An Interpretative Phenomenological Analysis of the Experiences of Young Adult Grandchild Caregivers of Grandparents with Dementia

Khushbu S. Patel

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Megan L. Dolbin-MacNab, Chair

Pamela Teaster

Tina Savla

Caroline Sanner

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Abstract

In 2023, an estimated 11.5 million individuals provided approximately 18.4 billion hours or unpaid care to family members with Alzheimer's disease or related dementias. While the burdens of dementia caregiving have been well-documented, less is known about the experiences of young adults who serve as caregivers to their grandparents. These caregivers, aged 18 to 29 years, are in the developmental stage of emerging adulthood, a period characterized by identity exploration, pursuit of autonomy, and life transitions—factors often at odds with the demands of caregiving. This study examined the uncommon caregiving dynamic of grandchildren supporting grandparents, contrasting the more typical pattern of grandparent-to-grandchild care. This qualitative study employed Interpretative Phenomenological Analysis (IPA) to explore how young adult grandchildren made sense of their caregiving roles and how their caregiving experiences intersected with the developmental tasks of emerging adulthood. Eight young adults, who were actively providing or had previously provided care for a grandparent with dementia, participated in semi-structured interviews. Participants described how they navigated identity tensions between their desire for autonomy and the dependency required by the caregiving role. They expressed a perceived loss of typical young adult experiences, often shaped by social isolation and the unique challenges of caregiving. Despite these difficulties, participants found opportunities for personal growth through meaning-making and by integrating caregiving into their future-oriented identities. These findings provide a nuanced understanding of the caregiving experience within this population, highlighting the complexity of assuming an off-time caregiving role during the sensitive developmental period of emerging adulthood. Implications for future research and practice are discussed.

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General Audience Abstract

In 2023, over 11 million people cared for loved ones with Alzheimer's or other dementias—often without pay. While caregiving is challenging for anyone, it can be especially difficult for young adult grandchildren between the ages of 18 and 29 years. This stage of life, known as emerging adulthood, is usually a time to explore one's identity, build relationships, and plan for the future. But those caring for a grandparent with dementia often face unique pressures. This study looked at the less common situation where grandchildren take care of their grandparents, instead of the more typical setup where grandparents are the ones caring for their grandkids. This study explored the experiences of young adult caregivers by interviewing eight people who had helped care for a grandparent with dementia. Participants talked about how they struggled to balance wanting independence with the responsibilities that came with caregiving. They felt like they were missing out on normal young adult experiences, especially because of how isolating and challenging caregiving could be. Still, many shared that they grew from the experience by finding meaning in it and seeing how it shaped who they're becoming. These findings help us better understand what it's like for this group to take on a caregiving role at a time in life when that's not usually expected — during the already challenging stage of emerging adulthood. This work offers ideas for future research and for how professionals can better support young adults in caregiving roles.

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Chapter 1: Introduction

In 2020, 41.8 million Americans provided unpaid care to an adult 50 years or older (Samuels, 2022). Of those 41.8 million American caregivers, 89% were caring for a relative or family member (Samuels, 2022). Given their many roles and responsibilities, caregivers provide essential services in U.S. society and the healthcare system. According to a 2023 report by AARP (2023), the 2021 economic value of unpaid family caregiving in the U.S. was approximately $600 billion. This estimate was based on nearly 38 million caregivers providing about 36 billion hours of care in a year, valued at an average of $16.59 per hour (AARP, 2023). Over time, family members' caregiving responsibilities have been increasing, both in terms of the number of caregivers and the complexity of care. For example, caregiving roles have become more intensive and prolonged, often leaving caregivers unprepared for the evolving demands of their roles (Committee on Family Caregiving for Older Adults et al., 2016). Additionally, the National Alliance for Caregiving and AARP found that 24% of caregivers provide care for more than 5 years and 15% for more than 10 years (National Alliance for Caregiving & AARP, 2020). The time commitments of caregiving also significantly impact caregivers' ability to work. In a 2024 report by AARP, 67% of family caregivers reported struggling to manage their job responsibilities alongside caregiving (AARP, 2024). This leads to 27% of these individuals reducing their workload, with 16% of caregivers temporarily leaving the workforce in order to meet caregiving demands (AARP, 2024). These statistics showcase how caregiving is intensively time-consuming, affecting caregivers' ability to work and provide for themselves and/or their families, which can leave significant impacts on their lives.

Among the broader group of family caregivers, the number of people caring for an older adult with a dementia or Alzheimer's diagnosis has increased over the past few decades (National Alliance for Caregiving, 2020). In 2020, 26% of Americans were caring for a family member with an Alzheimer’s disease or dementia diagnosis, compared to 22% in 2015 (National Alliance for Caregiving, 2020). More specifically, of these caregivers, 83% were relatives to the care recipient. Of those, the majority were adult children (57%), with the rest consisting of spouses (12%), other relatives (14%), and non-relatives such as friends, neighbors, and others (17%) (National Alliance for Caregiving, 2020). One particular group of individuals who are dementia caregivers are grandchildren. Caregiving to people with dementia is of particular importance because it keeps them safe and helps maintain a certain level to their quality of life as their disease progress and they begin to lose their ability to care for themselves. Caregivers also help manage symptoms, routines, and provide emotional connection.

Given the consistent increase in the number of people providing care overall, and specifically the number of dementia caregivers, it appears that caregiving duties are extending beyond the traditional spousal and adult children caregivers, caregiving duties are now extending to grandchildren as well (Fruhauf et al., 2006). Caregiving is innately collaborative in nature because it often involves family, friends, and healthcare providers. Furthermore, spouses and/or adult children who are caregiving to older adults with dementia, often have difficulties managing their workload, organizing personal childcare, coordinating care for the individual with dementia, and struggle with their personal mental and physical health (National Alliance for Caregiving & AARP, 2020). As such, grandchildren may be increasingly called upon or volunteer to help take care of older adults with or without a dementia diagnosis (Dellmann-Jenkins et al., 2000). Sometimes grandchildren live with their grandparent(s) with dementia or see their parents providing extensive care, and due to their closeness and availability, they may be asked to help with age-appropriate tasks (Dellmann-Jenkins et al., 2000). Also, cross-culturally, other family members such as grandchildren, cousins, siblings, etc. often hold caregiving responsibilities (Fruhauf et al., 2006). Although grandchildren providing care to a grandparent is a novel phenomenon in American culture, since it is typically more common among first- and second-generation family members (Fruhauf et al., 2006). Not a lot is known about grandchildren caregivers in the current literature so this study sough to fill this gap by examining how young adult grandchildren caregivers experience the intersection of caregiving with developmental tasks associated with emerging adulthood. Young adults are typically focusing on their own lives, thinking about their future careers and romantic relationships, exploring different possibilities, and overall simply exploring (Arnett et al., 2014). Given how caregiving responsibilities can significantly impact a caregiver's life, young adult caregivers are an interesting group to study since their developmental focus is about figuring out who they are which could conflict with caregiving demands.

The population of interest for this study was young adult grandchildren caring for their grandparent(s) with dementia. Young adults are defined as individuals between the ages of 18 to 29 years old, who are different from developmental stages of adolescence and traditional adulthood in theory and based on previous research, which will be discussed later in this chapter (Arnett et al., 2014). Currently, there are no statistics on the number of young adults who are caregivers to a grandparent with dementia. However, examination of statistics on young adult caregivers and caregivers for grandparents provide some information about the scope of the percentage who fall into these categories and how common this type of caregiving is. Specifically, the percentage of young adult (ages 18 to 25 years) caregivers to family members is approximately 6% of the total number of adult caregivers in the U.S. (National Alliance for Caregiving, 2020). These family members, who are receiving care, include parents, parent-in-laws, grandparents, grandparents-in-law, and other relatives (National Alliance for Caregiving, 2020). In terms of the grandchild role, it has been estimated that 10% of dementia caregivers are providing care to a grandparent or grandparent-in-law (National Alliance for Caregiving, 2017).

Regardless of their age and relationship to the care recipient, research has clearly demonstrated that caregivers experience high levels of stress and burden (Choi et al., 2024; Tu et al., 2022). As noted previously, caregivers have difficulties managing their paid jobs, organizing personal childcare, coordinating care for the care recipient, and experience negative impacts on their mental, emotional, and physical health (Choi et al., 2024; National Alliance for Caregiving & AARP, 2020; Tu et al., 2022). Compared to adult caregivers, young adult caregivers are in a unique developmental stage of their life. They are in a phase of life where they are exploring their identities, experiencing instability while changing jobs, living situations, relationships, etc., and working towards independence (Arnett, 2007). They may be deciding between continuing their education, getting a different job, testing romantic relationships, and simply learning about themselves (Arnett, 2007). Being a young adult, combined with distinctive impacts of caregiving such as time constraints affecting their social life, educational goals, and/or employment and their emotional well-being (Arnett, 2007), can create strain during this stage of development.

Dementia Caregiving & Caregiver Outcomes

Previous research has demonstrated that caregivers of individuals with dementia experience excessive strain on their mental and physical health, familial relationships, and employment issues due to the amount of time they spend on caregiving tasks, the intensity of the caregiving responsibilities, changes in relationships within the family and with the care recipient, and the lack of help with caregiving (National Alliance for Caregiving, 2017; Ory et al., 1999; Venters & Jones, 2021). However, dementia caregiving is a uniquely demanding form of caregiving, given the nature of the disease and the demands it places on caregivers. Specifically, dementia caregivers spend more time per week providing care than caregivers for those without dementia. For example, on average, dementia caregivers spend approximately 28 hours each week providing care, compared to their non-dementia caregiving counterparts, who are providing care for about 24 hours per week (National Alliance for Caregiving, 2017). In addition, dementia caregivers report helping with more Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) compared to non-dementia caregivers (National Alliance for Caregiving, 2017; Ory et al., 1999). ADLs include basic self-care tasks such as walking, feeding, dressing, toileting, bathing, and transferring (Pashmdarfard & Azad, 2020). IADLs include more complex skills such as managing finances, using transportation, preparing meals, shopping, cleaning, taking medications, and utilizing the phone (Pashmdarfard & Azad, 2020). The National Alliance for Caregiving (2017) collected data on the number of ADLs and IADLs completed by dementia and non-dementia caregivers. Their report indicated that, on average, dementia caregivers engaged in 2.1 ADLs and 4.7 IADLs compared to non-dementia caregivers, who participated in 1.5 ADLs and 4.1 IADLs, confirming that dementia caregivers are conducting more caregiving tasks (National Alliance for Caregiving, 2017). ADL and IADL care can be physically, emotionally, and mentally exhausting because of the hands-on care they are providing and feelings of frustration and emotional distress (Ory et al., 1999).

Research exploring and understanding the effects of dementia caregiving for family members is robust, however there is limited literature on young adults as caregivers of people with dementia. It is important to explore the factors that influence a caregiver’s experience since it can provide a viewpoint on the caregiving experiences for young adults. Several factors have been found to influence the caregiver’s experiences, in terms of the demands and constraints of caring for an individual with dementia.

First, the actual dementia diagnosis of the care recipient is very important (Gilhooly et. al., 2016). The type of dementia diagnosis, the severity of the symptoms, and the prognosis of the disease can cause caregivers to become more stressed in their caregiving duties, leading to more negative outcomes of feeling overworked due to the caregiving demands (Raggi et al., 2015). Moreover, the diagnosis affects both the person who was diagnosed and their family members, who are typically providing care since the caregiver experiences higher levels of stress (Gilhooly et. al., 2016). For example, a common symptom of Alzheimer's disease is memory loss, and for vascular dementia, a loss of focus and organization (Alzheimer's Association, 2023). As these diagnoses develop over time and the severity of the symptoms gets worse, the demands and requirements on the caregiver are increased, leading to higher levels of stress (Schulz et al., 1995).

Second, the accessibility of other caregivers in the family can significantly impact a caregiver's experience, in terms of their personal well-being, both for dementia and non-dementia caregivers (Gilhooly et. al., 2016). For example, a spouse may be the only person in the household available to take care of the person with dementia, whereas other families may have adult children or grandchildren in the household to help with caretaking responsibilities (Gilhooly et. al., 2016). Having additional support systems and caregiving assistance can help reduce the strain on the caregiver because it allows for a distribution of care responsibilities or respite time. These additional support systems are less common for dementia caregivers compared to non-dementia caregivers, leading dementia caregivers to feel more isolated and more caregiver burden compared to their counterparts (Gilhooly et. al., 2016).

Third, the caregiver's own physical and/or mental health can drastically impact the caregiving experience for both dementia and non-dementia caregiving (Gilhooly et. al., 2016).

However, dementia caregivers face elevated levels of stress, anxiety, and depression compared to their counterparts due to the progressive and demanding nature of dementia (Schulz & Martire, 2004). Also, due to these demands of dementia caregiving, they are at a higher risk for cardiovascular issues, diabetes, arthritis, and compromised immunity (Schulz & Martire, 2004). If the caregiver is not doing well physically or mentally, they may not be able to provide adequate care for the person with dementia.

Lastly, dementia caregivers experience a variety of relational changes due to the caregiving process. Dementia caregivers report experiencing both negative and positive relational impacts (Lindeza et al., 2020; Marques et al., 2024). Negative impacts included role reversals, social isolation, emotional burden, role strain, and communication issues with other family members regarding the lack of caregiving support (Lindeza et al., 2020; Marques et al., 2024). Positive impacts include increased resilience, learning patience and empathy, strengthened bonds with others, and feeling closer to the personal with dementia (Lindeza et al., 2020; Marques et al., 2024). The negative impacts lead to increased stress due to the pressures of dementia caregiving, the inability to have leisure time or spend time with friends, and lack of understanding or help from other family members (Lindeza et al., 2020; Marques et al., 2024). However, the positive impacts help the dementia caregiver find worth in the caregiving process, build better relationships with those who try to help or understand the caregiving experience, and gain a deeper understanding/appreciation with their relationship with the care recipient (Lindeza et al., 2020; Marques et al., 2024).

Grandchildren Caregivers

Research has demonstrated that caregiving duties extend beyond the usual caretakers, such as spouses or adult children, to include grandchildren (Fruhauf et al., 2006). It is known that grandchildren are helping families and their grandparents with Activities of Daily Living and Instrumental Activities of Daily Living, such as transferring, feeding, medication management, cleaning, shopping, transportation, etc. (Fruhauf et al., 2006). They begin assisting with ADLs and IADLs as household chores to help their parents care for their grandparent (Fruhauf et al., 2006). These responsibilities can increase depending on the grandparent's needs and family expectation (Fruhauf et al., 2006).

Furthermore, the relationship between grandchildren and grandparents is unique in nature, which can therefore impact the caregiving experience and outcomes for grandchildren caregivers. Grandparents typically have more power over the grandchild due to the hierarchy that exists within family systems (Breheny et al., 2013). Grandparents also have influence and control over things the grandchild does which are often rooted in the cultural norms of a family (Breheny et al., 2013). Depending on the type of relationship the grandchild has with their grandparent and how close they are, it can impact how the grandchild experiences the caregiving process (Celdrán et al., 2012). Depending on if the relationship is close, distant, or ambivalent, it can impact the grandchild's willingness to perform caregiving tasks and their emotional response, especially when their grandparent has dementia (Celdrán et al., 2012).

The type of relationship between grandchildren and grandparents varies depending on the role the grandparent serves in the grandchild's life. Grandparents play various roles in a grandchild's life, which is different compared to other relationships a grandchild has in their life (Weston & Qu, 2009). That is, grandparents may serve as additional caretakers for grandchildren and often play roles such as a historian, mentor, and/or playmate (Weston & Qu, 2009). Grandparents are often the keepers of family history, where they share stories and traditions with their grandchildren, helping grandchildren feel more connected to their heritage and building onto their self-identity (Olsen et al., 2000). They are also mentors, often providing guidance, support, and wisdom, which influences the grandchild's values and behaviors (Olsen et al., 2000). Finally, as playmates, they engage in activities with their grandchildren, fostering bonding and providing enjoyment, contributing to their social and emotional development (Olsen et al., 2000). Depending on the type of role the grandparent plays in their grandchild's life, it can significantly shape the power dynamics that occur within the relationship (Celdrán et al., 2012). For example, a grandchild who was emotionally close to and support by their grandparent may feel more positively about being willing to provide care. Whereas more distant or authoritative relationships might have more emotional conflict that impacts the grandchild willingness to perform caregiving tasks.

In instances where the grandparents are providing some level of care to a grandchild, typically in childhood or in instances where the grandparent is the primary caregiver, their relationship can become reciprocal in nature (Creasey & Jarvis, 1989). Some grandparents help nurture the grandchild and, when the grandchild gets older, the grandchild has the opportunity to take care of their grandparent (Creasey & Jarvis, 1989). In these situations, having a grandchild assume caregiving responsibilities for a grandparent can be difficult because of the power and role shifts (Venters & Jones, 2021). Grandparents, for example, may have a hard time letting their grandchild provide care for them because they are supposed to and/or have been the caregiver previously for parts of the grandchild's life (Venters & Jones, 2021). This can impact caregiving because the grandparent may not want to accept the help being offered by the grandchild. It may be an unknown feeling and adjustment for both parties as this is a new role for both individuals. When these situations occur, it can increase the stress experienced by the grandchild caregiver (Venters & Jones, 2021). Power is also shifted in this new type of relationship since the grandchild may be making decisions on behalf of the grandparent (Venters & Jones, 2021). In contrast to relationships where the grandparent was not caregiving for the grandchild, similar situations occur in terms of the stress experienced by the grandchild caregiver due to the power shift that occurs in the relationship (Venters & Jones, 2021).

Similar to adult caregivers, grandchildren caregivers experience various impacts of caregiving. Grandchildren caregivers report higher levels of stress, anxiety, and emotional burnout when caring for someone with dementia (Miron et al., 2019). Caregiving as a young grandchild often interferes with the developmental tasks of emerging adulthood such as creating their identity, becoming independent, being self-focused, etc.; more on the developmental considerations will be covered in the next section (Fruhauf & Orel, 2008). Grandchildren caregivers also report missing out on social activities and struggling to balance work with school (Hamill, 2012). Finally, despite the challenges of caregiving, grandchildren caregivers express they learned how to be more patient, empathetic, and have healthier relationships with others (Celdrán et al., 2014).

Given the unique nature of the relationship between grandparents and grandchild and the impacts of caregiving, there is need for research focused on describing the experiences of grandchildren caregivers to grandparents with dementia. This study contributed to the current literature on grandchildren caregivers by focusing on the intersection of caregiving with the developmental tasks of emerging adulthood. It also added to the understanding of grandchildren as dementia caregivers and what that role looks like for them when caring for a grandparent.

Developmental Considerations of Young Adults

The population of interest in this study were young adult grandchildren caregivers, with young adults being defined as individuals between the ages of 18 and 29 years. Compared to adult caregivers, young adult caregivers have their own unique developmental needs, due to their distinct positioning in the life cycle, specifically emerging adulthood. In emerging adulthood, young adults face a variety of developmental tasks including exploring their personal identity, testing various life possibilities such as employment, worldviews, and romantic relationships, having feelings of instability or being in-between life stages, and being self-focused (Arnett, 2007; Havighurst, 1948). Essentially, young adults are trying to become independent persons away from the comfort of having their parents continue to take care of them while they are determining their likes, dislikes, personal philosophies, etc. (Arnett, 2007). Also, young adults are maturing, pursuing a career or further education, at the least trying to figure out which path they may want to follow (Arnett, 2007). During this time, they are also forming relationships, both romantically and within a specific community to build long lasting bonds (Arnett, 2007). Moreover, if they have moved out of their childhood home, young adults are attempting to find and manage a residence (Arnett, 2007). The age range for emerging adulthood is widespread from 18 years old to 29 years old. This big age range can contribute to how young adults fulfill different developmental tasks. For example, an 18-year-old might be in their first year of college, living in a dorm, trying to make new friends, and figuring out their major. In contrast, a 29-year-old might have already found a career, gotten married, and bought a house. Therefore, it is important to keep in mind that the developmental tasks, although important for the whole age range, can look different based on age and maturity. However, all of the previously mentioned developmental tasks are essential for young adults to be successful in middle adulthood and beyond (Arnett, 2007).

To better understand this stage of life and the intersection of caregiving with a grandchild's developmental tasks, Arnett's Theory of Emerging Adulthood and Role Theory were used as the conceptual foundations for this study. As previously discussed, the young adult age range, 18 to 29 years old, is associated with a variety of developmental tasks that are required to be accomplished to successfully transition into middle adulthood. These developmental considerations are best described within the Theory of Emerging Adulthood which helped understand the population of interest in this study (Arnett, 2007). The Theory of Emerging Adulthood by Arnett specifically notates that the developmental period between 18 to 29 is a distinct life stage defined by identity exploration, feeling in-between, self-focus, and exploring possibilities (Arnett, 2007). Emerging adulthood can be classified as a sensitive period (Bornstein, 1989) in a young adult's life because they are trying to figure out who they want to be as an adult (Arnett, 2000).

In the case of young adult grandchildren caregivers, these developmental tasks can be additional stressors to their caregiving responsibilities. Caregiving is an intense process to begin with and, when combined with this specific developmental stage, it can lead to additional strain on the grandchildren caregiver and the relationships these caregivers engage with (Venters & Jones, 2021). For young adult grandchildren caregivers trying to figure out who they are, who they want to be, find their next step in life, or their forever partner are important yet difficult tasks to complete (Arnett, 2007). When the added responsibilities of caregiving, such as completing ADLs and IADLs, are stacked on top of the developmental tasks, it leads to stress, anxiety, emotional and physical strain, and the need for support (Venters & Jones, 2021).

In addition to the developmental considerations, it is important to understand the role of a grandchild caregiver. Grandchildren caregivers can experience role reversals in the caregiving relationship with their grandparent and possibly with other family members, which is best understood within Role Theory because it helps humans make sense of their purpose in relationships (Biddle, 1986). Young adult grandchildren caregivers are also occupying an off-time role (caregiver) during a non-normative stage of life (emerging adulthood) (Neugarten et al., 1965). Caregiving during emerging adulthood can change career plans, limit social time, and impact physical and emotional well-being for emerging adults which can lead to role strain, a concept described in Role Theory. Role theory explains how people behave in different social contexts based on expectations and responsibilities associated with a specific role, which in this study were young adult grandchildren caregivers (Biddle, 1986). The theory also discusses role strain, role overload, and role conflict, all of which can happen when one role demands more than other roles, when many roles compete with each other, or when expectations in various roles are different (Biddle, 1986). The possible role reversal experienced in the caregiving relationship between the grandchild caregiver and their grandparent, may lead to extra stress about role conflict, role strain, and role overload (Biddle, 1986). The shift in power dynamics within familial relationships may lead to uncertainty or conflict in these relationships, impacting the grandchild caregiver's sense of self or purpose. Overall, grandchildren between the ages of 18 to 29 years old are at a developmental stage that is critical to their future (sensitive period), and they are taking on caregiving responsibilities that may shift how they complete their developmental tasks (off-time role), potentially offering them a unique experience compared to their non-caregiving peers.

Purpose of the Study

The intersection of emerging adulthood and the associated developmental tasks with caregiving for a grandparent with dementia is an interesting phenomenon given how emerging adulthood is a sensitive period for figuring out who you want to be in the future and the role of grandchildren caregivers in this developmental period is an off-time role of caregiving which is stressful in general. The main contribution of this study is that it explored the experiences that young adult caregivers encounter at the intersections of development and caregiving, a phenomenon that has not yet been explored in the current literature. Essentially, this intersection requires young adult caregivers to be in two places at the same time – building their identities as a young adult, by meeting specific developmental milestones, and caregiving for their grandparents with dementia. Furthermore, this intersection is important because the current literature on emerging adulthood outlines how if a young adult does not meet the developmental milestones of emerging adulthood, they may not be successful in adulthood and when caregiving is added to this mix, it can amplify the challenges of completing the developmental tasks.

The current literature demonstrates that caregiving is a stressful experience, and caregivers often have a difficult time managing the demands of caregiving along with other responsibilities (Gilhooly et. al., 2016). Emerging adulthood is a unique developmental period, given how young adults do not fit in with adolescents or adults (Arnett, 2007). They are also the most demographically different age range compared to other life stages since they are in a major transitioning stage of their lives (Arnett, 2007). For example, there are various trajectories grandchildren can take such as moving out from their parent's homes into their own, leaving for college or work, testing different worldviews and romantic relationships, etc. The diversity of experiences during this life stage impact caregiving in terms of cultural expectations, familial responsibilities, and personal goals. Depending on what is required of them, expected of them, and what they actually want to do, the caregiving experience can be positive and/or negative. In addition to being a caregiver, grandchildren are taking on various other roles such as student, homeowner/renter, employee, partner, etc. Emerging adulthood signifies a time where young adults are gaining more autonomy and independence to establish themselves, which could create tension between personal development and caregiving responsibilities (Arnett, 2007; Venters & Jones, 2021). This complex experience is what I wanted to understand through this study because the role of caregiving as a grandchild can conflict with the developmental tasks of emerging adulthood due to the nature of a grandchild-grandparent relationship and the intensity of dementia caregiving, possibly making it a unique challenge. Therefore, it is important to understand how these individuals make meaning of this experience and the intersections of the various roles they are navigating in their lives.

Therefore, the purpose of this qualitative study was to describe the intersection of grandchildren caregiving for grandparent(s) with dementia and the developmental tasks of emerging adulthood. I strived to describe these experiences by conducting a study that was theoretically informed by the Theory of Emerging Adulthood (Arnett, 2000) and Role Theory (Biddle, 1986). In addition to expanding the empirical understanding of grandchildren as caregivers, these research findings could guide future work in social policy, create specialized resources and supports, and therapeutic interventions.

Chapter 2: Literature Review

Grandchildren as Caregivers to Grandparents

Caregiving has been extensively researched in the literature; however, relatively limited attention has been given to the experiences of grandchild caregivers (Venters & Jones, 2021). This study focused on exploring the intersection of caregiving to a grandparent with dementia while navigating the developmental tasks of emerging adulthood. The theories that guided this research are Arnett's Theory of Emerging Adulthood (Arnett, 2007), given the age range of the participants and the focus on emerging adulthood, and Role Theory (Biddle, 1986), to help understand the role of a grandchild caregiver. The grandparent-grandchild relationship is unique given the role of power and closeness in the relationship (Celdrán et al., 2012). When caregiving responsibilities are added to that relationship dynamic while the grandchild is in emerging adulthood, it creates an interesting intersection given the need for successful transition into adulthood.

Given the consistent increase in the individuals requiring care and the current trend of increased life expectancy, the number of unpaid caregivers will continue to increase in the future because more and more people will be older, who will require additional care from family members. This is important because, in 2015, there were 43.5 million unpaid caregivers; however, that number has greatly increased over time to 53 million individuals caregiving in 2020 (National Alliance for Caregiving & AARP, 2020). Furthermore, it is estimated that, by 2060, the population of people aged 65 and older will rise to 88.8 million (Administration for Community Living, 2024). Therefore, for the population of interest in this study, grandchildren caregivers, this percentage could increase over time as life expectancy increases, given how grandchildren are caring for their grandparents already (Fruhauf et al., 2006).

In addition to the life expectancy trend, grandchildren caregivers will also experience a change in family dynamics. Previous research indicates that young adults, ages 18 to 29, are caregiving to their grandparents by assisting with Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) (Fruhauf et al., 2006). ADLs included walking, transferring, and dressing and IADLs included cleaning, shopping, cooking, etc. (Fruhauf et al., 2006). According to the research, grandchildren were motivated to assist with caregiving tasks due to potential chronic illness for the grandparent, naturally aging, or there was a need to assist (Fruhauf et al., 2006). Given the age range and developmental stage of these individuals, it is important to understand their experiences since they are occupying off-time roles (caregiver) in a sensitive period of their lives (emerging adulthood) (Fruhauf et al., 2006). Similar to adult caregivers, young adults also experience role reversals with the care recipient and shifts in power with the care recipient and other familial relationships, which can lead to additional stress on the young adult (Venters & Jones, 2021). More specifically for grandchildren caregivers, the grandparent-grandchild relationship is typically one where the grandparent has more power than the grandchild (Szinovacz, 2003). Grandparents make decisions for their grandchildren when they are younger since they are not able to make decisions on their own yet. Therefore, when the grandchild is in a position of caregiving to their grandparent due to any reason, and those caregiving duties begin to increase over time, the power dynamic shifts in the relationship. In the context of this study, as the dementia progress the grandparent is unable to care for themselves or make decisions, therefore the grandchild takes on that responsibility, creating more power in that role reversal. The shift in power can create tension within the relationship depending on the type of relationship between grandparents and grandchildren (Celdrán et al., 2012). The type of relationship can also impact how the grandchild feels about caregiving overall.

Specific to this study, emerging adulthood is a unique period of development for young adults as they learn to navigate the world and learn about themselves. According to Arnett (2007) there are specific developmental tasks associated with this life stage that need to be met in order to successfully transition into adulthood such as feeling in-between, being self-focused, and creating a sense of self; more will be discussed in the next section. Therefore, given the unique intersection of caregiving and the developmental stage of young adults, it is important to begin to understand their experiences since the developmental tasks associated with emerging adulthood are not typically conducive to the demands of caregiving. Therefore, the purpose of this study was to understand how young adult grandchildren, between the ages of 18 to 29, experience the intersection of caregiving for a grandparent with dementia and navigating the developmental tasks of emerging adulthood. This chapter focused on the two guiding theories, Arnett's Theory of Emerging Adulthood and Role Theory, and how these theories intersected for the purpose of this study, in addition to reviewing the current literature on grandparent-grandchild relationships and caregiving for individuals with dementia.

Arnett's Theory of Emerging Adulthood

The age range of interest in this study was 18- to 29-year-old individuals who are in the emerging adulthood stage of their lives. This stage of life is theoretically different from other developmental stages as explained by Arnett's Theory of Emerging Adulthood (Arnett, 2007). The age range of 18 to 29 is different compared to other developmental stages due to the developmental tasks necessary for the transition into adulthood. The specific tasks necessary for a successful transition into adulthood include testing different careers, philosophical worldviews, romantic partnerships, exploring self-identity (Arnett, 2007). In fact, researchers have suggested that emerging adulthood is the only period of time where nothing is normative demographically

(Arnett, 2000). For example, in adolescence, there is little variation in the demographics of these individuals, since 98% of them are unmarried, 95% live at home with a parent, and over 95% are enrolled in school. When these adolescents get older and enter the young adult stage of life, it becomes difficult to predict their demographic status in these areas since they are testing different paths of life, which serves as a reflection of the exploratory quality of this period of time (Arnett, 2000). Moreover, the theory underlines how emerging adulthood is a unique time for individuals given the societal changes that have occurred over the past century. More emerging adults are attending postsecondary education and training, entering parenthood and marriage later in life, and have a greater acceptance for cohabitation and premarital sex (Arnett, 2007). Societal changes, in combination with the developmental tasks specific for this age group, separate them from adolescents and adults – it is the middle time frame between those two life stages.

Furthermore, given how the focus of this emerging adulthood is on testing various life choices and explore self-identity, the addition of caregiving responsibilities can severely impact how emerging adults engage with these tasks. Caregiving places time, social, and emotional constraints on what the caregiver can and cannot do (Ory et al., 1999), which impacts their autonomy in terms of becoming independent, a critical task of emerging adulthood. For example, the demands of caregiving may require the emerging adults to rethink career or school choices and even romantic relationships due to the difficulty of managing caregiving requirements. Given the focus of this study is on young adults grandchildren and how they navigate caregiving and the unique developmental tasks of emerging adulthood, Arnett's theory of emerging adulthood helps account for the developmental stage of the participants, and can provide guidance in terms of explaining how they might make decisions or how they think about the roles they play in their lives, such as grandchild caregiver, student, parent, etc., and provides some guidance about potential points of tension between successfully completing the developmental tasks while managing the demands of caregiving responsibilities (Arnett, 2000).

Role Theory

In addition to understanding emerging adulthood, it is also important to take into consideration the meaning people make about the roles they play in their lives and the impact of these roles on their personal lives. Roles refer to the specific behaviors expected, responsibilities, and societal norms associated with a given social position (Biddle, 1986). Roles help humans make sense of their purpose in relationships and role theory states that roles are defined in relation to others (Biddle, 1986). There are a set of normative expectations based on others and larger societal constructions that are associated with each role (Biddle, 1986). For example, the role of caregiver is typically defined by the caregiving relationship that occurs between the caregiver and the care receiver. The caregiver role has its own societal expectations and norms associated with it such as being physically, emotionally, and mentally available and ready to provide care and if one is able to successfully provide care then they are seen as good people in society. Similarly, for the population of interest in this study, the roles of grandparents and grandchildren are important to understand. Grandparents can play a variety of roles in their grandchild’s life such as mentor, playmate, historian, etc. (Weston & Qu, 2009) and typically have more power due to the hierarchical structure of families (Szinovacz, 2003). Therefore, when grandchildren begin caregiving to their grandparents, they experience a shift in the power dynamics and a reversal in their roles, which is a new role they are occupying that comes with its own set of caregiver expectations.

Roles are important in maintaining well-being for individuals since it is presumed that the delineation of roles results from a shared definition in the relationship the roles occurring in. Roles that may not be well-defined or changing over time, can potentially lead to stress in the role occupier and in the related relationship. Given the unique intersection of navigating caregiving and the developmental tasks of emerging adulthood, young adult grandchildren caregivers can potentially face three challenges specific to their roles - role strain, role conflict, and role overload (Biddle, 1986; Creary & Gordon, 2016). Role strain is when the demands of a single role become too overwhelming (Biddle, 1986). For example, the young adult caregiver may struggle to provide physical care for their care recipient or feel guilt for wanting to spend time with romantic partners or friends. Role conflict occurs when two or more social roles conflict with each other and/or are incompatible (Biddle, 1986; Creary & Gordon, 2016). For young adult caregivers, they may be juggling multiple roles in their lives such as being a student, a romantic partner, friend, and caregiver. Sometimes the caregiver role may conflict with their role as student when the grandchild caregiver is expected to be emotionally available at home while trying to meet assignment deadlines, creating this conflict of being a good caregiver or a successful student. Finally, role overload is when the individual attempts to fulfill many roles at the same time, but they lack the appropriate resources to successfully perform them, or when the demands of a particular role become too overwhelming (Biddle, 1986; Creary & Gordon, 2016). For example, it may be very difficult for the emerging adult to be a student, romantic partner, friend, and caregiver all at the same time due to limited time, lack of support, and the pressure to do it all. Utilizing role theory in this study helped give more insight into the intersecting roles of grandchildren caregivers as emerging adults and helped to understand how emerging adults are navigating role shifts and changes.

The Intersection of Role Theory & Emerging Adulthood

To gain a complete understanding of how young adult grandchildren, between the ages of 18 to 29, experience the intersection of caregiving for a grandparent with dementia and navigating the developmental tasks of emerging adulthood, it is useful to integrate Arnett's Theory of Emerging Adulthood (Arnett, 2007) and Role Theory (Biddle, 1986). When thinking about emerging adulthood, the typical experiences of emerging adults include going to college or getting their first jobs, exploring their options of what they want to do in the future, and possibly testing different romantic relationships, etc. All of these activities are very self-focused and help the emerging adult find their own identity. Therefore, when associating the concept of caregiving with emerging adulthood, especially a grandchild taking care of their grandparent, the two are at competing odds since caregiving is not a self-focused experience.

The three roles of and expectations of being a young adult, a grandchild, and a caregiver do not necessarily align with each other. There is a distinct tension at that intersection, which is what I aimed to understand in this study. Being an emerging adult means testing new ways of living and making good or bad choices. Being a grandchild to their grandparent carries its own weight of the emotional connection and the power shifts within role reversals. Being a caregiver requires responsibility for another human being. The mistakes and choices that are acceptable in emerging adulthood are not acceptable when thinking of the role of a grandchild caregiver (Fruhauf et al., 2006; Fruhauf & Orel, 2008). For example, the emerging adult is in a phase of their life where they can make mistakes, learn from them, and integrate them into their identity since those mistakes are typically only affecting the emerging adult. In contrast, a grandchild caregiver is responsible for their grandparent, who is dependent on them to varying degrees and if they make a mistake or are not available for their grandparent, it could lead to harsher impacts.

Theoretically, the role of being an emerging adult can conflict with the role of being a grandchild caregiver in certain cultures and societally since the societal expectations are completely different for each role, possibly leading to role strain. When taking into consideration the other roles an emerging adult has such as a friend, employee, student, etc. it can lead to role conflict and overload since these individuals are occupying an off-time of being a caregiver since it is not a normative role typically associated with the age range of 18- to 29-year-olds. Therefore, to fully understand and attempt to answer the research question, it was important to understand if and how caregiving as a grandchild caregiver within the developmental context of being an emerging adult impacts this population and their experiences.

Grandparent-Grandchild Relationships

Grandparents can play a significant role in a grandchild's life. They can play various roles which include a caretaker, historian, mentor, and/or playmate (Celdrán et al., 2014; Weston & Qu, 2009). In some families, grandparents may be the primary caretaker of the grandchild, or they may be caretaking to a certain extent such as babysitting or playing with the grandchild to help the parents (Weston & Qu, 2009). Grandparents hold knowledge about their families and their worldly experiences, which can be of value to grandchildren who are interested in learning about their family or general experiences (Weston & Qu, 2009). Moreover, grandparents can be mentors given their knowledge and experience (Weston & Qu, 2009). Grandparents present to their grandchildren in a variety of ways which include being compassionate, remote, involved, influential, supportive, passive, authority-oriented, and/or detached (Dolbin-MacNab, 2019). Depending on the type of relationship the grandparent and grandchild have with each other, it can impact how the grandchild experiences the caregiving relationship and their level of involvement in caregiving responsibilities (Celdrán et al., 2012).

The level of involvement of a grandparent in a grandchild's life is dependent on a variety of factors including their relationship with their adult children (i.e., the grandchild's parent(s)), their health and well-being, time constraints, gender, physical distance, etc. (Mueller & Elder, 2003; Sari, 2023). Depending on the quality of the relationship the grandparent has with their adult child, it plays a role in how often their child lets them be with their grandchild (Mueller & Elder, 2003). For example, if the relationship is good between the grandparent and their adult child, they may be more likely to be in their grandchild's life. This relationship can be influenced on previous trauma, history, and levels of trust (Mueller & Elder, 2003). Relatedly, the grandparent's health is an important factor when determining how they will engage with their grandchild. That is, if they are healthy, then they can do more for the grandchild but if they require active care, it may alter the type of role they serve for the grandchild since it limits their ability to participate in caregiving or play time (Sari, 2023). Lastly, depending on how much time grandparents have, due to employment or other caregiving responsibilities, it can influence their level of involvement with the grandchild (Mueller & Elder, 2003).

Previous research has shown that grandchildren who have grandparent involvement in their lives reported positive impacts such as feeling closer to their grandparent, learning family history, and gaining support from the grandparent (Weston & Qu, 2009). In these instances, the grandparent serves as a historian of family traditions and history, a mentor offering guidance, and an additional emotional support person (Weston & Qu, 2009). The varying roles that grandparents can play in a grandchild's life, how they show care, and their level of voluntary involvement contributes to the uniqueness of this relationship.

Challenges of Caregiving for Grandparents

Previous research has shown that caregivers struggle with balancing their paid workload, managing childcare responsibilities, coordinating care for the care recipients, and experiencing adverse effects on their mental, emotional, and physical well-being (Choi et al., 2024; National Alliance for Caregiving & AARP, 2020; Tu et al., 2022). These challenges often lead to caregivers experiencing caregiver burden due to the psychological and physical health consequences of caregiving demands (Choi et al., 2024). Caregivers suffer from higher levels of depression and anxiety compared to non-caregivers due to the stress and emotional strain of caregiving (Schulz & Martire, 2004). Caregivers also are at risk of developing chronic health conditions such as high blood pressure, diabetes, arthritis, cardiovascular problems, and a compromised immune system (Schulz & Martire, 2004).

Many caregivers end up quitting or temporarily leaving their jobs due to caregiving demands (AARP, 2024). In conjunction with the care responsibilities, many caregivers have difficulty managing childcare due to the time constraints (National Alliance for Caregiving & AARP, 2020). These time constraints leave caregivers wanting and needing additional help, whether from family or professionals, in order to have time for themselves or to spend time with friends and other family members (National Alliance for Caregiving & AARP, 2020). Due to the intensity of care required, it can lead to burnout. It is reported that almost 32% of caregivers experience significant burden in their caregiving experience (Choi et al., 2024).

When conducting the literature review on the topic of grandchildren caregivers to grandparents with dementia one article conducted a systematic review on the same experience. Venters and Jones (2021) only found twelve articles focused on grandchild caregivers to those with dementia, including one article that was not entirely focused on dementia (Venters & Jones, 2021). The review included articles which used qualitative, quantitative, and mixed methodologies with a range of grandchildren of different ages and life stages (Venters & Jones, 2021). Nine articles included individuals in the range of 18 to 25 years old, but none consisted of a sample that was strictly between that age range. All of the articles focused on different aspects of the caregiving process such as coping strategies, emotions, perceptions, and the grandchild's relationship with their grandparent but not all of them focus specifically on the caregiving itself. The systematic review revealed six themes common between all the articles reviewed. These themes include role transitions, dementia related changes to their grandparent, embracing a new relationship with their grandparent, the multiple impacts of caregiving, the positive consequences of caregiving, and the impact of other familial relationships (Venters & Jones, 2021). This systemic review will be discussed throughout the next few sections on challenges, coping, and benefits of caregiving to grandparents since the themes are varied across these topics.

One theme focused on the negative changes with their grandparent due to the nature of the dementia diagnosis affecting cognition and behavior (Venters & Jones, 2021). Negative changes included unpredictability, fear of the grandparents losing shared memories, and overall change in the way the grandparent behaved (Celdrán et al, 2014; Howard & Singleton, 2001; Szinovacz, 2003). Additionally, grandchildren reported the multiple aspects and impacts of caregiving (Venters & Jones, 2021). They would help their grandparents with activities of daily living, which include eating, bathing, dressing, transferring, toileting, and moving around/walking. They stated how the caregiving process impacted their physical and psychological health such as increased sleep difficulties and heightened feelings of depression and stress (Celdrán et al, 2012; Hamill, 2012; Howard & Singleton, 2001; Huvent-Grelle et al., 2016; Szinovacz, 2003).

In addition to the systematic review and the themes associated with it discussed previously (Venters & Jones, 2021), one of the most important topics in the current research findings on young adult caregivers was the challenges of caregiving. Fruhauf et al. (2006) is one the preliminary articles exploring the perceptions of grandchildren, ages 21 to 29 years old, caring for their grandparents. In this study, 17 adult grandchildren were interviewed and asked about how they came to care for their grandparent, what they learned about themselves, and how this experience impacted their lives (Fruhauf et al., 2006). Findings highlighted the challenges of caregiving which included time constraints, feelings of frustration, depression, and anxiety, sacrificing personal goals and aspirations, and experiencing stress (Fruhauf et al., 2006). Grandchildren reported how they felt like they could not grow in their careers or have personal time because they were always engaging in caregiving, which meant they had to sacrifice their personal goals (Fruhauf et al., 2006). These frustrations led to feeling stressed, depressed, and anxious, which manifested as doubting their caregiving abilities, worrying about their grandparents, and being concerned about doing the wrong thing (Fruhauf et al., 2006). This research is one of few studies that have evaluated grandchildren's perceptions of caregiving for a grandparent, but it did not focus specifically on caring for a grandparent with dementia, which is a more nuanced experience that the current study attempted to build on and extend by exploring how grandchildren caregivers made meaning of their experience of caregiving while attempting to successfully complete the developmental tasks required for this life stage.

Another study, Fruhauf and Orel (2008) focused on the developmental issues of grandchildren, ages 21 to 29 years old, when caring for their grandparents. The researchers conducted 34 interviews about the care they provided, other's perceptions of their caregiver role, stress they experienced, and how they coped (Fruhauf & Orel, 2008). Emotions and feelings related to caregiving to a grandparent were important findings as well (Fruhauf & Orel, 2008). Grandchildren reported fear of their grandparent passing, guilty for times when they did not want to provide care or chose to engage in a personal matter over caretaking for their grandparents, and feeling pulled in various directions of the caregiving process (Fruhauf & Orel, 2008; Blanton, 2013). Fear and guilt were significant emotions expressed by grandchildren due to the nature of aging and the pressures of caregiving.

An additional experience that is vital to understanding the experiences of grandchildren caregivers is the intergenerational nature of the caregiving process. Intergenerational relationships were described as having continuity and diversity. Blanton (2013) discusses young adult grandchildren, ages 17 to 30 years old, as auxiliary caregivers to frail grandparents. The researchers interviewed 10 young adult grandchildren on what they expected about caregiving and what contexts influenced their experiences (Blanton, 2013). Their findings highlighted that the grandchild-grandparent relationship presented in different ways such as high on solidarity and low on conflict or vice versa which was reflective of the type of relationship between the grandchild and grandparent (Blanton, 2013). If the grandparent was unkind or mean to the grandchild, it impacted how they felt about their grandparent and as these grandchildren got more experience caregiving to their grandparents, they were able to make sense of why their grandparent may have been a certain way in childhood (Blanton, 2013). Different backgrounds and situations impacted how much solidarity and conflict was present in the relationships which impacted the caregiving process (Blanton, 2013). In relationships were there was less conflict between the grandparent and grandchild, the grandchild was more willing to help with caregiving tasks (Blanton, 2013). Also, the dynamics between family members were constantly changing based on the caregiving roles and responsibilities for each person, which impact the caregiving experience for everyone involved since everyone had a different relationship with the grandparent (Blanton, 2013). The findings from this article focus on positive aspects of caregiving, due to their sample and the participant's experiences. It is important to continue to understand young adult caregiver's experiences because not all of them are strictly positive or negative experiences when caring for their grandparents.

Coping with Caregiving for Grandparents

Although grandchild caregivers experienced a variety of challenges related to the demands of caregiving (Fruhauf et al., 2006), they also developed different coping mechanisms (Fruhauf et al., 2006; Fruhauf & Orel, 2008). Pulling from the previously discussed study by Fruhauf and Orel (2008) on the developmental issues of grandchildren when caring for their grandparents, one of the main findings from this study focused on grandchildren's coping strategies which included such as spending time on hobbies, seeking support from friends and family, engaging in religious activities, traveling, and exercising, and getting some amount of respite. Coping strategies were created by grandchildren in order to balance caregiving responsibilities with maintaining a healthy mental and physical state (Fruhauf & Orel, 2008).

Drawing from the earlier mentioned systematic review (Venters & Jones, 2021), grandchildren reported having to adopt a new type of relationship with their grandparents as their dementia progressed (Celdrán et al, 2011, 2014; Creasey & Jarvis, 1989; Creasey et al., 1989; Miron et al., 2019). They worried about how to interact with their grandparents due to their diagnosis and reported changes in their frequency of contact, emotional closeness, and relationship satisfaction. Despite these changes, grandchildren were able to implement problem-focused and emotion-focused coping strategies such as planning out what to talk about and incorporating other family members (Miron et al., 2019). Another finding from that same systematic review was that grandchildren reported how important familial and social support is when caregiving (Celdrán et al, 2012; Creasey & Jarvis, 1989; Creasey et al., 1989; Szinovacz, 2003). Also, grandchildren caregivers described how stress experienced by other family members can impact the grandchild's caregiving experience, making it a positive or negative one, and their relationship with their grandparent, either more stressful or easygoing. Therefore, it is important to recognize and understand the impact of other familial relationships on the grandparent-grandchild relationship.

At an age and developmental stage that is essential to being successful in adulthood, understanding these fears, feelings, and coping strategies practiced by emerging adult caregivers is important. Emerging adulthood is a sensitive period of time where an individual is trying to figure out who they are and specifically for the population of interest in this study – grandchildren caregivers – the nature of emerging adulthood combined with the relational context of caring for a grandparent and the demands of caregiving make this a unique experience. Grandchildren caregivers are occupying an off-time role of being a caregiver during a time in their lives when they are supposed to be self-focused, possibly creating challenges for them. Therefore, I have attempted to unpack these two roles, being an emerging adult and a grandchild caregiver, and how these individuals make meaning of their experience in these roles, and how they manage the role conflict that occurs during the caregiving process.

Benefits of Caregiving for Grandparents

Another important topic when discussing caregiving is the benefit of that experience and process grandchildren caregivers. Fruhauf et al. (2006) analyzed what grandchildren caregivers liked about their caregiver tole. When asked about the benefits they experience, grandchildren reported benefits such as learning about themselves and their families, developing skills such as patience and caretaking, and emotional and financial compensation (Fruhauf et al., 2006). The caregiving process helped reaffirm personal insights for the grandchild, such as being a helper or liking to take care of others (Fruhauf et al., 2006). Grandchildren also learned more about their families including how they function, make decisions, and their history. Moreover, caregiving taught grandchildren new skills and/or helped continue developing skills they were practicing before and got them interested in learning about how to effectively caretake for an older adult (Fruhauf et al., 2006). Finally, grandchildren reported that spending time with their grandparent was emotionally and financially rewarding (Fruhauf et al., 2006). At times, their grandparents provided emotional support, and it felt good to just be there for them and some grandchildren even were paid for their time and efforts. This study examined the challenges and benefits of caregiving for grandparents as young adult grandchildren, but further research needs to be conducted in order to learn about more nuanced experience of being a grandchild caregiver who is attempting to navigate the developmental tasks associated with emerging adulthood.

Referencing the previously discussed systematic review on the experiences of grandchildren caregiving to their grandparent(s) with dementia, grandchildren caregivers reported various positive experiences to their caregiving role (Venters & Jones). These included role transitions, the positive changes they see in their grandparent, positive aspects of caregiving overall (Venters & Jones, 2021).

Transitions occurred for both grandchildren and grandparents (Celdrán et al., 2011, 2012). For example, grandparents are often individuals who care for their grandchildren throughout their childhood (Celdrán et al., 2014). However, after the grandparent is diagnosed with dementia, grandchildren shift into the role of taking care of their grandparents. Some grandchildren see it as their duty to give back to their grandparents who has taken care of them for parts of their lives (Celdrán et al., 2009, 2012). Compared to grandchildren who were still caregiving to grandparents but not specifically for a grandparent with dementia, dementia caregivers described how what the grandparent did behaviorally, and their attitude were less important to them (Werner & Lowenstein, 2001).

Positive change included how their grandparent was still themselves, except they showed their qualities in new ways (Celdrán et al, 2014). In addition to positive change, grandchildren described positive aspects of caregiving as well (Venters & Jones, 2021). Grandchildren felt that caregiving was a rewarding experience and associated their experiences with feelings of happiness and satisfaction and increased maturity (Celdrán et al, 2009, 2012; Hamill, 2012; Huvent-Grelle et al., 2016). The act of caregiving helped the grandchildren develop an understanding of dementia, its symptoms, and its progression and developed skills in caregiving-related tasks.

Based on the previously discussed articles, the feelings and emotions experienced by grandchildren (Blanton, 2013; Fruhauf et al., 2006; Fruhauf & Orel, 2008), costs and benefits (Fruhauf et al., 2006; Fruhauf & Orel, 2008; Venters & Jones, 2021), coping strategies (Fruhauf & Orel, 2008; Venters & Jones, 2021), and the intergenerational aspect of caregiving (Blanton, 2013; Venters & Jones, 2021) are beginning to be known in the literature. However, there is not a lot of information describing the experiences of emerging adults in particular nor accounting for the developmental tasks associated with this stage of the life cycle. Therefore, since emerging adulthood in the context of grandchildren caring for their grandparents is not very well explored in detail, this study aimed to understand a more nuance experience of how young adult grandchildren, between the ages of 18 to 29, experience the intersection of caregiving for a grandparent with dementia while navigating the developmental tasks of emerging adulthood.

Furthermore, it is important to ground the research in theory since many of the articles were exploratory in nature (Venters & Jones, 2021). Theories help provide a lends through which to interpret findings by helping the researcher understand individual experiences within broader frameworks, which in this study is the intersection of caregiving as a grandchild during emerging adulthood.

The Current Study

Recent literature extensively examines dementia caregiving, with increasing attention given to young adult grandchildren in caregiving roles. Research highlights the unique challenges grandchildren caregivers face, including role transitions, adapting to dementia-related changes in their grandparent, redefining their relationship, and navigating the broader impacts of caregiving (Venters & Jones, 2021). Additionally, caregiving presents further difficulties such as time constraints, frustration, depression, anxiety, sacrificing personal aspirations, and heightened stress levels (Fruhauf et al., 2006). Despite these challenges, young adult grandchildren caregivers develop coping mechanisms to manage stress and balance their caregiving responsibilities while maintaining their mental and physical well-being (Fruhauf & Orel, 2008). However, there is a significant gap in understanding the intersection of being a young adult and being a grandchild caregiver.

Given the demanding nature of caregiving and the diverse life paths experienced during emerging adulthood, is important to understand the how these young adult grandchildren are navigating these competing demands. They occupy an off-time role, as a grandchild caregiver for their grandparents, while being a young adult in a sensitive period of their life known as emerging adulthood. Therefore, the purpose of this study was to explore the experiences of the intersection of caregiving for a grandparent with dementia and navigating the developmental tasks of emerging adulthood for young adults by utilizing Interpretative Phenomenological Analysis (IPA). This research methodology fills a gap in the current knowledge of this population because it allowed the researcher to explore one specific phenomenon – being a young adult grandchild caregiver to a grandparent with dementia. IPA helped the researcher explore this lived experience and understand how these individuals make sense of that experience. Overall, this study aimed to answer the research question of – how do young adult grandchildren, between the ages of 18 to 29, experience the intersection of caregiving for a grandparent with dementia and navigating the developmental tasks of emerging adulthood?

Chapter 3: Methodology

Guided by Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2007), the purpose of this study was to explore how young adult grandchildren, between the ages of 18 to 29, experience the intersection of caregiving for a grandparent with dementia and navigating the developmental tasks of emerging adulthood. IPA was selected as the guiding methodology for this study due to its focus on describing the lived experiences of participants (Creswell & Poth, 2016), which has not been adequately addressed by previous research. This approach explores how individuals make sense of their personal experiences of a particular phenomenon and focuses on the meaning they derive from those experiences (Creswell & Poth, 2016). These phenomena can include emotional states, social constructs, professional descriptors, roles, etc. (Creswell & Poth, 2016). In this study, the phenomenon of interest was caregiving for a grandparent with dementia as a young adult grandchild.

Interpretative Phenomenological Analysis (IPA) was particularly well suited for this study due to the nature of how it draws from phenomenology, hermeneutics, and idiography (Eatough & Smith, 2017; Smith & Osborn, 2007). Phenomenology is a way of studying the lived human experience through a philosophical lens (Smith & Nizza, 2022). Hermeneutics focuses on the subjective interpretations of different phenomena (Smith & Nizza, 2022). Idiography places the focus on something in particular, which is important given the case-by-case analysis in this methodology (Smith & Nizza, 2022). This specific methodology was chosen to understand the experiences of young adult grandchildren caregivers to grandparents with dementia because it captures the essence of the lived experience of these individuals (idiography) and how they make sense of their role (hermeneutics). Furthermore, phenomenology helps provide the philosophical foundation to explore these subjective experiences from the participants' own perspectives. In this process, the researcher also takes an active role in the analytic process, by recognizing their own biases and assumptions as they attempt to understand participants' lived experiences. In this way, IPA can be described as a double hermeneutic process, given how the participant is trying to understand their world and how the researcher is trying to understand how the participants are attempting to understand their world (Smith & Osborn, 2007).

Participants

The sample consisted of 8 young adult grandchildren between the ages of 18 and 29 years who 1) self-identified as being a caregiver to a grandparent (step-, adoptive, or biological) with dementia, 2) were actively caregiving for at least 6 months or had previously cared for a grandparent with dementia for at least 6 months, and 3) could speak English. The age range of 18 to 29 years old was chosen based on Arnett's Theory of Emerging Adulthood (2000), which specifies this age range as a distinct developmental stage. Grandparents were not required to have a specific type of dementia diagnosis. However, the dementia diagnosis must have been provided by a physician and be recognized by the National Institute on Aging (National Institute on Aging, 2022). These possible dementia diagnoses include Alzheimer's, frontotemporal, Lewy body, vascular, or mixed dementias (National Institute on Aging, 2022). Caregiving was defined as helping their grandparent(s) in their daily life, specifically assisting with Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs) (Pashmdarfard & Azad, 2020). The time frame of caregiving for at least 6 months was chosen to ensure that the grandchild had been caregiving for a long enough period of time to develop an understanding of their role as a caregiver and be able to reflect on and describe any emotional, relational, or practical changes that occurred during their time caregiving. While the grandchild was not required to be living with the grandparent(s), it was required that the grandparent be living at home – any grandchildren caregiving for a grandparent who was living in a care facility were excluded from the study. Finally, the grandchild did not need to be the sole caregiver for the grandparent. They could still participate in the study if they were sharing caregiving responsibilities with others, such as family members and/or paid assistance.

Given the intensive nature of IPA, a small sample size of approximately ten participants is considered appropriate for conducting an in-depth analysis of participants' experiences (Smith & Nizza, 2022). In this study, there were eight participants, which is somewhat smaller than the recommended amount. However, this sample of eight was still adequate for answering the research question because IPA prioritizes depth over breadth within the data. By the sixth and seventh interviews, the participants began describing similar experiences in their caregiving duties, the roles they occupied, and how they made sense of and coped with their various roles. In these later interviews, little new information emerged. Since the interviews were starting to become homogenous, in terms of the content, I concluded recruitment of additional participants and determined that saturation had been reached (Creswell & Poth, 2016). Overall, the participants that were interviewed provided sufficient data for understanding their experiences of caregiving for a grandparent with dementia while navigating the developmental tasks of emerging adulthood. It was also appropriate that the sample be somewhat homogenous in terms of the study's inclusion criteria, due to the need to conduct an in-depth exploration of the specific experience of caregiving for grandparents with dementia (Smith et al., 2009). If the sample were too heterogenous, any differences across the interviews could be the result of a variety of factors, such as cultural background or socioeconomic status, which may be unrelated to the phenomena under investigation – whereas, with a homogenous sample, any differences among participants are more likely to inform the researcher about variation in how the actual phenomenon is experienced by specific individuals rather than differences due to other characteristics (Smith & Nizza, 2022).

Recruitment

Participants were recruited using convenience and snowball sampling (Emerson, 2015). Convenience sampling involves locating participants that are easiest to access and who are willing to participate in the study (Emerson, 2015). Flyers were posted on social media platforms and at a variety of physical locations and emails were distributed to professors, organizations, and university listservs (details provided below), which allowed for quick and accessible recruitment. Posting on social media platforms led to a number of responses that raised concerns about fraudulent participation. To prevent this, I relied heavily on snowball sampling, which is recruitment strategy that takes place when the researcher knows a few participants to begin with and then asks those participants to refer others who fit the inclusion criteria (Emerson, 2015; Smith & Nizza, 2022). Both sampling methods are commonly used in IPA studies, given the need for a small but specific group of participants who have experience with the phenomenon under investigation. Since this study explored the specific intersection of grandchildren caregiving for their grandparent(s) with dementia and the developmental tasks of young adulthood, snowball sampling was particularly useful in identifying participants who are part of this population and genuinely connected to this experience.

After receiving IRB approval (Appendix A), recruitment efforts were organized across several sectors. At the university level, recruitment flyers (Appendix B) were shared with Valdosta State University and Virginia Tech campuses via listservs and emailed to multiple faculty members at these institutions to share with the students in their courses (Appendix E). In the South Georgia region, where the researcher is physically located, physical flyers were posted in community centers, senior centers, hospitals, and doctor's offices. In addition, recruitment emails were sent to various organization directors (Appendix D) who work with caregiving youth such as the American Association for Caregiving Youth and Hilarity for Charity. Lastly, information about the study was posted on social media platforms such as Facebook and Instagram (Appendix C). Of the eight participants, 3 learned about the study from university campuses, 2 from social media, and 3 from snowball sampling or word-of-mouth. Although many recruitment strategies were local, the sample was recruited nationally, as the researcher posted on various platforms that covered the entirety of the United States. Four participants were from Georgia, while the remaining participants were each from a different state: New York, California, Florida, and Virginia.

Potential Fraudulent Participants

A total of 13 interviews were conducted for this study, however 5 interviews were deemed fraudulent and subsequently excluded from data analysis. These participants gave inconsistent or illogical responses that raised concerns about the authenticity of their caregiving experiences. Examples included inconsistencies regarding the type of care they were providing and the dementia diagnoses of their grandparents. Furthermore, all of the fraudulent participants described having the exact same caregiving arrangement; they all stated that they were living alone with their grandparent and going to college, making them the sole caregiver in the household. During the interviews, the fraudulent participants also provided notably similar answers to several of the interview questions, suggesting that they were using some type of "script" for their responses. Finally, in terms of recruitment, all five participants stated they saw the recruitment flyer on Facebook and emailed with their interest in the study in rapid succession within a few minutes of the flyer being posted online. A few of these participants were also insistent on wanting to schedule an interview and emailed me about participating multiple times, which was not the case with the non-fraudulent participants. Collectively, due to these multiple indicators of fraudulent participation, I decided to remove these five participants from the data analysis. To prevent further potential fraudulent participants, I removed the recruitment flyer from all public social media platforms and limited future posts to private groups. Additionally, I intensified recruitment efforts thorough local community centers, university campuses, and snowball sampling from individuals who either fit the study criteria or knew of others who met the criteria and would be willing to participate.

Procedures

Data collection involved screening participants for eligibility and then conducting an in-depth interview. In terms of the consent and screening process, interested participants contacted me via phone or email, and I established participant eligibility by asking a series of screening questions (Appendix F). After establishing eligibility, participants who meet the inclusion criteria were permitted to participate in the study and those who do not were offered resources and supports on caregiving (Appendix G), if they were interested. Only one participant was deemed ineligible after screening, and they refused any resources or supports on caregiving.

After confirming eligibility, the participant and I scheduled a time to conduct the open-ended interview, which lasted between 30 to 60 minutes, with an average interview time of 37 minutes. All interviews took place via Virginia Tech's HIPAA compliant version of Zoom. Prior to the interview, each participant was emailed (Appendix I) a unique Zoom link, and a reminder of the date and time of the interview. In addition, I also emailed participants the informed consent form (Appendix H) for the participant to review.

When the participant entered the Zoom meeting for the interview, they were required to wait in the waiting room until I let them into the main Zoom room. This process allowed for an extra layer of protection in case others were attempting to join the interview using the Zoom link. At the beginning of the interview, I verbally reviewed the informed consent form with the participant (Appendix H) and asked if they had any questions or concerns. After addressing any questions or concerns, I asked for their verbal consent to sign the informed consent document, which was shared on screen, and to begin the interview. Participants received a $20 electronic Amazon gift card via email after completing the interview, as compensation for their participation in the study.

Interview Protocol

After reviewing the informed consent form (Appendix H), I asked the participant demographic questions (Appendix J). Following those demographic questions, I began asking the open-ended interview questions (Appendix K) about the participants' experiences of being a caregiver.

Demographic questions (Appendix J) included the participant's age, race, ethnicity, occupation, gender, education, income, work status, and relationship status. Specific to their caregiving role, participants were also asked who they were currently living with, how long they have been caregiving for their grandparent, how often they participated in caregiving activities weekly by specifying the number of times, the grandparent's specific dementia diagnosis, and specific IADL and ADL caregiving activities.

The open-ended interview questions (Appendix K) aimed to explore participants' lived experiences of being a young adult caregiver to a grandparent with dementia. These questions were informed by Arnett's Theory of Emerging Adulthood (Arnett, 2000) and Role Theory

(Biddle, 1986). Arnett's theory focuses on key experiences relevant to individuals ages 18 to 29 such as identity exploration, instability, self-focus, feeling in-between, and optimism (Arnett, 2000). For example, Arnett's theory was showcased by inquiring about "How has caregiving impacted your life at this age? In terms of work, school, friendships, romantic relationships, life choices, mentally, emotionally, physically, etc." This question asks about the possible impacts on being self-focused, their identity, and the possibilities they can or cannot participate with in their lives. Role Theory examines how individuals behave based on the social roles they occupy in certain contexts (Biddle, 1986). In the following question, "What does the role of a caregiver mean for you?," the participant is being asked to define their caregiver role. Interview questions addressed the following topics: (a) the relationship with grandparent before and after the dementia diagnosis, (b) the impact of caregiving on relationships, and (c) the developmental impact of caregiving on grandchildren's identity. Questions about understanding the shift in participants' relationships with their grandparents before and after the dementia diagnosis aimed to understand the systemic nature of caregiving. For example, "How has your relationship with your grandparent changed over time or stayed the same?" and "What was the impact of the dementia diagnosis on the relationship, specifically in relation to caregiving?" Interview questions about the impact of caregiving on relationships focused on understanding how caregiving responsibilities and duties affected participants' personal relationships. For example, "How has caregiving to your grandparent impacted other relationships in your life with your parents, friends, siblings, etc.?" Finally, questions about the developmental impact of caregiving were focused on capturing the unique circumstances that emerging adults are navigating while balancing the responsibility of being a caregiver. For example, "In comparison to your peers, how are you similar and/or different given your role as a caregiver?" and "How have you changed and stayed the same (socially, developmentally, personally, etc.) as a result of being a caregiver as an emerging adult who is learning how to navigate the world ahead of them?"

Data Analysis

Data Preparation and Protection

The interviews were audio and video recorded for transcription and stored in a password protected folder on OneDrive provided by my dissertation chair. The audio was transcribed verbatim via an online transcription service, TranscribeMe, and checked for accuracy, once each transcription was complete. The participants were differentiated by utilizing identifiers such as "Participant 1" in order to protect the participants' identifying information. I kept a digital de-identified copy of each transcribed interview on a password protected file on my protected computer. Any transcripts or recordings with identifying information were stored on the OneDrive folder provided to the researcher. Transcripts were also printed for the data analysis portion without any identifying information and kept in a locked file cabinet when not being utilized.

Exploratory Notes

For the first part of the data analysis, I printed out each transcript and read through it while listening to the audio recording to check for any missing information or inaccuracies within the transcription. Afterwards, I re-read the transcript and made written notes in the right margins of the transcript about my first reactions. In accordance with IPA, these reactions included anything that intrigued me about the data or seemed important (Smith, & Osborn, 2007). Making notes helped me bracket my thoughts on what I may have been assuming about the participants' experiences. For example, I noted things like "living with grandparent for many

many years," "grandparent cared for them when they were younger," and "feeling guilty for leaving."

The initial read through also helped me start identifying key passages or words used by the participants and I made notes of similarities, differences, amplifications, and contradictions in what the participant described in the same right-hand margin and by highlighting key responses (Smith & Osborn, 2007). More specifically, during the exploratory read through, I made three types of notes in the right margin: descriptive, linguistic, and conceptual (Smith et al., 2009). Descriptive notes focused on the content of the interview, including different elements that structured the participant's experiences, such as "choosing to go to university close to home" (Smith et al., 2009). Linguistic notes pertained to the exact words that were spoken such as pronouns, pauses, hesitations, tone, etc., for example, "participant was discussing with frustration but also a sound of defeat that they are not able to be young – "*they get to go to work and party and have fun*"" (Smith et al., 2009). Finally, conceptual notes came in the form of questions relevant to the participant's and my understanding of what was being discussed, such as "where does the guilt come from?" (Smith et al., 2009). All three types of notes were utilized, in the margins of the transcript, to help me engage with the data in a more in-depth manner.

Experiential Statements

After reading each transcript and making the exploratory notes, I moved onto creating handwritten experiential statements in the left margin of the transcripts using those exploratory notes. The goal was to identify one or more experiential statements for each time the participant spoke during the interview (Smith & Osborn, 2007). These statements were phrases or a sentence that summarized what I learned about the meaning of the phenomena under investigation for the participant in any given section of the transcript and aimed to capture the psychological and meaning making processes of their lived experiences (Smith et al., 2009). The theories utilized in this study, Arnett's Theory of Emerging Adulthood (Arnett, 2000) and Role Theory (Biddle, 1986), helped guide me in thinking about what to look for in the participant's responses. For example, in one interviewee's response about the impact of caregiving their physical, mental, and emotional health, I made exploratory notes of "making sure to have a plan for meals," "*I've learned to be more responsible,*" and "how does she cope with emotional impact?" I used these exploratory notes to create the experiential statement "managing increased responsibility."

Connecting and Grouping Experiential Statements

In the third step of the analytical process, I reviewed and clustered the experiential statements I created throughout the entire interview (Smith et al., 2009). The number of experiential statements varied depending on the length of the interview and the density of the data (Smith & Nizza, 2022). Throughout this step, I started grouping similar experiential statements, which is called clustering (Smith et al., 2009). For example, I grouped the following experiential statements together: "gaining a different perspective," "learning to cherish family," "learning to balance emotions," and "learning responsibility." All of these statements related to each other because they focused on the participants' personal growth related to caregiving. Clustering helped me make sense of the key features of the participants' experiences with caring for their grandparent as a young adult, where they are occupying a role that is not typically associated with this age group (Smith et al., 2009).

In order to effectively complete this portion of the analysis, I created a list of the experiential statements, printed them out, cut them into individual paper strips, and placed them on the floor. This helped me gain a panoramic view of all of the experiential statements and reposition them as I created and organized clusters of experiential statements. Taking from the previous example on clustering “learning responsibility,” I initially placed it with a different set of experiential statements such as “managing responsibilities,” “time management,” “flexibility,” and “making a schedule.” However, after taking a broader look, I moved it into the cluster consisting of “gaining a different perspective,” “learning to cherish family,” and “learning to balance emotions” because this cluster focused on what the participants learned from their experience and how they personally grew whereas the original cluster focused on how they dealt with increased responsibilities. Another cluster I created consisted of “no social life,” “not having time to spend with friends,” “giving up friends/social life,” “fear of missing out,” and “different than peers” since all of these experiential statements focused on the social aspect and impact of caregiving on participants.

Creating Themes

After creating the clusters of experiential statements, I used them to create a table of themes. Each cluster was named as a specific theme that encompassed the main idea of the experiential statements in that cluster (Smith et al. 2009). The table consisted of the theme, the clusters of experiential statements that fell under that theme, and the participant interviews where that theme was reflected (Smith et al., 2009). The purpose of this table was to help the reader and myself understand how the themes were created. Furthermore, the theories utilized to conceptualize this study, Arnett’s Theory of Emerging Adulthood and Role Theory, helped inform the creation of the themes (Arnett, 2007; Creary & Gordon, 2016). Continuing from the previous example, the cluster consisting of “no social life,” “not having time to spend with friends,” “giving up friends/social life,” “fear of missing out,” and “different than peers” was named as the theme of *Social Challenges* since it reflected the social impacts of the participant’s caregiving responsibilities. Another cluster comprised of “lack of self-care,” “don’t want to leave grandparent alone," and "not engaging in activities the participant enjoys" was named as the theme of *Guilt* because it showcased how the participant did not put themselves first and felt badly about leaving their grandparent alone.

Moving onto the Next Case

Once the analysis process described above was completed with the first transcript, I moved onto the second transcript and began with the first step of making exploratory notes. With each new transcript, I aimed to bracket my experience by making notes in my journal about my thoughts about the prior cases, and accumulating thoughts about the cases as a whole. For example, for each case, I made notes on how the participant's behavior in the interview included whether they answered all of the questions, repeated a lot of the same answers for different questions, if they had a good relationship with their grandparent, the level of involvement in their grandparent's care, if they seemed nice and talkative or more reserved in their answers, etc. Making these notes helped me mentally keep each interview separate from one another so I could interview each participant with fresh eyes and avoid carrying over any personal feelings that I may have had with previous interviewees. The analysis process, as outlined above, was continued and repeated until all of the transcripts were analyzed.

Cross-Case Analysis

Once all the transcripts were analyzed, I conducted a cross-case analysis. A cross-case analysis involved reviewing all of the theme tables for each interview and beginning to identify connections, similarities, and differences across them (Smith et al., 2009). From this analysis, group experiential themes emerged that captured the nuances between the individual theme tables and showcased how participants, as group, made sense of their personal experiences. To accomplish the cross-case analysis, I printed out the group experiential themes and looked for similarities and differences across them. If there were similarities, I physically grouped those experiential themes together. For example, one of the themes for this study is *Missing Out on Life*. In creating this final theme, I grouped two clusters together, *Social Challenges* and *Guilt* since both of these clusters spoke to how the participants do not get to live the life they imagined they would, and how they believe they are truly missing out on certain aspects of their lives due to social challenges and feelings of isolation and guilt. When grouping themes together for the final theme table, there was one theme that was different and did not necessarily fit into any group.[1]

Once all of the comparisons were made, I created a final theme table that showcased the overall group experiential themes (Smith et al., 2009). The table included the group experiential themes with multiple individual experiential themes under each theme and examples of these individual sub-themes using words spoken by the participants themselves and the corresponding participation quotations (Smith et al., 2009).

Trustworthiness

In qualitative research, is it important to demonstrate the trustworthiness of the data analysis. There are four principles that help establish trustworthiness including credibility, transferability, dependability, and confirmability (Dabengwa et al., 2020). Credibility refers to how much the findings really reflect what the participants experienced (Dabengwa et al., 2020). To support credibility in my study, I aimed to make sure that the participants' experiences were represented appropriately. I did this by identifying multiple themes, using participants' actual

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[1] This theme was *Emotional Impact of the Diagnosis,* and it focused on how the participants reacted when hearing about the dementia diagnosis. Even though this theme offered valuable insight into the participants' experiences, it did not answer the focus of this study which is the intersection of caregiving for a grandparent while navigating the developmental tasks of emerging adulthood. Therefore, this theme was not included in the final table of themes.

words when creating experiential statements and/or themes, and including direct quotes in presenting the results, in order to highlight participants' voices (Dabengwa et al., 2020). For example, three final themes were created and shaped by using participants' actual words, and each theme and sub-theme was illustrated using direct quotes from the participants.

Transferability is the degree to which the findings can be applied to other contexts (Dabengwa et al., 2020). Transferability is demonstrated by using thick descriptions of the participants, methodology, research question, interpretation of the results, and themes (Dabengwa et al., 2020). This was done by including dense descriptions of how the study was conducted, how the data was analyzed, and how the themes were chosen, so others can understand the context and consider whether these results may apply to other contexts.

Dependability reflects how well the research process is documented is anyone else wanted to follow the same process (Dabengwa et al., 2020). For dependability, I aimed to be as transparent as possible in how I collected and analyzed the data (Dabengwa et al., 2020). I have included explanations of how participants were selected, how the interviews were planned and conducted, and the steps I followed to analyze the data. I also discussed issues that came up throughout this process, such as having to identify and remove potentially fraudulent participants.

Finally, confirmability is how clearly the results came from the participant's responses rather than the researcher's biases or assumptions (Dabengwa et al., 2020). Confirmability was increased via audit trails and reflexivity of the researcher's position by utilizing memos, a reflective journal, and including a reflexivity statement (Dabengwa et al., 2020). Audit trails include describing the decisions regarding conceptualizing the research and collecting and examining data (Dabengwa et al., 2020). The audit trails also support other indicators of trustworthiness. In the case of this study, I kept a journal for field notes and memos. The document allowed me to reflect on my feelings and thoughts about the overall research experience and the individual interviews. It helped me bracket my personal beliefs and assumptions, handle my subjectivity, stay objective throughout the process, and provide an opportunity to separate myself from the participant's experiences (Charmaz, 2014). For example, after the interview with an African American male participant who was caring for his maternal grandmother, I noted that the interview went well overall, he seemed very frustrated about missing out on a social life, stressed about caregiving, school, work, etc., the impact of caregiving on his life, and how his family expected him to full caregiving responsibilities. This helped me separate myself from his experience because I was able to see how his frustrations were similar to mine when I was that age and had to fulfill expected caregiving duties for my grandfather. Strategies I implemented to bracket myself included writing a reflexivity statement that states my history with caregiving, explores the cultural experiences impacting my views, expresses how my background informs my approach and interpretation of the data, and delineates what I hoped to gain from the study (Creswell & Poth, 2016). Keeping a reflective document added to the trustworthiness of the study since it provided additional material to reflect on and a place to practice bracketing (Rossman & Rallis, 2012).

Reflexivity Statement

Every interaction we have requires the self to be present, whether physically, emotionally, or mentally. Therefore, the researcher is part of the process from beginning to end and it is important to acknowledge that position and the biases, assumptions, and pre-conceived notions that exist due to their role (Smith et al., 2009). In IPA research, the researcher is engaged in a double hermeneutic process which can be described as the participants trying to make sense of their experiences and the researcher trying to make sense of how the participants make sense of those experiences (Smith & Nizza, 2022). This means that the researcher's thoughts, reflections, and interpretations are very important to the data analysis process. While practicing this double hermeneutic process, the researcher must also be reflexive, according to IPA (Smith & Nizza, 2022). How a researcher positions themselves in the project and the process they utilize to monitor their impact, such as conveying in specific sections of their study their background, ideas that inform their work, and what they hope to gain from the study are important as well (Creswell & Poth, 2016).

Given the personal nature of the research process, I believe it is important to be passionate about the work you are doing. My personal experiences guided and drew me to my research interests of aging, intergenerational relationships, and caregiving. All my life, I have served as a caregiver to my parents, grandparents, siblings, and my extended family. The identity of a caregiver has followed me from childhood to adolescence, and now into adulthood. Throughout my journey, I have learned how to cope with the struggles and challenges being a caregiver brings into one's life. Being a first-generation college student to an immigrant Indian family has taught me how to balance being a source of support for my family while forming my own identity in society. I like to say that being a caregiver is the story of my life. By being a part of the caregiver community, I have had the chance to interact with other caregivers, of various ages and backgrounds, and I have seen the compassion they have for the people for whom they care. I have also been privy to the challenges they face with other family members, the healthcare system, and larger systemic systems set in place. Seeing these struggles and going through my own problems with similar systems drove my passion to understand caregivers, especially grandchild caretakers who are still trying to make their way in the world. I believed that my experiences and passion would continue to make me excited to conduct and produce research for years to come.

Although my passion for my research was great, it could also be a source of bias in this study. I had innate assumptions, based on my experiences, which I thought could make it difficult to find underlying stories of resilience or to see the small benefits experienced by the participants. For instance, when I thought about this population, I often made the assumption that grandchild caregivers struggled with tasks such as coming of age, deciding on education or employment, navigating friendships and/or romantic relationships, creating a sense of self, etc. In the media and society, your twenties are the time when you have fun, make mistakes, find your identity in the world, and figure out what you want for your future. If caregiving is added to these other tasks, I assumed it became a deciding factor for decisions about relationships, careers, college, etc. While my data analysis largely aligned with my assumptions, it was important that I acknowledged these assumptions, so it did not cloud my judgment when I conducted interviews and analyzed the data.

Chapter 4: Results

The purpose of the current study was to understand how young adult grandchildren, between the ages of 18 and 29, experience the intersection of caregiving for a grandparent with dementia and navigating the developmental tasks of emerging adulthood. By utilizing Interpretative Phenomenological Analysis (IPA; Smith & Osborn, 2007), I explored how these young adult grandchildren experienced the caregiver role while being in a developmental stage that emphasizes the exploration of their identities, relationships, life philosophies, and careers (Arnett, 2007). This study highlights that caregiving is not about checking off tasks, but it is about the relationship between the grandchild and their grandparent. The quality of their connection shaped how the caregiving experience was felt and understood by the grandchild caregiver, which will be discussed throughout this chapter. In this chapter, I report on the demographic characteristics of my sample and the themes that emerged from the data analysis.

Sample Demographics

The sample consisted of a total of 8 participants. Each participant is described in Table 1 below. On average, participants were 23.25 years old (*SD* = 1.85; Range = 21 – 27). Five participants (62.5%) identified as females, two (25%) as males, and one (12.5%) as gender questioning. Three participants (37.5%) identified as White, three (37.5%) as Black, one (12.5%) as Asian, and one (12.5%) as Multiracial (i.e., White and Asian). Most participants reported that they did not have a partner (*n* = 5; 62.5%), while three (37.5%) reported being partnered. Five participants (62.5%) were active, full-time students at various universities, one (12.5%) identified their occupation as a caregiver, another (12.5%) was a manager at their business, and one participant (12.5%) was not employed. In terms of educational attainment, five participants (62.5%) had completed their bachelor's degrees, two (25%) had finished high school, and one

(12.5%) had finished some college but did not receive a degree. Of the eight participants, the majority (*n* = 6; 75%) did not have children of their own and two (25%) had one child.

In terms of caregiving, six of the eight participants (75%) were currently caring for their grandparents. Participants were related to their care recipient grandparents as follows: four participants (50%) were caring for their maternal grandmothers, two (25%) were caring for their maternal grandfathers, and one (12.5%) each were caring for their paternal grandmother and paternal grandfather. Two remaining participants were not actively caregiving for their grandparent. The first participant cared for their maternal grandfather intensely while they were living at home before transitioning into graduate school. The second participant took care of their paternal grandmother during the coronavirus pandemic before their grandmother passed away in the previous year. Seven (87.5%) of the eight participants' grandparents had been diagnosed with Alzheimer's dementia and one (12.5%) grandparent had been diagnosed with Vascular Dementia. Participants reported varying lengths of caregiving. One participant (12.5%) had provided care for 4 months before moving away for graduate school. Two participants (25%) had been caregiving for one year and were still actively providing care at the time of the interview. Three participants (37.5%) had been caregiving for three years and remained actively involved. One participant (12.5%) had provided care for five years before their grandparent passed away in the previous year. Lastly, one participant (12.5%) had been caregiving for 12 years and was still actively involved in providing care. Regarding the frequency of care, four participants (50%) described providing care to their grandparent every day, three (37.5%) reported providing care between two and four times per week, and one (12.5%) five to six times per week. Demographic information about the study sample is displayed in Table 1 and Table 2 below.

Table 1

Participant Summaries (N = 8)

1	Participant #1 is a 24-26-year-old African American male who is single and currently enrolled in college. He lives with his maternal grandmother, who has Alzheimer's Disease, and has been her caregiver for the past three years. He provides care every day and assists with all ADLs and IADLs.
2	Participant #2 is a 21-23-year-old African American female who is single and has finished her bachelor's degree. She lives with her maternal grandmother, who has Vascular Dementia, and has been her caregiver for the past year. She provides care every day and assists with all ADLs and IADLs.
3	Participant #3 is a 24-26-year-old Asian female who is partnered, has finished her bachelor's degree, and pursuing additional education. She lives alone currently but takes care of her paternal grandfather, who has Alzheimer's Disease, and has been his caregiver for the past 12 years. She provides care at least four times a week and assists with no ADLs but all IADLs.
4	Participant #4 is a 21-23-year-old multiracial individual who is questioning their gender identity, partnered, and currently completing their bachelor's degree. They currently live with a roommate. They cared for their paternal grandmother, who had Alzheimer's Disease, for 5 years before she passed away earlier this year. They provided care every day and assisted with all ADLs and some IADLs such as managing medications, cooking, and cleaning.
5	Participant #5 is a 21-23-year-old Caucasian female who is partnered and has finished high school. She lives with her maternal grandmother, who has Alzheimer's Disease, and has been her caregiver for the past year. She provides care every day and assists with all ADLs and IADLs.
6	Participant #6 is a 21–23-year-old Caucasian female who is single and has finished her bachelor's degree and is pursuing further education. She currently lives with a roommate. She intensely cared for her maternal grandfather, who has Alzheimer's Disease, for four months and recently transitioned to caring a couple times each week. She assists with no ADLs but helps with some IADLs such as shopping, cooking, cleaning, helping use communication devices, and transporting.

7	Participant #7 is a 24-26-year-old African American male who is single, has finished his bachelor’s degree, and is currently pursuing additional education. He lives with his cousin. He cared for his maternal grandmother, who has Alzheimer’s Disease, and has been her caregiver for the past three years. He previously provided daily care but now provides care three times per week. He assists with all ADLs and IADLs.
8	Participant #8 is a 27-29-year-old Caucasian female who is single and has finished some college. She lives alone with her son and cares for her maternal grandfather, who has Alzheimer’s Disease, and has been his caregiver for the past three years. She provides care almost every day and assists with one ADL – transferring – and some IADLs such as shopping, cooking, cleaning, and helping communicate.

Table 2

Participant Demographics (N = 8)

Demographics	*n* (%)
Gender Identity	
Female	5 (62.5)
Male	2 (25)
Questioning	1 (12.5)
Race	
Caucasian	3 (37.5)
African American	3 (37.5)
Other	2 (25)
Relationship Status	
Partnered	3 (37.5)
Not Partnered	5 (62.5)
Relationship to Grandparent	
Maternal Grandmother	4 (50)
Maternal Grandfather	2 (25)
Paternal Grandmother	1 (12.5)
Paternal Grandfather	1 (12.5)
Dementia Diagnosis	
Alzheimer	7 (87.5)
Vascular Dementia	1 (12.5)
Occupation	
Student	5 (62.5)
Caregiver	1 (12.5)
Manager	1 (12.5)
None	1 (12.5)
Education	
Bachelors	5 (62.5)
Some College	1 (12.5)
High School	2 (25)
Length of Caregiving	
Less than 1 year	1 (12.5)
1 to 3 years	5 (62.5)
More than 4 years	2 (25)
Frequency of Caregiving	
Everyday	4 (50)
2-4 times per week	3 (37.5)
5-6 times per week	1 (12.5)

The participants varied in the types of care they provided to their grandparents. They reported providing care related to both Activities of Daily Living (ALDs) and Instrumental Activities of Daily Living (IADLs). ADLs are basic self-care tasks such as walking, feeding, dressing, toileting, bathing, and transferring (Pashmdarfard & Azad, 2020). On average, participants assisted their grandparents with 3.88 ADL tasks (*SD* = 2.76), with a range of 0 to 6 tasks. More specifically, five participants (62.5%) helped their grandparents with ADLs such as walking, feeding, toileting, bathing, and dressing. Six (75%) participants helped with all of the previous ADL tasks as well as transferring. Two (25%) participants did not help their grandparents with any ADL tasks. However, these two participants did help with IADLs. IADLs are more complex tasks such as managing finances, using transportation, cooking, shopping, cleaning, handling medications, and helping use the phone (Pashmdarfard & Azad, 2020). In terms of IADLs, on average, participants assisted with 5.88 IADL tasks (*SD* = 1.54), with a range of 3 (from 5 to 8 IDAL tasks). All of the participants (*n* = 8; 100%) helped their grandparents with cooking and house cleaning, seven (87.5%) helped with shopping and communication, six (75%) assisted with managing medication and transportation, and five (62.5%) helped with managing finances. The ADLs and IADLs that caregivers engaged in with their grandparents are outlined below in Table 3.

Table 3

ADL and IADL Caregiving (N = 8)

Activities of Daily Living	*n* (%)	Instrumental Activities of Daily Living	*n* (%)
Walking	5 (62.5)	Managing Medications	6 (75.0)
Feeding	5 (62.5)	Shopping	7 (87.5)
Toileting	5 (62.5)	Cooking	8 (100)
Transferring	6 (75.0)	House Cleaning	8 (100)
Bathing	5 (62.5)	Helping with Communication	7 (87.5)
Dressing	5 (62.5)	Transportation	6 (75.0)
None	2 (25.0)	Managing Finances	5 (62.5)

Navigating Caregiving Responsibilities Amid Developmental Transitions

The overall finding from this research was that young adult grandchildren caregiving for their grandparents experience complex, on-going, and dynamic tensions between the demands of caregiving for their grandparents with dementia and their own developmental tasks of emerging adulthood. Dimensions of this major tension formed the three main themes within the findings. The first theme, *Identity as a Tension Between Autonomy and Dependency*, revealed how participants experienced a strain within themselves, both relationally and emotionally, when trying to figure out how to balance the expectations and demands of being caregiving for their grandparent while also being a young adult. The second theme, *Missing Out on Life*, described how participants experienced social challenges, due to the expectations of caregiving as well as the isolation they felt in their caregiving roles. The final theme, *Growing from the Tension, Visioning the Future Self*, details how the tensions of caregiving shaped how participants conceived of their future selves, as they incorporated their experiences and learnings into their ideas of who they want to be in the future and how they anticipate handling other life challenges.

Identity as a Tension Between Autonomy and Dependency

Participants described how caregiving required them to navigate the tension of balancing caregiving responsibilities (feelings of dependency) with the developmental expectations of emerging adulthood (feelings of autonomy), and that they managed this tension internally, relationally, and emotionally (*n* = 8; 100%). Essentially, participants described a fight between doing the things they want to do or need to do for successful transition into adulthood versus being depended and relied upon by their grandparent with dementia and other family members to fulfill caregiving tasks. Within this major theme, three subthemes will be presented - *Expectations of Self and Family, Making Meaning of the Tension*, and *Emotion Regulation and Coping*. In navigating the tension between autonomy and dependency, the participants described having to deal with internal and familial expectations, learning how to negotiate their caregiving role within their personal lives and within their families, and how they handled these intense issues via understanding how to regulate their emotions by practicing different coping mechanisms.

The tension of autonomy and dependency arose from the differing expectations of their roles as a caregiver to their grandparent and as a young adult. Participants described how they had to be present and helpful for their grandparent since many of them were caregiving every day or almost every day. They helped with various ADLs and IADLs such as transferring, cooking, managing medications, feeding, bathing and many more. One participant, who was a 24-year-old African American male graduate student who had been caring for his maternal grandmother with Alzheimer’s Disease for the past three years, expressed this tension between needing and wanting to help but also missing out on his personal life, illustrating how participants wrestle with the internal expectation to care for their grandparent.

> “I couldn't go to certain events. I had to be home and stay home by a certain time. So, I just felt like my life just became work, take care of my grandma and mom, and that was it. There was no me time.”

This expectation to help and take care of their grandparent was an internal experience, with participants wanting to help and feeling like they were giving back to their grandparent for all the caregiving they did for them when they were younger. However, it was also an external experience, with family members asking and telling the young adult to perform caregiving duties. Participants described how, in their younger years, their grandparent would take care of them, whether it was by babysitting, playing with them, feeding them, sharing stories, etc. Moreover, participants who described having good relationships with their grandparent wanted to help care for their grandparent due to the previous closeness of their relationship. Therefore, when their grandparent’s health declined and they needed help, these grandchildren wanted to repay their grandparent to some extent. The desire to provide care to the grandparent was particularly strong for those grandchildren who had close, positive relationships with their grandparents. Overall, participants described feeling good about giving back to their grandparents but not without experiencing some personal dilemmas. One participant, who was a 24-year-old African American male undergraduate student caring for and living with his maternal grandmother with Alzheimer’s Disease, described the extent to which he goes to make sure he is okay when he has to leave for school, showcasing how he wants to be sure his grandmother is safe.

> “So that's why I actually found that every time I'm out of school, even before going to school in the morning, I make sure I help her. Make sure everything is fine. [inaudible] food in the refrigerator if probably to make something. I make sure her medication, and I

> try to help her set an alarm. Probably she wants to forget her medication. I make sure to set an alarm. I try to volunteer to buy an alarm clock that rings very well. So I set an alarm each time for her to use her medication, even probably I'm in class at a particular time."

Another participant, who was a 21-year-old Caucasian female caring for and living with her maternal grandmother who raised her as a child, expressed how she wanted to repay her grandmother for all that she did for the grandchild when she was little.

> "How I feel since she had took care of me since I was little, I feel like that I have been deserved and been loved by the person that has taken care of me that she actually cares about me. And it's my turn now since she got older. It's my turn to take care of her and start loving her and how she treated me since I was little when she needed me, like I needed her."

In addition to the internal expectation to provide care, participants also shared how some of their family members expected them to help since they lived at home or were perceived as having the time to do so. Furthermore, for some participants this external expectation came in the form of cultural norms of caregiving, such as who should be caring for aging adults in families. A 24-year-old African American male participant, who was caring for his maternal grandmother daily for the past three years until he moved in with his cousin and transitioned to caregiving several times a week, stated how it was culturally expected for him to care for his grandparent which adds onto the external pressure and expectation to perform caregiving tasks.

> "As far as family members, she just really expected everyone to care for her. I think that's like a cultural norm within my race. We just have to take care of our parents and our grandparents and stuff like people that have fallen ill."

Another participant, who was a 24-year-old Asian female pursuing higher education while caring for her paternal grandfather for the past 12 years, described how caregiving responsibilities were handed down to her by her brother, showcasing the familial expectation that she will continue caregiving similar to others in her family.

> "…within my family, my brother used to take care of them as well. But once he moved on to medical school, I kind of was handed down all the responsibilities because I was still at home living with them. And so after that, it was primarily myself that took care of them."

As a young adult in emerging adulthood, they are supposed to be more self-focused, but the expectations of caregiving present a dilemma. Participants described feeling like they have to spend their time and efforts caring for their grandparent due to self and familial expectations, but it leads to having less time and energy to do what they want to do, feeling trapped in their role. Participants expressed how they feel a push-pull tension within their experiences due to competing demands in each role as a caregiver and young adult. One participant, a 21-year-old Caucasian female caring for her maternal grandmother who raised her in childhood, stated:

> "Whenever I leave her house and when she is feeling sick or something like that... it makes me start overthinking and start having panic attack. I feel like I'm the one that's going crazy what if something happened to her."

This illustrates the struggle grandchildren are facing because they cannot leave their grandparent and go do whatever it is they want to do with their lives. They are depended on by their grandparent, so in their caregiver role they are expected to be present both internally and externally.

However, when thinking about the ages and the experiences young adult grandchildren caregivers should or want to have, they cannot do so due an aspect of dependency. Therefore, the tension between wanting to be independent versus being depended upon are at constant odds with each other. For participants, the tension between autonomy and dependence was never fully resolved, since something new (e.g., starting a new job, beginning graduate school, managing care with professionals or family members) was always occurring in their lives. For example, participants described having to negotiate within themselves if they should hang out with their friends or if they should not, or when they would even have the time to hang out with their friends. Many stating that they did not socialize as much due to feeling depended on by their grandparent, creating a tension between wanting to be autonomous to leave whenever but having someone hold them back. To illustrate this on-going tension, and the fact that it was difficult to resolve, one participant, who was a 23-year-old African American female caring for her maternal grandmother for the past year and helping with all ADLs and IADLs, described how she is the sole caregiver and often thinks about her personal life development.

> "I am taking care of her fully, and I am staying with her in her house. So I am in charge of everything. [Inaudible], cooking, the house, making sure that appointments are booked for the doctor. … I can say sometimes I think about my life and how maybe I am going to develop my career. Maybe when I start thinking about looking forward, and I need maybe to make an income or maybe start my own family and all that. So when I think about my life in general, sometimes it gives me worry of how it is going to turn out, how things are going to be for me eventually, or I will spend the rest of my life maybe taking care of her, yeah?"

The challenge of learning how to care for someone with dementia, especially a grandparent, and all of the responsibilities that came along with that, was difficult for many participants. The relationship the grandchild participant had with their grandparent impacted how they completed caregiving duties and their personal desire to do so.

Expectations of Self and Family. Part of the reason for the overarching experience of tension between autonomy and dependence stems from caregivers' expectations of self and family (*n* = 6; 75%). Participants described how their relationships with their grandparent and other family members changed when they began assuming more caregiving responsibilities. Participants described how they switched from being taken care of by their grandparent to now being their carer, making it a new experience for them. The change in roles between the grandparent and grandchild stemmed from multiple reasons such as the grandchild feeling obligated to care for their grandparent because they did a lot for them in the grandchild's youth and the quality of their relationship, an internal expectation. Participants who described having a good or positive relationship with their grandparent in childhood discussed how they wanted to help care for their grandparent due to the closeness in their relationship. None of the participants had particularly negative relationships with their grandparent. Second, the grandchild was the primary caregiver, going to doctor's appointments and making decisions on behalf of their grandparent. Lastly, the grandchildren expressed how family members expected them to manage care responsibilities, an external expectation. More specifically, with the role reversal between grandparents and grandchildren, participants described their desire to fulfill the expectations associated with the role successfully. Some participants described how they did not want to let their grandparents down given how they used to take care of them and how close they were to their grandparent in their youth, demonstrating the internal expectation to give back to their grandparent. To showcase this role reversal, one participant, who was a 23-year-old African American female caring for and living with her maternal grandmother with Vascular Dementia as the sole caregiver, detailed how she is now doing the same things that her grandmother did for her in the past, illustrating how the roles have switched and the internal expectation the participant has to give back to her grandmother.

> "She was the one doing things for me… now it is the opposite. I have to take care of her. I have to be there for her. I have to make sure she has taken her medication, her food."

Participants also experienced the expectations to provide care from external sources, more specifically their family members. In particular, participants described the frustration of having other family members, such as uncles, aunts, cousins, and siblings, expect them to carry out caregiving responsibilities. These family members expected the grandchild to assume these duties for a variety of reasons such as them living with the grandparent, having more perceived time compared to other family members, or not being in school or employed. The caregivers either felt positively or negatively about their familial support. On the positive side, participants described how family members supported them emotionally, physically, and/or financially when they would ask for help. Participants did not rank which type of help they preferred, they expressed just being thankful they could rely on others when needed. A 21-year-old mixed race participant, who had previously cared for their paternal grandmother for 5 years, described the positive experience they had with family when it came to caregiving duties by stating:

> "Aunt Rose would volunteer. My uncle Bob would volunteer. There was no shortage of family members who were willing to step up to the plate if need be."

On the negative end, participants described their experiences with a lack of assistance in caregiving tasks, often leading to feelings of frustration or resentment. The expectation that the grandchild would take care of everything was not discussed nor asked to the grandchild. The lack of help from siblings and other family members adds more responsibilities onto the grandchildren, which can be overwhelming. Another participant, who was a 24-year-old African American male caring for his maternal grandmother for the past three years with all ADLs and IADLs, described this feeling of frustration with family members due their own expectation that the grandchild would do all of the caregiving without any shared responsibility.

> “As far as my cousins, they kind of put this pressure on me to always take care of her, which was really annoying at first because I was just like, ‘Well, what are you doing?’ If I'm doing all of this-- and at the time I was only 21. I was like, ‘You're in your 30s.’ Some of my cousins are in their 40s, so I'm like, ‘What are y’all doing? I cannot be the man of the house right now.”

Having to deal with these self and familial expectations adds onto the tensions these grandchildren feel between autonomy and dependency since they expect themselves to help via feelings of obligation and re-payment but have others setting that expectation for them as well, often leading to feelings of inadequacy related to their personal autonomy. Many participants described feeling bound in this tension since they created or shifted their schedules around their grandparent, could not engage in social activities, and overall felt a lack of balance in their roles as a caregiver but as a young adult. One participant, who was a 22-year-old Caucasian female who provided intensive care for her maternal grandfather before relocating for graduate school shared:

> “It made it more, I guess, not difficult to schedule things, but I had to think more of... 'I can’t. I’m at my grandfather’s right now, and I’m cooking him spaghetti. I can’t leave for another three hours.”

This illustrates how her grandfather needs his granddaughter to help him with things he cannot do on his own, which makes it difficult as a grandchild to be able to do what she may want to do, when she wants to do it, impacting her sense of personal autonomy and further reinforcing the tension between autonomy and dependency.

Making Meaning of the Tension. As a response to managing the expectations participants held of themselves and that were held by their family members, participants attempted to manage the tension between dependency and autonomy by finding meaning in their various roles, both with themselves and within their families (*n* = 5; 62.5%). Many participants reported balancing multiple roles such as a student, worker, friend, partner, etc., in addition to being a caregiver. Therefore, they had to internally negotiate or find meaning in their multiple roles, often leaving themselves feeling overwhelmed by the competing demands. Participants described how they constantly thought about which role to fulfill at what time, weighing which role was more important. This internal negotiation process varied based on the age of the participants. Those grandchildren who were older (e.g., 25 – 29 years) were typically more established in their lives, with stable careers and families, compared to the young participants, who were often in college and still exploring their personal identities. For example, one participant, who was a 27-year-old female, had a stable job as a manager at her company, her own home, and a child, whereas one of the younger participants in the study was a 21-year-old female exploring what she wants to do in life and possibly going to college. The older grandchildren found the role negotiation to be more stable since they were able to better understand and prioritize their responsibilities. This internal role negotiation was experienced as being constant, because participants were thinking about which responsibilities were most important, often dictating where their time and energy should go. This pressure to figure out which responsibility was more important at a given time was a course of significant emotional strain. For example, participants wrestled with possibly leaving their grandparent alone to hang out with their friends or to go to work to provide – all of which are important in their own ways, but the grandchild has to constantly think about which role to prioritize creating a sense of an active renegotiation of conflicting roles. To depict how grandchildren tried to resolve the tension between roles via internal role negotiation, one participant, who was a 24-year-old African American male pursuing an undergraduate degree caring for his maternal grandmother with Alzheimer’s Disease, said:

> “Actually, I would say life, as I've said before, life is like a circle. We actually revolving around it. So for me, going to school, communicating with friends, coming back home, having to take care of my grandma. I've seen these as a day-to-day activities that I enjoy myself. I don't know how to [inaudible]. I'm enjoying myself to do this thing as my day-to-day priorities.”

Participants had various ways to resolve the tension between roles in their lives. For the previously mentioned participant, he understood that caregiving duties, school, and spending time with friends, were all part of his day-to-day life. Other participants expressed how they learned to prioritize themselves by making a wellness plan in order to push through the burnout of various roles. Another participant, who was a 24-year-old Asian female caring for her paternal grandfather with Alzheimer’s Disease since middle school, shared her experience with juggling the different roles she plays in her life such as caregiver, student, and employee. The constant management and competing demands of her different roles made it difficult for her to prioritize her caregiver role at times.

> "Just having all these added responsibilities, it was a lot to deal with. Having academics, working a part-time and a full-time job sometimes, also trying to accommodate with where they need to go... that was challenging."

These caregivers discussed how they would try to resolve the tension by advocating and prioritizing themselves in response the new role of caregiver they are embodying in their families. Participants went from being a simple grandchild to now being a caregiver to an adult. Grandchildren expressed their internal battle with caregiving to their grandparent out of obligation or personal expectation while trying to be a student, friend, employee, etc. However, this responsibility and role change can become tiring due the constant back and forth in how grandchildren are making meaning of the different roles in their lives, learning which one to prioritize and possibly how to re-story their role. One participant, who was a 27-year-old Caucasian female who had one son and had been caring for her maternal grandfather with Alzheimer's Disease for the past three years, mentioned how she behaves in very similar ways as a manager, caregiver, and mother illustrating that she can think about those relationships similarly on a certain level, almost being able to find the same meaning in all three roles, which is learning about them and their triggers.

> "I'm a manager at work... Learning someone and what is going to upset them, not upset them, how to bring things up that are hard to talk about, things like that, which is definitely something that you have to do with my grandfather. And while sometimes you can know what's going to upset him by what you're saying, sometimes you don't. And sometimes you're trying to figure out what did upset him. So very similar there. And then caring for my kid. It's very similar to-- because he's, like I said, a lot more like a toddler."

Another participant, who was a 24-year-old Asian female student in higher education caring for her paternal grandfather who cared for her in childhood, expressed during the interview how being a caregiver in addition to the other roles she has in her life, such as student and employee, can take a toll on her mentally and emotionally. Therefore, she mentioned that she has to think about how to balance the roles and emotions with being a good caregiver.

> "I overbear myself with every responsibility that I need to have. And then I feel like I'm not the best caregiver if I don't get something done for them."

The attempt at trying to find internal meaning in the various roles that participants play in their lives, in addition to being caregivers, was a complex one. Participants tried to resolve the tension of autonomy and dependency by attempting to prioritize and advocate for whichever role was important at a given time.

Emotion Regulation and Coping. Another way that participants attempted to resolve the tension between autonomy and dependency, the expectations placed on themselves internally and externally and being able to find meaning in their multiple roles, was learning how to regulate emotions (*n* = 5; 62.5%) and practice various coping skills (*n* = 8; 100%).

Participants went through a range of emotional highs and lows as they navigated their caregiving responsibilities. They expressed initial sadness, fear, and uncertainty upon learning about the dementia diagnosis which contributed partly to the tension they felt. This tension was also increased as the dementia progressed, and the participants saw how their grandparents were changing. One participant, who was a 21-year-old mixed-race individual in undergraduate school, who cared for their paternal grandmother for 5 years before she passed away, shared:

> "One thing I remember when I was younger was when I would give her hugs to say goodbye, they would always be like, "Don't squeeze too tight," because I would always

> try to hug her with all my might. But now that I was taking care of her and she was older, I'm always like, "Oh, my gosh. She is so fragile. I am so scared." And so the fragility wasn't something that I associated with her before. And it really didn't feel like she knew what was going on a lot of the time. And previously, before her dementia diagnosis, I was always like, "Wow, she knows everything. She's so smart." But then she couldn't remember things anymore, and she stopped being able to communicate as well. And so that sucks."

Another participant, a 23-year-old African American female who identified caregiving for her maternal grandmother as her job, stated:

> "I felt bad at first. I was not sure if she was going to be able to make it through the condition. I was wondering how things are going to be for her."

Both of these instances showcase how emotional it was for participants to find out that the grandparent who took care of them when they were younger was now facing a disease, where one day even they might be forgotten. The emotional reaction to the diagnosis partly contributed to grandchildren's tension between autonomy and dependency because it fostered an emotional obligation to stay and help when they could be doing other things.

In addition to their initial reactions and responses to the dementia diagnosis, the grandchildren had to learn how to regulate their emotions in times of high stress or feelings of being overwhelmed. Learning to be patient was a shared experience among the participants as a way to regulate their emotions. Participants described how it was difficult for some of them because they did not practice it to such a degree before assuming caregiving duties. Being patient was important during times their grandparent would lash out at them or when they did not how to respond to their grandparent. One participant, who was a 22-year-old Caucasian female who cared intensely for her maternal grandfather before moving away for graduate school, shared:

> "I think it made it to where I had to learn more patience and more emotional control because I can't fight with him on stuff." "He would get mad at me more recently... I have to kind of just walk away from it and deal with it somewhere else because I don't want him to see that he's upset me." "So being helpless honestly felt like I was trapped in my own body of I have to keep all this in and not let you see that I'm upset because then you'll be upset, and we won't be able to communicate why."

These instances demonstrate how participants made sure not to blame their grandparents for the emotions they experienced related to caregiving. These grandchildren learned to walk away, brush things off, talk with other family members, and practice patience when their emotions get heightened by their grandparent's behaviors, so their responses are not hurting their grandparents. Over time, grandchildren caregivers developed emotional regulation strategies to manage stress, sadness, and frustration, which contributed to the development of a variety of coping mechanisms to help with these complex emotions.

Given how caregiving is an emotional, mental, and physical toll on a caregiver's health and how grandchildren caregivers wrestle with the tension between autonomy and dependency, young adults described finding ways to take care of themselves. Grandchildren caregivers looked for emotional support from family or professionals, learned to shift their expectations of caregiving, and tried to practice self-care. Typical coping mechanisms participants described were watching television, reading, going on walks, playing video games, listening to music, going to therapy, and praying. A 21-year-old Caucasian female, who was providing daily IADL and ADL care to her maternal grandmother, described during the interview how she wanted to give back to her grandmother because of everything she did for the grandchild in her youth but there were challenging days, especially when she also has to take care of her child simultaneously. She stated that prayer was an important coping skill for her since it helped gather strength to keep going and advocating for herself when she needs help from other family members.

> “What I like to do for myself is to go to church and study Bible to be with God... He can help me out, make it through it.”

Another participant, who was a 23-year-old African American female caring for her maternal grandmother without much help from family or professionals, shared:

> “I used to see a therapist, and my mom was helping me during the weekends, and I would go to hang out with my friends, and I would recharge that way.”

Practicing self-care coping strategies, helped the grandchildren manage their emotions of frustration, overwhelm, sadness, etc. and cope with the tension of wanting to be autonomous but are depended on by their grandparent. If they did not cope with their emotions, participants described feeling like they were going to “lose it”, “it” being their sanity in these high stress experiences. Not being able to regulate their emotions took a toll on the grandchild’s mental health since they are also struggling with the tension of wanting to be independent. Since most participants described not being able to leave whenever they wanted to, creating a feeling of being trapped, it was important these caregivers learned how to manage their emotions.

In addition to the self-care practices, participants attempted to find small moments of joy in caregiving such as valuing the times when their grandparent was happy, or the grandchild was able to have a real moment with their grandparent similar to how their relationship was before they were diagnosed. To showcase how young adults find joy in the small moments, one participant, who was a 22-year-old Caucasian graduate student who now provides occasional care, but previously cared daily for his maternal grandfather for several months before moving away for college, stated:

> "The easiest were the times when he just would want to have a funny conversation. He always would try and do little jokes or something... and he would look at you and crack a grin and just go, 'I'm just kidding.' Then you knew it was okay to laugh... So those good times when he would actually just want to talk to you... those were great."

Practicing these coping skills helped these grandchildren deal with the tension they feel when wrestling with their autonomy and dependency.

Missing Out on Life

The second theme revolved around how participants experienced missing out on their lives as an emerging adult (*n* = 8; 100%). Within this major theme, two subthemes will be presented – *Social Isolation* and *Feelings of Guilt*. As previously mentioned, emerging adulthood is a time where young adults are deciding who they are, what they want to be, focusing on themselves outside of parent- or school-directed routines, testing all sorts of possibilities, etc. However, for these participants, the added demands of caregiving for their grandparent with dementia limited how much they could engage in those possibilities. Participants mentioned how they do not have a well-rounded social life due to the lack of time to spend with friends or potential significant others reinforcing how they are missing out on the social aspect of their lives compared to their non-caregiving peers. Grandchildren explained how they could not travel or leave the house freely compared to their peers, leading to feelings of isolation and difficulty maintaining friendships and relationships. Participants described their circumstances of really missing out on parts of their lives as frustrating since they could not do what they wanted to for themselves when they wanted to do it. To give a general snapshot of the experience participants suffer within their social life and their times of missing out, a 24-year-old African American male caregiver for his maternal grandmother for the past three years, now pursuing a graduate degree voiced:

> "None of my friends are going through this. They get to live their lives. They get to go to work and party and have fun. Not that I want to party, but I want to do something. I feel like I should be able to do it when I want to."

Social Isolation. Part of what made the sense of missing out so real for grandchildren caregivers was seeing how they cannot do what their non-caregiving peers can do – who are free to be independent and autonomous, without having anyone depend on them for care. The other part that created this sense of missing out is feeling socially isolated in their caregiver role. Most participants did not have friends that shared the same experience of caring for their grandparent so grandchildren expressed how they could not share their feelings with them since they would not understand what the grandchild was going through. Many participants described feeling socially isolated because taking the time to hang out with their friends or just do anything fun was rare for them. Participants described how it was a battle of "Do I go and have fun while my grandparent may be lonely, or do I sacrifice my desires to be present for my grandparent?"

Moreover, these participants cannot leave whenever they want and go do whatever they wish to do because they have their grandparent relying on them for basic self-care tasks so if they wanted to go spend time with friends, they had to make sure someone else will come to help or make sure their grandparent has everything they need for the time they are gone. One participant mentioned putting cameras in the home for when they are gone so they can check on their grandparent to make sure everything is okay, illustrating the lengths grandchildren went to ensure their grandparent’s safety so they could leave for some time and be socially active. A participant who was a 24-year-old Asian female caring for her paternal grandfather for the past 12 years assisting primarily with IADLs shared how she has to adjust her schedule to center her caregiving responsibilities, often rescheduling or cancelling time scheduled to hang out with friends.

> “…, but just not having time for maybe hanging out with my friends in the evening. When I get home from either class or work at 5:00, I come home, and there's always a list of, ‘Oh, hey, I need to do this. I need to go here. I want to go there.’ And then I have to shift my plans with maybe going out to dinner with a friend or just hanging out with my parents or doing something for my parents. So socially, it has impacted as in having to shift my schedule around for whatever they might need to get done.”

Another participant, a 23-year-old African American female sole caregiver to her maternal grandmother for the past year described how she does not have time to socialize with caregiving duties but feels like she should give her age.

> “I do not really have enough time to hang out with my friends and socialize with everyone. Maybe go out on parties. I sometimes feel that I am young and maybe I should be out there living in my life, enjoying, yeah?”

These instances showcase how grandchildren really do miss out on the opportunities to socialize with their friends due to the extent of their caregiving responsibilities. Watching the world and their non-caregiving peers live their lives instead of worrying about or focusing on being there for a dependent, more specifically their grandparent. Missing out on the social aspects of their lives fostered feelings of frustration in many grandchildren, ultimately highlighting the tension between autonomy and dependency.

Feelings of Guilt. When participants sough to prioritize their own desires, often times they felt guilty (*n* = 3; 37.5%). Grandchildren wanted to take time for themselves, go out with friends, engage in self-care, etc. However, due to the caregiving responsibilities and duties they carry, participants reported not doing those things because their grandparent was reliant on them. If they did use the time they would be caring for their grandparent for themselves, they felt selfish and guilty. The selfishness and guilt stemmed from the feelings of obligation and personal desire to help their grandparent, especially in the grandparent-grandchild relationships where the grandparent took care of the grandchild in their young years and had a positive relationship. The participants who had a positive relationship described how emotionally and/or physically close they were with their grandparent growing up. Their relationship was typically loving, caring, and fun. To illustrate how participants felt guilty about the way they had to treat their grandparent due to their increasing needs of care, one participant, who was a 27-year-old Caucasian female caring for her maternal grandmother for the past three years, and helping with transferring, cooking, cleaning, communicating, and shopping, said:

> "I mean, it's definitely changed a lot, and it's something that I kind of feel guilty about because he's not an adult anymore and definitely not my grandfather that I grew up with. I treat him a lot more like I treat my toddler. And that's not necessarily a bad thing. That's because that's what he needs right now at this stage in his life. But it is sad because that's not who he always was."

Another participant, who was a 22-year-old Caucasian female caring for her maternal grandfather, with whom she shared a close relationship, described how she felt when she moved away for graduate school:

> “I feel more guilt a lot of times about leaving home because I’m not 20 minutes down the road. I’m four hours away.”

The feeling of missing out on their lives was exacerbated by these feelings of guilt. Participants operated under expectations set by themselves and family members and are depended on by their grandparent to fulfill caregiving duties. Moreover, the relationship these participants have – being a grandchild caring for their grandparent – makes the guilt worse for them because they feel personally obligated to stay and help. Therefore, when they begin to think about ways they can prioritize themselves, guilt kicks in because they “should” be caregiving, and they “should” be present for their grandparent.

Growing From the Tension, Visioning the Future Self

The third theme related to how, as participants were navigating the demands of caregiving for a grandparent, they were also learning about who they are going to be in the future ($n = 8$; 100%). All of the participants described facing significant challenges but also reflected on their experiences as opportunities for personal growth. Within this major theme, three subthemes will be presented – *Shifting Perspective on Aging, Sense of Resilience,* and *Impact on Future Planning.* These subthemes outline the different ways the participants grew from their experiences of caregiving to their grandparents.

The overall theme of, *Growing From the Tension, Visioning the Future Self*, represents how grandchildren shifted in their experiences. This experience was not only influenced by their caregiving role but also marked by key aspects of their overall developmental journey, shaping their understanding of themselves and their relationships with others. As they navigated their caregiving responsibilities, they tried to understand who they are and what they value. Participants discussed how they are taking their learnings from their experiences and incorporating them into defining their future self, in terms of understanding aging, dealing with other challenges, and deciding on their education and/or career choices. To showcase the overall experience of how they have grown in their experiences, a 24-year-old African American male who has been caregiving for his maternal grandmother with Alzheimer's Disease for the past three years—providing support with all ADLs and IADLs—while in graduate school shared:

> "In ways I've learned to be more patient... but also more kind and more generous to myself... I'm learning myself while also learning other people... just learning how to navigate through different challenges that arise."

Participants were growing from the tension by deepening their sense of empathy and cultivating a heightened sense of responsibility. Through this experience, participants were learning to be more empathetic towards their grandparent and even themselves. Learning to give grace for all the hard work they are doing while being there for their grandparent even when they feel like they want to give up. Another participant, a 24-year-old African American male undergraduate student caring for his maternal grandmother for at least three years shared:

> "I believe I get to know how to relate well with people, even much more with elder people. You understand? Because I know when people grow old, the way you interact with them is different from the way you have to conversate with someone of same the age."

Furthermore, related to the tension young adults face in their lives, many grandchildren were learning how to manage the increased responsibilities that came with caregiving. Before they became a caregiver, participants stated they would help with common household chores or volunteer with certain caregiving duties, but it was not their official responsibility. Now, participants are learning to be flexible with their plans, managing their time wisely, and creating their schedules with their grandparent in mind. One participant, who was a 27-year-old female caring for her maternal grandfather with Alzheimer's Disease for the past three years explained:

> "So there was a period of time where he was in and out of the hospital a lot. And I did had to rearrange my work schedule. I had to leave work just unexpectedly in the middle of the day a couple of times just so I could go to the hospital with them or help them take care of the house."

This is a major shift compared to before stepping into the caregiver role, when participants could prioritize their personal needs and desires. Now these participants are having to prioritize their grandparent to make sure they were properly supported.

Shifting Perspective on Aging. Through their caregiver role, participants began to alter their views on the aging process (*n* = 5; 62.5%). Participants described how they did not really think about getting older and how life would look for them but caring for their grandparent is offering a new perspective about aging. Participants expressed that their experiences gave them a newfound perspective on aging, health, and the fragility of life, fostering a deeper appreciation for their loved ones. For example, some participants shared how they did not realize how fragile memory can be and that it can go away so quickly. Their experiences in their caregiving responsibilities also are reshaping their understanding of aging and mortality, prompting them to view these aspects of life through a more complex and often challenging lens. More specifically, many participants stated how getting older feels scary now whereas before it felt like a natural process. To exemplify how young adults may continue to shift their perspective on aging, one participant, a 24-year-old Asian female who had spent 12 years caring for her paternal grandfather with Alzheimer's Disease, expressed:

> “It has helped me realize not everyone is independent their whole life. And someday I might be dependent on someone and how that would make me feel versus how I need to be better about making them feel towards taking care of me maybe in the future, what to watch out for, or some aspects of caregiving to keep in mind. That's definitely given me a better perspective while taking care of my grandpa.”

Another participant, a 27-year-old Caucasian female who is a parent and employee, and has been caring for her maternal grandfather for the past three years, stated:

> “Once you've seen someone that's really close to you in your life start to have issues, no matter what they are, health issues, memory issues, it can definitely make you think about-- it's so easy to think your grandparents, your parents are going to be there forever, but they're not. So it's definitely made me prioritize spending time with my family more as opposed to any other myriad of activities I could choose to do…”

Both of these perspectives depict how participants are experiencing shifts in thinking about aging, both positively and negatively. The first participant illustrated the more negative perspective, by describing how seeing their grandfather dependent on them made them wonder what will happen to themselves as they age. In contrast, the second participant expressed how they learned to value their time with their loved ones and prioritize family first. Caregiving provided grandchildren a new outlook on aging that is impacting their thoughts now and may guide how they approach the future.

Sense of Resilience. Despite the difficulties participants faced, they cultivated resilience by discovering a deeper sense of meaning in their caregiving role. All of the participants ($n = 8$; 100%), described finding strength in their caregiving experiences which helped them build a sense of resilience as they learned how to deal with other challenges such as stress, tough situations with family members, and their grandparent with dementia. These young adults explained how to they are learning to be strong through their experiences, especially in times when they have no additional support. Practicing patience and trusting they can push through the tough times and what they are doing is to the best of their ability is helping these grandchildren believe they are a resilient person. It goes beyond learning how to simply cope with their stressful circumstances by practicing self-care, rather participants are learning how to adapt to this new situation and new role in their lives by continuing to care about their grandparent and learning to be patient in their responses to their grandparent. To demonstrate the sense of resiliency of young adult caregivers, one 21-year-old mixed race participant, who was exploring their gender identity and pursuing a bachelor's degree while caring for their paternal grandmother before her recent passing, shared:

> "That experience kind of helped me realize that dealing with people, trying to make sure that they get that sort of quality of care was something that I wanted to do. And that I might feel like I'm out of depth the whole time, but it's still something."

This instance illustrates that despite feeling overwhelmed, the participant continued to fulfill caregiving responsibilities and even thought about their future goals. This shift demonstrates that the participant develops a sense of resilience through growth.

Impact on Future Planning. The responsibilities of caregiving played a significant role in shaping participants' future life choices, influencing their career aspirations, personal relationships, and long-term goals (n = 5; 62.5%). For some participants, the demands of caregiving required them to postpone or alter their educational and professional trajectories. Participants described how they chose to go to university in their local town, postponed starting graduate school, changed their majors in college, and lived at home instead of moving out of state. To illuminate how caregiving significantly impacts young adults' futures, one participant, who was a 21-year-old mixed race individual who had cared for their paternal grandmother for five years, described a major shift in their career path when discussing how caregiving changed them. The participant expressed, as evidenced below, how they changed their college major to human development from computer science after realizing through their caregiving experience how inequalities exist in quality of care.

> "Initially, when I came into [University], I was a computer science major. And so I've since switched to human development... I want to make sure that people get that quality of care."

Another participant, who was a 27-year-old Caucasian female caring for her maternal grandfather while balancing working as a manager and being a mom, shared during the interview her choice to stay close to her family. She described how actively caregiving to her grandfather and seeing the progression of his dementia changed her perspective on the future and she was learning the value of family in her life.

> "I would probably choose to stay here or within a close distance to them."

These grandchildren are prioritizing their relationship and caregiving responsibilities with their grandparent over personal aspirations, reflecting the bond and loyalty grandchildren have with their grandparents. These experiences of rethinking their careers and choosing to stay close to home illustrate how complex the caregiving experience is for the participants. Instead of thinking only about their personal wishes, they were choosing to think about their grandparent and their needs. Grandchildren's roles as a caregiver are not separate from who they are becoming in their future, rather their experiences are integrating into how they see themselves and how they stay connected to their grandparent.

Chapter 5: Discussion

This study aimed to explore how young adult grandchildren, between the ages of 18 and 29, navigated the intersection of providing care for a grandparent with dementia and the developmental tasks of emerging adulthood. Interviews were conducted with eight young adult grandchildren who were either currently caregiving or had previously cared for a grandparent with dementia. The findings revealed three central themes: (1) identity experienced as a tension between autonomy and dependency, (2) missing out on key aspects of life due to caregiving, and (3) personal growth that emerged from navigating this tension, which shaped how participants envisioned their future selves.

Identity as a Tension Between Autonomy and Dependency

A central finding of this study was the ongoing, internal and relational struggle the grandchildren caring for their grandparents experienced as they attempted to navigate the demands of their caregiving roles and the developmental expectations of emerging adulthood. Previous research has demonstrated that caregiving can interfere with the typical experiences and tasks of young adulthood, but this study adds an additional layer to the intersection of development and caregiving from a grandchild caregiver perspective (Del-Pino-Casado et al., 2019; Levine et al., 2005). This study showcases that grandchildren who are caregiving to their grandparent and who are also a young adult experience an interference when managing their caregiving responsibilities and an on-going tension within their experiences. This tension is marked by the continuous push-pull between wanting to be independent and autonomous and feeling depended on by their grandparent. This push-pull happens when the grandchild desires to pursue personal aspirations such as moving away from home or simply hanging out with their friends whenever they want and the sense of obligation they feel from the internal and external familial expectation to be present for and available to their grandparent. In this study, it was found that participants were not just adjusting their developmental trajectories as caregiving grandchildren, but they were actively trying to fulfill multiple roles at once, often feeling emotionally and physically stretched.

In the process of navigating this tension, participants engaged in a constant meaning making process. These grandchildren caregivers were trying to speak up for what they needed while still meeting the caregiving expectations set for them by other family members and themselves. This process of finding meaning in the various roles grandchildren caregivers occupy in their lives has received limited attention in the current caregiving literature. Previous research on young caregivers has often depicted them as either burdened or heroic, but this study reveals a third narrative – one of internal sense-making (Smyth et al., 2011). For example, some participants advocated for more support, questioned their families' distribution of responsibilities, and wrestled with internal guilt when prioritizing themselves. These experiences suggest that caregiving for a grandparent as a grandchild is not simply a feeling of being overwhelmed. This experience is complex, dynamic, emotionally draining, process of their personal identity development.

Role theory offers a helpful lens through which to understand these findings, since the data clearly demonstrate that the young adult grandchildren were simultaneously experiencing role conflict, role strain, and even role overload (Biddle, 1986). Participants described being pulled in multiple directions (role conflict), in the context of their roles as students, employees, and caregivers, leading to exhaustion, frustration, and emotional tension. One participant defined this conflict by comparing caregiving to "having three full-time jobs." This illustrates role overload, where the demands of multiple roles exceed the individual's capacity to meet them

(Goode, 1960). The participants often discussed feeling the need to fulfill their caregiving role fully and, while doing so, other roles such as being a friend or even a student would suffer. In addition to feeling role overload, participants also dealt with role strain when they had to manage conflicting values and expectations that came with being a grandchild caregiver. For example, while autonomy and identity exploration are core developmental tasks in emerging adulthood (Arnett, 2000), caregiving requires emotional labor, time commitment, and often sacrifices that directly impact those same tasks. For participants in this study, they expressed feelings of frustration when it came to being independent because their time and efforts were primarily occupied by completing caregiving responsibilities, not leaving a lot of time to do what they wished to do for themselves. This frustration was exacerbated by the grandchild-grandparent relationship since many grandchildren reported feeling obligated to help their grandparent. Participants described how their grandparent took care of them when they were children so caregiving for them during this time is a way they can repay them for all they did in the past.

The findings in this study also contribute to the emerging adulthood literature, specifically concerning the developmental task of independence which is a core feature for this stage of life. Emerging Adulthood theory (Arnett, 2007) describes how this life stage is characterized by identity exploration, focusing on the self, and feelings of instability. However, participants in this study expressed a different developmental pathway, not because of their personal failures to make a successful transition into adulthood but due to their commitment to caregiving for their grandparent. As described by the participants in the study, they are living a different version of emerging adulthood, which is shaped by responsibility rather than exploration. This reframe of living a different version of emerging adulthood offers a more layered view to a unique developmental period because it shows that these caregiving grandchildren are not growing up by exploring their freedoms but through the weight of their role.

Another topic that came up was how important emotion regulation was in dealing with the constant tension between wanting independence and being depended on by their grandparent. Participants reported many ways they coped with overwhelming feelings, such as walking, watching tv, praying, and going to therapy. These strategies were not simply coping mechanisms for handling role conflict and overload, they were ways the participants stayed resilient in their experiences. This finding is similar to and extends existing research on young caregivers' emotional coping. It builds on Becker's (2007) work, which highlights how young caregivers often take on significant emotional labor as part of their unpaid caregiving roles and they develop coping strategies out of necessity. However, this study adds in the developmental layer, which is not typically attended to in the caregiving research, because participants were not only learning how to cope emotionally with their role as a grandchild caregiver, they were doing that while also trying to be a young adult. Rather than avoiding or minimizing their caregiver role due to the stress of it, participants were trying to find ways to regulate their emotions in their experiences. This suggests that identity development is not hindered by caregiving but shaped by it. This idea also echoes what Fruhauf et al. (2006) found in their study on grandchild caregivers. Participants in that study described similar emotional and practical challenges in the grandchild's caregiving experience but also found that grandchildren found a deep sense of meaning in their caregiving relationship. The researchers noted how caregiving was not something the grandchildren dealt with, but it was an experience they make sense of in their own way. This study builds on that by showcasing how this meaning-making process is tied into identity development within the tension of autonomy and dependency. For these participants, caregiving did not delay their development into adulthood, it becomes part of that process. Furthermore, Fruhauf et al. (2007) found that grandchildren caring for their grandparents reported stronger emotional bonds with their grandparent, while this was not explored in the study, a few participants described how they bonded more with their grandparent after they bean caring for them more often. The type of relationship between the grandparent and grandchild impacted how much the grandchild wanted to help, felt obligated to help, and how they found meaning in their role as a caregiver. Most participants described having good relationships with their grandparent, so caregiving was not a burden per se, but it was challenging and demanding given their age range.

The tension between autonomy and dependency does not simply go away, these participants learn to work through it and let it shape who they are becoming.

Missing Out on Life

The theme of *Missing Out on Life* reflects a distinct and often underexplored dimension of grandchildren caregivers, namely the emotional toll of feeling socially isolated and the guilt felt in their caregiving journey. Participants consistently shared how they felt a sense of loss and missing out, not just of time and freedom, but of the typical experiences that usually come with emerging adulthood such as traveling, spending time with friends, exploring academic interests, and building romantic relationships. While previous research on young caregivers has documented disruptions to education and social life, this study extends a more emotionally charged layer of that disruption (Becker, 2007; Levine et al., 2005). Participants did not simply report missing out on their lives, but they described the emotional toll of watching their peers move forward in their lives while they were occupied with caregiving responsibilities. Grandchildren reported feeling frustrated and sad about missing out on different social activities compared to their non-caregiving peers. They always had to prioritize their grandparent in their daily schedules which meant skipping get-togethers with friends or having to reschedule, ultimately impacting their friendships for some participants. Grandchildren caregivers shared feeling stuck in a place that did not match where they thought they would be at this stage in their lives.

This feeling of missing out is deeply entangled with the developmental tasks associated with emerging adulthood. According to Arnett (2000), this life stage is characterized by identity exploration, instability, and self-focus, all of which require time, space, and a degree of independence. Caregiving, by contrast, brings structure, responsibility, and relational dependence by the participants' grandparents. What emerged in this study is that participants experienced a sense of missing out in their lives because they directly experienced the daily reality of caregiving and how it can impact one's life. One caregiver shared how their friends can leave whenever they want to do and do whatever they want to while they had to coordinate caregiving coverage just to leave the house. This experience captures how the feeling of missing out was not just hypothetical but really happening for the participants.

This feeling of missing out on life was also deepened by the social isolation the participants felt in their caregiving experiences. Participants reported feeling distant from their friends, not because they did not care about them, but because they did not have the time or energy to maintain them. Also, many participants described how their friends did not understand their experience of caregiving because they were not caregiving, so it was difficult to share their feelings and frustrations with them. Due to their caregiving responsibilities, grandchildren caregivers had to prioritize their grandparent over their personal desires to hang out with their friends. Fruhauf at al. (2006) also found that caregiving grandchildren reported similar feelings of social isolation due to the demands of caregiving. This social isolation exists for these grandchildren caregivers, especially when they see their peers socializing and living their lives without having to think about anyone.

Furthermore, participants' feelings of missing out were intensified by feelings of guilt, especially when they attempted to prioritize their own needs over caregiving duties. This aligns with past studies that have shown young caregivers often experience emotional ambivalence such as feeling pulled between love and obligation and care and resentment (Kavanaugh et al., 2016; Marques et al., 2024), However, the findings in this study offer a more nuanced view where the guilt is not just about stepping away from caregiving duties, but about wanting a life outside of those duties (Marques et al., 2024). Participants wrestled with questions like, "Am I selfish for wanting to go out?" or "Is it wrong to want a life that looks more like my peers'?" These questions and the guilt stem from the expectations and obligations they feel in their lives concerning the dependency aspect of caregiving.

Emerging adulthood theory helps explain why these conflicts of being socially isolated and dealing with feelings of guilt are particularly significant for this age group. Arnett (2004) emphasizes that one of the central features of this stage is feeling "in between," where one is no longer an adolescent, but not yet fully an adult. For caregiving grandchildren, this sense of being "in between" is intensified by their unusual responsibilities of caring for their grandparent. These caregiving duties make them different from their peer group. This difference can contribute to feelings of social isolation since they are not engaging in the same ways as their peers. When participants do try to indulge in their desires, guilt kicks in. The guilt is rooted in wanting to be present for their grandparent and not let them down but also wanting to be independent.

Importantly, this study adds depth to the caregiving literature by highlighting that young adult grandchildren caregivers are not only navigating losses related to time or opportunity but also in terms of belonging. They often feel out of sync with their peers and disconnected from the cultural expectations that typically define their life stage. These caregivers are occupying off-time roles, which can be described as fulfilling a role that is not typically associated with the life stage of young adulthood (Neugarten et al., 1965). Most young adults are finding employment, going to school, travelling, forming romantic relationships, etc. but these caregiving grandchildren are busy taking care of their grandparents. They are managing medications, coordinating care, and staying at home to be there for their grandparent. Unlike older caregivers, who are often socially supported or societally acknowledged in their caregiver roles (Del-Pino-Casado et al., 2018), these grandchildren caregivers are sometimes met with lack of support from family and/or professional help. This lack of help with caregiving duties can increase young adult grandchild caregivers' feelings of missing out because they are giving up their time and desires and truly missing out on different aspects of their lives due to caregiving responsibilities.

Growing From the Tension, Visioning the Future Self

The final theme, *Growing From the Tension, Visioning the Future Self,* captures the transformative potential within the caregiving experience for emerging adult grandchildren. While much of the caregiving literature has focused on burden, stress, and developmental disruption for young caregivers, participants in this study also discussed the unexpected personal growth that came from caregiving (Levine et al., 2005). For example, any participants described how, as a result of caregiving, they gained a sense of purpose, patience, and inner strength they did not know they possessed. These findings align with previous research that explored caregiving as not only a strain but also one of positive meaning-making and identity development (Roth et al., 2015; Fruhauf et al., 2006). This study offers a more refined understanding of how the meaning making process is shaped by the developmental complexities of emerging adulthood and the relationship between the grandparent and grandchild. As these young adults try to develop their identity and become more independent, caregiving responsibilities are intertwined into that identity development. For example, one participant switch from a computer science major to human development after seeing the lack of quality of care concerning caregiving, an issue she may not have known about if it were not for her direct experience of caregiving for her grandmother. In addition to the developmental tasks, the relationship between the grandparent and grandchild is also vital in shaping what meaning grandchildren caregivers obtain from their experiences. Extending beyond the emotional connection and feelings of obligation to help, some participants described how it was expected of them to help from family members and culturally. The caregiving responsibilities were handed down in some cases from one sibling to another and in others, family members assumed the grandchild would take care of their grandparent due to proximity, having more free time, and/or not having a job or school to attend. Learning how to navigate the expectations to care for their grandparent, the obligation they felt, and the personal desire to help all contribute to how young grandchildren caregivers are thinking about who they want to become in the future.

Importantly, participants' reflections on their future selves were shaped by their caregiving experiences, not despite it, but through it. This adds a unique contribution to the existing literature by emphasizing the ways caregiving may influence future planning and identity development. Most caregiving studies on caregivers in general focus on present burden or past sacrifice but this study centers on how caregiving changes the grandchildren caregivers’ future orientation. One participant described rethinking their career trajectory to stay close to family; another mentioned how caregiving reshaped their understanding of what it means to grow older. These reflections show that, for many young adult caregivers, their experience of caregiving to their grandparents is laying a foundation for who they are becoming in the future.

According to emerging adulthood theory, emerging adulthood is marked by exploration, instability, and the active shaping of future identity (Arnett, 2004). Participants spoke of becoming more empathetic, practicing patience, developing stronger coping mechanisms, and shifting their perspectives on aging, responsibility, and life priorities. Previous research completed by Fruhauf et al. (2006) found similar positive outcomes such as increased empathy and a stronger sense of purpose. The direct impacts of caregiving to their grandparents reflects a deeper integration of caregiving into participants' future identity narratives suggesting that, for many grandchildren, caregiving is not just a disruption or pause in their developmental growth. These grandchildren are caring for someone who they have a relationship with and that bring a different perspective into play compared to caring for someone they do not know. The type of relationship, close or distant, can impact how the grandchild feels about caregiving and how they actually execute caregiving tasks. Therefore, understanding the nuance of the grandparent-grandchild relationship is important since it impacts the overall experience for grandchildren caregivers.

Role theory also helps make sense of the identity shifts participants experienced throughout their caregiving journey. While previous themes illustrated role conflict and overload, this theme reveals how participants gradually began to internalize and adapt to their caregiving role. Their identities were changing due to various reasons such as being a young adult, caregiver, student, friend, partner, employee, etc. One of the more important reasons is due to their caregiver role to their grandparent. As a grandchild caregiver, participants were physically, emotionally, and mentally fulfilling a role that not many other grandchildren are occupying. Rather than staying stuck in the tension between autonomy and dependency, participants described how they grew through it because they were able to use their caregiving experience as a lens to better understand their own limits, capacities, and values. This aligns with role accumulation theory, which suggests that taking on multiple roles can be beneficial since it provides access to resources, perspectives, and personal enrichment (Sieber, 1974). In this study, the caregiving role challenged participants but also gave them a sense of maturity and emotional depth that they understood as valuable to their long-term development.

Moreover, this theme underscores how resilience is not simply a reactive process, but a developmental one. Participants built a sense resilience not just to survive their caregiving role, but to adapt it into their vision of the kind of adult they want to become. This echoes Fruhauf et al. (2006) who found that caregiving grandchildren report personal growth such as maturity, empathy, and finding a purpose in their experience. Similarly, Hayslip et al. (2019) highlight how resilience can be a mediating force between caregiver stress and positive adjustment, reinforcing the idea that resilience is not just about bouncing back, it is about growing through the caregiving journey.

In sum, *Growing From the Tension, Visioning the Future Self* offers an important counterpoint to problem-focused narratives of caregiving in emerging adulthood. The findings extend the existing literature by showing how young adults grandchildren caregivers internalize and repurpose the caregiving role over time and by demonstrating how responsibility and sacrifice, which are typically seen as things that hold young caregivers back, can actually push them forward in life. This theme shows that caregiving is not limiting; rather, it can actually reshape how grandchildren see their roles and themselves.

Limitations

Several limitations should be considered when interpreting the findings of this study. First, the sample was predominantly composed of women, which, while reflective of broader demographics of caregivers, limits the exploration of gender differences in caregiving experiences. Male and nonbinary grandchildren may navigate caregiving roles differently due to variations in societal expectations, emotional expression, and access to support (Anderson et al., 2021; Bueno, 2024). Additionally, the racial and ethnic makeup of participants was primarily limited to Black and White individuals. As caregiving is deeply influenced by cultural norms, family structures, and intergenerational expectations (Feliciano et al., 2022), the limited diversity in the sample constrains the cultural applicability of the findings.

Another notable limitation is the wide age range of participants, spanning from 18 to 29 years old. While all participants fell within the developmental stage of emerging adulthood, experiences during this period can vary significantly. For instance, the caregiving responsibilities and psychosocial challenges faced by an 18-year-old may differ considerably from those of a 29-year-old, who may be more established in their career or family life. For example, in this sample, the youngest participant was 21 years old and the oldest was 27 years old. The younger participant talked more about managing school with caregiving duties and described how they would have to find time to do their homework in between ADLs and IADLs, whereas the older participant described almost a routine of how they managed caregiving tasks with going to work and raising their child. This variation may have introduced a broad spectrum of perspectives that, while rich in detail, complicate efforts to interpret the findings through a uniform developmental lens.

Lastly, the study included both participants who were currently engaged in caregiving and those reflecting on past experiences. This mix may have shaped the stories and reflections the participants made in their interviews. The participants who were reflecting on the past might have described things differently because of a memory error (recall bias) or how they made have made sense of their experiences over time. In contrast, the participants who were actively caregiving may have given more accurate perspectives. The inclusion of both current and pass caregiving experiences reflected adjustments made to the inclusion criteria, due to challenges with potentially fraudulent participants and low response rates. Despite these limitations, the study offers meaningful insight into the complex experiences of grandchildren navigating caregiving roles during a critical stage of development.

Directions for Future Research

Building on the findings and limitations of this study, future research should prioritize greater demographic diversity to deepen the understanding of how caregiving experiences are shaped by gender, race, ethnicity, and culture. As this study was predominantly composed of women and participants who identified as either Black or White, future work should intentionally seek to include voices from underrepresented groups, such as Asian, Latinx, Indigenous, and multiracial individuals, as well as male and nonbinary caregivers. Since caregiving roles are often influenced by cultural norms and expectations surrounding family, aging, and intergenerational relationships (Feliciano et al., 2022), capturing these nuances would offer a more comprehensive view of the grandchild caregiver experience. Additionally, exploring the differences between younger versus older young adult caregivers would help understand how caregiving intersects with specific developmental milestones within the broader period of emerging adulthood.

In addition to broader and more focused sampling, future studies would benefit from employing longitudinal designs to capture how caregiving roles and their relational and developmental impacts evolve over time for grandchildren caregivers. A longitudinal approach would allow researchers to track the ongoing effects of navigating the tension of autonomy and dependency or the impacts of missing out on the social aspect of life for this population, who will continue to grow and experience different life stages along the way. It would be interesting to see if and how their adult identity creates narratives around obligation and growth or how they make meaning of their caregiving experience as a young adult grandchild in later adulthood.

Additionally, future research could explore qualitative questions such as: What emotional or psychological impacts arise from feeling left out of typical young adult experiences? How does caregiving influence how caregiving grandchildren envision their future selves, particularly in terms of family, career, and identity development? These questions build on the themes that emerged in the present study—such as the feelings of missing out on life, and the transformative potential of caregiving—and point toward a need for research that captures both the costs and the personal growth that can occur through caregiving during this pivotal stage of life.

Practice Implications

The findings of this study underscore the importance of tailoring caregiving support to the unique developmental and relational experiences of young adult grandchildren who care for grandparents with dementia. For therapists, particularly those working from a family systems perspective (Gurman & Kniskern, 2014), this population presents a complex intersection of generational caregiving roles, emerging adult identity formation, and shifting family dynamics. These caregivers are not just completing different caregiving tasks, they are navigating their relationship with their grandparent, who may have raised them or been an important presence in their life making it feel more like an obligation to help them versus a personal desire to help, which can impact how these grandchildren create meaning out of their experience. Depending on the closeness of the relationship between the grandchild and grandparent, there can be an additional layer of wanting to pay their grandparent back for all the times their grandparent was present in their lives. Therapy can offer a space to unpack various aspects of the caregiving experience such as obligations or pressures to help, the constant push-pull for the need to be autonomous but having someone depend on you, feelings of guilt and social isolation, and how the grandchild grows from their experiences into someone they want to become. For example, therapists can help grandchildren caregivers navigate the tension between autonomy and dependency by making space for conflicting emotions, helping them reframe caregiving as part of their evolving identity rather than a barrier to development.

Caregiver Family Therapy (Qualls, 2008) and Narrative therapy (White & Epston, 1990) may be particularly helpful for young adult grandchild caregivers. Sara Qualls has developed the model, Caregiver Family Therapy, specifically for working with families with aging members with a systems-based approach (Qualls, 2008). This model could be helpful when working with grandchildren caregivers since it can help empower them with the challenges they face in their caregiving duties. Narrative therapy can also be helpful since it allows clients to re-author their stories identity development, explore how the caregiving role fits into the caregivers' personal and relational story with their grandparent and others, and help shift from viewing caregiving responsibilities from a possible burden into a meaningful experience in their lives.

Beyond individual and family therapy, psychoeducational interventions for caregivers should be reexamined to assess their relevance for young adult grandchildren caregivers. While a wide range of programs exist to support caregivers—offering education on dementia, stress management, and communication skills—most are designed with adult children or spousal caregivers in mind (Chiu et al., 2013; Cintoli et al., 2024). These existing models may not fully address the developmental needs, life circumstances, or emotional struggles of younger caregivers and grandchildren caregivers. For example, grandchildren caregivers may benefit from psychoeducational content that also addresses identity development, peer support, and academic and career planning. These tools should include resources on how to navigate intergenerational boundaries, whether they are a how-to guide or more formal resources such as therapy or group support. In addition, it is important to help young caregivers and grandchildren caregivers to individuals with dementia learn how to communicate about dementia with other family members, how to manage dementia related behavioral problems, and how to support their grandparent as they progress in their disease. Addressing these various topics can help grandchildren caregivers understand and validate their experiences. Adapting existing programming or developing new, age-appropriate curricula could help ensure that grandchild caregivers are not overlooked or underserved within the broader caregiving support landscape.

From a broader policy perspective, grandchild caregivers often fall through the cracks of support services (The Recognize, Assist, Include, Support, and Engage (RAISE) Act Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren, 2022). Many families are not eager to share information about young caregivers, making it difficult to gauge what type of help and how much support they really need (RAISE Act Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren, 2022). Many of these grandchildren in caregiving roles are trying to balance school, careers, financial instability, etc. often without any formal resources being offered to them. Expanding access to supports such as respite care, financial support, and even flexible options for school and/or work can help acknowledge the struggles of grandchildren caregivers (RAISE Act Family Caregiving Advisory Council & The Advisory Council to Support Grandparents Raising Grandchildren, 2022). Community-based organizations, educational institutions, and health systems can also play a role in helping identify and supporting young caregivers through outreach, resource hubs, and partnerships with mental health professionals.

As this study highlights, the caregiving experience in emerging adulthood is not simply a younger version of adult caregiving—it is its own distinct experience. This experience is shaped by the intersection of life stage, family roles, and cultural expectations. To truly support this group, we need approaches that are responsive, age-appropriate, inclusive, and rooted in the understanding of what this experience truly means for grandchildren caregivers to their grandparents.

Conclusion

This study examined the unique experiences of young adult grandchildren who take on caregiving roles for grandparents with dementia during a pivotal stage of identity formation and life transition. At a time when these caregivers are supposed to be figuring out who they are, exploring their independence, and shaping their futures, they were managing caregiving responsibilities. Through interpretative phenomenological analysis, the findings revealed how young adult grandchild caregivers experienced the constant tension between autonomy and dependency, had feelings of missing out on their lives related to the typical experiences of young adults, and grew from these tensions in terms of their ideas about their future selves. The relational context of this study shows that caregiving is not about checking off tasks, but it is about the relationship itself. The bond between the grandchild and their grandparent plays a significant role in shaping what the caregiving experience feels like and how it is understand by the caregiver. By grounding their stories in both the grandparent-grandchild relationship and the developmental challenges of emerging adulthood, this research brought a more nuanced understanding of this population. These insights highlighted the need for greater recognition of young adult grandchildren caregivers in policy, clinical practice, and research. They also call for support systems that honor both their caregiving responsibilities and the developmental tasks of emerging adulthood.

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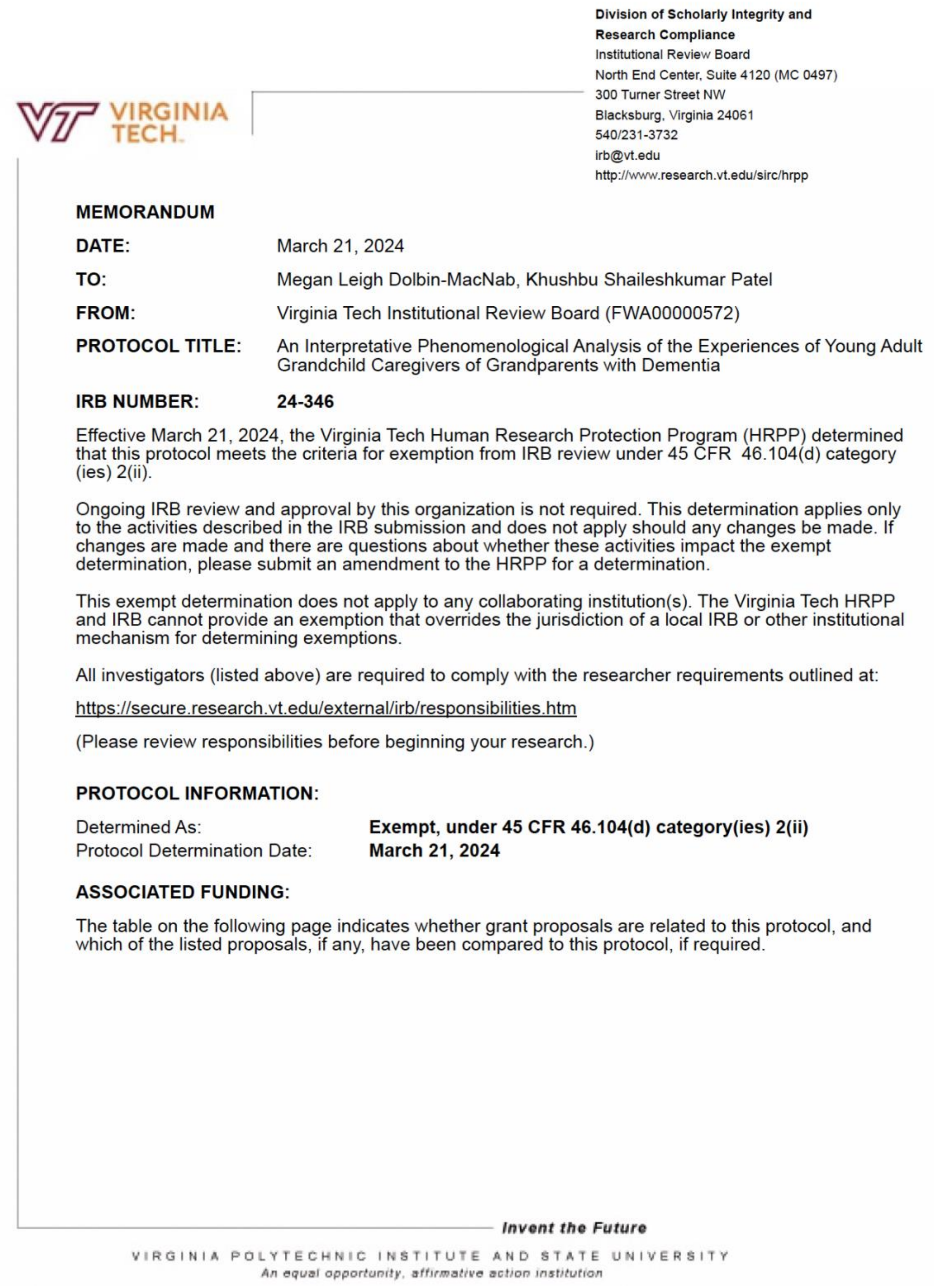
Appendices

Appendix A: IRB Approval Letter



Division of Scholarly Integrity and
Research Compliance
Institutional Review Board
North End Center, Suite 4120 (MC 0497)
300 Turner Street NW
Blacksburg, Virginia 24061
540/231-3732
irb@vt.edu
http://www.research.vt.edu/sirc/hrpp

MEMORANDUM

DATE: March 21, 2024

TO: Megan Leigh Dolbin-MacNab, Khushbu Shaileshkumar Patel

FROM: Virginia Tech Institutional Review Board (FWA00000572)

PROTOCOL TITLE: An Interpretative Phenomenological Analysis of the Experiences of Young Adult Grandchild Caregivers of Grandparents with Dementia

IRB NUMBER: **24-346**

Effective March 21, 2024, the Virginia Tech Human Research Protection Program (HRPP) determined that this protocol meets the criteria for exemption from IRB review under 45 CFR 46.104(d) category (ies) 2(ii).

Ongoing IRB review and approval by this organization is not required. This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these activities impact the exempt determination, please submit an amendment to the HRPP for a determination.

This exempt determination does not apply to any collaborating institution(s). The Virginia Tech HRPP and IRB cannot provide an exemption that overrides the jurisdiction of a local IRB or other institutional mechanism for determining exemptions.

All investigators (listed above) are required to comply with the researcher requirements outlined at:

https://secure.research.vt.edu/external/irb/responsibilities.htm

(Please review responsibilities before beginning your research.)

PROTOCOL INFORMATION:

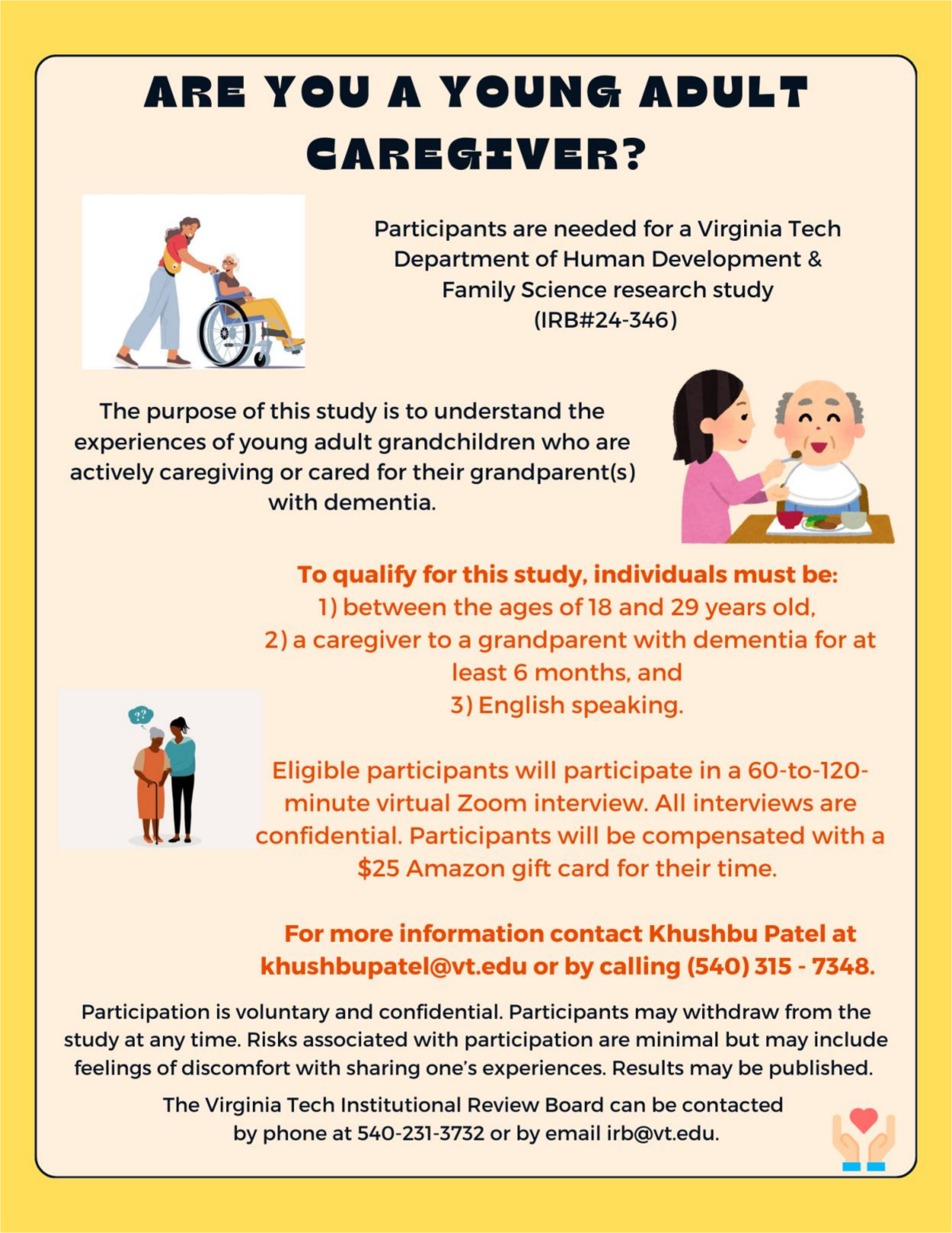
Determined As: **Exempt, under 45 CFR 46.104(d) category(ies) 2(ii)**
Protocol Determination Date: **March 21, 2024**

ASSOCIATED FUNDING:

The table on the following page indicates whether grant proposals are related to this protocol, and which of the listed proposals, if any, have been compared to this protocol, if required.

Invent the Future

Appendix B: Recruitment Flyer



ARE YOU A YOUNG ADULT CAREGIVER?

Participants are needed for a Virginia Tech Department of Human Development & Family Science research study (IRB#24-346)

The purpose of this study is to understand the experiences of young adult grandchildren who are actively caregiving or cared for their grandparent(s) with dementia.

To qualify for this study, individuals must be:

1) between the ages of 18 and 29 years old,
2) a caregiver to a grandparent with dementia for at least 6 months, and
3) English speaking.

Eligible participants will participate in a 60-to-120-minute virtual Zoom interview. All interviews are confidential. Participants will be compensated with a $25 Amazon gift card for their time.

For more information contact Khushbu Patel at khushbupatel@vt.edu or by calling (540) 315 - 7348.

Participation is voluntary and confidential. Participants may withdraw from the study at any time. Risks associated with participation are minimal but may include feelings of discomfort with sharing one’s experiences. Results may be published.

The Virginia Tech Institutional Review Board can be contacted by phone at 540-231-3732 or by email irb@vt.edu.

Appendix C: Social Media Post

I am posting to ask for your help with a research study! The purpose of this study is understanding the experiences of young adult grandchildren who are caregiving to their grandparent(s) with dementia. To participate in the study, individuals must be 1) between the ages of 18 and 25 years, 2) self-identify as a caregiver to a step-, adoptive-, or biological grandparent with dementia, and 3) English speaking. If you know any young adults who are providing care to their grandparent(s) with dementia, could you please share the information about this study with them?

Participation in this study involves young adult grandchildren caregivers completing a 60-to-120-minute Zoom interview. All interviews are confidential. As compensation, each participant will receive a $25 Amazon gift card.

If you are interested in participating please contact me at khushbupatel@vt.edu.

Virginia Tech IRB #24-346. To contact Virginia Tech's Institutional Review Board by phone 540-231-3732 or by email irb@vt.edu.

Please see the flyer below for more information.

Appendix D: Recruitment Email for University Professionals

Subject Line: Young Adult Caregivers to Grandparents - Virginia Tech Research Study

Dear ___,

My name is Khushbu Patel, I am a doctoral candidate in the Department of Human Development and Family Science at Virginia Tech. I am writing to let you know about an opportunity to inform others to participate in a research study exploring the experiences of young adult grandchildren caregivers to their grandparents with dementia.

As someone who is in contact with young adults, who may be caregivers, we are writing to ask for your help with a research study. The purpose of this study is to explore the intersection of young adult grandchildren caregiving to their grandparent(s) with dementia and their developmental tasks of being young adults. Since these individuals may be difficult to locate, we are asking for your help in spreading the word about this study. If you know any young adults who are providing care to their grandparent(s) with dementia, could you please share the information about this study with them? I have attached an informational flyer for you to give to potential participants or to post/pass around.

Participation in this study involves young adult grandchildren caregivers completing a 60-to-120-minute Zoom interview. All interviews are confidential. Participation in this study is completely optional. As compensation, each participant will receive a $25 Amazon gift card. Virginia Tech IRB #24-346, to contact Virginia Tech's Institutional Review Board by phone 540-231-3732 or by email irb@vt.edu.

Thank you, in advance, for your help in spreading the word about this study. Individuals who are interested in participating can contact me by phone at 540-315-7348 or by email at khushbupatel@vt.edu.

Sincerely,

Khushbu Patel, Doctoral Candidate

Department of Human Development and Family Sciences

Virginia Tech

Appendix E: Recruitment Email for Organizations

Subject Line: Young Adult Caregivers to Grandparents - Virginia Tech Research Study

Dear ___,

My name is Khushbu Patel, I am a doctoral candidate in the Department of Human Development and Family Science at Virginia Tech. I am writing to let you know about an opportunity to inform others about a research study exploring the experiences of young adult grandchildren caregivers to their grandparents with dementia.

As someone who is in contact with dementia caregivers, I am writing to ask for your help with this research study. The purpose of this study is to explore the intersection of young adult grandchildren caregiving to their grandparent(s) with dementia and their developmental tasks of being young adults. Since these individuals may be difficult to locate, I am asking for your help in spreading the word about this study. If you know any young adults who are providing care to their grandparent(s) with dementia, could you please share the information about this study with them? I have attached an informational flyer for you to give to potential participants or to post/pass around.

Participation in this study involves young adult grandchildren caregivers completing a 60-to-120-minute Zoom interview. All interviews are confidential. Participation in this study is completely optional. As compensation, each participant will receive a $25 Amazon gift card. This study has been approved by the Virginia Tech IRB #24-346. The Virginia Tech Institutional Review Board can be contacted by phone at 540-231-3732 or by email irb@vt.edu.

Thank you, in advance, for your help in spreading the word about this study. Individuals who are interested in participating can contact me by phone at 540-315-7348 or by email at khushbupatel@vt.edu.

Sincerely,

Khushbu Patel, Doctoral Candidate

Department of Human Development and Family Sciences

Virginia Tech

Appendix F: Eligibility Screening Questionnaire

1. How old are you?
2. Do you attend college/university? If so, where?
3. Do you identify as a grandchild who caretakes for your grandparent with a dementia diagnosis?
4. Which grandparent do you caretake for?
5. How old is your grandparent?
6. What is your grandparent(s)dementia diagnosis and who provided them with this diagnosis?
7. How old was your grandparent when they were diagnosed?
8. How long have you been caregiving for your grandparent(s)?
    a. How many years?
    b. How many times a week?
    c. How many hours per week?
9. Do you assist your grandparent with any of the following activities?
    a. ADLs
        i. Walking
        ii. Feeding
        iii. Dressing
        iv. Toileting
        v. Bathing
        vi. Transferring
    b. IADLs
        i. Managing Finances
        ii. Using Transportation
        iii. Preparing Meals
        iv. Shopping
        v. Cleaning
        vi. Taking Medications
        vii. Utilizing The Phone
10. What is your email address and phone number?

Appendix G: Caregiver Resources

* Resources from National Association of Caregivers – https://www.caregiving.org/resources/

State Based Resources

No Wrong Door - https://nwd.acl.gov/index.html

- Empowers individuals to make informed decisions, to exercise control over their long-term care needs, and to achieve their personal goals and preferences.

U.S. Department of Health and Human Services - https://www.hhs.gov/aging/state-resources/index.html

- Indicates which resources are available for older adults and their caregivers in your state.

Eldercare Locator - https://eldercare.acl.gov/Public/Index.aspx

- Enter your ZIP code or city and state to find resources in your community including Area Agencies on Aging that provide information and assistance for older adults and caregivers.

State Health Insurance Assistance Programs (SHIPs) - https://www.medicare.gov/talk-to-someone#resources/ships

- Find phone numbers and websites for organizations in your state with information about local, personalized counseling and assistance to people with Medicare and their families.

General Resources

Health Center Resource Clearinghouse – https://www.healthcenterinfo.org/

- An online "one-stop shop" where health center staff can access a vast collection of training and technical assistance resources and promising practices to support their staff and implement quality, effective and innovative operations.

National Family Caregiver Support Program – https://www.acl.gov/programs/support-caregivers/national-family-caregiver-support-program

- The National Family Caregiver Support Program (NFCSP), established in 2000, provides grants to States and Territories, based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.

Family Caregiver Alliance – http://caregiver.org/

- Established in 2001 as a program of Family Caregiver Alliance, the National Center on Caregiving (NCC) works to advance the development of high-quality, cost-effective policies and programs for caregivers in every state in the country. Uniting research, public policy and services, the NCC serves as a central source of information on caregiving and long-term care issues for policy makers, service providers, media, funders and family caregivers throughout the country.

Caregiver Action Network – http://www.caregiveraction.org/

- Resources from the Caregiver Action Network, including a Peer Forum, a Story Sharing platform, the Family Caregiver Toolbox and more. CAN also provides support for rare disease caregivers at http://www.rarecaregivers.org

Next Step in Care – http://www.nextstepincare.org

- Next Step in Care provides easy-to-use guides to help family caregivers and health care providers work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients.

Alzheimer's & Dementia Caregiving

Alzheimer's Association – https://www.alz.org/

- The Alzheimer's Association works on a global, national and local level to provide care and support for all those affected by Alzheimer's and other dementias. They offer help through a professionally staffed 24/7 Helpline (1.800.272.3900), face-to-face support groups and educational sessions in communities nationwide, and comprehensive online resources and information through the Alzheimer's and Dementia Caregiver Center.

Alzheimer's Foundation of America – https://alzfdn.org/

- The Alzheimer's Foundation of America offers a national, toll-free helpline (866-232-8484) staffed by licensed social workers, educational materials, a free quarterly magazine for caregivers and "AFA Partners in Care" dementia care training for healthcare professionals. For more information about AFA, call 866-232-8484, visit www.alzfdn.org.

The Association for Frontotemporal Degeneration (AFTD) – https://www.theaftd.org/

- AFTD promotes and funds research into finding the cause, therapies and cures for frontotemporal degeneration. They also offer information, education and support to persons diagnosed with an FTD disorder, and for their families and caregivers. To learn more about AFTD, visit www.theaftd.org.

The Lewy Body Dementia Association (LBDA) – https://www.lbda.org/

- LBDA works to raise awareness of Lewy body dementias (LBD), promoting scientific advances, and supporting people with LBD, their families, and caregivers. LBD is a complex disease that can present a range of physical, cognitive, and behavioral symptoms. It dramatically affects an estimated 1.4 million individuals and their families in the United States. To learn more, visit www.lbda.org.
- Alzheimers.gov – For the People Helping People with Alzheimer's Resources from the Administration for Community Living on Alzheimer's disease and other forms of dementia.

National Institute on Aging: Alzheimer's Disease Education and Referral Center – https://www.nia.nih.gov/health/alzheimers-and-dementia

- Resources from the National Institutes of Health on Alzheimer's disease and other forms of dementia, including information on clinical trials and current advances in scientific research.

U.S. Department of Veterans Affairs: Dementia Care (including Alzheimer’s) – https://www.va.gov/GERIATRICS/pages/Alzheimers_and_Dementia_Care.asp

- For those caring for a Veteran, resources on dementia care through the VA and information on new research on dementia in Veterans.

Appendix H: Informed Consent

Information Sheet for Participation in a Research Study

Principal Investigator: Megan L. Dolbin-MacNab, Ph.D., 840 University City Blvd, Suite 1, Blacksburg, VA 24060; email: mdolbinm@vt.edu

Co-Investigator: Khushbu Patel, Doctoral Candidate, Department of Human Development and Family Science, Virginia Tech; email: khushbupatel@vt.edu

IRB# and Title of Study: IRB #24-346 - An Interpretative Phenomenological Analysis of the Experiences of Young Adult Grandchild Caregivers of Grandparents with Dementia

You are invited to participate in a research study. This form includes information about the study and contact information if you have any questions.

My name is Khushbu Patel, and I am a graduate student at Virginia Tech, and I am conducting this research as part of my course work.

➢ WHAT SHOULD I KNOW?

The goal of this study is to learn more about the intersection of grandchildren caregiving to their grandparent(s) with dementia and their developmental tasks of being young adults. Roughly 15 young adult grandchildren, between the ages of 18 to 25 years old, caring for a grandparent with dementia will be interviewed for this study.

If you decide to participate in this study, you will complete an on-camera video interview via Zoom. You will receive an email containing a copy of the consent form at least 24 hours before the beginning of the scheduled interview. Prior to beginning the interview, researcher will go over the study requirements and obtain consent from participants. During the interviews, young adult grandchildren will answer basic demographic questions and be invited to answer semi-structured interview questions about their caregiving experiences and how it impacts their developmental milestones of being a young adult. These interviews will be recorded using Virginia Tech's Zoom platform. Audio and video recording is required for participation. Approximately 15 interviews will be conducted.

The data collected as part of the study will be used to better understand the experiences of young adult grandchildren caregivers to their grandparent(s) with dementia and possibly identify service needs or ideas for support services for these individuals.

The study should take approximately 60 to 120 minutes of your time.
The risk associated with this study are very low. However, you might have some emotional reactions such as anger or sadness. You do not have to answer any questions that make you uncomfortable. You can stop the interview at any time without penalty or loss of benefits.

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so.

➢ CONFIDENTIALITY

We will do our best to protect the confidentiality of the information we gather from you, but we cannot guarantee 100% confidentiality.

Any data collected during this research study will be kept confidential by the researchers. Your interview will be audio and video–recorded using the Zoom platform and then transcribed. I will type your responses to the interview questions. While doing this, I will remove your name, the names of your family members, and any other information that can be used to identify you. The written copy of your interview answers will also get a code number. Any computer files with your identifying information will be encrypted. All personal information and data gathered will be stored on a Virginia Tech OneDrive folder that only the primary investigator and I will be able to access. The typed answer to your interview questions will be kept. Only the researchers will be able to use this information. Upon completing the data analysis, audio and video files will be permanently deleted.

Confidentiality will be protected, unless we learn about current child abuse or elder abuse. Abuse can be emotional, physical, or sexual abuse. This information must be given to the appropriate government authorities. Also, if we think that you are a threat to yourself or others, we must report this to authorities. These are the only times that your confidentiality will not be protected.

➢ WHO CAN I TALK TO?

If you have any questions or concerns about the research, please feel free to contact Khushbu Patel by phone at 229-834-4991 or by email at khushbupatel@vt.edu or Megan Dolbin-MacNab by email at mdolbinm@vt.edu**.** You are not waiving any legal claims, rights, or remedies because of your participation in this research study. If you have questions regarding your rights as a research participant, contact the Virginia Tech HRPP Office at 540-231-3732 (irb@vt.edu).

To summarize, we are asking you to spend sixty to one-hundred twenty minutes answering questions about your role as a caregiver and how this impacts your developmental milestones as a young adult. You will let the researcher know if you have any questions or concerns about being in the study.

Subject's Permission

Now I am going to read you some questions so that I know that you would like to participate in the study.
First, do you understand this form and what it means to be in this study? __________
Second, do you agree to participate? __________
Third, do you have any questions about the study or what will happen by being in the study? ___
Are you ready to begin the interview? __________
Are you okay with me beginning the audio and video recording of our interview? __________

Participant's Name	Date

If you have any questions about this study, your rights as part of this study, and who you should contact if you are injured because of this study, please contact:
Khushbu Patel at 229-834-4991 or at email khushbupatel@vt.edu <<OR>> Megan Dolbin-MacNab, Principal Investigator, at 540-231-6807 or at mdolbinm@vt.edu.

Researcher Verification

I certify that I have explained the study to this participant, answered their questions, and received verbal consent to proceed with data collection. _______________

Researcher's Signature	Date

I certify that I explained participation in this study to this participant, answered their questions, and politely terminated the Zoom video when the participant decided not to participate.

Researcher's Signature	Date

Appendix I: Email for Scheduled Participants

Subject Line: Consent Information Sheet for Participation in Research Study

Hello,

I hope that you are doing well! It was great speaking with you and learning a bit more about you. Attached you will find a Consent Information document which provides details about the study and information about what you can expect as a participant. Please read over this document before the interview.

We will discuss the Consent Information in detail when we have the interview on _______(date) at ____(time). I have pasted the interview Zoom link for an on-camera virtual interview below. Please let me know if this email address is incorrect or if there is another email address you prefer that I use. Furthermore, please let me know if you have any additional questions or concerns about the interview.

Zoom link –

Should you need to reschedule for any reason, please email me or give me a call at 540-315-7348. I look forward to speaking with you again soon.

Kindly,

Khushbu Patel

Appendix J: Demographic Questionnaire

1. How old are you?
2. What is your race? What is your ethnicity?
3. What is your gender identity?
4. What is your occupation? How long have you been in this position? Full-time or part-time?
5. What is your education level?
6. Are you still in school? Full-time or part-time? Where?
7. What is your relationship status?
8. Who are you currently living with?
9. Do you have any children?
10. Which grandparent do you caretake for?
11. What dementia diagnosis does your grandparent have?
12. When did your grandparent get diagnosed?
13. How long have you been caregiving for your grandparent?
14. How often are you caregiving for your grandparent?
15. How do you caretake for your grandparent? (Probe with ADLs and IADLs)

Appendix K: Interview Protocol

1. What was your relationship with your grandparent like before the dementia diagnosis versus after?
    i. What was the impact of the dementia diagnosis on the relationship, specifically in relation to caregiving?
        - How has your relationship with your grandparent changed over time or stayed the same?
2. How did it feel when you found out that your grandparent was diagnosed with dementia?
    i. Given that you have been caregiving for X amount of time, how do you feel now about the diagnosis?
3. How did you begin caregiving for your grandparent?
    i. Has there been an evolution in your care responsibilities, if so what was the evolution?
4. How do you feel about caregiving to your grandparent?
    i. What is the most difficult part of caregiving? What is easiest part of caregiving?
        - Generational differences? Age differences?
    ii. How has caregiving benefited you? Challenged you?
5. Do you have any help from other family members, friends, or healthcare workers, such as respite?
    i. How does your family respond to you asking for help, if you do ask for it?
    ii. How does your grandparent respond if you ask for help with caretaking responsibilities?
    iii. How do your friends respond to you if you ask for help?
6. How has caregiving to your grandparent impacted other relationships in your life with your parents, friends, siblings, etc.?
7. In comparison to your peers, how are you similar and/or different given your role as a caregiver?
8. How has caregiving impacted your life at this age?
    i. In terms of work, school, friendships, romantic relationships, life choices, mentally, emotionally, physically
9. What does the role of a caregiver mean for you?

   i. How much, if any, value do you place on your role as a caregiver?
   ii. How does being a caregiver relate to other valued roles?
10. Do your roles such as being a partner/student/employee/caregiver align with each other?
   i. If they do, how so? What makes them similar?
   ii. If they do not, why not? What makes them different?
   iii. How do you navigate conflicting (non-aligning) roles?
11. How do you cope with the various roles you have in your life?
12. How have you changed and stayed the same (socially, developmentally, personally, etc.) as a result of being a caregiver as a young adult who is trying to figure themselves out in the world?