.org
Agencies: North Central Texas Area Agency on Aging: **Phone:** 1-800-272-3921
Website: www.nctcog.org/cs/aging

Area Agency on Aging of North Texas: (940) 322-5281; 1-800-460-2226

This agency has a lot of resources for ICGs: Aging Service Council of North Texas: https://www.agingservicescouncil.org/
National Family Caregiver Support Program: https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program

Respite: Most personal home care services offer respite care. To find out if you qualify for any assistance, go to the Texas website Take Time Texas https://apps.hhs.texas.gov/taketimetexas/what-is-respite.html
Accommodations: There are several adult daycare facilities in the area. Check out memory care facilities; they usually have adult daycare as an option.
Personal Care Providers: There are quite a few, such as Home Instead and Visiting Angels. They usually require 4-hour time blocks. These are all franchise-owned, so shop around and check reviews! You can also use Care.com to direct hire. If you direct hire, Poppins Payroll is a great inexpensive online payroll service that will handle all taxes and filings at a very affordable rate.

Financial Assistance: Best to contact Health & Human Services at https://apps.hhs.texas.gov

Health Information: In addition to the HHS (see above), the ACL is also a great tool (see above)

Legal Aide: Again, check with ACL; they are dedicated specifically to eldercare, and they are the most helpful. Also, there are several attorneys who have free workshops regarding wills, living wills, and living trusts. If you Google "help with living trust" you will find services; most offer free consultations and only charge if you contract them to create a will or trust.

Appendix F: Interview Guide

Greet person, introduce self and explain my role. Go over the informed consent, Any questions? Obtain signature of consents and PHI.

Housekeeping questions:

Name____

Age___________

Gender_____________

Hours work a week_____________

Nature of job: _____________________

Care recipient's relation: ______________________

CR's age: _______________________________

CR's health status: ________________________

How long you have been caring for the CR in your home while working? ___________

Contact information

Are you comfortable to begin this interview? If yes, state "I am turning on the recorder now; remember if at any point you wish to terminate this interview, simply tell me you do not want to continue, and I will turn off the recorder and end this interview."

Intro questions

Tell me about your experience as a dual-role ICG.

How has being a dual-role ICG changed your life?
At home? At work?

(NOT ASKED, THIS IS FOR REFERENCE: RQ1: What support strategies do informal caregivers perceive to be beneficial in managing time conflicts associated with their dual roles as employees and caregivers to an aged family member)

1. How do you feel being a dual-role ICG has impacted your time?
2. Can you give me specifics? At home and at work?
3. Which role has been more affected by time issues, work or home? How? Can you give me an example?

4. How do you manage this?

5. Of what you have shared, what do you think has been most helpful with managing your time? Why?

(NOT ASKED, FOR REFERENCE ONLY: RQ2: What support strategies do informal caregivers perceive to be beneficial in managing stress conflicts associated with their dual roles as caregivers to an aged family member and employee?)

1. Thinking of your dual roles, what are the greatest stress factors?
2. How has this stress impacted your health? Relationships? Work? Being a caregiver?
3. How have you been coping in these areas?
4. How do you cope with the stress?
5. Have you found any techniques that bring the greatest relief from stress?

(NOT ASKED, FOR REFERENCE ONLY: RQ3: What support strategies do informal caregivers perceive to be beneficial in managing behavioral conflicts associated with their dual roles as caregivers to an aged family member and employee?)

1. Time pressures and stress often lead to behavioral issues: anger, depression, blowing up at work, blowing up at your CR, or just feeling like you don't care (compassion fatigue). Have you experienced any of this or similar problems? (Such as?)
2. How would you say the pressures from your dual role have affected your behavior? Can you give me an example?
3. What did you do about it?
4. Have you found ways to manage this behavior?

1. Overall, what would you say causes the greatest strain on you as a DR caregiver?

2. What do you feel has been your coping method to continue to work and care give?

3. Do you think this will allow you to continue in both roles? If so, why or why not?

Is there anything else you would like to add?

Thank you so much for your time. Turn off recorder. Give $25*

Explain next steps: Transcribe, peer reviewer, member checking steps: Agree on how to provide this and why and how/when I will get it back.

*To be given even if interview is terminated

Appendix G: Interview Guide Panel Survey

This is study is being conducted as part of my dissertation to complete my doctorate at Walden University. The purpose of this study is to explore coping strategies working informal care workers use to remain in both the workforce and the role of caring. The participants will be informal caregivers (ICGs) of a family member over the age of 70 living in the same household who have been ICGs for at least 1 year.

I will be conducting face-to-face interviews to answer the three research questions posed in this study.

INSTRUCTIONS:
Beneath each of the research questions (identified as RQ1, RQ2, RQ3 and in bold type) are several questions to elicit information pertaining to the research question. I will not be asking the participants the actual research questions; rather I am collecting data on each RQ.

Please rate each question on a scale of 1-3 for relevance and clarity to understand as follows:

Relevancy:

1-most relevant 2-moderately relevant 3-not at all relevant

Clarity:

1-very clear 2-somewhat clear 3-not at all clear

(Please rate each question in relationship to the RQ preceding it. There should be two ratings per interview question. I have also given a place if you'd like to make a comment.

____

RQ1: What support strategies do informal caregivers perceive to be beneficial in managing time conflicts associated with their dual roles as caregivers to an aged family member and employees?

6. How do you feel working and caring has impacted your time? ___R __C
    a. Can you give me specifics?
        i. at home
        ii. at work?
7. Which role has been more affected by time issues work or home? ___R ___C
    a. How?

b. Can you give me an example?

8. How do you manage the issues you just shared? ___ R ____ C

9. Of what you have shared what do you think has been most helpful with managing your time? ___ R ____ C

a. Why?

(comments:

____

____

____

RQ2: What support strategies do informal caregivers perceive to be beneficial in managing stress conflicts associated with their dual roles as caregivers to an aged family member and employee?

1.Thinking of your dual roles, what are the greatest stress factors? ____ R ____C

2. How has this stress impacted your health? _____R ____C

a. Relationships?

b. Work?

c. Being a caregiver?

3. How have you been coping in these areas? ____ R _____C

4. How do you cope with the stress? ______R ____C

5. Have you found any techniques that bring the greatest relief from stress? ____R ____C

Comments:____

____

RQ3: What support strategies do informal caregivers perceive to be beneficial in managing behavioral conflicts associated with their dual roles as caregivers to an aged family member and employee?

1.Time pressures and stress often lead to behavioral issues: anger, depression, blowing up at work, blowing up at your care recipient, or just feeling like you don't care. Have you experienced any of this? ____ R ______C

2. How would you say the pressures from working and caring have affected your behavior? ___R _____C

Can you give me an example?

3. What did you do about it? ____R _____C

4. Have you found ways to manage this behavior? _____R _____C

How?

Comment____

____

____

Extra questions to expound on any of the above that may need additional:

4. Overall, what would you say causes the greatest strain on you as a working caregiver? __R ___C

5. What do you feel has been your coping method to continue to work and care give? ___R ___C

6. Do you think this will allow you to continue in both roles? ____R ____C
    a. If not, why?
    b. If so, why?

This concludes the interview questions. Please feel free to make any final comments or recommendations below:

I sincerely appreciate you taking the time and effort to help me in this process.

Gratefully,

Lorilee Maldonado, Ph.D. Candidate

Appendix H: List of Interview Guide Evaluators

D. G.	Director of Aging	General program questions
M. B	Author/Speaker	On Aging
F. U.	Director	Care U
B. C.	Regional Ombudsman	Assisted living issues–facilities in Collin, Denton, Wise counties
M. G.	Benefits Counselor	Benefits counseling
L. W.	Ombudsman Program Assistant	Ombudsman, general information
S. W.	Regional Ombudsman	Nursing home issues—facilities in Collin, Ellis, Hunt, Kaufman, Navarro, Rockwall counties

Appendix I: Instrument Panel Analysis

RQ1	**P1**	**P2**	**P3**	**P4**	**CVR**
Q1					
RELEVANT	1	1	1	1	1
CLARITY	1	2	1	1	0.5
Q2					
RELEVANT	1	1	1	1	1
CLARITY	1	3	1	3	0
Q3					
RELEVANT	1	1	1	1	1
CLARITY	1	1	1	1	1
Q4					
RELEVANT	1	1	1	1	1
CLARITY	1	1	1	1	1
RQ2					
Q1					
RELEVANT	1	1	1	1	1
CLARITY	1	1	1	1	1
Q2					
RELEVANT	1	1	1	1	1
CLARITY	1	1	1	1	1
Q3					
RELEVANT	1	1	1	1	1
CLARITY	1	2	1	1	1
Q4					
RELEVANT	1	1	1	1	1
CLARITY	1	1	1	1	1
Q5					
RELEVANT	1	1	1	1	1
CLARITY	1	1	1	1	1
RQ3					
Q1					
RELEVANT	1	1	1	1	1
CLARITY	1	1	1	3	0.5
Q2					
RELEVANT	1	1	1	1	1
CLARITY	1	1	1	1	1
Q3					
RELEVANT	1	1	1	1	1
CLARITY	1	1	1	1	1
Q4					
RELEVANT	1	1	1	1	1

CLARITY	1	1	1	1		1
Q5						
RELEVANT	1	1	1	1		1
CLARITY	1	1	1	1		1

RELEVANT TOTAL = 14/14= CVI 1
CLARITY TOTAL = 11/14= CVI 0.78
TOTAL CVI = 1

Appendix J: Pilot Study Complete Results

Coping strategies working informal (not paid) caregivers use to manage both caregiving and working.

My name is Lorilee Maldonado. I am a graduate student in the Health Sciences program at Walden University. I am studying the ways informal (not paid) caregivers manage various stress factors associated with working while providing care to an elderly person.
If you are an informal caregiver who is working and providing care to an elderly person living in the same household with you, you are invited to participate in this research.

This study takes approximately 30 minutes to complete and is done entirely online. All of your answers will be kept confidential. Your answers will not be connected to any of your personal information. Participation in this study is voluntary and there is no compensation for doing so. You can also end your participation in the study at any time. No identifying information will be obtained, responses are completely confidential, and no one will contact you for additional information. Please be aware that some questions could cause emotional discomfort, feel free to skip any portion of this survey for any reason.

To participate in this research, please click on the link below

Q1: How long have you provided care to an elderly person in your home (Answered: 16 Skipped: 0)

1-3 Years	7
3-5 years	3
5 or more years	6

Q2: How has being an informal (not paid) caregiver affected your time with:

Work:

- Very much
- Luckily, I can work from home, but I feel like I’m not focused on my work as much while also not completely giving the kind of care I would like.
- frequently tired
- Frequent unpaid time off from work.
- Frequent days off and flex hours
- Use vacation days for Dr appts
- Very difficult to work outside the home

- I had to quit my paying job to take care of my mom
- Have taken PFL and now work PT. Major decrease in income. Very challenging financially.
- tired
- It didn't affect my time to much, I had my husband's help.
- had to cut back on time away from loved one..working part time or having another caring person available for the safety and wellbeing of my loved one..
- Straight from work to take care of my mother
- Take moderate time off; perhaps up to 10 hours every 2 wks
- It left me some tired days or being distracted hoping everything at home was ok.
- Minimal

Family:

- Very much
- Not much.
- Stained relationships
- unpredictable day to day events.
- Not as much time with children and grandchildren
- Hasn't
- Have a very small family. Not much support
- I say no to most events as my mother cannot be left alone. My kids are growing up without me.
- Caregiving for mother, so with her every day and night. Brother visits 2-3 times month for 2 hrs. Strained relationship because he does not help as much as needed.
- less time
- We didn't see family much, hard for her to get around.

- the illness of my loved one brought close family members together more often...but time with distant close family was severely limited..as i could not go see them as often as i would've liked
- My daughter became angry that I chose to care for my mother instead of spending the time with them
- Little to no time
- We knew what we were getting into, so we knew we'd have stressful days, but overall, it was not terrible.
- missed out on some special occasions; mostly not being available to other family members

Social:

- A little
- Sometimes I felt guilty going out but knew that I needed to for my sanity and to be mentally healthy for my mom.
- lack energy to go out
- Much less time for social events.
- DO not have one
- Limited social life
- Has really limited my social life
- No to just about everything.
- Drastically limited. Rarely go out socially because need to provide meals and medicines. Can't leave town or be gone overnight.
- no time
- We have lots a sweet friends, sometimes we would take her with us. Other times we would stay home or be gone for a very short period.
- my social life was enriched by being a part of what brought joy or needful social outings to my loved one..but my own time and energy to go do what i would like to do was forsaken for the greater good. most times. and i think i am the better for it...
- Not much time left for others
- I have no social life

- We had a lot less of a social life or took our elderly person with us.
- minimal

Q3: How have you best learned to cope with these time pressures? (Answered: 16 Skipped: 0)

- Prioritizing and planning ahead as much as possible. Accepting help when it's offered. Asking for help.
- Work out and do things for myself. Massages help.
- launching a business
- Share the caregiving load with other family members—siblings, children, nephews, and nieces.
- Scheduling time to do the things needed
- Meditation
- Plans have to often be changed, so I always just take my time
- Keep going forward and saying, "it is what it is."
- Prioritize and reduce commitments. Do best as possible but always feel stressed, late and behind in work responsibilities, and have had to let go of many personal responsibilities.
- think what is in the best interest of my parent
- Just had to realize this was the norm for us especially since it's our loved ones.
- having loving support and help from family and friends..and letting go and letting God. having faith .. ..or trusting that God is my helper too...and that love is what matters most..b/c. this too shall pass!
- I continue to keep a date night (once a week) with my wife
- Thankfully, I have very supportive supervisors and I have filed for FMLA at work.
- You start a little earlier getting ready and you don't try not to get upset if things get cancelled.
- go into survival mode; compartmentalize

Q4: What do you feel affected most by stress associated with managing both work and caregiving? ranked 1-4 with 1 being the highest. (Answered: 16 Skipped: 0)

–	**1–**	**2–**	**3–**	**4–**	**TOTAL–**	**SCORE–**
– Physical health	8.33% 1	33.33% 4	41.67% 5	16.67% 2	12	2.33
– Financial pressures	25.00% 4	25.00% 4	25.00% 4	25.00% 4	16	2.50
– Relationships	13.33% 2	33.33% 5	20.00% 3	33.33% 5	15	2.27
–	43.75% 7	12.50% 2	25.00% 4	18.75% 3	16	2.81

–	**1–**	**2–**	**3–**	**4–**	**TOTAL–**	**SCORE–**
Mental health						

Q5: Which role do you believe causes the greatest strain? (Answered: 16 Skipped: 0)

Work: 6.25 % 1 response
Caregiving 93.75% 15 response

Q6: What have you found provides the greatest relief from this strain? (Answered: 16 Skipped: 0)

- Asking for help from family and talking with my employer about my situation.
- Employee assistance program through work
- Maintaining a social life.
- working on my business, biking, travel, and walking
- Adequate sleep and good meals.
- Doing things I enjoy away from caregiving responsibilities
- Yoga
- When I am able to talk with another caregiver
- Laughter, emotional support, periodic breaks (respite care)
- Not much yet. Need more money and/or time.
- talking on the phone
- Truly being selfless and reminding yourself how much that person did for you or your spouse your whole life. Knowing that’s what family is supposed to do for you loved ones when they get old.
- getting space and time away. Getting rest..
- When things run smoothly it removes most of the strain more is removed when the caregiver is able to get away and relax.
- Giving myself quiet time at night, after I put Mom to bed
- Help from family
- spending time with family

Q7: Time pressures and stress often lead to anger, depression, and outbursts at work or home. Have you experienced any of these or similar problems? If so please provide a brief explanation (Answered: 16 Skipped: 0)

- Yes, for sure. I’ve experienced all of these. Usually I can overcome these feelings with communication with my family. My husband has been most helpful pulling me through the darkest times.
- I’ve been short with my partner and impatient. Also impatient with my mom and dad and brother
- n/a
- Frequent internalized anger—I try not to externalize my upset at or with others.

- Yes, there is never enough time to get everything done. I feel divided between my obligations and responsibilities. Everything I do, while it gets done is not enough or not good enough.
- Anxiety not anger
- Yes, angry outburst at a dear friend. I apologized and she understood
- Yes, when the pressure builds, and there are no means to release or 'lift the lid to let the steam out', it is extremely difficult to manage and to express happiness, positive behaviors, or to even be pleasant around.
- I get frustrated at times and have to walk away and let it go. More harmful to hold on to it. Sometimes feel alone in this process which makes me feel slightly depressed or sad at times.
- Nothing yet
- It's hard when your taking care of elderly and being patient is so hard when trying to get them to do something and they refuse. I [had] a situation where it was time for a bath and I couldn't get Memaw to get up for her bath, so I tried to be stern and I got slapped by her. I had to walk away and cool off and tell myself "she's old and can't help herself".
- if i was believing that i was being victimized by the tyranny of the afflicted..(deliberately)..and felt powerless to take care of my real needs..i was angry..and frustrated by the inability to communicate in a loving, mutually respectful ..and self-nurturing way...to get free of the bondages imposed on my life..
- When you have too much on your plate it causes pressure and stress which lead to anger, depression, and outbursts. Time is needed away to renew strength and gain new perspectives.
- Yes, I have. Outbursts, or raised voice at work and screaming at the top of my lungs at my mother, who I care for. She was getting very argumentative about wanting to go home, and I had already tried daily living centers and home health aide. I was driving into work with her in the car with me, and during the course of our argument, I slapped her in the face. I have never ever been violent, not even punch a pillow when I get angry.
- Sure, if you are the only one giving the care you can get resentful. If your elderly person has dementia sometimes repeating your self gets tiresome and you have outbursts that you then regret and feel some pangs of depression.
- No, thankfully.

Q8: Where do you have more difficulty controlling yourself? (Answered 15 Skipped: 1)

Work 13.33 %	2 responses
Home 86.67 %	13 responses

Q9: How have you found ways to manage this behavior? (Answered: 16 Skipped: 0)

Work:

- Talking with my boss. Using the employee benefits to find resources
- Stay on schedule.
- deep breathing, meditation, lunch time walk

- Sleep enough to focus.
- Meditation
- Practice deep breathing
- Take all available breaks, go for a walk, get fresh air.
- Have reduced work hours and take more sick time as mental health wellness time.
- na
- Deep breaths think happy thoughts.
- work is a relief sometimes..and financially needful...
- Don’t take home issues to work.
- Realize what I had done and try to remind myself that I’m doing the best I can and try to become aware of when an outburst might happen.
- Take a walk, deep breaths
- separate the two

Home:

- Talking with my husband and friends
- Have a routine
- biking walking
- Eat well at home. Hydrate frequently. Adequate sleep.
- Walking away to get time alone even for a minute
- Listening to music
- Practice deep breathing and walking
- Plan for ‘me time’ if possible, organize chores and meals to create pockets of down time.
- Try not to dwell and just let stuff go, not carry it with me.
- na
- Deep breath and think how I would feel if the roles were reversed.

- getting outside..doing physical work helps burn off frustration...prayer..and distancing myself for a while...having a caring listening friend..or sister is a God send..knowing what your feeling is totally ok..but knowing how to handle it is something else..

- Don’t take work home.

- Not really, but have realized when an outburst had happened, what caused it and try to tell myself to take a few breaths before reacting.

- Music, alone time, get out and drive

- prayer and reading to take mind of problems

Q10: Overall, what do you feel has been your best coping method to continue to work and provide care? (Answered: 16 Skipped: 0)

- So far just support from friends and close family members. As it gets harder I will need more help from professionals
- Praying and spending time with mom ultimately.
- circle of support
- Being with family for support.
- Taking time away for me to mentally destress and breathe.
- Use of Wyze cam to see what going on when not home
- To think about the very good quality of life that my family member has because I am the caregiver. I walk a lot, have a cat and dog and am grateful...I just take my time
- Patience, love, support from family, and friends in support of in-home care!
- Reducing unnecessary commitments. Saying no. Meditation.
- Long term goal realized
- Love, absolutely love!!
- Support of others, family, Friends and.. time away to rest and clear the mind and emotions..
- Go to God with everything before it gets to be Too much, forgive quickly, and don’t hold a grudge. Ask God for love to cover all involved.
- Realize that I’m only one person and the sole caregiver for my mom and try to take a deep breath or two before responding or reacting if I feel myself getting angry or frustrated.
- Humor, understanding the situation and that it is not permanent, and I would want to be treated with respect should I ever need a caregiver.
- Knowing that this too shall pass. As my father would say, “It is what it is”

Appendix K: Study Participant Log

ID	Scheduled interview date	Consent sent	Consent verbal	Consent signed	Gave copy of consent	Interview exit explained	Gift card	Member check sent	Member check returned

Appendix L: Audit Log

ID	J1C1/P1	T2S2/P2	C3D3/P3	T4H4/P4	S5H5/P5	C6H6/P6	E7C7/P7	V8S8/P8	A9C9/P9	A10M10/P10	removed	J12D12/P12
name	J C(file A)	TS (none)	C C D(File B)	T S H(file C)	S H (file D)	C H (file E)	E C (File F)	V S (File G)	A C (file H)	AM (ph Rec)	R W (deleted)	J D (File I)
Age	67	55	57	48	60	62	32	40	31	60	NA	62
CR age	88	87	80	73	82	91	84	72	83	82,81	NA	91
phone	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx	xxxxx		xxxxx
email	xxxxxx@yahoo.com	xxx@mindspring.com	xxxxr@yahoo.com	Tracye07@att.net	sxxxxx@courts.az.gov	Cxxxx@gmail.com	Exxx@gmail.com	Vsxxxx@gmail.com	axxxxx@yahoo.com	exxx@yahoo.com		Jxxxx@Gmail.com
date of Iv	4/27/19	7/12/19	7/15/19	7/25/19	7/28/19	11/7/19	10/31/19	1/11/20	1/16/20	2/1/20	2/25/20	3/20/20
location	my house	Richardson Lib	School	rockwall lib	her home*	her office	her office	coffee shop	her office	her home	his home	my office
consent	X	x	x	x	x	x	x	X	x	x	X	X
transcribed	done	done	done	done	done	Done	done	done	done	done	not done	done
member ck sent	x 3/30/20texdt	x 3/30/20	x 3/29/20	x 3/29/20	x 3/30/20	x 3/29/20	x 3/29/20	x 3/29/20	x 3/29/20	x 3/29/20	removed due to mother passing	x
returned	4/2/20	No respons	No respons	4/2/20	3/31/20	ok	ok	No response	bad email	4/3/20		x
thnk u $	X	x	x	x	x	x	x	x	x	x		
anal #1	x	x	x	x	X	x	x	x	x	x		x
Anal #2	x	x	x	x	x	x	x	x	x	x		x
Anal #3	x	x	x	x		x	x	x	x	x		x
complete	x	x	x	x	x	x	x	x	x	x	exclude	x
PR sent	x	x	x	x	x	x	x	x	x	x	exclude	x
PR rtn	x	x	x	x	x	x	x	x	x	x		x

Appendix M: Sample Interview Transcript

Transcription #5 S5H5 (CR health: poor, copd, emphysema, heart issues CG , 5 yrs, age: 82)

I: Tell me a little bit about your experience as a caregiver just in your own words.

SH: Well when she first came I wanted to spend every moment with her because I didn't know how long she would live. They gave her a year to live and we're going on 5 years. I don't have a lot of backbone so she is real (interruption). Growing up, both my parents were very strong. We never questioned them or nothing. I took that as, okay, we don't cross that boundary, so it's really hard. My dad told me when she moved in with me that I'm going to have to switch those roles. Every couple of years, he would ask me "so how's the role switching going?" and I'd say it's not happening! It's never going to happen because she wants what she wants and wants it her way. It's very hard to talk to her as we have different opinions. She came in and I gave her my master bedroom, master bath, and another bedroom of my daughter's. She's been wanting to move from there to the living room and basically take over my home. I finally had to say "nope, you have those two rooms and the rest of the house is mine." She got very offended but it's like if I let her she will just swallow me up.

She's been able to take care of herself while I'm at work, and anytime my sister would come over once in a while and check on her. My sister went through a whole year of being on prescription drugs, so between that and my mom I had no time to myself at all. I still don't have time to myself. It's hard for me because they don't ever consider that I work full-time, I clean all day Saturday and Sunday, I'm in church all day, which is never taken into consideration. What I need is some "me time" and my mom will say "you need to go do this, you need to take some time," but I go downstairs for 5 minutes and then she's calling me, "What are you doing down there?" HAVING "ME TIME"!

I don't want to hurt her feelings, but I'm finding that we don't have a lot to talk about anymore because we both don't do anything. Before she lived in another state and I would call her every Saturday and talk to her and make her a part of our lives, but now that we live together, nothing is happening in either of our lives. I quit doing a lot of church activities and going out with friends. I just quit because I thought she was going to die in a year and this was only a season, but the season has been longer, longer and longer. I don't want her to die, but I kind of need to have some hope to get back to my life in order—without hurting her. My sister and brother said, "you let her move in so that's your problem" when they were wanting me to have her move in and not worry about probating my mother's estate in another state, which now is kind of stupid.

I think my biggest mistake was letting her move in. Right now, she needs somebody to help her, but the last 5 years she could have managed on her own. She would have struggled, but I would have come over and brought groceries and took her places. She would have felt more independent. I know she struggles with not being in her own home and not having her own space. She felt like there was nothing left in life. It feels like both of our lives have just stopped and she has nothing to live for. Although she does not express she has nothing to live for, she just sits in her room all day and I try to pull her out to break the boredom. She struggles getting in the car because she can't breathe. Her chest tightens up and it's hard to get her to go anywhere now, but I felt I took her independence away by not making her get a home. She came from a place and the property values here were much higher, so she was going to have to get a loan. We just took the path of least resistance and allowed her to move in.

I haven't been able to go see my grandkids much and they live an hour and a half away. They don't want to come down because one of them is always sick and they don't want to get her sick. I feel like chunks of my life are being taken and I haven't been able to really enjoy those times in life. My grandson is 7 now and I took her in when he was 2 years old. I've done two or three things with him so that's about it. I don't know what I'm going to do when she gets really bad and needs a full-time caregiver.

I: So talking about time you said that you go downstairs. How are you coping with all of the pressure? Do you feel that it has impacted your time most at home or at work? How has work been affected by your role as a caregiver?

SH: I've taken family medical leave whenever she has a doctor appointment. That's pretty much covered. I have to use 40 hours in my vacation time and then it kicks into my catastrophic time and we've never gone past the 40 hours. So basically, I've given up a week's vacation each year. That has been wonderful because she has not needed more care. I live downstairs in my bedroom because I had been living upstairs. Her TV was so loud that I could literally hear it downstairs, but I could shut the door and shut it out. When I was sleeping upstairs, she wanted me to stay there but I had to just say: "No Mom, I'm not getting any sleep. You keep waking me up." It was an escape to go downstairs and get away for a few moments. She can't go down the stairs. When I'm downstairs, I can't rest because I'm thinking "I wonder what she's thinking up there. Does she think I'm ostracizing her? Does she think I'm ignoring her," which I don't want her to think! I used to quilt, and I can't even concentrate anymore because I'll be right in the middle of something or trying to figure something out and she'll call me, so I just finally say "forget it." I can't even do that—I guess I could if I really forced the issue.

I: What do you do to get your mind off her?

SH: Well lately, within this last year I've driven somewhere. She believes I'm going to church. I will drive and most of the time I do go to church, but lately I don't. I just have to go sit in a parking lot and destress. I just want to go somewhere and talk to a friend or just get out of the house. One time, I didn't go to work one day. I called in and took the day off and I'm thinking, "Oh my gosh! What if she calls me at work, what am I going to do? I mean it's terrible because I feel like this little [sense of] playing hooky, but it's the only time I get for sanity. I think I'll drive to see my grandkids, which is an hour and a half away, but what if I get into an accident and caught lying to her by not admitting I'm not going to work? I don't want to hurt her feelings. I guess I should just be honest, but it would really hurt her, and I don't want that. Then there's me, I've just been pleading with my siblings, "please just help!" It's so bad that I can go in a room to vacuum and she will not leave the room. She will sit in the chair and then I say, "mom would you please go in the other room so I can vacuum under the chair." She'll get up on her bed and watch me and dissect everything I do. "You don't polish that without... you don't do that...."

and I think, “I’m the one doing it, okay. You can’t do it, so don’t complain about the way it’s being done.”

I don’t want to shampoo the rugs because I’m afraid she’s going to slip because right past my bedroom there is tile and she’s going to go in the kitchen with wet feet. I don’t want that, so I ask my siblings, “Could you please just take her for a week so I can get these things done at my house?” She’s broke in my blinds, destroyed my carpet, had Direct TV put huge holes in my siding. She had the cable person come, and you know I’m a single parent and I don’t know how to fix that stuff and now the dog has destroyed the stairs going up and down. I’m just like “oh my gosh! How am I going to pay for all of this?” My microwave broke, it’s a year-and-a-half year old and I can’t get it to work. It either keeps tripping or she keeps doing something that’s making it not work. I could just go out and flip the switch but now that’s not working at all. I have no idea if she’s left it on thinking it’s a timer and it’s actually cooking inside. I don’t know. I’ve come home and she’s had the burners on. She’s pretty good about being cognizant, but sometimes she’s not. I think “don’t blow my house up,” but in my mind, I’m constantly going over this whole thought process of “you’re dying. I don’t want to die alone with you.” I don’t know how to put that in words.

She feels like she’s dying, but then she never takes into consideration that she’s sucking the life out of me. It’s not that she’s sucking the life out of me, but my whole life has changed. I have sacrificed a lot to make her comfortable and be there for her. I don’t know if she realizes how much I have sacrificed. I have no friends, have nothing, and just serve her, and then when you die what am I going to have? I’ve disowned everything that I knew before in my life. The best coping mechanism is to get out of the house away from the situation, rethink things, go do something fun. When I have taken off my sister has come over. I went to Alaska for 2 weeks. She said “I’ll be there every night”; she came over only one, the first night I was gone, and left my mom alone the whole time. And thank God my mom can make her own meals, but she’s getting to the point now that’s really hard and she’s struggling with that. We try to make chili and put it in freezer containers, so we have three other containers she can just pull out of the fridge. We did that with marinara and turkey soup. It’s getting to the point where she can’t even stand. She was sitting down trying to make a salad because she didn’t have enough air to stand and make it.

I: How long ago was it that you took off and went to Alaska?

SH: That was probably 3 years ago. I went to Hawaii last year for 1 week.

I: Do you try to take one trip a year?

SH: Yeah, I do try, but you know, two times 2 weeks this year. I told my mom ahead of time, “look, I’m going to take this week off so we can do something, if you want me to drive you somewhere so you can see your sister, I will be happy to do that. If you want to stay there I’ll stay with you,” and she’s getting to the point where she doesn’t want to go and expects everybody to come to her. She complains that my kids don’t call, but I ask her “when’s the last time you called?” And she says “I just don’t do that. I don’t know their schedule.”

Reflecting back, as I grew up we had kids and everything and I was the one who was constantly calling both of my parents. They both expected me to come to them. They don't reciprocate, and my mom left when I was 20 years old. I think the only time she ever came back was one time when I had my firstborn. I don't think she even realizes that's kind of painful for me looking back. You know, she rarely called, and we always went to her, but that's what they [my parents] expect. That's been the history, I guess. My boss has been wonderful, you know, all I have to say is "my mother has a doctor's appointment" and you know, I'm fine, and I have enough vacation time that 1 week I'm taking.

But getting back to the vacation, she will just sit there all week long and do nothing and that drives me crazy. It's like if I want to go to the store she'll say "you don't need to go to the store." Basically, a mother telling her sixteen-year-old, "no you don't need to go" and that drives me crazy. We just got into an argument. Yesterday my daughter's mother-in-law had surgery and she wanted me to go by and see her and my mother said, "you don't need to go by and see her because she just had surgery and she's not going to feel up to it, she just wants family around" and I had to look at my mom and say, "I am family, mom! I'm her daughter-in-law's mother. I am family and I want to be a part of that family." She's kind of really controlling like that—"no, you don't need to do that."

And for the longest time when she first lived here the plan was if something happened to her I would buy her car and give each sibling a third of what it's worth, but when my sister went through all of her trouble she kept sucking my mom for money. I told my Mom I had a solution, i.e., let me pay her now while you're alive and then you can transfer the title over to me. I did that for 10 months and then I paid my brother out, and then my mother didn't want to sign the title over to me! I don't get it! So finally, when she got her insurance bill for $600 she decided I could have the vehicle, but she still considers it her car! I try not to tell her when I'm doing stuff, like when I'm getting new tires or whatever, because she'll say "no, you don't need to do that," and I'll say "yes, I need tires." I don't want her worrying about me spending money, and my sister is the type she'll just take whatever she can get. She just loves it when my mother gives her $500 for her birthday, and a month later she'll give me 500 and I hate it!

I don't want to take it, and I've told my mom you need to respect my wishes just as much as my sister. If my sister wants it, fine, but I don't need it. I get along fine without it. I just feel like I want to help her [my mom]. I don't know, it makes me feel cheap, like she's paying me to do this. Now a birthday is a different thing. She's paying all the utilities because she uses so much electricity and water with her concentrator and has a ventilator on at least 6 hours a day. She wonders why she can't help. She said, "because you're paying the mortgage," which I understand, but if you weren't here I'd be paying it all anyway. I appreciate her trying to help me, but at the same time she has to pay for everything but the mortgage, which I don't think is right. It has kind of been a battle on that, and she's relenting now finally. To me it wasn't real service and real caring when somebody is giving back to you, but maybe that's her way of showing her appreciation to me.

I: Going back to the relationships, you said a little earlier you've sacrificed a lot and she doesn't realize how much. I've given up my girlfriends, and you mentioned earlier your siblings not helping you out. What about your relationship with your own children?

SH: Yes, it's affected them. They typically resent that I'm doing it, yet, at the same time are proud, but they see that my life has changed switched gears, and everything is about Nana and not about going and doing. They're concerned about me and they've seen a decline in my own health because I don't get out and do stuff. I was active before and moving. I go and sit 9 hours at work and then come home, have dinner with her for a half hour, and then she wants me to sit in her bedroom with her. Half the time she falls asleep and then she gets mad when I get up and leave until 9 every night. I've been doing that for 5 years and I'm exhausted.

There's good days and bad days. I came home the other day completely exhausted and slept 12 hours. I just passed out. I just felt all day long I was just dragging, so I went to bed that night at 10. I didn't get up until 9:15 the next morning and I said "whoa." I don't know, it's just everything, we worry about everything they do. I could retire right now, but I can't afford the medical and my mortgage so if something drastic happened to her she doesn't want to be put in a home, and I don't think I'll ever put her in a home, but I may have to face the situation. Maybe she could help pay for my medical. I think I cannot make that lifelong decision with what's happening right now because I must consider myself the rest of my life. If I leave the county and lose their insurance it's like $500 a month, which is kind of what I'm leaning towards doing, but if that gets cut short I may not have the ability to get that insurance if I quit and return to work. I really don't want to come back when I retire. I want to go live my life. Part of that is raising three kids on my own, and finally when one went off to college and then I was helping her get her wings, my mom moved in. I feel like I've always been taking care of someone other than myself.

I: If you're retired will you be home all day long?

SH: Yes, I don't think I could do that because it becomes a prison. My home becomes a prison, like I can't get out, I can't say I'm going to the store, you know, it's just an argument about everything. I say black, she says white. I don't even know if she really realizes. I talked to her a little bit about being negative all the time. It crushed her because she's constantly negative, constantly talking politics. We went to lunch today and she was complaining about the prices. I'm like "crying out loud mom, you've got more money than you've ever had in your whole life and you're complaining about $2 more for a meal?" You know, it just wears on you! Tell my mom, "don't you just get tired and sick of it, like listening to the news all the time? They just go over the same things all the time! Don't you get tired of it?"

It's just negative. I didn't have a TV for 18 years. I could have cared less about having a good TV and she'll say "don't you want to watch this movie with me" and I'll say "no, I don't want to watch any TV." She looks at me like, why not? My kids brought that to my attention. They said "Mom whenever we go visit Nana we just watch TV all week, we wouldn't do anything, we'd just watch TV." She's been doing this for years even before she got sick.

The other day my mother said that was her mistake of being so connected to her family that she didn't have friends outside her family. When they all started dying off, she realized she didn't have anybody. She is down to one sister and a friend from high school that she calls. Every time the lady calls her she says she was just thinking about calling. She rarely calls anyone and complains nobody calls her. I've told her when she'll think about her friend, I'll say "why don't you call her?" "oh yeah, I need to," and then her friend beats her to it. I don't know if it's a generational thing that she thinks she's interrupting. I just said "Mom, if she can't talk to you leave a message and she'll call you back," but she refuses to call.

I: How would you describe how your behavior has changed from the stress and handling both roles?

SH: Road rage! Yeah, I just feel like the whole world is going so slow. I'm trying. It's like I'm all sped up trying to get places. It hasn't been good. I've really had to pray. I've had to say, yeah, there's times I don't even feel like I'm a Christian half the time because I have these emotions, these feelings of wanting to have time to myself, and I'm thinking God paid the ultimate price and gave everything and here I am complaining. I'm blessed I have my mother in my home, but I just feel squeezed sometimes. I told my friend don't worry about me for 3 months when my mom dies because I will probably be sleeping [laughs]. Because I'm exhausted. But they feel the same way we do. I think they feel humiliated that they can't do for themselves anymore. My mother has been in fear that she can't even walk from the bedroom to the kitchen anymore. She is worried and scared that this disease is taking her breath from her. For a long time, she was scared about eternity, but she got her heart right on that issue. She still has a lot of doubts.

I: How do you manage all that behavior, the road rage? I'm hearing guilt, exhaustion, depression.

SH: I have to hit the reset button and tell myself, this is a season and when she's gone she's gone for good. I also must stand up and say "no Mom, I am going." Like yesterday, she did not want me to go see my daughter's mother-in-law. I told her "I'm not going today." I'm giving her time to be at home and get situated, but I will check in on her tomorrow. And another time she didn't want me to go to the store and I said: "I am going to the store." You see, my mother's never had that for me. I've always been a goody-two-shoes and so I don't think she realizes how much no freedom feels anymore on my part. I have to sit there and think, she sits there all day long by herself doing nothing, so when I get home she wants to come spend time with me. We don't even say much to each other. We just go watch TV. Just that I'm sitting there with her brings her comfort, and I'm more like, can't we talk about stuff, and I'm like, there's nothing going on in my life.

I'll ask her about she was younger and stuff like that, and that's been interesting. The only thing I would do different. We talked about work, and that gets her mind off other stuff, and that helps me. She's wise on some things, or she'll laugh about something that happened. I try to bring out the positive. The only thing I would have done different, and it's only because I've gone through it, is I would not have let her move in right away. At the time she was really sick, so it was the deciding factor. We had our little differences about where things should go in the house. I have so much stuff in my house it looks like a secondhand place because she will not get rid of anything. Will not! She has clothes, probably 11 tubs of clothes from 40 years ago and refuses to let go of them, nor do they fit her! I sit there and ponder why? Let them go! She won't and it's crazy. My siblings are like "when she dies, we will come up here and help you" and I'm like "yeah like you've helped me in the last 5 years." I'm just going to open up my house and say "get what you want and leave whatever you want."

I: What would you say overall, looking at time, emotional, and behavioral stress issues, cause the greatest strain on you as a working caregiver?

SH: The biggest stress for me was when my mom moved in. She was constantly riding me about my weight, my hair, and about everything about me. I'm the one out of all the three siblings that is here. My brother is a workaholic. He has not been up here since he retired about a year ago. I thought after he retired he would come up once a month. It would make a world of difference for my mom's attitude. The biggest thing was the emotional part of it. I told my mom once, "Is there anything that you do like about me? I'm responsible and own my own house." My sister has blown all her own money, has no place to live. I told my mom, "You would think that character is more important than the outward," and after that she kind of relaxed a bit on me, but still has her tendencies.

I'll just look at her and say "don't start" because I can tell by the way she's looking at me. She's looking at my shirt or this and that and she's about to say something. I'll just say "don't" because she literally, for the first 6 months, has destroyed everything in me. I would tell my friends as I was driving to work. I'm in tears driving to church because of the things she said. I know she doesn't do it intentionally to hurt me. That's kind of where I pushed it aside, because if I knew she was being vindictive and mean, it would be another thing, but I know my mom well enough to know she's not mean like that. Although sometimes I would take it like that. I think "man, why she doesn't she just stop! Why isn't she just happy that I opened my home up to her?"

It almost made me feel like "I'm not good enough for you," and she was ashamed of what I looked like. I would be emotional because I deal with it. I would wonder if it was right for me to be thinking like this. I'm a Christian! I never wanted any harm to come to her. I told my dad that you realize living with somebody how selfish you really are. I kind of took more of the blame than my mom. As a Christian, I felt I should have had the upper hand. The tenacity to know right from wrong and know that character does mean more than the outward appearance. I think that's the biggest thing, is the emotions for me.

I: What do you feel has been your coping method to keep going?

SH: I know nobody else will step up and do anything. I told my mom that I love her, and I would be there for her. She has nobody. And it's at the point now where she gave her inheritance to my sister and my brother and myself. I put it in a bank account and said "Mom, that's your money and as long as you're alive will be your money. If you need it for anything we're going to draw from that," and for a long time she felt like I was being insensitive or ungrateful. I told her probably two weeks ago "Mom, that's not my money." I don't consider that my personal money. I'm grateful for what you've done, and you've helped me with utilities and stuff but that's yours. I think she was going through this thing that I was feeling ungrateful with the money that she's giving me to put in the bank but from the get-go I explained to her this is yours.

So that's the way I cope, is to get away. I go up to see my kids for 3 days, but then I feel guilty because I'm leaving her. Then I feel guilty that I'm leaving my kids and not spending time with them. My life would be completely different without her around. Even when she lived in a different state and had her own home. She feels like that's her home and mine is mine. I could come and go, where now I can't just come and go. I have someone else that is worrying about me concerned about me and you know, I can be 5 minutes late from getting home and she'll say "where have you been," and that will just get on me because I don't feel like I can even stop at the store without calling and saying "hey I'm stopping at the store" and she'll say "why are you stopping at the store?" Etc.

I: Do you think you're going to be able to continue on in this mode for much longer?

SH: I think I will. I have to be constantly resetting myself with a lot of prayer and go back and say this is a "season." I need to just realize when it's unbearable to go on vacation. Somebody's going to have to watch her, and that just forces my siblings to help, but at the same time they tell me that they're going to help, but then they don't. My sister has gotten much better than she was, but now she's moving an hour and a half from here. I'm not going to have anybody around now. My brother lives 2 hours away and she lives an hour and a half away. When she gets put in the hospital or whatever I will use my catastrophic hours. I have 400 catastrophic hours and I have 12 weeks of family medical leave I'll just try to balance it. And I know, part of it is me because I have that personality

I: Do you feel like your personality is still that? Do you feel like you're getting a little stronger?

SH: I'm getting a little better. She can push me, but at a certain point I'll push back. Still in my heart I say "why do you have to push me? Why can't you just stop?" Then I realize I need help. I'm only one person. My mom is a clean freak, and I was for years until about 7 years ago, and then I decided I don't have the energy to do all that now. I clean her floor, bathroom, and kitchen and if my room doesn't get clean for 2 weeks I'm not going to worry about it.

You just got to let things go. I think you reach a point where you just can't take anymore, and you just have to stop. I go downstairs, take a deep breath and pray and ask God to help me and then I go back up with a better attitude. She might say something else which upsets me, but I walk away, and I ask God to help. I think about giving to her and not putting myself first. My kids get really upset with me because they say "mom, there's not going to be anything left of you when Nana passes."

My daughter got into it with my mother and my mom was trying to press the issue and my daughter said "no, you have no idea what my mom has done to let you stay here. Don't make it worse by being negative." I didn't think they'd have a relationship afterwards, but my daughter persevered. She can still be mad at me, but I'm still going to love her. My mom was offended that I didn't stand up for her against my daughter, but I said "neither one of you were listening to me. I tried to break you both up!" I know there's a lot of sacrifice, but I know in the end I'll be happy that I did what I've done.

Concluded interview.

Appendix N: Codebook

Nodes

Name	Description	Files	References
Adjust to role by assimilation		10	74
ACCEPTANCE		10	52
ADJUST		4	7
COMPROMISE		2	4
MARTYDOM		2	5
OBEDIENCE		2	3
PLEASER		1	3
Adjust to role by segregate		10	67
COMPARTMENTALIZE		1	1
ESCAPE		10	37
IMPERSONALIZE		2	8
ROI		4	4
SEASON		7	12
WORK REPRIEVE		3	5
Find support for role externally		10	46
EMPLOYER SUPPORT		4	9
FAMILY SUPPORT		8	19
OUTSIDE SUPPORT		6	18
Find support for role internal		1	1
EXCERCISE		3	6
FAITH		4	15
HEALTH		4	6
HELPING OTHERS		2	5
PEP TALK		3	10
SELF-HELP AIDE		1	2
SMALL PLEASURES		3	6
I don’t have a lot of backbone		1	1
Manage role passive acceptance		10	110
EMPATHY		8	37
JUSTIFIY		4	6
LIVE IN THE NOW		9	20
MAKE HER HAPPINESS A PRIORITY		6	13
NEG TO POSITIVE		7	15
OBLIGATION		7	12

Name	Description	Files	References
PERSONAL GROWTH OPPORTUNITY		2	7
Manage role tangible methods		10	134
COMMITTMENT		6	8
GIVE VALUE		4	6
GIVE VALUE PURPOSE (Nodes)		3	6
Good memory		1	1
JUGGLING		1	2
KNOW LIMITITATIONS		8	24
MAINTAIN CR INDEPENDENCE		5	11
PLAN AHEAD		4	8
PRIORITIZE REAL NEEDS		2	3
SELF AWARENESS		7	19
SET OR KNOW LIMITITATIONS (Nodes)		2	15
STRUCTURE		6	20
TAKE BACK SOME CONTROL		2	5
TECHNOLOGY TOOLS		3	6

Appendix O: Peer Reviewer Final Comments

I think that you have clearly identified significant areas for family caregivers. Among these are their coping mechanisms, the lack of personal “space”, boundary issues, work-life balance, managing feelings of guilt and distress, as well as competing needs of other family members and their own needs. Nowhere in your analysis and excerpts would I think that you were reporting from your own experience. It was a well-reasoned analysis and objective reporting based on the themes that arose from your interviews.

I anticipate in your literature review that you have given the reader and future researchers the background to understand your themes fully. I think that when it is written up that your study will make a significant contribution to family caregiving research as well as the phenomenological method that you used in your interviewing. Mary T. June 20, 2020.