

**AGE DIFFERENCES IN CAREGIVER BURDEN: THE ROLE OF SOCIAL
SUPPORT, PREPARATION, AND SOCIAL CONTEXTS**

by

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Age Differences in Caregiver Burden: The Role of Social Support, Preparation, and Social Contexts

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ABSTRACT

Despite over a quarter of informal caregivers in the United States being young adults, a majority of caregiving research focuses on middle-aged and older adults. The limited literature on young adult caregivers indicates that caregivers at this age may experience more burden than older caregivers, along with distinct risk factors for burden (Becker & Becker, 2008a; Levine et al., 2005). The purpose of this study was to compare the levels of burden in caregivers across the lifespan and to test whether support and preparedness for caregiving also vary in ways that could explain the potential age differences in burden. Self-identified caregivers ($n = 452$) were recruited online to complete questionnaires and demographic questions. As hypothesized, when compared to older caregivers, young caregivers reported more subjective burden despite lower objective burden, but contrary to hypotheses young adults reported similar preparation for caregiving, higher social and instrumental support. The hypothesized mediating effects of preparedness, social support, and instrumental support between age and subjective burden were not found. The results indicate that age plays a role in differing perceptions of the caregiving experience likely due to the caregiving context related to age (i.e., relationship status and relation to caregiver), rather than age itself. Future research should focus on how the caregiving context impacts caregiver burden and what practices may be implemented to decrease that burden.

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CHAPTER I

INTRODUCTION

Over the past few decades, a growing amount of research has focused on processes and impacts of informal family caregiving (Burgio, Gaugler, & Hilgeman, 2016). Despite the strides that have been made in understanding family caregivers, the focus has been almost exclusively on middle- and late-life caregivers, adding little to the understanding of the experience of young caregivers (Levine et al., 2005). However, according to the National Alliance for Caregiving's 2015 report, approximately a quarter of informal caregivers in the United States are between 18 and 34 years old (National Alliance for Caregiving & American Association of Retired Persons, 2015). Based on the small literature on young adult caregivers (e.g., Greene, Cohen, Siskowski, & Toyinbo, 2017), it is evident that young adult caregivers experience burden equally if not more so than middle and older adult caregivers. However, no published research assesses how the timing of caregiving affects people differently by directly comparing young adult caregivers and middle-aged and older adult caregivers. Thus, the purpose of the present study was to compare the experience of caregiving across age groups in order to assess how the timing of caregiving (i.e., the age at which it occurs) may be associated with different contexts of caregiving (level of preparation and amount of social and instrumental support for caregiving) that relate to level of burden.

Informal Caregiving Definition

For the purpose of this study, an informal caregiver was defined as ‘an adult who has a significant relationship with, and provides a broad range of assistance for, an adult loved one (e.g., a spouse or parent) with a physical condition,’ which is adapted from the Family Caregiver Alliance’s definition: “any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition” (Family Caregiver Alliance, 2014, para. 6). More specifically, a ‘significant relationship’ is someone who is important to the caregiver outside of the caregiving role, such as a family member or close friend. Furthermore, a ‘loved one’ is someone who the caregiver is affectionate towards in some way, ranging from someone who the caregiver feels obligated to help to someone who the caregiver genuinely wishes to help, depending on the quality of the relationship. Common tasks associated with caregiving are assisting with activities of daily living (e.g., getting in and out of bed/chair, getting dressed, and using the toilet) as well as instrumental activities of daily living (e.g., transportation, shopping, and housework) (NAC & AARP, 2015). Informal caregivers may also help with other activities including communication and advocacy for the care recipient with healthcare professionals, providing emotional support, and monitoring the care recipient's health (NAC & AARP, 2015). Overall, it is estimated that 43.5 million Americans acted as a caregiver for an adult at some point in 2014 (NAC & AARP, 2015).

Theoretical Framework: Lifespan Development

The question of whether and how caregiving differs for younger versus middle or older adult caregivers implies that developmental factors may be involved in the

experience of caregiving, and vice versa. Lifespan developmental psychology is a theoretical orientation that views development as a life-long process that is highly dependent on context as well as individual differences (Baltes, 1987). The experiences of life are viewed as factors that drive development, including events that are history-graded (experienced by a birth cohort), age-graded (experienced by all people of the same age), and nonnormative (experienced individually) (Baltes, 1987).

In the present study, participants were grouped into four groups with age definitions that represent one operationalization of life stages, that although imperfect, distinguishes among groups that are likely to be experiencing similar age-graded experiences. The four age groups included young adult (18-29 years old), early midlife (30-50 years old), late midlife (51-70 years old), and older adult (over 70 years old). By using age as a proxy for development, age-graded events can be viewed as the developmental tasks that are typical of each life stage. Young adults are deciding on their futures by preparing for and entering careers or employment. They are also forming close relationships with friends and may seek a romantic partner (Erikson, 1968). Furthermore, some young adults choose to start a family and engage in child-rearing. The timing of these activities that lead to commitment to life structures is typically in the 20's or can be delayed into the early 30's (Arnett, 2000; Rotz, 2016). Those in early midlife are more likely to be married and engage in child-rearing. They are also more likely to be more settled into their careers of choice compared to those in young adulthood (Arnett, 2000). If they had children as young adults, then they may also be focused on helping to launch their children into adulthood. However, if they had children later then this is more likely to be a focus of late midlife (Erikson, 1968). Late midlife adults also are focused on their

career and planning for retirement typically towards the end of the late midlife stage. Older adults are often most concerned with retirement, finding fulfillment outside of work and child-rearing roles, and adapting to the effects of age-related health challenges (Erikson, 1968).

Social factors related to the age-graded events can influence the experience and outcomes of nonnormative events (Hultsch & Plemons, 1979; Villarreal & Heckhausen, 2015). For instance, those who marry or have children off-time as teenagers report fewer educational and occupational opportunities compared to their peers who marry and/or have children at a normative age (i.e., young or middle adulthood) (Rook, Catalano, & Dooley, 1989). Similarly, those who are widowed at a young age (i.e., middle adulthood or younger) have a different experience than those who become a widow at a more typical age (i.e., older adulthood). Younger widows typically have more social roles and less financial stability compared to older widows, which may help explain why they experience greater psychological distress (Lopata, 1979). A more recent study of widowhood revealed that younger widows report greater declines in self-rated health compared to older widows (Liu, 2012). Furthermore, off-time widows report fewer friendships than on-time widows, who are more likely to have friends in a similar situation whereas off-time widows are more likely to have married friends who may have less time to socialize with single friends (Lopata, 1979).

The experience of caregiving as a nonnormative event may also vary based on the age-graded events that one is currently experiencing. The estimated prevalence of being an informal caregiver for an adult in the United States is about 16% at any given time (NAC & AARP, 2015) although lifetime prevalence is obviously much higher

(computation of lifetime prevalence is not yet published). Given this low prevalence and that caregiving is experienced as an individual and not by an age group or birth cohort, caregiving at any age can be considered a nonnormative event. The present study focused on two social antecedents of caregiving that are highly likely to be experienced differently by young adults versus middle and older adults: preparation for caregiving and social support (from friends/family and medical professionals). This study examines how these two variables may predict burden differently by age, with age being used as a proxy for developmental context for the purpose of this study.

Informal Caregiving and Subjective Burden

No published research was found by this author that has directly compared caregivers across the lifespan in terms of the level of subjective burden (i.e., the caregiver's perception of burden) that they experience due to caregiving. The current study tested the hypothesis that young adults perceive themselves as more burdened than middle-aged and older caregivers, based on the timing of the event and the level of preparedness and support that could be related to the timing of the event. What is known is that there is evidence that some caregivers across the lifespan report significantly poorer physical and mental health compared to non-caregivers (Berghlund, Lytsy, & Westerling, 2015; Butterworth, Pymont, Rodgers, Windsor, & Anstey, 2010; Greene et al., 2017). However, none of these studies included caregivers ranging from young adulthood to older adulthood. Furthermore, they assessed anxiety and depressive symptoms using different measures (and did not all report effect sizes), so a more direct comparison is needed. At this point, the psychological distress of caregivers across the lifespan, whether it be measured based on subjective caregiver burden or

anxiety/depressive symptoms, has not been previously assessed in the same study. In the current study, it is anticipated that young adult caregivers will report feeling less prepared and having less support compared to older caregivers, which will be further discussed below. Greater preparation and support have been correlated with lower distress among middle-aged and older adult caregivers (Archbold et al., 1990; Pakenham, Chiu, Bursnall, & Cannon, 2007; Shiba, Shiba, & Kondo, 2016). Thus, it is hypothesized that young adult caregivers will report more subjective burden compared to older caregivers.

Furthermore, it is hypothesized that this relationship between caregiver age and subjective burden will be at least partially mediated by level of caregiver preparedness, social support, and instrumental support from health providers.

Informal Caregiving and Objective Burden

Objective burden related to caregiving refers to the actual tasks/time involved in caregiving. Some typical measures of objective burden used in caregiving research include number of hours spent caregiving per week (Greene et al., 2017; van Ryn et al., 2011) and the type of tasks done by the caregiver that are usually described as activities of daily living (ADLs) and instrumental activities of daily living (IADLs). ADLs refer to the more basic life tasks (i.e., eating, bathing, dressing, transfers, etc.) and IADLs refer to the more complex tasks that support life in the community (i.e., medication management, shopping, housework, driving, etc.) (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963; Lawton & Brody, 1969).

In terms of the objective workload, caregivers of different age groups differ in amount of time spent providing caregiving services but not in the tasks done (Levine et al., 2005; NAC & AARP, 2015). According to Levine and colleagues (2005), young adult

caregivers help their care recipient with both ADLs and IADLs with the exception of more personal tasks, such as bathing which is not commonly reported by young adult caregivers. Furthermore, young adult caregivers most commonly reported helping with the same IADLs (i.e., shopping, transportation, and housework) and ADLs (i.e., getting out of bed, dressing, and toileting) as middle-aged and older adult caregivers reported in the National Alliance for Caregiving's 2015 report (Levine et al., 2005; NAC & AARP, 2015).

However, there does appear to be a difference in number of hours spent caregiving per week across these age groups, which is a typical measurement of objective burden used in caregiving research (Greene et al., 2017; van Ryn et al., 2011). Based on the National Alliance for Caregiving's 2015 report, young adults provide the least amount of care per week ($M = 29.79$ hours, $SD = 31.53$ hours), followed by early midlife caregivers ($M = 30.62$ hours, $SD = 29.41$ hours), late midlife caregivers ($M = 34.68$ hours, $SD = 31.31$ hours), and older adults who provide the most amount of care per week ($M = 38.92$ hours, $SD = 31.59$ hours). There are some confounding variables that can help explain these differences on hours spent caregiving. For instance, younger caregivers are more likely to be employed, thus they have less time to devote to their caregiving responsibilities. Furthermore, those who care for a spouse ($M = 47.91$ hours, $SD = 30.40$ hours) spend more time caregiving compared to those who care for a parent ($M = 29.01$ hours, $SD = 29.58$ hours). Younger caregivers are more likely to care for a parent and older caregivers are more likely to care for a spouse, which means they spend more time caregiving than younger caregivers. Thus, it appears that, generally, the older the caregiver is, the more time they invest in the caregiving workload due to their

caregiving context (i.e., less likely to be employed, more likely to live with care recipient, and more likely to be caring for a spouse which requires more care). This study predicts that young adult caregivers will report lower number of hours spent caregiving per week compared to older caregivers due to the context of the caregiving situation.

Informal Caregiver Age and Preparedness

Due to social expectations as well as previous experience, older caregivers may be more prepared for the tasks of caregiving than younger caregivers. Although caregiving at any age is considered nonnormative, it is particularly nonnormative for those caregiving during young adulthood given that it is off-time. According to the National Alliance for Caregiving's 2015 report, only 24% of adult caregivers are between the ages of 18 and 34 and 53% of caregivers are 50 years old or older (NAC & AARP, 2015). Thus, cultural awareness may lead young adults to recognize that they are "off-time" (Neugarten & Hagestad, 1976) which may contribute to them feeling less prepared. Studies on timing of major life events showed that, in general, those who feel off-time compared to their peers, often feel a sense of incompetence and decreased overall well-being (Helson, Mitchell, & Moane, 1984; Sharon, 2016). A study that assessed attitudes about caregiving among non-caregiving college students revealed that they reported low levels of preparedness, despite their positive attitudes towards potentially caring for their older relatives (Joshi, 2016). This could be explained partially by the fact that young adults have less opportunity than middle-aged or older adults to have had their own caregiving experience. Although some young adults may have experience caring for their children, they are less likely to have had their own experience caring for an adult, such as a parent or grandparent. Moreover, given the lower prevalence of caregiving as a young

adult, young caregivers likely have had less opportunity to observe the caregiving experiences of friends and family compared to older caregivers.

Age may influence perception of preparedness, a factor that would be important given that lack of preparedness has been shown to contribute to subjective caregiver burden. Middle and older adult caregivers who reported feeling more prepared for the tasks of caregiving also reported lower subjective caregiver burden (Archbold, Stewart, Greenlick, & Harvath, 1990; Scherbring, 2002). Although the relationship between preparedness and subjective burden has not been specifically studied in young adult caregivers, research has indicated that experiencing life events off-time may be more stressful because there is less time to prepare for the event (Neugarten & Hagestad 1976). Given that caregiving is considered off-time in young adulthood, it is hypothesized that young adult caregivers will report lower preparedness for caregiving compared to older caregivers. Assuming this hypothesis is supported, it is also hypothesized that preparedness may mediate the anticipated relationship between age and subjective caregiver burden, discussed above.

Informal Caregiving and Social Support

The level of social support from friends and family can significantly impact perceptions of the caregiving experience (Haley et al., 1995; Pakenham et al., 2007). Perceived social support refers to how supported a person feels, whereas received social support refers to the number of people that visit them. A higher reported level of perceived social support has been found to be related to significantly less subjective burden and better adjustment, whereas received social support is not significantly related to level of burden or adjustment (del-Pino-Casado et al., 2018; Haley, Levine, Brown, &

Bartolucci, 1987; Pakenham et al., 2007; Shiba et al., 2016). Yet, caregivers often report less perceived social support than non-caregivers of a similar age (Butterworth et al., 2010; Dellman-Jenkins & Blankemeyer, 2009). A study conducted by Haley and colleagues (1995) revealed that middle-aged and older adult caregivers reported more visits from extended family members compared to non-caregivers (i.e., more received support), but less satisfaction from that social support compared to non-caregivers (i.e., less perceived support) (Haley et al., 1995). Furthermore, compared to non-caregivers, caregivers reported fewer social activities and decreased ability to leave the home due to their care recipient's needs. Although the increased visits from family members help to compensate for caregivers' decreased ability to socialize, it appears that caregivers view this support as lower quality compared to the support they may receive if they were more able to engage in social activities like they were prior to taking on the caregiving role (Haley et al., 1995).

Although research has not yet directly compared levels of perceived social support between age groups, it may be that young adult caregivers perceive less support compared to older caregivers because of their developmental context. More specifically, it may be that the decrease in received support may be more salient to young adult caregivers because socialization and formation of close relationships with others is particularly important during the young adulthood stage (Erikson, 1968). Research has indicated that, among young adults, social support from family, friends, and romantic partners can mediate the relationship between stress and well-being (Lee, Goldstein, & Dik, 2017). Furthermore, due to the timing of the event, young caregivers may perceive less support because their peers are unlikely to relate to their caregiving situation. A

national study conducted by Young Carers International in the United Kingdom found that young adult caregivers feel a ‘burden of maturity,’ which makes it difficult for them to relate to their non-caregiving peers (Becker & Becker, 2008a). In contrast, older caregivers likely have more friends who understand their situation given that their age-peers are more likely to act as caregivers for their aging parents and/or spouses based on the higher prevalence rate of older caregivers compared to younger caregivers (NAC & AARP, 2015). Moreover, compared to older caregivers, young adult caregivers are less likely to be caring for a spouse (NAC & AARP, 2015). Haley and colleagues (1995) found that those caring for a spouse had more received social support than those caring for persons other than a spouse. Thus, due to differences in both the caregiving and developmental context, this study predicts that young adult caregivers will report less social support related to caregiving compared to older caregivers. Assuming this hypothesis is supported, it is also hypothesized that social support may mediate the anticipated relationship between age and subjective caregiver burden discussed above.

Informal Caregiving and Instrumental Support from Providers

The presence of instrumental support from health providers (i.e., doctors, nurses, social workers, etc. providing support and information to caregivers) can also impact the caregiving experience. For instance, 42% of caregivers who engage in medical/nursing tasks, do so without training and are subsequently likely to experience higher caregiver burden (NAC & AARP, 2015). Similarly, both young adult caregivers (Becker & Becker, 2008a; Levine et al., 2005) and middle/older adult caregivers (Lund, Ross, Petersen, & Groenvold, 2015) report being dissatisfied with the amount of information that they received from medical professionals. As is the case with social support, researchers in the

United States have not yet directly compared younger and older caregivers' perception of instrumental support from medical professionals and other caregiving resources.

However, research conducted in the United Kingdom has indicated that support services for young adult caregivers (i.e., 18-24 years old) are particularly limited compared to support services for caregivers of other ages given that they no longer qualify for services directed toward child caregivers (under 18 years old) and that services for adult caregivers are not directed towards this age group (Becker & Becker, 2008b). Based on this finding, the present study predicts a similar finding that young adult caregivers will report less instrumental support from health providers compared to older caregivers.

Assuming this hypothesis is supported, it is also hypothesized that instrumental support from health providers may mediate the anticipated relationship between age and subjective caregiver burden discussed above.

Present Study

The purpose of the present study was to assess how the timing of caregiving within the lifespan (as measured by age) differently impacts the amount of burden experienced, the level of preparedness for caregiving, and the level of social support perceived. After reporting descriptive findings on the levels of preparation, support, and burden in the four age groups (young adult, early midlife, late midlife, and older adult) of caregivers, specific hypotheses will be tested. Young adult caregivers are expected to differ from late midlife and older adult caregivers but not from early midlife caregivers based on the idea that young adult and early midlife caregivers may be engaged in different normative age-graded events but are both likely to view the caregiving experience as "off-time" and, thus, are unlikely to significantly differ from each other in terms of their perceptions of

caregiving. Given that young adults and those in early midlife are not hypothesized to significantly differ from one another, the early midlife group was excluded from the tests of these primary hypotheses.

- 1) Young adult caregivers will report significantly more subjective burden than late midlife caregivers or older adult caregivers.
- 2) Young adult caregivers will report significantly less objective burden (as measured by hours per week spent caregiving) than late midlife caregivers or older adult caregivers.
- 3) Young adult caregivers will report significantly lower preparation for caregiving than late midlife caregivers and older adult caregivers.
- 4) Young adult caregivers will report significantly lower social support related to caregiving than late midlife caregivers and older adult caregivers.
- 5) Young adult caregivers will report significantly lower instrumental support from health professionals than late midlife caregivers and older adult caregivers.
- 6) The relationship between caregiver age and subjective burden will be partially mediated by 3 variables:
 - a. Level of preparation
 - b. Social support
 - c. Instrumental support

After testing these primary hypotheses, secondary analyses will be conducted to assess whether any differences found between age groups in preparedness, support, and burden are due to the caregiver's age or due to other relevant contextual factors, relationship status and relationship to caregiver. Based on the present sample and the

national sample (NAC & AARP, 2015), young adult and early midlife caregivers are primarily unmarried and caring for a parent or grandparent, whereas late midlife and older adult caregivers are primarily married and caring for a spouse or parent. Thus, secondary analyses using these context variables will be beneficial in assessing whether changes in preparedness, support, and burden are due to the caregiver's age or other aspects of the caregiving context.

CHAPTER II

METHODS

Participants

Self-identified caregivers ($n = 452$) were surveyed for this study. All participants were English-speaking, living in the United States, and 18 years or older. Each participant indicated meeting the definition of caregiving described at the start of the study: an adult who has a significant relationship with and provides a broad range of assistance for an adult loved one (e.g., a spouse or parent) with a physical condition (e.g., cancer, diabetes, stroke, Alzheimer's/dementia, etc.). Participants were recruited through Quest MindShare, a research panel company that utilized their targeted caregiver panel as well as their general United States population panel to recruit relevant participants. Compared with other panel companies (i.e., Qualtrics and Amazon Mechanical Turk), Quest MindShare projected a sample that best fit with the racial demographic of the National Alliance for Caregiving's 2015 report of caregivers in the United States. Thus, this company appeared to be the best match for collecting data in a timely manner that best represented the national sample. For the present study, quota sampling was used in order to ensure that the number of participants in each age group was relatively equal. Data collection ran for approximately one month from November 9, 2018 to December 4, 2018. Of the 2,179 initial respondents, 1,671 endorsed being a caregiver. Of the 1,671, 1,219 were eliminated due to failing the primary attention check ($n = 1,160$), inconsistently responding to both age questions ($n = 5$), typing randomly in open-text

questions ($n = 23$), or reporting their care recipient having a non-physical condition ($n = 31$). Across two studies conducted by Hauser and Schwarz (2016), the attention check pass rates were 39% and 26%. Although 27% for the present study is toward the lower end, the pass rate is comparable to past research. The remaining 452 (27%) of the 1,692 caregivers were considered valid and included in the final analysis (see Figure 1).

Sample descriptives are listed in Tables 1 and 2. In order to compare to national demographics, the National Alliance for Caregiving's 2015 report was used. The data from the 2015 report were limited to adult participants caring for an adult with a physical condition with complete data which aligns with the specifications of the present study. It is notable that the present sample differed in some ways from the national sample. The sample ($n = 452$) of the present study was primarily female (75.4%), White (69.7%), and married (56.2%). This somewhat differs from the national sample ($N = 393$) which was 61.1% female, 58.3% White, and 59.8% married. In the present study, 52.4% of the sample was employed and in the national sample about 42.7% were employed. In terms of living situation, 69.0% of caregivers in the present study reported living with the care recipient, whereas 59.8% of the national sample reported living with the care recipient. All participants in the national sample reported being a primary caregiver, and 86.9% of the present study sample reported being a primary caregiver. In both samples, caregivers primarily cared for a parent (43.4% in present sample; 45.5% in national sample) or spouse (30.1% in present sample; 27.2% in national sample). Due to deliberate sampling to meet age group quotas, the average caregiver age in the present study was 48.77 ($SD = 17.22$), compared with 58.60 ($SD = 16.66$) in the national study. Lastly, caregivers in

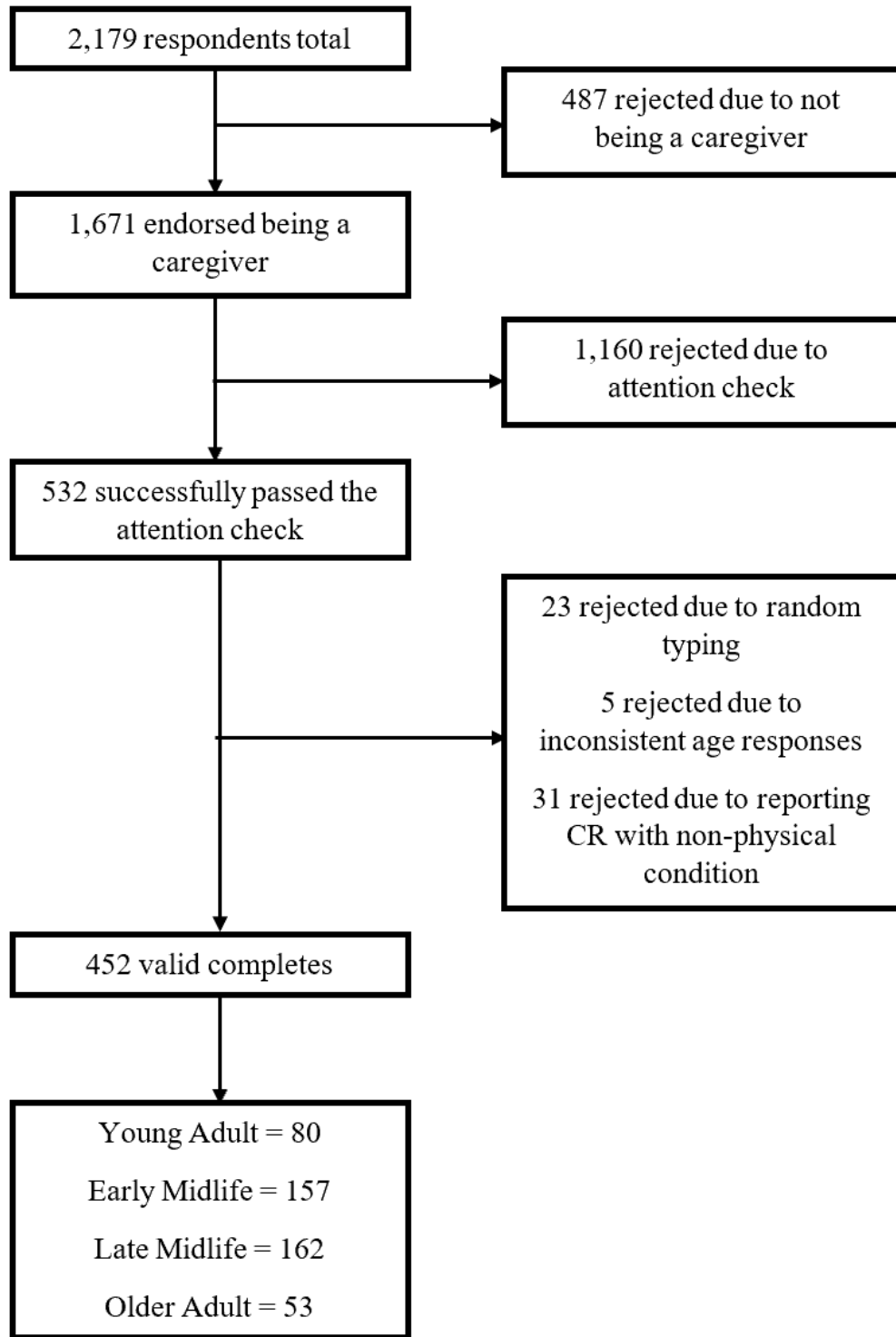


Figure 1. Sampling Flowchart

Table 1

Demographic frequencies

Variable	Full Sample (N = 452)		Young Adult (n = 80)		Early Midlife (n = 157)		Late Midlife (n = 162)		Older Adult (n = 53)	
	%	N	%	N	%	N	%	N	%	N
Gender										
Male	24.6	111	18.8	15	24.8	39	24.1	39	34.0	18
Female	75.4	341	81.3	65	75.2	118	75.9	123	66.0	35
Race										
White	69.7	315	55.0	44	63.1	99	76.5	124	90.6	48
Black	13.9	63	21.3	17	18.5	29	10.5	17	0.0	0
Hispanic	7.3	33	17.5	14	6.4	10	4.9	8	1.9	1
Asian	6.0	27	5.0	4	8.9	14	3.7	6	5.7	3
Other	3.1	14	1.3	1	3.2	5	4.3	7	1.9	1
Employment										
Employed	52.4	237	81.3	65	67.5	106	37.0	60	11.3	6
Not employed/ retired	47.5	215	18.8	15	32.5	51	63.0	102	88.7	47
Relationship status										
Married	56.2	254	31.3	25	49.7	78	67.9	110	77.4	41
Previously Married	16.6	75	1.3	1	16.6	26	23.4	38	9.4	5
Never Married	27.2	123	67.5	54	33.8	53	8.6	14	3.8	2
Relation to caregiver										
Parent	43.4	196	42.5	34	57.3	90	42.0	68	7.5	4
Spouse	30.1	136	8.8	7	15.9	25	41.4	67	69.8	37
Grandparent	12.6	57	40.0	32	14.0	22	1.9	3	0.0	0
Other	13.9	63	8.9	7	12.6	20	14.8	24	22.6	12
Involvement level										
Primary Caregiver	86.9	393	77.5	62	87.3	137	90.7	147	88.7	47
Not Primary Caregiver	13.0	59	22.5	18	12.7	20	9.2	15	11.3	6
Living arrangement										
With care recipient	69.0	312	65.0	52	68.2	107	67.3	109	83.0	44
Not with care recipient	31.0	140	35.0	28	31.8	50	32.7	53	17.0	9

Table 2

Independent and dependent variable descriptives by age group M (SD)

Variable	Full Sample (N = 452)	Young Adult (n = 80)	Early Midlife (n = 157)	Late Midlife (n = 162)	Older Adult (n = 53)
Age (in years)	48.77 (17.22)	24.49 (3.47)	39.74 (6.12)	60.79 (5.39)	75.47 (4.60)
Physical Health	3.20 (0.97)	3.53 (1.01)	3.16 (1.00)	3.07 (0.90)	3.25 (0.92)
Social Support	7.31 (4.68)	9.71 (4.57)	8.18 (4.92)	5.85 (3.98)	5.53 (3.96)
Instrumental Support	5.47 (4.29)	6.39 (4.60)	5.83 (4.61)	4.95 (4.00)	4.57 (3.25)
Preparedness	3.00 (1.08)	3.06 (1.12)	3.01 (1.10)	2.94 (1.09)	3.08 (0.96)
Subjective Burden	33.56 (18.24)	36.51 (18.57)	35.62 (18.95)	32.75 (16.87)	25.42 (17.58)
Hours Spent Caregiving	44.90 (42.05)	36.89 (33.23)	41.96 (37.92)	51.57 (47.30)	45.43 (46.65)

both the present study ($M = 3.20$, $SD = 0.97$) and the national study ($M = 3.30$, $SD = 0.95$) reported their physical health as average.

The four age groups created for the present study differed significantly on several but not all demographic variables. The younger age groups were significantly more racially diverse compared to the older age groups, $\chi^2(12) = 42.71$, $p = .03$. Specifically, 55% of young adults reported being White compared to 63.1% of those in early midlife, 76.5% of those in late midlife, 90.6% of older adults. Furthermore, young adult and early midlife caregivers were more likely to report being employed compared to those in late midlife and older adulthood, $\chi^2(6) = 162.22$, $p = .00$. In terms of relationship status, the older the caregiver, the more likely they were to be married, $\chi^2(6) = 115.75$, $p = .00$. Lastly, differences were found in terms of the caregivers' relationships to their care recipients, $\chi^2(9) = 154.10$, $p = .00$. Young adult and early midlife caregivers primarily provide care for parents and grandparents, whereas late midlife and older adult caregivers primarily provide care for parents and spouses. No significant group differences were found in terms of gender, care involvement, and whether the caregiver lives with or does not live with the care recipient.

Measures

Caregiver Burden. The Zarit Burden Interview (ZBI) assessed subjective caregiver burden. The 22-item self-report measure uses an item response format of a 5-point Likert scale ranging from 0 (*Never*) to 4 (*Nearly always*) that is summed to produce a potential score range of 0-88 (Zarit, Reever, & Back-Peterson, 1980). Sample items include "Do you wish you could leave the care of your care recipient to someone else?" and "Are you afraid what the future holds for your care recipient?". The ZBI

demonstrates internal consistency reliability ($\alpha = .92$) and convergent validity with the Center for Epidemiological Studies Depression Scale among family caregivers of dementia patients (Hérbert, Bravo, & Prévile, 2000). In the present study, the measure was found to be internally consistent ($\alpha = .95$).

Caregiving Preparedness. The Caregiver Preparedness Scale (CPS) assesses preparation to care for the care recipient's physical needs and emotional needs, as well as to manage their health care and emergency situations (Archbold et al., 1990). The CPS is an 8-item measure using a 5-point Likert response scale ranging from 0 (*Not at all prepared*) to 5 (*Very well prepared*) (Archbold et al., 1990). Sample items include “How well prepared do you think you were to respond to and handle emergencies that involve your care recipient?” and “How well prepared do you think you were to take care of your care recipient's physical needs?”. The measure is scored by averaging the responses to the eight statements; thus, scores range from 0 to 5 with a higher mean score indicating better preparedness (Archbold et al., 1990). The measure demonstrates test-retest reliability and convergent validity with the Caregiver Competence Scale, Rewards of Caregiving Scale, and the Hospital Anxiety and Depression Scale among caregivers (Petruzzo et al., 2017). In the present study, the measure was found to be internally consistent ($\alpha = .94$).

Social Support. The social support measure used for this study is the Personal Support section of the Duke Social Support and Stress Scale (DUSOCS) that asks about the level of support available from 10 types of relationships (e.g., significant other, children/grandchildren, neighbors, etc.) (Parkerson, Broadhead, & Tse, 1991). Participants are asked to decide how much each person (or group of persons) is supportive for them related to their caregiving experience. Response options include

“None”, “Some”, “A lot”, and “There is no such person” that are scored from 0 (none or no such person), 1 (some), 2 (a lot). The items are summed into a score ranging from 0 to 20, with higher scores reflecting higher levels of support. Among adult family practice patients, the measure demonstrates test-retest reliability and convergent validity with the DUKE health profile (i.e., physical health, mental health, social health, general health, perceived health, and self-esteem), Family Strengths measure, and the Family Inventory of Life Events (Parkerson et al., 1991; Parkerson, Broadhead, & Tse, 1992). In the present study, the measure was found to be internally consistent ($\alpha = .79$).

Instrumental Support. Instrumental support was measured using a slightly adapted response format for responding to the eight types of instrumental social support that were chosen by Shiba, Kondo, and Kondo (2016). Participants are asked to select all sources of support available to them in response to the question, “Do you have anyone to consult when you have trouble with caregiving?” (Shiba et al., 2016). For this study, in order to be consistent with the social support questions, these additional sources were displayed in the same format as the DUSOCS and used the response options “None”, “Some”, “A lot”, and “There is no such person” that are scored from 0 (none or no such person), 1 (some), 2 (a lot) (Parkerson et al., 1991). Participants are asked to decide how much each person (or group of persons) is supportive for them related to their caregiving experience. The instrumental support relationships assessed include caregiver’s family physician, care managers, home-helpers, visiting nurses, public health nurses, social workers, officers, in public institutions, and others (Shiba et al., 2016). The items were summed into a single instrumental support score ranging from 0 to 16, with higher scores indicating higher levels of support. Although there has not been a published validation

assessing instrumental support as it is used in this adapted measure, the presence of these forms of instrumental support have been significantly correlated with decreased caregiver burden (Shiba et al., 2016). In the present study, this adapted measure was found to be internally consistent ($\alpha = .85$).

Caregiver Demographics/Information. All participants were asked to report their age, gender, race, employment status, relationship status, and perceived physical health. Age (measured in years) was used as a continuous variable for the path analyses. Age was used as a grouping variable for the ANOVA analyses with four groups; young adult (18-29 years old), early midlife (30-50 years old), late midlife (51-70 years old), and older adult (over 70 years old). Perceived physical health was assessed by asking “how would you rate your overall physical health?” with responses on a Likert scale ranging from 1 (*poor*) to 5 (*excellent*) (Jylha, 2009). They were also asked to answer questions regarding their relationship to the caregiver, the amount of time they spend caregiving each week (in hours), whether the care recipient lives with the caregiver, and whether or not they are the primary caregiver for their care recipients.

Procedure

Upon approval of the protocol from the UCCS Institutional Review Board (Appendix A), the Qualtrics survey was activated and Quest MindShare staff began participant recruitment. Quest MindShare utilized their targeted caregiver panel as well as their general United States population panel to recruit relevant participants. Participants were first asked whether they fit the definition of an informal caregiver (Appendix B). If they stated that they fit with the definition, they were shown a consent form and asked to agree to participate prior to continuing with the rest of the survey (Appendix C).

Participants were then asked for their age and their relationship to the person for whom they provide care (Appendix D). Participants then were asked to complete the Zarit Burden Interview (Appendix E), the social support and instrumental support measures (Appendix F), and the Caregiving Preparedness Scale (Appendix G). The order of the scales was counterbalanced across participants. They were then presented with an attention check (Appendix H). The attention check page began with the following statement: “This question is not related to the caregiving experience. To show that you are reading this question, please choose the second choice, green. This helps to ensure that the researchers are collecting quality responses that reflect the true caregiving experience.” Below the statement, the question was “What color is the sky?” with the response options of “blue” or “green”. Based on the opening paragraph, only those who answered “green” passed the attention check. Lastly, they were asked to complete the series of demographic questions (Appendix I) and were shown the debriefing page (Appendix J). In addition to the primary attention check, participant responses were screened for other attention errors, such as random typing in questions with a text box and inconsistencies in responses (i.e., reporting one age at the beginning of the survey and a different age at the end). In order to receive the type of compensation agreed upon with Quest Mindshare (e.g., money, gift cards, airline miles, etc.), the participant identification codes were shared with Quest MindShare following data collection. Compensation was handled through Quest MindShare, who offers participants a variety of compensation options that each participant chooses when they join Quest MindShare’s research pool. The average time spent completing the survey was approximately 30 minutes.

Data Analysis Plan

Descriptive statistics of participant demographics and independent and dependent variables are reported for the current sample. ANOVAs and test of indirect effects using structural equation modeling are used to test all hypotheses. All statistical analyses were conducted using IBM SPSS v.25 and IBM SPSS AMOS 25.

Step 1: Data cleaning. After downloading participant responses from Qualtrics to SPSS, the data were screened for missing data and imputation errors. Scores for each questionnaire (i.e., Caregiver Preparedness Scale, Zarit Burden Interview, etc.) were summed and/or averaged based on the scoring instructions for each questionnaire explained in the Measures section.

Step 2: Descriptives. Frequencies for all demographic variables as well as descriptive statistics for the independent and dependent variables were calculated based on the whole sample as well as based on each age group. Skewness and kurtosis statistics were used to assess normality of continuous variables and to check for outliers. Statistical violations were handled in accordance with best practice given the pattern and impact on the data.

Step 3: One-Way ANOVAs. The statistical assumptions of ANOVA were assessed prior to testing the hypotheses. Hypotheses 1 through 5 were tested using five one-way ANOVAs with age group as the independent variable and preparedness, social support, instrumental support, subjective burden, and objective burden as the dependent variables. For all tests significant at the $p < .05$ level, planned contrasts were calculated comparing the young adults to the other three age groups. For variables that met the assumption of homogeneity of variance, the “equal variances assumed” output was used.

For variables that did not meet the assumption of homogeneity of variance, the “equal variances not assumed” output was used.

Step 4: Mediation Analysis. In order to assess the combined mediational impact of preparedness level, social support, and instrumental support on the relationship between age and subjective burden, a test of indirect effects using structural equation modeling (SEM) was utilized. Testing mediation through SEM is superior to testing mediation through multiple regression given that it controls for Type I error by allowing multiple potential mediators to be tested simultaneously (Musil, Jones, & Warner, 1998).

Step 5: Two-Way ANOVAs. The statistical assumptions of ANOVA were assessed prior to testing the hypotheses. For the secondary analyses, ten two-way ANOVAs were conducted. Four were done with relationship to caregiver (parent, spouse, or other) and age (young adult, early midlife, late midlife, and older adult) as the independent variables and subjective burden, objective burden, preparedness, social support, and instrumental support as the dependent variables and the remaining four were done with relationship status (married or not married) and age (young adult, early midlife, late midlife, and older adult) as the independent variables and subjective burden, objective burden, social support, and instrumental support as the dependent variables.

CHAPTER III

RESULTS

Age Differences in Burden, Support, and Preparation for Caregiving

The means and standard deviations of all variables of interest are listed in Table 2. All dependent variables (i.e., preparedness level, level of social support, level of instrumental support, level of subjective burden, and number of hours spent caregiving per week) were relatively normally distributed with skewness indices ranging from 0.03 to 1.70. The statistical assumption of independence of participants was satisfied given that each participant only served in one age group and they were not influenced by other's responses because they participated individually. For all tests significant at the $p < .05$ level, planned contrasts were calculated comparing the young adults to the other three age groups.

The main effect of age on level of subjective burden was significant, $F(3, 172.82) = 5.16, p = .00, \eta_p^2 = .03$ (Figure 2). The assumption of homogeneity of variances was met ($p = .43$) so planned contrasts were calculated using the "equal variances assumed" option in SPSS. Planned contrasts revealed that young adults ($M = 36.51, SD = 18.57$) reported significantly higher levels of subjective burden compared to older adults ($M = 25.42, SD = 17.58$), $F(115.68) = 3.49, p = .001$. No significant differences in level of subjective burden were found between young adults and those in late midlife ($M = 32.75, SD = 16.87$), *ns*.

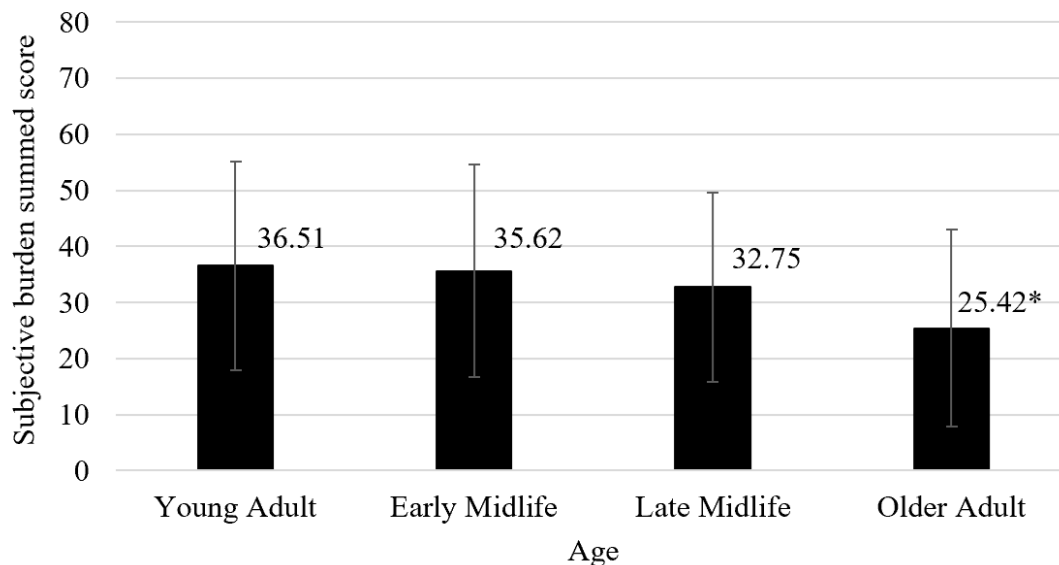


Figure 2. Hypothesis 1: Subjective burden as a function of age

* Group significantly differs from young adults, $p < .05$

The main effect of age on objective burden was significant, $F(3, 169.83) = 2.71, p = .04, \eta_p^2 = .02$ (Figure 3). The assumption of homogeneity of variances was violated ($p = .01$), so planned contrasts were calculated based on “equal variances not assumed” in SPSS. Planned contrasts revealed that young adults ($M = 36.89, SD = 33.23$) reported significantly less objective burden, as measured by the number of hours spent caregiving per week, compared to those in late midlife ($M = 51.57, SD = 47.30$), $F(212.02) = -2.79, p = .01$. No significant differences in level of objective burden were found between young adults and older adults ($M = 45.43, SD = 46.65$), *ns*.

The main effect of age on preparedness level was not significant, $F(3, 448) = 0.35, ns$, so no planned contrasts related to this variable were calculated (Figure 4).

The main effect of age on social support was significant, $F(3, 175.11) = 19.10, p = .00, \eta_p^2 = .11$ (Figure 5). The assumption of homogeneity of variances was violated ($p = .00$) so planned contrasts were calculated using the “equal variances not assumed”

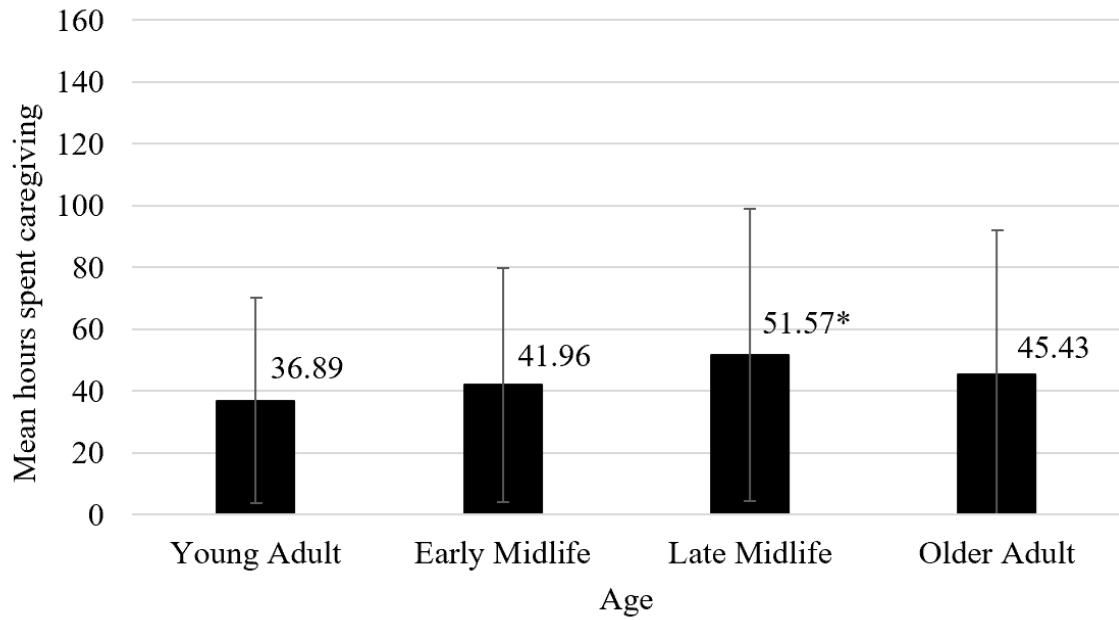


Figure 3. Hypothesis 2: Objective burden as a function of age

* Group significantly differs from young adults, $p < .05$

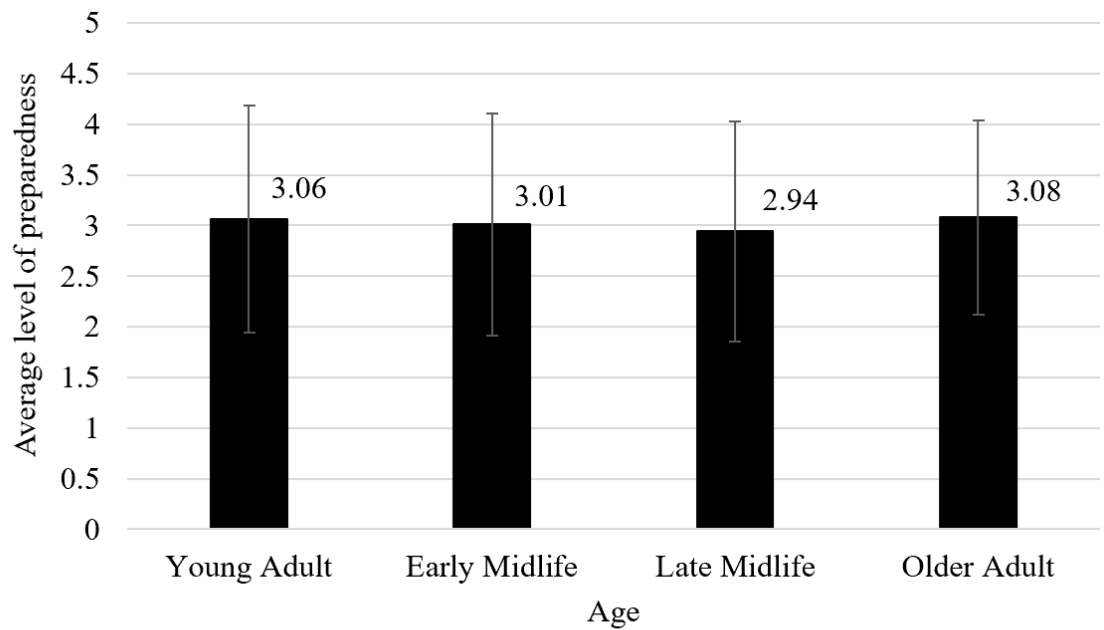


Figure 4. Hypothesis 3: Preparedness as a function of age

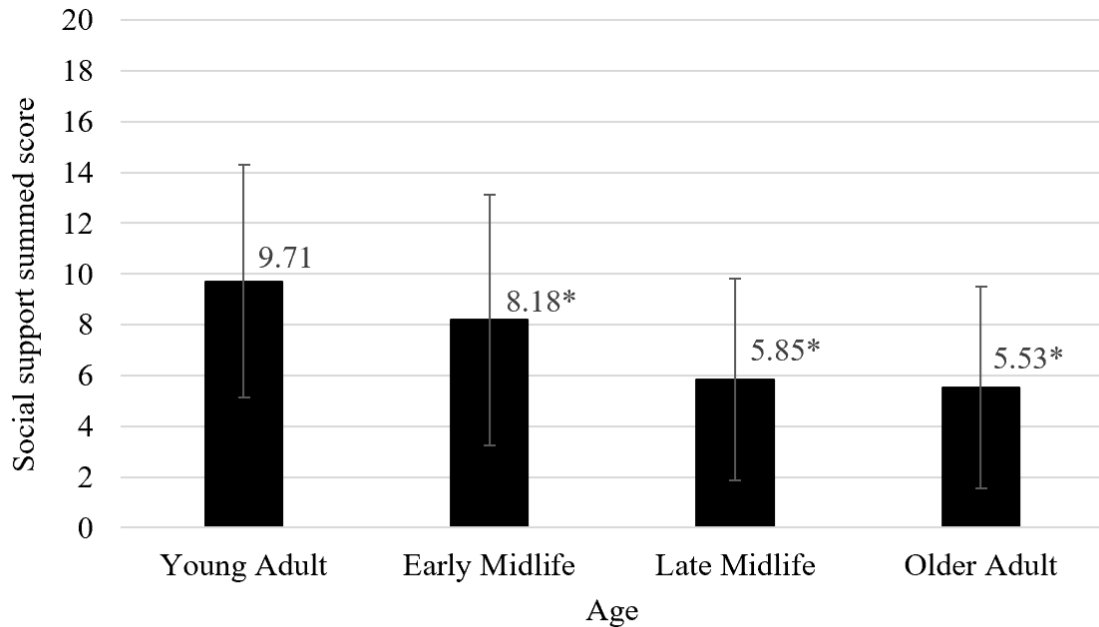


Figure 5. Hypothesis 4: Social support as a function of age

* Group significantly differs from young adults, $p < .05$

option in SPSS. Planned contrasts revealed that young adults ($M = 9.71$, $SD = 4.57$) reported significantly more social support than those in late midlife ($M = 5.86$, $SD = 3.98$), $F(139.76) = 6.43$, $p = .00$, and older adulthood ($M = 5.53$, $SD = 3.96$), $F(121.76) = 5.60$, $p = .00$.

The main effect of age on instrumental support was significant, $F(3, 181.53) = 3.47$, $p = .02$, $\eta_p^2 = .02$ (Figure 6). The assumption of homogeneity of variances was violated ($p = .02$) so planned contrasts were calculated based on “equal variances not assumed” in SPSS. Planned contrasts revealed that young adults ($M = 6.39$, $SD = 4.60$) reported significantly more instrumental support than those in late midlife ($M = 4.95$, $SD = 4.00$), $F(139.39) = 2.39$, $p = .02$. Young adults also reported significantly more instrumental support than older adults ($M = 4.57$, $SD = 3.25$), $F(130.42) = 2.68$, $p = .01$.

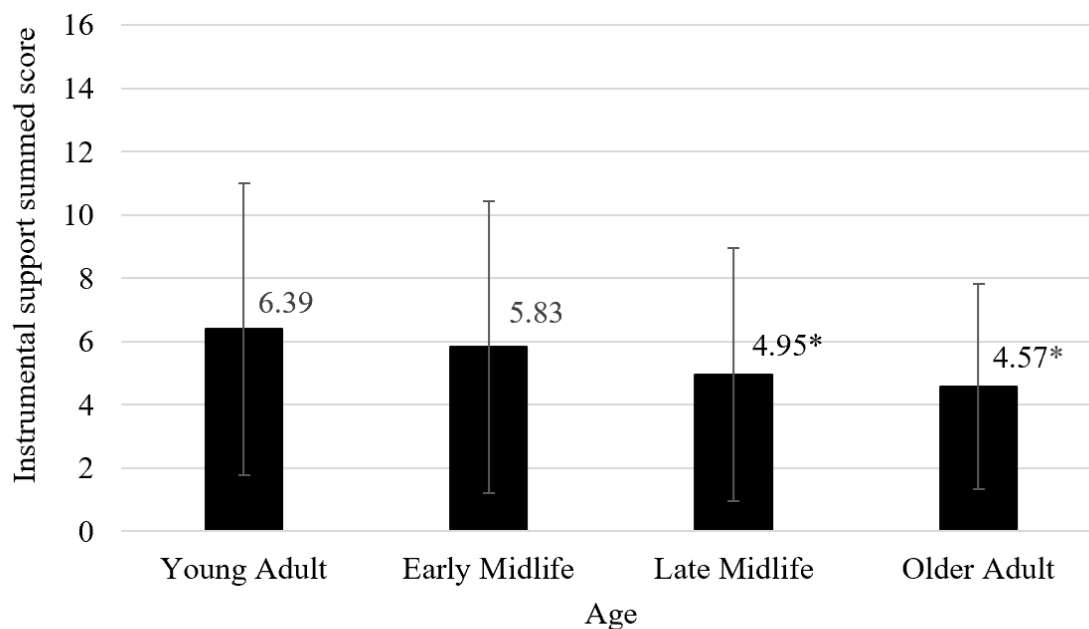


Figure 6. Hypothesis 5: Instrumental support as a function of age

* Group significantly differs from young adults, $p < .05$

Social Contexts as Mediators of Age Differences in Subjective Burden

A test of indirect effects using structural equation modeling (SEM) was calculated to assess the combined mediating effects of preparedness, social support, and instrumental support between caregiver age (continuous) and subjective burden (Figure 7). All variables were normally distributed as evidenced by skewness indices ranging from 0.03 to 0.85 and kurtosis values ranging from -1.09 to -0.08. The model chi square, $\chi^2 = 165.79$, $df = 3$, $p = .00$ and model chi square to degrees of freedom ratio, $\chi^2/df = 55.26$ indicates that this model is an unacceptable fit because it is significantly different from the data. In terms of the goodness of fit indices, comparative fit index (CFI = 0.37) does not indicate a good fit, while Tucker-Lewis index (TLI = -1.10) also does not indicate a good fit. Root mean square of approximation (RMSEA = 0.35, 90% CI: 0.30 to

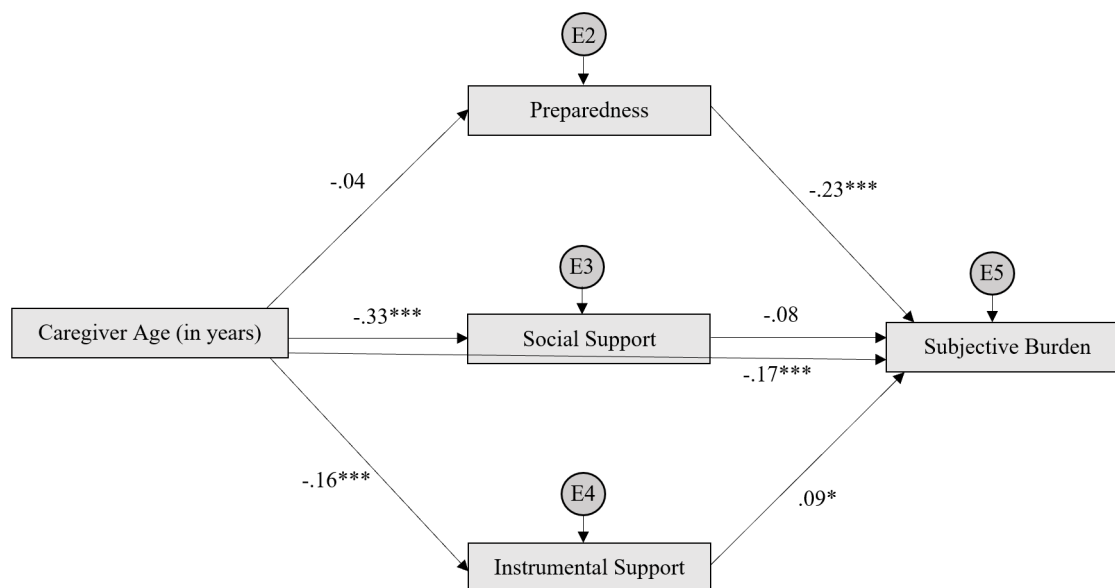


Figure 7. Preparedness, social support, and instrumental support as mediators between age and subjective burden. * $p < .05$; ** $p < .01$, *** $p < .001$

0.39) indicates a poor fit. Together, the indices indicate that the hypothesized model does not fit the underlying data and should be rejected. However, given that the purpose of the analysis was to assess whether the relationship between age and subjective burden was multivariately mediated by social and instrumental support, it did not make theoretical sense to use modification indices to respecify the model. Thus, the original hypothesized model was used to interpret the mediation. Although there were several significant correlations in the model, the pathway from age to subjective burden was not significantly mediated by preparedness (indirect effect $\beta = .00$, *ns*), social support (indirect effect $\beta = .00$, *ns*) or instrumental support (indirect effect $\beta = .00$, *ns*).

Exploration of Potential Differences in Caregiving Context as Indicators of Differences in Social Contexts

To assess whether the group differences found were due to age or aspects of the caregiving context (e.g., relationship status and relationship to caregiver) that are confounded with age, additional analyses were conducted. Because younger adults were less likely to be married, they were also less likely to be caring for spouses than for parents or others. Thus, separate examinations of the impact of age and relationship to caregiver, and age and relationship status (married/not) were conducted on the two burden and two support variables (preparedness was not included because it did not vary across age groups). If the age effects are driven by variations across age groups in the relationship to caregiver or relationship status, then that should be evident in the main effects of the relationship variables or interactions of those variables with age. Given that age is the primary focus in these analyses, the interactions of the relationship variables with age is most important. The assumptions of normality (skewness ranges from 0.45 to 1.70) and independence of participants were met. However, the assumption of homogeneity of variances was only met for subjective burden.

Impacts of Relationship to Caregiver and Age on Caregiving Experience.

Five two-way ANOVAs were conducted with relationship to caregiver (parent, spouse, or other) and age (young adult, early midlife, late midlife, and older adult) as the independent variables and subjective burden, objective burden, preparedness, social support, and instrumental support as the dependent variables.

When assessing effects of age and relationship type on subjective burden, there was no significant interaction between relationship to caregiver and age on level of

subjective burden, $F(6, 436) = 0.86$, *ns*. There also was no significant main effect of age on level of subjective burden, $F(3, 436) = 0.90$, *ns*. However, a significant main effect was found for relationship to caregiver in that those caring for parents ($M = 37.25$, $SD = 18.94$) reported significantly more subjective burden compared to those who provide care for a spouse ($M = 29.01$, $SD = 16.77$), $F(2, 436) = 4.03$, $p = .02$. Those who cared for someone other than a parent or spouse ($M = 33.03$, $SD = 17.54$) did not significantly differ in level of subjective burden compared to either of the other two groups.

There was a significant interaction between relationship to caregiver and age on objective burden $F(6, 436) = 2.19$, $p = .04$. In order to determine the nature of the interaction, seven follow up one-way ANOVAs were conducted. The first three one-way ANOVAs assessed age differences in objective burden among only those caring for a parent, only those caring for a spouse, and only those caring for someone other than a parent or spouse. Among those caring for a parent as well as among those caring for someone other than a parent or spouse, there are no significant differences in objective burden between age groups. However, among those caring for a spouse, young adult caregivers ($M = 28.00$, $SD = 21.61$) and early midlife caregivers ($M = 38.08$, $SD = 23.98$) reported significantly fewer hours spent caregiving per week compared to late midlife caregivers ($M = 67.80$, $SD = 53.49$), $F(3, 133) = 3.35$, $p = .02$ (Figure 8). There was no significant main effect of relationship to caregiver on objective burden, $F(2, 436) = 1.08$, *ns*. There was a significant main effect of age on objective burden, which was reported above.

The other four one-way ANOVAs were conducted to assess how relation to caregiver is related to level of objective burden among each age group. Among young

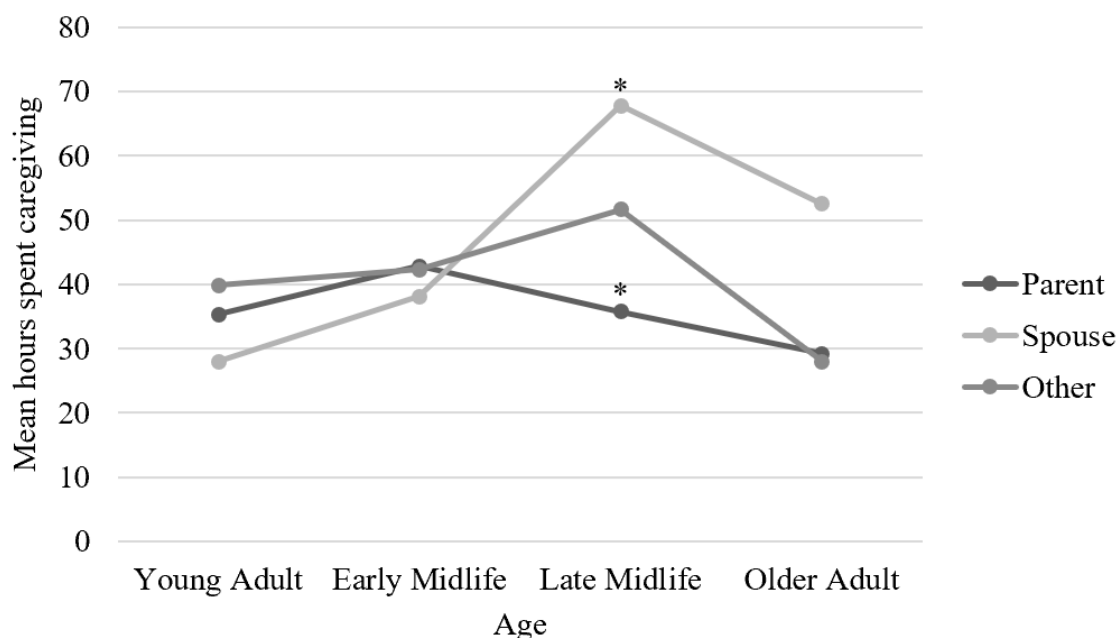


Figure 8. Level of objective burden as a function of age and relation to caregiver

* groups significantly differ from one another, $p < .05$

adult, early midlife, and older adult caregivers, level of objective burden did not significantly differ based on the care recipient's relation to the caregiver. However, among late midlife caregivers, those who cared for a spouse reported significantly more hours spent caregiving per week ($M = 67.80$, $SD = 53.49$) compared to those caring for a parent ($M = 35.79$, $SD = 32.36$), $F(2,160) = 8.38$, $p = .00$ (Figure 9). A significant main effect of age on objective burden was also found, late midlife caregivers report significantly more objective burden ($M = 51.57$, $SD = 47.29$) than young adult caregivers ($M = 36.89$, $SD = 33.23$), $F(3, 436) = 2.89$, $p = .04$. No other significant differences based on age were found. The main effect of relationship to caregiver on objective burden was not significant, $F(2, 436) = 1.08$, *ns*.

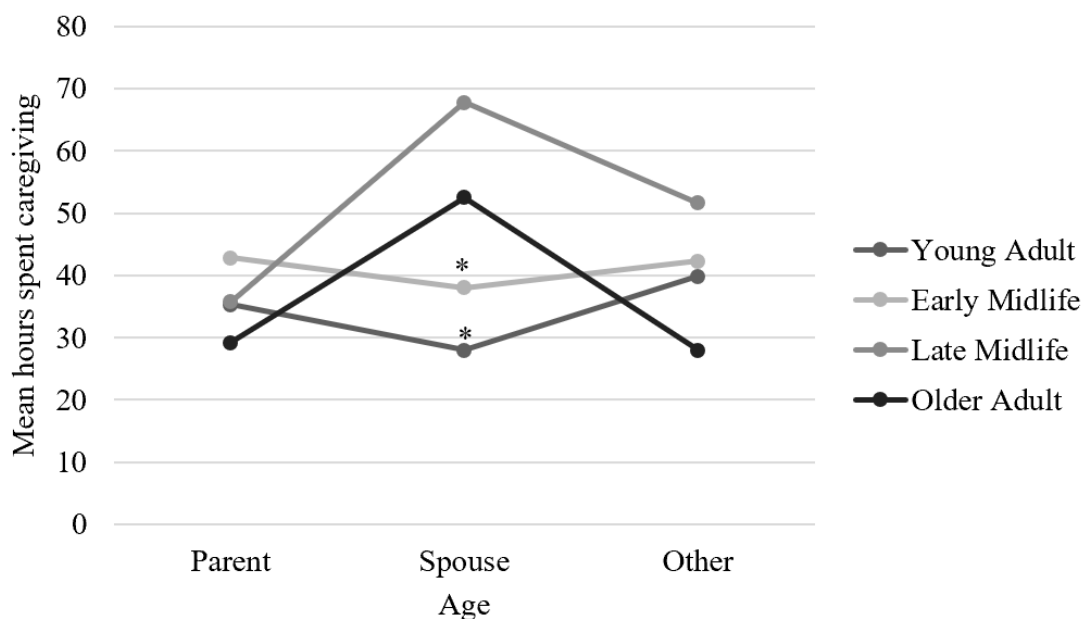


Figure 9. Level of objective burden as a function of age and relation to caregiver

* groups significantly differ from late midlife spousal caregivers, $p < .05$

There was no significant interaction between relationship to caregiver and age on level of preparedness, $F(6, 436) = 1.15, ns$. There also was no significant main effects of age, $F(3, 436) = 0.23, ns$, or relationship to caregiver on level of preparedness, $F(2, 436) = 0.88, ns$.

There was no significant interaction between relationship to caregiver and age on level of social support, $F(6, 436) = 0.96, ns$. A significant main effect of age on level of social support was found and reported above, but no significant main effect of relationship to caregiver on level of social support, $F(2, 436) = 0.97, ns$.

Analyses of effects on instrumental support found there was not a significant interaction between relationship to caregiver and age on instrumental support, $F(6, 436) = 0.12, ns$. There also were no significant main effects of relationship to caregiver, $F(2, 436) = 2.33, ns$, or age, $F(3, 436) = 1.99, ns$.

Impacts of Relationship Status and Age on Caregiving Experience. An

additional five two-way ANOVAs were conducted with relationship status (married or not married) and age (young adult, early midlife, late midlife, and older adult) as the independent variables and subjective burden, objective burden, preparedness, social support, and instrumental support as the dependent variables.

There was not a significant interaction between relationship status and age on subjective burden, $F(3, 440) = 0.64, ns$. No significant main effect of relationship status on subjective burden was found, $F(1, 440) = 0.60, ns$. A significant main effect of age on subjective burden was found and reported above.

There was no significant interaction of relationship status and age on objective burden, $F(3, 440) = 1.08, ns$. A significant main effect of relationship status on objective burden was found in that married caregivers ($M = 49.10, SD = 44.85$) reported more objective burden than caregivers who are not married ($M = 39.51, SD = 37.60$), $F(1, 440) = 4.06, p = .04$. The main effect of age on objective burden was not significant, ns .

There was not a significant interaction of relationship status and age on level of preparedness, $F(3, 440) = 0.59, ns$. There also was no significant main effects of age, $F(3, 440) = 0.31, ns$, or relationship status on level of preparedness, $F(2, 440) = 1.02, ns$.

There was a significant main effect of age on social support as explained above, but no significant interaction between relationship status and age on social support, $F(3, 440) = 1.91, ns$. There was a significant main effect of relationship status on social support in that those who are married ($M = 7.69, SD = 4.75$) reported significantly more social support than unmarried caregivers, ($M = 6.82, SD = 4.60$), $F(1, 440) = 19.98, p = .00$.

There was not a significant main effect of age, $F(3, 440) = 2.87, ns$, or a significant interaction between relationship status and age on instrumental support, $F(3, 440) = 0.78, ns$. The main effect of relationship status was also not significant, $F(1, 440) = 0.99, ns$.

CHAPTER IV

DISCUSSION

The purpose of the present study was to compare the experiences of caregivers in different age groups within the same study. Although the key variables (i.e., caregiver burden, support, and preparedness for caregiving) have been studied previously, the age of the caregiver has not been a primary variable when assessing variation in perceptions of the caregiving experience. More specifically, young caregivers and older caregivers have not been compared directly on these variables in previously published research. Thus, the results of this study enhance our understanding of how the caregiving experience differs across the lifespan. The results indicate that young caregivers reported more subjective burden than older adult caregivers. The younger caregivers reported less objective burden than late midlife caregivers but no differences from older caregivers. Although age groups reported similar levels of preparedness, the young caregivers reported more social support and more instrumental support from health providers, but those factors did not mediate the relationship of age and subjective burden.

As expected, younger caregivers reported more subjective burden than older adult caregivers, but they did not significantly differ from late midlife caregivers. Although caregiving is considered more “on-time” for both late midlife and older adult caregivers, late midlife caregivers have more competing role demands, which can cause increased distress, compared to older adult caregivers (Lachman, 2004). Thus, it could be that

young adult caregivers who are off-time and late midlife caregivers, who are more on-time but having competing roles, may experience similar levels of burden even if for different reasons. Another possibility is that the difference found between young adults and older adults in level of subjective burden is due to the caregiving relationship (caring for a parent versus a spouse) because young adult caregivers primarily are caring for a parent and older adults are primarily caring for a spouse.

Young adult caregivers reported significantly more social support and instrumental support from health providers than late midlife and older adult caregivers in the opposite direction to what was hypothesized. It was initially expected that older caregivers would report higher support because they are more on-time and may have access to more instrumental support services and more friends that relate to their experience and are able to provide support. A possible explanation for the opposing results is that because caregiving is more off-time at a younger age, family/friends and healthcare professionals may actually provide more support for the caregiver (Rook et al., 1989). Alternatively, it may be that young caregivers are better able to use technology (i.e., the internet) to seek out caregiving services compared to older caregivers and thus feel supported regardless of how professionals respond to them. It is also possible that this study's recruitment method (online) versus other studies (in-person/phone interviews) may have impacted the results in that those who are a part of a caregiver online research panel may also be proactive in seeking other services related to caregiving compared to those who are not as active online.

As expected, young adult caregivers reported significantly less objective burden than late midlife adults. However, older adults did not differ from the young. It was

initially expected that older adults would also report significantly more objective burden than young adults given that that was the pattern in the national sample (NAC & AARP, 2015). One reason the results of this study may have differed from the national sample is that the national sample conducted phone interviews and this study was online. It could be that the older adults who participated in this study had more time to seek out online research opportunities (as opposed to being called randomly), so only those who provide lower levels of care were sampled in this study. Another option that was not considered is that older adults may be more likely to be caring for a spouse who is placed in an assisted living facility, which would require less care by the family caregiver. Younger caregivers are more likely to be caring for a parent, who may not be at the age or have a condition that requires an assisted living facility. The variables that were hypothesized to help us understand the relationship of caregiver age to subjective burden did not follow predicted patterns.

The initial hypotheses were primarily based on the thought that being off-time would lead to less support and preparedness, when the opposite turned out to be true. A possible explanation for this is that the context related to age may be more impactful on how the caregiver perceives the caregiver experience as opposed to just the timing of the event. Lifespan development theory asserts that the social contexts related to a nonnormative event can experience perceptions of that event. While it was anticipated that timing of the event (i.e., age at which one is a caregiver) would be the primary driver behind differences in the caregiving experience, it appears that other contextual factors may better explain these differences.

The context factors that were explored were relationship to caregiver and relationship status. These factors were chosen given that the likelihood of being married changes across the lifespan, and thus the likelihood of caring for a spouse versus a parent or other loved one changes as well. Young adult and early midlife caregivers were more likely to be unmarried and care for a parent or grandparent compared to late midlife and older adult caregivers who were more likely to be married and care for a parent (in the case of late midlife caregivers) or spouse. The results of this study revealed that those who cared for a parent reported more subjective burden than those who cared for a spouse. This could help explain why young adults reported more subjective burden because young adults were much more likely to care for a parent compared to older caregivers. Furthermore, married caregivers reported more objective burden than non-married caregivers, which could help explain why older caregivers reported more objective burden compared to younger caregivers. These secondary analyses indicated that the caregiving context (i.e., relationship to caregiver, relationship status, etc.) may better explain the differences in the caregiving experience rather than the caregiver's age itself.

Although other demographic variables, such as employment, race, gender, were not included in primary or secondary analyses, it is notable that the age groups differed in these areas as well. For instance, the young adult caregivers were more often female, non-white, and employed compared to late midlife and older adult caregivers. It is probable that these variations by age also play a role in the differing perceptions of the caregiving experience. Thus, it is important to pay attention to the caregiving context

when assessing risk for caregiver burden and the caregiver's age may indicate certain contexts (e.g., younger caregivers more likely to care for a parent).

Limitations

The cross-sectional design limits the study to assessing participants at one time point and their answers may have been impacted by their current thoughts/feelings about their caregiving situation. For instance, the Caregiver Preparedness Scale asked participants to retrospectively report how prepared they were for the caregiving tasks, it is possible that the participants may have underestimated or overestimated how prepared they were based on how effective they are currently feeling as a caregiver. The cross-sectional design is also not able to control for cohort or history effects, which may have confounded the results.

The data collection method (i.e., online) can also be considered a limitation given that only those who have access to a computer were able to participate. The data collection method also could have led to a biased sample in terms of only those who have relatively steady caregiving situations and can take the time to complete a survey. Furthermore, collecting the data online may have limited the range of older adults who were able to participate to only those who are able to navigate the internet, who are less likely than younger people to use the internet (Pew Research Center, 2017). The quota sampling method that was used in order to obtain participants across the lifespan made it evident that recruitment of a large number of caregivers ($n > 100$) in the young adult and older adult groups was far more difficult than in the two midlife groups. Ultimately, the group sizes were unequal due to recruitment challenges in the young and older caregiver groups. The study was discontinued when the sample was of adequate size to have power

to detect at least medium effect sizes in most variables because the pending holiday period created a risk for varied results due to distinct stresses and supports available during holiday periods. The national sample by NAC and AARP that the results of this study were compared to did not use the same quota sampling method that was used for this study, which could help explain the age differences between the national sample ($M = 58.60$, $SD = 16.66$) and the sample of the present study ($M = 48.77$, $SD = 17.22$).

Future Directions

Given the limited research that examines the caregiving experience across the lifespan, several potential directions for future research have yet to be explored. One worthwhile option would be to replicate the study with a different sample by using a method other than an online research panel to recruit participants. Another recruitment method may allow for more equal sized groups and allow for caregivers who do not have a computer to learn about the study and participate. Another potential focus is to assess other factors that may help to explain why younger caregivers appear to experience more subjective burden than older caregivers. For instance, future research could put more focus on the developmental aspects related to age, as opposed to using age as a proxy for development. Similarly, future research would benefit from including other demographic factors, such as race, education, and socioeconomic status, as primary variables. Another potential focus is to assess one's perception of the timing of the onset of caregiving to see if there are differences across the lifespan. A cross-sequential design could be used to assess caregivers at multiple ages over time. Ideally, caregivers would first be assessed at the start of their caregiving experience and followed through the end of the experience; thus, the study could start with new young adult, midlife, and older adult caregivers, and

test them at multiple time points. This design could help protect against confounding cohort or history effects for age differences.

There are several implications of these results outside of research as well. The results of this research indicate that caregivers of all ages can report burden and typically do not feel prepared for the caregiving tasks. This is important for medical and mental health professionals to understand so that they can pay attention to the needs of caregivers, as well as the care recipients, and work to prepare them more effectively for the tasks of caregiving. This could potentially be achieved by identifying level of preparedness early and working to increase self-efficacy in those who reported low levels of preparedness. Similarly, in terms of policy, the results of this research indicate that caregiving programs should be directed towards caregivers of all ages since all caregivers can experience burden, and young adults, due to the caregiving context, are particularly susceptible to experiencing caregiver burden.

REFERENCES

- Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health, 13*, 375-384. doi: 10.1002/nur.4770130605
- Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist, 55*, 469-480. doi: 10.1037/0003-066X.55.5.469
- Baltes, P. B. (1987). Theoretical propositions of life-span developmental psychology: On the dynamics between growth and decline. *Developmental Psychology, 23*, 611-626. doi: 10.1037/0012-1649.23.5.611
- Becker, F. & Becker, S. (2008a). *Young adult carers in the UK: Experiences, needs and services for carers aged 16-24*. London: The Princess Royal Trust for Carers.
- Becker, S. & Becker, F. (2008b). *Service needs and delivery following the onset of caring amongst children and young adults: Evidence based review*. London: Young Carers International Research and Evaluation.
- Berglund, E., Lytsy, P., & Westerling, R. (2015). Health and wellbeing in informal caregivers and non-caregivers: A comparative cross-sectional study of the Swedish general population. *Health and Quality of Life Outcomes, 13*(109), 1-11. doi: 10.1186/s12955-015-0309-2
- Burgio, L. D., Gaugler, J. E., & Hilgeman, M. M. (2016). *The spectrum of family caregiving for adults and elders with chronic illness*. New York, NY: Oxford University Press.
- Butterworth, P., Pymont, C., Rodgers, B., Windsor, T. D., & Anstey, K. J. (2010). Factors that explain the poorer mental health of caregivers: Results from a community survey of older Australians. *Australian and New Zealand Journal of Psychiatry, 44*, 616-624. doi: 10.3109/00048671003620202
- Dellmann-Jenkins, M. & Blankemeyer, M. (2009). Adolescent caregivers. In K. Shifren (Ed.), *How caregiving affects development: Psychological implications for child, adolescent, and adult caregivers* (pp. 65-91). Washington, DC: American Psychological Association.

- del-Pino-Casado, R., Friás-Osuna, A., Palomino-Moral, P. A., Ruzafa-Martínez, M. & Ramos-Morcillo, A. J. (2018). Social support and subjective burden in caregivers of adults and older adults: A meta-analysis. *PLoS ONE*, *13*(1), 1-18. doi: /10.1371/journal.pone.0189874
- Erikson, E. H. (1968). *Identity: Youth and crisis*. New York: Norton.
- Family Caregiver Alliance. (2014). Definitions. Retrieved from <https://www.caregiver.org/definitions-0>
- Greene, J., Cohen, D., Siskowski, C., & Toyinbo, P. (2017). The relationship between family caregiving and the mental health of emerging young adult caregivers. *Journal of Behavioral Health Services and Research*, *44*, 551-563. doi: 10.1007/s11414-016-9526-7
- Haley, W. E., Levine, E. G., Brown, S. L., & Bartolucci, A. A. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*, *2*, 323-330. no doi
- Haley, W. E., West, C. A. C., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J.,...Roth, D. L. (1995). Psychological, social, and health impact of caregiving: A comparison of black and white dementia family caregivers and noncaregivers. *Psychology and Aging*, *10*(4), 540-552. doi: 10.1037/0882-7974.10.4.540
- Helson, R., Mitchell, V., & Moane, G. (1984). Personality and patterns of adherence and nonadherence to the social clock. *Journal of Personality and Social Psychology*, *46*(5), 1079-1096. doi: 10.1037/0022-3514.46.5.1079
- Hérbert, R., Bravo, G., & Prévile, M. (2000). Reliability, validity, and reference values of the Zarit Burden Interview for assessing informal caregivers of community-dwelling older persons with dementia. *Canadian Journal on Aging*, *19*, 494-507. doi: 10.1017/S0714980800012484
- Hultsch, D. F. & Plemons, J. K. (1979). Life events and life-span development. *Life Span Development and Behavior*, *2*, 1-36.
- Joshi, G. (2016). Caregiving preparedness and attitudes towards their older relatives among college students. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, *77*(2-B). no doi
- Jylha, M. (2009). What is self-rated health and why does it predict mortality? Towards a unified conceptual model. *Social Science & Medicine*, *69*, 307-316. doi: 10.1016/j.socscimed.2009.05.013
- Katz, S., Ford, A. B., Moskowitz, R. W., Jackson, B. A., & Jaffe, M. W. (1963). Studies of illness in the aged: The index of ADL: A standardized measure of biological and psychosocial function. *JAMA*, *185*(12), 914-919. doi: 10.1001/jama.1963.03060120024016

- Lachman, M. E. (2004). Development in midlife. *Annual Review of Psychology*, *55*, 305-331. doi: 10.1146/annurev.psych.55.090902.141521
- Lawton, M. P. & Brody, E. M. (1969). Assessment of older people: Self-maintaining and instrumental activities of daily living. *The Gerontologist*, *9*(3), 179-186. doi: 10.1001/jama.1963.03060120024016
- Lee, C-Y. S., Goldstein, S. E., & Dik, B. J. (2017). The relational context of social support in young adults: Links with stress and wellbeing. *Journal of Adult Development*, *25*, 25-36. doi: 10.1007/s10804-017-9271-z
- Levine, C., Hunt, G. G., Halper, D., Hart, A. Y., Lautz, J., & Gould, D. A. (2005). Young adult caregivers: A first look at an unstudied population. *American Journal of Public Health*, *95*, 2071-2075. no doi
- Liu, H. (2012). Marital dissolution and self-rated health: Age trajectories and birth cohort variations. *Social Science and Medicine*, *74*(7), 1107-1116. doi: 10.1016/j.socscimed.2011.11.037
- Lopata, H. Z. (1979). *Women as widows: Support systems*. New York: Elsevier.
- Lund, L., Ross, L., Petersen, M. A., & Groenvold, M. (2015). The interaction between informal cancer caregivers and health care professionals: A survey of caregivers' experiences of problems and unmet needs. *Support Care Cancer* *23*, 1719-1733. doi: 10.1007/s00520-014-2529-0
- Musil, C. M., Jones, S. L., & Warner, C. D. (1998). Structural equation modeling and its relationship to multiple regression and factor analysis. *Research in Nursing & Health*, *21*, 271-281.
- National Alliance for Caregiving & AARP Public Policy Institute. (2015). *Caregiving in the U.S. 2015*. Retrieved from <https://www.aarp.org/content/dam/aarp/ppi/2015/caregiving-in-the-united-states-2015-report-revised.pdf>
- Neugarten, B. L. & Hagestad, G. O. (1976). Age and the life course. In R. H. Binstock & E. Shanas (Eds.), *Handbook of aging and the social sciences*. New York: Van Nostrand-Reinhold.
- Pakenham, K. I., Chiu, J., Bursnall, S., Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology*, *12*, 89-102. doi: 10.1177/1359105307071743
- Parkerson, G. R. Jr., Broadhead, W. E., & Tse, C-K, J. (1991). Validation of the Duke Social Support and Stress Scale. *Family Medicine*, *23*, 357-360. no doi

- Parkerson, G. R., Broadhead, W. E., & Tse, C-K, J. (1992). Quality of life and functional health of primary care patients. *Journal of Clinical Epidemiology*, *45*(11), 1303-1313. doi: 10.1016/0895-4356(92)90171-I
- Petruzzo, A., Paturzo, M., Buck, H. G., Barbaranelli, C., D'Agostino, F., Ausili, D., Alvaro, R., & Vellone, E. (2017). Psychometric evaluation of the Caregiver Preparedness Scale in caregivers of adults with heart failure. *Research in Nursing and Health*, *40*, 470-478. doi: 10.1002/nur.21811
- Pew Research Center. (2017). *Internet use by age*. Retrieved from <https://www.pewinternet.org/chart/internet-use-by-age/>
- Rook, K. S., Catalano, R., Dooley, D. (1989). The timing of major life events: Effects of departing from the social clock. *American Journal of Community Psychology*, *17*(2), 233-258. doi: 10.1007/BF00931009
- Rotz, D. (2016). Why have divorce rates fallen?: The role of women's age at marriage. *Journal of Human Resources*, *51*(4), 961-1002. no doi
- Scherbring, M. (2002). Effect of caregiver perception of preparedness on burden in an oncology population. *Oncology Nursing Forum*, *29*, E70-E76. doi: 10.1188/02.ONF.E70-E76
- Sharon, T. (2016). Constructing adulthood: Markers of adulthood and well-being among emerging adults. *Emerging Adulthood*, *4*(3), 161-167. doi: 10.1177/2167696815579826
- Shiba, K., Kondo, N., & Kondo, K. (2016). Informal and formal social support and caregiver burden: The AGES caregiver survey. *Journal of Epidemiology*, *12*, 622-628. doi: 10.2188/jea.JE20150263
- Van Ryn, M., Sanders, S., Kahn, K., van Houtven, C., Griffin, J. M., Martin, M.,...& Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue?. *Psycho-Oncology*, *20*, 44-52. doi: 10.1002/pon.1703
- Villarreal, B. & Heckhausen, J. (2015). Lifespan development, theory of. In Wright, J. D. (Ed.), *International Encyclopedia of the Social & Behavioral Sciences: Second Edition* (pp. 100-107). United Kingdom: Elsevier Health Sciences.
- Zarit, S. H., Reever, K. E., & Back-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*, 649-655. doi: 10.1093/geront/20.6.649

APPENDIX A



University of Colorado
Colorado Springs

Institutional Review Board (IRB) for the Protection of Human Subjects

Date: 11/9/2018

IRB Review

APPROVED

IRB PROTOCOL NO.:19-067

Protocol Title: Age differences in caregivers' perceptions of burden: Preparation and social support as potential mediators

Principal Investigator: Kelsey Bacharz

Faculty Advisor if Applicable: Sara Qualls

Application: New Application

Type of Review: Expedited 7

Risk Level: No more than Minimal Risk

Renewal Review Level (If changed from original approval) if Applicable: N/A No Change

This Protocol involves a Vulnerable Population: N/A (No Vulnerable Population)

Expires: 8 November 2019

*Note, if exempt: If there are no major changes in the research, protocol does not require review on a continuing basis by the IRB. In addition, the protocol may match more than one review category not listed.

Externally funded: No Yes

Thank you for submitting your Request for IRB Review. The protocol identified above has been reviewed according to the policies of this institution and the provisions of applicable federal regulations. The review category is noted above, along with the expiration date, if applicable.

Once human participant research has been approved, it is the Principal Investigator's (PI) responsibility to report any changes in research activity related to the project:

- The PI must submit all protocol, recruitment, advertising, and consent form amendments/revisions to the IRB for approval.
 - The IRB must approve these changes prior to implementation.
- Changes in funding status must be reported to the IRB as quickly as possible to ensure funding requirements are met.
- If you are a student, please note that it is required to include the IRB approval letter to the library when you submit the dissertation/thesis.
- The PI must promptly inform the IRB of all unanticipated serious adverse (within 24 hours). All unanticipated adverse events must be reported to the IRB within 1 week (see [45CFR46.103\(b\)\(5\)](#)). Failure to comply with these federally mandated responsibilities may result in suspension or termination of the project.
- Renew study with the IRB at least **10 business days prior to expiration**.
- Notify the IRB when the study is complete

If you have any questions, please contact Research Compliance Program Director in the Office of Sponsored Programs and Research Integrity at 719-255-3903 or irb@uccs.edu.

Thank you for your concern about human subject protection issues, and good luck with your research.

Sincerely yours,

Michele Okun, Ph.D.
IRB Reviewer

APPENDIX B

1. An informal caregiver is an adult who has a significant relationship with and provides a broad range of assistance for an adult loved one (e.g., a spouse or parent) with a physical condition (e.g., cancer, diabetes, stroke, Alzheimer's/dementia, etc.).

Based on this definition, do you identify as an informal caregiver?

- a. Yes, I am currently providing unpaid care for a loved one
- b. No, I do not fit this definition, or I am not currently providing unpaid care for a loved one

APPENDIX C

University of Colorado
Colorado Springs (UCCS)
Consent to be a Research Subject

Title: Caregiving Experience

Principal Investigator: The research study is conducted by Kelsey Bacharz under the guidance of the faculty sponsor, Sara Qualls, Ph.D.

Introduction

You are being asked to be in a research study. This form is designed to tell you everything you need to think about before you decide to consent (agree) to be in the study or not to be in the study. It is entirely your choice. If you decide to take part, you can change your mind later on and withdraw from the research study.

Before making your decision:

- Please carefully read this form or have it read to you.
- Please ask questions about anything that is not clear.

Feel free to take your time thinking about whether you would like to participate. By agreeing to be in the study you will not give up any legal rights. You may want to print a copy of the consent form for your records.

Study Overview

This study plans to learn more about how age may impact one's experience of caring for a loved one with a chronic, physical illness. Ultimately, this research may be disseminated at a scientific research conference or published in a journal.

Procedures

You are being asked to be in this research study because you fit the provided definition of informal caregiver. You will be asked to complete a series of questionnaires about the caregiving experience. This study may be completed online within 15 – 30 minutes using a computer with internet access.

Other people in this study: Up to 450 people will participate in this study.

Risks and Discomforts

Some of the questions may be perceived as sensitive, such as questions about your emotions and personal experiences. If you experience discomfort or distress, feel free to

discontinue the study by closing the web browser. If the distress continues, please seek help by contacting a mental health professional in your area.

Benefits

This study is designed for the researcher to learn more about what factors may contribute to one's subjective experience of caregiving. Findings from this study are anticipated to furnish further information for researchers to better understand this topic. There are no direct benefits to the participant.

Compensation

Upon completion of the study, you will receive compensation in the amount that you have agreed to with Quest MindShare.

Confidentiality

To keep your responses confidential, you will not be asked for your name at any point during this study. Data collected are encrypted and password protected. After the study has concluded, the data will be aggregated across participants for the purpose of statistical analyses. Participant privacy will be maintained in all presentations and publications that result from the findings.

Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties.

Certain offices and people other than the researchers may have access to study records. Government agencies and UCCS employees overseeing proper study conduct may look at your study records. These offices include the UCCS Institutional Review Board, and the UCCS Office of Sponsored Programs and Research Integrity. UCCS will keep any research records confidential to the extent allowed by law. A study number rather than your name will be used on study records wherever possible. Study records may be subject to disclosure pursuant to a court order, subpoena, law or regulation.

Voluntary Participation and Withdrawal from the Study

Taking part in this study is voluntary. You have the right to leave the study at any time without penalty. Withdrawal will not interfere with your future care or services at UCCS. You may refuse to answer any questions that you do not wish to answer. If you withdraw from the study, you may request that your research information not be used by contacting the Principal Investigator listed above and below.

Contact Information

Contact (PI's info): kbacharz@uccs.edu; squalls@uccs.edu
if you have any questions about this study or your part in it,

- if you have questions, concerns or complaints about the research, or
- if you would like information about the survey results when they are prepared.

Contact the Research Integrity Compliance Program Director at 719-255-3903 or via email at irb@uccs.edu:

- if you have questions about your rights as a research participant, or
- if you have questions, concerns or complaints about the research.

Electronic Consent

Please print a copy of this consent form for your records, if you so desire.

I have read and understand the above consent form, I certify that I am 18 years old or older and, by clicking the submit button (right arrow button below) to enter the survey, I indicate my willingness to voluntarily take part in the study.

APPENDIX D

1. Who do you provide care for?

If you provide care for more than one person, please choose the one who requires the most care and keep that person in mind for the rest of the survey.

- c. A parent
- d. A spouse/significant other
- e. A child
- f. A sibling
- g. A grandparent
- h. A grandchild
- i. Other (open textbox)

2. How old are you? (open text box)

APPENDIX E

Please select the response that best describes how you feel.

	Never	Rarely	Sometimes	Quite frequently	Nearly always
Do you feel that your care recipient asks for more help than he/she needs?					
Do you feel that because of the time you spend with your care recipient that you don't have enough time for yourself?					
Do you feel stressed between caring for your care recipient and trying to meet other responsibilities for your family or work/school?					
Do you feel embarrassed over your care recipient's behavior?					
Do you feel angry when you are around your care recipient?					
Do you feel that your care recipient currently affects your relationships with family members or friends in a negative way?					
Are you afraid what the future holds for your care recipient?					
Do you feel your care recipient is dependent on you?					
Do you feel strained when you are around your care recipient?					

Do you feel your health has suffered because of your involvement with your care recipient?					
Do you feel that you don't have as much privacy as you would like because of your care recipient?					
Do you feel that your social life has suffered because you are caring for your care recipient?					
Do you feel uncomfortable about having friends over because of your care recipient?					
Do you feel that your care recipient seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
Do you feel that you don't have enough money to take care of your care recipient in addition to the rest of your expenses?					
Do you feel that you will be unable to take care of your care recipient much longer?					
Do you feel you have lost control of your life since your care recipient's illness?					
Do you wish you could leave the care of your care recipient to someone else?					
Do you feel uncertain about what to do about your care recipient?					
Do you feel you should be doing more for your care recipient?					

Do you feel you could do a better job caring for your care recipient?					
Overall, how burdened do you feel in caring for your relative?					

APPENDIX F

A supportive person is one who is helpful, who will listen to you, or who will back you up when you are in trouble.

Instructions: Please look at the following list and decide how much each person (or group of persons) is supportive for you related to your caregiving experience?

	None	Some	A lot	There is no such person
Your wife, husband, or significant other person				
Your children or grandchildren				
Your parents or grandparents				
Your brothers or sisters				
Your other blood relatives				
Your relatives by marriage (for example: in-laws, ex-spouse)				
Your neighbors				
Your co-workers				
Your church members				
Your other friends				
Your family physician				
Your care recipient's primary physician				
Your care recipient's care managers				
Professional home-helpers				
Visiting nurses				
Social workers				
Therapists				
Officers in public institutions				

APPENDIX G

Please select the level of preparedness that best applies to your feelings when you began caring for your loved one.

	Not at all prepared	A little prepared	Somewhat prepared	Mostly prepared	Very well prepared
How well prepared do you think you were to take care of your care recipient's physical needs?					
How well prepared do you think you were to take care of your care recipient's emotional needs?					
How well do you think you were to find out about and set up services for your care recipient?					
How well prepared do you think you were for the stress of caregiving?					
How well prepared do you think you were to make caregiving activities pleasant for both you and your care recipient?					
How well prepared do you think you were to respond to and handle emergencies that involve your care recipient?					

How well prepared do you think you were to get the help and information you need from the health care system?					
Overall, how well prepared do you think you were to care for your care recipient?					

APPENDIX H

This question is not related to the caregiving experience. To show that you are reading this question, please choose the second choice, green. This helps to ensure that the researchers are collecting quality responses that reflect the true caregiving experience.

What color is the sky?

- a) Blue
- b) Green

APPENDIX I

1. How old are you?
 - a. Under 18 years old
 - b. 30 to 50 years old
 - c. 51 to 70 years old
 - d. Over 70 years old
2. What is your gender?
 - a. Male
 - b. Female
3. What is your race?
 - a. Caucasian
 - b. African American
 - c. Hispanic
 - d. Asian
 - e. Other (open textbox)
4. What is your ethnicity?
 - a. Not Hispanic or Latino
 - b. Hispanic or Latino
5. How many years of formal education do you have? (open text)
6. What is your relationship status?
 - a. Married
 - b. Widowed
 - c. Divorced
 - d. Separated
 - e. Never married

7. What is your employment status?
 - a. Employed (including being a student)
 - b. Unemployed and seeking further employment
 - c. Retired
8. What is your annual income? (open text)
9. How involved are you in your loved one's care?
 - a. Primary caregiver (you are the person most involved in the care)
 - b. Secondary caregiver (someone else is most involved in the care)
 - c. Caregiving from a distance (you do not live in the same state as your loved one)
10. Do you live with your care recipient (i.e., in the same home)?
 - a. Yes
 - b. No
11. How many hours per week do you spend caring for your loved one? (open text)
12. What physical conditions/illnesses does the person you care for have?
13. Who do you provide care for? (open text)
14. How would you rate your overall physical health?
 - a. Poor
 - b. Below average
 - c. Average
 - d. Above average
 - e. Excellent

APPENDIX J

Thank you for your participation in this survey. The results of this will help the researchers better understand how the age at which a person becomes a caregiver may impact their experience of that event. If you have any questions/concerns, please contact the principal investigator, Kelsey Bacharz, at kbacharz@uccs.edu