DISSERTATION

FAMILY CAREGIVING, FAMILY DYNAMICS, AND PREPAREDNESS FOR THE TRANSITION TO END-OF-LIFE CARE

Submitted by

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In partial fulfillment of the requirements

For the Degree of Doctor of Philosophy

Colorado State University

Fort Collins, Colorado

Summer 2021

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ABSTRACT

FAMILY CAREGIVING, FAMILY DYNAMICS, AND PREPAREDNESS FOR THE TRANSITION TO END-OF-LIFE CARE

Taking on the role of family caregiver to an adult family member with health or functional needs can be a time consuming, stressful, and physically demanding responsibility, and often leads to adverse psychological or physical outcomes. As family members near the end of their life, their physical, emotional, social, and spiritual care needs may become increasingly complex, and family caregivers are an integral part of providing care and comfort during this time. Yet, individuals providing end-of-life (EOL) care for a family member are vulnerable to additional emotional and psychological stress and strain, and often indicate they do not have the knowledge or skills needed for providing this type of care. Little is known about what factors may help family caregivers feel more prepared for EOL caregiving, or how family dynamics (such as relationships, interactions, and communication) between the caregiver, care receiver, and other family members may affect these feelings of preparedness.

Thus, the purpose of this dissertation was to explore how family caregivers perceive their preparedness for the transition to EOL caregiving and how family dynamics may be associated with feelings of preparedness. To frame this work, the manuscript in Chapter 2 presents the *Conceptual Framework for a Bioecological Model of Family Dynamics and the Transition to EOL Caregiving*. This model is an innovative theoretical approach to investigating the various individual- and family-level contexts that may affect family caregiver outcomes. The conceptual framework provides a tool to examine family caregivers' personal characteristics, family contexts (such as the familial relation between the caregiver and care receiver), factors of time (such as duration of care and hours of care provided each week), and family processes (such as advance care planning conversations) that may be connected to perceived preparedness for the transition to EOL caregiving. The study presented in Chapter 3 utilizes the conceptual framework to explore family caregivers' perceived preparedness for caregiving. Results indicate that overall, family caregivers feel somewhat prepared to provide care to their care receiver but feel not too well prepared for the transition to EOL caregiving, regardless of age, gender, race, ethnicity, or education. The study presented in Chapter 4 builds on these findings and explores how family dynamics may be associated with family caregivers' feelings of preparedness. The results of this study failed to demonstrate an association between the constructs of family dynamics and caregiver preparedness, and several theoretical and methodological considerations are examined to potentially explain these findings. It may be that family dynamics are not well understood in caregiving families, and different elements of family dynamics are important at different stages of caregiving and during the transition to EOL care.

The results, strengths, and limitations of this comprehensive dissertation study should inform future basic and applied studies to advance family caregiving research. Importantly, there is a need to development more valid and reliable measures of family dynamics for aging and caregiving families, and interventions to help families prepare for future care needs and caregiving transitions such as the transition to EOL care. As researchers and practitioners learn more about how to prepare family caregivers and their families for the transition to EOL care, this may improve family caregiver and family-level outcomes, and help families best meet the care wishes and improve life satisfaction for individuals at the end of their life.

ACKNOWLEDGEMENTS

This dissertation would not have been possible without the support, guidance, and love of my advisors, committee, friends, and family. First and foremost, I would like to thank my amazing mentor and advisor, Christine Fruhauf. She encouraged and supported me from day one and helped me build the skills and confidence to become an independent researcher. I appreciate the patience she showed as I worked through my many ideas and plans, and the guidance she provided throughout the planning, implementation, and completion of this dissertation study. Christine's wisdom and experience will serve as a guiding light as I navigate the transition into my own career in gerontology.

Next, I thank my co-advisor, Julia Sharp. Her statistical expertise and teaching ability helped me move this dissertation from a semi-coherent research question to a methodologically sound comprehensive study. I appreciate her example and pragmatic recommendations for balancing work, research, and parenthood. I would also like to thank my committee members, Manfred Diehl, Gloria Luong, and Karen Atler, for their advice, detailed feedback, and recommendations. This dissertation is a stronger product because they were each willing to share their expertise and help me further develop my own understanding of research processes.

Finally, to my family and friends, thank you for your unconditional love, encouragement, and sacrifices. I thank my friends for their encouragement and reminders to give myself grace. And to Ryan, Tyson, Charlie, and Samantha, I would not have survived this endeavor without your support. This dissertation is truly a product of a family effort. I thank my kids for their patience, hugs, and reminding me that "you can do it!", and I thank Ryan for always being my person, and his unwavering confidence in my ability to complete this dissertation.

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CHAPTER 1

INTRODUCTION AND REVIEW OF THE LITERATURE

Family members engage in helping relationships and often provide care to each other across the lifespan. As families age and children become adults, the care-giving relationship becomes more complex. That is, family members change roles in the types of care given at different times in their lives (Fingerman et al., 2009). A family member who takes on the role of providing care to another adult family member is considered a *family caregiver*. A family caregiver can be broadly defined as an adult (including a family member, relative, partner, friend, or neighbor) who provides unpaid care and support to an adult with health or functional needs (Schulz et al., 2020). Nearly one in five adults currently provide care to an adult family member, friend, or neighbor (National Alliance for Caregiving (NAC) & AARP, 2020).

As more adults are living longer into older adulthood, and family demographics (such as declining fertility and geographic mobility) limit the number of family members available to provide care (Carr & Utz, 2020), the family caregiver role is becoming more complex and challenging. For example, family caregivers provide care for more than 4 years on average, exceeding 30 hours of care per week (Wolff et al., 2018) and more Americans than ever before are providing care to more than one person and often to someone with Alzheimer’s disease or related dementia (NAC & AARP, 2020). Many family caregivers may become overwhelmed by caregiving responsibilities, balancing other life roles and responsibilities, and the increasing care needs of their care receiver (J. Zarit, 2009). As family members receiving care approach the end of their life, their care needs may become increasingly complex. For example, end-of-life (EOL) care has been broadly defined as comprehensive care that addresses the medical, emotional, social, and spiritual needs during the last stages of a person's life (Given & Reinhard, 2017).

Furthermore, the responsibility of providing care at EOL effects all aspects of a family caregiver's life, including their physical, emotional, and social well-being (Ornstein et al., 2017). Thus, it is not surprising that family members who take on the role of family caregiver are at risk of adverse health and well-being outcomes as a result of caregiving responsibilities (Schulz et al., 2020). However, family members provide an important and necessary service to their care receiver (National Academies of Sciences, Engineering, and Medicine (NASEM), 2016) which may bring about their own personal growth (and improve their care receiver's quality of life (Anderson & White, 2018). Given how important family caregiving is to a care receiver's health and well-being and family functioning, researchers have recommended advancing family caregiving research to examine the different contexts caregiving occurs within (NASEM, 2016; Schulz et al., 2020) and how families navigate caregiving roles and responsibilities together (S. H. Zarit, 2009).

To address these recommendations and gaps in family caregiving research, the overall aim of this dissertation is to explore how family caregivers perceive their preparedness for the transition to EOL caregiving and how family dynamics may be associated with feelings of preparedness. To set the foundation for this research, the dissertation begins with an overview of the family caregiving literature which includes a discussion of how research on aging families and common theoretical approaches helped develop an understanding of the risks and rewards of caregiving. The review of this literature leads to the identification of contextual circumstances of family caregiving that have largely been overlooked in caregiving research. Family caregiving at EOL, and how families address the unique challenges associated with the transition to EOL care, is a specific stage of caregiving that is not well understood (Cohen-Mansfield et al., 2018) and deserves further attention in caregiving research. A brief review of the limited research on EOL caregiving and how families prepare for the transition to EOL care is then presented, along with a discussion of what researchers have yet to learn about families' experiences during this transition. Following the review, this introductory chapter concludes with an overview of the remainder of the dissertation, including the purpose, research questions, and hypotheses posed in three papers presented in Chapters 2, 3, and 4.

Background of Research on Aging Families

Caregiving research has evolved from studies focused on addressing family development and functioning in early years, to increasing attention paid to the functioning of aging families. In the 1960s, much of the research focused on kinship structure and family interaction (Troll, 1971). Late-life research focused on widowhood without regard to specific experiences, such as caregiving. During this time, perspectives on individual and family development ran separate yet parallel (Troll, 1971). As theorists began to study interactional processes, new ideas concerning more systemic approaches to development emerged, with researchers calling for new theory to accommodate these shifts. Over the next decade, in the 1970s, a major change in public perception began influencing research. For example, the family unit, once considered to be of private concern, now became a public entity, with the functioning of families a matter for society as a whole (Streib & Beck, 1980). With this change came new focus on interdisciplinary approaches to family functions including nurturance, economic, residential, legal and cultural functions (Streib & Beck, 1980).

As family interactions within these areas were examined, research on declining health in late-life emerged, paving the way for studies of how caregiving impacts family involvement (Streib & Beck, 1980). Caregiving research continued to build in the 1980s. Emphasis shifted from describing how family members were providing care to how families reorganized roles and responsibilities to provide care (Streib & Beck, 1980). Researchers also began to closely examine caregiving experiences, with emphasis on gender differences (Zarit et al., 1986) and the division of care between adult children (Brubaker, 1990). At this time, there was a call to explore caregiving within the context the family relationship between caregiver and care receiver (Brubaker, 1990) and unique family situations.

Caregiving literature was criticized for failing to address common limitations, including a focus on family interactions, the needs of the care receiver, and neglect of the total caregiving support network (Allen et al., 2000). As a result, caregiving became increasingly viewed as a whole family effort, with multiple family members coordinating the provision of care and assistance (Silverstein & Giarrusso, 2010). In more recent studies, the family caregiving experience is examined as a multi-layered (Allen et al., 2000) and dynamic process that includes both negative and positive outcomes (Silverstein & Giarrusso, 2010). Current research on aging families and caregiving highlights the intensifying demands on family caregivers (Carr & Utz, 2020) as more older adults survive longer (experiencing cognitive and physical declines associated with extreme old age) and fewer family members are available (due to declining fertility and geographic mobility) to share caregiving responsibilities. As this brief review demonstrates, shifts in family and individual focus have influenced much of the caregiving research. Current recommendations for moving caregiving research forward include expanding the focus from the individual caregiver to a broader family context (Qualls, 2016; Roberto & Blieszner, 2015; Schulz et al., 2020; Utz et al., 2017).

Theoretical Approaches in Caregiving Research

To date, research on aging families and family caregiving have been guided by a variety of human development and family science theories. Yet, as this literature review demonstrates, the aging experience, caregiving needs, and the structure and functions of families have become more complex with changing demographic trends (Carr & Utz, 2020). It is important to understand how traditional theoretical perspectives have helped researchers and service providers understand the caregiving experience (Humble et al., 2020), and perhaps even more critical to use those traditional approaches to guide novel use of theory to advance family caregiving research. Two of the most common theoretical perspectives utilized in family caregiving research are life course theory (Elder & Giele, 2009) and the stress process model (Pearlin et al., 1990).

Life Course Theory

Traditionally, a life course theoretical approach (Elder & Giele, 2009) has been used to study life transitions and stress processes. Life course theory continues to be important to family caregiving research as researchers explore how developmental stages and age-related norms and expectations influence the caregiving experience. From a stress perspective, life transitions such as taking on the role as family caregiver and subsequent EOL caregiving, require individuals to adapt physical and psychological resources (Almeida & Wong, 2009). This perspective can be used in research to help identify the multiple contexts (age, employment status, role strain, etc.) within the lifespan that may impact a family caregiver's perceived burden and coping abilities. An important area of emphasis in life course theory is the concept of timing. Elder and Giele (2009) define timing as the idea that "developmental antecedents and consequences of life transitions, events, and behavioral patterns vary according to their timing in a person's life" (p.

156). Life events may be considered on-time or off-time depending on when they occur in the life course and how age expectations and social timetables (Elder & Giele, 2009) influenced the anticipation and preparation for those events. It is uncertain in caregiving literature how the timing of and transition to EOL caregiving are experienced by families and family caregivers.

Stress Process Model

Stress process models (Pearlin et al., 1990) have long been utilized to examine the links among caregiver stressors, psychosocial resources, and caregiver well-being (Goode et al., 1998). Using this perspective, caregiver stress is viewed as a process of multiple interrelated conditions influenced by the sociodemographic characteristics and resources of family caregivers and primary and secondary stressors present (Bainbridge et al., 2009). Primary stressors are the challenges directly related to the caregiving role and responsibilities (such as the care receiver's diagnosis and care needs), whereas secondary stressors are produced or affected by primary stressors (such as loss of income due to changing work hours to accommodate caregiving responsibilities; Montgomery et al., 2016). In general, caregiving stressors can lead to the appraisal of caregiving as burdensome and thus to poor health outcomes (Knight & Sayegh, 2010). Much of caregiving research has focused on identifying stressors and strains associated with caregiving, and how caregiving stressors are associated with caregiver outcomes (Carr & Utz, 2020; Knight & Sayegh, 2010; NASEM, 2016; Pinquart & Sörensen, 2003; Schulz et al., 2020). Recent research has begun to identify potential mediators of caregiving stressors, such as family and social support (NASEM, 2016) and preparedness for caregiving responsibilities (Roth et al., 2015b), that may mitigate negative caregiver outcomes. Although the stress process model has helped researchers understand the risks associated with caregiving (Montgomery et al., 2016), there is value in shifting to focus on individual potential and family capacity using strengths-based approaches (Hughes, 2015) to identify mechanisms of resilience (Blieszner & Voorpostel, 2016) in the study of family gerontology.

Family Caregiving Research

Taking on the role of a family caregiver is now considered a normative life event (Roberto & Jarrott, 2008), and a responsibility that adults should prepare for the eventuality of with their families. The caregiving experience is not unique to age, gender, race, ethnicity, socioeconomic status, education, rural or urban, or nationality and presents universal challenges and opportunities (NASEM, 2016). The bulk of caregiving responsibility most often falls to one family member (typically a spouse first, then an adult child – most often a daughter), referred to as the primary caregiver (Wolff et al., 2018). Caregiving research typically focuses on the outcomes of the primary family caregiver, yet oftentimes caregiving responsibilities, especially during caregiving transitions, may be divided among a network of family members, friends, and even neighbors (Gitlin & Wolff, 2011). These individuals are occasionally acknowledged in caregiving research and referred to as secondary or tertiary caregivers (Stephens & Franks, 2009). Regardless, the role of family caregiver involves unpaid provision of care to an adult family member with health or functional needs (NAC & AARP, 2020). Additionally, much of caregiving research defines the areas of care required by care receivers into two groups (Segal et al., 2018): basic activities of daily living (ADLs) which includes personal care related to dressing, feeding, bathing, toileting, and transferring; and instrumental activities of daily living (IADLs) which include functions of independent living such as transportation, cooking, housework, and management of finances. Further delineation of the types of care provided by family caregivers (NASEM, 2016) includes tasks related to household management, self-care, supervision, and mobility, emotional and social support, health and medical care, advocacy and care coordination, and surrogacy (decision-making and legal matters).

The effects of taking on these responsibilities as a family caregiver range widely (NASEM, 2016), and depend on a variety of individual and contextual characteristics. One in five caregivers report that their own health is fair to poor (NAC & AARP, 2020) and that caregiving is financially and physically challenging (NASEM, 2016). Almost 45% of caregivers find family caregiving to be emotionally difficult (NASEM, 2016). It is important to recognize and understand the physical, emotional, and financial toll that caregiving has on family caregivers, and that these adverse outcomes may affect more family members and other individuals than just the primary caregiver. The adverse psychological effects of caregiving disperse throughout the family (Schulz et al., 2020), with relationships and quality of life of many family members impacted by caregiving demands. Thus, it is important to continue exploring the outcomes associated with family caregiving at both the individual and family levels.

Risks Associated with Caregiving

An early, comprehensive review of the caregiving literature (Pinquart & Sörensen, 2003) found that family caregivers experienced higher levels of depression and stress, and lower levels of subjective well-being, physical health, and self-efficacy than non-caregivers. Additional reviews of caregiving research over the years confirmed these findings (Henry et al., 2018; NASEM, 2016; Roberto & Jarrott, 2008; Schulz et al., 2020; Stephens & Franks, 2009) and started to examine the mechanisms of the caregiving experience that lead to adverse outcomes. For example, family caregiving is time-consuming and exhausting (Robert & Jarrott, 2008) and caregivers often neglect their own self-care and jeopardize their health to focus on the care needs of the care receiver. Managing the hassles of daily caregiving responsibilities increases stress and can cause family caregivers to experience burnout (Henry et al., 2018), resulting in declines in health and the ability to manage other life responsibilities. Family caregiving can also create strain on financial responsibilities as caregivers juggle employment with caregiving responsibilities (Roberto & Jarrott, 2008). More than 60% of family caregivers are still employed (NAC & AARP, 2020), and meeting the needs of a care receiver can interfere with their availability to work and job performance (Schulz et al., 2020) which may lead to decreases in wages.

Studies on family caregiving continue to identify the circumstances that may increase the risk of negative outcomes. Particular caregiving situations are associated with more adverse outcomes, including caregivers who help with more caregiving tasks for longer periods of time (Segal et al., 2018), caregivers caring for individuals with Alzheimer's disease or related dementias (NASEM, 2016), and caring for individuals at the end or final stages of their life (Schulz et al., 2020). Social support is another factor that is associated with caregiver outcomes. Family caregivers who lack help from others in their caring responsibilities, those that lack emotional support from family and friends, and caregivers who experience family conflict all experience worse health and well-being outcomes (Lin et al., 2012) than family caregivers with more social support. In a comprehensive review of the caregiving literature, Schulz, Czaja, Martire, and Monin (2020) identified seven categories of risk factors associated with family caregivers' adverse outcomes: a) sociodemographic factors (such as lower income, less education, being a spouse caregiver, and living with the care receiver), b) high intensity caregiving (more hours, dementia care, medical care), c) an individual's lack of choice in taking on the role of family caregiver, d) caregivers who perceive a high rate of care receiver suffering,

e) caregivers in poor health or with restricted physical functioning, f) limited social or professional support, and g) challenging home environments (such as clutter, lacking appropriate home modifications). This extensive review and identification of risk factors may help researchers and practitioners better understand the needs of family caregivers in challenging circumstances.

In addition to the personal factors that are associated with negative outcomes experienced by family caregivers, family-level and cultural influences, interactions, and processes have also been found to be associated with risk of adverse outcomes. The care needs of one family member can create stress throughout the entire family by disrupting historical and ongoing dynamics across the overall family system (Schulz et al., 2020). For example, as family members focus on the needs of one family member, it may disrupt the rules, roles, and interactions that have been established in the family system over time (Henry et al., 2018). As a result, flexibility is required of families to adapt to the demands of family caregiving (Qualls, 2018) as they navigate decision-making and care distribution together. These family dynamics have the potential to create tension and serious conflict between individual family members and within the whole family system (Utz et al., 2017).

Family structure and the familial relationship between the family caregiver and care receiver may influence caregiver outcomes as well. For example, Pinquart and Sörensen (2011) found that spouses who are the primary caregiver report more depressive symptoms and lower levels of subjective well-being, and greater financial and physical burden than children and child-in-law who provide care. However, these differences may be due to higher intensity care provision (Wolff et al., 2018). Several studies and reviews have also explored differences in caregiver outcomes by race and ethnicity (Dilworth-Anderson et al., 2002; Knight & Sayegh, 2010; Liu et al., 2020; Moon et al., 2020; Pinquart & Sörensen, 2005). Many studies found little or no differences in caregiver depression or burden between race and ethnic groups (Dilworth-Anderson et al., 2002; Liu et al., 2020) or higher levels of depression or burden among Whites than other groups. Results from one review found that among family caregivers, all race and ethnic groups reported worse physical health than Whites (Pinquart & Sörensen, 2005), but it is important to note that there were also differences between race and ethnic groups in socioeconomic status, age, familial relationships between caregiver and care receiver, and social support. These characteristics have been identified as risk factors for adverse outcomes and may account for the differences in caregiver health and well-being (Dilworth-Anderson et al., 2002; Moon et al., 2020). Decades of caregiving research has highlighted the negative health and well-being outcomes and risk factors associated with family caregiving for both family caregiver and other family members. However, with those challenges there exist rewards for caregiving, including positive outcomes and opportunities for personal and interpersonal growth for family caregivers, care receivers, and their families.

Rewards of Family Caregiving

Although taking on the role of a family caregiver brings risks and potential for poor health and well-being outcomes, not all caregivers report high levels of stress or burden (Schulz et al., 2020) and many family caregivers find rewards in the caregiving experience. For example, family caregivers often cope well with caregiving responsibilities and may feel a stronger bond to their care receiver as a result of providing care (Pinquart & Sörensen, 2003). Family caregivers also report that the role often brings a sense of personal growth and gains in self-worth (Roberto & Jarrott, 2008). These are just a few examples of the positive dimensions of caregiving that contribute to positive aspects of caregiving (Cohen et al., 2002).

The construct of *positive aspects of caregiving* emerged in caregiving research as studies began shifting from needs-based approaches and the stress process model to strengths-based perspectives on caregiving. Positive aspects of caregiving include dimensions of the positive experiences, emotions, appraisals, and the resources and strengths that family caregivers draw upon when facing caregiving challenges (Zarit, 2012). A recent study found that when caregivers identify positive aspects of caregiving, they have an easier time adapting to the caregiving role and can focus on the benefits of providing care for their care receiver and their own growth (Quinn & Toms, 2019). Positive aspects of caregiving were also associated with less depressive symptoms, higher quality of life, and feelings of competency (Quinn & Toms, 2019).

It is important to note that several studies found significant differences in positive aspects of caregiving between racial and ethnic groups. Both Hispanic and African Americans or Black individuals experience more positive aspects of caregiving, while Whites reported the lowest levels of positive aspects of caregiving of all races and ethnicities (Cho et al., 2016; Roth et al., 2015a). These results may be related to differences in cultural justifications for caregiving (Dilworth-Anderson et al., 2005), wherein cultural values and beliefs shape families' and individuals' attitudes about caregiving and the caregiver role. Caregiving studies continue to explore additional factors that may protect against caregiving stress and burden and promote positive aspects of caregiving. These study results demonstrate that there may exist associations between cultural values and expectations, caregiver self-efficacy and preparedness (Henry et al., 2018), and caregiver resilience and positive outcomes.

A few studies have also examined family-level factors that are associated with more positive outcomes for family caregivers. For example, Anderson and White (2018) found that family cooperation, emotional engagement, and adaptability contributed to positive outcomes for care receivers with chronic illness and higher appraisals of the caregiving experience from family caregivers. After an extensive review of caregiving research, Henry, Hubbard, Struckmeyer, and Spencer (2018) categorized family processes that protect against the burdens and stresses of family caregiving into four main areas: family adaptation (how families adjust roles and responsibilities to meet the needs of the care receiver and other family members), finding family meaning (reframing caregiving challenges in meaningful ways, such as reappraising life’s priorities), family control systems (including flexibility in roles and patterns of authority within the family system), and family emotion systems (healthy communication, cooperative emotion regulation, and a balance between connectedness and autonomy). These family processes strengthen family organization and family caregiver resilience, thus improving well-being outcomes for caregivers, care receivers, and their families (Henry et al., 2018). This research demonstrates that while family caregiving can be a challenging responsibility, this time can be one of personal growth and family connection. Advancing caregiving research should continue to include family-level analysis of the appraisal of family caregiving and an exploration of how family functioning during different transitions of caregiving relate to caregiver outcomes.

End-of-Life Caregiving

Providing care to family members approaching the end of their life brings additional psychological, physical, and emotional strain to the family caregiving role (Bainbridge et al., 2009; Given & Reinhard, 2017). There is no exact definition of the stage at which an individual is at the end of life or what constitutes EOL caregiving (Given & Reinhard, 2017), yet there exist various definitions of EOL that apply in different circumstances. For example, the National Institutes of Health (2004) identified factors, that if exist, constitute EOL, including the presence of chronic disease or functional impairments that persist over time, of which require care assistance and can lead to death, or extreme older age and frailty. Caregiving at EOL has been defined as care given to people who have stopped treatment to cure or control their disease (National Cancer Institute, 2021) which includes physical, emotional, social, and spiritual support. This care may be considered comfort care and may include palliative or hospice care (Given & Reinhard, 2017). One study explored how family caregivers defined EOL care (Cohen-Mansfield et al., 2018) and found that most families identified the EOL stage by an unexpected event in the care of their family member (such as a new medical diagnosis or accident) or changes in the existing condition of the care receiver (such as significant declines in health status or cognitive state). Researchers have identified that one of the important characteristics of EOL caregiving is how caring interactions may evoke intense emotions due to a sense of finality and impending loss (Phillips & Reed, 2010).

As previously introduced, the care needs of a family member approaching the EOL often increase, and family caregivers must often balance the responsibilities of assisting with more activities of daily living, managing medications and symptoms, providing emotional support, and coordinating care and communication with health care providers (NASEM, 2016). As these care needs become more complex, caregivers are often tasked with providing more direct care (such as oxygen, wound dressings, catheters, and injections) and coordinating physical therapy and hospice care (Given & Reinhard, 2017). Transitioning to long-term care or hiring professional caregivers are common EOL occurrences that can be a difficult and costly decision (Ornstein et al., 2017), which may add additional burden to family caregivers and their families.

Additional stress and burden to family caregivers may be caused by family conflict. Family conflict during EOL caregiving may be a result of disagreements over care decisions, or a history of strained relationships (Given & Reinhard, 2017). One study found that adult children (siblings) often argue over care decisions for their parents, and this conflict is associated with family caregiver burden and anger (Kramer & Boelk, 2015). Family conflict often extends beyond adult children, as distant family members who had not previously been involved in caregiving desire to be involved in EOL care decision making (Kramer & Boelk, 2015). Unfortunately, family conflict not only adds burden and stress for caregivers, but it may also decrease quality of life for care receivers (Ornstein et al., 2017) and create barriers for health care providers to deliver palliative or hospice services (Kramer & Boelk, 2015).

Regardless of how the EOL stage, EOL care, or EOL caregiving is defined, the demands on a family caregiver intensify (NASEM, 2016) with the progression of disease, illness, or older age. The physical and emotional toll of EOL caregiving can be extensive (Bainbridge et al., 2009), yet many family members prefer these responsibilities to seeing their family member placed in a care facility. This research demonstrates that EOL caregiving warrants further investigation, yet caregiving studies seldom focus exclusively on EOL (Cohen-Mansfield et al., 2018) or how prepared caregivers feel for EOL caregiving. Distinctions have been made in the caregiving trajectories of specific disease groups such as Alzheimer's disease or cancer (Waldrop et al., 2005) and within different care settings (Ornstein et al., 2017), from home-based care to long-term care facilities. However, few studies have examined how families and family caregivers navigate the increasingly complex medical, physical, social, and emotional needs of a dying family member.

Preparedness for the Transition to EOL Caregiving

Given the likelihood of taking on responsibilities of providing care to aging family members (NASEM, 2016), researchers and practitioners have acknowledged that it is imperative to educate and prepare adults for caregiving (Schulz et al., 2020). These recommendations extend to the transition to EOL caregiving, as the decision to stop curative care to focus on the comfort of family members at the end of their life is one of the most challenging caregiving decisions families and individuals make (Given & Reinhard, 2017). Family caregivers who feel unprepared for EOL caregiving experience more adverse outcomes (Nielsen et al., 2016), such as higher levels of depressive symptoms, greater caregiver burden (McMillan, 2005), less time for themselves, and a greater impact on other roles (Ornstein et al., 2017). Caregiving at EOL also brings intensified physical and emotional strain (Bainbridge et al., 2009) as family caregivers often place the needs of their dying family member above their own health and well-being (Oechsle, 2019).

Health care professionals and advocacy groups have recommended (Fowler et al., 2014) families communicate about the type of care that might be needed in the future, preferences for family or professional caregivers, and who will help make care decisions. This type of family communication may help family caregivers feel more prepared for EOL caregiving, which in turn is associated with less caregiver worry and lower depressive symptoms (Henriksson & Ârestedt, 2013). Many studies have identified advance care planning as a tool to help families cope with decision making and difficult emotions at EOL (Carr & Luth, 2017; Egbert et al., 2017; Fowler & Fisher, 2009; Given & Reinhard, 2017; Redinbaugh et al., 2003), yet a recent study found more than 40% of adults aged 50-80 years old had not had any discussions with family or friends about the types of care they would want if they became seriously ill (Perumalswami et al., 2021). It appears that families continue to struggle to talk about EOL care issues, despite evidence that these discussions may help family caregivers, their care receivers, and their families cope with the difficult responsibilities and emotional burden of EOL care.

Purpose of this Dissertation

From the family caregiving research, it is clear that little is known about how families, family caregivers, and care receivers navigate the transition to EOL caregiving and what factors may be associated with how prepared family caregivers feel for that transition. Thus, the purpose of this dissertation is to explore how family caregivers perceive their preparedness for the transition to EOL caregiving and how family dynamics may be associated with feelings of preparedness. The three papers introduced in this dissertation collectively represent a comprehensive study addressing this gap in caregiving research. The first paper, *Family Dynamics and the Transition to End-of-Life Caregiving: A Brief Review and Conceptual Framework*, is presented in Chapter 2 and provides a conceptual framework that guides the comprehensive study. The second paper, *Family Caregivers' Feelings of Preparedness for the Transition to End-of-Life Caregiving*, is presented in Chapter 3 and explores caregivers' perceived preparedness for EOL caregiving. The final paper, *Understanding the Association Between Family Dynamics and Preparedness for the Transition to End-of-Life Caregiving*, is presented in Chapter 4 and examines the connection between caregiver preparedness and family dynamics. A brief overview of each chapter and paper is provided in the following paragraphs. At the conclusion of the dissertation, in Chapter 5, the results of each study are summarized, and the implications of this work are discussed. In addition, recommendations for future basic and applied research are addressed.

Chapter 2: Family Dynamics and the Transition to End-of-Life Caregiving: A Brief Review and Conceptual Framework

In this chapter, a brief review of extant literature and an innovative conceptual framework with which to explore family dynamics and preparedness for the transition to EOL caregiving is presented. Several definitions are discussed to provide clarity in identifying the population of interest. For example, definitions (for the purpose of this dissertation) are provided for family caregiver, family, and EOL care. This study also acknowledges the importance of using theory to guide research. Until recently, as discussed in the introduction of this dissertation, the use of life course theory and stress process models have dominated family caregiving research. As identified in the literature, these perspectives often focus on individual caregiving experiences, without allowing for the exploration of the family-level factors that may be associated with caregiver outcomes. Providing a new theoretical approach with which to study caregiving transitions and family caregiver outcomes in the context of the family system may help generate new knowledge about the complexity of family caregiving and support empirical studies as they address the diversity of caregiving experiences. The framework presented and discussed in this conceptual paper is then used to guide the development of a family caregiver survey utilized in the empirical studies presented in Chapters 3 and 4.

Chapter 3: Family Caregivers’ Feelings of Preparedness for the Transition to End-of-Life Caregiving

Although some studies have identified preparedness as a protective factor of caregiver well-being, few studies have explored family caregivers’ perceived preparedness for the transition to EOL caregiving. This study utilizes the conceptual framework presented in Chapter 2 to explore how personal characteristics of family caregivers (such as age, gender, race, ethnicity, education, and income), the family context (such as familial relationship between caregiver and care receiver, living arrangements between the two), time (such as duration of care and time spent caregiver per week), and family processes (such as advance care planning) may be associated with perceived preparedness for the transition to EOL caregiving. Thus, the purpose of this study is to explore the construct of caregiver preparedness and investigate how family caregivers perceive their preparedness for the transition to providing EOL care.

The hypotheses addressed in this chapter include:

1. *Personal demographics such as age, gender, race, education, and income, will be associated with feelings of preparedness for EOL caregiving.*
2. *Characteristics of caregiving, such as having another person providing care, will be associated with feelings of preparedness for EOL caregiving.*
3. *Cultural reasons for providing care will be associated with preparedness for EOL caregiving, such that family caregivers with more cultural reasons for caregiving will feel more prepared for EOL caregiving than caregivers with less cultural reasons for caregiving.*
4. *Burden of caregiving will be associated with preparedness for EOL caregiving, such that family caregivers who report greater perceived caregiving burden will be associated with lower feelings of preparedness than caregivers who report less perceived caregiving burden.*
5. *Duration of care will be associated with preparedness for EOL caregiving, such that family caregivers who have provided care for longer will feel more prepared for EOL caregiving than caregivers providing care for shorter periods of time.*
6. *Number of tasks completed related to EOL conversations and decision making will be associated with preparedness for EOL caregiving, such that family caregivers who have completed more tasks will report feeling more prepared for EOL caregiving than caregivers who have completed fewer tasks.*

Chapter 4: Understanding the Association Between Family Dynamics and Preparedness for the Transition to End-of-Life Caregiving

Building on the factor structure of caregiver preparedness identified in Chapter 3, an examination of caregivers' perceived preparedness for EOL caregiving is presented in Chapter 4. The purpose of this study is to explore the association between family caregivers' family dynamics and their perceived preparedness for the transition to EOL caregiving. Using the conceptual framework introduced in Chapter 2, this study examines caregivers' perceived preparedness for EOL caregiving while considering the family context, such as family cohesion and the familial relation between the caregiver and care receiver, that care occurs within. In addition, emphasis is placed on family processes, such as communication and advance care planning, to understand how family dynamics may promote or hinder caregiver preparedness for the transition to EOL care. The hypotheses addressed in this chapter include:

1. *Family caregivers with balanced family dynamics will report greater perceived preparedness for the transition to EOL caregiving than family caregivers with unbalanced family dynamics.*
2. *The association between family dynamics and preparedness for the transition to EOL caregiving will be mediated by number of tasks completed related to EOL care planning.*

CHAPTER 2

FAMILY DYNAMICS AND THE TRANSITION TO END-OF-LIFE CAREGIVING: A BRIEF REVIEW AND CONCEPTUAL FRAMEWORK[1]

Many adults will become a caregiver to an aging family member at some point in their life, yet few are preparing for those responsibilities. The number of family caregivers continues to rise due to increased longevity, thus leading to a growing aging population, as well as health care increasingly moving from acute care settings into family homes (National Academies of Sciences, Engineering, and Medicine [NASEM], 2016). On average, approximately 48 million Americans provided unpaid care to an adult in the past 12 months (National Alliance for Caregiving [NAC] & AARP, 2020), saving the United States approximately $470 billion in economic value (Reinhard et al., 2019). Although millions of individuals provide unpaid care, it is not without experiencing caregiving burden and strain (Pinquart & Sörensen, 2011). Trends in family demographics, such as smaller family sizes, marital dissolution, and increased geographic mobility leave fewer family members available to provide care (Carr & Utz, 2020) and may add to caregiver burden. In addition, experiences of family caregivers include navigating past and present relationship dynamics with the care receiver and other family members (Greene & Kropf, 2014) as they take on the roles and responsibilities of providing care.

To better understand the caregiving experience, it is important to identify who family caregivers are and the types of care they provide. A federal, legal definition of family caregiver is "an adult family member, or other individual, who is an informal provider of in-home and

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[1] Fox, A. F., Sharp, J. L., & Fruhauf, C. A. (2021). *Family dynamics and the transition to end-of-life caregiving: A brief review and conceptual framework* [Manuscript submitted for publication]. Department of Human Development and Family Studies, Colorado State University.

community care to an older individual or to an individual with Alzheimer’s disease or a related disorder with neurological and organic brain dysfunction” (42 U.S.C. § 3022). For the purpose of this study, and aligning with family caregiving research, a broader definition of family caregiver includes relatives, partners, friends, or neighbors who offer unpaid care and support to adults who experience physical, mental, or cognitive limitations (NASEM, 2016). This definition also allows for wider interpretations of both *family* and *caregiving*. Federal and legal definitions of family vary slightly, but typically are limited to groups of two or more persons related by birth, marriage, or adoption who live together (Health Resources & Services Administration, 2017; United States Census Bureau, 2020). Within family studies, researchers again apply a broader definition of family, recognizing that families vary in many ways including structure (such as multiple generations or fictive kin), provision of support, and type of relationship and commitment (Connidis, 2020). Similarly, family caregivers differ in their level of involvement in primary or supplemental provision of care to a care receiver, their relationship and living arrangements with the care receiver, and the type of care provided (Roth et al., 2015).

Caregiving roles and responsibilities can range vastly from regularly checking in, assistance with daily activities (such as household maintenance, transportation, or meal preparation), to providing direct medical care and coordinating complex health care and social services (Schulz et al., 2020). The care needs of a care receiver can vary, and often increase over time. Acute care is associated with short-term care needs, such as provision of care after a medical treatment or minor illness, whereas long-term care often accompanies chronic illness or disease and declining physical, mental, or cognitive health as care receivers age. Long-term care often requires substantial family adaptation (Qualls, 2018), such as changes in family roles and communication, as care needs increase and demands on family caregivers are more intensive.

An important caregiving context that is noticeably overlooked in caregiving research, end-of-life (EOL) care is emerging as a distinct phase and transition for family caregivers and their care receivers (Cohen-Mansfield et al., 2018). End of life care can be defined as comprehensive, often palliative, care that addresses medical, emotional, spiritual, and social needs during the last stages of a person's life (Given & Reinhard, 2017). Palliative care is medical care (offered at any illness stage with curative or other treatments) focused on providing relief from symptoms and improving quality of life for patients and their families (National Institute on Aging, 2020). A prospective study indicates that almost one million adults approaching EOL are receiving extensive care and support from over two million family caregivers (Ornstein et al., 2017). Family members caring for these EOL needs are more vulnerable to emotional stress and psychological and physical strain than caregivers not providing EOL care (Given & Reinhard, 2017). Yet, few studies exist that examine how to prepare for EOL caregiving and how families navigate the adjustment to increasing care demands and decision making associated with the transition to EOL care.

Current recommendations for moving family and caregiving research forward include focusing on interpersonal dynamics within families providing care and support to their older members (Carr & Utz, 2020). Family dynamics are broadly defined as how families interact (Olson, 2000) and include many dimensions of cohesion (such as emotional bonds, shared decision making, shared interests, and family togetherness), flexibility (such as family leadership, discipline, negotiation styles, and stability versus change), and communication (such as listening and speaking skills, self-disclosure, empathy, and problem-solving skills). A growing number of studies indicate that family dynamics during childhood have lasting effects into adolescence and early adulthood and throughout the life course (Umberson & Thomeer, 2020), demonstrating the importance of examining family dynamics in aging families.

The purpose of this study is to present a brief review of extant literature and a conceptual framework designed to foster research in family caregiving systems, specifically how family dynamics are associated with preparedness for the transition to EOL caregiving. To begin, we provide a brief review of caregiving research, including a focus on theoretical traditions and caregiving stages and transitions, with a call to address research gaps at the intersection of family caregiving, family dynamics, and the transition to EOL care. We then discuss our theoretical foundation, based on bioecological theory, and present a conceptual framework to guide research on family dynamics and caregiving transitions. We conclude with recommendations for future directions of research using the conceptual framework and a discussion about the implications of this work.

Brief Review of Caregiving Research

Family caregiving research emerged decades ago as scholars began to examine the experiences of aging families. Several theories dominated caregiving research during this time. Traditionally, a life course theoretical approach (Elder & Giele, 2009) was used to study life transitions and stress processes. Life course theory continues to be important in caregiving research to examine how developmental stages and age-related norms and expectations influence the caregiving experience. From a stress perspective, life transitions such as family caregiving and subsequent EOL caregiving require individuals to adapt physical and psychological resources (Almeida & Wong, 2009). Caregiving research that focused on outcomes such as health, well-being, coping, burden appraisal, and personal gains are founded in stress process models (Pearlin et al., 1990) and are applied to examine the relationships among caregiving stressors, psychosocial resources, and caregiver well-being (Goode et al., 1998). In general, caregiving stressors lead to the appraisal of caregiving as burdensome and thus to poor health outcomes (Knight & Sayegh, 2010). In recent years, there has been a call to move away from needs-based studies and interventions to focus on strength-based approaches (Hughes, 2015). Strength-based approaches to studying family caregiving allows for the inclusion of dimensions associated with individual and family potential and capacity (Hughes, 2015). For example, exploring flexibility, problem-solving skills, and social support among individuals and families may identify opportunities for resilience-building work.

Caregiving Transitions

Providing care for a family member is a dynamic process that involves increasing complexity and scope of caregiving responsibilities (NASEM, 2016). For example, caregiving stages have been defined by beginning with an awareness of a problem (e.g., a family member is diagnosed with cancer) (NASEM, 2016), transitions in the care needs of the care recipient (e.g., cognitive decline or decreasing mobility) (Gitlin & Wolff, 2011), changes in family caregiver roles (e.g., increasing time spent providing care) (NASEM, 2016), and the setting (i.e., home vs. care facility) in which care is provided (Gitlin & Wolff, 2011). Tasks required of the family caregiver, such as help with personal care and household management, are cumulative and bring new challenges (Gitlin & Wolff, 2011) over time as the increasing needs of the care receiver require more assistance and time from the caregiver (NASEM, 2016). For example, a spouse may increasingly notice memory and cognition struggles in their partner, spend more time monitoring symptoms, receive testing and a diagnosis from a health care professional, take time off work to ensure closer monitoring as symptoms progress, and over time acquire even more responsibilities of providing personal care, symptom management, and monitoring. Caregiving responsibilities may limit the spouse's ability to maintain employment, family and social relationships, and self-care, thus increasing the burdens and risks associated with the caregiving role. Caregiving transitions are an important context of caregiving because they are often experienced as a time of crisis for families (Gitlin & Wolff, 2011). These transitions can be overlooked as an anticipatable point of opportunity for research exploration and intervention (Christ & Blacker, 2005) that may improve outcomes for family caregivers.

Transition to EOL Care

Researchers have identified several events or actions that may delineate the transition to EOL caregiving from other caregiving stages. Typically, people who have stopped treatment to cure or control their disease are considered to be in the EOL stage (National Cancer Institute, 2020). Therefore, the decision to stop curative care is one indicator of the transition to EOL. Terminal care, hospice care, and palliative care are terms and courses of treatment that are often used interchangeably with EOL care (Izumi et al., 2012). Terminal care in health care settings indicates unresponsiveness to treatment or a prognosis of less than six months to live (Holland & Prost, 2019). Hospice is a type of comfort care or program designed to provide relief from symptoms and address the psychological, social, and spiritual needs of an individual and their family (Izumi et al., 2012). As individuals approach EOL, palliative care can help them and their families understand choices for medical treatment with an increased emphasis on comfort care. Other factors that may indicate a transition to EOL care include changes in existing conditions (such as cognitive state) (Cohen-Mansfield et al., 2018), shifting caregiving focus from physical care to emotional and spiritual care (Cagle & Kovacs, 2009), admission to services that provide high-needs care, and old age with chronic illness and multiple comorbidities (Holland & Prost, 2019). The process through which families navigate the transition from curative care to EOL care or self-identify their care receiving family member as approaching EOL is poorly understood (Sercu et al., 2018) and is an important context with which to examine family caregiving experiences.

Research Gaps and a Call to Examine Family Dynamics and Caregiving Transitions

Few researchers have examined how the transition to EOL caregiving effects family caregivers' overall health outcomes (Aoun et al., 2018) and no published research could be found, other than those focused on advanced care planning (i.e., Kramer & Boelk, 2015; Nielsen et al., 2016), that examine how family dynamics are related to caregiver preparedness for the transition to EOL care. Although research on the transition to EOL care is limited, it is clear that EOL caregiving can be a time of potential crisis for families, with family caregivers and their care receivers exposed to the bulk of such experiences. Understanding how family dynamics are associated with preparedness for the transition to EOL care may help family caregivers and their care receivers identify tools to improve family cohesion, effectively communicate needs and care preferences, obtain support from family members, and deal with difficult feelings so they can increase confidence in their role and feel more prepared for the transition to EOL care.

EOL caregiving research is lacking in theoretical foundations and empirical work, and knowledge of EOL caregiving experiences continues to be constrained by research limitations (Ornstein et al., 2017). Researchers investigating family caregiving seldom focus exclusively on EOL caregiving (Cohen-Mansfield et al., 2018) nor address the unique challenges associated with the transition to providing EOL care. Another limitation is the result of recall bias (Aoun et al., 2018), wherein many studies only report on caregiving experiences after the care recipient's death (Ornstein et al., 2017). Finally, caregiving research both as a broader context and within EOL has focused on the experiences of a primary caregiver and their care recipient (Tabler et al.,

2015) without identifying caregiving as a family matter (Qualls & Noecker, 2009). Family conflict can adversely affect caregiver and care recipient well-being (Kramer & Boelk, 2015) and yet empirical studies and intervention efforts to encourage families to engage in cooperative caregiving are lacking (Keith, 1995), especially during the transition to EOL care.

As approaches to theory, research, and practice take contextual differences of family caregiving into account, it may be easier to identify specific sources of burden and stress, strengths and coping, and with this knowledge design intervention programs to improve the health and well-being of family caregivers. Theoretical approaches, such as the proposed use of bioecological theory described in the next section, are innovative and should be used to guide research and interventions that will support families and individuals as they transition to EOL care. Adding a focus on the family context of caregiving can promote recognition of the diversity of contemporary families and how that complexity is associated with individual aging experiences (Humble & Price, 2017; Umberson & Thomeer, 2020). Furthermore, a focus on family dynamics in caregiving provides greater depth and breadth to family gerontology studies (Allen et al., 2000; Carr & Utz, 2020) essential to the fields of family studies and adult development and aging.

Conceptual Framework for a Bioecological Model of Family Dynamics and the Transition to EOL Caregiving

Bronfenbrenner’s bioecological theory provides the foundation with which to explore the diverse and complex contexts and processes that might influence family caregivers’ outcomes associated with the transition to providing EOL care. The bioecological theory examines human development, a phenomenon of continuity and change in the biopsychological characteristics of individuals (Bronfenbrenner & Morris, 2006), as a process over the life course, across generations, and through historical time. Bioecological theory may be used to examine family caregiver outcomes while recognizing that family caregiving occurs within the context of family systems. The focus of bioecological theory is on the interactions between four key components (see Figure 2.1); person, context, time, and processes (Bronfenbrenner & Morris, 2006; Rosa & Tudge, 2013). We discuss each of these components, while highlighting the importance of understanding how family characteristics and family interactions may be associated with both family and family caregiver outcomes.

Person

The first concept of bioecological theory is person. This concept highlights the importance of how personal characteristics of an individual shape development and influence proximal processes (Rosa & Tudge, 2013; Tudge et al., 2009). Bronfenbrenner and Morris (2006) distinguish three types of characteristics most influential in shaping development: dispositions, resources, and demand characteristics. Dispositions refer to differences in personality traits such as temperament, motivation, and persistence. For example, caregiver confidence (or self-efficacy) and coping styles have been identified as having positive moderating or mediating effects on family caregiver outcomes (Cagle & Kovacs, 2009; Redinbaugh et al., 2003; Roberto & Jarrott, 2008). Also, higher levels of caregivers' confidence in their ability to resolve caregiving difficulties resulted in decreased stress (Redinbaugh et al., 2003). Resources are the characteristics required for effective functioning of proximal processes (Bronfenbrenner & Morris, 2006), including abilities, experience, knowledge, and skills. For example, many family caregivers report a lack of knowledge and skills necessary for providing EOL care and feel unprepared for this role (Given & Reinhard, 2017). Further, perceptions of low preparedness are associated with poor health and well-being outcomes in family caregivers

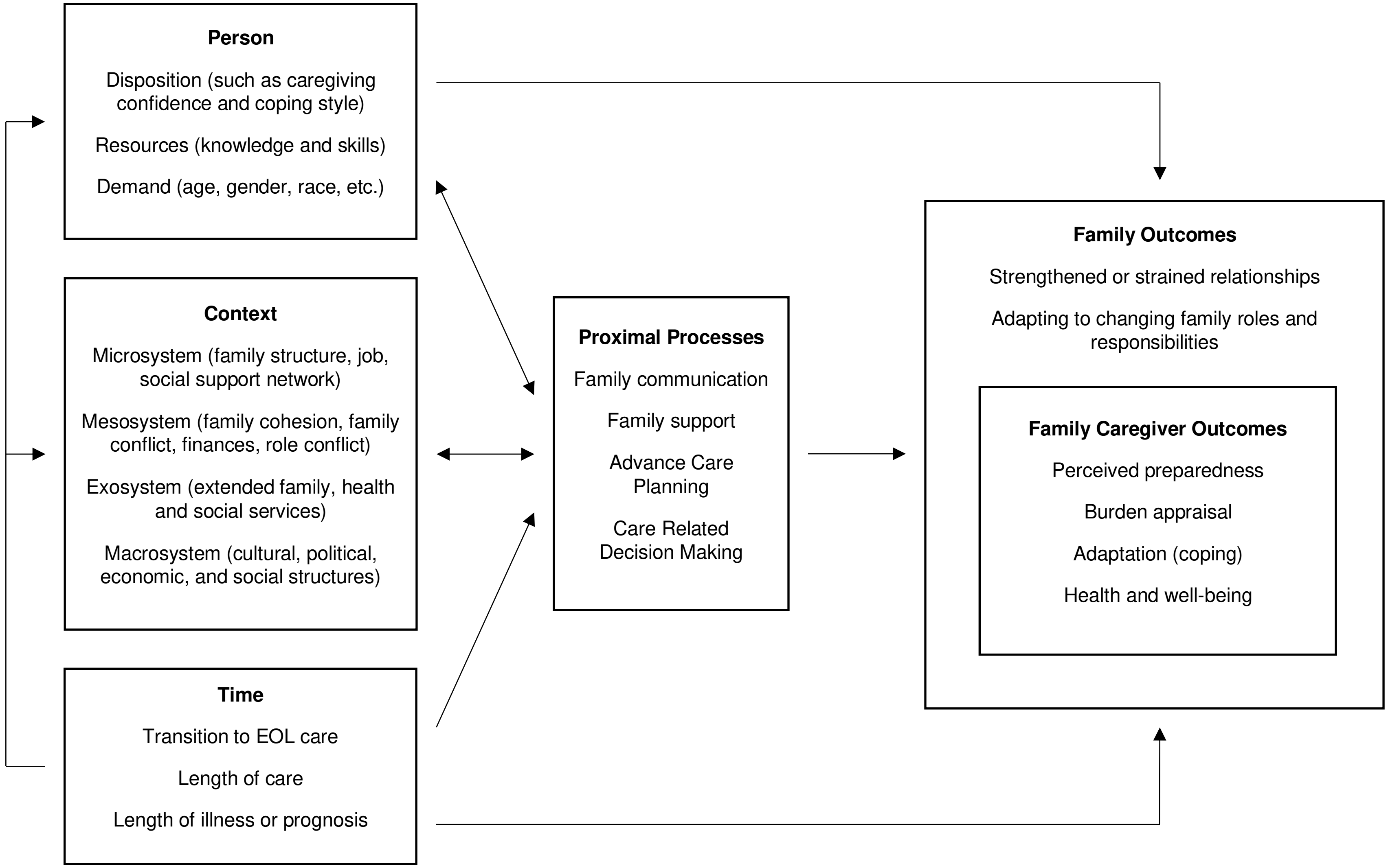

Figure 2.1. *Conceptual Framework for a Bioecological Model of Family Dynamics and the Transition to EOL Caregiving*

(Nielsen et al., 2016). Finally, demand characteristics, such as age, gender, or race invite or discourage social reactions which may foster or disrupt proximal processes (Bronfenbrenner & Morris, 2006). Personal characteristics may relate to the caregiving responsibilities and roles placed on different family members, how involved family members are in sharing caregiving responsibilities, and how families communicate about and plan for future care needs.

Context

The second concept of the bioecological theory, context, is comprised of four interrelated systems (microsystem, mesosystem, exosystem, and macrosystem) of environment. Proximal processes occur within and between these systems, making them an integral influence on family and family caregiver outcomes. The family system and its functioning are enmeshed within each system of context. Much like family caregiving, family-level analysis should integrate a broad definition of family (as addressed previously) and multiple family system levels, including individual family members (such as caregiver, care receiver, parent, spouse, etc.), family subsystems (such as partners or spouses, siblings, parent-child, grandparent and grandchild, etc.), and the overall family system (Henry et al., 2018). Relationships among family members are an important proximal process wherein contextual factors influence and mutually reinforce each other (Osher et al., 2017). Proximal processes within the family context can serve as the foundation for individual resilience, or adaptation to life stressors such as family caregiving.

The challenges associated with caregiving can put families at risk as family members adapt roles, responsibilities, and interactions within the family system (Henry et al., 2018). Much of caregiving research focuses on the individual caregiver and their care recipient. There are two important reasons for including the family context in the study of family caregiving. The family caregiver exists within a family system and a bioecological approach encourages a focus on bidirectional influences family members have on individual responses (Humble & Price, 2017) to caregiving and vice versa. In addition, a singular focus on the individual restricts theory, research, and practice to a primary caregiver and care receiver model (Keith, 1995). When individual- and family-level factors are included in the analysis, the proximal processes that influence family caregiving decisions, caregiving contributions of many family members (not limited to the primary caregiver), and family and family caregiver outcomes could be further examined. Thus, the following examples of micro-, meso-, exo-, and macro-systems include factors that may affect both family and family caregiver outcomes.

The microsystem, such as home, family structure, work, and social support network, is where the individual engages in a great deal of activities and interaction (Tudge et al., 2009). At this level, family caregivers' attitudes and actions exist within interpersonal relationships with other family members, friends, and acquaintances (Connidis, 2020). Family structure, including generational composition of families and ties between extended family members or blended families may affect how many family members are available to provide care and who is involved in care decisions during the transition to EOL care. Work environments may provide additional burdens or support as family caregivers adjust to the increasing care needs of their care receiver. Although social support networks can improve resilience in family caregivers, those networks often change or shrink as caregiving demands increase and caregivers' mobility and leisure time decrease (Roth, 2018). Each of these contexts are examples of microsystem influences that may help to improve or worsen outcomes for both families and family caregivers.

The mesosystem consists of interrelations between various microsystems. Results of these interrelations may include differences in family cohesion, family conflict, individual and family finances, and role adjustment or conflict. Families may experience improved family cohesion during the transition to EOL care (Given & Reinhard, 2017), as they unite to support their dying family member. Conversely, the transition to EOL caregiving may be a source of family conflict as families navigate differences in opinions about an appropriate course of action for the care receiver's treatment, the seriousness of their condition, or even supporting the primary family caregiver (Schulz et al., 2020). Another important element of the mesosystem is the financial resources of individuals and families. The potential costs associated with caregiving, such as adjusting the care receiver's living arrangements, income loss due to reduced employment (or early retirement), and the care receiver's need for long-term care services or home health care, can have long term impacts on the financial stability of many family members (Schroeder & Osteen, 2018). Without adequate financial resources, caregiving may place too heavy a burden on families and family caregivers, thus increasing the likelihood of negative outcomes. Another source of strain within the mesosystem relates to how family caregivers are often involved in multiple micro-level contexts, such as family responsibilities and employment. Caregiving can limit time available for other responsibilities, thus creating role conflict (Connidis, 2020).

The exosystem includes those contexts that individuals may not have direct interaction within, but that still may influence outcomes. For example, within the family system, extended or distant family members that had previously not been involved in family life may choose to get involved in decision-making as a care receiver nears the EOL (Given & Reinhard, 2017). Another context within the exosystem that is very important to family and family caregiver outcomes during the transition to EOL care is within health and social services. Families and family caregivers are often very involved in their care receiver's daily care, management of medicines, medical appointments, and treatment decisions (Schulz et al., 2018), yet they are often ignored by or disconnected from health care professionals (Qualls, 2018). Family members of a patient have limited access to health information and are not supported in their roles of providing care (Schulz et al., 2018). Without adequate support and information from health care professionals, families and family caregivers may not feel prepared for the decision-making process or responsibilities associated with the transition to EOL care.

At the macrosystem level, individual and family outcomes may be influenced by the opportunities and barriers created by cultural, social, economic, and political structures (Connidis, 2020). For example, individuals may take on the role of caregiver as a result of cultural values or societal expectations. Although many caregiving experiences are common among all races and ethnicities, research has shown that cultural values and family dynamics shape a range of psychosocial outcomes related to caregiving (Apesoa-Varano et al., 2015), including perceived burden and reward, interactions with health care services, and coping skills. In addition, social policies may provide support and funding for improved access to quality health care services or social and aging services (Henry et al., 2018). These programs, and the social norms and values that promote them, may help to improve outcomes for families and family caregivers.

Time

The third concept in the bioecological theory is time. Bronfenbrenner's construction of time is founded in life course theory (Elder & Giele, 2009), proposing two elements of time influential to development. First, individuals are embedded in and shaped by historical time, place, and events experienced over their lifetime (Bronfenbrenner & Morris, 2006). Second, the influence of life transitions or events on individual development varies depending on when they occur in a person's life (Bronfenbrenner & Morris, 2006). As individuals are living longer and fertility rates decline, family caregiving is now considered a normative life event (Roberto & Jarrott, 2008). However, several components of time are important to the family caregiving experience, including the timing of the transition to EOL care. For example, a family member who has provided care for an individual living with a diagnosis for many years may experience the transition to EOL care much differently than a family wherein an individual receives a sudden 6-month prognosis. Or, an 80-year-old woman caring for her spouse with a cancer diagnosis and a 30-year-old woman with a young child and career caring for a dying parent will likely have different expectations for and experiences of caregiving. Considering the component of time and how entry into the caregiving role and family caregiving transitions align with normative life-course developmental expectations is an important aspect of studying family and family caregiver outcomes.

Proximal Processes

The focus of the bioecological theory lies within its final concept, process. Process refers to forms of interaction between an individual and the environment (Bronfenbrenner & Morris, 2006). Bronfenbrenner posited that interactions that serve as the primary mechanisms producing human development, or proximal processes, must operate on a regular basis over time with increasing complexity (Bronfenbrenner & Morris, 2006). How proximal processes influence development vary depending on the functions of the remaining three key components of the theory: the characteristics of the person, the environmental contexts, and the timing in which the processes take place (Bronfenbrenner & Morris, 2006). For example, family caregivers report that one of the most difficult decisions they face is to stop curative care and shift to comfort care for the care receiver (Given & Reinhard, 2017). Furthermore, care-related decisions often cause additional stress due to family conflict over decision making uncertainty (Given & Reinhard, 2017). These examples demonstrate the importance of family communication, family support, and advance care planning for preparing family caregivers for the transition to providing EOL care. The bioecological model highlights the importance of examining family communication over time to determine the influence of this proximal process on family and family caregiver outcomes.

Communication between family members is crucial to improve preparedness for caregiving (Aoun et al., 2018). For example, conversations pertinent to caregiving may include caregiving responsibilities and expectations, sharing care responsibilities between family members, and older family members' (i.e., care receivers) preferences for future care and medical directives. These conversations may prepare family members for future caregiving responsibilities, decision-making, and the transition to EOL care. Yet, many family caregivers report not discussing care preferences with their care receiver (Aoun et al., 2018). Most families greatly underestimate the need to discuss EOL issues, even when family members approach old age (Egbert et al., 2017). Researchers have found that strained or nonexistent communication in aging families is highly correlated with family conflict and perceived low preparedness for the transition to EOL care (Kramer & Boelk, 2015; Nielsen et al., 2016). Advance care planning, or communication about preferences for EOL care, is considered essential for minimizing physical pain and emotional distress of the care recipient (Carr & Luth, 2017) and ensuring their treatment preferences are respected. In addition, advance care planning helps families cope with difficult emotions (Given & Reinhard, 2017) and lightens the burden of caregiving and family decision-making.

Many older adults and their families do not engage in advance care planning and communication about EOL issues to avoid facing mortality and dealing with difficult emotions

(Egbert et al., 2017). However, avoiding these conversations until a time of crisis or when a dying family member is unable to communicate their care preferences can result in more family conflict (Kramer & Boelk, 2015) and higher distress for caregivers (Carr & Luth, 2017). Family communication about care preferences and advance care planning can help prepare family caregivers for the transition to EOL care (Aoun et al., 2018) and allow family members to address potential conflict before a crisis occurs (Egbert et al., 2017). These findings suggest the importance of focusing on family communication and dynamics while examining caregiving experiences during the transition to EOL.

Outcomes

The last element of the conceptual framework encompasses family and family caregiver outcomes during and beyond the transition to EOL care. As a result of the influence of personal characteristics of each family member, context, time, and family processes, families may experience differences in relationship quality and adaptation to changing roles and responsibilities during the transition to EOL care. In addition, family caregivers may experience differences in perceived preparedness, burden appraisal, adaptation (or coping), and health and well-being (such as physical health, quality of life, self-care, and psychological reactions to stress) during this time. These family caregiver outcomes, in the context of general caregiving, are well-established in caregiving research. Yet, few studies have examined family caregiver or family outcomes during the transition to EOL care. Research has yet to establish how specific caregiving transitions, such as the transition to EOL care, may relate to caregiving outcomes at the individual and family level.

Family Outcomes

The transition to EOL care may be a point of crisis for families for a variety of reasons. Demographic shifts, such as late-life divorce and declining fertility rates, have created increasingly complex family networks in which members must navigate caregiving responsibilities (Carr & Utz, 2020). Further complicating such dynamics is the fact that family caregiving at the EOL requires families to adjust roles and has the potential to both place strain and even strengthen relationships (Rabow et al., 2004). For example, caregiving stress and responsibilities may cause stress throughout the family, beyond the primary caregiver and care receiver (Henry et al., 2018). Some caregivers struggle to relinquish old beliefs and feelings about the care receiver and their relationship, resulting in difficulty adjusting to new familial roles and expectations associated with EOL care (Roberto & Jarrott, 2008). One such expectation of family caregiving during the transition to EOL care that may cause additional emotional strain is the responsibility of medical care decision making. Despite actively participating in EOL decision-making, most families only receive sparse information on EOL care from health care providers and oftentimes it comes very late in the dying trajectory (Phillips & Reed, 2010). The EOL stage can also result in the presence of family members who have not been involved in previous care and decision-making, which may contribute to family conflict (Kramer & Boelk, 2015). Thus, family dynamics, including how families communicate, may play a role in the experiences of caregiving at the EOL.

Family Caregiver Outcomes

Although literature identifying the risks and rewards of family caregiving has been well established (Pinquart & Sörensen, 2003), the research addressing the antecedents and consequences of caregiving at the EOL is scant. However, it is known that many family caregivers report a lack of knowledge and skills necessary for providing EOL care and feel unprepared for this role (Given & Reinhard, 2017). During this transition period, family caregivers may be expected to meet the increasing physical needs of their care receiver, provide medical assistance that they are not trained for, cope with challenges associated with increasing cognitive decline, and balance responsibilities including caregiving, employment, and other family roles. Perceptions of low preparedness are associated with poor health and well-being outcomes in family caregivers (Nielsen et al., 2016). For example, feeling unprepared and lacking the ability to access support through family, friends, and/or service providers creates additional stress and burden for family caregivers (Ornstein et al., 2017). In addition, family members providing EOL care are even more vulnerable to depression, health problems, and increased mortality rates than the general population, and all aspects of their life are affected including physical, emotional, and social well-being (Oliver et al., 2013) than caregivers not providing EOL care. The strain and exhaustion of family caregiving impede caregiver self-care behaviors and results in relational deprivation from a loss of social contacts (Roberto & Jarrott, 2008). Compared to non-EOL caregivers, most EOL family caregivers report having no time for themselves (Ornstein et al., 2017).

Further complicating the EOL caregiving experience is the fact that many family caregivers, while providing intense care (e.g., home medical treatments, organization of medications) and making difficult care decisions (e.g., deciding when health needs are emergent), must adjust other family and work-related roles (Stephens & Franks, 2009) to accommodate the time and burden associated with EOL caregiving. Such family and work role adjustments may include family caregivers that are still employed and taking care of their own children (Stephens & Franks, 2009). Personal and social relationships may suffer from lack of involvement (Greene & Kropf, 2014) as caregiving responsibilities limit time available for social interaction (Lai & Thomson, 2011). Thus, role conflict (e.g., trying to balance work, family, and caregiving responsibilities) during EOL care may leave family caregivers more vulnerable to emotional stress and physical strain (Given & Reinhard, 2017). Recognizing the importance and burden of EOL caregiving, many family caregivers jeopardize their own health in the process of caring for another person (Roberto & Jarrott, 2008).

Whereas much of family caregiving research focuses on the negative outcomes associated with this role, there exists many benefits of providing care to a family member. With support from family, friends, and community services and resources, family caregivers can cope quite well with their role and derive benefits from the caregiving experience (Pinquart & Sörensen, 2003). Family caregivers report feeling closer to the family member being cared for, satisfaction at fulfilling one’s duty (Pinquart & Sörensen, 2003), and personal gain in the form of inner growth by instilling a sense of purpose (Bainbridge et al., 2009). Family members may gain a sense of competence and build confidence in other relationships as a result of their caregiving role (Roberto & Jarrott, 2008). Although these findings are not specific to EOL care, perhaps the transition to EOL caregiving may further enhance these experiences; future research should examine the rewards of providing care at the EOL. End-of-life caregivers often view their role as generative, in that they are nurturing others, contributing to society by providing care, and experiencing an intense awareness of their own mortality (Phillips & Reed, 2010). Caregivers may value the opportunity to enhance the care receivers’ present quality of life and create a legacy that honors them and their relationship (Phillips & Reed, 2010). It is clear that family relationships may play a key role in how family caregivers’ experience their role during the transition to EOL caregiving.

Bronfenbrenner urged the importance of using the bioecological theory to connect theory to research method and practice. Across theory, research, and practice, it is understood that human development is not fixed or linear. Every individual developmental trajectory, such as family caregivers', and family outcome is influenced and responsive to person characteristics, context, time, processes, and the interaction between these properties. In response to proximal processes, developmental and family outcome trajectories are continuously adapting, organizing and reorganizing, and subject to change across the lifespan (Osher et al., 2017). Our conceptual framework, utilizing bioecological theory, provides not only a path to examine how family dynamics influence family caregiver preparedness for the transition to providing EOL care, but also direction to bring theory and basic science together to improve support delivered to aging families and family caregivers.

Future Directions for Research Using This Conceptual Framework

Applying the proposed conceptual framework in future research studies allows for the examination of individual- and family-level constructs, the interactions between them, and a variety of aging and family caregiver outcomes. For example, a study on predictors of family conflict at the EOL found that it is important to evaluate historical and current family relationship quality, resources, and advance care planning discussions (Kramer & Boelk, 2015). Another example addresses the tasks and responsibilities of caregivers, of which a vast amount of research exists (Pinquart & Sörensen, 2011; 2003), and yet little is known about how and why families allocate tasks and responsibilities to certain family members, especially during the transition to EOL care. These examples highlight the gaps in caregiving research, which lacks focus on both family-level experiences and transitions to EOL care.

To advance theoretical and empirical research in family caregiving, research design must bridge the conceptual framework to applied research through thoughtful selection of research methods. Ultimately, a mixed-methods, longitudinal study that allowed for following individuals and families through their caregiving experiences, including before and during the transition to EOL care, throughout EOL caregiving, and through bereavement would be ideal. However, it is important to establish empirical support of the conceptual framework before investing time and resources in such a longitudinal study. A quantitative approach allows for the exploration of operationalized constructs identified in the framework, including the relationships between possible mediators and moderators of family and family caregiver outcomes. As previously reviewed, such mediators and moderators include family communication, family support, advance care planning, and care-related family decision making. Following the establishment of basic science, research on families and the transition to EOL care can progress to family-level intervention development and testing.

A brief review of caregiver intervention meta-analyses and systematic reviews (Corry et al., 2014; Knight et al., 1993; Lopez-Hartmann et al., 2012; Northouse et al., 2010; Schulz et al., 2020; Sörensen et al., 2002) reveal several gaps in applied research relevant to the transition to EOL caregiving. Intervention programs specific to the EOL caregiver population are limited, and of those that exist, few interventions have been rigorously tested, are descriptive in nature, and include only small pilot studies (Oliver et al., 2013). There is growing recognition for the need to develop programs to help family caregivers self-identify and recognize the importance of seeking help from family members, friends, and community services and resources when making the transition to EOL care so they can provide effective care, best meet the EOL wishes for their family member, and protect their own well-being (Rosalynn Carter Institute for Caregiving

[RCIC], 2012). Using the conceptual framework proposed in this review to guide development of interventions may enhance the assistance already provided by hospice and palliative care programs and provide opportunities to reach families and caregivers before they become overwhelmed with the responsibilities of providing EOL care.

These recommendations can guide future research in family dynamics across the life course and EOL caregiving and support the development of intervention programs that aim to improve the health and well-being of family caregivers. The proposed conceptual framework, founded in principles of bioecological theory, can be used to examine how family dynamics may be associated with preparedness for the transition to EOL care. This basic science is the first step to inform the development of a family-level, strengths-based intervention. Developing and testing the efficacy of an intervention will be the next step to determine if family factors, such as cohesion, flexibility, and communication, may improve family caregiver preparedness for the transition to EOL caregiving. When theory and basic science guide the development of interventions and programs that support families through caregiving transitions, family caregivers may be more prepared to provide quality care to their care receiver, which results in improved well-being for both (RCIC, 2012). Expanding theory and research foci from the family caregiver and care-receiver dyad to family caregiving systems will improve researchers' ability to explore the diverse and complex contexts of family caregiving. The conceptual framework for family dynamics and the transition to EOL caregiving provides a theoretically sound base from which to guide advances in caregiving research.

Conclusion

The research presented in this review demonstrates the importance of advancing theoretical and empirical approaches to understanding the experiences of families and their caregiving experiences during the transition to EOL care. Caregiving research abounds, yet researchers and practitioners must not assume the results apply to all family systems and caregiving experiences, including the transition to EOL care. The purpose of this study was to briefly review the research on EOL family caregiving and provide an innovative conceptual framework with which to examine how family dynamics may be associated with how family caregivers experience the transition to EOL caring. Caregiving is now considered a normative event in the life course and focusing on caregiving transitions and the family context may offer novel methods to improve caregiver outcomes. In the future, we plan to use the conceptual framework to guide research and intervention development to investigate why and how families get involved in EOL caregiving, how families navigate EOL caregiving decisions, and how family dynamics relate to resilience during the transition to EOL care. We hypothesize that investigating these questions within the family context of caregiving will lead to identification of new variables that impact family caregiver health, well-being, burden appraisal, and preparedness for the transition to EOL care. Ultimately, the gaps in caregiving research and recommendations in aging research have necessitated new approaches to study design and intervention development. Our conceptual framework for the transition to EOL family caregiving offers a dynamic and innovative theoretical approach to studying the complexities of family caregiving and may perhaps create a space for new research questions on the quest to advance the study of family caregiving.

CHAPTER 3

FAMILY CAREGIVERS' FEELINGS OF PREPAREDNESS FOR THE TRANSITION TO END-OF-LIFE CAREGIVING

Family caregiving is a role that many individuals will assume at some point in their lives. In fact, nearly 20% of adults are providing some type of care to an adult family member or friend with health or functional needs (National Alliance for Caregiving (NAC) & AARP, 2020). Family caregiving can be broadly defined as providing assistance to another adult individual, including a family member, partner, friend, or neighbor (Gitlin & Wolff, 2011; National Academies of Sciences, Engineering, and Medicine (NASEM), 2016) in a variety of circumstances, including different living arrangements and duration and type of care provided. Regardless of how researchers, health care professionals, service providers, families, or individuals define the caregiving role, family caregiving is now considered a normative developmental experience (NASEM, 2016) that brings with it a variety of challenges and opportunities. As family caregivers represent nearly every age, and all genders, races, ethnicities, and income-levels, improving outcomes for family caregivers should be a national priority and of critical importance in research.

Decades of research on family caregiving has confirmed that the stressors and burdens associated with caregiving can negatively affect a caregiver's physical and emotional health and well-being (Goode et al., 1998; Pinquart and Sörensen, 2003; Schulz 2020). However, researchers continue to study the varying contexts family caregiving occurs within to better understand and address specific factors that may improve caregiver outcomes. For example, health care for an aging or ailing family member continues to move increasingly into family homes, placing more caregiving responsibilities and burden on the family caregiver (McMillan, 2005). In addition, those caregiving responsibilities often intensify as the age or disease of care receivers progresses (Bainbridge et al., 2009).

Providing care for a family member at the end of their life brings additional psychological, physical, and financial burden to family caregivers (Bainbridge, et al., 2009). End-of-life (EOL) caregiving can be defined as “comprehensive care that addresses medical, emotional, spiritual, and social needs during the last stages of a person’s terminal illness. Much of this care is palliative or supportive, and provided when life-prolonging treatment and interventions are no longer appropriate” (Given & Reinhard, 2017, p. 50). Few studies exist that examine how family caregivers prepare for the additional challenges and burdens associated with EOL caregiving, and researchers are beginning to recognize that the transition to EOL caregiving is a distinction in the caregiving role that warrants further investigation (Ornstein et al., 2017). Examining the mechanisms that help family caregivers feel more prepared for the unique challenges associated with EOL caregiving may help improve family caregiver health and well-being. This research may support family caregivers in their role as a caregiver, but also as they experience the death of their care receiver and through bereavement and grief. Although studies continue to explore the diverse contexts of caregiving, including the trajectories of care between different diagnoses and aging outcomes, advancing caregiving research requires an investigation of how family caregivers navigate these transitions and how prepared they feel to take on additional and potentially more complex caregiving responsibilities.

Literature Review

Family Caregiving Transitions

Along the caregiving trajectory, there are several transitions that may require family caregivers to adjust the amount and type of care they provide (NASEM, 2016). These transitions often bring new challenges for family caregivers. For example, one study found that abrupt changes in the caregiving role, such as from a medical emergency, are associated with increased stress and depression over time (Ivery & Muniz, 2017). In addition, family caregivers must often adjust other roles and responsibilities (such as employment and parenting) to meet the increasing care needs of their care receiver (NASEM, 2016). Caregiving transitions may even be perceived as times of crisis for families (Christ & Blacker, 2005) if family members disagree about the course of action for medical treatment, where treatment should be provided, or how family roles and responsibilities must shift to accommodate transitions in care (NASEM, 2016). As families navigate these decisions and family caregivers experience increasing complexity and scope of their caregiving responsibilities, caregivers may also experience greater stress and tension as they balance the expectations of family members, the needs of the care receiver, and their own health and well-being (Ivery & Muniz 2017). Yet, research on family caregivers' experiences during caregiving transitions is limited (Burton et al., 2003; Given & Reinhard, 2017). Caregiving transitions are often anticipated periods of time that may be an opportunity to provide education and support to family caregivers (Christ & Blacker, 2005), which may improve caregiver health and well-being outcomes.

Caregiver Preparedness

Preparation for the caregiving role and future caregiving transitions is essential for adapting to and coping with the stressors and emotions associated with caregiving (Waldrop et al., 2005). Caregiving preparedness has both practical and emotional components (Waldrop et al., 2005), can range from the abstract (becoming aware of care needs) to concrete activities (such as advance care planning conversations) (Fowler & Fisher, 2009), and can be broadly defined as family caregivers’ perception of their readiness for the tasks, responsibilities, and demands of the caregiving role (Henriksson & Ârestedt, 2013). Gitlin and Wolff (2011) identified several core competencies families and family caregivers need for caregiving transitions, including effective communication, problem-solving skills, advocacy, conflict management, coordination of care, and self-care. In addition, family caregivers need specialized knowledge and skills relevant to their care receiver’s particular needs (NASEM, 2016). Preparedness for the caregiving role may protect family caregiver well-being (Henriksson & Ârestedt, 2013), yet most caregivers receive inadequate preparation for the responsibilities they assume (NASEM, 2016). In addition, studies have shown that families rarely prepare for future care needs (Fowler & Fisher, 2009; Gitlin & Wolff, 2011; Given & Reinhard, 2017), nor do they communicate with each other about their expectations for caregiving or care receiving. Without taking steps to prepare for future care needs or communicating with family about wishes and plans for future health goals and medical treatment, family caregivers may lack the knowledge, tools, and skills necessary for adhering to their care receiver’s expectations for care and meeting the challenges of caregiving.

Without the resources required for caregiving, including insufficient health care information, coping skills, help from other family members or formal care, and community resources, family caregivers can experience high levels of stress (Roth et al., 2015), worry, depression, and caregiver burden (Henriksson & Ârestedt, 2013). Specific to caregiving transitions, feelings of preparedness may protect family caregivers from perceiving caregiving as increasingly challenging and burdensome as care receiver's needs change and caregiving demands increase (Henriksson & Ârestedt, 2013).

During the transition to EOL caregiving, family caregivers and other family members may face important and emotional medical decisions (such as shifting from curative to comfort care) and increasing care needs of the care receiver. Researchers have suggested that experiences and planning in the early stages of an illness and caregiving may shape caregivers' preparedness and expectations for care during the EOL stage (Penrod et al., 2011). Yet, studies in family caregiving research that focus on preparedness for EOL caregiving are limited.

Preparedness for EOL Caregiving

The EOL stage is often difficult to define for both families and health care professionals, however, Waldrop and colleagues (2005) identified four characteristics associated with the transition to EOL caregiving. First, families recognize the terminality of the care receiver's illness and that they are dying. Next, health care professionals share information about the changing care needs of their patient, often discussing the option of the transition from curative to comfort care or offering palliative or hospice care. In addition, family members and caregivers often observe declines in their care receiver's physical and executive functioning. Finally, the transition to EOL caregiving is often marked by final care decision making. Defining preparedness for this stage of caregiving should include feelings of readiness for the emotional, psychosocial, and spiritual challenges associated with loss and the approaching death of the care receiver (Nielsen et al., 2016).

The few studies that examine preparedness for EOL caregiving typically focus on how a family caregiver is preparing for the death of their care receiver (Nielsen et al., 2016) rather than preparedness for the transition to EOL caregiving. Of these studies, low preparedness for EOL caregiving has been associated with increases in caregiver depression and anxiety (Aoun et al., 2018), less frequent use of hospice services (Kumar et al. 2020), and complicated grief after the care receiver dies (Nielsen, et al., 2016). Yet, several barriers are identified in caregiving research that may hinder preparation for EOL caregiving. For example, as their care receivers near the end of life, family caregivers tend to focus on the needs of the care receiver over their own well-being (Penrod et al., 2011). In addition, information and resources from health care providers or hospice personnel to support family caregivers often comes too late in the dying trajectory to prepare them for the EOL caregiving role (Phillips & Reed, 2010). Further exacerbating the lack of support for family caregivers during this time, almost one in four family caregivers providing EOL care report that they provide care without help from other family members or friends (Ornstein et al., 2017). These studies demonstrate how the psychosocial burden on family caregivers during EOL caregiving may exceed the burden of care needs of the care receiver (Oechsle, 2019), and highlight the importance of preparing for this role.

When family caregivers feel prepared for the EOL transition, they experience lower levels of caregiver strain (Henriksson & Ârestedt, 2013) and families experience less conflict over EOL decision making (Fowler & Fisher, 2009; Gitlin & Wolff, 2011; Waldrop et al., 2005). Caregiver preparedness for the transition to EOL caregiving may be associated with better mental health (Henriksson & Ârestedt, 2013) and positive caregiving outcomes such as a stronger relationship with their care receiver (Pinquart & Sörensen, 2003), inner growth and a sense of purpose (Bainbridge et al., 2009), and confidence in their caregiving role (Roberto & Jarrott, 2008). As more individuals are living longer, and caregiving responsibilities increasingly fall to family members, identifying the risk factors associated with a lack of preparation for the caregiving role is important for improving outcomes for family caregivers. Overlooking the transition to EOL caregiving as a critical point for family caregivers' physical, mental, and emotional well-being is a barrier to advancing caregiving research. Addressing this gap in caregiving research is crucial for understanding and supporting family caregivers' health and well-being across the caregiving trajectory and through the death and bereavement of their care receiver.

Theoretical Framework

Bioecological theory (Bronfenbrenner & Morris, 2006) provides the foundation for this study, and the Conceptual Framework for a Bioecological Model of Family Dynamics and the Transition to EOL Caregiving (Fox et al., 2021) is used to examine concepts related to preparedness for family caregiving. Bioecological theory focuses on four areas that predict individual developmental outcomes: person, context, time, and proximal processes (Bronfenbrenner & Morris, 2006). In this study, it is important to examine what factors in each of these focus areas may be associated with preparedness for EOL caregiving. Personal factors, such as age, gender, and race, may be associated with preparedness, as they are known to be related to disparities in caregiving intensity and caregiver quality of life (Cohen et al., 2017). For example, an older adult caring for a spouse may feel more prepared for the caregiving role than a young adult caring for a parent with new medical diagnosis. Similarly, context also matters. For family caregivers, contextual factors that may be related to preparedness include the reasons they are providing care (and their willingness to take on that role), the burdens associated with caregiving responsibilities, and varying contextual characteristics of caregiving, such as the care receiver's diagnosis or how many other family members help provide care. Time may also contribute to preparedness, such that passage of time may allow family caregivers to build skills, establish a support network, or develop a routine for providing care. Finally, the interactions between an individual and contexts and environments, or proximal processes (such as family communication), may be associated with family caregivers' feelings of preparedness for the transition to EOL caregiving. Further exploration of these focus areas may provide a better understanding of what may be indicators of varying levels of caregiving preparedness, or what factors may be associated with feelings of preparedness for the EOL caregiving role.

Purpose of this Study

This study is an exploration of family caregivers' feelings of preparedness for the transition to EOL caregiving. As demonstrated in the literature review, few studies have focused on the antecedents of preparing for EOL caregiving, and this study may inform future basic and applied research and practice to identify individuals who may feel underprepared to take on the role of providing care at EOL. Exploration of this topic and future studies may also help identify mechanisms of change for preparing families and individual caregivers for the transition to EOL care and improve family caregiver health and well-being outcomes. The purpose of this study is to investigate how family caregivers perceive their preparedness for the transition to EOL care, and what factors may be associated with those feelings of preparedness. This study is a foundational component of answering a broader research question examining if and how family dynamics are associated with family caregivers' feelings of preparedness for the transition to providing EOL care. Based on previous research described in the literature review and using bioecological theory to guide this research, this study tests the following hypotheses:

H1: Personal demographics such as age, gender, race, education, and income, will be associated with feelings of preparedness for EOL caregiving.

H2: Characteristics of caregiving, such as having another person providing care, will be associated with feelings of preparedness for EOL caregiving.

H3: Cultural reasons for providing care will be associated with preparedness for EOL caregiving, such that family caregivers with more cultural reasons for caregiving will feel more prepared for EOL caregiving than caregivers with less cultural reasons for caregiving.

H4: Burden of caregiving will be associated with preparedness for EOL caregiving, such that family caregivers who report greater perceived caregiving burden will be associated with lower feelings of preparedness than caregivers who report less perceived caregiving burden.

H5: Duration of care will be associated with preparedness for EOL caregiving, such that family caregivers who have provided care for longer will feel more prepared for EOL caregiving than caregivers providing care for shorter periods of time.

H6: Number of tasks completed related to EOL conversations and decision making will be associated with preparedness for EOL caregiving, such that family caregivers who have completed more tasks will report feeling more prepared for EOL caregiving than caregivers who have completed fewer tasks.

Method

Sample

Prior to national recruitment efforts, a survey for family caregivers was pilot tested with six participants. These participants provided feedback on the ease of survey completion, clarity of questions, and how responses may have been different given survey completion during the COVID-19 Pandemic (Savla et al., 2021). Recommended changes, including minor edits and the addition of definitions for certain terms, were made to the survey and efforts began for wide distribution.

Online communication and advertisements were employed to recruit 523 family caregivers for this study. A variety of national and local aging and caregiving service agencies shared a recruitment flyer in emails or newsletters to their guests or clients. The agencies and services included county offices on aging, adult day care centers, caregiver support groups, religious organizations, and professional organizations related to aging and family caregiving research. In addition, recruitment flyers were posted around local grocery stores, community centers, and public libraries. The recruitment flyer and communication included a short description of the research aims, a definition of a family caregiver, eligibility criteria, and a link to the survey website hosted on a Qualtrics application (Qualtrics, 2020). To be eligible to participate in the study, individuals needed to consent to participate and be over the age of 18 years old providing unpaid care to a family member over the age of 18 years old. Participants were asked how many family members they were providing unpaid care or assistance to, and if more than one, were asked to complete the survey referring to the individual they provide the most care to as their care receiver. Individuals were excluded from analysis if they had been providing care for less than six months, knowing that the first few months of caregiving can be an adjustment period that may impact feelings of preparedness.

Procedure

All human subject procedures complied with the institutional review board protocol. After recruitment, family caregivers were asked to complete a self-report survey online. The survey took 20 to 30 minutes to complete, and participants were instructed that they could pause survey completion and return to the survey within two weeks. The survey was anonymous and de-identified if the participant provided follow-up contact information. Participation and survey completion was voluntary, and compensation was provided in the form of a drawing for one of ten $50 Amazon gift cards. Study participants were required to read a cover letter that included consent prior to accessing the survey. The letter explained the study purpose, potential harms and benefits, and the procedure to maintain anonymity of information shared. Participants were informed that there were no known risks or benefits for participating in the survey. However, because survey questions may have brought up negative feelings or emotions, participants were told the research team would coordinate with local agencies to make a referral for counseling services in their area if necessary. Participants were informed of the importance of the survey to better understand the strengths and needs of caregivers and their families in order to inform research, services, and programming for caregivers.

Measures

The survey measures used in this study had strong psychometric properties and additional questions related to the caregiving experience were created based on bioecological theory. The survey included questions about caregiver and caregiving characteristics, demographics of the caregiver and care receiver, preparedness, cultural reasons for caregiving, and burden appraisal (stress associated with caregiving).

Preparedness

Preparedness was assessed using an adaptation of the Preparedness for Caregiving Scale (PCS; Archbold et al., 1990). The PCS measures how well-prepared caregivers believe they are for different domains of caregiving. The PCS includes questions such as “How well prepared do you think you are to take care of your family member’s physical needs,” and “How well prepared do you think you are to get the help and information you need from the health care system.” (Zwicker, 2018). Participants respond on a 5-point Likert scale ranging from *not at all prepared* (1) to *very well prepared* (5). Responses were scored by taking the mean of all items answered, with higher scores indicating the caregiver feels more prepared for caregiving and lower scores indicating feeling less prepared. Multiple studies have reported on the internal consistency of the PCS (Archbold et al., 1990; Hudson & Hayman-White, 2006; Pucciarelli et al., 2014), with Cronbach's alpha ranging from .88 to .94.

To further investigate perceptions of preparedness for the transition to providing EOL care, 6 items were added to the PCS in the survey. Questions added include "How well prepared do you think you are to meet the end-of-life medical needs of your care receiver," and "How prepared do you think your family members are (or were) for the transition to end-of-life care for your care receiver?". The additional items were reported on the same 5-point scale and scored using the PCS method. Cronbach's alpha for the extended preparedness measure (including both the established and new questions) was .94, indicating the measure was reliable with this sample of caregivers.

Number of Tasks Completed to Prepare for the Transition to EOL Care

The number of tasks completed to prepare for the transition to EOL care measure was created to identify the different steps caregivers had taken to prepare for EOL caregiving. The measure included nine tasks ranging from have you "talked to your care receiver about their spiritual or religious needs when nearing the end of their life" to have you "signed official papers naming a person or group of people to make medical decisions for your care receiver if they become unable to do so". For each question, participants were presented with a two-part option for responding. First, caregivers could choose between *No, but I plan to approximately…* or *Yes, I did this approximately….* If they responded *yes*, they had the option to choose if they had done this approximately *3 months ago*, *6 months ago*, *1 year ago*, or *more than a year ago*. If participants responded *no*, they had the option to choose if they planned to complete this task approximately *3 months from now*, *6 months from now*, *1 year from now*, *more than a year from now*, *I never plan to discuss this*, or *I don't know*. For the purpose of this study, responses were coded as *no* or *yes* for completing each task and summed to create a scale score of number of tasks completed related to preparing for EOL caregiving.

Cultural Reasons for Caregiving

The Cultural Justifications for Caregiving Scale (CJCS; Dilworth-Anderson et al., 2005) was used to measure caregivers' cultural reasons and expectations in providing care. Participants were presented with a dichotomous response (no or yes) and the 10-item measure was scored by summing responses. Questions include "I give care because I was taught by my parents to take care of older dependent family members," and "I give care because my family expects me to provide care". Higher scores indicate stronger cultural reasons for giving care. Cronbach's alpha from a sample of caregivers (Dilworth-Anderson et al., 2005) was .86. The measure also had acceptable reliability with this sample of family caregivers ($\alpha = .75$).

Burden Appraisal

Burden appraisal was assessed using the Short Form Zarit Burden Interview (ZBI-12; Bédard et al., 2001). The 12-item scale measures the perceived stress of providing care on the physical and emotional health, relationships, and social life of caregivers. Participants responded using a 5-point Likert scale ranging from 1 (*Never*) to 5 (*Nearly always*). Questions include "Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)," and "Do you feel that your relative currently affects your relationship with family members or friends in a negative way". A recent study of the ZBI-12 resulted in very good internal consistency, $\alpha = .81$, for use with family caregivers (Gratão et al., 2019), and was highly reliable ($\alpha = .91$) with this study's sample of family caregivers.

Caregiving Stage

To further examine the characteristics of care provided by family caregivers, and to understand how family caregivers defined their role, caregivers were asked to describe their current stage along a caregiving trajectory on a sliding scale. Participants could respond along the following categories: *sporadic care* (awareness of problem, accompany to doctor, help with light errands, checking-in, monitoring), *regular care* (monitor symptoms or medication, coordinate care, helping with household tasks), *increasing care demands, personal care* (increased supervision of care receiver, personal care assistance, provide health care assistance or manage symptoms), *end-of-life and comfort care* (advance care planning, minimize suffering and symptom control, provide emotional support), or *nearing death of care receiver*. This scale of a caregiving trajectory was adapted from an example of a dementia care trajectory (NASEM, 2016).

Data Analysis

After data were collected, recorded, and coded, analyses were conducted in SPSS version 26 (IBM, 2019) to examine study hypotheses. The data were analyzed to investigate how family caregivers perceive their preparedness for the transition to EOL care, and what factors may be associated with those feelings of preparedness. Descriptive statistics were used to identify the demographic characteristics of family caregivers included in the study, as well as characteristics of their caregiving role and responsibilities. Next, a parallel analysis and exploratory factor analysis (EFA) was conducted to decompose the construct of caregivers' feelings of preparedness. Maximum likelihood extraction with direct oblimin rotation was used to extract factors. Upon extraction and rotation, each factor was identified and labeled. After the EFA was conducted, several one-way analyses of variance (ANOVA) and Tukey's HSD post-hoc tests were conducted to examine differences in the means of the preparedness for EOL caregiving factor by levels of different caregiver demographics and characteristics (gender, race, ethnicity, marital status, education level, employment, income, living arrangement with the care receiver, how many individuals caregivers are providing care to, the relation of the care receiver to the caregiver, duration of care, hours of care provided each week, if there is another care provider for the care receiver, and stage of care along the caregiving trajectory). A multiple regression analysis was conducted to examine which of the hypothesized predictors (i.e., cultural reasons for caregiving, burden of caregiving, duration of care, and number of tasks related to EOL caregiving completed) were associated with mean differences in the preparedness for EOL caregiving factor after controlling for caregiver demographics.

Results

Sample demographics and characteristics

Of the 523 individuals who accessed the survey, 252 family caregivers were included in analyses for this study (see Figure 3.1). Results from Little's Missing Completely At Random test (χ^2 (179, N = 336) = 171.497, p = .643) indicated that data were missing at random, therefore, participants with no responses to the preparedness measures were removed from analysis using listwise deletion. The age of family caregivers ranged from 20 years old to 81 years old (M = 52.5 years, SD = 14.53 years), whereas the age of their care receiver ranged from 18 years old to 97 years old (M = 68.5 years, SD = 18.24 years; Table 3.1). The average family caregiver participant was female (55.2%), White (50.4%), non-Hispanic, Latino, or Spanish origin (51.6%), married or in a domestic partnership (49.2%), employed full-time (19.8%), earned a bachelor's degree (16.7%), had a yearly household income above the national poverty level for a 4-person household (45.6%), and lived with their care receiver (42.1%).

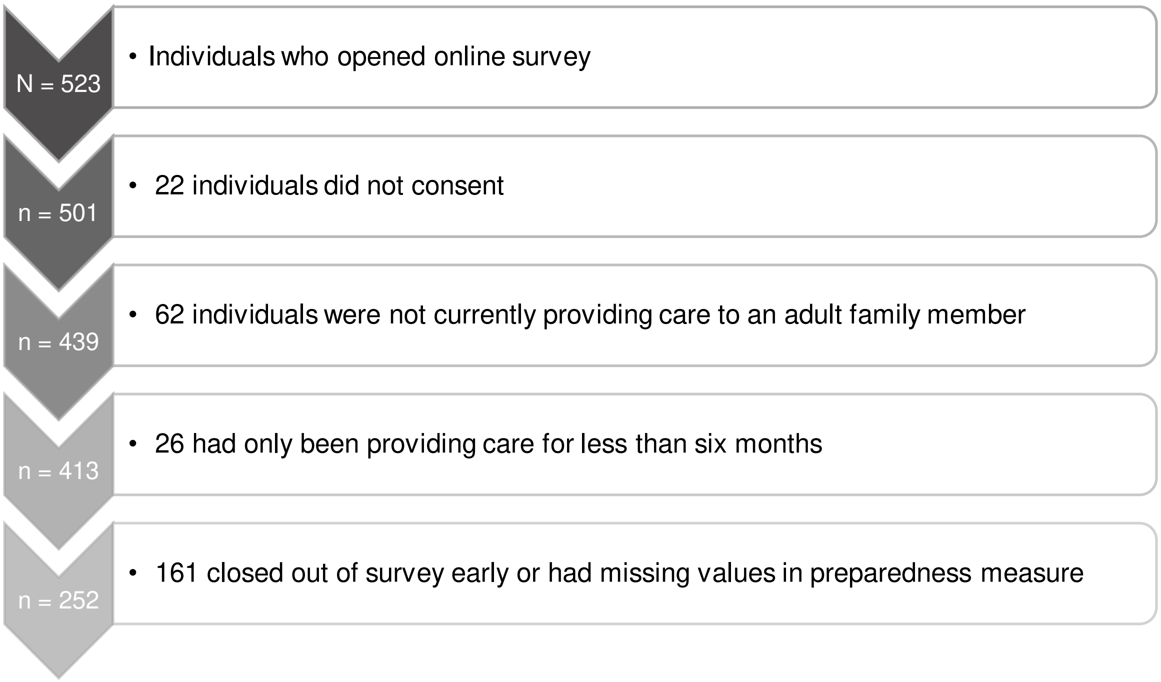

Figure 3.1. *Flow Diagram of Online Cross-Sectional Survey Completion by Individual Family Caregivers.*
Note. The total number of individuals who completed the preparedness measure, *n* = 252, were included in this analysis.

Table 3.1. *Sample Demographic Characteristic Descriptive Statistics Including Mean (M) and Standard Deviation (SD) for Age and Sample Size (n) and Percentage (%) for Categorical Characteristics for the Participants Eligible for the Study (N = 252).*

		Caregiver		**Care Receiver**	
		M	***SD***	***M***	***SD***
Age, years	Caregivers: 20-81	52.5	14.53		
Range	Care receivers: 18-97			68.5	18.24
		n	***%***	***n***	***%***
Gender identity					
	Female	139	55.2	78	31.0
	Male	22	8.7	81	32.1
	Non-binary	0	0.0	1	0.4
	Prefer not to say	2	0.8	1	0.4
Race					
	American Indian or Alaskan Native	2	0.8	1	0.4
	Asian	6	2.4	6	2.4
	Black or African American	12	4.8	14	5.6
	White	127	50.4	128	50.8
	Other or multiple race	16	6.3	14	5.6
Ethnicity					
	Hispanic, Latino, or Spanish origin	22	8.7	18	7.1
	Not Hispanic, Latino, or Spanish origin	130	51.6	135	53.6
Marital Status					
	Single, never married	17	6.7	24	9.5
	Married or domestic partnership	124	49.2	83	32.9
	Widowed	5	2.0	41	16.3
	Divorced	17	6.7	13	5.2
	Separated	0	0.0	2	0.8
Employment status					
	Employed full-time	50	19.8	8	3.2
	Employed part-time	34	13.5	9	3.6
	Unemployed, stay-at-home parent	15	6.0	5	2.0
	Unemployed, student	2	0.8	3	1.2
	Unemployed, looking for work	5	2.0	1	0.4
	Unemployed, not looking for work	2	0.8	4	1.6
	Unemployed, disabled/not able to work	6	2.4	41	16.3
	Retired	49	19.4	92	36.5
Highest level of education completed					
	Less than high school	3	1.2	29	11.5
	High school/GED	24	9.5	50	19.8
	Post-secondary technical training	12	4.8	8	3.2
	Some college	35	13.9	20	7.9
	Associate degree	14	5.6	8	3.2
	Bachelor's degree	42	16.7	31	12.3
	Graduate degree	33	13.1	16	6.3
Yearly household income based on national poverty level:		**4-person household**		**2-person household**	
	Below poverty level	47	18.7	81	32.1
	Above poverty level	115	45.6	80	31.7
Living arrangements for caregiver/care receiver dyad					
	Caregiver lives with care receiver			106	42.1
	Lives apart from care receiver:				
	Care receiver lives in own home, alone			26	10.3
	Care receiver lives in own home with spouse or partner			21	8.3
	Care receiver lives in an assisted living facility			9	3.6
	Care receiver lives in a skilled nursing facility			1	0.4

Note. Frequencies and percentages may not sum to group totals due to unreported data.

Although most family caregivers were providing care for only one person, more than 23% were providing care for two or more individuals (Table 3.2). Thirty-nine percent of caregivers were providing care to a parent, 30.2% to a spouse, and the rest to other family members. Most family caregivers had been providing care for one to three years (40.5%) and providing more than 40 hours per week of care (40.5%). Forty-five percent of caregivers had another person who was also providing care for their care receiver, and of those, 13.9% were the care receiver's adult child, 8.3% were the care receiver's spouse or partner, and 7.9% were a professional or paid caregiver. Most (18.3%) of the additional caregivers spent six to twenty hours per week providing care. Of family caregivers who identified their caregiving stage, most were at the stage of *increasing care demands and need for personal care* (36.9%)*,* and only 9.1% of family caregivers identified their caregiving stage as providing *end-of-life or comfort care* or *nearing death of their care receiver*.

Of family caregivers in this study, the most commonly reported primary conditions of their care receiver included Alzheimer's disease or dementia (38.8%, *n* = 98), physical disability (28.6%, *n* = 72), and intellectual, cognitive, or developmental disability (18.2%, *n* = 46) (Figure 3.2). Additional descriptive statistics provide an overview of the tasks related to EOL caregiving family caregivers had completed or not (see Table 3.3). The most commonly completed task was discussing or planning legal and financial matters (such as estate planning and wills) (*n* = 103, 40.9%) and signing official documents naming a person or group of people to make medical decision for the care receiver if they became unable to do so (*n* = 94, 37.3%). Despite these preparations, the majority of family caregivers (ranging from 63% to 73%) had not talked with their care receiver about the emotions they may be feeling, their spiritual or religious needs, or their social needs as they approach the EOL.

Table 3.2. *Sample Caregiver Characteristics Descriptive Statistics Including Sample Size (n) and Percentage (%) of Categorical Characteristics for the Participants Eligible for the Study (N = 252).*

	n	*%*
How many family members providing care for?		
One	193	76.6
Two or more[1]	59	23.4
The person you provide care for is your:		
Spouse or partner	76	30.2
Parent	99	39.3
Adult child	20	7.9
Sibling	14	5.6
Other family member[2]	43	17.1
How long providing care for family member?		
6 months to 1 year	34	13.5
1 to 3 years	102	40.5
4 to 10 years	66	26.2
More than 10 years	48	19.0
How much time do you spend each WEEK providing care?		
5 hours per week or less	28	11.1
6 to 20 hours per week	77	30.6
21 to 40 hours per week	45	17.9
More than 40 hours per week	102	40.5
Is there another person who also provides care for your care receiver?		
No	137	54.4
Yes	115	45.6
What is that person's relationship to care receiver?		
Spouse or partner	21	8.3
Parent	13	5.2
Adult child	35	13.9
Sibling	9	3.6
Other family member	9	3.6
Friend	4	1.6
Professional or paid caregiver	20	7.9
Other	3	1.2
How much time does that person spend each week providing care?		
5 hours per week or less	22	8.7
6 to 20 hours per week	46	18.3
21 to 40 hours per week	21	8.3
More than 40 hours per week	25	9.9
Identify where you would best describe your current stage along caregiving trajectory:		
Sporadic care	9	3.6
Regular care	30	11.9
Increasing care demands, personal care	93	36.9
End-of-life, comfort care	17	6.7
Nearing death of care receiver	6	2.4

Note. Frequencies and percentages may not sum to group totals due to unreported data.

[1] If providing care for more than one person, participant was asked to complete all questions referring to the individual they provide the most care for.

[2] Other family members included Aunt, Uncle, Grandparent, Sister-, Mother-, or Father-in-law, Cousin, Ex-spouse, Partner's parent.

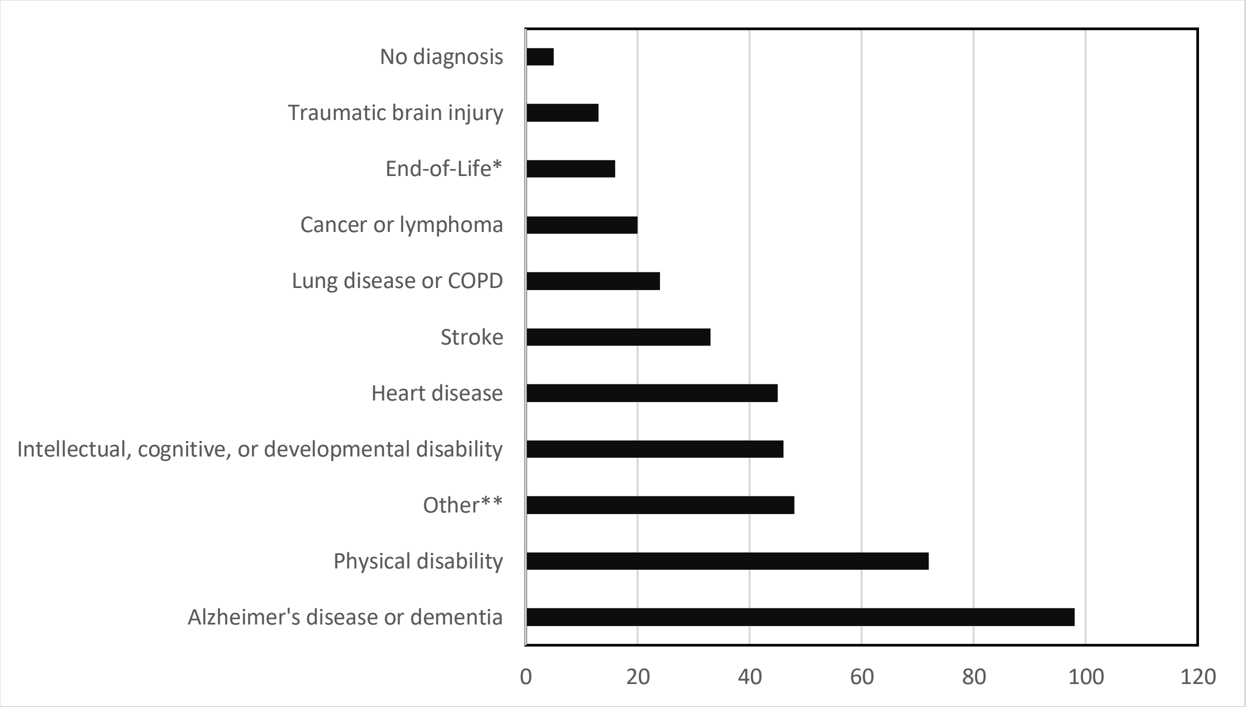

Figure 3.2. *Number of Participants with Particular Primary Condition(s) of the Care Receiver, as Reported by the Caregiver in Sample (N = 252)***.**

*End-of-life defined as "person has stopped treatment to cure or control their disease and is nearing end-of-life, may include palliative care, supportive care, and hospice care."

**Other diagnoses included: ALS, arthritis, cerebral palsy, chronic pain, COVID-19, diabetes, mental illness, multiple sclerosis, Parkinson's disease, PTSD, and schizophrenia.

Table 3.3. *Responses of Whether Caregivers (N = 252) Had Completed Tasks Related to Preparing for Their Care Receiver's (CR) End of Life (EOL) Where N is the Number of Participants that Responded to the Question, and n and % are the Number and Percentage of Participants that Responded to the Question Affirmatively, Respectively.*

	n	Yes
Talked with CR about emotions they may be feeling when nearing the EOL (N=156)	42	26.9%
Talked with CR about how to meet their spiritual or religious needs when nearing the EOL (N=155)	56	36.1%
Talked with CR about how to meet their social needs as they near EOL (N=158)	43	27.2%
Talked with CR about the kind of medical care they would want if they were very sick or near EOL (N=156)	84	53.8%
Talked with CR's doctor about the kind of medical care they want if they are very sick or near EOL (N=157)	74	47.1%
Signed official papers putting CR's wishes in writing about the kind of medical care they want if they are very sick or near EOL (N=156)	87	55.8%
Signed official papers naming a person or group of people to make medical decisions for CR if they become unable to do so (N=154)	94	61.0%
Discussed or planned legal and financial matters (estate planning, will, etc.) (N=155)	103	66.5%
Talked with CR about what they would like planned for funeral arrangements (N=156)	85	54.5%

Note. Samples sizes (*N*) do not total study sample size (N = 252) due to incomplete survey measure.

The Structure of Caregivers' Feelings of Preparedness

On average, family caregivers felt the most prepared to respond to and handle emergencies that involve their care receiver (*M* = 3.60, *SD*, 1.147), and felt least prepared to meet their care receiver's emotional needs at the end of their life (*M* = 2.61, *SD* = 1.351; Table 3.4). Family caregivers also reported, on average, that other family members are not too well prepared for the care receiver's transition to EOL care (*M* = 2.34, *SD* = 1.251).

Exploratory Factor Analysis

An exploratory factor analysis (EFA) was conducted to examine the structure of the preparedness measure. Prior to completing the EFA, assumptions were evaluated. The sample

Table 3.4. *Descriptive Statistics (Mean (M) and Standard Deviation (SD)) of Caregiver Responses to Preparedness Questions (N = 252).*

How well prepared do you think you are…	*M*	*SD*
To take care of your care receiver's physical needs?	3.54	1.141
To take care of their emotional needs?	3.39	1.086
To find out about and set up services for them?	3.48	1.186
For the stress of caregiving?	2.94	1.213
To make caregiving activities pleasant for both you and your care receiver?	3.46	1.113
To respond to and handle emergencies that involve your care receiver?	3.60	1.147
To get the help and information you need from the health care system?	3.45	1.130
For the transition to hospice, palliative, or end-of-life care (comfort care) for your care receiver?	2.73	1.403
To meet the end-of-life medical needs of your care receiver?	2.66	1.386
To meet their end-of-life emotional needs?	2.61	1.351
To meet their end-of-life spiritual needs?	2.93	1.408
To meet their end-of-life social needs?	2.75	1.399
How prepared do you think your family members are for the transition to end-of-life care for your care receiver?	2.34	1.251
Overall, how prepared do you think you are to care for your care receiver?	3.50	1.091

Note. Participants responded on the scale where 1 is "*not at all prepared*", 2 is "*not too well prepared*", 3 is "*somewhat well prepared*", 4 is "*pretty well prepared*", and 5 is "*very well prepared*".

size (*N* = 252) was sufficiently large enough, cases with missing values were removed, and there were no univariate or multivariate outliers in the sample. Inspection of the normal probability plot as well as the data scatterplot indicated that assumptions of normality and linearity were met. In addition, based on the correlation matrix, there was no evidence of multicollinearity, and some correlations were large enough to indicate the factorability of the correlation matrix (correlations ranged from .305 - .808).

The parallel analysis, using 1000 datasets and the 95th percentile, identified two factors to be extracted. Visual inspection of the scree plot, as well as eigenvalues greater than one, were used to identify the optimal number of factors to retain (Finch, 2020) for the purposes of this exploratory study. Maximum likelihood extraction with direct oblimin rotation was used to extract the two factors. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was sufficiently high (KMO = .920) and Bartlett's Test of Sphericity was significant ($\chi^2(91) = 2660.291$, $p < .001$), indicating that this sample was suitable for factor analysis. These two factors had an intercorrelation value of .70 and explained 62.3% of the variance. Table 3.5 reports the rotated loadings of variables on two factors, communalities, eigenvalues, Cronbach's alpha, and percentages of variance explained by each factor. Simple structure was observed, and all communalities and loadings were high. With a minimum factor loading level of 0.5, all preparedness variables were included in one of the two factors, and there were no cross-loaded items. The first factor, labeled "general preparedness for caregiving" explained 53.2% of the variance and showed a Cronbach's alpha of .91. This factor included each (and only) those questions in the Preparedness for Caregiving Scale (PCS, Archbold et al., 1990). The second factor included questions that were added to the PCS for the purpose of this study and were associated with preparedness for EOL caregiving. The second factor, labeled "preparedness for transition to EOL care" explained 9.2% of the variance with a Cronbach's alpha of .93.

One-Way ANOVAs to Examine Caregiver Demographics and Characteristics and Differences in Preparedness

Of the one-way ANOVAs conducted on preparedness for transition to EOL caregiving by demographic characteristics, there was only evidence of differences among group means of the relation of the care receiver to the caregiver ($F(5, 246) = 3.541$, $p = .004$, $\eta^2 = .06$) and stage of

Table 3.5. *Rotated Factor Loadings, Communalities (h^2), Eigenvalues, Percent Variance Explained, and Cronbach's Alpha for Maximum Likelihood Extraction and Direct Oblimin Rotation on Preparedness for Caregiving Measure (N = 252).*

Preparedness question	Factor		h^2
	General preparedness for caregiving	Preparedness for transition to EOL care	
Prepared to care for physical needs	.884		.63
Overall preparedness to care for care receiver	.875		.73
Prepared to care for emotional needs	.752		.57
Prepared to handle emergencies	.725		.57
Prepared to make activities pleasant	.704		.53
Prepared for stress of caregiving	.702		.53
Prepared to get help from health care system	.636		.57
Prepared to set up services for CR	.633		.46
Prepared to meet EOL social needs		.896	.77
Prepared to meet EOL emotional needs		.881	.82
Prepared to meet EOL medical needs		.837	.76
Prepared to meet EOL spiritual needs		.826	.67
Prepared for transition to EOL care		.765	.64
Preparedness of family for CR transition to EOL care		.708	.48
Eigenvalue	7.862	1.581	
Variance	53.16	9.16	
Cronbach's alpha	.913	.929	

Note. Only loadings of at least 0.5 are included. These two factors explained 62.3% of the variance.

care along the caregiving trajectory ($F(5, 149) = 2.606$, $p = .027$, $\eta^2 = .08$; Table 3.6). Family caregivers providing care to a sibling felt more prepared for the transition to EOL caregiving ($M = 3.57$, $SD = 1.17$) than family caregivers providing care to an adult child ($M = 2.13$, $SD = 1.23$) or a parent ($M = 2.56$, $SD = 1.08$). Family caregivers providing only sporadic care (early in the caregiving trajectory) felt less prepared for this transition ($M = 1.69$, $SD = 0.96$) than all other caregivers further along in the caregiving trajectory (providing more regular and personal care). Age was found to be negatively but not meaningfully correlated with preparedness for the transition to EOL caregiving ($r(161) = -.003$, $p = .971$). In addition, other caregiver demographics and caregiving characteristics that were examined and found to not have

Table 3.6. *Results, Including Means and Standard Deviations, of One-Way ANOVA Tests and Tukey HSD Post Hoc Tests of Differences in Preparedness for the Transition to EOL Caregiving by Caregiving Demographics or Characteristics (N = 252).*

	Preparedness for the transition to EOL caregiving		
Caregiver demographic or characteristic	*n*	Mean	*SD*
Gender			
Female	139	2.65	1.20
Male	22	2.30	1.12
Prefer not to say	2	3.08	0.59
Race			
American Indian or Alaskan Native	2	1.92	1.30
Asian	6	1.92	0.98
Black or African American	12	2.26	1.30
White	127	2.69	1.20
Other or multiple race	16	2.57	1.09
Ethnicity			
Hispanic or Latino or Spanish origin	22	2.74	1.20
Not Hispanic, Latino, or Spanish origin	130	2.57	1.23
Marital Status			
Single, never married	17	2.52	1.20
Married or in domestic partnership	124	2.64	1.19
Widowed	5	3.50	1.10
Divorced	17	2.26	1.10
Employment			
Employed full-time	50	2.59	1.15
Employed part-time	34	2.78	1.32
Unemployed (stay-at-home parent)	15	2.61	1.29
Unemployed (student)	2	2.83	2.59
Unemployed (looking for work)	5	2.97	1.03
Unemployed (not looking for work)	2	1.92	1.30
Unemployed (disabled, not able to work)	6	2.22	0.80
Retired	49	2.54	1.16
Education level			
Less than High School	3	2.78	0.84
High School diploma/GED	24	2.94	1.43
Post-secondary technical training	12	3.00	1.26
Some college	35	2.70	1.17
Associate degree	14	2.43	1.11
Bachelor’s degree	42	2.48	1.16
Graduate degree	33	2.36	1.08
Income Level (based on US poverty levels for 4-person house)			
Below poverty level	47	2.77	1.22
Above poverty level	115	2.56	1.18

Table 3.6. – continued

	Preparedness for the transition to EOL caregiving		
Caregiver demographic or characteristic	*n*	Mean	*SD*
Living arrangements with care receiver			
Lives with care receiver	106	2.64	1.20
Lives apart from care receiver (who lives in own home, alone)	26	2.73	1.07
Lives apart from care receiver (who lives in own home with spouse or partner)	21	2.32	1.29
Lives apart from care receiver (who lives in an assisted living facility)	9	2.70	1.35
Lives apart from care receiver (who lives in a skilled nursing facility)	1	2.00	--
How many people do you provide care for			
One	193	2.68	1.19
Two or more	59	2.65	1.13
Relationship of care receiver to caregiver (participant)			
Spouse or partner	76	2.75	1.20
Parent[a]	99	2.56	1.08
Adult child[b]	20	2.13	1.23
Sibling[a,b]	14	3.57	1.17
Other family member	43	2.69	1.09
Duration of care			
6 months to 1 year	34	2.82	1.21
1 to 3 years	102	2.66	1.07
4 to 10 years	66	2.70	1.13
More than 10 years	48	2.55	1.44
Hours per week providing care			
5 hours or less[d]	28	2.17	1.03
6 to 20 hours	77	2.53	1.15
21 to 40 hours	45	2.85	1.12
More than 40 hours per week[d]	102	2.84	1.21
Is there another person who also provides care for your care receiver?			
No	137	2.74	1.24
Yes	115	2.58	1.09
Stage of Caregiving			
0 – Sporadic care	9	1.69	0.96
1 – Regular care	30	2.17	1.21
2 – Increasing care demands, personal care	33	2.71	1.16
3 – Increasing care demands, more personal care	60	2.84	1.16
4 – End-of-life or comfort care	17	2.67	1.22
5 – Nearing death of care receiver	6	2.75	1.10

Note. Statistics were significant ($p < .05$) for relationship of care receiver to caregiver and stage of caregiving. Means that are statistically significant differences are denoted by “a” and “b”. If two means are denoted by the same letter, this means there was a significant difference between the two groups.

significant group differences in preparedness for the transition to EOL care means included gender, race, ethnicity, marital status, employment status, education level, income level, living arrangements with the care receiver, number of people the caregiver is providing care for, duration of care, hours per week providing care, and if there is another person who provides care to the care receiver (Table 3.6).

Multiple Regression to Examine Predictors of Feelings of Preparedness for the Transition to EOL Care

In the multiple regression analysis with preparedness for the transition to EOL caregiving as the response of interest, the factors of interest (cultural reasons for caregiving, burden of caregiving, duration of care, and number of tasks related to EOL caregiving completed) had predictive utility ($F(13, 112) = 5.283$, $p < .001$), with an adjusted R^2 of .308 (Table 3.7). Duration of care ($\beta = 0.02$, $t(125) = 0.18$, $p = .861$) and cultural reasons for caregiving ($\beta = 0.02$, $t(125) = 0.24$, $p = .814$) did not significantly predict feelings of preparedness for the transition to EOL caregiving. Burden of care significantly predicted preparedness for the transition to EOL care ($\beta = -0.46$, $t(125) = -5.71$, $p < .001$), such that after controlling for caregiver demographics, lower levels of perceived burden was associated with increased preparedness. The number of tasks related to EOL caregiving also significantly predicted preparedness for the transition to EOL care ($\beta = 0.35$, $t(125) = 4.29$, $p < .001$), such that after controlling for caregiver demographics, more tasks completed was associated with increased preparedness.

Discussion

This study fills a gap in family caregiving research addressing feelings of preparedness for EOL caregiving. Although some studies have examined the outcomes associated with a lack of preparedness for EOL caregiving (Aoun et al., 2018; Henriksson & Ârestedt, 2013),

Table 3.7. *Results (Coefficients, Test Statistics p-Values) from Multiple Regression Analysis of Predictors of Interest on the Preparedness for the Transition to EOL Care (N = 252).*

	β	*t*	*p*	*F*	*df*	*p*	adj. R^2
Factor 2: Preparedness for the transition to EOL care							
Overall model				5.28	13, 112	.000	.308
Gender	0.01	0.17	.864				
Age	-0.04	-0.31	.759				
Race	0.05	0.50	.621				
Ethnicity	0.07	0.84	.401				
Marital status	-0.04	-0.53	.600				
Education	-0.10	-1.11	.271				
Employment	-0.03	-0.28	.778				
Income	0.02	0.27	.789				
Living arrangements	-0.14	-1.76	.081				
Duration of care	0.02	0.18	.861				
Burden of care	-0.46	-5.71	.000				
EOL tasks completed	0.35	4.29	.000				
Cultural reasons for caregiving	0.02	0.24	.814				

preparedness for the death of the care receiver (Nielsen, et al., 2016), or an individual's preparedness for their own EOL care (such as advanced care planning) (Carr & Luth, 2017), few studies have examined the factors that are associated with caregivers' feelings of preparedness for the complex responsibilities of EOL caregiving. The purpose of this study was to explore family caregivers' feelings of preparedness for the transition to EOL caregiving and examine what characteristics of the family caregiver or their caregiving role were associated with their feelings of preparedness. Bioecological theory and the conceptual framework for a bioecological model of family dynamics and the transition to EOL caregiving provided a framework to examine the personal, contextual, timing, and process characteristics that may hinder or improve feelings of preparedness for EOL caregiving.

Family caregivers are balancing a lot of responsibilities. Of the participants in this study, many caregivers were providing more than 40 hours per week of care, had been caregiving for more than four years, and continued to be employed part- or full-time. In addition, almost one in four family caregivers were providing care to more than one family member and more than half of responding caregivers in this study did not have another person assisting with the provision of care for their care receiver. These statistics are similar to those in larger, national caregiving studies (NAC & AARP, 2020), and highlight the importance of identifying strategies to help older adults and their families prepare for changing roles, including those associated with long-term and EOL care (National Institute on Aging, 2020).

Overall, family caregivers in this study felt somewhat prepared to care for their care receiver. However, these caregivers felt less prepared for the transition to EOL caregiving and tasks associated with EOL caregiving, reporting on average they felt not too well prepared for those responsibilities. Caregivers also reported that they felt their family members were also not to well prepared for the transition to EOL care for their care receiver. As previously discussed, a lack of preparation for caregiving is associated with a variety of negative outcomes for caregivers, including increased depression, anxiety, and family conflict (Gitlin & Wolff, 2011; Waldrop et al., 2005). The PCS measure (Archbold et al., 1990) has been used extensively in family caregiving research to examine caregivers' feelings of preparedness but is limited by its broad approach to caregiving. More recent studies of family caregiving (NASEM, 2016; Schulz et al., 2020) recognize the complexities of caregiving contexts, including periods of increasing care responsibilities and shifting of roles during caregiving transitions. By adding questions related to EOL caregiving to the measure, testing the factor structure of the adapted measure, and using those factors to explore family caregivers' feelings of preparedness for EOL caregiving, this study provides a more nuanced and informed understanding of the support family caregivers may need during the later stages of caregiving.

Family Caregiving Demographics and Preparedness for EOL Care

The first two study hypotheses framed the expectation that family caregivers' personal demographics and characteristics would be associated with feelings of preparedness for EOL caregiving. Family caregivers across all adult ages, and of different gender, race, ethnicity, marital status, education level, employment, income, and other caregiving characteristics experience similar feelings of preparedness for the transition to EOL caregiving. Surprisingly, the only differences between groups in caregiver demographics and characteristics that were associated with preparedness for the transition to EOL caregiving were relationship of the care receiver to the caregiver and stage of care along the caregiving trajectory. Family caregivers providing care to an adult child and those early in the trajectory of caregiving tended to report feeling less prepared for the transition to EOL caregiving than other family caregivers.

The finding that the relationship of the care receiver to the caregiver was associated with preparedness highlights the importance of recognizing that family caregiver and care receiver experiences occur within the context of family relationships. The association between preparedness and the stage of care indicate that time and timing are important factors to consider when studying the caregiving experience and developing interventions to support family caregivers. The hypotheses that personal demographics and characteristics of caregiving would be associated with feelings of preparedness of EOL caregiving were not supported, except for those variables mentioned. These results indicate that future research and the development of interventions to support caregiver preparedness for EOL care should not be limited by specific caregiving populations.

The additional four hypotheses (H 3-6) identified several variables that may predict caregivers' feelings of preparedness for EOL caregiving, including cultural reasons for caregiving (H3), burden of caregiving (H4), duration of care provided (H5), and number of tasks completed related to EOL care planning (H6). Duration of care and cultural reasons for caregiving were not statistically significant predictors of preparedness. These results are of practical importance to inform future studies as well as recognizing that feelings of preparedness for EOL caregiving and resulting caregiver outcomes may be more universal to the caregiving experience than expected. Duration of care may be just one aspect of the component of timing important to caregiver preparedness. If differences in caregivers' feelings of preparedness are not related to how long the caregiver has been providing care, it might be that the rate of progression of the care receiver's medical condition or age-related losses in physical or cognitive capacity may influence caregivers' feelings of preparedness. Future studies should continue to explore various aspects of timing to investigate when family caregivers would benefit the most from knowledge, skill-building, and support to increase their preparedness for EOL caregiving. Similarly, although cultural reasons for caregiving did not predict feelings of preparedness, additional research should examine how family members' decision-making process for the provision of care and taking on the role of caregiver is associated with caregivers' feelings of preparedness for EOL caregiving.

Of the hypothesized predictors, only perceived burden of caregiving and number of tasks completed related to EOL caregiving significantly predicted preparedness for the transition to EOL caregiving. Much of family caregiving research has focused on the stressors and burdens associated with caregiving (Gitlin & Wolff, 2011; Pinquart & Sörensen, 2003; Schulz et al., 2020), and the results of this study provide another avenue with which to understand and address caregiver outcomes associated with caregiving burdens. Advance care planning, represented in this study by the tasks associated with EOL care, and communication between family members and health care professionals has also been studied extensively (Carr & Luth, 2017; Egbert et al., 2017; Redinbaugh et al., 2003). Yet, linking these tasks with family caregivers' feelings of preparedness for the transition to EOL caregiving has been overlooked in caregiving research. These results provide additional support for encouraging families to discuss preferences for future medical care, wishes for caregiving, and other legal and financial matters before a medical emergency or rapidly failing health necessitate decision-making. The benefits of advance care planning extend beyond the ailing or aging individual to the family members who take on the family caregiving role.

Limitations of this Study

The results of this study demonstrate how common it is for family caregivers to feel unprepared for the transition to EOL caregiving, regardless of caregiver demographics. The identification of specific factors associated with feelings of preparedness expands new avenues with which to examine how and when family caregivers may need support for EOL care. In addition to the contributions and strengths of this study, there are limitations that should be acknowledged. Although the sample size used for analyses was adequate to fulfill the purpose of this exploratory study, a large number of participants did not fully complete the online survey. Also placing a limitation on sample size, recruitment was focused on passive recruitment efforts, such as sharing study information through organizational newsletters or on social media sites, rather than in-person active recruitment. The lack of personal connection and engagement with family caregivers may have resulted in lower investment in contributions to the study. The limitations of recruitment strategies and study design were largely due to research restrictions in place as a result of the global COVID-19 pandemic. All recruitment and survey distribution and collection occurred online, thus preventing the opportunity to engage with family caregivers during recruitment and offer support during survey completion.

In addition to the limitations placed on the study method during COVID-19, resulting stay-at-home and social distancing recommendations may have led to different types of responses from family caregivers. For example, the experience of caregiving during the COVID-19 pandemic may have been different than caregiving prior to COVID-19, thus influencing how study participants felt and responded about their feelings of preparedness. To address this potential threat to internal validity, a small pilot study was conducted prior to recruitment and survey distribution with a convenience sample of family caregivers. Participants were asked for feedback following completion of the survey. Follow-up questions included "Do you feel like your answers would have been different if you were responding before our current situation with COVID-19?" and "If we were to add the following item to the survey, how do you think they would influence caregiver responses? – How has your caregiving changed since the COVID-19 outbreak?" Responses to the pilot survey indicated that family caregivers would not have responded differently to the survey prior to COVID-19. The most common response to follow-up questions regarding COVID-19 were that individuals were now taking on the role of family caregiver as a result of COVID-19. Participants in the pilot study made no recommendations for edits to the survey to accommodate the caregiving experience during COVID-19.

Another limitation of the study is the lack of a culturally diverse sample. Roles, responsibilities, and perceptions of the caregiving experience may differ by race or ethnicity (Fabius et al., 2020; Roth et al., 2015), thus it is important to acknowledge that the generalizability of this study may be limited, and it may not fully capture the complexity of individuals' feelings of preparedness for EOL caregiving. Future studies, then, should expand the study method in study design, recruitment efforts, and data collection methods to reach a larger and more diverse sample of family caregivers.

Conclusion

Novel research examining factors associated with family caregivers' feelings of preparedness for EOL caregiving and innovative use of bioecological theory make this study an important contribution to family caregiving research. The results of this exploratory study highlight the importance of examining caregivers' feelings of preparedness for EOL caregiving and provide preliminary evidence of the different personal, contextual, timing, and process-related characteristics of caregiving that are associated with preparedness. Recommendations made for future research directions will help advance family caregiving research and perhaps identify new avenues through which to identify protective factors for family caregiver outcomes and inform the development of interventions to support their health and well-being. Studies of EOL caregiving are typically limited to specific diagnoses or care settings (Ornstein et al., 2017), yet the need for EOL caregiving (and the knowledge and skills required to provide that care) does not discriminate between these factors or those caregiver demographics and characteristics discussed throughout this paper.

Future studies should build on this exploratory work to identify additional contextual factors and caregiver characteristics that are mechanisms for improving family caregivers' feelings of preparedness for the transition to EOL caregiving. For example, although the focus of this study was the experiences and perceptions of individual family caregivers, it is important to study preparedness for EOL caregiving and the EOL caregiving experience within the broader family system. Recent studies have found that family relationships are important in helping shape EOL preparations for older family members and their caregivers (Duggleby et al., 2017; Oliver et al., 2017), and that family factors are often associated with advance care planning for EOL (Fowler et al., 2014; Kumar et al., 2020). Ultimately, understanding the diverse and complex contexts of family caregiving will provide researchers, service providers, and policy makers with increased awareness of the challenges and opportunities caregivers face and more opportunities to support the health and well-being of the growing number of family caregivers who provide invaluable service to their family members, friends, and neighbors.

CHAPTER 4

UNDERSTANDING THE ASSOCIATION BETWEEN FAMILY DYNAMICS AND PREPAREDNESS FOR THE TRANSITION TO END-OF-LIFE CAREGIVING

A primary function of many families is providing care to each other across the life course. Family members are the primary care providers of older adults (Stephens & Franks, 2009) and almost one in five adults in the U.S. are providing unpaid care to an adult family member or friend with health or functional needs (National Alliance for Caregiving (NAC) & AARP, 2020). Family caregivers are commonly defined as relatives, partners, or friends who provide unpaid care to an adult family member or friend (NAC & AARP, 2020). Family caregiving roles and expectations are deeply embedded within the family system, wherein adult family members are linked in reciprocally beneficial, complex relationships that can be challenging and meaningful (Stephens & Franks, 2009). In addition, the diversity of contemporary families makes patterns of caregiving involvement and responsibilities incredibly complex across family structures (Roberto & Blieszner, 2015). Much of caregiving research has focused on the experiences, health, and well-being of individual family caregivers and their care receivers, but it is clear that these outcomes should be considered within a family system. Families share culture, environments, and lifestyles that can influence aging and health outcomes (Utz et al., 2017) as well as caregiving experiences.

Care provided by family caregivers can include, but is not limited to, helping with household chores, personal care, and arranging medical care or health care services (National Academies of Sciences, Engineering, and Medicine (NASEM), 2016). Caregiving research has long focused on and identified many stressors and strains associated with these caregiving responsibilities (Carr & Utz, 2020; NASEM, 2016; Schulz et al., 2020). For example, compared to non-caregivers, family caregivers report higher levels of stress and depression, and lower levels of self-efficacy, physical health, and subjective well-being (Pinquart & Sörenson, 2003). More researchers are moving away from needs-based studies that focus on the known stressors associated with caregiving (Schulz et al., 2020) and focusing on strength-based approaches (Henry et al., 2018). This approach uses empowerment as a tool to help individuals identify and utilize their abilities to solve problems (Saleebey, 2011). A strengths-based approach to studying family dynamics (or patterns of interactions between family members, their roles, and their responsibilities; Gerhardt, 2020) across the life course and family caregiving allows for the inclusion of dimensions of human potential and family capacity (Hughes, 2015) thus enabling opportunities for resilience-building work. For example, researchers have found that family caregivers can cope quite well with caregiving responsibilities when they identify the positive aspects of caregiving (Zarit, 2012) such as personal growth and strengthening bonds with their care receiver (Quinn & Toms, 2019). In turn, caregiver strengths may help mitigate negative caregiver outcomes along with family and social support (NASEM, 2016), preparedness for caregiving responsibilities (Roth et al., 2015), and intervention efforts (Schulz et al., 2020).

There is still much to learn about how families and individuals can prepare for the eventuality of providing care. Transitions into and within the caregiving experience may be challenging times for families and family caregivers as their family member's health declines, care needs increase or change, and families navigate changing roles and responsibilities of providing care (NASEM, 2016). The transition to providing end-of-life (EOL) care to a family member can be particularly challenging for families and family caregivers as they are faced with potentially difficult decisions regarding medical care and course of treatment (Hebert & Schulz, 2006), increasing caregiving responsibilities (Given & Reinhard, 2017), and the anticipatory grief of the impending death of their family member (Haley et al., 2002). The unique challenges associated with EOL caregiving may also cause tension between family members (Haley et al., 2002) if care for aging family members had not been previously planned or discussed (Fowler et al., 2014) and family members disagree about a course of action for care. Families and family caregivers often report feeling unprepared (Moon, 2017; Nielsen et al., 2016) for meeting the complex emotional, spiritual, social, and medical needs of their dying family member.

Of the few studies that have explored preparedness and EOL caregiving, low preparedness was associated with higher levels of caregiver strain (Henriksson & Ârestedt, 2013), increased levels of depression and anxiety (Aoun et al., 2018), and complicated and prolonged grief after the death of the family member (Nielsen et al., 2016). Higher levels of preparedness for EOL caregiving were associated with less family conflict over EOL decision making (Fowler & Fisher, 2009; Gitlin & Wolff, 2011; Waldrop et al., 2005) and a greater sense of purpose as family caregivers enhance their care receiver's quality of life at the end of their life (Phillips & Reed, 2010). Studies have recently begun to identify various family factors that may promote EOL care planning, such as spousal support (Boerner et al., 2013), positive family communication (Van Scoy et al., 2016), and even family structure (Cooney et al., 2018) that may, in turn, increase family caregivers' feelings of preparedness for the transition to EOL caregiving.

Despite the breadth and depth of family caregiving research, little is known about how family relationships and interactions may influence the caregiving experience, specifically in difficult transition periods such as the transition to EOL care (Nielsen et al., 2016). This intersection of family caregiving, caregiving transitions, and family processes warrant further investigation. Exploring family caregivers' feelings of preparedness for the transition to EOL caregiving and how family dynamics are associated with those feelings of preparedness may help researchers and practitioners identify tangible ways that interventions could be implemented to help caregiving families navigate difficult caregiving transitions. Taking preventive steps to help prepare families for caregiving transitions, including the transition to EOL care, may help families avoid conflict and disagreements about care decisions, and improve quality of life for family caregivers and care receivers. This research will also support broader understanding of the importance of family relationships across the life course (Humble & Price, 2017) and the impact family roles and responsibilities (such as caregiving) have on the aging process.

Gaps in Caregiving Research

Research on aging families and family caregiving has existed for many decades, yet much of caregiving research continues to focus on the experiences of an individual family caregiver and their care receiver without acknowledging those experiences occur in the context of a family system (Pillemer & Gilligan, 2018). Overlooking the family system in relation to caregiving limits understanding of family members' motivations for getting involved in caregiving (Gitlin & Wolff, 2011) and the caring roles, contributions, and experiences of all family members (Keith, 1995; Zarit, 2009). Relatively few studies have focused on the caregiving experience and outcomes associated with transitioning to and providing EOL care (Aoun et al., 2018). Although there are studies that examine advance care planning (Kramer & Boelk, 2015; Nielsen et al., 2016), few studies investigate how families are involved in planning for EOL care. As previously mentioned, family members are often responsible for EOL care decisions (Haley et al., 2002), yet little is understood about how prepared family caregivers are for these responsibilities (Fox, 2021b) or how family dynamics might influence EOL caregiving.

Addressing these gaps in caregiving research requires new approaches in methods and theory utilization. Researchers must recognize that different family members may experience caregiving and family interactions in very different ways (Umberson & Thomeer, 2020) and that the caregiver and care receiver dyad is embedded in a complex network of other family relationships (Pillemer & Gilligan, 2018). These family relationships are formed from diverse family structures (Thomas et al., 2017) and history of complex and shifting family dynamics across the life course. Shifting from a focus on the individual to the family as the unit of analysis, which allows for multiple views of a caregiving situation, will contribute more meaningful information about care needs and care provision in diverse aging families (Roberto & Blieszner, 2015). This approach, along with a focus on the transition to EOL caregiving, will provide a more accurate reflection of the complex reality of the lived experiences of older adults (Pillemer & Gilligan, 2018) and their family members. Learning more about how families can prepare for the transition to EOL caregiving may help identify family processes to promote resilience (Pinquart & Sörensen, 2011) in aging individuals and families.

In addition to recommendations for methodological advances in caregiving and aging families research, there has been a push for new and innovative theoretical approaches in family gerontology (Fox, 2021a; Humble et al., 2020). For example, Humble and Price (2017) encourage utilizing theories such as Bronfenbrenner's bioecological theory (Bronfenbrenner & Morris, 2006) to examine how individuals and their families navigate the aging process and related stressors (such as increasing care needs and caregiving roles) within multiple systemic levels. Identifying and exploring new avenues of caregiving research, such as family dynamics and EOL caregiving, will help bring attention to the unique and complex challenges facing aging individuals and families today.

Purpose of this Study

The purpose of this study is to explore the association between family caregivers' family dynamics and their perceived preparedness for the transition to EOL caregiving. This study will address gaps in caregiving research, wherein little is known about how family dynamics, such as cohesion and communication, are associated with family caregivers' feelings of preparedness for caregiving. In addition, a focus on feelings of preparedness for the transition to EOL caregiving allows for an exploration of the unique and complex challenges families face near the end of a family member's life. Thus, it is hypothesized that family caregivers who report more functional family dynamics will report greater perceived preparedness for caregiving, including preparedness for the transition to EOL caregiving, than family caregivers who report more dysfunctional family dynamics. It is also hypothesized that the association between family dynamics and preparedness for the transition to EOL caregiving is mediated by tasks completed related to EOL care planning.

Theoretical Framework

This study utilizes a lens of Bioecological theory (Bronfenbrenner & Morris, 2006) to explore variables of interest and provide a framework for understanding predictive pathways and individual outcomes. In addition, the Conceptual Framework for a Bioecological Model of Family Dynamics and the Transition to EOL Caregiving (Fox et al., 2021a) guides the development of a hypothesized model to understand the associations between family dynamics and caregiver preparedness. For the purpose of this study, bioecological theory and the aforementioned conceptual framework help contextualize the experience of family caregivers, specifically within the four focus areas that predict individual developmental outcomes

(Bronfenbrenner & Morris, 2016): personal characteristics, environmental context, time, and proximal processes.

The concept of person refers to different personality traits, knowledge and skills, and characteristics (such as age, gender, race, and ethnicity) of a family caregiver that may affect interactions with their family or outcomes associated with caregiving. Contexts are interrelated systems (microsystem, mesosystem, exosystem, and macrosystem) of a family caregiver's environment, such as the number of family members available to help provide care or the familial relation between the family caregiver and care receiver. The concept of time, for a family caregiver, could include the duration of care provided or time spent per week providing care, each potentially influential on caregiver outcomes. The final concept, proximal processes, refers to the interactions between the family caregiver and their environment (such as within the family system). These processes for caregiving families may include the types and number of conversations they have about future care needs.

The framework of the hypothesized model for this study examines how family dynamics are associated with caregiver preparedness. Family dynamics, which fall within the environmental context focus area, can include family closeness or cohesion, family adaptability or flexibility, family communication and satisfaction with family interactions and functioning. The identification and utilization of these constructs to explore family dynamics is founded in Olson's Circumplex Model of Marital and Family Systems (Olson et al., 2019). Caregiver preparedness in this study, contextualized as an individual outcome, is made up of two factors; preparedness for general caregiving tasks and responsibilities, and preparedness for the transition to EOL caregiving (Fox et al., 2021b). The structure of bioecological theory is further utilized in the hypothesized model to examine the mediating role of number of tasks related to EOL care completed (contextualized as a proximal process) between family dynamics and caregiver preparedness.

Use of the Circumplex Model of Marital and Family Systems

The Circumplex model of marital and family systems (Olson et al., 2019) was developed to bridge the gap between theory, research, and practice in family research and examine changes in family dynamics over time. For the purpose of this study, the model provides a tool to conceptualize and operationalize the construct of family dynamics into four factors: family cohesion, family flexibility, family communication, and family satisfaction. Olson defines family cohesion as the emotional bonding that family members have toward one another (Olson & Gorall, 2003) and how families balance separateness and togetherness. For example, researchers have identified aspects of intergenerational solidary that can influence family relations, such as familial practical and emotional support, relationship quality, and contact frequency (Voorpostel & Blieszner, 2008). Family flexibility is defined as the amount of change in family leadership, role relationships, and relationship rules (Olson & Gorall, 2003) and how families balance stability with change. For example, active (problem-solving focused) coping strategies help family caregivers solve caregiving problems and reduce caregiver strain whereas avoidant coping promotes denial and disengagement, leading to worse outcomes (Knight & Sayegh, 2010). Communication is considered a facilitating dimension (Olson & Gorall, 2003) that enables families to alter their levels of cohesion and flexibility to meet the stressor demands.

Through decades of testing the Circumplex model, Olson (2011) found that when families report balance between separateness and togetherness (cohesion), and stability and change (flexibility), without extremes in either direction, they tend to be more functional across the lifespan than families with unbalanced dynamics. Olson's work has focused on marital and family systems across time, including multiple family members in assessment. However, for the purpose of this study and based on study hypotheses, the model is utilized to examine family caregivers' perceptions of family dynamics within their own family system.

Method

Sample

A sample of 523 family caregivers were recruited for this study. Family caregivers were identified and recruited through online communication and advertisements from national and local aging and caregiving service agencies or organizations. Such groups included caregiver support groups, county offices on aging, Facebook groups for caregivers, and professional organizations related to aging and family caregiving support and research. A snowball sampling recruitment technique was also utilized to identify and recruit family caregivers within social networks. All recruitment materials included a brief description of the study, a definition of a family caregiver, eligibility criteria, and a link to the survey (hosted on Qualtrics; Qualtrics, 2020). The inclusion criteria for this study included being over the age of 18 years old, providing unpaid care to a family member over the age of 18 years old, and having been providing care to this family member for more than six months.

Procedure

Prior to conducting this study, approval of human subject procedures was obtained from the institutional review board of the university at which the research was conducted. Family caregivers recruited for the study were directed to a self-report online survey. Prior to accessing the survey, individuals were presented with information about the survey and study, including the approximate time required to complete the survey (20-30 minutes), anonymity of the survey (and de-identification process if the individual provided follow-up contact information), and instructions to pause survey completion and return within two weeks. Individuals were also informed that participation and survey completion was voluntary, and that potential compensation was provided in the form of a drawing for one of ten $50 Amazon gift cards. This introduction letter also informed individuals of the study purpose, potential harms or benefits from participating (no known risks or benefits), and the procedure to maintain anonymity of information shared. At the conclusion of the introduction letter, family caregivers were asked to consent to participation, and if agreed, were given access to the survey.

Measures

The survey used in this study included questions about family caregiver and care receiver demographic characteristics (e.g., age, gender, race, ethnicity, education level, and income). In addition, questions about caregiver and caregiving characteristics were included to learn more about the individual's caregiving role and responsibilities as well as their preparedness. Several questions and measures were created based on the conceptual model of bioecological theory that frames this study and included to further examine the caregiving experience. Additional measures, such as cultural reasons for caregiving (CJCS; Dilworth-Anderson et al., 2005) and burden appraisal (ZBI-12; Bédard et al., 2001) were included as they relate to caregivers' appraisals of the caregiving experience, and each had strong psychometric properties. A family dynamics measure was included to investigate how family caregivers rate their family's cohesion, flexibility, communication, and overall satisfaction with their family relationships. A preparedness measure was included to explore the association between caregivers' family dynamics and feelings of preparedness for EOL caregiving. To test the hypothesis that completing tasks related to EOL care planning would mediate the association between caregivers' family dynamics and feelings of preparedness, a final measure was created to explore the types and number of tasks related to EOL care that family caregivers had completed with their care receiver.

Family Dynamics

To measure elements of family dynamics, the Family Adaptability and Cohesion Evaluation Scale IV (FACES-IV; Olson, 2011) was included in the survey. The FACES-IV includes four scales. The first scale includes 18 items that measure family cohesion (such as "Family members are involved in each other's lives" and "We spend too much time together") and the second scale includes 24 items that measure family flexibility (such as "My family is able to adjust to change when necessary" and "Family members are on their own when there is a problem to be solved"). The remaining two scales in the FACES-IV are the Family Communication Scale (10 items, such as "Family members can calmly discuss problems with each other") and the Family Satisfaction Scale (10 items, such as "How satisfied are you with your family's ability to cope with stress"). The Circumplex model hypothesizes that (1) balanced levels of cohesion and flexibility promote healthy family functioning, (2) communication is a facilitating dimension that helps families balance levels of cohesion and flexibility, and (3) the satisfaction measure assesses the degree of to which individuals are happy with their family functioning (Olson, 2011). Family caregivers responded to the family cohesion, family flexibility, and family communication scales using a 5-point Likert scale ranging from "*strongly disagree*" (1) to "*strongly agree*" (5). Responses to the family satisfaction scale were also on a 5-point Likert scale, ranging from "*very dissatisfied*" (1) to "*extremely satisfied*" (5).

Family dynamics scores were considered in multiple ways, both as individual scale scores and combined as a latent construct. To score family cohesion and flexibility, guidelines from the Circumplex model (Olson, 2011) were followed to create a ratio score to evaluate the level of perceived functional versus dysfunctional behavior (balanced or unbalanced) within the family system. According to Olson (2011; 2019), ratio scores ≤ 1 indicate unbalanced family dynamics, whereas scores > 1 indicate balanced family dynamics. From the calculated ratio score, a dichotomous variable was created for both family cohesion and family flexibility, wherein family caregivers' responses indicated unbalanced (0) or balanced (1) dynamics. Scores from the family communication scale and family satisfaction scale were summed to provide a raw score for each scale. A family dynamic scale score was also created by averaging the standardized scores of family cohesion, family flexibility, family communication, and family satisfaction.

Alpha reliability analyses in previous studies (Olson, 2011) resulted in a range of results from .77 to .93, indicating fair to excellent reliability for all scales within the FACES-IV. With the sample of family caregivers in this study, Cronbach's alpha values were .68 for the cohesion scale, .69 for the flexibility scale, .92 for family communication, and .96 for family satisfaction. Similar to previous studies, reliability values of the FACES-IV measure with this sample range from fair to excellent.

Preparedness

Family caregivers' feelings of preparedness were measured using an adaptation of the Preparedness for Caregiving Scale (PCS; Archbold et al., 1990). The original PCS is an eight-item scale that measures how well-prepared caregivers believe they are for different general domains of caregiving. The PCS was adapted for the purpose of this study by including six additional questions related to domains of EOL caregiving. Original questions include "How well prepared do you think you are to take care of your family member's physical needs," and "How well prepared do you think you are to get the help and information you need from the health care system." (Zwicker, 2018). Additional questions related to EOL care included "How well prepared do you think you are to meet the end-of-life medical needs of your care receiver," and "How prepared do you think your family members are (or were) for the transition to end-of-life care for your care receiver?". For each question, family caregivers responded on a 5-point Likert scale ranging from *not at all prepared* (1) to *very well prepared* (5). Responses were scored by taking the mean of all items answered, with higher scores indicating the caregiver feels more prepared for caregiving and lower scores indicating feeling less prepared.

In a previous study (Fox et al., 2021b), the factor structure of the adapted PCS was evaluated, identifying two factors of caregiver preparedness: general preparedness for caregiving and preparedness for the transition to EOL caregiving. Multiple studies have reported on the internal consistency of the original PCS (Archbold et al., 1990; Hudson & Hayman-White, 2006; Pucciarelli et al., 2014), with Cronbach's alpha ranging from .88 to .94. Cronbach's alpha for the adapted preparedness measure and this study sample is .95 (.92 for general preparedness and .94 for preparedness for EOL caregiving), indicating the adapted measure was reliable with family caregivers in this study.

Number of Tasks Completed to Prepare for the Transition to EOL Care

In addition to asking family caregivers about their feelings of preparedness for EOL caregiving, a measure was included to identify the number of tasks caregivers and their care receivers had completed to prepare for the transition to EOL. The measure included nine tasks ranging from have you "talked with your care receiver about the kind of medical care they would want if they were very sick or near the end of life" to have you "signed official papers putting your care receiver's wishes in writing about the kind of medical care they want if they are very sick or near the end of life". For each question, family caregivers could choose to respond *No* or

Yes. If caregivers responded *No*, they were presented with the option to choose whether they planned to complete this task *3 months from now*, *6 months from now*, *1 year from now*, *more than a year from now*, *I never plan to discuss this*, or *I don't know*. If caregivers responded Yes, they had completed the task, they were presented with the option to choose if they had completed the task *3 months ago*, *6 months ago*, *1 year ago*, or *more than a year ago.* Caregivers' responses were coded as *No* = 0 and *Yes* = 1 and summed to create a scale score representing the number of tasks completed related to EOL care. This scale score was utilized to test the mediation hypothesis of this study. To test the reliability of the tasks completed scale, Cronbach's alpha was calculated, .93, indicating the scale was reliable with the study sample of family caregivers.

Data Analysis

SPSS version 26 (IBM, 2019) was used to analyze the data. Prior to analysis, the data were examined for missing responses. For the purpose of this study, the data were analyzed to examine the reported family dynamics of family caregivers, and if family dynamics were associated with caregivers' feelings of preparedness for the transition to EOL caregiving. Descriptive statistics for each of the demographic characteristics and characteristics of the caregiving role and responsibilities of family caregivers included in the study were computed. Independent samples t-tests, Chi-square comparisons, and one-way analyses of variance (ANOVA) and Tukey's HSD post-hoc tests were used to examine differences in caregiving characteristics and experiences, including those specific to different familial relationships between the family caregiver and care receiver. Additional Chi-square and independent samples t-tests were used to explore the differences in caregiver characteristics and family dynamics between the family caregivers who reported feeling not at all prepared for every component of

EOL caregiving assessed compared to the remaining family caregivers who reported at least some preparedness for some components of EOL caregiving.

To examine the link between family caregivers' family dynamics and caregiving preparedness, a structural equation model (SEM) using AMOS 26.0 software (Arbuckle, 2014) was considered. Family dynamics was the latent variable constructed of measured variables of family cohesion, family flexibility, family communication, and family satisfaction. The caregiver preparedness latent variable was constructed of the measured variables of preparedness for general caregiving and preparedness for the transition to EOL caregiving. The hypothesized mediation model included number of tasks related to EOL caregiving completed as a mediator in the association between the independent latent variable of family dynamics and the dependent latent variable of caregiver preparedness. The connections among the variables of interest for this analysis were first examined using Pearson's correlation coefficient (*r*). Prior to SEM analyses, each predictor variable was centered and standardized as the variables were measured on different scales. This process ensured variables were comparable in the same units of measurement. Several indices were used to assess model fit, including normed Chi-square (χ^2/df), the root mean square error of approximation (RMSEA), incremental fit index (IFI), the Tucker-Lewis index (TLI), and comparative fit index (CFI). The hypothesized and tested model(s) would be considered a close fit of the data when Chi-square was non-significant ($p > .05$) and $\chi^2/df < 3$, when RMSEA ≤ 0.08, and IFI, TLI, and CFI ≥ 0.90.

After considering various SEM models, a simple mediation analysis was conducted using the PROCESS version 3.4 macro for SPSS (Hayes, 2017). This analysis was used to confirm SEM results and test the study hypothesis that the link between family dynamics and preparedness for EOL caregiving would be mediated by tasks completed related to EOL care. The averaged family dynamic scale score was used in this analysis.

Results

Sample Demographics and Characteristics

There were 173 family caregivers included in the analysis of this study. Of the 523 individuals who accessed the survey, 22 did not consent, 62 were not currently providing care to an adult family member, 26 had only been providing care for less than six months, and 161 individuals did not complete the survey or had missing values in the preparedness measure. Of the remaining 252 individuals, another 79 had almost fully missing data in the FACES-IV measure (and measures and demographic questions that followed). Results from Little's Missing Completely At Random test (χ^2 (953, *N* = 252) = 949.865, *p* = .523) indicate these data were missing at random, therefore, participants missing data in the FACES-IV and subsequent measures were removed from analysis using listwise deletion. Family caregivers' age ranged from 18 years old to 81 years old (*M* = 52.3 years, *SD* = 14.43 years), and their care receiver's age ranged from 18 years old to 97 years old (*M* = 67.7 years, *SD* = 19.03 years). The average family caregiver (see Table 4.1) was female (79.2%), White (72.3%), not Hispanic, Latino, or of Spanish origin (74.6%), married or in a domestic partnership (71.1%), employed full-time (28.9%), earned a bachelor's degree (24.3%), had a yearly household income above the national poverty level for a 4-person household (65.9%), and lived with their care receiver (61.3%). Most family caregivers are providing care to one family member (79.2%), have provided care for 1 to 3 years (40.5%), and provide more than 40 hours per week of care (37%). Almost half of the family caregivers have another person that helps provide care to their care receiver (46.2%), with that person most likely being and adult child (15.6%) who spends 6 to 20 hours providing care

Table 4.1. *Sample Demographic Descriptive Statistics Including Mean (M) and Standard Deviation (SD) for Age and Sample Size (n) and Percentage (%) for Categorical Characteristics for the Participants Eligible for the Study (N = 173).*

		Caregiver		**Care Receiver**	
		M	***SD***	***M***	***SD***
Age, years	Caregivers: 20-81	52.3	14.43		
Range	Care receivers: 18-97			67.7	19.03
		n	***%***	***n***	***%***
Gender identity					
	Female	137	79.2	76	43.9
	Male	22	12.7	82	47.4
	Non-binary	0	0.0	1	0.6
	Prefer not to say	2	1.2	1	0.6
Race					
	American Indian or Alaskan Native	2	1.2	1	0.6
	Asian	6	3.5	6	3.5
	Black or African American	12	6.9	14	8.1
	White	125	72.3	126	72.8
	Other or multiple race	16	9.2	14	8.1
Ethnicity					
	Hispanic, Latino, or Spanish origin	21	12.1	17	9.8
	Not Hispanic, Latino, or Spanish origin	129	74.6	134	77.5
Marital Status					
	Single, never married	16	9.2	23	13.3
	Married or domestic partnership	123	71.1	83	48.0
	Widowed	5	2.9	41	23.7
	Divorced	17	9.8	12	6.9
	Separated	0	0.0	2	1.2
Employment status					
	Employed full-time	50	28.9	8	4.6
	Employed part-time	34	19.7	9	5.2
	Unemployed, stay-at-home parent	15	8.7	5	2.9
	Unemployed, student	2	1.2	3	1.7
	Unemployed, looking for work	5	2.9	1	0.6
	Unemployed, not looking for work	2	1.2	4	2.3
	Unemployed, disabled/not able to work	5	2.9	40	23.1
	Retired	48	27.7	91	52.6
Highest level of education completed					
	Less than high school	3	1.7	29	16.8
	High school/GED	23	13.3	49	28.3
	Post-secondary technical training	12	6.9	8	4.6
	Some college	35	20.2	19	11.0
	Associate degree	14	8.1	8	4.6
	Bachelor's degree	42	24.3	31	17.9
	Graduate degree	32	18.5	16	9.2
Yearly household income based on national poverty level:		**4-person household**		**2-person household**	
	Below poverty level	46	26.6	79	45.7
	Above poverty level	114	65.9	80	46.2
Living arrangements for caregiver/care receiver dyad					
	Caregiver lives with care receiver			106	61.3
	Lives apart from care receiver:				
	Care receiver lives in own home, alone			25	14.5
	Care receiver lives in own home with spouse or partner			20	11.6
	Care receiver lives in an assisted living facility			9	5.2
	Care receiver lives in a skilled nursing facility			1	0.6

Note. Frequencies and percentages may not sum to group totals due to unreported data.

(18.5%). The average family caregiver in this study identifies as being at a stage in their caregiving trajectory of providing regular care with increasing care demands (37.0%), including personal care for their care receiver (see Table 4.2).

Family Dynamics

Of this sample of family caregivers, most reported balanced family cohesion (75.1%) and balanced family flexibility (75.7%). Although these numbers indicate the majority of family caregivers experience balanced family dynamics, family caregivers report only low to moderate family communication (*M* = 33.65, *SD* = 8.98) and very low to low family satisfaction (*M* = 29.66, *SD* = 9.80). There were no meaningful differences in means of family communication or family satisfaction between the different types of family relation of the caregiver and care receiver (communication: *F*(5, 167) = 0.79, *p* = .561, η^2 = .02; satisfaction: *F*(5, 167) = 0.93, *p* = .462, η^2 = .03) or between different living arrangements of the caregiver and care receiver (communication: *F*(4, 156) = 1.12, *p* = .351, η^2 = .03; satisfaction: *F*(4, 156) = 0.95, *p* = .436, η^2 = .02). There was also no association found between unbalanced (*M* = 4.06, *SD* = 3.10) or balanced (*M* = 4.26, *SD* = 3.16) family cohesion and tasks completed related to EOL caregiving; *t*(143) = -0.33, *p* = .744. Nor was there an association found between unbalanced (*M* = 3.66, *SD* = 3.39) or balanced (*M* = 4.39, *SD* = 3.05) family flexibility and tasks completed related to EOL caregiving; *t*(143) = -1.21, *p* = .230.

Preparedness for EOL Caregiving

Family caregivers with balanced family cohesion felt more prepared for the transition to EOL caregiving (*M* = 2.68, *SD* = 1.19) than caregivers with unbalanced family cohesion (*M* = 2.47, *SD* = 1.26), but this difference was not significant or meaningful; *t*(171) = -0.10, *p* = .319. Similar results were found for family flexibility, wherein family caregivers with balanced family

Table 4.2. *Sample Caregiver Characteristics Descriptive Statistics Including Sample Size (n) and Percentage (%) of Categorical Characteristics for the Participants Eligible for the Study (N = 173).*

	n	%
How many family members providing care for?		
One	137	79.2
Two or more[1]	36	20.8
The person you provide care for is your:		
Spouse or partner	58	33.5
Parent	63	36.4
Adult child	14	8.1
Sibling	8	4.6
Other family member[2]	30	17.3
How long providing care for family member?		
6 months to 1 year	25	14.5
1 to 3 years	70	40.5
4 to 10 years	44	25.4
More than 10 years	33	19.1
How much time do you spend each WEEK providing care?		
5 hours per week or less	17	9.8
6 to 20 hours per week	61	35.3
21 to 40 hours per week	31	17.9
More than 40 hours per week	64	37.0
Is there another person who also provides care for your care receiver?		
No	93	53.8
Yes	80	46.2
What is that person's relationship to care receiver?		
Spouse or partner	16	9.2
Parent	7	4.0
Adult child	27	15.6
Sibling	5	2.9
Other family member	5	2.9
Friend	2	1.2
Professional or paid caregiver	15	8.7
Other	2	1.2
How much time does that person spend each week providing care?		
5 hours per week or less	16	9.2
6 to 20 hours per week	32	18.5
21 to 40 hours per week	14	8.1
More than 40 hours per week	17	9.8
Identify where you would best describe your current stage along caregiving trajectory:		
Sporadic care	8	4.6
Regular care	26	15.0
Increasing care demands, personal care	64	37.0
End-of-life, comfort care	15	8.7
Nearing death of care receiver	2	1.2

Note. Frequencies and percentages may not sum to group totals due to unreported data.

[1] If providing care for more than one person, participant was asked to complete all questions referring to the individual they provide the most care for.

[2] Other family members included Aunt, Uncle, Grandparent, Sister-, Mother-, or Father-in-law, Cousin, Ex-spouse, Partner's parent.

flexibility felt more prepared for the transition to EOL caregiving (*M* = 2.70, *SD* = 1.20) than caregivers with unbalanced family cohesion (*M* = 2.40, *SD* = 1.20), and this difference was also not significant or meaningful; *t*(171) = -1.41, *p* = .161 (see Table 4.3).

Table 4.3. *Independent Sample t-test Results from Examining Overall Preparedness for EOL Caregiving Between Family Caregivers with Unbalanced and Balanced Family Dynamics (N = 173).*

Group	*N*	Mean	*SD*	*SE*	*t*	*p*
Family Cohesion						
Unbalanced	43	2.47	1.26	.19	-1.00	.319
Balanced	130	2.68	1.19	.10		
Family Flexibility						
Unbalanced	42	2.40	1.20	.19	-1.41	.161
Balanced	131	2.70	1.20	.10		

Examination of the preparedness for EOL caregiving variable (see Figure A.1 in Appendix A), revealed that a large portion of family caregivers in this sample (20.2%) responded "*not at all prepared*" to all of the six questions that composed this factor (indicating lack of preparedness for every element of EOL caregiving addressed), compared to the remaining 79.8% of the sample responding in a normally distributed manner across the range of "*not too well prepared*" to "*very well prepared*" (indicating at least some level of preparedness for some elements of EOL caregiving).

Family caregivers from each gender, race, ethnicity, relation to care receiver, and family cohesion and flexibility (unbalanced or balanced) group did not report substantial differences in their feelings of preparedness for EOL caregiving (Chi-square *p*-value range = .059-.755). In addition, family caregivers of any age (above 18 years of age), having provided care for different periods of time, and time spent per week providing care also did not differ in feelings of preparedness for EOL caregiving (independent sample t-test *p*-value range = .087-.149). However, there were meaningful associations between responses to preparedness for EOL caregiving and family caregiver reported perceived burden, tasks completed for EOL care, family communication, and family satisfaction. Family caregivers who felt not at all prepared for every component of EOL caregiving reported higher levels of caregiving burden (*M* = 3.16, *SD* = 0.88) than those who felt prepared for some components of EOL caregiving (*M* = 2.67, *SD* = 0.82); *t*(156) = 2.93, *p* = .004. Family caregivers who felt not at all prepared for every component of EOL caregiving also reported completing fewer tasks related to EOL care (*M* = 2.03, *SD* = 2.37) than the caregivers who felt more prepared for some components of EOL care (*M* = 4.86, *SD* = 3.06); *t*(66.62) = -5.62, *p* ≤ .001. In addition, family caregivers who felt not at all prepared for any component of EOL caregiving reported lower family communication (*M* = 29.60, *SD* = 9.31) and family satisfaction (*M* = 23.77, *SD* = 8.92) than those who felt at least somewhat prepared for some components of EOL care (communication: *M* = 34.68, *SD* = 8.62, *t*(171) = -3.06, *p* = .003; satisfaction: *M* = 31.16, *SD* = 9.48, *t*(171) = -4.17, *p* ≤ .001; see Table 4.4).

Table 4.4. *Results from Independent Sample t-Tests and Chi-square Tests Examining Differences in Preparedness for EOL Caregiving (0 = not at all prepared, 1 = somewhat prepared to very well prepared) by Selected Variables (N = 173).*

Variable	Preparedness for EOL Caregiving			
	df	χ^2	*t*	*p*
Gender	2	0.56		.755
Race	4	6.16		.188
Ethnicity	1	0.08		.783
Relation to care receiver	5	10.64		.059
Family cohesion (unbalanced or balanced)	1	3.55		.060
Family flexibility (unbalanced or balanced)	1	1.22		.269
Age	157		-1.45	.149
Duration of care	170		1.72	.087
Time caregiving per week	171		-1.59	.114
Perceived burden	156		2.93	.004*
Tasks completed for EOL care	66.62		-5.62	.000**
Family communication	171		-3.06	.003*
Family satisfaction	171		-4.17	.000**

Note. Chi-square test used for categorical variables. **p* < .01, ***p* ≤ .001

Structural Equation Analyses

The caregiver characteristics and variable correlations for the hypothesized model are shown in Table 4.5. Within both latent constructs (family dynamics and caregiver preparedness), the observed variables were significantly intercorrelated.

Table 4.5. *Mean, Standard Deviation (SD), and Correlation Between Observed Variables of Proposed SEM (N = 173).*

Variable	Mean	*SD*	Correlations between variables						
			1	2	3	4	5	6	7
Family dynamics									
1. Cohesion (unbalanced = 0, balanced = 1)	0.75	0.43	1						
2. Flexibility (unbalanced = 0, balanced = 1)	0.76	0.43	.58**	1					
3. Communication (range = 10-50)[1]	33.65	8.98	.49**	.48**	1				
4. Satisfaction (range = 10-50)[1]	29.66	9.81	.41**	.34**	.85**	1			
Mediating variable									
5. Tasks Completed (range = 0-9)	4.21	3.14	.03	.10	.06	.10	1		
Caregiver Preparedness									
6. For general caregiving[2]	3.44	0.93	.14	.14	.25**	.29**	.23*	1	
7. For EOL caregiving[2]	2.62	1.21	.08	.11	.32**	.38**	.34**	.71**	1

[1]Higher score indicates more satisfaction with these family dynamics.
[2]Higher score indicates feeling more prepared.
* p < .01; ** p ≤ .001.

Of all models tested, the hypothesized model (Figure 4.1) fit the data best, yet did not meet the criteria of a good fitting model of the data ($\chi^2/df = 4.78$, RMSEA = 0.15, IFI = 0.91, TLI = 0.79, and CFI = 0.91). Other models examined were based on theoretical considerations and are presented in the Appendix A (see Table A.1). Adjustments to the model included adding various caregiver demographics and characteristics as covariates, removing the proposed mediating variable, and simplifying the outcome variable from the latent construct of caregiver preparedness (composed of the observed variables of both preparedness for general caregiving and preparedness for EOL caregiving) to the observed variable of preparedness for EOL caregiving. None of these adjustments demonstrated improved model fit over the hypothesized model in Figure 4.1. Results of the final model are reported in Tables A.2 and A.3 in Appendix

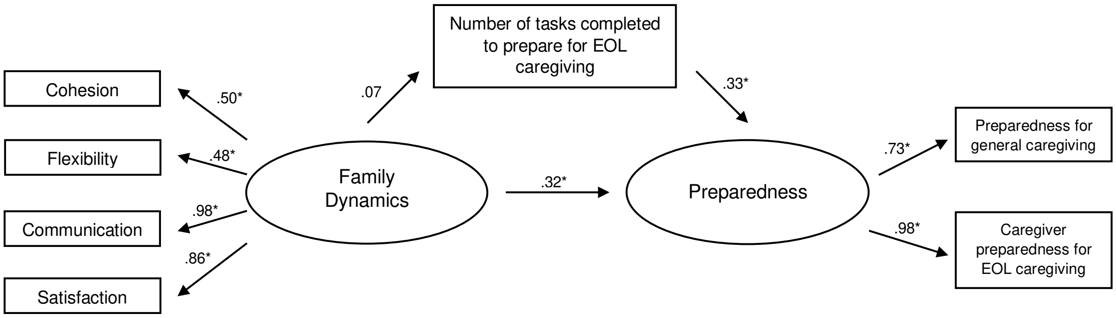

Figure 4.1. *The Hypothesized and Final (Best Fitting) Model of Family Dynamics and Caregiver Preparedness with Tasks Related to EOL Care Completed as a Proposed Mediating Variable.*
Note. All values represent standardized parameter estimates.
$^*p \leq .001$

A and include the standardized and unstandardized coefficients and standard errors, as well as the direct, indirect, and total effects of the model.

After failing to achieve good model fit of the data for SEM, the simplified mediation analysis confirmed the lack of mediation from a family dynamics variable to preparedness for EOL caregiving by tasks completed related to EOL care. The direct effect of family dynamics on preparedness for EOL care was significant ($B = 0.36$ ($\beta = 0.26$), $p \leq .001$), as was the total effect of the simplified mediation model ($B = 0.40$ ($\beta = 0.30$), $p \leq .001$). However, the indirect effect, calculated using bootstrapping procedures (unstandardized indirect effects computed for each of the 5000 bootstrapped samples), was 0.05 with the 95% confidence interval ranging from -0.02 to 0.13, thus indicating the indirect effect was not statistically significant. Therefore, the number of tasks completed to prepare for EOL caregiving was not considered a mediator in the association between family dynamics and preparedness for the transition to EOL caregiving.

Discussion

The purpose of this study was to explore the association between family caregivers' family dynamics and their perceived preparedness for the transition to EOL caregiving. This study addresses a gap in caregiving research wherein family dynamics have been overlooked as a potential source of variability in family caregivers' well-being. Innovative use of bioecological theory and the Circumplex model of family and marital systems provided a novel approach to explore how feelings of preparedness for caregiving and the transition to EOL caregiving may differ depending on family factors such as cohesion and communication. It was assumed that family caregivers with balanced family dynamics would report greater perceived preparedness for caregiving and the transition to EOL caregiving that caregivers with unbalanced family dynamics. In addition, it was hypothesized that the connection between family dynamics and caregiver preparedness for EOL caregiving would be mediated by tasks completed related to EOL care planning.

Utilizing a SEM analytic technique, acceptable model fit of the data was not achieved, indicating there may not be a meaningful association found in this sample between the construct of family dynamics and caregiver preparedness. In addition, the hypothesized mediating role of tasks completed related to EOL care planning between family dynamics and caregiver preparedness was not supported. Although study hypotheses were not supported, there were many lessons learned from the data and analyses that can serve to inform future studies and the development of new measures to better understand caregiving families.

Caregiver Characteristics and Demographics

National statistics (NAC & AARP, 2020) indicate that most family caregivers provide care to a parent or parent-in-law (50%) or a spouse or partner (12%). The results of this study echo these findings, with the majority of individuals caring for a parent (36.4%) or spouse or partner (33.5%). Yet, it is important to note that many family caregivers provided care to a variety of other family members. Family caregivers in this study were providing care for siblings, grandparents, aunts and uncles, in-laws, ex-spouses, and cousins. In addition to the variety of relations between the family caregiver and care receiver, almost half of family caregivers reported that another person helped provide care to their care receiver, 35% of whom were another family member. This demonstrates that much of caregiving responsibilities are at least somewhat shared with other family members.

An important lesson learned from these data is that researchers and service providers must consider the variety of family relationships that may exist between a care receiver and their caregiver, and that more family members may be involved in helping provide care than just the primary family caregiver (Qualls, 2016). Thus, it is important to acknowledge in caregiving research that outcomes associated with caregiving may extend beyond a spouse or one adult child. The many relationships identified in this data are complex, often intergenerational, and built upon a life course of family processes and interactions.

Family Dynamics and Preparedness for the Transition to EOL Care

This study framed the construct of family dynamics through the observed variables of family cohesion, family flexibility, family communication, and family satisfaction (as presented in the Circumplex model of marital and family systems; Olson et al., 2019). Both measures of cohesion and flexibility resulted in a designation of unbalanced or balanced family functioning. Most family caregivers reported balanced family cohesion and flexibility (75%), and there was no association between unbalanced or balanced cohesion and flexibility and preparedness for the transition to EOL caregiving. Although these results did not support the hypothesis that family caregivers with balanced family dynamics would report greater perceived preparedness than family caregivers with unbalanced family dynamics, perhaps there are useful explanations of the results to explore. For example, perhaps balanced family cohesion and flexibility (wherein families are not too distant or too enmeshed) serve a protective factor, such that families who are well connected to each other think they may be more prepared for the transition to EOL care.

Other caregiver demographics and characteristics were also not related to differences in preparedness for EOL caregiving, including age, gender, race, ethnicity, duration of care and time caregiving per week. It was somewhat surprising that some of these factors were not associated with differences in preparedness for EOL caregiving, given that time (within the context of age, duration of care, and time caregiving per week) is often associated with increased preparedness (Nielsen et al., 2016). These results support previous research that suggests preparedness for EOL caregiving remains not well understood (Christ & Blacker, 2005) and despite efforts to encourage family conversations about planning for EOL care, families remain ill-prepared for EOL care decision making (Fowler et al., 2014).

Despite most family caregivers reporting balanced family cohesion and flexibility, caregivers also reported low to moderate family communication and very low to low family satisfaction. Surprisingly, there was no one type of family relation or living arrangement that was related to differences in family communication or satisfaction. Previous research has found that the relationship between the caregiver and care receiver (which may be more or less close depending on the familial relation) was associated with caregiver outcomes, including higher levels of affective communication between the caregiver and care receiver and higher caregiving satisfaction (Fauth et al., 2012).

Family communication and family satisfaction was, however, associated with preparedness for EOL caregiving, along with perceived burden of caregiving and tasks completed related to EOL care. With results more in line with the study hypotheses, family caregivers who reported lower family communication and satisfaction felt less prepared for EOL caregiving than caregivers who reported higher levels of family communication and satisfaction. These results support previous research that found that caregivers who report low preparedness for caregiving often have low levels of communication with family members about death and dying (Nielsen et al., 2016) and that gaps in communication with family and medical professionals can cause caregiver suffering and distress (Christ & Blacker, 2005). The discrepancies in findings between family cohesion, flexibility, communication, and satisfaction demonstrate potential problems with combining these four factors together to make up the construct of family dynamics, particularly with aging families. It may be that family relationships, interactions, and processes grow more complex as families age and individuals take on new and different roles (such as family caregiving) within the family system.

Failure to Identify Acceptable Model Fit

There are several potential explanations for why the SEM analyses were unable to find acceptable model fit of this study data. These explanations are grounded in both statistical and theoretical issues. Detailed examination of the data revealed that there existed increasing variation (random scatter with no patterns) in the variables of interest as well as a lack of linear association between some of the variables (see Figures A.2 - A.7 in Appendix A). This is particularly noticeable in the hypothesized mediating variable, tasks completed related to EOL care, and the outcome variable of preparedness for EOL caregiving. For example, as previously discussed, a large portion of family caregivers responded that they were "*not at all prepared*" for any of the assessed EOL caregiving responsibilities, while the remaining caregiver responses were more equally distributed from "*not too well prepared*" to "*very well prepared*", indicating at least some preparedness for some components of EOL caregiving.

Although these results make inferential analyses difficult, the data are meaningful. From this, we learn that 20% of family caregivers indicated that they are not at all prepared to meet the medical, emotional, spiritual, and social needs of their care receiver at the end of their life. In addition, those family caregivers are not at all prepared for the transition to hospice, palliative, or EOL comfort care for their care receiver, and believe that their family members are also not at all prepared for their care receiver's transition to end-of-life care. Future studies should continue to examine what will help family caregivers and their families feel more prepared for the transition to EOL care. Perhaps further exploration into what makes families and family caregivers feel more prepared for this transition may help identify different family processes or interactions that can be recommended to help all family caregivers feel more prepared for the transition to EOL caregiving. It is also important to examine how low preparedness for this stage may be associated with the caregiving experience during the care receiver's end of life and later health and well-being outcomes of the caregiver after the death and bereavement of their family member.

In addition to statistical explanations for the lack of model fit to this data, there are several potential theoretical reasons why the hypothesized model was not supported. First, family-level, longitudinal data are important to appropriately assess family processes (Pritchett et al., 2011; Roberto & Blieszner, 2015; Utz et al., 2017) and the causes, correlations, and interactions that may lead to specific outcomes for caregivers and their families. The cross-sectional, self-report survey developed for this study relied on responses from individual family caregivers, without examining multiple family members with a family system. Future studies should continue exploring family dynamics and caregiver preparedness by including more family members in the study, measuring patterns of family responses over time, and focusing on both individual- and family-level analyses. In addition to the lack of family-level data for these analyses, another major theoretical issue with the study is the lack of options of family dynamics measures for use with aging families.

Use of the FACES-IV (Circumplex Model) Measure

Two important issues justified the inclusion of the FACES-IV measure in the survey for this study of family caregivers. First, caregiving research lacks reliable and valid measures of family dynamics using a strengths-based approach. Measuring family strengths, rather than focusing on deviations from “idealized characterization of family structure and function” (Early, 2001, p. 225) allows family science and practice to move towards more effective and efficient ways to identify solutions to family problems and support family well-being (Early, 2001). Review of two comprehensive assessment measure inventories (Cella et al., 2010; Family Caregiving Alliance, 2012) identified family-related measures appropriate for caregiving only relating to conflict and relationship strain. Focusing on these family stressors, without regard to family strengths (such as togetherness and adaptability), may limit researchers’ ability to identify which family strengths are most strongly associated with family caregivers’ preparedness for the transition to EOL caregiving. The FACES-IV measure was the only validated tool identified that seemed to capture different domains of family dynamics from a strengths-based perspective.

Second, it was important to explore the potential of moving the Circumplex model science forward in the context of aging issues. Few studies were identified (Koutra et al., 2016; Pereira & Teixeira, 2013; Sutter et al., 2014; Tramonti et al., 2019) that used the FACES-IV questionnaire in family caregiving research. It is important to note that the FACES-IV measure is typically utilized in clinical settings (Olson et al., 2019) to assess family functioning over time and treatment. Again, the selection of this measure for use in the study was based on limited availability of family dynamics measures. The FACES-IV measure was satisfactorily reliable (Taber, 2017) with the family caregivers in this study, however, Cronbach's alpha for the family cohesion (.68) and family flexibility (.69) scales were slightly low. As the focus of this study was to examine the association between family dynamics and caregiver preparedness, the results (and lack of acceptable model fit to the data) indicate that the FACES-IV measure may not be an effective tool to study family dynamics of family caregivers.

Future Directions for Studying Family Dynamics and Family Caregiving

As caregiving research advances, novel research questions are developed, and new measurement tools become necessary to further explore and understand the caregiving experience and caregiver outcomes. Examining EOL caregiving, specifically how prepared family caregivers feel for these responsibilities, and how family dynamics may be associated with this experience is an example of advancing caregiving research. This study demonstrates the necessity of developing new measures to explore how family processes may relate to family caregiver experiences and outcomes. According to best practices for developing and validating new measures (Boateng et al., 2018), the first step involves the identification of a research domain. Boateng and colleagues (2018) describe the process of domain identification as: a) acknowledging the significance of the domain; b) confirmation that no instruments exist that adequately measure the domain (or justifying why the development of a new instrument is appropriate); and c) providing a conceptual definition of the domain. After a thorough review of extant literature to meet these criteria, a researcher can begin the process of developing questions for inclusion in the new measure through a variety of deductive or inductive methods (Boateng et al., 2018).

This study, along with previous studies on developing a conceptual framework (Fox et al., 2021a) and caregiver preparedness (Fox et al., 2021b), fulfill this first step of domain identification. It is clear from these results that many family caregivers feel not at all prepared for the transition to EOL care and that family communication and family satisfaction are associated with those feelings of preparedness. The next step in exploring family dynamics and preparedness for family caregiving is to use this study to inform the development of a new, strengths-based family dynamics measure that is appropriate for use with aging families. Based on the strengths and limitations of this study, it is recommended that an appropriate approach to develop new questions involves gathering qualitative data (such as observations and interviews with caregiving families) and using exploratory research methods (focus groups). These additional methods will help to inductively identify items relevant and important to family processes and interactions of caregiving families.

Limitations of this Study

This exploratory study is important to caregiving research and family science as a means to better understand how family dynamics and functioning across the lifespan may be associated with caregiver outcomes. However, a number of limitations should be acknowledged. The data collected for this study were cross-sectional, a method chosen to meet the exploratory expectations of a broader research question. As previously discussed, there is a gap in caregiving research wherein the study of family systems across the lifespan and family caregiver experiences and outcomes merge. It is important to build a foundation of basic science to understand the significance of this intersection, thus this cross-sectional exploratory study can inform future studies and the development of appropriate measures in this burgeoning field. Longitudinal studies with multiple individuals within a family (allowing for multi-level family analysis) would likely improve the accuracy of findings and allow clearer conclusions about the association between family dynamics and the caregiving experience.

Interpretations of the data were also limited by sample size. There have been many recommendations for appropriate sample size to conduct SEM, anywhere from > 300 (Tabachnick & Fidell, 2019), to an observation to estimated parameters ratio of 20:1 (Kline, 2015) or as low as 10:1 (Schreiber et al., 2006). The biggest barrier to sample size in this study was the number of incomplete surveys. More than half of participants who consented and started the survey completed less than half of the survey. Many participants stopped completion of the survey among the family dynamics questions. This result may be another indicator that the FACES-IV scales may not be appropriate or applicable for use with family caregivers and their families. As the survey was self-administered and completed online, future studies should vary distribution methods to improve survey completion.

It is also important to note that the sample was not a diverse sample and is likely not representative of the diverse experiences of family caregivers. Research has shown that there are unique family caregiving challenges associated with culture, race, and ethnicity (Dilworth-Anderson et al., 2005) and individual and family needs and strengths may differ among diverse populations (Dilworth-Anderson et al., 2020). Including analysis of varying demographic characteristics (such as race, ethnicity, and gender) as covariates was an attempt to partially address this issue. However, it remains important for future studies to both increase sample size and make efforts to recruit a diverse sample that may more closely represent the experiences of all of our nation's family caregivers.

Finally, as previously mentioned, the family dynamics measures utilized in this study were limited in their capacity to fully capture the dynamics of aging families as they navigate caregiving decisions, roles, and responsibilities. Family dynamics, especially studied over time, is a broadly applicable construct that would benefit from the inclusion of features specific to the complexities of diverse, aging families to allow for a more comprehensive assessment of family functioning relative to family caregiving. Future studies should continue to investigate what factors related to different family dynamics contribute to the prediction of preparedness for caregiving.

Conclusion

Providing care to aging, adult family members is now considered a normative part of individual and family development (NASEM, 2016), yet research studies continue to frame caregiving within the individual experience or within the caregiver and care-receiver dyad. This study adds to caregiving literature by beginning to explore the association between family dynamics and the caregiving experience and making recommendations for future research and measure development. Family caregivers' feelings of preparedness for caregiving vary widely, and many feel not at all prepared for the transition to EOL caregiving. This study will inform future research questions, hypotheses, and methods, to continue exploring why and how families (and different family members) get involved with EOL caregiving, how families navigate EOL caregiving decisions together, and how different family dynamics may support or hinder family caregivers' feelings of preparedness for the transition to EOL caregiving. The long-term purpose of this research is to guide family-centered practices and the development of interventions to support individuals and their caregivers and families as they navigate the transition to EOL care.

CHAPTER 5

GENERAL DISCUSSION AND CONCLUSION

Family members are the primary care providers to adults with health or functional needs and play an integral role in providing care and comfort at the EOL. Individuals providing this care are vulnerable to physical, psychological, and emotional stress, and often indicate they do not have the knowledge or skills needed for providing EOL care. Yet, few studies have examined the mechanisms that may help family caregivers feel more prepared for EOL caregiving. A focus on caregiving transitions, the different contexts of the caregiving experience (such as family relationships and interactions), and including family-level studies may help move caregiving research forward and identify new research questions in the study of individual and family aging experiences.

The first chapter of this dissertation provided a broad overview of family caregiving, including a discussion of how research on aging families and common theoretical perspectives guided family caregiving research. It also included an examination of the limited research on EOL caregiving and making the transition to EOL care. Through this review of caregiving literature, it is clear that little is known about how family caregivers, along with their care receivers and other family members, prepare for the transition to EOL care. Thus, the manuscripts included in Chapters 2, 3, and 4 addressed gaps in family caregiving research, each contributing to an exploration of how family caregivers perceive their preparedness for the transition to EOL caregiving and how family dynamics may be associated with feelings of preparedness. A summary of the key contributions and findings from each manuscript are presented in the following paragraphs. After the summaries, the implications of the studies and this dissertation are discussed within the context of advancing family caregiving research and recommendations for the development of intervention programs to support caregiving families.

Summary of Chapter 2

Chapter 2, *Family Dynamics and the Transition to End-of-Life Caregiving: A Brief Review and Conceptual Framework*, introduced a conceptual framework adapted from Bronfenbrenner's bioecological theory of human development (Bronfenbrenner & Morris, 2006). The framework focuses on four key interacting components that drive development, including person, context, time, and proximal processes. As conceptualized in this framework, each of these constructs included factors related to characteristics of family caregivers and the caregiving experience, as well as the form and functioning of the aging family. The conceptual framework provides a model for examining family caregiver and family-level outcomes associated with the transition to EOL caregiving.

This manuscript provides one approach for addressing current recommendations for advancing research on aging families and caregiving. These recommendations include focusing on interpersonal dynamics within aging families providing care to each other (Carr & Utz, 2020), examining how the transition to EOL caregiving effects family caregivers' health and well-being (Aoun et al., 2018), and utilizing innovative theoretical approaches to guide studies of aging families (Humble et al., 2020). In addition, Bronfenbrenner recommended the use of the bioecological model to bridge theory to research method and practice (Bronfenbrenner & Morris, 2006). The conceptual framework for a bioecological model of family dynamics and the transition to EOL caregiving was utilized to develop the methods for the studies in Chapters 3 and 4, specifically the development of a survey for family caregivers (see Appendix B) and selection and creation of appropriate measures, the approaches to data analysis, and the interpretation of results. The framework also informs the plans for next steps to advance family caregiving research and developing interventions to prepare individuals and aging families for EOL caregiving.

Summary of Chapter 3

The purpose of the study presented in Chapter 3, *Family Caregivers' Feelings of Preparedness for the Transition to End-of-Life Caregiving*, was to explore how family caregivers perceive their preparedness for the transition to EOL care and to investigate what factors may be associated with those feelings of preparedness. This study addresses gaps in caregiving research wherein little is known about the factors that may influence family caregivers' feelings of preparedness for the transition to EOL care. As discussed in the literature review, many family caregivers lack the skills to provide the physical, emotional, spiritual, and social needs of their care receiver at the EOL. These complex needs of a dying family member contribute to the increased physical and psychosocial burdens of EOL caregiving, which considered together demonstrate the importance of understanding how to help family caregivers prepare for the transition to EOL care.

In this study, 252 family caregivers were recruited to complete a self-report online survey. The survey included measures to learn more about caregivers' preparedness for caregiving, cultural reasons for caregiving, number of tasks completed to prepare for the transition to EOL care, burden appraisal, and other various demographics and characteristics of their care receiver and the caregiving experience. To learn more about family caregivers and their perceived preparedness fort the transition to EOL care, analyses of the data included utilization of descriptive statistics, EFA (to identify factors within the construct of preparedness), ANOVAs, and a multiple regression. Several key findings are important for understanding family caregiver preparedness. For example, on average, family caregivers felt somewhat prepared for general caregiving responsibilities, but not too well prepared for the transition to EOL care and EOL caregiving responsibilities. These feelings were common among family caregivers of all ages, gender, race, ethnicity, education level, and income. Differences in preparedness for EOL caregiving were found between different familial relation of the caregiver and care receiver, stage of care along caregiving trajectory, and hours of care provided each week. In addition, perceived burden of caregiving and number of tasks related to EOL care completed were both associated with differences in caregivers' preparedness for EOL caregiving.

Overall, the findings of this study identified fewer demographics and characteristics of caregivers and the caregiving experience that were associated with preparedness for EOL care than hypothesized. Yet, several factors (including family relation between caregiver and care receiver and number of tasks related to EOL care completed) were related to family structure, interactions, and processes. Previous studies have explored how advance care planning and communicating with health care professionals can help individuals feel more prepared for EOL care (Carr & Luth, 2017; Egbert et al., 2017; Redinbaugh et al., 2003), but few have examined how to encourage families to discuss potential future care needs and decisions or how those interactions may influence family caregiver outcomes. It may be that a lack of preparedness for EOL caregiving is a universal feeling, not limited to specific caregiving populations, and future studies (and subsequent intervention development) should further explore how to help all individuals and their families feel more prepared for EOL care.

Summary of Chapter 4

The study presented in Chapter 4, *Understanding the Association Between Family Dynamics and Preparedness for the Transition to End-of-Life Caregiving*, continued building on the research from the previous chapter. The purpose of this study was to explore the association between family caregivers' family dynamics and their perceived preparedness for the transition to EOL caregiving. Most of family caregiving research continues to focus on the experiences and outcomes of a primary family caregiver, occasionally exploring dyadic experiences of the caregiver and care receiver, without recognizing the impact caregiving and caregiving transitions have on the whole family system (Qualls, 2018). Drawing from the same study sample in Chapter 3, survey responses from 173 family caregivers were analyzed to examine family dynamics and caregivers' perceived preparedness for caregiving. Family dynamics were measured using scales developed from the Circumplex model of marital and family systems (Olson & Gorall, 2003). It is important to note that these scales were selected for use in this study for their strengths-based and comprehensive questions measuring multiple dimensions of family functioning and interaction. The few measures of family dynamics identified for use in caregiving research only focused on family conflict and relationship strain (Cella et al., 2010; Family Caregiving Alliance, 2012).

The key finding of this study was that the hypothesized model considered in the SEM (including all other tested models) failed to achieve acceptable model fit of the data. In addition, the mediating role of number of tasks completed related to EOL care was not confirmed. A variety of possible statistical and theoretical explanations for this finding were considered, including random variation and a lack of linear association amongst some of the variables of interest, and the appropriateness of the family dynamic measure for use in a cross-sectional, individual-level study. Although statistical significance was not achieved in the hypothesized model, the practical significance of the findings are important and inform plans for the next steps of this research discussed in the upcoming section.

In addition to the issues discussed with use of the family dynamics measure in the SEM, there were conflicting results of comparisons of each dynamics scale included in the measure (flexibility, cohesion, communication, and satisfaction) with preparedness for EOL caregiving. The average family caregiver reported balanced family cohesion and flexibility, but also reported low family communication and satisfaction. Balanced cohesion and flexibility were not associated with preparedness for EOL caregiving, but family communication and satisfaction were. These results suggest that the association between family dynamics and preparedness for EOL caregiving in not well understood, and further research is important. It may be that each of these constructs of family dynamics are uniquely important at different stages of caregiving and during the transition to EOL care. Thus, there is a need for more valid and reliable measures of family dynamics for aging, caregiving families.

Practical Implications

These exploratory studies pave the way for advancing empirical and applied studies of family caregiving. Chapters 2-4 included recommendations for future studies, drawing from reviews of extant literature and the results and limitations of each study. The following paragraphs bring together these discussions with recommendations from key caregiving studies to provide an overview of how this dissertation can be used to advance caregiving research. Specific examples of next steps are provided for both research and intervention development.

Advancing Family Caregiving Research

Much of family caregiving research has focused on identifying the stresses and burdens of providing care to family members. In addition, researchers have extensively studied the adverse physical, mental, emotional, social, and financial outcomes associated with the family caregiver role and responsibilities. Yet, there remains gaps in caregiving research that leave unanswered questions about the family caregiving experience and caregiver outcomes (Schulz et al., 2020), such as how family interactions may influence identification of the positive aspects of caregiving. The exploratory studies in Chapters 3 and 4 were guided by the conceptual framework for a bioecological model of family dynamics and the transition to EOL caregiving presented in Chapter 2. This approach demonstrates how innovative uses of theory may be used to explore these unanswered questions.

This dissertation and the acknowledged limitations of each study have provided suggestions of how to build off this research to develop new research questions and improve on study methods to advance family caregiving research. These recommendations focus on three themes: a) shifting from individual-level, cross-sectional methods to longitudinal, family-level methods (including multiple family members in studies) to better understand the family experience of caregiving and how family dynamics over time may relate to caregiver outcomes; b) improving the study design, recruitment efforts, and data collection methods to reach a larger and more diverse sample of family caregivers; and c) continue to explore how to prepare families for caregiving transitions. Developing longitudinal studies that measure family members' responses over time may improve researchers' ability to draw conclusions about how family dynamics are associated with the caregiving experience and caregiver outcomes. More diverse study samples will improve the generalizability of study findings and help researchers explore caregiving experiences and outcomes that more closely represent those of all family caregivers. And finally, to pull all of these themes together, understanding how and why family members get involved in EOL care and decision making, how families navigate the transition to EOL care together, and how family dynamics may relate to caregiver outcomes requires an appreciation of individuals’ and families’ racial, ethnic, cultural, community, and family backgrounds and history (Dilworth-Anderson et al., 2011).

Using the recommendations from caregiving literature, findings from this dissertation, and the lessons learned from the limitations of these studies, there are two main next steps for advancing this line of family caregiving research. The first step will be to develop a new measure of family dynamics to explore how perceptions of family functioning, closeness, and interactions may be associated with the caregiving experience and caregiver outcomes. As discussed in Chapter 4 (and based on findings from utilizing the Circumplex model measure of family dynamics (Olson & Gorall, 2003)), there is a lack of available strengths-based measures of family dynamics appropriate for use with aging, caregiving families. Each of the studies in this dissertation provide evidence of the significance of the family dynamic construct within family caregiving research and justification for why a new measure is appropriate (both elements of the process of domain identification for best practices of measure development and validation; Boateng et al., 2018). A diverse sample of family caregivers will be recruited to assist in the process of scale development using inductive, qualitative methods including family observations and interviews. Following the development of the measure, it will be tested in focus groups and refined based on participant feedback. Another sample with then be recruited to test the edited measure, after which responses will be analyzed to confirm the factor structure of the family dynamics measure and assess the validity and reliability of the measure.

After a new family dynamic measure has been created, tested, validated, and deemed reliable for use with aging, caregiving families, the next step to advance this research is to continue exploring the association between family dynamics and perceived preparedness for the transition to EOL care in a longitudinal, family-level study. Ideally, a mixed method approach would be utilized to assess family dynamics (as perceived and reported by different family members and as observed by the researcher) over time. The research methods and findings from these proposed studies will help researchers and practitioners better understand how family functioning, interactions, and processes may influence family caregivers' perceived preparedness for EOL caregiving, and which of those should be recommended for all families to help them feel more prepared for the transition to EOL care. In turn, this work will inform the development of an intervention aimed at helping prepare individuals and families for the transition to EOL caregiving.

Interventions for Caregiving Families

This dissertation has several implications for applied family caregiving research, including the development and implementation of interventions for family caregivers and their families. As families care for each other in different capacities across the lifespan, each family member's roles and responsibilities are likely to change along with the care needs of others. Yet, most caregiving interventions are designed for a primary family caregiver or a dyadic program for both the caregiver and care receiver (NASEM, 2016), despite the knowledge that multiple family members are often involved in the provision of care and family dynamics are associated with caregiver and care receiver outcomes (Qualls & Noecker, 2009). In addition, most rigorously tested interventions are designed for specific caregiving populations (such as caring for individuals with dementia or cancer), thus limiting the reach of caregiving interventions (Segal et al., 2018) from any caregiving family that faces the challenges of caregiving transitions. A recent review of caregiver interventions (Zarit, 2018) found that caregivers want proactive solutions to future caregiving problems and want to focus on the positive aspects of caregiving (such as positive emotions and family interactions). These findings support recommendations in caregiving research to utilize strengths-based approaches to intervention development, which allows for the identification and building of individual- and family-level potential and capacity (Hughes, 2015) and supports resilience in caregiving families.

Based on these recommendations and those addressed throughout the literature reviews in this dissertation, the next step to advance this research is to develop or adapt a strengths-based intervention for caregiving families to prepare them for the transition to EOL care. Following the National Institutes of Health stage model for behavioral intervention development (NIA, 2021), stage 0 of intervention development involves conducting basic science to inform the development of an intervention. The results from this dissertation and the future studies addressed in the previous section will fulfill stage 0, assuming the mechanisms of change within family systems that are associated with preparedness for EOL caregiving will have been identified. Thus, the next step for this research is Stage 1 of intervention development which involves the creation and preliminary test of the intervention (or adaptation or modification of an existing intervention; NIA, 2021).

Ideally, the intervention would be designed for multiple family members (continuing the family-level approach to research and intervention recommended throughout this dissertation) and would include opportunities for education and skill-building to enhance individual and family self-efficacy and preparation for caregiving responsibilities and decision-making related to EOL care. As discussed in Chapter 3, researchers have identified core competencies for families and family caregivers important to caregiving transitions, including effective communication skills, problem-solving skills, conflict management, sharing and coordination of care, and self-care (Gitlin & Wolff, 2011). These elements would provide the foundation for the intervention curriculum and inform the development of outcomes assessment. As these skills are important to any caregiving family, regardless of a care receiver's diagnosis or care needs, the intervention would be widely generalizable and could be easily adapted to meet the needs of different caregiving populations.

Implications for Practice

After the intervention has been developed and pilot tested (stage I of the NIH stage model for behavioral intervention development), next steps would include testing for feasibility and acceptability, experimental efficacy testing in first research (controlled) and then real-world settings, and finally testing effectiveness of the intervention in community settings with the help and support of community partners and service providers. These steps would fulfill stages II-IV of the NIH model (NIA, 2021) and inform moving the empirically supported intervention into practice in the final stage (V) of implementation and dissemination. There is much work to be done to move this dissertation research forward from its current stage to a community-practiced, evidence-based intervention. Yet, much of what has been discussed in this dissertation study may inform implementation of interventions (both current and future) for caregiving families and how practitioners can support the health and well-being of family caregivers, their care receivers, and their families.

In addition to the recommended components of the intervention discussed previously, it will be important to focus on recruitment strategies while testing the intervention. Most caregivers do not self-identify as a family caregiver (RCIC, 2012), so one approach for recruitment is to limit exclusion criteria and have researchers and practitioners stress the importance of care receivers and their family caregivers seeking help from not only family members and friends, but also service providers and community resources regardless of the type or amount of care that is currently provided. Researchers have recommended educating and preparing all adults for caregiving, understanding the likelihood and importance of needing or providing care in the future (Schulz et la., 2020). An intervention designed specifically to help prepare all individuals and families for the likelihood of the eventual transition to EOL care for a family member will complement hospice and palliative care programs prepare families for EOL caregiving long before they face the challenges of the transition to this stage.

Practitioners working with patients or clients should be aware of their family caregivers, inform them of the potential for transitions in care needs and caregiving responsibilities, and encourage family communication about caregiving transitions. By including family caregivers in a patient or client's course of care and decision-making, practitioners may be more able to identify families that do not feel prepared for the transition to EOL care. These families can be directed to community programs and resources (such as an intervention) that will help them plan for future care, communicate about care wishes and plans, and build skills to be able to adapt to the increasing complexities of caregiving responsibilities.

Conclusion

The primary aim of this dissertation was to explore how family caregivers perceive their preparedness for the transition to EOL caregiving and how family dynamics may be associated with how prepared family caregivers feel for that transition. This dissertation provides evidence that many family caregivers do not feel prepared for the transition to EOL caregiving. The adaptation of Bronfenbrenner's bioecological model (Bronfenbrenner & Morris, 2006) into the *Conceptual Framework for a Bioecological Model of Family Dynamics and the Transition to EOL Caregiving* and findings from the subsequent studies provide direction and support for future studies to advance family caregiving research and inform intervention development. As researchers and practitioners continue efforts to understand the risk and protective factors associated with caregiving, the recommendations made in this dissertation may help identify new research questions to explore and opportunities for prevention and intervention science to help individuals and families feel more prepared for receiving care, providing care, and navigating caregiving transitions, such as the transition to EOL care. Currently, the end of life is a developmental stage that remains largely overlooked in research across a variety of fields, including human development, family science, gerontology, psychology, sociology, and social work. Family members often have the opportunity or responsibility to provide care and comfort at this stage to a dying family member. Helping families and individuals prepare for this time and the unique challenges and opportunities of EOL caregiving may not only improve family caregiver and family-level outcomes, but more importantly, help families best meet the care wishes and improve life satisfaction for individuals at the end of their life.

REFERENCES

Allen, K. R., Blieszner, R., & Roberto, K. A. (2000). Families in the middle and later years: A review and critique of research in the 1990s. *Journal of Marriage and the Family, 62*(4), 911-926). https://doi.org/10.1111/j.1741-3737.2000.00911.x

Almeida, D. M., & Wong, J. D. (2009). Life transitions and daily stress processes. In Elder Jr., G. H., & Giele, J. Z. (Eds.), *The craft of life course research* (pp. 141-162). New York, NY: The Guilford Press.

Anderson, E. W., & White, K. M. (2018). "This is what the family does": The family experience of caring for serious illness. *American Journal of Hospice and Palliative Medicine, 35*(2), 348-354. https://doi.org/10.1177%2F1049909117709251

Aoun, S. M, Ewing, G., Grande, G., Toye, C., & Bear, N. (2018). The impact of supporting family caregivers before bereavement on outcomes after bereavement: Adequacy of end-of-life support and achievement of preferred place of death. *Journal of Pain and Symptom Management, 55*(2), 368-378. https://doi.org/10.1016/j.jpainsymman.2017.09.023

Apesoa-Varano, E. C., Tang-Feldman, Y., Reinhard, S. C., Choula, R., & Young, H. M. (2015). Multi-cultural caregiving and caregiver interventions: A look back and a call for future action. *Generations, 39*(4), 39-48.

Arbuckle, J. L. (2014). *Amos* (Version 26.0) [Computer Program]. IBM SPSS.

Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health, 13*(6), 375-384. https://doi.org/10.1002/nur.4770130605

Bainbridge, D., Krueger, P., Lohfeld, L., & Brazil, K. (2009). Stress processes in caring for an end-of-life family member: Application of a theoretical model. *Aging & Mental Health, 13*(4), 537-545. https://doi.org/10.1080/13607860802607322

Bédard, M., Molloy, D. W., Squire, L., Dubois, S., Lever, J. A., & O'Donnell, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*(5), 652-657. https://doi.org/10.1093/geront/41.5.652

Blieszner, R., & Voorpostel, M. (2016). Families and aging: Toward an interdisciplinary family-level approach. In V. L. Bengtson, & R. A. Settersten Jr. (Eds.), *Handbook of theories of aging* (3rd ed., pp. 327-348). Springer Publishing Company.

Boateng, G. O., Neilands, T. B., Frongillo, E. A., Melgar-Quiñonez, H. R., & Young, S. L. (2018). Best practices for developing and validating scales for health, social, and behavioral research: A primer. *Frontiers in Public Health, 6*(149), 1-18. https://dx.doi.org/10.3389%2Ffpubh.2018.00149

Boerner, K., Carr, D., & Moorman, S. (2013). Family relationships and advance care planning: Do supportive and critical relations encourage or hinder planning? *The Journals of Gerontology: Series B, 68*(2), 246-256. https://doi.org/10.1093/geronb/gbs161

Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In R. M. Lerner (Ed.), *Handbook of child psychology, Vol. 1, Theoretical models of human development* (6th ed., pp. 793-828). Wiley. https://doi.org/10.1002/9780470147658.chpsy0114

Brubaker, T. H. (1990). Families in later life: A burgeoning research area. *Journal of Marriage and Family, 52*(4), 959-981. https://doi.org/10.2307/353313

Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *The Gerontologist, 43*(2), 230-241. https://doi.org/10.1093/geront/43.2.230

Cagle, J. G., & Kovacs, P. J. (2009). Education: A complex and empowering social work intervention at the end of life. *Health & Social Work, 34*(1), 17-27. https://doi.org/10.1093/hsw/34.1.17

Carr, D., & Luth, E. A. (2017). Advance care planning: Contemporary issues and future directions. *Innovations in Aging, 2017, 1*(1), 1-10. https://doi.org/10.1093/geroni/igx012

Carr, D., & Utz, R. L. (2020). Families in later life: A decade in review. *Journal of Marriage and Family, 82*(1), 346-363. https://doi.org/10.1111/jomf.12609

Cella, D., Riley, W., Stone, A. A., Rothrock, N., Reeve, B. B., Yount, S., Amtmann, D. D. B., Choi, S., Cook, K. F., et al. (2010). The Patient Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *Journal of Clinical Epidemiology, 63*(11), 1179-1194. https://doi.org/10.1016/j.jclinepi.2010.04.011

Cho, J., Ory, M. G., & Stevens, A. B. (2016). Socioecological factors and positive aspects of caregiving: Findings from the REACH II intervention. *Aging & Mental Health, 20*(11), 1190-1201. https://doi.org/10.1080/13607863.2015.1068739

Christ, G., & Blacker, S. (2005). Enhancing our understanding of the impact of transition to end-of-life caregiving. *Palliative Medicine, 8*(3), 622. https://doi.org/10.1089/jpm.2005.8.622

Cohen, C. A., Colantonio, A., & Vernich, L. (2002). Positive aspects of caregiving: Rounding out the caregiver experience. *Geriatric Psychiatry, 17*(2), 184-188. https://doi.org/10.1002/gps.561

Cohen, S. A., Cook, S. K., Sando, T. A., Brown, M. J., & Longo, D. R. (2017). Socioeconomic and demographic disparities in caregiving intensity and quality of life in informal caregivers: A first look at the national study of caregiving. *Journal of Gerontological Nursing, 43*(6), 17-24. https://doi.org/10.3928/00989134-20170224-01

Cohen-Mansfield, J., Cohen, R., Skornick-Bouchbinder, M., & Brill, S. (2018). What is the end of life period? Trajectories and characterization based on primary caregiver reports. *The Journals of Gerontology: Series A, 73*(5), 695-701. https://doi.org/10.1093/gerona/glx195

Connidis, I. A. (2020). Who counts as family later in life? Following theoretical leads. *Journal of Family Theory and Review, 12*(2), 164-179. https://doi.org/10.1111/jftr.12367

Cooney, T. M., Shapiro, A., & Tate, C. E. (2019). End-of-life care planning: The importance of older adults' marital status and gender. *Journal of Palliative Medicine, 22*(8), 902-907. https://doi.org/10.1089/jpm.2018.0451

Corry, M., While, A., Neenan, K., & Smith, V. (2014). A systematic review of systematic reviews on interventions for caregivers of people with chronic conditions. *Journal of Advanced Nursing, 71*(4), 718-734. https://doi.org/10.1111/jan.12523

Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of race on cultural justifications for caregiving. *Journals of Gerontology: Series B, 60*(5), S257-S262. https://doi.org/10.1093/geronb/60.5.S257

Dilworth-Anderson, P., Busby-Whitehead, J., & Palmer, M. H. (2011). Conclusions and recommendations. In P. Dilworth-Anderson & M. H. Palmer (Eds.), *Annual Review of Gerontology and Geriatrics, 31*, 255-261. Springer.

Dilworth-Anderson, P., Moon, H., & Aranda. M. P. (2020). Dementia caregiving research: Expanding and reframing the lens of diversity, inclusivity, and intersectionality. *The Gerontologist, 60*(5), 797-805. https://doi.org/10.1093/geront/gnaa050

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: A 20-year review (1980-2000). *The Gerontologist, 42*(2), 237-272. https://doi.org/10.1093/geront/42.2.237

Duggleby, W., Tycholiz, J., Holtslander, L., Hudson, P., Nekolaichuk, C., Mirhosseini, M., Parmar, J., Chambers, T., Alook, A., & Swindle, J. (2016). A metasynthesis study of family caregivers' transition experiences caring for community-dwelling persons with advanced cancer at the end of life. *Palliative Medicine, 31*(7), 602-616. https://doi.org/10.1177%2F0269216316673548

Early, T. J. (2001). Measures for practice with families from a strengths perspective. *Families in Society: The Journal of Contemporary Social Services, 82*(3), 225-232. https://doi.org/10.1606%2F1044-3894.235

Egbert, N., Child, J. T., Lin, M., Savery, C., & Bosley, T. (2017). How older adults and their families perceive family talk about aging-related EOL issues: A dialectical analysis. *Behavioral Sciences, 7*(2), 54-61. https://doi.org/10.3390/bs7020021

Elder, G. H., & Giele, J. Z. (Eds.). (2009). *The craft of life course research*. The Guilford Press.

Fabius, C. D., Wolff, J. L., & Kasper, J. D. (2020). Race differences in characteristics and experiences of Black and White caregivers of older Americans. *The Gerontologist, 60*(7), 1244-1253. https://doi.org/10.1093/geront/gnaa042

Family Caregiver Alliance & Benjamin Rose Institute on Aging (2012). Selected caregiver assessment measures: A resource inventory for practitioners (2nd edt.). https://www.caregiver.org/sites/caregiver.org/files/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf

Fauth, E., Hess, K., Piercy, K., Norton, M., Corcoran, C., Rabins, P., Lyketsos, C., & Tschanz, J. (2012). Caregivers' relationship closeness with the person with dementia predicts both positive and negative outcomes for caregivers' physical health and psychological well-being. *Aging & Mental Health, 16*(6), 699-711. https://doi.org/10.1080/13607863.2012.678482

Finch, W. H. (2020). Using fit statistic differences to determine the optimal number of factors to retain in an exploratory factor analysis. *Journal of Educational and Psychological Measurement, 80*(2), 217-241. https://doi.org/10.1177%2F0013164419865769

Fingerman, K. L., Miller, L. M., & Seidel, A. J. (2009). Functions families serve in old age. In S. H. Qualls, & S. H. Zarit (Eds.), *Aging families and caregiving* (pp. 19-43). Wiley.

Fowler, C., & Fisher, C. L. (2009). Attitudes toward decision making and aging, and preparation for future care needs. *Health Communication, 24*(7), 619-630. https://doi.org/10.1080/10410230903242226

Fowler, C., Fisher, C. L., & Pitts, M. J. (2014). Older adults' evaluations of middle-aged children's attempts to initiate discussion of care needs. *Health Communication, 29*(7), 717-727. https://doi.org/10.1080/10410236.2013.786278

Fox, A. L., Sharp, J. L., & Fruhauf, C. A. (2021a). *Family dynamics and the transition to end-of-life caregiving: A brief review and conceptual framework* [Manuscript submitted for publication]. Department of Human Development and Family Studies, Colorado State University.

Fox, A. F., Sharp, J. L., & Fruhauf, C. A. (2021b). *Family caregivers' feelings of preparedness for the transition to end-of-life caregiving* [Unpublished manuscript]. Department of Human Development and Family Studies, Colorado State University.

Gallagher-Thompson, D. & Coon, D. W. (2007). Evidence-based psychological treatments for distress in family caregivers of older adults. *Psychology and Aging, 22*(1), 37-51. https://psycnet.apa.org/doi/10.1037/0882-7974.22.1.37

Gerhardt, C. (2020). *Families in motion: Dynamics in diverse contexts*. Sage.

Gitlin, L. N., & Schulz, R. (2012). Family caregiving of older adults. In T. R. Prohaska, L. A. Anderson, & R. H. Binstock, (Eds.), *Public health for an aging society* (pp. 181-205). The Johns Hopkins University Press.

Gitlin, L. N., & Wolff, J. (2011). Family involvement in care transitions of older adults: What do we know and where do we go from here? In P. Dilworth-Anderson & M. H. Palmer (Eds.), *Annual Review of Gerontology and Geriatrics, 31*, 31-64. Springer.

Given, B. A., & Reinhard, S. C. (2017). Caregiving at the end of life: The challenges for family caregivers. *Generations, 41*(1), 50-57.

Goode, K. T., Haley, W. E., Roth, D. L., & Ford, G. R. (1998). Predicting longitudinal changes in caregiver physical and mental health: A stress process model. *Health Psychology, 17*(2), 190-198. https://psycnet.apa.org/doi/10.1037/0278-6133.17.2.190

Gratão, A. C. M., Brigola, A. G., Ottaviani, A. C., Luchesi, B. M., Souza, É. N., Rossetti, E. S., de Oliveira, N. A., Terassi, M., & Pavarini, S. C. I. (2019). Brief version of Zarit Burden Interview (ZBI) for burden assessment in older caregivers. *Dementia & Neuropsychologia, 13*(1), 122-129. https://doi.org/10.1590/1980-57642018dn13-010015

Greene, R. R., & Kropf, N. P. (2014). *Caregiving and care sharing: A life course perspective*. NASW Press.

Haley, W. E., Allen, R. S., Reynolds, S., Chen, H., Burton, A., & Gallagher-Thompson, D. (2002). Family issues in end-of-life decision making and end-of-life care. *American Behavioral Scientist, 46*(2), 284-298. https://doi.org/10.1177%2F000276402236680

Hayes, A. F. (2017*). Introduction to mediation, moderation, and conditional process analysis: A regression-based approach* (2nd ed.). Guilford Press.

Health Resources & Services Administration (2020). Definition of Family. https://www.hrsa.gov/get-health-care/affordable/hill-burton/family.html

Hebert, R. S., & Schulz, R. (2006). Caregiving at the end of life. *Journal of Palliative Medicine, 9*(5), 1174-1187. https://doi.org/10.1089/jpm.2006.9.1174

Henriksson, A., & Ârestedt, K. (2013). Exploring factors and caregiver outcomes associated with feelings of preparedness for caregiving in family caregivers in palliative care: A correlational, cross-sectional study. *Palliative Medicine, 27*(7), 639-646. https://doi.org/10.1177%2F0269216313486954

Henry, C. S., Hubbard, R. L., Struckmeyer, K. M., & Spencer, T. A. (2018). Family resilience and caregiving. In W. A. Bailey, & A. W. Harrist (Eds), *Family caregiving: Fostering resilience across the life course* (pp. 1-26). Springer.

Holland, M. M., & Prost, S. G. (2019). The end of life within social work literature: A conceptual review. *Journal of Death and Dying, 82*(4), 668-691. https://doi.org/10.1177%2F0030222819835650

Hudson, P. L., & Hayman-White, K. (2006). Measuring the psychosocial characteristics of family caregivers of palliative care patients: Psychometric properties of nine self-report instruments. *Journal of Pain and Symptom Management, 31*(3), 215-228. https://doi.org/10.1016/j.jpainsymman.2005.07.010

Hughes, M. E. (2015). A strengths perspective on caregiving at the end-of-life. *Australian Social Work, 68*(2), 156-168. https://doi.org/10.1080/0312407X.2014.910677

Humble, A. M., & Price, C. A. (2017). Stress and coping in later life. In C. Price, K. Bush, & S. J. Price (Eds.), *Families and change: Coping with stressful events and transitions* (5th ed., pp. 119-136). Sage.

Humble, A. M., Seidel, A. J., Yorgason, J. B., & Redden, M. (2020). A 10-year portrait of theorizing in family gerontology: Making the mosaic visible. *Journal of Family Theory & Review, 12*(2), 147-163. https://doi.org/10.1111/jftr.12372

IBM Corp. Released 2019. *IBM SPSS Statistics for Windows*, Version 26. IBM Corp.

Ivery, J. M., & Muniz, G. R. (2017). Caregiving transitions: Developmental and gendered perspectives. *Journal of Human Behavior in the Social Environment, 27*(4), 311-320. https://doi.org/10.1080/10911359.2017.1284028

Izumi, S., Nagae, H., Sakurai, C., & Imamura, E. (2012). Defining end-of-life care from perspectives of nursing ethics. *Nursing Ethics, 19*(5), 608-618. https://doi.org/10.1177%2F0969733011436205

Keith, C. (1995). Family caregiving systems: Models, resources, and values. *Journal of Marriage and the Family, 57*(2), 179-189. https://www.jstor.org/stable/353826

Kelly, K., Reinhard, S. C., & Brooks-Danso, A. (2008). Executive summary: Professional partners supporting family caregivers. *American Journal of Nursing, 108*(9), 6-12. https://doi.org/10.5175/JSWE.2008.773247712

Kline, R. B. (2015). *Principles and practice of structural equation modeling* (4th ed.). Guilford Press.

Knight, B. G., Lutzky, S. M., & Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist, 33*(2), 240-248. https://doi.org/10.1093/geront/33.2.240

Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated sociocultural stress and coping model. *Journal of Gerontology: Psychological Sciences, 65B*(1), 5-13. https://doi.org/10.1093/geronb/gbp096

Koutra, K., Simos, P., Triliva, S., Lionis, C., & Vgontzas, A. N. (2016). Linking family cohesion and flexibility with expressed emotion, family burden, and psychological distress in caregivers of patients with psychosis: A path analytic model. *Psychiatry Research, 240*, 66-75. https://doi.org/10.1016/j.psychres.2016.04.017

Kramer, B. J., & Boelk, A. Z. (2015). Correlates and predictors of conflict at the end of life among families enrolled in hospice. *Journal of Pain and Symptom Management, 50*(2), 155-162. https://doi.org/10.1016/j.jpainsymman.2015.02.026

Kumar, V., Ankuda, C. K., Aldridge, M. D., Husain, M., & Ornstein, K. A. (2020). Family caregiving at the end of life and hospice use: A national study of medicare beneficiaries. *Journal of the American Geriatrics Society, 68(*10), 2288-2296. https://doi.org/10.1111/jgs.16648

Laditka, S. B., (2017). “It can’t happen soon enough.” The role of readiness in residential moves by older parents. *The Gerontologist, 57*(1), 6-11. https://doi.org/10.1093/geront/gnw101

Lai, D. W. L., & Thomson, C. (2011). The impact of perceived adequacy of social support on caregiving burden of family caregivers. Families in Society, 92(1), 99-106. https://doi.org/10.1606/1044-3894.4063

Lin, I-F., Fee, H. R., & Wu, H-S. (2012). Negative and positive caregiving experiences: A closer look at the intersection of gender and relationship. *Family Relations, 61*(2), 343-358. https://doi.org/10.1111/j.1741-3729.2011.00692.x

Lin, I-F., & Wolf, D. A. (2020). Division of parent care among adult children. *The Journals of Gerontology: Series B, 75*(10), 2230-2239. https://doi.org/10.1093/geronb/gbz162

Liu, C., Badana, A. N. S., Burgdorf, J., Fabius, C. D., Roth, D. L., & Haley, W. E. (2020). Systematic review and meta-analysis of racial and ethnic differences in dementia caregivers’ well-being. *The Gerontologist, 2020*, 1-16. https://doi.org/10.1093/geront/gnaa028

Lopez-Hartmann, M., Wens, J., Verhoeven, V., & Remmen, R. (2012). The effect of caregiver support interventions for informal caregivers of community-dwelling frail elderly: A systematic review. *International Journal of Integrated Care, 12*, e133. https://doi.org/10.5334/ijic.845

McMillan, S. C. (2005). Interventions to facilitate family caregiving at the end of life. *Palliative Medicine, 8*(1), S132-S139. https://doi.org/10.1089/jpm.2005.8.s-132

Montgomery, R. J. V., Kwak, J., & Kosloski, K. D. (2016). Theories guiding support services for family caregivers. In V. L. Bengtson, & R. A. Settersten Jr. (Eds.), *Handbook of theories of aging* (3rd ed., pp. 443-462). Springer Publishing Company.

Moon, H. E., Haley, W. E., Rote, S. M., & Sears, J. S. (2020). Caregiver well-being and burden: Variations by race/ethnicity and care recipient nativity status. *Innovation in Aging, 4*(6), 1-13. https://doi.org/10.1093/geroni/igaa045

Moon, M. (2017). The unprepared caregiver. *The Gerontologist, 57*(1), 26-31. https://doi.org/10.1093/geront/gnw080

National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. National Academies Press.

National Alliance for Caregiving & AARP Public Policy Institute (2020). *Caregiving in the U.S.: 2020 Report*. https://www.caregiving.org/wp-content/uploads/2020/06/AARP1316_RPT_CaregivingintheUS_WEB.pdf

National Cancer Institute (2020). *NCI dictionary of cancer terms: End-of-life care*. https://www.cancer.gov/publications/dictionaries/cancer-terms

National Institute on Aging (2020a). *The national institute on aging: Strategic directions for research, 2020-2025*. https://www.nia.nih.gov/about/aging-strategic-directions-research

National Institute on Aging (2020b). *What are palliative care and hospice care?* https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care

National Institute on Aging (2021). *NIH stage model for behavioral intervention development*. https://www.nia.nih.gov/research/dbsr/nih-stage-model-behavioral-intervention-development

National Institutes of Health (2004). *National institutes of health state-of-the-science conference statement on improving end-of-life care*. https://consensus.nih.gov/2004/2004endoflifecaresos024html.htm

Nielsen, M. K., Neergaard, M. A., Jensen, A. B., Bro, F., & Guldin, M. (2016). Psychological distress, health, and socio-economic factors in caregivers of terminally ill patients: A nationwide population-based cohort study. *Support Care Cancer, 24*, 3057-3067. https://doi.org/10.1007/s00520-016-3120-7

Northouse, L. L., Katapodi, M. C., Song, L., Zhang, L., & Mood, D. W. (2010). Interventions with family caregivers of cancer patients: Meta-analysis of randomized trials. *CA: A Cancer Journal for Clinicians, 60*(5), 317-339. https://doi.org/10.3322/caac.20081

Oechsle, K. (2019). Current advances in palliative & hospice care: Problems and needs of relatives and family caregivers during palliative and hospice care – an overview of current literature. *Medical Sciences, 7*(3), 43. https://doi.org/10.3390/medsci7030043

Oliver, D. P., Albright, D. L., Washington, K., Wittenberg-Lyles, E., Gage, A., Mooney, M., & Demiris, G. (2013). Hospice caregiver depression: The evidence surrounding the greatest pain of all. *Journal of Social Work in End-of-Life & Palliative Care, 9*(4), 256-271. https://doi.org/10.1080/15524256.2013.846891

Olson, D. (2011). FACES IV and the Circumplex Model: Validation study. *Journal of Marital and Family Therapy, 37*(1), 64-80. https://doi.org/10.1111/j.1752-0606.2009.00175.x

Olson, D. H., & Gorall, D. M. (2003). Circumplex model of marital and family systems. In F. Walsh (Ed.), *Normal Family Processes* (3rd ed., pp. 514-547). Guilford.

Olson, D. H., Waldvogel, L., & Schlieff, M. (2019). Circumplex model of marital and family systems: An update. *Journal of Family Theory and Review, 11*(2), 199-211. https://doi.org/10.1111/jftr.12331

Ornstein, K. A., Kelley, A. S., Bollens-Lund, E., Wolff, J. L. (2017). A national profile of end-of-life caregiving in the United States. *Health Affairs, 36*(7), 1184-1192. https://doi.org/10.1377/hlthaff.2017.0134

Osher, D., Cantor, P., Berg, J., Steyer, L., & Rose, T. (2017). Drivers of human development: How relationships and context shape learning and development. *Applied Developmental Science, 24*(1), 6-36. https://doi.org/10.1080/10888691.2017.1398650

Pearlin, L. I., Mullan, J. T., Semple, S. J., & Skaff, M. M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594. https://doi.org/10.1093/geront/30.5.583

Penrod, J., Hupcey, J. E., Shipley, P. Z., Loeb, S. J., & Baney, B. (2011). A model of caregiving through the end of life: Seeking normal. *Western Journal of Nursing Research, 34*(2), 174-193. https://doi.org/10.1177%2F0193945911400920

Pereira, M. G., & Teixeira, R. (2013). Portuguese validation of FACES-IV in adult children caregivers facing parental cancer. *Contemporary Family Therapy, 35*, 478-490. https://doi.org/10.1007/s10591-012-9216-4

Perumalswami, C., Burke, J., Singer, D., Malani, P., Malani, P., Kirch, M., Solway, E., Kullgren, J., & Skolarus, L. (2021). *Older adults' experiences with advance care planning*. University of Michigan National Poll on Healthy Aging. http://hdl.handle.net/2027.42/167012

Phillips, L. R., & Reed, P. G. (2010). End-of-life caregiver's perspectives on their role: Generative caregiving. *The Gerontologist, 50*(2), 204-214. https://doi.org/10.1093/geront/gnp116

Pillemer, K., & Gilligan, M. (2018). Translating basic research on the aging family to caregiving intervention: The case of within-family differences. *Innovation in Aging, 2*(1), 1-11. https://doi.org/10.1093/geroni/igx035

Pinquart, M., & Sörensen, S. (2011). Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging, 26*(1), 1-14. https://psycnet.apa.org/doi/10.1037/a0021863

Pinquart, M., & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: A meta-analysis. *The Gerontologist, 45*(1), 90-106. https://doi.org/10.1093/geront/45.1.90

Pinquart, M., & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250-267. https://doi.org/10.1037/0882-7974.18.2.250

Pritchett, R., Kemp, J., Wilson, P., Minnis, H., Bryce, G., & Gillberg, C. (2011). Quick, simple measures of family relationships for use in clinical practice and research: A systematic review. *Family Practice, 28*(2), 172-187. https://doi.org/10.1093/fampra/cmq080

Pucciarelli, G., Savini, S., Byun, E., Simeone, S., Barbaranelli, C., Vela, R. J., Alvaro, R., & Vellone, E. (2014). Psychometric properties of the Caregiver Preparedness Scale in caregivers of stroke survivors. *Heart & Lung, 43*(6), 555-560. https://doi.org/10.1016/j.hrtlng.2014.08.004

Qualls, S. H. (2018). Therapeutic interventions for caregiving families. In W. A. Bailey, & A. W. Harrist (Eds), *Family caregiving: Fostering resilience across the life course* (pp. 27-43). Springer.

Qualls, S. H. (2016). Caregiving families within the long-term services and support system for older adults. *American Psychologist, 71*(4), 283-293. https://psycnet.apa.org/doi/10.1037/a0040252

Qualls, S. H., & Noecker, T. L. (2009). Caregiver family therapy for conflicted families. In S. H. Qualls, & S. H. Zarit (Eds.), *Aging families and caregiving* (pp. 155-188). John Wiley & Sons.

Qualtrics (2020). Qualtrics software. https://www.qualtrics.com/

Quinn, C., & Toms, G. (2019). Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. *The Gerontologist, 59*(5), e584-e596. https://doi.org/10.1093/geront/gny168

Rabow, M. W., Hauser, J. M., & Adams, J. (2004). Supporting family caregivers at the end of life: “They don’t know what they don’t know.” *JAMA, 291*(4), 483-491. https://jamanetwork.com/journals/jama/article-abstract/198062

Redinbaugh, E. M., Baum, A., Tarbell, S., & Arnold, R. (2003). End-of-life caregiving: What help family caregivers cope? *Palliative Medicine, 6*(6), 901-909. https://doi.org/10.1089/109662103322654785

Reinhard, S. C., Feinberg, L. F., Houser, A., Choula, R., & Evans, M. (2019). *Valuing the Invaluable: 2019 Update*. AARP Public Policy Institute. https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf

Roberto, K. A., & Blieszner, R. (2015). Diverse family structures and the care of older persons. *Canadian Journal on Aging, 34*(3), 305-320. https://muse.jhu.edu/article/591529

Roberto, K. A., Blieszner, R., & Allen, K. R. (2006). Theorizing in family gerontology: New opportunities for research and practice. *Family Relations, 55*(5), 513-525. https://doi.org/10.1111/j.1741-3729.2006.00422.x

Roberto, K. A., & Jarrott, S. E. (2008). Family caregivers of older adults: A life span perspective. *Family Relations, 57*(1), 100-111. https://doi.org/10.1111/j.1741-3729.2007.00486.x

Rosa, E. M., & Tudge, J. (2013). Urie Bronfenbrenner’s theory of human development: Its evolution from ecology to bioecology. *Journal of Family Theory & Review, 5*(4), 243-258. https://doi.org/10.1111/jftr.12022

Rosalynn Carter Institute for Caregiving (RCIC). (2012). *Averting the caregiving crisis: An update*. http://www.rosalynncarter.org/UserFiles/File/PositionPaperUpdate3-19-12.pdf

Roth, A. R. (2018). Informal caregiving and network turnover among older adults. *The Journals of Gerontology: Series B, 75*(7), 1538-1547. https://doi.org/10.1093/geronb/gby139

Roth, D. L., Dilworth-Anderson, P., Huang, J., Gross, A. L., & Gitlin, L. N. (2015a). Positive aspects of family caregiving for dementia: Differential item functioning by race. *The Journals of Gerontology: Series B, 70*(6), 813-819. https://doi.org/10.1093/geronb/gbv034

Roth, D. L., Fredman, L., & Haley, W. E. (2015b). Informal caregiving and its impact on health: A reappraisal from population-based studies. *The Gerontologist, 55*(2), 309-319. https://doi.org/10.1093/geront/gnu177

Saleebey, D. (2011). Some basic ideas about the strengths perspective. In F. J. Turner (Ed.), *Social work treatment: Interlocking theoretical approaches* (5th ed., pp. 477-485). Oxford University Press.

Salva, J., Roberto, K. A., Blieszner, R., McCann, B. R., Hoyt, E., & Knight, A. L. (2021). Dementia caregiving during the "stay-at-home" phase of COVID-19 pandemic. *The Journals of Gerontology: Series B, 76*(4), e241-e245. https://doi.org/10.1093/geronb/gbaa129

Schreiber, J. B., Nora, A., Stage, F. K., Barlow, E. A., & King, J. (2006). Reporting structural equation modeling and confirmatory factor analysis results: A review. *The Journal of Educational Research, 99*(6), 323-338. https://doi.org/10.3200/JOER.99.6.323-338

Schroeder, L. A., & Osteen, S. R. (2018). Planning for and managing costs related to caregiving. In W. A. Bailey, & A. W. Harrist (Eds), *Family caregiving: Fostering resilience across the life course* (pp. 121-142). Springer.

Schulz, R., Beach, S. R., Czaja, S. J., Martire, L. M., & Monin, J. K. (2020). Family caregiving for older adults. *Annual Review of Psychology, 71*, 635-659. https://doi.org/10.1146/annurev-psych-010419-050754

Segal, D. L., Qualls, S. H., & Smyer, M. A. (2018). *Aging and mental health* (3rd ed.). Wiley.

Sercu, M., Beyens, I., Cosyns, M., Mertens, F., Deveugele, M., & Pype, P. (2018). Rethinking end-of-life care and palliative care: Learning from the illness trajectories and lived experiences of terminally ill patients and their family carers. *Qualitative Health Research, 28*(14), 2220-2238. https://doi.org/10.1177%2F1049732318796477

Silverstein, M. & Giarrusso, R. (2010). Aging and family life: A decade review. *Journal of Marriage and Family, 72*(5), 1039-1058. https://doi.org/10.1111/j.1741-3737.2010.00749.x

Sörensen, S., Mak, W., & Pinquart, M. (2011). Planning and decision making for care transitions. In P. Dilworth-Anderson & M. H. Palmer (Eds.), *Annual Review of Gerontology and Geriatrics, 31*, 111-142. Springer.

Sörensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*(3), 356-372. https://doi.org/10.1093/geront/42.3.356

Streib, G. F., & Beck, R. W. (1980). Older families: A decade review. *Journal of Marriage and the Family, 42*(4), 937-956. https://www.jstor.org/stable/351834

Stephens, M. A. P., & Franks, M. M. (2009). All in the family: Providing care to chronically ill and disabled older adults. In S. H. Qualls, & S. H. Zarit (Eds.), *Aging families and caregiving* (pp. 155-188). Wiley.

Sutter, M., Perrin, P. B., Chang, Y., Hoyos, G. R., Buraye, J. A., & Arango-Lasprilla, J. C. (2014). Linking family dynamics and the mental health of Colombian dementia caregivers. *American Journal of Alzheimer's Disease and Other Dementias, 29*(1), 67-75. https://doi.org/10.1177%2F1533317513505128

Tabachnick, B., & Fidell, L. (2019). *Using multivariate statistics* (7th ed.). Pearson Education.

Taber, K. S. (2017). The use of Cronbach's alpha when developing and reporting research instruments in science education. *Research in Science Education, 48*, 1273-1296. https://doi.org/10.1007/s11165-016-9602-2

Tabler, J., Utz, R. L., Ellington, L., Reblin, M., Caserta, M., Clayton, M., & Lund, D. (2015). Missed opportunity: Hospice care and the family. *Journal of Social Work in End-of-Life & Palliative Care, 11*(3-4), 224-243. https://www.tandfonline.com/doi/full/10.1080/15524256.2015.1108896

Title 42 - The Public Health and Welfare, *Chapter 35: Programs for Older Americans*, codified as amended at 42 U.S.C. § 3022. https://uscode.house.gov/view.xhtml?path=/prelim@title42/chapter35&edition=prelim

Thomas, P. A., Liu, H., Umberson, D. (2017). Family relationships and well-being. *Innovation in Aging, 1*(3), 1-11. https://doi.org/10.1093/geroni/igx025

Tramonti, F., Bonfiglio, L., Bongioanni, P., Belviso, C., Fanciullacci, C., Rossi, B., et al. (2019). Caregiver burden and family functioning in different neurological diseases. *Psychology Health & Medicine, 24*(1), 27-34. https://doi.org/10.1080/13548506.2018.1510131

Troll, L. E. (1971). The family of later life: A decade review. *Journal of Marriage and the Family, 33*(2), 263-290. https://www.jstor.org/stable/349414

Tudge, J. R. H., Mokrova, I., Hatfield, B. E., & Karnik, R. B. (2009). Uses and misuses of Bronfenbrenner's bioecological theory of human development. *Journal of Family Theory and Review, 1*(4), 198-210. https://doi.org/10.1111/j.1756-2589.2009.00026.x

Umberson, D., & Thomeer, M. B. (2020). Family matters: Research on family ties and health, 2010 to 2020. *Journal of Marriage and Family, 82*(1), 404-419. https://doi.org/10.1111/jomf.12640

United States Census Bureau (2020). *Subject Definitions: Family.* https://www.census.gov/programs-surveys/cps/technical-documentation/subject-definitions.html#family

Utz, R. L., Berg, C. A., & Butner, J. (2017). It's a family affair: Reflections about aging and health within a family context. *The Gerontologist, 57*(1), 129-135. https://doi.org/10.1093/geront/gnw081

Van Scoy, L. J., Green, M. J., Reading, J. M., Scott, A. M., Chuang, C. H., & Levi, B. H. (2016). Can playing an end-of-life conversation game motivate people to engage in advance care planning? *American Journal of Hospice and Palliative Medicine, 34*(8), 754-761. https://doi.org/10.1177%2F1049909116656353

Voorpostel, M. & Blieszner, R. (2008). Intergenerational solidarity and support between adult siblings. *Journal of Marriage and Family, 70*(1), 157-167. https://doi.org/10.1111/j.1741-3737.2007.00468.x

Waldrop, D. P., Kramer, B. J., Skretny, J. A., Milch, R. A., & Finn, W. (2005). Final transitions: Family caregiving at the end of life. *Palliative Medicine, 8*(3), 623-638. https://doi.org/10.1089/jpm.2005.8.623

Walker, A. J., Pratt, C. C., Shin, H-Y., & Jones, L. L. (1990). Motives for parental caregiving and relationship quality. *Family Relations, 39*(1), 51-56. https://doi.org/10.2307/584948

Wolff, J. L., Mulcahy, J., Huang, J., Roth, D. L., Covinsky, K., & Kasper, J. D. (2018). Family caregivers of older adults, 1999-2015: Trends in characteristics, circumstances, and role-related appraisal. *The Gerontologist, 58*(6), 1021-1032. https://doi.org/10.1093/geront/gnx093

Zarit, J. (2009). Assessment and intervention with family caregivers. In S. H. Qualls, & S. H. Zarit (Eds.), *Aging families and caregiving* (pp. 113-130). Wiley.

Zarit, S. H. (2018). Past is prologue: How to advance caregiver interventions. *Aging & Mental Health, 22*(6), 717-722. https://doi.org/10.1080/13607863.2017.1328482

Zarit, S. H. (2012). Positive aspects of caregiving: More than looking on the bright side. *Aging & Mental Health, 16*(6), 673-674. https://doi.org/10.1080/13607863.2012.692768

Zarit, S. H. (2009). Future directions in family caregiving: Clinical, policy, and research initiatives. In S. H. Qualls, & S. H. Zarit (Eds.), *Aging families and caregiving* (pp. 311-317). Wiley.

Zarit, S. H., Todd, P., & Zarit, J. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist, 26*(3), 260-266. https://doi.org/10.1093/geront/26.3.260

Zwicker, D. (2018). Preparedness for caregiving scale. Try this: Best practices in nursing care to older adults. *Hartford Institute for Geriatric Nursing, New York University*. https://consultgeri.org/try-this/general-assessment/issue-28.pdf

APPENDIX A

CHAPTER 4 SUPPLEMENTARY MATERIAL

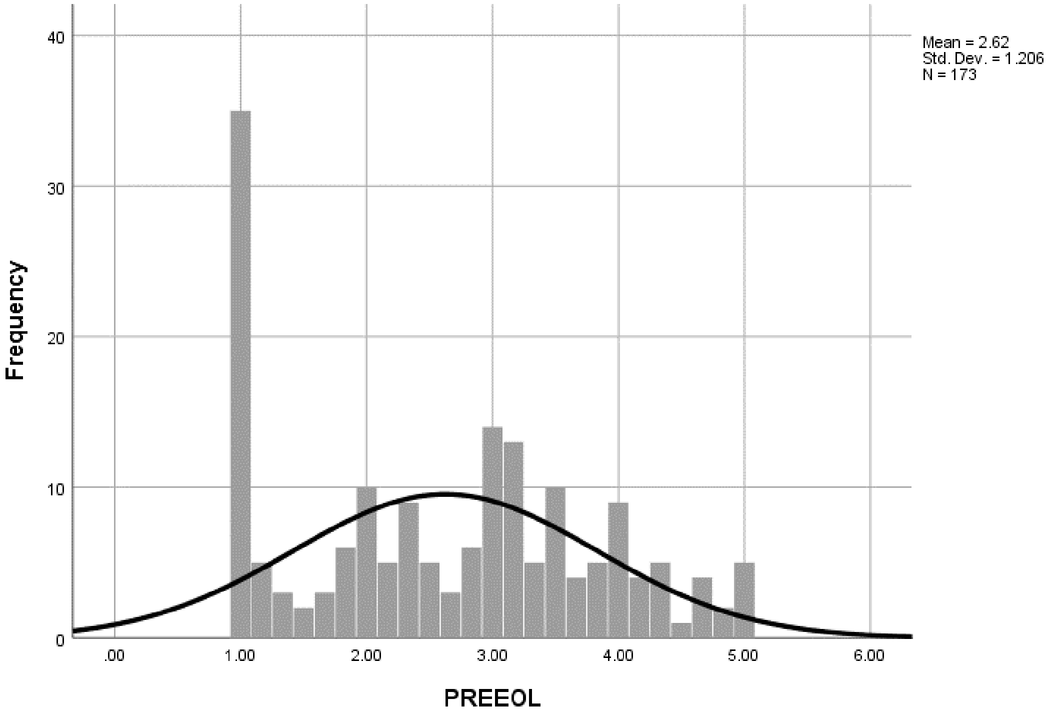

Figure A.1. *Histogram Depicting Responses from Family Caregivers (N = 173) to the Preparedness for the Transition to EOL Caregiving Variable, Wherein Responses from Six Questions in the Preparedness Measure (Identified as a Factor of Preparedness) Were Averaged to Create this Factor Score.*

After testing the hypothesized model, adjustments were made based on theoretical considerations of the *Conceptual Framework for a Bioecological Model of Family Dynamics and the Transition to EOL Caregiving*. Several caregiver demographics and characteristics (gender, familial relation between the caregiver and care receiver, and duration of care) were added in Model 2 to examine if it was important to account for differences in these factors. After this analysis, the covariates were removed from the model, as was the hypothesized mediator of number of tasks completed related to EOL care. Model 3 focused solely on the association between the constructs of family dynamics and preparedness. The final adjustment included the hypothesized mediator once again, but the outcome construct was simplified. Model 4 removed the construct of preparedness (which included both the preparedness for general caregiving and preparedness for EOL caregiving factors) and focused the outcome on only the observed variable of preparedness for EOL caregiving (given that this was the outcome of interest).

Table A.1. *Results of Models Tested Using SEM, Including Model Fit Statistics of Normed Chi-Square (χ^2/df), the Root Square Error of Approximation (RMSEA), Incremental Fit Index (IFI), the Tucker-Lewis Index (TLI), and Comparative Fit Index (CFI).*

Model	χ^2/df	RMSEA	IFI	TLI	CFI
Initial (hypothesized) model	4.78	0.15	0.91	0.79	0.91
Model 2	5.74	0.18	0.88	0.75	0.88
Model 3	9.13	0.22	0.89	0.79	0.89
Model 4	9.54	0.22	0.86	0.73	0.86

Note. Commonly used acceptable values to assess model fit include $\chi^2/df < 3$, RMSEA ≤ 0.08, and IFI, TLI, and CFI ≥ 0.90.

Table A.2. *Standardized and Unstandardized Coefficients and Standard Errors from the Hypothesized, Best-Fitting Structural Equation Model Examining the Association Between the Independent Latent Variable of Family Dynamics and the Dependent Latent Variable of Caregiver Preparedness, and the Role of the Hypothesized Mediating Variable of Number of Tasks Completed Related to EOL Caregiving.*

Observed variable	Latent construct	*β*	*B*	*SE*
Family cohesion	Family dynamics	0.50	0.25	0.04
Family flexibility	Family dynamics	0.48	0.24	0.04
Family communication	Family dynamics	0.98	1.15	0.08
Family satisfaction	Family dynamics	0.86	1.00	
Preparedness for general caregiving	Preparedness	0.73	1.00	
Preparedness for EOL caregiving	Preparedness	0.98	1.73	0.28

Table A.3. *Direct, Indirect, and Total Effects, including Standardized and Unstandardized Coefficients and Standard Errors from the Hypothesized, Best-Fitting Structural Equation Model Examining the Association Between the Independent Latent Variable of Family Dynamics and the Dependent Latent Variable of Caregiver Preparedness, and the Role of the Hypothesized Mediating Variable of Number of Tasks Completed Related to EOL Caregiving.*

	β		*B*			
Model	Dynamics	Tasks	Dynamics	Tasks	*SE*	*R²*
Direct						
Tasks completed	0.07		0.09		.10	0.01
Preparedness	0.32	0.33	0.25	0.23	.07	0.23*
Indirect						
Tasks completed						
Preparedness	0.03		0.02			
Total						
Tasks completed	0.07		0.09			
Preparedness	0.34	0.33	0.27	0.23		

*p ≤ .001

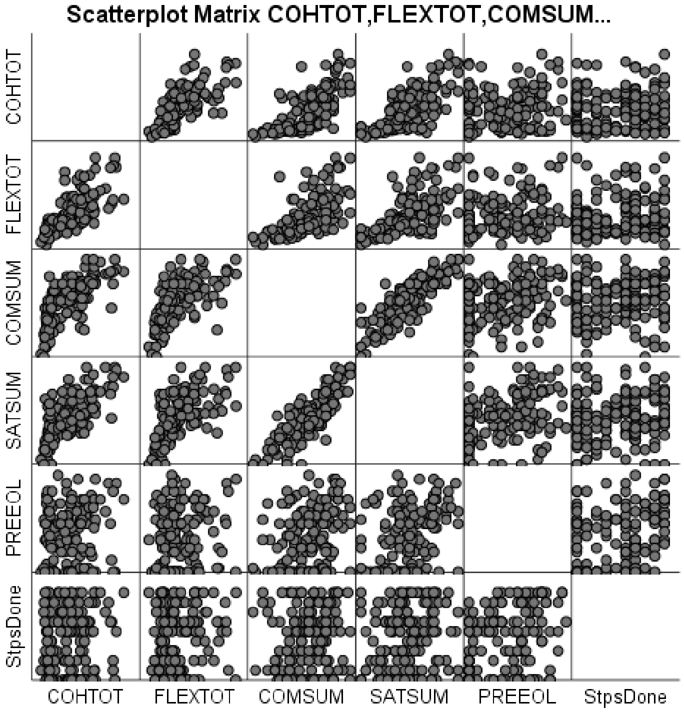

Figure A.2. *Scatterplot Matrix Depicting the Correlations Between Variables of Interest in this Study, Including: Family Cohesion (COHTOT), Family Flexibility (FLEXTOT), Family Communication (COMSUM), Family Satisfaction (SATSUM), Preparedness for End-of-Life (EOL) Caregiving (PREEOL), and Tasks Completed Related to EOL Caregiving (StpsDone).*

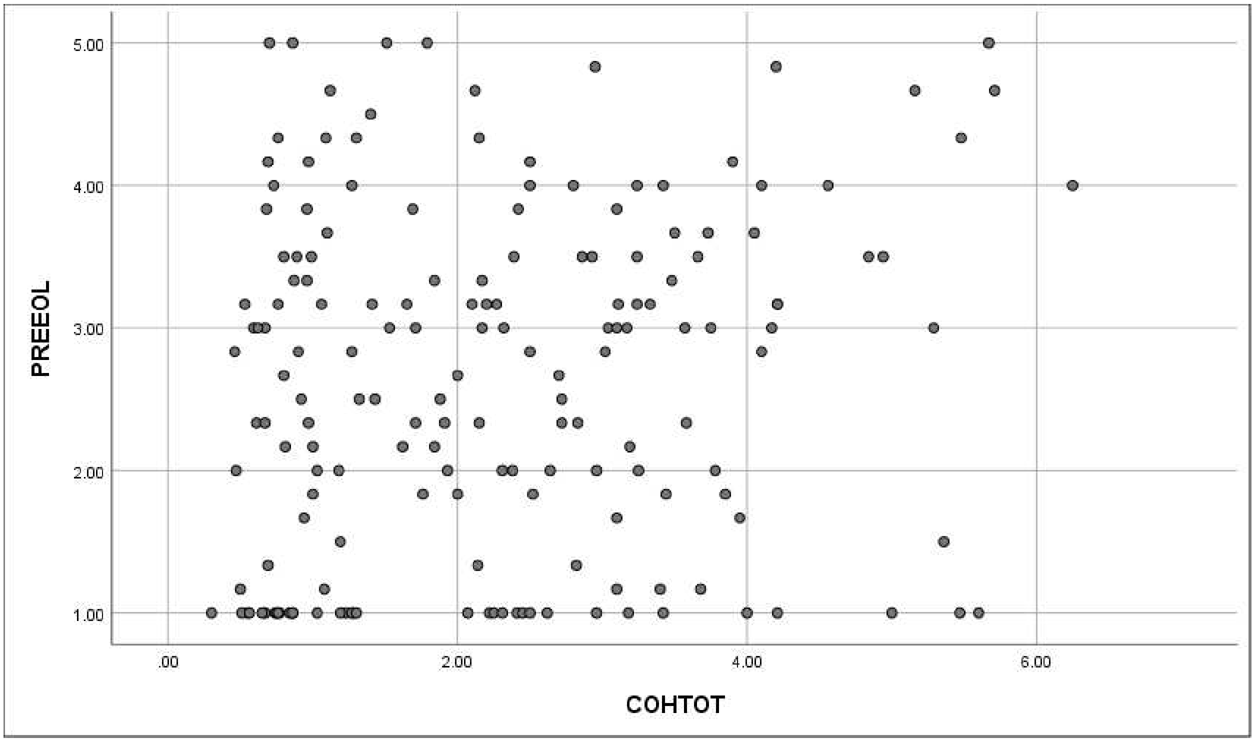

Figure A.3. *Scatterplot of Pairwise Comparison of Family Cohesion (COHTOT) and Preparedness for EOL Caregiving (PREEOL).*

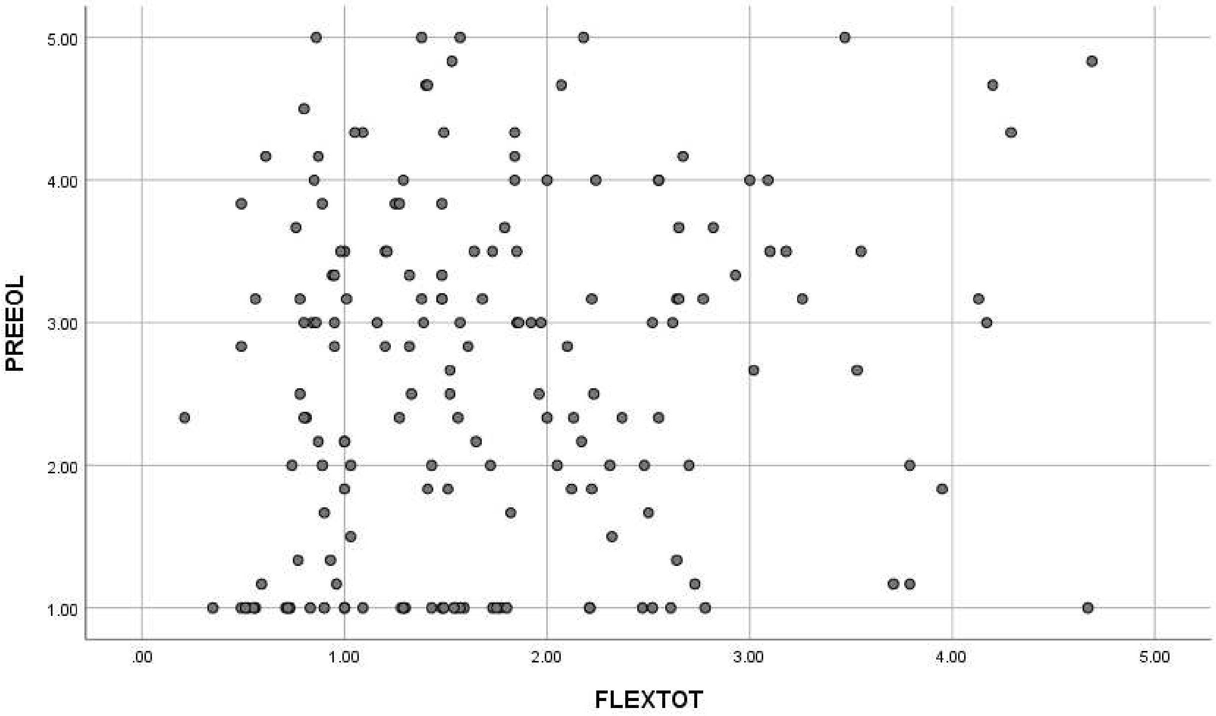

Figure A.4. *Scatterplot of Pairwise Comparison of Family Flexibility (FLEXTOT) and Preparedness for EOL Caregiving (PREEOL).*

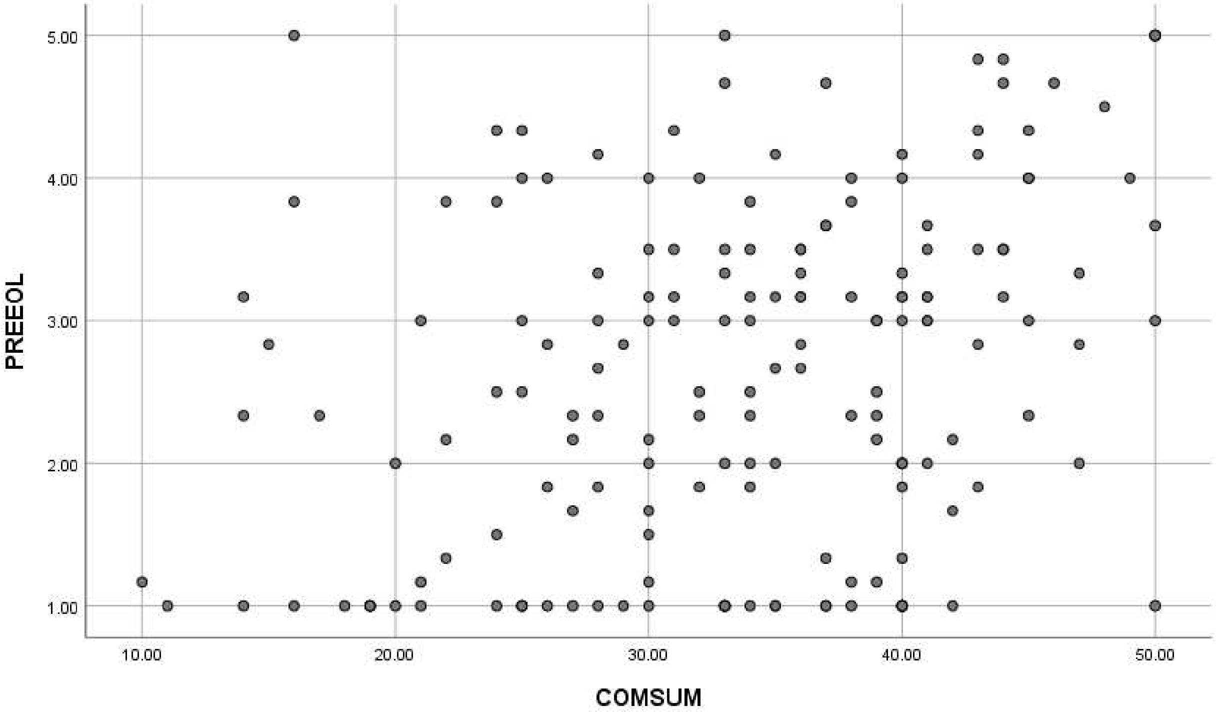

Figure A.5. *Scatterplot of Pairwise Comparison of Family Communication (COMSUM) and Preparedness for EOL Caregiving (PREEOL).*

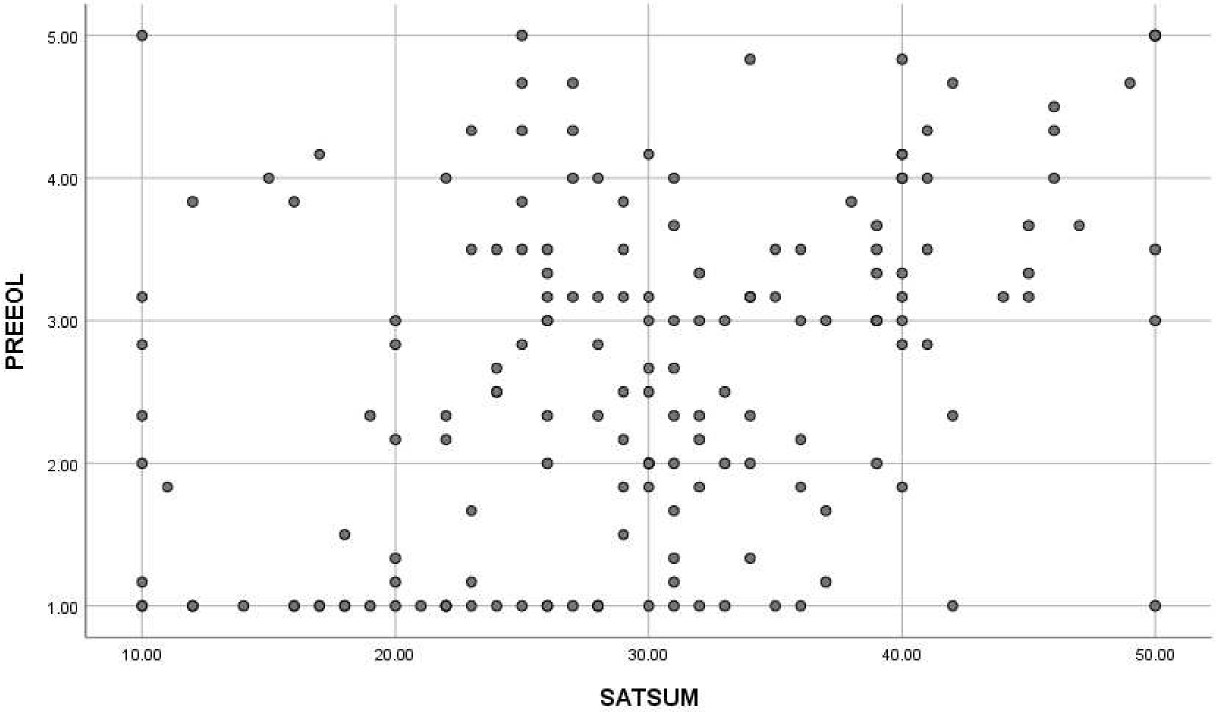

Figure A.6. *Scatterplot of Pairwise Comparison of Family Satisfaction (SATSUM) and Preparedness for EOL Caregiving (PREEOL).*

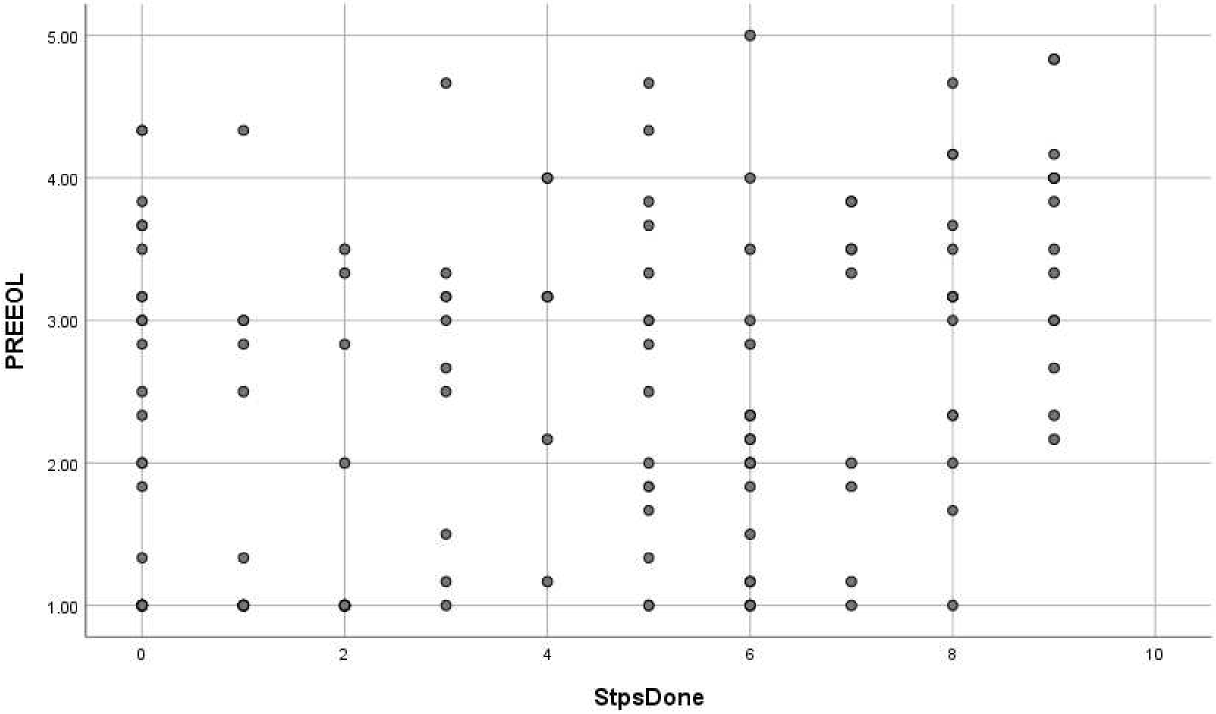

Figure A.7. *Scatterplot of Pairwise Comparison of Tasks Related to EOL Care Completed (StpsDone) and Preparedness for EOL Caregiving (PREEOL).*

APPENDIX B

FAMILY CAREGIVING AND PREPAREDNESS SURVEY

1) Do you consider yourself to be a caregiver for a family member?
    - ☐ Yes
    - ☐ No

Please read the following statement and answer the questions below: Some people provide regular unpaid care or assistance to a family member who has physical or mental limitations, a health condition, long-term illness, or disability. Assistance can range from a few hours of shopping and cleaning to intensive medical or personal care. Tasks may include cooking, feeding, giving medications, bathing, toileting, transferring, and managing finances, transportation, or communication, and so forth.

2) Are you currently providing unpaid care or assistance as described above to a family member?
    - ☐ Yes…for the purpose of this study, we will consider you a **caregiver**. The family member that you provide care for will be referred to as the **care receiver**.
    - ☐ No … **thank you for participating in our survey. [SKIP TO END]**

3) How many family members are you providing unpaid care or assistance to?
    - ☐ One
    - ☐ Two or more … **if providing care for more than one person, complete the remaining questions referring to the individual you provide the most care**.

4) The person you provide care for is your:
    - ☐ Spouse or partner
    - ☐ Parent
    - ☐ Adult child
    - ☐ Sibling
    - ☐ Other family member: ____________
    - ☐ Other: _____________

5) How long have you been providing care for your family member?
    - ☐ Less than 6 months
    - ☐ 6 months to 1 year
    - ☐ 1 to 3 years
    - ☐ 4 to 10 years
    - ☐ More than 10 years

6) How much time do you spend each week helping your care receiver?
    - ☐ 5 hours per week or less
    - ☐ 6 to 20 hours per week
    - ☐ 21 to 40 hours per week
    - ☐ More than 40 hours per week

7) Is there another person who also provides care for your care receiver?
   - ☐ No [**SKIP TO QUESTION 10**]
   - ☐ Yes

8) What is that person’s relationship to your care receiver?
   - ☐ Spouse or partner
   - ☐ Parent
   - ☐ Adult child
   - ☐ Sibling
   - ☐ Other family member: ____________
   - ☐ Friend
   - ☐ Professional or paid caregiver
   - ☐ Other: __________________

9) How much time does that person spend each week helping your care receiver?
   - ☐ 5 hours per week or less
   - ☐ 6 to 20 hours per week
   - ☐ 21 to 40 hours per week
   - ☐ More than 40 hours per week

10) The caregiving role is often described based on stages of awareness and responsibilities. Along the following caregiving trajectory, identify where you would best describe your current role:

○	○	○	○	○
SPORADIC CARE: *Awareness of problem(s) *Accompany to doctor *Help with light errands *Check-in/monitor	**REGULAR CARE**: *Monitor symptoms or medication *Coordinate care *Helping with household tasks	**INCREASING CARE DEMANDS, PERSONAL CARE**: *Increased supervision of care receiver *Personal care assistance *Provide health care assistance or manage symptoms	**END-OF-LIFE CARE**: *Advance care planning *Minimize suffering and symptom control *Provide emotional support	**DEATH OF CARE RECEIVER:** *Bereavement *Recover from caregiver role

CONTINUED ON NEXT PAGE.

11) **What kinds of care do you provide for your care receiver?**

Please indicate no or yes for each item	**NO**	**YES**
Check-ins, help with light errands		
Companionship (talking, reading, keeping company) or supervision		
Comfort care (end-of-life care to control pain and other symptoms)		
Financial assistance (paying bills, managing budget)		
Healthcare assistance (help with medications, wound care)		
Housekeeping (shopping, cleaning, preparing meals)		
Monitoring symptoms or medications		
Personal care assistance (feeding, bathing, toileting, dressing, grooming)		
Transportation (driving to doctor's appointments, driving for errands)		
Other:		

12) **Which of the following is the primary condition(s) of your care receiver?**

- ☐ Alzheimer's disease or dementia
- ☐ Cancer or lymphoma
- ☐ End-of-life (person has stopped treatment to cure or control their disease and is nearing end-of-life, may include palliative care, supportive care, and hospice care)
- ☐ Heart disease
- ☐ Intellectual, cognitive, or developmental disability
- ☐ Lung disease or COPD
- ☐ Physical disability
- ☐ Stroke
- ☐ Traumatic brain injury
- ☐ Other: ________________________
- ☐ No diagnosis

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For the purpose of this study, the **end-of-life** is defined as the period preceding a care receiver's death from a process that is unlikely to be prevented by medical care.

End-of-life care is given to people at this stage, often after they have stopped treatment to cure or control their disease. The goal of **end-of-life care** is to control pain and other symptoms so the care receiver can be as comfortable as possible.

The **transition to end-of-life care** can include changing the place of care, changing the goals of care, and changing the providers of care (i.e., to hospice care). **End-of-life care** includes physical, emotional, social, and spiritual support for care receivers and their families.

13) Has your care receiver received a prognosis from a doctor of one year or less to live?
  ☐ No
  ☐ Yes

14) Is your care receiver currently receiving **end-of-life care**?
  ☐ No
  ☐ Yes **[SKIP TO QUESTION 18]**
  ☐ Unsure

15) Do you have any reason to believe that your care receiver is nearing the end of their life (with less than one year to live)?
  ☐ No
  ☐ Yes

16) Why do you believe that your care receiver is nearing the end of their life?
____
____

17) When do you anticipate needing to **transition to end-of-life care** for your care receiver?
  ☐ Less than 3 months
  ☐ 3 to 6 months
  ☐ 7 to 12 months
  ☐ More than 1 year
  ☐ Unsure

18) Is your care receiver currently receiving hospice care?
  ☐ No
  ☐ Yes

CONTINUED ON NEXT PAGE.

19) **Your Preparation for Caregiving**

We know that people may feel well prepared for some aspects of giving care to another person, and not as well prepared for other aspects. We would like to know how well prepared you think you are to do each of the following, whether or not you are doing that type of care now.

	Not at all prepared	**Not too well prepared**	**Somewhat well prepared**	**Pretty well prepared**	**Very well prepared**
How well prepared do you think you are to take care of your care receiver's physical needs?	0	1	2	3	4
How well prepared do you think you are to take care of their emotional needs?	0	1	2	3	4
How well prepared do you think you are to find out about and set up services for them?	0	1	2	3	4
How well prepared do you think you are for the stress of caregiving?	0	1	2	3	4
How well prepared do you think you are to make caregiving activities pleasant for both you and your care receiver?	0	1	2	3	4
How well prepared do you think you are to respond to and handle emergencies that involve your care receiver?	0	1	2	3	4
How well prepared do you think you are to get the help and information you need from the health care system?	0	1	2	3	4
How prepared do you think you are for the transition to hospice, palliative, or end-of-life care (comfort care) for your care receiver?	0	1	2	3	4
How well prepared do you think you are to meet the end-of-life *medical* needs of your care receiver?	0	1	2	3	4
How well prepared do you think you are to meet their end-of-life *emotional* needs?	0	1	2	3	4
How well prepared do you think you are to meet their end-of-life *spiritual* needs?	0	1	2	3	4

	Not at all prepared	**Not too well prepared**	**Somewhat well prepared**	**Pretty well prepared**	**Very well prepared**
How well prepared do you think you are to meet their end-of-life *social* needs?	0	1	2	3	4
How prepared do you think your family members are for the transition to end-of-life care for your care receiver?	0	1	2	3	4
Overall, how well prepared do you think you are to care for your care receiver?	0	1	2	3	4

20) What would you like to be better prepared for as a caregiver?

____

____

____

21) Please indicate whether or not you have taken each of the steps below (no or yes) and when you might have or will take the steps to prepare for your care receiver's end-of-life:

	NO	**YES**
Talked with your care receiver about the emotions they might be feeling when nearing the end of their life.	☐ No, but I plan to approximately… ☐ 3 months from now ☐ 6 months from now ☐ 1 year from now ☐ More than a year from now ☐ I never plan to discuss this ☐ I don't know	☐ Yes, I did this approximately… ☐ 3 months ago ☐ 6 months ago ☐ 1 year ago ☐ More than a year ago
Talked with your care receiver about how to meet their spiritual or religious needs when nearing the end of their life.	☐ No, but I plan to approximately… ☐ 3 months from now ☐ 6 months from now ☐ 1 year from now ☐ More than a year from now ☐ I never plan to discuss this ☐ I don't know	☐ Yes, I did this approximately… ☐ 3 months ago ☐ 6 months ago ☐ 1 year ago ☐ More than a year ago
Talked to your care receiver about how to meet their social needs as they near the end of their life.	☐ No, but I plan to approximately… ☐ 3 months from now ☐ 6 months from now ☐ 1 year from now ☐ More than a year from now ☐ I never plan to discuss this ☐ I don't know	☐ Yes, I did this approximately… ☐ 3 months ago ☐ 6 months ago ☐ 1 year ago ☐ More than a year ago

Talked to your care receiver about the kind of medical care they would want if they were very sick or near the end of life.	☐ No, but I plan to approximately… ☐ 3 months from now ☐ 6 months from now ☐ 1 year from now ☐ More than a year from now ☐ I never plan to discuss this ☐ I don’t know	☐ Yes, I did this approximately… ☐ 3 months ago ☐ 6 months ago ☐ 1 year ago ☐ More than a year ago
Talked with your care receiver’s doctor about the kind of medical care they want if they are very sick or near the end of life.	☐ No, but I plan to approximately… ☐ 3 months from now ☐ 6 months from now ☐ 1 year from now ☐ More than a year from now ☐ I never plan to discuss this ☐ I don’t know	☐ Yes, I did this approximately… ☐ 3 months ago ☐ 6 months ago ☐ 1 year ago ☐ More than a year ago
Signed official papers putting your care receiver’s wishes in writing about the kind of medical care they want if they are very sick or near the end of life.	☐ No, but I plan to approximately… ☐ 3 months from now ☐ 6 months from now ☐ 1 year from now ☐ More than a year from now ☐ I never plan to discuss this ☐ I don’t know	☐ Yes, I did this approximately… ☐ 3 months ago ☐ 6 months ago ☐ 1 year ago ☐ More than a year ago
Signed official papers naming a person or group of people to make medical decisions for your care receiver if they become unable to do so.	☐ No, but I plan to approximately… ☐ 3 months from now ☐ 6 months from now ☐ 1 year from now ☐ More than a year from now ☐ I never plan to discuss this ☐ I don’t know	☐ Yes, I did this approximately… ☐ 3 months ago ☐ 6 months ago ☐ 1 year ago ☐ More than a year ago
Discussed or planned legal and financial matters (estate planning, will, etc.).	☐ No, but I plan to approximately… ☐ 3 months from now ☐ 6 months from now ☐ 1 year from now ☐ More than a year from now ☐ I never plan to discuss this ☐ I don’t know	☐ Yes, I did this approximately… ☐ 3 months ago ☐ 6 months ago ☐ 1 year ago ☐ More than a year ago
Talked with your care receiver about what they would like planned for funeral arrangements.	☐ No, but I plan to approximately… ☐ 3 months from now ☐ 6 months from now ☐ 1 year from now ☐ More than a year from now ☐ I never plan to discuss this ☐ I don’t know	☐ Yes, I did this approximately… ☐ 3 months ago ☐ 6 months ago ☐ 1 year ago ☐ More than a year ago

22) Please explain how your family members are involved in your preparedness for providing end-of-life care. ____
____
____
____

23) **I give care because:**

Please indicate no or yes for each item	**NO**	**YES**
It is my duty to provide care to older dependent family members.		
It is important to set an example for the children in my family.		
I was taught by my parents to take care of older dependent family members.		
Of my religious or spiritual beliefs.		
By giving care to elderly dependent family members, I am giving back what has been given to me.		
It strengthens the bonds between me and them.		
I was raised to believe care should be provided in the family.		
It is what my people have always done.		
I feel as though I am being useful and making a family contribution.		
My family expects me to provide care.		

CONTINUED ON NEXT PAGE.

We would like to know more about families in the context of providing care. For the following questions, please consider and answer the questions based on experiences with family members of you and the person you provide care for. This could include spouses, siblings, parents, children, and other extended family and friends. Using the scale provided, please indicate the degree to which you agree or disagree with each statement about this family.

24)	**Strongly Disagree**	**Generally Disagree**	**Undecided**	**Generally Agree**	**Strongly Agree**
Family members are involved in each other's lives.	**1**	**2**	**3**	**4**	**5**
Our family tries new ways of dealing with problems.	**1**	**2**	**3**	**4**	**5**
We get along better with people outside our family than inside.	**1**	**2**	**3**	**4**	**5**
We spend too much time together.	**1**	**2**	**3**	**4**	**5**
There are strict consequences for breaking the rules in our family.	**1**	**2**	**3**	**4**	**5**
We never seem to get organized in our family.	**1**	**2**	**3**	**4**	**5**
Family members feel very close to each other.	**1**	**2**	**3**	**4**	**5**
Parents equally share leadership in our family.	**1**	**2**	**3**	**4**	**5**
Family members seem to avoid contact with each other when at home.	**1**	**2**	**3**	**4**	**5**
Family members feel pressured to spend most free time together.	**1**	**2**	**3**	**4**	**5**
There are clear consequences when a family member does something wrong.	**1**	**2**	**3**	**4**	**5**
It is hard to know who the leader is in our family.	**1**	**2**	**3**	**4**	**5**

	Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree
Family members are supportive of each other during difficult times.	**1**	**2**	**3**	**4**	**5**
Discipline is fair in our family.	**1**	**2**	**3**	**4**	**5**
Family members know very little about the friends of other family members.	**1**	**2**	**3**	**4**	**5**
Family members are too dependent on each other.	**1**	**2**	**3**	**4**	**5**
Our family has a rule for almost every possible situation.	**1**	**2**	**3**	**4**	**5**
Things do not get done in our family.	**1**	**2**	**3**	**4**	**5**

25)	Strongly Disagree	Generally Disagree	Undecided	Generally Agree	Strongly Agree
Family members consult other family members on important decisions.	**1**	**2**	**3**	**4**	**5**
My family is able to adjust to change when necessary.	**1**	**2**	**3**	**4**	**5**
Family members are on their own when there is a problem to be solved.	**1**	**2**	**3**	**4**	**5**
Family members have little need for friends outside the family.	**1**	**2**	**3**	**4**	**5**
Our family is highly organized.	**1**	**2**	**3**	**4**	**5**
It is unclear who is responsible for things (chores, activities) in our family.	**1**	**2**	**3**	**4**	**5**
Family members like to spend some of their free time with each other.	**1**	**2**	**3**	**4**	**5**

	Strongly Disagree	**Generally Disagree**	**Undecided**	**Generally Agree**	**Strongly Agree**
We shift household responsibilities from person to person.	**1**	**2**	**3**	**4**	**5**
Our family seldom does things together.	**1**	**2**	**3**	**4**	**5**
We feel too connected to each other.	**1**	**2**	**3**	**4**	**5**
Our family becomes frustrated when there is a change in plans or routines.	**1**	**2**	**3**	**4**	**5**
There is no leadership in our family.	**1**	**2**	**3**	**4**	**5**
Although family members have individual interests, they still participate in family activities.	**1**	**2**	**3**	**4**	**5**
We have clear rules and roles in our family.	**1**	**2**	**3**	**4**	**5**
Family members seldom depend on each other.	**1**	**2**	**3**	**4**	**5**
We resent family members doing things outside the family.	**1**	**2**	**3**	**4**	**5**
It is important to follow the rules in our family.	**1**	**2**	**3**	**4**	**5**
Our family has a hard time keeping track of who does various household tasks.	**1**	**2**	**3**	**4**	**5**
Our family has a good balance of separateness and closeness.	**1**	**2**	**3**	**4**	**5**
When family problems arise, we compromise.	**1**	**2**	**3**	**4**	**5**
Family members mainly operate independently.	**1**	**2**	**3**	**4**	**5**

	Strongly Disagree	**Generally Disagree**	**Undecided**	**Generally Agree**	**Strongly Agree**
Family members feel guilty if they want to spend time away from the family.	**1**	**2**	**3**	**4**	**5**
Once a decision is made, it is very difficult to modify that decision.	**1**	**2**	**3**	**4**	**5**
Our family feels hectic and disorganized.	**1**	**2**	**3**	**4**	**5**
26)	**Strongly Disagree**	**Generally Disagree**	**Undecided**	**Generally Agree**	**Strongly Agree**
Family members are satisfied with how they communicate with each other.	**1**	**2**	**3**	**4**	**5**
Family members are very good listeners.	**1**	**2**	**3**	**4**	**5**
Family members express affection to each other.	**1**	**2**	**3**	**4**	**5**
Family members are able to ask each other for what they want.	**1**	**2**	**3**	**4**	**5**
Family members can calmly discuss problems with each other.	**1**	**2**	**3**	**4**	**5**
Family members discuss their ideas and beliefs with each other.	**1**	**2**	**3**	**4**	**5**
When family members ask questions of each other, they get honest answers.	**1**	**2**	**3**	**4**	**5**
Family members try to understand each other's feelings.	**1**	**2**	**3**	**4**	**5**
When angry, family members seldom say negative things about each other.	**1**	**2**	**3**	**4**	**5**
Family members express their true feelings to each other.	**1**	**2**	**3**	**4**	**5**

27)

How satisfied are you with:	**Very Dissatisfied**	**Somewhat Dissatisfied**	**Generally Satisfied**	**Very Satisfied**	**Extremely Satisfied**
The degree of closeness between family members.	**1**	**2**	**3**	**4**	**5**
Your family's ability to cope with stress.	**1**	**2**	**3**	**4**	**5**
Your family's ability to be flexible.	**1**	**2**	**3**	**4**	**5**
Your family's ability to share positive experiences.	**1**	**2**	**3**	**4**	**5**
The quality of communication between family members.	**1**	**2**	**3**	**4**	**5**
Your family's ability to resolve conflicts.	**1**	**2**	**3**	**4**	**5**
The amount of time you spend together as a family.	**1**	**2**	**3**	**4**	**5**
The way problems are discussed.	**1**	**2**	**3**	**4**	**5**
The fairness of criticism in your family.	**1**	**2**	**3**	**4**	**5**
Family member's concern for each other.	**1**	**2**	**3**	**4**	**5**

28) Do you feel…	**Never**	**Rarely**	**Sometimes**	**Quite Frequently**	**Nearly Always**
That because of the time you spend with your care receiver that you don’t have enough time for yourself?	**0**	**1**	**2**	**3**	**4**
Stressed between caring for your care receiver and trying to meet other responsibilities (work/family)?	**0**	**1**	**2**	**3**	**4**
Angry when you are around your care receiver?	**0**	**1**	**2**	**3**	**4**
That your care receiver currently affects your relationship with family members or friends in a negative way?	**0**	**1**	**2**	**3**	**4**
Strained when you are around your care receiver?	**0**	**1**	**2**	**3**	**4**
That your health has suffered because of your involvement with your care receiver?	**0**	**1**	**2**	**3**	**4**
That you don’t have as much privacy as you would like because of your care receiver?	**0**	**1**	**2**	**3**	**4**
That your social life has suffered because you are caring for your care receiver?	**0**	**1**	**2**	**3**	**4**
That you have lost control of your life since your care receiver’s illness?	**0**	**1**	**2**	**3**	**4**
Uncertain about what to do about your care receiver?	**0**	**1**	**2**	**3**	**4**
You should be doing more for your care receiver?	**0**	**1**	**2**	**3**	**4**
You could do a better job in caring for your care receiver?	**0**	**1**	**2**	**3**	**4**

Please provide the following information for both yourself and the person you care for.

	You	***The Person You Care For***
To which gender identity do you most identify?	☐ Female ☐ Male ☐ Non-binary ☐ Prefer not to say ☐ Other: __________	☐ Female ☐ Male ☐ Non-binary ☐ Prefer not to say ☐ Other: ___________
Age	_________	___________
Race	☐ American Indian or Alaskan Native ☐ Asian ☐ Black or African American ☐ Native Hawaiian or Other Pacific Islander ☐ White ☐ Other or multiple race	☐ American Indian or Alaskan Native ☐ Asian ☐ Black or African American ☐ Native Hawaiian or Other Pacific Islander ☐ White ☐ Other or multiple race
Ethnicity	☐ Hispanic or Latino or Spanish origin ☐ Not Hispanic, Latino, or Spanish origin	☐ Hispanic or Latino or Spanish origin ☐ Not Hispanic, Latino, or Spanish origin
Marital Status	☐ Single, never married ☐ Married or domestic partnership ☐ Widowed ☐ Divorced ☐ Separated	☐ Single, never married ☐ Married or domestic partnership ☐ Widowed ☐ Divorced ☐ Separated
Education – highest level completed	☐ Less than high school ☐ High school diploma/GED ☐ Post-secondary technical training ☐ Some college ☐ Associate degree ☐ Bachelor’s degree ☐ Graduate degree	☐ Less than high school ☐ High school diploma/GED ☐ Post-secondary technical training ☐ Some college ☐ Associate degree ☐ Bachelor’s degree ☐ Graduate degree
Employment	☐ Employed full-time ☐ Employed part-time ☐ Unemployed ☐ Stay-at-home parent ☐ Student ☐ Looking for work ☐ Not looking for work	☐ Employed full-time ☐ Employed part-time ☐ Unemployed ☐ Stay-at-home parent ☐ Student ☐ Looking for work ☐ Not looking for work ☐ Disabled, not able to work

	☐ Disabled, not able to work ☐ Retired	☐ Retired
YEARLY household income	☐ Less than $26,200 ☐ More than $26,200	☐ Less than $17,240 ☐ More than $17,240
Living Arrangements	☐ Lives with care receiver ☐ Lives apart from care receiver ☐ Care receiver lives in own home, alone ☐ Care receiver lives in home, with spouse or partner ☐ Care receiver lives in an assisted living facility ☐ Care receiver lives in a skilled nursing facility ☐ Care receiver lives in a hospice facility	

38) How has your caregiving changed since the COVID-19 outbreak?

____

____

____

39) Would you be willing to let us contact you for a follow-up interview in 6 months to 1 year from now? You have the right to say “no” if you change your mind.

☐ No
☐ Yes…. Please provide the best way of contacting you: _____________________

40) Would you be interested in taking part in similar research in the future? You have the right to say “no” if you change your mind.

☐ No
☐ Yes…. Please provide the best way of contacting you: _____________________

If you are interested in being entered into a drawing to receive a **$50 Amazon gift card**, please provide the best way of contacting you: ________________________________

Thank you for your help! Your responses will help us better understand the experiences and needs of family caregivers.