EMERGING ADULTHOOD AND WILLINGNESS TO CAREGIVE

by

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*We also certify that written approval has been obtained for any proprietary material contained therein.
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Emerging Adulthood and Willingness to Caregive

Abstract

by

JESSICA ALVA

A great deal of research has been conducted on caregiving experiences for relatives with Alzheimer’s disease (AD). However, virtually no research exists on the factors associated with willingness to caregive before entering the caregiver role. Furthermore, little is known about caregiving during emerging adulthood despite the unique juxtaposition of gains in autonomy concurrent with declining degrees of dependency common in the developmental period. This study investigated whether emerging adults differ in AD caregiving beliefs based on relationship (parent vs. grandparent), as well as which factors best predict willingness to caregive. Caregiving beliefs were assessed through a survey given to emerging adult undergraduate students (n = 150). All caregiving influences with the exception of forecasted stress were significantly different across relationships. Willingness to caregive for parents was predicted by comfort in caregiving tasks while confidence, institutionalization, and felt obligation predicted willingness for grandparents. Clinical and theoretical implications are discussed.
Emerging Adulthood and Willingness to Caregive

Alzheimer’s disease (AD) is the sixth-leading cause of death across all ages in the United States (Kochanek, Xu, Murphy, Miniño, & Kung, 2011) affecting an estimated 5.4 million Americans. Nearly 15 million Americans provide unpaid care for a relative with AD and other dementias (Alzheimer’s Association, 2011). The nature of AD is such that it not only affects the diagnosed individual, but also extends to the patient’s family. Yet many studies on AD caregiving focus solely on the primary caregiver (Beach, 1997), typically the spouse or adult child of the individual with AD. Relatively little is known about non-primary caregivers such as younger family members who often assist with caregiving tasks and are indeed affected by the caregiving experience (Lieberman & Fisher, 1999; Pinquart & Sörensen, 2003).

Young caregivers, defined here as people up to age 25 providing unpaid care to a dependent individual, are most often children and grandchildren of individuals with AD. A small, albeit growing, body of research has explored the experiences of young AD caregivers. However, existing research on young AD caregivers has been limited in several ways. First, research has primarily focused on the estimated 250,000 adolescent caregivers 18 years and younger (Alzheimer’s Association, 2011), thus excluding the remainder of young caregivers between the ages of 19 and 25. Although age 18 marks the legal transition to adulthood, complete autonomy from parents and the entrance into adulthood is frequently not achieved until the mid 20s (Arnett, 2000). Therefore, by neglecting to explore the experience of caregivers aged 19 to 25, our understanding of young caregiving experiences has been incomplete. Second, research on young caregivers has often overlooked the developmental stage of this population which goes
beyond the mere years in age. That is, young caregivers can be in one of various developmental stages in their transition from childhood to adulthood and the characteristics and qualities that distinguish these stages may influence each young caregiver’s experience. Third, there is a paucity of research pertaining to the experience of young caregivers whose parent has been diagnosed with AD. Although the nature of AD makes it less common for children under the age of 25 to experience such circumstances, research in this area has yet to investigate the differences that exist between children whose parent has been diagnosed with AD and grandchildren whose grandparent has been diagnosed with AD. Finally, little is known about the factors that influence young individuals’ willingness to caregive before they take on a caregiving role.

The current study addressed these gaps in the literature by focusing on emerging adulthood, an important developmental stage that is typically overlooked in caregiving research, and differences in AD caregiving influences based on the relationship to the AD patient (child/parent vs. grandchild/grandparent). Namely, caregiving influences included forecasted willingness to caregive, felt obligation (Stein, 1992), forecasted consideration of institutionalization, relationship closeness (Berscheid, Snyder, & Omoto, 1989), forecasted comfort with caregiving, forecasted confidence in caregiving, forecasted stress of a parent or grandparent’s AD diagnosis, experience with AD, and knowledge of AD. Additionally, this study investigated the factors that influence willingness to caregive for each relationship, thereby assessing the unique predictors of caregiving for parents and grandparents with AD. Furthermore, by utilizing hypothetical vignettes, this study aimed to simulate the introduction of AD to one’s life. Rather than
investigating the experience of emerging adults who are already immersed in a caregiving role, the current study focused on emerging adults’ reactions to a new AD diagnosis and their thoughts about caregiving as if the event just occurred.

Literature Review

Emerging Adulthood

Arnett (2000) proposed a new theory of development including the distinct stage of emerging adulthood, the developmental period from ages 18 to 25 characterized by frequent change, exploration, and demographic heterogeneity. Emerging adults tend to have a wide range of possible life experiences to explore including residential mobility, employment status, school attendance, intimate relationships, and worldviews and beliefs. Unlike adolescents (ages 10 to 18) and young adults (ages 26 to 40), emerging adults are not limited by normative responsibilities and roles. While adolescents tend to live with and depend on their parent(s), attend school, and be less frequently married or parents themselves, young adults are much more likely to be fully independent, stably employed, married, and parents of young children. In contrast, emerging adult demographics have considerable variability (Arnett, 2000). Having gained independence since adolescence, emerging adults have more opportunities to obtain a variety of experiences without yet facing the enduring responsibilities characteristic of young adulthood.

According to Arnett (2000), emerging adulthood is a distinct transitional period between adolescence and young adulthood. In fact, in a study of over 500 participants, Arnett (2001) found that, unsurprisingly, the majority (86%) of young-to-midlife adults and the minority (19%) of adolescents felt they had reached adulthood. Between these
two developmental periods, about half (46%) of emerging adults felt they had reached adulthood. These findings further support emerging adulthood as a diverse and unstable period, full of new opportunities and exploration for people who identify as neither child nor full adult.

The qualities of emerging adulthood are likely to influence their perceptions of caregiving, specifically in how willing they are to care for a relative with AD. On one hand, emerging adults may be willing to care for a relative with AD because they have fewer commitments compared to young adults. On the other hand, emerging adults may be hesitant or unwilling to hinder their exploration before settling down in young adulthood. Moreover, emerging adults’ increased autonomy since adolescence affords them more freedom in deciding whether or not to be involved in caregiving. The independence of emerging adults coupled with their lack of normative roles to fulfill leaves them with a wider range of options, one of which may be the decision to care for a relative with AD.

Despite the potentially unique relationship between emerging adults and their willingness to caregive, virtually no studies have explored this topic. As a result, the current study pulled from the literature on young caregivers including emerging adults to infer how the developmental processes in emerging adulthood are associated with willingness to caregive. First, research on adolescent caregivers is reviewed, as this age group comprises the vast amount of literature on young caregivers.

Adolescent Caregivers

Little is known about the experience of adolescent AD caregivers and the few findings from the studies that do explore this developmental stage are weakened by small
sample sizes. Regardless, research on adolescent caregivers indicates that, like their older counterparts, they report both positive and negative consequences of caregiving. Adolescents report closer family bonds, especially with the primary caregiver who is typically their mother (Beach, 1994; Beach, 1997; Svanberg, Stott, & Spector, 2010), greater understanding of the elderly population (Beach, 1997), and increased feelings of maturity, autonomy, and pride in contributing to caregiving responsibilities (Svanberg et al., 2010). Negative effects include feeling neglected by primary caregivers (Beach, 1994; Svanberg et al., 2010) altered peer relationships due to a lack of peer understanding, limited free time to spend with peers, and apprehension about having peers visit in the presence of the care recipient (Beach, 1994; Svanberg et al., 2010). Additionally, some adolescents have reported negative effects of caregiving on school achievement and attendance (Svanberg et al., 2010).

**Emerging Adult Caregivers**

While the literature on young caregivers is minimal, there are even fewer studies on emerging adult caregivers. Although some studies have included emerging adults in their sample, they have not been investigated independently from either adolescents (e.g., Celdran, Triado, Villar, 2009; Szinovacz, 2003) or young adults (e.g., Dellmann-Jenkins, Blankemeyer, & Pinkard, 2001). Thus, these studies fail to recognize the distinction between emerging adulthood and its neighboring developmental stages. Additionally, grouping multiple developmental stages together prevents the investigation of differential caregiving experiences that may exist between each developmental period. Due to the lack of research exclusively on emerging adult caregivers, studies in which emerging adults are grouped with caregivers in the age groups surrounding emerging
Adulthood (i.e. adolescence and young adulthood) are referenced in order to provide a comprehensive review of the literature.

Adolescent and emerging adult caregivers. Szinovacz (2003) conducted a mainly qualitative study on 17 children between the ages of 12 and 19 whose parents were primary caregivers for a person with Alzheimer’s or a similar dementia. However, Szinovacz’s study only partially included emerging adults—90% of the sample were adolescent—thus, these findings do not truly illustrate the potentially different ways caregiving is experienced by emerging adults. Like many studies on young caregivers, these children were viewed as bystanders rather than active participants even though many were directly involved in caregiving activities. While 29% of these adolescents and emerging adults reported stronger bonds with the primary caregiver (typically their mother), 53% noticed a negative change in this relationship. Specifically, adolescents and emerging adults felt that their caregiving parent displayed decreased involvement with them after becoming caregivers. Primary caregivers were also described as being more strict, temperamental, irritable, and argumentative since the onset of caregiving by the young participants.

Emerging adult and young adult caregivers. A study by Dellmannn-Jenkins, Blankemeyer, and Pinkard (2001) explored the strains and benefits of 50 emerging adult and young adult primary caregivers. Of this sample, 14% were between the ages of 18 and 23, 27% were between 24 and 29, 20% were between 30 and 35, and 39% were between 35 and 40. Thus, the sample was constituted mostly of young adult caregivers. Although the participants were not limited to dementia caregivers, the majority (81%) of care recipients had more than one cognitive or physical limitation. Whereas studies on
adolescent caregivers tend not to investigate the reasons for caregiving (most likely due to the adolescent’s minimal freedom in deciding whether to care), Dellmannn-Jenkins and colleagues found that 37% of the emerging adult and young adult caregivers reported that their current lifestyle afforded them the flexibility to caregive—a finding that supports Arnett’s (2004) description of emerging adulthood. Specifically, some caregivers were single, unemployed, part-time workers, or had no children. Although the study did not differentiate between the emerging and young adults in the sample, this finding illustrates the choice emerging and young adults have in their involvement in caregiving which differs from adolescents who are more often viewed as bystanders of the caregiving situation. Furthermore, because the sample was comprised mostly of young adults, it is possible that more participants would have reported having the flexibility to caregive had the sample included more emerging adults.

The emerging and young adult caregivers in this study were similar to adolescent caregivers in several ways. For instance, like adolescents, the participants reported stronger family bonds resulting from the caregiving experience. Also similarly, the emerging and young adults of this sample reported having less time to spend with friends (55%) and being negatively affected by the role reversal (36%) related to caregiving, especially for caregivers of Alzheimer’s disease, other dementias, or other cognitive impairments. However, while adolescents who were dependent on their parents experienced role reversal in accordance with increased responsibilities (Svanberg et al., 2010; Gelman & Greer, 2011), role reversal experienced by more independent emerging and young adults appears to have a different effect. For emerging and young adults caregivers, role reversal was related to decreased emotional support by their parents.
despite their increased independence. That is, emerging and young adult caregivers were negatively affected when they became the providers of emotional support to their care recipients rather than being the receivers of emotional support. This is especially important given that closeness to one’s parents during emerging adulthood can have significant consequences for self-esteem up to 20 years later (Roberts & Bengtson, 1996).

There were also differences evident between the emerging adult and young adult caregivers in this study and adolescent caregivers in other studies. Emerging and young adult caregivers reported benefits of caregiving on their personal development: 50% derived meaning from helping the care recipient avoid institutionalization and 40% gained satisfaction from being able to care for care recipients who cared for them in the past. These caregivers also reported strains from caregiving related to its impact on their developmental tasks including dating, marriage, parenting, and career development. Sixty eight percent of single caregivers (54% of the sample) reported less time available for dating. Of the married caregivers, 83% reported a decrease in the amount of time they were able to spend with their spouse and 78% reported that their spouse was not supportive of their caregiving role. Caregivers who were parents reported spending less time parenting (56%); only 22% reported increased bonds with their children as a result of caregiving. Perceived career development was negatively affected with 58% of caregivers reporting an impact on their job attendance. These findings highlight the increase in responsibilities as young individuals move from adolescence to emerging adulthood and later to young adulthood and to the impact caregiving can have on these developmental progressions.
While these studies add to the literature on young caregivers, they fail to account for developmental influences on the caregiving experience. That is, they look at age groups but disregard the developmental progress made in each stage pertaining to autonomy. Without directly considering increases in autonomy and a divergence from parental dependence, the degree to which emerging adults are willing to caregive for relatives with AD cannot be fully understood. Additionally, there is clearly an absence of research on emerging adults as they are either underrepresented or not included in samples of young caregivers.

Given emerging adults’ pursuit of independence from their parents coupled with some remaining degree of dependence, the relationship between emerging adults and the diagnosed relative is an area that requires exploration. While developmental processes may influence an individual’s willingness to caregive, the relationship between emerging adults and the AD patient may be an additional determining factor. In an attempt to address this gap, the current study focuses on the relationships between emerging adults and their parents and grandparents.

*Emerging Adults’ Relationships with Parents and Grandparents*

The relationship between emerging adults and their parents is particularly valuable given their transition in gaining independence and autonomy from their parents. Moreover, given that emerging adults commonly have more freedom than adolescents in deciding whether to caregive, their decision may be partially influenced by their relationship with the potential care recipient. Since the majority of children tend to be closer to and more dependent on their parents compared to their grandparents, emerging adults may be impacted more by a parent’s diagnosis of AD and thus more willing to care
for them as an effort to hold on to this valuable but threatened relationship. Furthermore, given the intimacy related to caregiving tasks in later stages of AD (e.g., bathing, toileting), children may feel more comfortable caring for a parent compared to a grandparent. Alternatively, the idea of helping an older grandparent is likely to be more salient assisting a parent. Thus, emerging adult grandchildren may feel more comfortable with caring for their grandparents than their parents. Although past research on young caregivers has included both children and grandchildren, they are often grouped together and thus do not permit comparisons to be made between the two groups (Szinovacz, 2003). The following studies are those which exclusively sampled either children or grandchildren caregivers.

*Child caregivers.* The number of young child caregivers is expected to rise due to medical advances resulting in longer life expectancy, delayed childbearing, and an increase in single-parent households (Gelman & Greer, 2011). Yet, few studies have focused on the unique experiences of young caregivers who are children of individuals with AD. These caregivers are usually children of an estimated 220,000 to 640,000 individuals with early-onset (or younger-onset) AD (EOAD) whose symptoms first appear before age 65 (Alzheimer’s Association, 2006). EOAD is typically diagnosed around age 50, although it can be diagnosed as early as age 30 and often interrupts parental and spousal roles as well as career advancement. Although EOAD constitutes a minority of AD cases, these patients and their families are often faced with unique challenges brought on by the uncommonly early onset of the disease (van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010).
Luscombe, Brodaty, and Freeth (1998) found that 75% of spousal caregivers reported that their children suffered psychological or emotional problems as a consequence of early dementia caregiving. Furthermore, the age of the caregiver and care recipient were negatively associated with the number and types of negative effects on the child. Specifically, younger child caregivers whose parent had an earlier onset of dementia were more likely to have problems at school and home as well as more conflict with their affected parent. In fact, conflict with the diagnosed parent was twice as likely for children whose parent was less than 50 years old (79%) compared to those with parents between the ages of 60 and 64 (36%). Unfortunately, Luscombe and colleagues did not report the age of the child caregivers. Therefore, it is unclear what stage(s) of development (i.e., childhood, adolescence, emerging adulthood, young adulthood) the sampled children were in. However, because parents were an average of 50 years old at the time of diagnosis, children were most likely adolescents or emerging adults.

While a few studies have investigated the experience of adolescents with parents with AD, the stress associated with caregiving for a parent with AD has yet to be explored in an emerging adulthood sample. For adolescents, perhaps the most detrimental outcome of a parent’s AD diagnosis is the premature role reversal that inevitably takes place. One aspect of this role reversal is caused by an increase in the adolescents’ responsibilities as the parent’s condition declines and they become increasingly dependent on their child caregiver (Gelman & Greer, 2011; Svanberg et al., 2010). Another, and arguably more important, aspect is the adolescent’s decreased ability to rely on their diagnosed parent (Svanberg et al., 2010) which often leads to grieving the loss of their previous child-parent relationship before the onset of AD.
(Gelman & Greer, 2011). Even as adolescents pursue autonomy from their parents, their expectation and need of parental emotional support does not decline (Dellmannn-Jenkins et al., 2001; Gelman & Greer, 2011). Thus, although independence is one objective of the transition to young adulthood, a child’s relationship with their parents continues to be one of support, at least emotionally. Therefore, an adolescent whose parent has AD may feel as though they are missing out on the emotionally warm child-parent bond common during their stage of development (Svanberg et al., 2010, Tiet et al., 1998).

Although research has yet to be conducted exclusively on emerging adults with parents with AD, the literature on emerging adult-parent relationships reflects how a parental AD diagnosis may negatively affect an emerging adult. As independence from parents becomes a salient objective, emerging adults commonly avoid high amounts of involvement with their parents and many will move out as a means to decrease their parents’ involvement in their lives (Arnett, 2004). Their strong desire to gain autonomy may deter emerging adults from becoming caregivers for their parent and having to remain in their parental household. However, even as emerging adults seek independence, they often continue to depend on their parents for emotional support (Arnett, 2004). In fact, emotional closeness with parents during emerging adulthood has positive consequences for self-esteem up to 20 years later (Roberts & Bengston, 1996). Because of this continued dependence on their parents, emerging adults may, on the other hand, be more willing to provide care for their diagnosed parent as an attempt to maintain this important relationship. Thus, the stress associated with a parent’s AD diagnosis and willingness to caregive may be related to the emerging adult’s autonomy and dependence on their parent.
The majority of studies on child caregivers have focused on adult children. Like young caregivers, adult-child caregivers simultaneously experience high levels of burden and personal growth (Ott, Sanders, & Kelber, 2007). However, while these studies may contribute to the literature on parent-child relationships in the caregiving context, the experience of adult children is arguably different from that of young caregivers. First, caring for a parent as an adult is more common than caring for a parent as an emerging adult. Thus, emerging adults are less likely to be psychologically prepared to manage a parent’s AD diagnosis and the role reversal that ultimately results from the diagnosis (Shifren, 2009). Second, AD is likely to lead to a greater disruption in the parent-child relationship for emerging adults compared to adult children because emerging adults are still somewhat dependent on their parents, at least to a greater extent than adult children. Third, since emerging adults are less likely to view themselves as having fully reached adulthood compared to adult-children (Arnett, 2001), they may feel less capable of meeting caregiving responsibilities and coping with a parent’s diagnosis. Thus, although adult children are psychologically and emotionally affected by a parent’s diagnosis (Luscombe, Brodaty, & Freeth, 1998), the relatively early development of emerging adults compared to those who have fully entered adulthood may result in greater negative consequences for them.

*Grandchild caregivers.* Commonly understood, grandchildren’s relationships with their grandparents are more likely to be auxiliary to their relationships with their parents. In addition, these already secondary relationships tend to reduce in contact as grandchildren pursue autonomy in their emerging adult years (Celdrán, Triado, & Villar, 2009). Thus, a grandparent’s AD diagnosis may not impact a grandchild’s life as much
as a parent’s diagnosis simply because of the closer relationship children have with their parents. In a study comparing adult children’s (mean age=49.4) caregiving experiences with their children’s experiences (the care recipients’ grandchildren; mean age=19.7), Pruchno, Peters, and Burant (1995) found that grandchildren reported higher positive affect and less burden than the adult children. It is unclear why these differences were found. While these results may represent the increased caregiving responsibilities of the adult children as the primary caregivers, studies have yet to explore whether these differences may be partially explained by the relational differences between care recipients and their children and grandchildren. That is, grandchildren may have reported higher positive affect and less burden because they were not psychologically or emotionally impacted as negatively as the children caregivers were from gradually experiencing the loss of a important familial bond. Furthermore, because independence from parents, rather than grandparents, is an objective of increasing importance as children develop, relationship changes may be less prominent in grandparent-grandchild relationships than in parent-child relationships. In fact, Pruchno and colleagues’ study supports the notion that experience with a grandparent’s AD diagnosis may be nearly equal for all grandchildren despite their developmental stage.

In an effort to tease apart two different developmental periods, Pruchno and colleagues attempted to separate the grandchildren into two groups: grandchildren less than or equal to 18 years old and those that were greater than 18. However, no significant differences emerged on any of the variables on caregiving burden or satisfaction, so the two groups were treated as a single group. The fact that both developmental periods were undifferentiated supports the idea that grandchildren’s
experiences may have less variability due to the secondary relationship between grandchildren and grandparents while children may have different experiences related to the diagnosis of a parent based on their stage of development.

*Caregiving Influences*

The current study focused on two caregiving influences (felt obligation, and knowledge of AD) of emerging adults based on previous research findings. In addition to these variables, four other possible caregiving influences were explored. These factors fall into three categories: (a) forecasted relational influences, (b), current relational influences, and (c) current non-relational influences. The relational influences are those that can be assessed individually for different relationships, in this case, child/parent and grandchild/grandparent. The non-relational influences are not contingent on relationship. Most research on AD focuses on family members who have already taken on the caregiver role and thus prevents the opportunity to learn more about the decision-making process involved with becoming a caregiver. This study’s hypothetical design allowed for the exploration of influences that affect caregiving beliefs prior to entering the caregiving role. *Willingness* to care, *stress* of diagnosis, consideration of *institutionalization*, *comfort* with caregiving, and *confidence* about caregiving were investigated as (a) forecasted relational influences. *Closeness* and *felt obligation* to the hypothetically diagnosed AD patient were included as (b) current relational influences. Finally, basic *knowledge* of and *experience* with AD were investigated as (c) non-relational influences. For the sake of brevity, the italicized descriptors will be used when referring to these factors in the remainder of this manuscript.
The research on forecasted caregiving influences are sparse. A thorough review of the literature provided minimal information, underscoring the need for research on non-caregivers. While research on caregivers is undoubtedly critical to increasing our understanding of the caregiving role, it bypasses the beginning of the caregiving process when emerging adults are first introduced to a parent or grandparent’s AD diagnosis. Existing research on caregiving influences are reviewed.

*Felt obligation.* Emerging adults’ willingness to care give may also be influenced by their perceived obligation in family relationships. Felt obligation is the set of perceived expectations of appropriate behavior based on negotiated commitments in specific ongoing relationships with relatives (Stein, 1992). Specifically, these expectations involve regular family contact and participation in family occasions (contact and family ritual); courtesy and respect (conflict avoidance); physical and emotional support (assistance); autonomy (self-sufficient); and discussion of personal and family matters (personal sharing; Stein, 1992). Throughout the life course, these expectations are determined, either explicitly or implicitly, such that individuals feel that they “should” or “ought” to say or do certain things within specific familial relationships (Stein, 1992). Although past research has explored the associations between caregiving and filial obligation (as well as filial responsibility, filial piety, and familism) felt obligation is better suited to explore emerging adults’ willingness to care give.

Whereas filial obligation refers to general attitudes and societal expectations about adult children’s responsibility towards their elderly parents, felt obligation is viewed as personal behavioral expectations in relationships with specific family members across the life span (Stein, 1992). Thus, felt obligation is influenced by the relationships
with specific family members (e.g., parents and grandparents) and applies to individuals of all ages. Furthermore, the expectations within felt obligation involve issues related to individuation and connectedness (Stein, 1992), both of which are central issues in emerging adulthood.

Felt obligation has been explored in research on caregiving for mentally ill parents (Abraham & Stein, 2010), mentally ill siblings (Jewell & Stein, 2002), and healthy parents and in-laws (Freeberg & Stein, 1996; Stein, 1992; Stein, Wemmerus, Gaines, Freeberg, & Jewell, 1998). This concept is highly associated with actual caregiving and willingness to care in the future (Jewell & Stein, 2002; Stein et al., 1998). In fact, felt obligation accounted for current caregiving and predicted future caregiving above and beyond gender (Stein et al., 1998), parental affection (Stein et al., 1998), and filial responsibility (Stein, 1992). Results of these studies also indicate that, in support of the relational approach of felt obligation, emerging adult children endorse higher levels of felt obligation than older children (Stein, 1992; Stein et al., 1998). According to Stein (1992), felt obligation should be particularly strong in younger child-parent relationships. This stems from the idea that children of all ages feel obligated to reciprocate the sacrifices their parents made during childrearing and gradually do so throughout their lifetime. Younger children have fewer opportunities to counter their parents’ sacrifices whereas older children have had more chances, over the course of their life, to perform duties to decrease their perceived indebtedness. Furthermore, time alone may decrease felt obligation; parental sacrifice is likely to be more salient for younger, more dependent children than older children who rely on their parents to a lesser extent.
Past results have also indicated that felt obligation differs between family members and relationships. Specifically, emerging adults have higher levels of felt obligation towards their mothers compared to their fathers (Abraham & Stein, 2010; Freeberg & Stein, 1996; Stein, 1992; Stein et al., 1998) and towards their parents compared to their in-laws (Stein, 1992). Although research has yet to examine possible differences in felt obligation between parents and grandparents, the greater direct sacrifices made by parents for their children relative to grandparents are likely to result in stronger feelings of indebtedness.

**Knowledge of AD.** A final factor that may affect emerging adults’ willingness to care give is knowledge of or personal exposure to AD. Research in this area is limited, mainly consisting of differences in AD knowledge among experts, paid care providers, family caregivers, and noncaregivers (Carpenter, Zoller, Balsis, Otilingam, & Gatz, 2011; Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009). It is unknown whether AD knowledge influences an individual’s decision to be a caregiver. However, being more informed about the symptoms, course, and other aspects of AD is arguably likely to change the ways in which individuals think about their potential role as a caregiver. In fact, higher levels of dementia knowledge, specifically the biomedical aspects, are predictive of increased anxiety among caregivers (Proctor, Martin, & Hewison, 2002). While this finding does not directly relate to willingness to care give, it suggests that anxiety associated with increased knowledge about dementia may possibly deter someone from taking on the caregiving role. However, findings on AD knowledge indicate that age is positively associated with knowledge (Carpenter et al., 2001). Thus, emerging adults are likely to have minimal knowledge related to AD with the exception of
individuals with previous experience with AD, such as a diagnosed family relative. Yet research examining the associations between AD knowledge and experience are mixed. Lundquist & Ready (2008) found that emerging adults without and without AD exposure had similar amounts of AD knowledge. In contrast, Carpenter et al. (2011) found that individuals with at least one family member with dementia had significantly higher scores of AD knowledge compared to those without a family history. The dearth of research in this area limits hypotheses about the relationship between AD knowledge and willingness to care give. It may be that emerging adults with more AD knowledge are more hesitant or unwilling to become caregivers because of the difficulty and burden associated with caring for an individual with AD. Conversely, more knowledge about the devastating consequences of AD may entice emerging adults’ desire to fill a highly important role. Of course, the influence of AD knowledge on emerging adults’ willingness to care give may depend on their relationship with the possible care recipient and their felt obligation towards them.

**Overview of Present Research**

The current study explored two areas of forecasted caregiving influences in emerging adults. First, this study investigated whether caregiving influences differ by relationship to a relative diagnosed with AD—child/parent and grandchild/grandparent. Children were expected to have higher levels of overall positive AD caregiving beliefs than grandchildren. Specifically, emerging adults’ willingness, felt obligation, closeness, comfort, confidence, and stress in caregiving were predicted to be higher for their parents compared to their grandparents, while institutionalization was expected to be lower. Second, this study assessed the predictors of willingness to care give and whether
differences exist between child/parent and grandchild/grandparent relationships. Closeness and felt obligation were predicted to be the strongest predictors of willingness to care for child/parent and grandchild/grandparent relationships, respectively. The findings of this study contribute to the nearly nonexistent literature on differences between emerging adult children and grandchildren caregiving influences.

**Method**

*Participants*

Participants included 150 undergraduate students (41% male; $M = 19.23$ years, $SD = 1.38$) from undergraduate introductory psychology classes at Case Western Reserve University (see Table 1). Two-thirds of the participants identified as White/Caucasian with the remainder identifying as Asian/Pacific Islander (28%), Black/African-American (3.3%), and Hispanic (2.7%). The sample fell in the emerging adulthood developmental stage (age range = 18-23 years) and, as expected, approximately two-thirds responded ambiguously to whether they feel they had reached adulthood, indicating they do not see themselves as adolescent but that they also do not identify entirely as adults ($M = 6.35$; $SD = 1.53$).
Table 1

Sociodemographic Characteristics of Respondents

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
<th>M (SD)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>19.23 (1.38)</td>
<td>18-23</td>
<td></td>
</tr>
<tr>
<td>Adulthood</td>
<td>6.36 (1.54)</td>
<td>1-10</td>
<td>2-10</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>61 (40.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>88 (59.1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
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<tr>
<td>White/Caucasian</td>
<td>99 (66.4)</td>
<td></td>
<td></td>
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<tr>
<td>Black/African American</td>
<td>5 (3.4)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian/Pacific Island</td>
<td>41 (27.5)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic/Latino</td>
<td>4 (2.7)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Procedure

Participants accessed and completed the study through the university’s research participation system. Informed consent was collected from all participants prior to participation. After completing basic demographic information including age, sex, and race, participants complete three measures that assessed (1) transition to adulthood, (2) AD knowledge, and (3) felt obligation towards parents and grandparents, separately (see the Appendix for the complete survey).

The remainder of the survey consisted of two versions of hypothetical vignettes—a parent version and a grandparent version—and corresponding measures. To increase the realness of the hypothetical vignettes, participants were required to have at least one
living parent and grandparent. Participants completed both versions, the order of which was counterbalanced to prevent order effects.

In the parent version, participants completed a measure assessing relationship closeness to their closest parent. With their chosen parent in mind, participants were directed to read a description of AD including basic information, symptoms, course, and common caregiving tasks followed by a hypothetical vignette which asked participants to imagine that their parent had been recently diagnosed with AD. Following the vignette, participants were asked a series of questions that assessed (1) willingness to caregive, (2) motives for choosing to caregive, (3) motives for choosing not to caregive, (4) consideration of institutionalization, (5) confidence in caregiving, (6) comfort in executing specific caregiving tasks, and (7) the stress of diagnosis.

The grandparent version was identical to the parent version with the exception of the person diagnosed with AD in the hypothetical vignette. Participants were asked to choose their closest grandparent and complete a measure assessing relationship closeness. The hypothetical vignette was modified so that the participants were asked to imagine that their grandparent has recently received an AD diagnosis. Participants were asked the same series of questions as in the parent version, but modified to account for relationships with grandparents rather than parents.

At the conclusion of the questionnaire, participants were asked about their experience with AD. Participants received two research participation credits for their involvement in the study.
Measures

**Emerging adulthood.** Participants were asked to answer the following question created by Arnett (2001) to assess their conceptions of their transition to adulthood: “Do you think that you have reached adulthood?” Responses options ranged from 1 (*Not at all*) to 10 (*Extremely*).

**Felt obligation.** The Felt Obligation Measure (FOM; Stein, 1992) was used to assess participants’ perceived expectations in their familial relationships. Participants indicated how often they felt they “need to” or “should” say and do things using a scale ranging from 1 (*Rarely*) to 5 (*Very often*). The FOM consists of 32 items associated with the five components of felt obligation: ritual and family contact (e.g., “Maintain regular contact”), assistance (e.g., “Take care of them in old age”), conflict avoidance (e.g., “Keep peace in the family”), self-sufficient (e.g., “Not get more than you give”), and personal sharing (e.g., “Talk about personal things”). Two versions were used to assess felt obligation separately for parents and grandparents. Similarly to Stein (1992), three items were removed based on their inappropriateness for participants who were neither married nor parents (“Talk about your spouse,” “Talk about your children,” and “Give them grandchildren”). Cronbach’s alpha was used to calculate the internal consistency reliability of the scale, indicating good reliability for both relationships (child/parent $\alpha = .98$; grandchild/grandparent $\alpha = .94$).

**Alzheimer’s disease knowledge.** The Alzheimer’s Disease Knowledge Scale (ADKS; Carpenter, Balsis, Otilingam, Hanson, & Gatz, 2009) measured knowledge about and familiarity with AD. The ADKS is a 30-item scale with a true/false response format consisting of statements about AD risk factors, assessment and diagnosis,
symptoms, course, life impact, caregiving, and treatment and management based on recent scientific understanding of AD ($\alpha = .53$). Examples of items include “Alzheimer’s disease cannot be cured.” and “Most people with Alzheimer’s disease remember recent events better than things that happened in the past.” The number of correct responses was summed for a potential range of 0 to 30.

**Relationship closeness.** Participants completed the Relationship Closeness Inventory (RCI; Berscheid, Snyder, & Omoto, 1989) on the parent and grandparent with whom they had the closest relationship. Closeness is defined as the combination of frequency of one-to-one face interaction, diversity of activities done together (child/parent $\alpha = .91$; grandchild/grandparent $\alpha = .88$), and strength of influence (child/parent $\alpha = .90$; grandchild/grandparent $\alpha = .93$). The frequency subscale was altered to assess the amount of time participants spent with their parent or grandparent over the past year (in weeks; rather than the past week). Original frequency scores ranged from 0 to 52. Following the procedure described in Bercheid et al. (1989), scores from the three subscales were converted to a 10-point scale. An overall closeness score was obtained by summing these values resulting in a potential range of 3 to 30.

**Willingness to caregive.** Participants’ willingness to caregive for parents and grandparents individually was assessed by means of a single question: “How willing are you to be involved in caring for your parent/grandparent?” Responses were made using a 10-point scale ranging from 1 (Not at all) to 10 (Extremely).

**Motives for Caregiving and Motives for not Caregiving.** A list of 24 motivations for caregiving and 14 motivations for not caregiving were compiled from various qualitative studies assessing caregiver’s reasons for caregiving (Feeney & Collins, 2003;
Globerman, 1996; Dilworth-Anderson, Goodwin, & Williams, 2004; Lyonette & Yardley, 2003; Camden, Livingston, Cooper, 2011; Carruth, 1996). Participants rated each motivation on a scale from 1 (Not at all) to 10 (Extremely). This scale was found to be highly reliable for motives (child/parent $\alpha = .89$; grandchild/grandparent $\alpha = .94$) and non-motives (child/parent $\alpha = .90$; grandchild/grandparent $\alpha = .90$).

**Consideration of institutionalization.** The extent to which participants would consider institutionalizing their parent or grandparent was assessed by means of a single item modified from the Desire to Institutionalize Scale (DIS; Morycz, 1985): “How likely are you to consider a nursing home, boarding home, or assisted living for your parent/grandparent?” This item differed from the original DIS item in that it (a) was reworded to assess desire to institutionalize based on a hypothetical situation and (b) used a 10-point scale ranging from 1 (Not at all) to 10 (Extremely) rather than a yes/no response format. Given the hypothetical nature of the current study, the remaining five questions in the DTI were omitted due to anticipated difficulty in forecasting such actions (e.g., “In the past six months, have you discussed the possibility of a nursing, boarding home or assisted living with family members or others?”).

**Confidence in caregiving.** A single question was used to assess levels of confidence in caregiving tasks for parents and grandparents: “How confident do you feel about being able to handle these caregiving tasks for your parent/grandparent?” A 10-point scale ranging from 1 (Not at all) to 10 (Extremely) was used. This question was pulled from the Revised Memory and Behavior Problems Checklist (Teri et al., 1992).

**Comfort in caregiving.** Participants rated their comfort in helping their parent and grandparent with specific activities of daily living and instrumental activities of daily
living pulled from two existing measures on care recipient physical impairment (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; Lawton & Brody, 1969). Each activity was rated on a scale from 1 (Not at all) to 10 (Extremely). Mean scores were calculated. Cronbach’s alpha was .91 for child/parent relationships and .94 for grandchild/grandparent relationships.

*Stress of diagnosis.* The extent to which a parent or grandparent’s AD diagnosis would impact the participant and his/her life was assessed by means of two questions: “How stressful would caregiving for your parent/grandparent with AD be for you?” “How much would caregiving for your parent/grandparent with AD impact your life?” and “How burdensome would caregiving for your parent/grandparent with AD be for you?” Participants responded to all questions using a 10-point scale ranging from 1 (Not at all) to 10 (Extremely). A mean score was derived, resulting in an overall score of stress ranging from 1 to 10. The total stress score was found to have good reliability (child/parent $\alpha = .72$; grandchild/grandparent $\alpha = .79$).

*Experience with AD.* Participants’ exposure to AD was assessed using a two questions adapted from Lundquist & Ready (2008): “Have any of your parent, grandparents, other relatives, or a close family friend been diagnosed with Alzheimer’s disease or another dementia?” “Have you ever spent time with someone with Alzheimer’s disease or developed some sort of close relationship with someone with Alzheimer’s disease?” Participants who respond affirmatively were asked two follow-up questions concerning their relationship to the person diagnosed and the extent to which they provided care using a 5-point scale ranging from 1 (not at all) to 5 (extremely).
Results

The descriptive statistics for caregiving influences are shown in Table 2. The majority of participants reported having no experience with AD; only 18% knew a family member or relative with AD, typically a grandparent (74%) whom most provided little or no care for ($M = 3.19, SD = 2.56$). None of the participants reported having a parent with AD. Intercorrelations indicate significant relationships between the majority of caregiving influences (see Table 3).

Table 2

<table>
<thead>
<tr>
<th>Caregiving Influence</th>
<th>Child/Parent</th>
<th></th>
<th></th>
<th>Grandchild/Grandparent</th>
<th></th>
<th></th>
<th>Within-Subject Differences</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>Range</td>
<td></td>
<td>M (SD)</td>
<td>Range</td>
<td></td>
<td>t</td>
</tr>
<tr>
<td>Willingness</td>
<td>9.19 (1.20)</td>
<td>1-10</td>
<td>4-10</td>
<td>7.21 (2.41)</td>
<td>1-10</td>
<td>1-10</td>
<td>11.44***</td>
</tr>
<tr>
<td>Institutionalization</td>
<td>3.83 (2.55)</td>
<td>1-10</td>
<td>1-10</td>
<td>5.05 (2.86)</td>
<td>1-10</td>
<td>1-10</td>
<td>-6.12***</td>
</tr>
<tr>
<td>Felt-Obligation</td>
<td>3.74 (0.49)</td>
<td>1-5</td>
<td>1.62-4.83</td>
<td>3.47 (0.73)</td>
<td>1-5</td>
<td>1-4.79</td>
<td>6.12***</td>
</tr>
<tr>
<td>Closeness</td>
<td>18.41 (3.56)</td>
<td>3-30</td>
<td>6-27</td>
<td>10.24 (2.91)</td>
<td>3-30</td>
<td>4-22</td>
<td>23.24***</td>
</tr>
<tr>
<td>Comfort</td>
<td>8.17 (1.39)</td>
<td>1-10</td>
<td>3.6-10</td>
<td>7.45 (1.73)</td>
<td>1-10</td>
<td>1-10</td>
<td>7.23***</td>
</tr>
<tr>
<td>Confidence</td>
<td>6.30 (2.41)</td>
<td>1-10</td>
<td>1-10</td>
<td>5.25 (2.55)</td>
<td>1-10</td>
<td>1-10</td>
<td>5.95***</td>
</tr>
<tr>
<td>Stress</td>
<td>7.21 (1.58)</td>
<td>1-10</td>
<td>2.67-10</td>
<td>7.37 (1.71)</td>
<td>1-10</td>
<td>1-10</td>
<td>-1.33</td>
</tr>
<tr>
<td>Knowledge</td>
<td>21.04 (3.43)</td>
<td>0-30</td>
<td>11-28</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. CI = confidence interval. * Denotes non-repeated measures.
* p < .05. *** p < .001.
A doubly multivariate repeated measures design was performed to investigate differences in combined caregiving influences across relationships. In this analysis, caregiving influences were limited to those that were measured for each relationship (i.e., willingness, institutionalization,felt-obligation, closeness, comfort, confidence, stress); experience and knowledge of AD were excluded. The seven caregiving influences were included simultaneously to provide further protection against inflation of type I error. The within-subjects factor was relationship to the hypothetically diagnosed relative: (a) child/parent and (b) grandchild/grandparent. The results indicate a statistically significant difference in combined caregiving influences across relationships, $F(7,143) = 77.53$, $p < .001$, partial $\eta^2 = .79$.
Seven univariate tests were calculated to investigate the caregiving influences individually. The Greenhouse-Geisser statistic was used to compensate for the inability to test for sphericity on only two independent variables. In addition, a Bonferroni alpha level of .007 was used to test for significance. Each of the individual caregiving influences, with the exception of forecasted stress, was significantly different across relationships (see Table 4).

<table>
<thead>
<tr>
<th>Caregiving Influence</th>
<th>$F$</th>
<th>$\eta^2$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Willingness</td>
<td>131.56</td>
<td>.47</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Institutionalization</td>
<td>37.52</td>
<td>.20</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Felt-Obligation</td>
<td>37.74</td>
<td>.20</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Closeness</td>
<td>515.97</td>
<td>.78</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Comfort</td>
<td>51.67</td>
<td>.26</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Confidence</td>
<td>34.94</td>
<td>.19</td>
<td>&lt;.001</td>
</tr>
<tr>
<td>Stress</td>
<td>1.45</td>
<td>.01</td>
<td>&lt;.23</td>
</tr>
</tbody>
</table>

*Note. Significant at the $p < .007$ level.*

To investigate the direction of the differences in relationship, paired-samples $t$-tests were conducted on each of the previously significant variables (see Table 2). As expected, emerging adults had statistically significant higher levels of willingness to caregive, felt-obligation, closeness, comfort, and confidence, and lower levels of institutionalization toward their parents compared to their grandparents.
**Forecasted Willingness to Caregive Predictors**

Multiple regression analyses were performed to investigate the predictive power of individual caregiving influences on willingness to caregive for each relationship (see Table 5). In these analyses, caregiving influences included the following variables: institutionalization, felt-obligation, closeness, comfort, confidence, and stress. Experience with and knowledge of AD were not substantially correlated with willingness to caregive \((r < .3)\) and were therefore left out of the analyses. Despite its non-significant difference across relationships, forecasted stress was included because its possible contribution to willingness to caregive is independent from its within-group differences.

In the child/parent model, caregiving influences explained 39.4% of the variance in willingness to caregive, \(F (6, 143) = 15.47, p < .001\). Inspection of the standardized regression models suggests that only two of the caregiving influences were statistically significant, with comfort contributing more to the model \((beta = .31, p = .001)\) than institutionalization \((beta = -.20, p = .005)\). In the grandchild/grandparent model, caregiving influences explained 49.7% of the variance in willingness to caregive, \(F (6, 139) = 22.90, p < .001\). Three caregiving influences were statistically significant: confidence \((beta = .31, p < .001)\), institutionalization \((beta = -.29, p < .001)\), and felt obligation \((beta = .28, p < .001)\).
Further analyses were conducted to examine the differences in individual caregiving influences across relationship using regression procedures described by Judd, McClelland, and Ryan (2009). To test the interaction between each predictor and relationship, the following formula was used as suggested by Paternoster, Brame, Mazerolle, and Piquero, (1998).

\[
SE_{b-difference} = \sqrt{(SE_{bG1}^2 + SE_{bG2}^2)}
\]

\[
Z = \frac{b_{G1} - b_{G2}}{\sqrt{(SE_{bG1}^2 + SE_{bG2}^2)}}
\]

Comparisons between regression weights in the parent and grandparent models indicated that the effects of felt obligation, institutionalization, confidence, and comfort were contingent on relationship. Specifically, confidence \((z = 2.86, p < .05)\) and felt obligation \((z = 2.75, p < .01)\) predicted willingness to care give for grandparents to a significantly greater extent than it predicted willingness to care give for parents. Comfort was a significant predictor of willingness to care give \((z = 7.43, p < .001)\) for parents but not for
grandparents. While institutionalization decreased emerging adults’ willing to care give, the effect was significantly pronounced in the grandchild/grandparent relationship \((z = 2.34, p = < 0.05)\). Closeness and stress did not reach significance, suggesting that the effect of these caregiving influences on willingness to care give does not significantly vary by relationship (see Table 5).

Discussion

While the prevalence of AD increases in our society and with it the amount of family caregivers, our understanding of young caregivers remains minimal. The years of emerging adulthood (Arnett, 2000) are particularly interesting given the high level of demographic heterogeneity between the dependence typical of adolescence and the serious responsibilities acquired in young adulthood. Furthermore, the relationship to the AD patient has often been overlooked in research on young caregivers. While the majority of young caregivers are grandchildren of their AD care recipients, young children have also been faced with caregiving for their parent with AD. The current study focused on the emerging adult developmental stage and differences between a child/parent and grandchild/grandparent relationship affected by AD to address the gaps in the literature.

This study utilized a hypothetical vignette to assess immediate reactions about caregiving upon disclosure of a diagnosis. By not limiting the sample to current caregivers, emerging adults’ caregiving beliefs were examined to investigate the factors that influence their willingness to be a caregiver for their parent or grandparent with AD (rather than the factors that influence the maintenance of an existing caregiver role).
A review of the caregiving literature revealed several factors that may influence beliefs about caregiving. Willingness to caregive and the consideration of institutionalization were included as direct but opposing measures of caregiving beliefs. Felt obligation (Stein, 1992) assessed perceived duties associated with individual relationships while closeness (Berscheid, 1989) measured the interdependence within relationships. Forecasted comfort and confidence in executing common caregiving tasks were examined. Forecasted stress of providing care for a parent or grandparent with AD was explored. Finally, knowledge about AD was assessed to determine whether an understanding of the symptoms and course of the disease influenced beliefs about caregiving.

The goal of the current study was two-fold. First, relational groups were compared to determine whether differences exist in forecasted responses to an AD diagnosis between child/parent and grandchild/grandparent relationships. Examining the extent of these differences is the first step in differentiating the experience of emerging adults when faced with a parental AD diagnosis from a grandparental AD diagnosis. Second, this study aimed to address the deficit of decision-making associated with caregiving in the literature. An understanding of the caregiving influences that predict willingness to caregive based on the relationship to a diagnosed individual will begin to shed light on the process of becoming (or not becoming) a caregiver.

**Relationship Differences in Caregiving Influences**

The results indicated that the majority of caregiving influences differed between child/parent and grandchild/grandparent relationships. As expected, children reported greater willingness to caregive, higher degrees of comfort and confidence in carrying out
caregiving tasks, and a lower likelihood of considering institutionalization for their parent compared to grandchildren’s forecasted responses about their grandparents. Unsurprisingly, children’s relationships to their parents were closer than grandchild/grandparent relationships in terms of the expectations they perceived and the level of interdependence in those relationships. Contrary to expectations, the amount of forecasted stress associated with caregiving for a parent or grandparent with AD was similar for children and grandchildren. The lack of existing research in this area limits the explanations for this finding; however, a few possibilities will be discussed.

First, it may be that the nature of AD creates a stressful situation regardless of an individual’s relationship to the diagnosed patient. The large amount of research on caregiver stress and burden is evidence for the high amounts of stress that affects the majority of caregivers. Unfortunately, these studies rarely focus on young caregivers, and in cases in which they do, stress associated with changes in the relationship with the primary caregiver (rather than the care recipient) is assessed. Furthermore, research on caregiver stress commonly explores gender differences rather than relational differences. One exception to this is a study conducted by Deimling, Bass, Townsend, and Noelker (1989) which found that spousal and adult-child ($M = 55$ years) caregivers in shared households reported similar levels of care-related stress. Thus, expected caregiving stress may be influenced more by an awareness of the debilitating symptoms and unrelenting course of AD rather than the relationship to the care recipient.

Second, the measure used to assess stress could be improved. Existing measures on stress assess specific aspects of stress that were inappropriate for the hypothetical scenario used in the current study (e.g., “In the last month, how often have you felt
difficulties were piling up so high that you could not overcome them?"; Perceived Stress Scale; Cohen, Kamarck, & Mermelstein, 1983). Thus, the three questions about forecasted burden, stress, and impact that made up the stress measure may lack content validity and be unrepresentative of the construct.

Lastly and related to the previous point, stress may be interpreted in different ways which may result in a similar overall score despite variation on certain dimensions. Admittedly, the stress measure used in this study was originally named *impact*. It was meant to assess the degree to which an individual expected an AD diagnosis to affect, influence, and change aspects of their life. Impact alone has an ambiguous valence; an individual can be impacted greatly by winning a competition as well as finishing last in the same competition. In contrast, stress and burden have a negative valence. Thus, it may be possible that the similarity of responses between children and grandchildren is based on a similar level of endorsement on different dimensions of stress/impact. To explore this idea, a paired-sampled *t*-test was conducted between relationships for each of the three items in the measure. While stress remained similar across groups (*z* = -.902, *p* > .05), impact and burden showed statistically significant differences for children and grandchildren. Specifically, forecasted impact was higher in the child/parent relationships (*z* = 2.43, *p* = .016) and forecasted burden was higher for the grandchild/grandparent relationships (*z* = -4.14, *p* < .001). These findings suggest that grandchildren may focus more on the negative impression of caregiving while children are more likely to view caregiving as a role that has a more general influence on them. Interestingly, differences in stress scores, although not significant, were similar to the other negatively valenced item—burden. Future research should differentiate these two
(and possible other) dimensions of impact in order to better understand the ways in which emerging adults expect caregiving to affect their lives.

Although the significant differences in caregiving influences revealed in this study may seem intuitive, these findings have strong implications that extend to actual cases of parental and grandparental AD diagnosis. For example, emerging adult grandchildren who choose to caregive may benefit from interventions focused on increasing their comfort with common caregiving tasks and their confidence in carrying out those tasks. While attempts to increase grandchildren’s closeness and felt obligation may be futile, psychoeducation about memory loss and increased dependence on others in AD may help grandchildren improve their levels of confidence and comfort potentially caused by thoughts about caring for a grandparent (often times in an intimate manner) with whom they have a relatively poorer relationship with.

Conversely, emerging adult children who choose to caregive may benefit from their relatively high levels of willingness, comfort, and confidence despite the difficulties associated with caregiving. While these positive expectations could serve as a buffer against the negative effects of caregiving, children may eventually be struck by the harsh reality of caregiving as they begin to learn more about and directly experience the caregiving role. Given the importance of continued emotional support provided by parents throughout young adulthood (Dellmann-Jenkins et al., 2001; Gelman & Greer, 2011), children may be especially vulnerable to their parents’ inevitable inability to provide that support as well as the role-reversal that occurs (Svanberg et al., 2010). Thus, interventions targeted toward children may be most beneficial when they include
psychoeducation about the reality of AD and provide social support when their expectations about caregiving are not met.

**Relationship Differences in Predictors of Willingness to Caregive**

Emerging adults’ willingness to caregive for their parent was predicted by (in order of importance) their perceived comfort in executing caregiving tasks and consideration of institutionalization. Grandchildren’s willingness to caregive was predicted by (in order of importance) confidence in caregiving, consideration of institutionalization, and felt-obligation towards their grandparent. Although institutionalization predicted willingness across both groups, the effects were significantly more pronounced among grandchild/grandparent relationships than child/parent.

These findings suggest that grandchildren are influenced by multiple factors when thinking about their willingness to provide care for a grandparent with AD. On the other hand, children’s beliefs about one factor—the comfort they will have in executing caregiving tasks—greatly influences their willingness to provide care for their parent. Emerging adults may be able to more easily imagine the comfort they would have in executing specific caregiving tasks for their parents compared to their grandparents. Grandchild/grandparent relationships are often auxiliary to their relationships with their parents. Thus, it is highly probable that emerging adults already assist their parents, but not their grandparents, in ways that are similar to caregiving tasks (e.g., help with shopping, food preparations, housekeeping).

Confidence in caregiving was a strong predictor for only grandchild/grandparent relationships. Although emerging adults had significantly greater levels of confidence for
their parents than their grandparents, willingness to caregive for a parent was only dependent on comfort levels with specific caregiving tasks. As emerging adults gain independence, their relationships with adult family members (parents and grandparents) changes so that both parties are seen as equals (Arnett, 1997). Differences in how well emerging adults are able to redefine themselves in their relationships with their parents and grandparents may contribute to their forecasted confidence in caregiving. For example, emerging adults may be able to reach an equality in their relationships with their grandparents sooner than they can with their parents. Thus it would follow that the sense of autonomy and maturity they receive from relationships with their grandparents may influence their confidence in taking on the responsibilities of caregiving.

Institutionalization was a significantly better predictor for willingness to caregive for grandparents but not for parents. Willingness and institutionalization were inversely correlated such that grandchildren with lower levels of consideration of institutionalization were more willing to caregive. Emerging adults are likely to have parents whose relatively young age makes it more difficult to imagine their placement in an institution, whereas thoughts about nursing home placement for older grandparents may be more salient.

For grandchildren, felt obligation to their grandparent dictated their willingness to care rather than the interdependence of that relationship. Grandchildren’s top motivations to care for their grandparent support this finding; on average, grandchildren reported they were motivated to caregive to avoid feeling guilty about not caring. The literature on felt obligation has yet to compare child/parent relationships and grandchild/grandparent relationships so the reason behind its predictive power for
grandchildren over children is not clear. However, considering societal norms of respect
towards the elderly and the typically auxiliary relationship between grandchildren and
their grandparents, grandchildren may be more likely to believe they should or ought to
care for their grandparents because it is their duty (Stein, 1992). Yet it is surprising that
children were not as influenced by felt obligation given Stein and colleagues’ (1998)
emphasis on emerging and young adults’ motivation to “repay” their parents for the care
and attention they received in the recent past. In fact, the sample in the current study,
similarly to the young sample in Dellmann-Jenkins et al. (2001), reported being
motivated to care for their parent to give back the care that had once been given to them.

Interestingly, relationship closeness was not a predictor of willingness to care
for either group. This is especially puzzling given that, on average, children reported that
having a positive and close relationship with their parent was one of their top motivations
to care for them. This may be explained by the changing and complex relationship
between children and their parents during emerging adulthood. Contrary to what is
expected in close relationships, emerging adults’ relationship quality with their parents is
inversely related to their physical proximity (Dubas & Peterson, 1996). Thus, the
simultaneous effort during emerging adulthood to gain autonomy from parents while
maintaining an emotionally supportive relationship (Dellmann-Jenkins et al., 2001;
Gelman & Greer, 2011) may complicate the influence of closeness on willingness to
caregive.

The existing research on factors predicting caregiving is limited to actual
caregivers and their characteristics that maintain their role as a caregiver (e.g., gender,
social support). The results of this study are the first step in understanding the factors
that contribute to the decision to enter a caregiving role. Children’s willingness to
caregive is almost entirely dependent on their forecasted comfort with specific caregiving
tasks while grandchildren consider three caregiving beliefs: confidence,
institutionalization, and felt obligation. These differences support the notion that the
decision to caregive is not the same for everyone.

The current study is not without its limitations. First, the hypothetical design of
this study limited the number of existing measures that were used. Therefore, many of
the measures were either adapted from validated measures or entirely created for this
study. Although Cohen’s alpha levels showed good internal consistency, the validity of
several measures that were composed of a single item could not be assessed. As
previously described, the measure created to assess stress may lack construct validity due
to the complexity of stress/impact. Much more work is needed to go beyond current
caregiving beliefs and accurately assess forecasted motivations for caregiving.

Second, closeness to the hypothetical care recipient may have been better assessed
by a measure other than the RCI (Berscheid et al., 1989). As described above, the RCI
defines closeness as the frequency of time spent together, the diversity of activities done
together, and the influence on different life areas. By focusing on these areas, the RCI
fails to account for other ways in which two individuals can have a close relationship.
This study could benefit from the use of measures that assess attachment and emotional
closeness in relationships.

Third, this study’s hypothetical design challenges the extent to which the findings
can be generalized (Finch, 1987). While the vignettes allowed the exploration of
caregiving beliefs prior to actual caregiving, it is unknown how much participants’
responses would hold true in a real-life situation. Furthermore, the self-report format may have increased participants’ likelihood of responding to survey questions in a manner to present themselves favorably. Future studies on this topic should control for social desirability, especially when assessing forecasted beliefs that cannot be verified.

Finally, since the participants were recruited from an undergraduate population, the demographic heterogeneity is less than what would be expecting from an emerging adult sample. However, school enrollment is only one variable associated with emerging adulthood. Other variables such as autonomy from parents, financial independence, relationship status, and employment were not assessed and are expected to be more diverse than uniformity seen in school attendance. While the characteristics of emerging adulthood has important implications for willingness to caregive, the current study does not permit comparisons to made between other developmental stages. Future research should expand the sample to include individuals in adolescence and young adulthood in order to further assess the uniqueness of emerging adulthood.

In conclusion, emerging adults children have more positive thoughts about caregiving for their parents than grandchildren have for their grandparents. The relationship dynamics during emerging adulthood help to explain these differences. When faced with the decision of whether to caregive, different caregiving beliefs predict willingness to caregive for children and grandchildren. Thus, an AD diagnosis is perceived differently in both general thoughts about caregiving and more specific factors that predict future caregiving based on relationship to the AD patient. These findings have important implications for interventions targeted toward emerging adults who are
faced with a parent or grandparent’s AD diagnosis during a complex developmental stage.
Appendix

Transition to Adulthood

To what degree do you think that you have reached adulthood?

1---------2---------3---------4---------5---------6---------7---------8---------9---------10
Not at all                      Extremely

Alzheimer’s Disease Knowledge

Below are some statements about Alzheimer’s disease. Please read each statement carefully and circle whether you think the statement is True or False. If you aren’t sure of the right answer, make your best guess. It’s important to circle an answer for every statement, even if you’re not completely sure of the answer. (Please complete this survey on your own without the help of outside sources (friends, online search)).

1. People with Alzheimer’s disease are particularly prone to depression.
2. It has been scientifically proven that mental exercise can prevent a person from getting Alzheimer’s disease.
3. After symptoms of Alzheimer’s disease appear, the average life expectancy is 6 to 12 years.
4. When a person with Alzheimer’s disease becomes agitated, a medical examination might reveal other health problems that caused the agitation.
5. People with Alzheimer’s disease do best with simple, instructions given one step at a time.
6. When people with Alzheimer’s disease begin to have difficulty taking care of themselves, caregivers should take over right away.
7. If a person with Alzheimer’s disease becomes alert and agitated at night, a good strategy is to try to make sure that the person gets plenty of physical activity during the day.
8. In rare cases, people have recovered from Alzheimer’s disease.
9. People whose Alzheimer’s disease is not yet severe can benefit from psychotherapy for depression and anxiety.
10. If trouble with memory and confused thinking appears suddenly, it is likely due to Alzheimer’s disease.
12. Poor nutrition can make the symptoms of Alzheimer’s disease worse.
13. People in their 30s can have Alzheimer’s disease.
14. A person with Alzheimer’s disease becomes increasingly likely to fall down as the disease gets worse.
15. When people with Alzheimer’s disease repeat the same question or story several times, it is helpful to remind them that they are repeating themselves.
16. Once people have Alzheimer’s disease, they are no longer capable of making informed decisions about their own care.
17. Eventually, a person with Alzheimer’s disease will need 24-hour supervision.
18. Having high cholesterol may increase a person’s risk of developing Alzheimer’s disease.
19. Tremor or shaking of the hands or arms is a common symptom in people with Alzheimer’s disease.
20. Symptoms of severe depression can be mistaken for symptoms of Alzheimer’s disease.
21. Alzheimer’s disease is one type of dementia.
22. Trouble handling money or paying bills is a common early symptom of Alzheimer’s disease.
23. One symptom that can occur with Alzheimer’s disease is believing that other people are stealing one’s things.
24. When a person has Alzheimer’s disease, using reminder notes is a crutch that can contribute to decline.
25. Prescription drugs that prevent Alzheimer’s disease are available.
26. Having high blood pressure may increase a person’s risk of developing Alzheimer’s disease.
27. Genes can only partially account for the development of Alzheimer’s disease.
28. It is safe for people with Alzheimer’s disease to drive, as long as they have a companion in the car at all times.
30. Most people with Alzheimer’s disease remember recent events better than things that happened in the past.

_Felt Obligation (parent)_

When it comes to their parents, many adults tell us that they sometimes feel they ought to say or do certain things and not other things because they are dealing with their parents. Some people talk about it as a 'need' and say they need to talk to their parents regularly whether they have something new to say or not, because it is important to keep in touch. Other people talk about it like they 'should' keep in touch because they sometimes feel badly if they don't. Here is a list of things people sometimes tell us they 'need to' or 'should' say or do in their relationship with their parents. For each item, use the following scale to indicate how often you feel that you 'need to' or 'should' say and do things in your relationship with parents.

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
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<tbody>
<tr>
<td>rarely</td>
<td>not very</td>
<td>occasionally</td>
<td>somewhat</td>
<td>very</td>
</tr>
<tr>
<td>often</td>
<td>often</td>
<td>often</td>
<td>often</td>
<td>often</td>
</tr>
</tbody>
</table>

1. Visit on holidays
2. Send cards for special occasions
3. Give them gifts for special occasions
4. Make them proud of you
5. Do what they suggest
6. Maintain regular contact
7. Talk about personal things
8. Do them favors
9. Keep peace in the family
10. Not get more than you give
11. Tell them things they want to hear
12. Get the family together for special occasions
13. Return favors
14. Talk about other family members
15. Not give more than you get
16. Do things to please them
17. Let them take care of you
18. Talk about your problems
19. Not ask them for financial help
20. Tell them you love them
21. Take care of them in their old age
22. Be different to them
23. Not argue with them
24. Be your own person when you are together
25. Offer them your help and advice
26. Loan them things
27. Make them happy
28. Keep the giving and the receiving equal in the relationship
29. Talk about their problems

Felt Obligation (grandparent)

[For the sake of brevity, the grandparent version of felt obligation is not show. The grandparent version is identical to the parent version, with the exception of the bolded relationship which was changed to grandparent.]

Parent Version

Relationship Closeness Inventory

As part of this study, please answer the following questions about your relationship with one of your living parents. Specifically, choose the one parent with whom you have the closest, deepest, most involved, and most intimate relationship, and answer the following questions with regard to this particular parent. Please choose this parent carefully since this decision will affect the rest of this questionnaire.

With this person in mind, please respond to the following questions:

1. Who is this person?
   a. Mother
   b. Father

2. How long have you lived with this parent in the past year? Please indicate the number of months/and or weeks (for example, 5 months, 2 weeks).
   _____ months _____ weeks

The following is a list of different activities that people may engage in over the course of one year. For each of the activities listed, please check all of those that you have engaged in alone with your chosen parent in the past year. Check only those activities that were done alone with your chosen parent and not done with your chosen parent in the presence of others.

In the past year, I did the following activities alone with my chosen parent: (Check all that apply)

_____ did laundry
____ prepared a meal
____ watched TV
____ went to an auction/antique show
____ attended a non-class lecture or presentation
____ went to a restaurant
____ went to a grocery store
____ went for a walk/drive
____ discussed things of a personal nature
____ went to a museum/art show
____ planned a party/social event
____ attended class
____ went on a trip (e.g., vacation or weekend)
____ cleaned house/apartment
____ went to church/religious function
____ worked on homework
____ discussed things of a non-personal nature
____ went to a clothing store
____ talked on the phone
____ went to a movie
____ ate a meal
____ participated in a sporting activity
____ outdoor recreation (e.g., sailing)
____ went to a play
____ went to a bar
____ visited family
____ visited friends
____ went to a department, book, hardware store, etc.
____ played cards/board game
____ attended a sporting event
____ exercised (e.g., jogging, aerobics)
____ went on an outing (e.g., picnic, beach, zoo, winter carnival)
____ wilderness activity (e.g., hunting, hiking, fishing)
____ went to a concert
____ went dancing
____ went to a party
____ played music/sang
The following questions concern the amount of influence your chosen parent has on your thoughts, feelings, and behavior. Using the 7-point scale below, please indicate the extent to which you agree or disagree by writing the approximate number in the space corresponding to each item.

1----------2----------3----------4----------5----------6----------7
I strongly disagree  I strongly agree

My chosen parent…
1. Will influence my future financial security.
2. Does not influence everyday things in my life.
3. Influences important things in my life.
4. Influences which parties and other social events I attend.
5. Influences the extent to which I accept responsibilities in our relationship.
6. Does not influence how much time I spend doing household work.
7. Does not influence how I choose to spend my money.
8. Influences the way I feel about myself.
10. Influences the basic values that I hold.
11. Does not influence the opinions that I have of other important people in my life.
12. Does not influence when I see, and the amount of time I spend with, my family.
13. Influences when I see, and the amount of time I spend with, my friends.
14. Does not influence which of my friends I see.
15. Does not influence the type of career I have.
16. Influences or will influence how much time I devote to my career.
17. Does not influence my chances of getting a good job in the future.
18. Influences the way I feel about the future.
19. Does not have the capacity to influence how I act in various situations.
20. Influences and contributes to my overall happiness.
22. Influences how I spend my free time.
23. Influences when I see them and the amount of time the two of us spend together.
25. Influences how I decorate my home (e.g., dorm room, apartment, house).
27. Influences what I watch on TV.

Using the scale below, please indicate the degree to which your future plans and goals are affected by your chosen parent. If an area does not apply to you (e.g., you have no plans or goals in that area), write a 1.

1----------2----------3----------4----------5----------6----------7
Not at all  A great extent
1. My vacation plans.
2. My marriage plans.
3. My plans to have children.
4. My plans to make major life investments (house, car, etc.).
5. My plans to join a club, social organization, church, etc.
6. My school-related plans.
7. My plans for achieving a particular financial standard of living.

Vignette

Dementia is a loss of brain function that occurs with certain diseases. Alzheimer’s disease is the most common form of dementia. It causes memory impairment, as well as problems with language, thinking, judgment, and behavior. These symptoms develop slowly, usually first appearing as forgetfulness, and get worse over time. Eventually, the symptoms of Alzheimer’s disease become severe enough to interfere with daily tasks.

In the early stages of Alzheimer’s disease, memory loss is mild. Individuals in the early stages may have difficulty doing things that take some thought but were once easy. For example, individuals may forget a favorite recipe, the way home from a friend’s house, and how to balance a checkbook. They may also have difficulty remembering people’s names and the names of familiar objects like “refrigerator” or “sweater”. Although memory loss is the main symptom in the early stages of Alzheimer’s disease, changes in personality also appear. For example, individuals with Alzheimer’s disease may become depressed or may get angry more easily.

As individuals enter the late stages of Alzheimer’s disease their symptoms get worse and they are no longer able to take care of themselves. They can no longer drive, read or write, go to the bathroom by themselves, or dress themselves. People with Alzheimer’s disease may become paranoid, believing that their family members are stealing their money or breaking into their house. They may have very little awareness about time, and place. For example, they may not know the year or even what country they are in. They lose the ability to carry on a conversation because they have difficulty speaking and understanding others. People with Alzheimer’s disease also forget who their family members are, even those especially close to them such as their spouse/partner and children. Eventually, people with Alzheimer’s disease forget their own name and history. In time, they can no longer walk or sit up by themselves. They also lose the ability to swallow, making it impossible for them to eat on their own.

Alzheimer’s disease is not a normal part of aging. Anyone can get diagnosed with Alzheimer’s disease even though they have lived a healthy life and they have no family history of it. Although Alzheimer’s disease is typically diagnosed in people 65 and older, people as young as 30 can get it. Those with Alzheimer’s live an average of eight years after their symptoms become noticeable to others, but survival can range from four to 20 years. Alzheimer’s disease has no current cure. Alzheimer’s disease can be especially difficult for the family of the person diagnosed because they watch their family member change into someone different from who they were in the past.
Usually, family members care for their relatives with Alzheimer’s disease at home although some people with Alzheimer’s disease live in nursing homes. Caring for a person with Alzheimer’s disease involves instrumental tasks such as preparing meals, running errands (shopping, banking), doing household tasks (laundry, yard work), doing financial tasks (balancing checkbook), and driving the person to the places they need to go. Caregiving during the late stages of Alzheimer’s disease can be a 24-hour responsibility. As the disease progresses, caregivers provide more assistance by helping the person take their medication, bathe, dress, eat, and use the toilet. People with Alzheimer’s disease in the late stages need to be watched closely to make sure they do not wander and get lost or hurt themselves (by falling, burning themselves on the stove, etc.).

Please imagine that the parent you chose in the previous section has been recently diagnosed with Alzheimer’s disease. Imagine that they have been forgetting things recently, and their visit to their doctor has confirmed that they have Alzheimer’s disease. Please imagine your family is deciding how to best care for your parent who will require more assistance in the future. Imagine that you have been asked to provide regular unpaid care for your parent. Imagine that you live close enough to provide care. If you choose not to help care for your parent, other family members may have to take on this responsibility if they are able to, or your parent may be placed in a nursing home. Please take a moment to think about this situation.

Answer the following questions with regard to the parent you chose in the previous section with whom you have the closest, deepest, most involved, and most intimate relationship …

Anticipated Willingness to Caregive

Please rate the extent to which you would be willing to provide care for your parent if they were diagnosed with Alzheimer’s disease.

\[
\begin{align*}
1 & \quad \text{Definitely}\quad 2 \quad \text{Definitely Willing} \\
3 & \quad \text{Willing} \quad 4 \quad \text{Not Willing}
\end{align*}
\]

Motives for Choosing to Caregive

People often have different motives for caregiving for someone with Alzheimer’s disease whether or not they would actually caregive. Please rate the extent to which the following statements are motivations for you to care for your parent:

\[
\begin{align*}
1 & \quad \text{Not at all} \quad 2 \quad \text{Not at all} \\
3 & \quad \text{Not at all} \quad 4 \quad \text{Not at all} \\
5 & \quad \text{Not at all} \quad 6 \quad \text{Not at all} \\
7 & \quad \text{Not at all} \quad 8 \quad \text{Not at all} \\
9 & \quad \text{Not at all} \quad 10 \quad \text{Extremely}
\end{align*}
\]

1. I am concerned about my parent's well-being and care
2. I feel responsible for my parent's well-being and care
3. I would get a great deal of happiness and pleasure from caring for my parent
4. I have a positive and close relationship with my parent
5. I would enjoy caring for my parent
6. Caring for my parent would make me feel good
7. I would be good at the caregiving tasks involved with caring for my parent
8. I would feel useful and as if I were making a family contribution if I care for my parent
9. I have a desire to care for my parent when they need it
10. Caring for my parent would allow me to avoid my responsibilities (e.g., school, work)
11. It would make me look good if I care for my parent; it would make me look bad if I don't care for my parent
12. I would be rewarded (e.g., praised, thanked, honored, etc.) for caring for my parent
13. I want to develop a closer relationship with my parent and caring for them would help achieve this
14. I would want my parent to be able to depend on me
15. My parent has helped me and cared for me in the past, I would be giving back what has been given to me
16. Caring for my parent would strengthen the bond between us
17. I would feel guilty if I didn't care for my parent
18. I would feel obligated to help my parent; it would be expected of me
19. I have to care for my parent in order for them to accept and love me
20. Caring for my parent would help me make up for a past transgression or offense
21. If I don't care for my parent no one else will
22. I have more flexibility with my work and school than others that would allow me to care for my parent
23. I would care for my parent because of my religious and spiritual beliefs
24. I wouldn't want my parent to be placed in a nursing home

Motives for Choosing Not to Caregive

People often have different motives for not caregiving for someone with Alzheimer's disease whether or not they would actually caregiving. Please rate the extent to which the following statements are motivations for you to not care for your parent using the following scale:

1---------2--------3-------4--------5--------6--------7--------8--------9--------10
Not at all                                               Extremely

1. I would not be good at the caregiving tasks involved with caring for my parent
2. I would not respond well to the stress of caring for my parent
3. I don't have any expertise in caring for someone with Alzheimer's disease
4. I'd prefer to maintain some distance; I'd rather not get involved in caring for my parent
5. Caring for my parent would be a bigger stress than what it's worth
6. I have too many serious responsibilities that would not allow me to care for my parent
7. I am not concerned about my parent's well-being and care
8. I don't have a strong desire to care for my parent
9. I don't feel responsible for my parent's well-being and care
10. I would not want to be tied down or held back by caring for my parent; I want to be able to explore different life opportunities
11. I do not have a close or positive relationship with my parent
12. Someone else in my family will most likely provide care for my parent if I don’t
13. Caregiving is something I cannot see myself doing for my parent
14. I think my parent would be better off in a nursing home

Consideration of Institutionalization

Sometimes family members are unable or unwilling to care for relatives with Alzheimer’s disease. In these cases, they may choose to place their family member in a nursing home rather than providing care at home.

How likely are you to consider a nursing home, boarding home, or assisted living for your parent if they had Alzheimer’s disease?

1-10

Not at all
Extremely likely

Confidence in Caregiving

How confident do you feel about being a caregiver for your parent if they had Alzheimer’s disease?

1-10

Not at all
Extremely confident

Comfort in Executing Caregiving Tasks

People often have different levels of comfort in helping someone with Alzheimer’s disease with specific tasks. Please use the scale below to rate how comfortable you would be in helping your parent with each of the following tasks:

1-10

Not at all
Extremely comfortable

1. Help getting into or out of a bed, chair, wheelchair
2. Help eating meals
3. Help bathing, either in the tub, or a sponge bath, such as rinsing or drying the body, excluding the back
4. Help dressing from the waist up
5. Help dressing from the waist down
6. Help toileting, such as adjusting clothing before and after toilet use
7. Help grooming, such as brushing teeth, combing or brushing hair, washing hands, washing face, and either shaving or applying makeup
8. Help using the telephone
9. Help with shopping (going to a store for light groceries)
10. Help with food preparations (making lunch or light food)
11. Help with housekeeping (making bed, vacuuming)
12. Help with doing laundry
13. Help traveling by car, bus, etc.
14. Help taking medications in the correct dosages or at the correct time
15. Help handling his/her finances

_Stress of Caregiving_

Please use the following scale:

1---------2---------3---------4---------5---------6---------7---------8---------9---------10
Not at all                                            Extremely

1. How stressful would caregiving for your **parent** with Alzheimer’s disease be for you?
2. How much would caregiving for your **parent** with Alzheimer’s disease impact your life?
3. How burdensome would caregiving for your **parent** with Alzheimer’s disease be for you?

_Grandparent Version_

[For the sake of brevity, the grandparent version is not show. The grandparent version is identical to the parent version, with the exception of the bolded relationship which was changed to **grandparent**.]

_Experience with Alzheimer’s Disease_

Have any of your parents, grandparents, other relatives, or a close family friend been diagnosed with Alzheimer’s disease or another dementia in the past five years? **Y/N**

Have you ever spent time with someone with Alzheimer’s disease or developed some sort of close relationship with someone with Alzheimer’s disease in the past five years? **Y/N**

If **Y**, what was your relationship with the person with Alzheimer’s disease?

________________________

If **Y**, to what extent have you provided care for this person?

1---------2---------3---------4---------5---------6---------7---------8---------9---------10
Not at all                                            Extremely
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