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YOUNG ADULT DEVELOPMENT AND CAREGIVING:
DISPOSITION AND INVOLVEMENT IN CARE

by

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B.S., University of Central Florida, 2015

A thesis submitted in partial fulfillment of the requirements
for the degree of Master of Science
in the Department of Psychology
in the College of Sciences
at the University of Central Florida
Orlando, Florida

Spring Term
2018

Major Professor: Daniel Paulson

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ABSTRACT

Caregivers are a diverse group of individuals with a variety of backgrounds and roles; however, research has widely overlooked young adults in this population. This study investigated young adult caregiver circumstance, burden, and use of support services with the purpose of improving future caregiving research and interventions. Study 1 compared burden and circumstance among young, middle aged, and older adult caregivers (N = 285) in addition to developmental indicators among young adults caregiver and demographically matched non-caregiver peers (n = 225). Study 2 surveyed caregivers from each age group (N = 151) on barriers to care, treatment preferences, and interest in services. Results from study 1 indicated that young adult caregivers adopted similar caregiving roles and factors linked to burden; however, they reported additional stressors such as higher rates of childcare and commuting to provide care. Compared to demographically matched-peers, young adult caregivers were more likely to work part-time and earn a substantially lower yearly income. Study 2 replicated original findings and revealed that young adult caregivers endorsed elevated attitudinal barriers to care and are the least likely age group to speak to physicians about caregiving. Overall, findings reveal the similarity in caregiving role that young adults take on, as well as several unique burden factors. Caregivers across age groups disclosed moderate treatment expectancy for support services, and all reported greater interest in online-based treatment. Young adult caregivers were more likely to take on responsibilities such as childrearing and employment, thus impacting their available time and financial support. However, these findings do not explain the overwhelming lack of young adult caregivers in research. Future studies should re-evaluate sampling methods and inclusion criteria, or explore more accessible means of intervention, such as web-based services.

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CHAPTER 1: INTRODUCTION

Informal caregivers are an essential but only recently acknowledged resource within aging societies. In the empirical research on caregivers of older adults, young adults remain particularly underrepresented. A progressively increasing life expectancy and maturation of large generations (e.g., “boomers”) has beckoned a distributional swing toward an older population, termed the “silver tsunami.” The corresponding increase in informal caregiving demand will necessitate the increased involvement of young adult caregivers, defined here as those between the ages of 18 and 39 (Talley & Crews, 2007). Presently, the number of caregivers for adults age 50 and up is estimated to be 34.2 million, 46% of whom care for recipients with Alzheimer’s disease or other dementia-related difficulties (National Alliance for Caregiving (NAC) and AARP Public Policy Institute, 2015). Young adults, sometimes interchanged with “millennials” (those born between 1981 and 1997), are estimated to provide 30% all adult caregiving and 20% of all dementia caregiving (NAC & AARP, 2015). Considering the lack of research on this population, further evaluation of how young adult caregivers fit into our current care model is essential.

Informal caregivers are unpaid individuals who assist friends, relatives, and/or loved ones with Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs); their involvement in a care recipient’s life can vary by task, proximity, time spent providing services, or connection of care (Colvin & Bullock, 2016). Caregivers tend to be females (60%) who care for one recipient (82%), usually a relative (85%), and are on average 49 years old; however, there is emerging interest in understanding individual differences, both demographic

and psychosocial, between dementia caregivers (NAC & AARP, 2015). Of concern to this study are the unique developmental and burden-related challenges faced by young adults in this role.

Though there exist major developmental differences across the lifespan, there is little research evaluating the unique impacts caregiving may have on young adults. In fact, much caregiver support research is void of younger caregivers. Though national samples of caregivers consistently report 20-30% of the population being under the age of 39 (AARP, 1997; Alzheimer's Association, 2015; NAC, 2005; NAC & AARP, 2015), intervention samples of caregivers often include fewer than 4% young adult caregivers. For example, the Resources for Enhancing Alzheimer's Caregiver Health (REACH and REACH II) studies (Elliott, Burgio, & DeCoster, 2010; Schulz et al., 2003) were two multi-site support interventions that provided education and support, resulting in enhanced caregiving to reduced burnout/burden. Within REACH, only 3.8% (n=71) of the 1889 individuals screened for the study were between the age of 18 and 39 (Schulz & Beach, 1999). Similarly, the final sample of REACH II included only 4 out of 177 individuals under the age of 40, the youngest of whom was 36 years old (Schulz et al., 2006). This theme may lead to restricted assumptions about the role age plays in caregiving. The reason for this discrepancy, however, is unknown. Recognizing this dissonance between samples used in epidemiological and interventional studies raises questions of sampling methods and intervention factors, and emphasizes the need for further exploration of this underrepresented population.

CHAPTER 2: YOUNG ADULT DEVELOPMENT

Young adults must navigate a complex and goal-saturated period of their lives in which they attempt to “settle down,” and either fall behind or get ahead, which becomes increasingly difficult to accomplish later in life (Robinson, 2012). Educational obtainment, employment, and intimacy building are prominent indicators of developmental progression. Adult development is often split into three broad categories of early, middle, and late adulthood. This taxonomy is roughly represented across numerous, commonly-used frameworks of development and is further specified by transition stages or theory-specific subdivisions. The encompassing theme of developmental theories, however, places a focus on an individual progressing through life in a healthy manner. Several milestones of young adulthood serve as foundational prerequisites to later-life developmental goals; therefore, failure to meet certain developmental achievements in early-life (e.g., career entry or education) may result in a life-long cascade in which milestones are postponed or extremely difficult to meet (Robinson, 2012). As previous literature has yet to explore the impact caregiving may have on young adult caregivers, building a developmental profile of this underrepresented population will enhance future support endeavors.

Healthy development is expected to fall within periods of “action opportunity,” or periods in which an individual is optimally able to achieve a task and within the age range in which many peers commonly achieve similar tasks (Heckhausen, Wrosch, & Schulz, 2010). Social, biological, and environmental factors create deadlines for many periods of action opportunity, after which completion becomes difficult or impossible. Young adulthood contains several periods of action opportunity, including: education, initial employment, marriage, childrearing, and beginning to save for retirement (Heckhausen et al., 2010). Of importance,

when an individual fails to navigate a developmental milestone in a healthy manner, “crisis” may occur. Crises are times of extreme transition that occur outside of normal planned life progress and leave an individual vulnerable to distress and impairment (Caplan, 1964; Parry, 1990; Robinson, 2012). Environmental influences such as needing to care for a loved one, serious medical problems, or disasters may interrupt or delay an individual’s pursuit and subsequent ability to complete these goals leading to an increased risk of crisis.

Intimacy is a broadly applied term within developmental theory (Erikson, 1968; R. Stevens, 2008). Young adults are the most likely group to initiate long-term relationships and marriage due to their place in a high-opportunity window of romantic development. Studies of marriage and cohabitation within the United States has found the median ages of entering a first marriage for woman and men to be 25.8 and 28.3 years, respectively (Copen, Daniels, Vespa, & Mosher, 2012). Two-thirds of unmarried young adults cohabitated with a romantic partner (Manning, 2013), and cohabitation is increasingly recognized as a similar achievement of romantic intimacy and long-term commitment. However, marriage and cohabitation should be treated as indicators of adult development, not causal factors. Ribar (2004) asserts that across marital literature, positive outcomes are better associated with economic resources, work skills, and parenting practices. Thus, marriage does not determine fiscal stability, employment ability, or mental health – but those who are more fiscally stable, enjoy better careers, and have better mental health are more likely to become married or enter into a stable relationship.

While marriage is an easily-used marker for development of romantic relationships, it does have clear limitations as a research variable. For example, 2015 was the first year the LGBT community had full marriage equality within the U.S., so endorsement of cohabitation, marriage,

and divorce rates for these individuals will be influenced by legal barriers. Individuals who identify as LGBT constitute 8.6% of adult caregivers and 9.1% of dementia caregivers (NAC & AARP, 2015), twice that of typical population estimates (Ward, Dahlhamer, Galinsky, & Joestl, 2014). While other important areas of intimacy exist, relationship status remains an indicator of intimacy development, which can be used as a metric to assess developmental achievement.

Post-secondary education has become increasingly sought-after as a strategy for augmenting financial development. Based on 2015 U.S. Census data, Ryan and Bauman (2016) reported that 88% of adults had completed high school, 59% had at least completed some college, 33% had at least obtained a bachelor's degree, and 12% had earned an advanced degree. Higher degree status is sought-after for numerous reasons: educational achievement is associated with increased or enhanced employment, yearly income, insurance coverage, civic engagement, physical and mental health, and national economic returns (Baum, Ma, & Payea, 2013; Perna, 2005). Baum et al. (2013) estimated the median earning of high school graduates at \$35,400, which was significantly smaller than those who earned an Associate Degree (\$44,800), Bachelor's Degree (\$56,500), Master's Degree (\$70,000), Doctoral Degree (\$91,000), or Professional Degree (\$102,200). Additionally, Baum et al. (2013) found unemployment rates for individuals who earned a bachelor's degree or higher as half that of those who earned a high school diploma. Young adult caregivers may be at increased risk of losing opportunities of education due to the time, financial, and mental demands associated with caregiving.

The transition to a stable long-term career is thought to balance areas of life with fiscal security and lay a foundation for retirement. Therefore, unemployment, reduction of work hours, shifts in job responsibility, and hastening career decisions may all contribute to crisis. Job loss

and insecurity is associated with a number of negative effects including worse self-reported health, restricted healthcare access, burnout, support system loss, decreased social contact, and long-term financial impact (De Witte, Pienaar, & De Cuyper, 2016; Dekker & Schaufeli, 1995; Schaller & Stevens, 2015). Conversely, those with stable jobs that contain high-quality support and conditions have been found to net positive effects on employee well-being (Modini et al., 2016). In total, the developmental milestone of career selection serves as a stabilizing factor that provides an individual with fiscal support and a range of secondary benefits. Recognizing the impact that slowed or interrupted careers or education may hold, this paper aims to evaluate the possible impacts caregiving may have on young adults.

CHAPTER 3: YOUNG ADULT CAREGIVERS

Considering young adult caregivers make up over a quarter of caregivers in the nation, and 20% of caregivers for those with dementia-related difficulties, there is a surprising lack of research exploring their involvement with caregiving interventions. In fact, many caregiver support studies report a startling lack of young adult caregiver participants. Notable examples of this are the aforementioned REACH and REACH II studies (Elliott, Burgio, & DeCoster, 2010; Schulz et al., 2003). However, this scarcity of young adult participants can be found across the field. For example, studies such as Almborg, Grafström, Krichbaum, and Winblad (2000) that found age to not be significantly related to burnout only contained caregivers aged fifty-two to ninety, entirely leaving out young adults and many middle-aged caregivers. Compounding this problem, other influential support services such as the Savvy Caregiver Program do not list a range of caregiver ages (Kally et al., 2014). It is apparent that caregiver sampling endeavors have failed to attract younger individuals; however, the reason for this discrepancy is unknown.

While many cited caregiver interventions were conducted a decade or more prior to the latest national samples of caregivers, comparable samples collected around those years reveal similar age distributions. For example, the Caregiving in the U.S. 2004 sample reported 26% of caregivers fell into the age range of 18 to 34 (National Alliance for Caregiving, 2005). The Alzheimer's Association replicated these findings within their review of Behavioral Risk Factor Surveillance System (BRFSS) caregiver data. Within this sample of 1,615 caregivers of individuals with dementia, over a quarter of caregivers fell between the ages of 18 and 44, half fell between the ages of 45 and 64, and a quarter were 65 years and older (Bouldin, 2013).

Nevertheless, meta-analyses of caregiver interventions are unclear as to how this age distribution is represented within intervention-based research. Chien et al. (2011) listed mean age of reviewed caregiver studies, which ranged from 44 to 72 years; however, this review was limited in that it did not report a grand-mean or variance in age, making interpretation of such samples limited. Other meta-analyses simply neglect to report age as a measured outcome variable (Brodaty, Green, & Koschera, 2003; Schoenmakers, Buntinx, & DeLepeleire, 2010), leading to a file drawer issue. This unexplained scarcity of young adult caregivers within support services has yet to be examined within the literature. This study explores these questions and expands upon the limited research which currently exists.

Within the extant literature, a few unique aspects of young adult caregivers have been explored, such as dissimilar demographic makeup, filial obligation, filial maturity, and coping strategies (Dellmann-Jenkins & Brittain, 2003; Gans & Silverstein, 2006; Levine et al., 2005; Mendonça & Fontaine, 2013; Stein et al., 1998). Levine et al. (2005) evaluated two separate samples of adult caregivers ages 18 to 25. The study reported an unexpected shift in gender proportions, in that 50% and 75% of caregivers were male in the samples. Conversely, typical assessments of caregivers report female majorities (Vogel, Hansen, Stiles, & Götestam, 2006). This finding is reflected in recent datasets that report an equal proportion of male and female millennial caregivers (NAC & AARP, 2015). In relation to coping strategies, Levine et al. (2005) reported several coping factors such as prayer (57.4%), social/familial support (54.1%), exercise (40%), internet use (34.5%), professional or spiritual counseling (13.2%), and taking medicine (2.8%). These young adult caregivers also reported unmet needs in their caregiving role. For example, a number reported difficulty obtaining medical help for the care recipient (16.8%),

difficulty obtaining nonmedical help (72.1%), a need for information about keeping the care recipient safe (31.5%), behavioral management information (15.1%), difficulty discussing end-of-life choices with healthcare providers (17.6%), need for more personal time (31.4%), and help managing stressors (22.9%; Levine et al., 2005). Finally, Levine and colleagues (2005) report a number of other qualitative experiences documented by participants such as need for more time, social/family support, and ceasing once enjoyed personal or social activities due to caregiving (Levine et al., 2005). The strength of Levine et al. (2005) is in its groundbreaking examination of young adult caregivers; however, as the authors note, additional research is required to examine developmental, intervention, and other-aged comparative factors in caregiving. This study replicates and expands upon these findings to better inform caregiving interventions, specifically for young adults.

Involvement of Young Adult Caregivers in Community Interventions

Absence within intervention research remains an unexplored fragment of the young adult caregiver puzzle. Further, data on young adult caregiver involvement in non-research community programs do not exist; however, attempts at quantifying sources of caregiving information may offer some clarification to this topic. Levine et al. (2005) described sources of caregiving information for fifty young adult caregivers. The two most frequent sources of information for these caregivers were the internet (31.2%) and friends and family (26.9%), while professional services such as doctors (12.2%), senior centers (2.6%), other healthcare professionals (1.8%), and support groups (0.1%) ranked low to lowest in utilization. Interestingly, these respondents most often requested support that would be specifically offered by professional services (e.g.,

care information, end-of-life choices, and behavioral management skills). Absence from research and low-level utilization of professional care services may result from several factors such as a lack of need, caregiver preferences, structural or attitudinal barriers to care, sampling methodology, or service format/location.

Foremost to evaluating the underrepresentation of young adult caregivers is a question of need. If need for support services does not exist or are not perceived, it follows that such services will remain unutilized. This topic has yet to be directly addressed; however, Levine et al. (2005) found many young adult caregivers report educational, stress-related, and professional support needs. Similarly, an evaluation of millennial caregivers within the Caregivers in the US (CUS) survey (NAC & AARP, 2015) reported providing an average of 21 hours of caregiving each week including 1.6 ADLs and 4 IADLs, medical or nursing tasks, and overall moderate burden of care levels. Thus, previous research indicates that young adult caregivers are providing substantial caregiving services and endorse a need for educational and support services

The primary focus of many caregiver support services is to extend time until professional care services are required. Interventions vary in their approach to impact time until professional care is required; however, reduction in caregiving burden is commonly utilized to gauge success of such interventions. Of importance, the identified scarcity of young adult caregivers in research implies a lack of representation of their needs in intervention development. Specifically, caregiver interventions focusing on primary caregivers or spousal caregivers may place constraints on sampling, which reduces the ability of younger caregivers to receive services. Comparisons between young adult caregiver and other-aged caregivers, while rare, typically highlight demographic, caregiving circumstance, and requested support differences of these

groups (Levine et al., 2005; NAC & AARP, 2015). Lack of inclusion in intervention research combined with age-based caregiver differences may contribute to a recursive cycle of non-access, generating little research and programs perceived as not relevant or ineffective to young adults.

The concept of barriers to care serves as foundational roadblocks to successful interventions. Barriers include instrumental, structural, attitudinal, and stigma related reasons to non-utilization of services. Therefore, an initial step to creating an effective intervention is to identify barriers to care unique to the targeted population. The literature detailing perceived barriers to care for individuals with physical and/or mental health issues is expansive; however, research on barriers to support services for caregivers is diminutive. Therefore, parallels and theory-based hypotheses must be drawn from existing literature.

Because caregiver support interventions are delivered in much the same way and often by the same practitioners as conventional psychotherapeutic interventions, the psychotherapy literature may inform barriers to caregiver care. Past research examining common reasons for individuals with mental health stressors to not seek treatment conclude that perceived need for care, attitudinal (stigma or misinterpretation of treatment), and structural (financial/logistic aspects of receiving care) complaints are the most common barriers to care (Andrade et al., 2014; Clement et al., 2015; Golberstein, Eisenberg, & Gollust, 2008; Gulliver, Griffiths, & Christensen, 2010; Sareen et al., 2007). Commonly, the recommended solution to attitudinal barriers is education of individuals or society, with hopes to reduce stigma and increase mental health literacy and awareness of available resources (Clement et al., 2015; Gulliver et al., 2010; Sareen et al., 2007a). While attitudinal solutions are based on patient-level modifications,

structural barriers to care require foundational changes to intervention or public/private support systems to reduce cost, increase accessibility, or shift care design. Structural barriers disproportionately affect those with less healthcare access, especially those who are currently unemployed (Ahmed, Lemkau, Nealeigh, & Mann, 2001). Considering the potential for a loss of healthcare parallel to career interruption or financial strain, specific attention should be given to structural barriers such as time and cost related to interventions.

This study contains two major aims: to create a profile of young adult caregivers compared to other-aged caregivers and non-caregiving peers (Study 1), and to identify factors contributing to the underrepresentation of young adult caregivers in caregiving interventions (Study 2). The first study sharpens our understanding of the general disposition of young adult caregivers, their caregiving circumstances, their experience of caregiving burden, and utilization/request for services. The second study of this thesis addresses the underrepresentation of young adult caregivers in research as it relates to intervention content, attitudinal and structural barriers to care, and need for care. Results of this study address the needs of young adult caregivers, both in research and clinical practice.

CHAPTER 4: THE DISPOSITION OF YOUNG ADULT CAREGIVERS COMPARED TO OTHER-AGED CAREGIVERS AND NON- CAREGIVING PEERS

Methods

This study utilized data from two complementary, nationwide, demographically representative samples to A) characterize young adult caregivers in reference to middle-aged and older adult caregivers, and B) contrast young adult caregivers against non-caregiving demographically matched peers.

It was hypothesized that young adult caregivers would differ from middle-aged and older adult caregivers in terms of caregiving relationship, burden, reported caregiving needs, utilization of support services, and involvement in care. With respect to developmental factors, it was hypothesized that compared to non-caregiving young adults, young adult caregivers would be less likely to have completed college, graduate, or professional degree programs, hold a full-time job, or be married or cohabitating with a partner.

Participants: Caregivers in the U.S.

The first nationwide datasets utilized in this study was the Caregivers in the U.S. (CUS) survey (NAC & AARP, 2015). This survey was purposed with creating a profile of caregivers with respect prevalence, demographic makeup of caregiver and recipients, services utilized, public policy views, and informational needs (NAC & AARP, 2015). Participants in this study were interviewed by phone or internet call. Data included a sample of 1,248 caregivers over the age of 18. For the purpose of this study, only caregivers of individuals with Alzheimer's disease or other memory disorders were included (n = 264). For further information on the methods,

data, or preliminary analyses of the CUS 2015 survey, please see original article (NAC & AARP, 2015).

Participants: Matched Case-control

In the second portion of this study, participants were matched with peers utilizing a five-to-n matched case-control design across age, gender, and race/ethnicity. Matching is a sampling approach that allows for unique populations to be compared to similar peers in a quasi-random fashion. This technique is utilized in epidemiological, observational, or case-study designs to reduce the undue bias that random sampling may produce (Kupper, Karon, Kleinbaum, Morgenstern, & Lewis, 1981; Rubin, 1973). Matching is thought to be most effective when utilized to reduce possible confounding variables (Kupper et al., 1981), though research cautions to remain vigilant of these confounds and to not overmatch samples to avoid misleading or biased matched-samples (Pearce, 2016). Due to the possible confounding nature that sampling dissimilar community members may have had, a limited matched sample procedure was utilized to provide a more accurate portrait on the impact caregiving has on demographically similar individuals (see Appendix B).

Each young adult caregiver ($n = 45$) from the CUS dataset was matched to five national peers ($n = 225$). Matched peers were randomly selected from the American Community Survey Public Use Microdata Sample (ACS PUMS; U.S. Census Bureau, 2015). The ACS PUMS 2015 sample functions as one portion of the U.S. Census Bureau's Decennial Census program, which provides nationwide population information between national census collections. This survey addresses a range of topics including demographic, education, social, economic, and housing among other topics (U.S. Census Bureau, 2015). After deleting data for individuals who did not

meet match criteria, 205,298 matches remained. A random number function in Excel selected the final sample.

Measures

Demographic Variables

Detailed background information on both the caregiver and care recipient were collected during the CUS interview. Demographic information included age, gender, race/ethnicity, relationship of caregiver and care recipient, living situation, and income. Race/ethnicity within the CUS study was limited by combining Hispanic status and racial background, resulting in 5 distinct groups including Caucasian, black/African American, Hispanic, Asian, and “other.”

Caregiving Circumstance Variables

Caregiving circumstance variables include information such as location of recipient, medical problems experienced by the recipient, number of Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) performed, medical or nursing tasks provided, choice in caregiving, weekly caregiving hours, and total time as a caregiver. The CUS survey was conducted as an interview and included open-ended responses, which were further coded into various categories. For detailed information on methodology or the questionnaire, see CUS main report appendix A & B (NAC & AARP, 2015).

Caregiving Burden

Burden level was determined using an adapted form of the Level of Care Index (Persons, 1997), a questionnaire used to characterize caregiving circumstance and predict caregiver

characteristics and needs based on nationwide surveys (National Alliance for Caregiving, 2005, 2009; NAC & AARP, 2015; Persons, 1997). In addition to direct caregiving burden factors, a series of questions evaluating the impact of caregiving on work were collected. These questions included employment, hours worked per week, absences, and warnings about performance or attendance.

Informational Needs and Caregiving Support

Respondents were asked a series of questions pertaining to interaction with, help and education offered by, and involvement of health care providers. Additional questions assessed caregiving support offered to and utilized by caregivers. Within each iteration of the CUS survey, informational needs and aspects of caregiving support were collected with the stated purpose of specifying the caregiving landscape and informing public policy (NAC & AARP, 2015).

Developmental Variables

Participants in both the CUS and ACS PUMS completed a series of questions related to developmental achievements. Self-reported variables that were compared between the two samples include highest level of education achieved, household income, hours worked per week, and relationship status. Some recoding of variables was done to make measurement of variables consistent between these two complementary datasets. For example, household income within the CUS dataset is categorized into blocks, while the ACS PUMS dataset uses an exact numerical value. ACS PUMS income was coded to match that used in the CUS dataset (see Appendix C).

Results

Comparisons between Caregivers

The CUS 2015 database of caregivers for those with Alzheimer's and dementia-related difficulties contained 285 participants. Demographic and individual differences between participants are provided in Table 1. Caregivers within this sample were predominately white (60.7%), female (57.2%), and nearly half had completed college or technical school (48.8%). Average age of the overall sample was 55.25 years ($SD = 14.26$). To be expected, specific demographic variables, such as marital status and employment, differed between categorical age groups and are noted in the demographics table.

Differences in caregiving circumstances were evaluated between groups. No significant difference existed between groups with respect to care recipient gender, number of care recipients, and length of time providing care. Young adult caregivers were significantly less likely to live with the care recipient (14%) compared to middle aged (31.9%) and older adult caregivers (40.0%; $\chi^2 (2, N = 281) = 8.68, p = 0.013$); however, for those who did not live with the care recipient, there was no significant difference in frequency of visits ($F (2,190) = 1.05, p = 0.352$). Older adults (69.7%) were significantly more likely to be the primary caregiver compared to young adult (55.6%) and middle-aged caregivers (52.4%; $\chi^2 (2, N = 288) = 6.45, p = 0.040$). When asked if they had a choice in taking on the role of caregiver, a significantly higher proportion of young adults (61.4%) endorsed having a choice compared to middle-aged (41.5%) and older adult caregivers (36.8%; $\chi^2 (2, N = 284) = 7.36, p = 0.025$). With respect to age of care recipient, young adult caregivers reported taking care of significantly younger

individuals ($M = 70.40$, $SD = 14.12$), compared to middle-aged ($M = 77.73$, $SD = 14.79$) and older adult caregivers ($M = 79.36$, $SD = 14.89$; $F(2,282) = 5.70$, $p = 0.004$, $\eta p^2 = .039$).

Caregiver burden was examined using the Level of Care Index, subjective impact, and external factors that may influence overall burden, such as hours worked per week and having a child/grandchild in the home while caregiving. Tables 2 and 3 report comparisons of caregiving burden by age group. All Level of Care Index subscales – length of time providing care, hours providing care each week, and number of ADLs and IADLs performed – were similar between groups. Similarly, burden index scores were not significantly different between groups. There was no significant difference between age groups in the number of work impacts resulting from caregiving responsibilities ($F(2,165) = 0.39$, $p = 0.678$; Table 3). When asked about subjective level of strain, caregivers reported similar levels of physical ($F(2,281) = 1.68$, $p = 0.188$), financial ($F(2,282) = 0.72$, $p = 0.371$), emotional ($F(2,278) = 2.246$, $p = 0.108$), and current health ($F(2,282) = 0.783$, $p = 0.458$). Conversely, when questioned about the impact of caregiving on current health, there was a statistically significant difference between groups ($F(2,280) = 3.47$, $p = 0.032$). Post-hoc tests revealed that young adults ($M = 2.114 \pm 0.84$) reported lower health impact compared to middle aged caregivers ($M = 2.354 \pm 0.43$). There was no significant difference between middle-aged and older adult caregivers ($M = 2.25 \pm 0.64$; $p = 0.195$). Of interest, young adult caregivers (51.1%) were significantly more likely to have a child living in the house compared to middle-aged (23.0%) and older adult caregivers (6.7%; $\chi^2(2, N=281) = 31.25$, $p < .001$).

A series of Chi-square analyses were conducted to identify group differences in these reported caregiving needs. Caregivers did not report different rates of others preparing them for

medical/nursing tasks ($\chi^2 (2, N = 188) = 1.216, p = 0.544$). Sample size of caregivers providing this form of care was too low to accurately interpret differences with respect to caregivers feeling prepared. With respect to other support needs, caregivers reported similar requests for information to keep care recipients safe at home ($\chi^2 (2, N = 285) = 1.129, p = 0.569$), management of emotional or physical stress ($\chi^2 (2, N = 285) = 1.520, p = 0.468$), making end of life decisions ($\chi^2 (2, N = 285) = 0.536, p = 0.765$), and finding non-English caregiving support material ($\chi^2 (2, N = 285) = 0.262, p = 0.877$). However, with respect to requesting information to manage challenging behavior, young adult caregivers (20.0%) reported the lowest need, followed by older adult caregivers (25.0%), and finally middle-aged caregivers (36.6%; $\chi^2 (2, N = 188) = 1.216, p = 0.044$). With respect to information on managing incontinence or toileting problems, young adult caregivers (11.1%) reported the lowest need, followed by older adult caregivers (18.4%), and finally middle-aged caregivers (26.8%; $\chi^2 (2, N = 285) = 5.883, p = 0.053$). Caregivers reported care recipients having future-care plans at similar rates ($\chi^2 (2, N = 250) = 0.844, p = 0.656$), but increasing likelihood to have plans for their own future care as age group increased ($\chi^2 (2, N = 284) = 5.896, p = 0.052$). Finally, when asked if they expected to be a caregiver in five years, young adults were most likely to be unsure (28.9%) when compared to middle-aged (14.6%) and older adult caregivers (19.7%; $\chi^2 (2, N = 285) = 10.933, p = 0.027$).

In addition to reports of requested caregiving information, participants were surveyed about their utilization of past support services. Different-aged caregivers reported similar levels of past use of respite services ($\chi^2 (2, N = 285) = 0.089, p = 0.957$), transportation services ($\chi^2 (2, N = 284) = 0.267, p = 0.875$), and modifications to the care recipient's home ($\chi^2 (2, N = 285) = 4.159, p = 0.125$). Similarly, groups reported comparable frequency of health professionals

discussing needs as a caregiver ($\chi^2 (2, N = 284) = 2.364, p = 0.307$) and personal help dealing with caregiving strain ($\chi^2 (2, N = 284) = 0.615, p = 0.735$). Conversely, young adult (27.3%) and older adult (27.6%) caregivers reported significantly lower frequency of requesting financial advising compared to middle-aged caregivers (44.8%; $\chi^2 (2, N = 283) = 8.817, p = 0.012$). Caregivers were asked about inclusion in discussions about care recipient's care; however, due to low cell-sizes, results could not be interpreted.

Young Adult Caregiver Development

Questions relating to whether young adult caregivers differed from non-caregiving age peers were addressed by matching participants between the CUS dataset and the ACS PUMS database, as described in the methods section. Due to matching procedure, age, race/ethnicity, and gender were identical between both groups. Table 1 contains these demographic variables for young adult caregivers.

Table 4 reports comparisons between caregiver and non-caregiver peers in education and relationship status. With respect to the highest level of education obtained, both groups reported similar overall education levels ($\chi^2 (2, N = 270) = 4.749, p = 0.314$). Of note, there was a disparity in higher-education levels. Young adult caregivers were more likely to have obtained a Bachelor's degree (33.3% versus 21.8%) and were less likely to report obtaining "some college" or technical school (20.0% versus 32.9%) when compared to non-caregiving peers. Both groups reported similar rates of being married, cohabitating, or being single ($\chi^2 (2, N = 253) = 1.993, p = 0.369$). Both samples were given the option to report divorce (0% and 4.0%), widowhood (2.3% and 0.9%), or separation (0% and 1.8%) – however, infrequent endorsement of these options made results uninterpretable.

With respect to work status, both groups reported similar rates of unemployment. Young adult caregivers more commonly reported part-time employment (28.9% versus 14.2%) and less frequently full-time employment (46.7% versus 63.6%) than did non-caregiving peers ($\chi^2 (2, N = 270) = 6.683, p = 0.035$). Further, of those who are employed, a significantly higher percentage of young adult caregivers reported being self-employed (27.3%) compared to their non-caregiving peers (8.6%; $\chi^2 (1, N = 208) = 9.513, p = 0.002$). This may contribute to the similarity in reports of absences taken from work between both groups, which did not differ significantly ($\chi^2 (1, N = 93) = 0.100, p = 0.752$). It should also be noted that about 65% of respondents' work absence data was missing in the ACS PUMS database. Finally, with respect to household income, a Mann-Whitney test indicated young adult caregivers reported significantly lower income ($Mdn = \$15,000$ to $\$29,999, IQR = 2 - 2$) than non-caregiving peers ($Mdn = \$50,000$ to $\$74,999, IQR = 3 - 5.25; U = 4113.5, p = 0.043$). Figure 1 depicts the difference between groups with respect to the income bracket reported.

Discussion and Implications

This study explored a recent sample of caregivers within the United States by comparing young adult caregivers to other-aged caregivers and similarly aged non-caregiving peers. Primary findings are that by comparison to middle-aged and older caregivers, young adult caregivers perform similar types and amounts of caregiving activities, and report similar levels of impact, despite being more likely to have childcare responsibilities and have to commute to provide caregiving. By comparison to non-caregiving age-peers, young adult caregivers are more

likely to work part-time rather than full-time, be self-employed, and report lower household incomes.

The first hypothesis, positing a dissimilarity in needs, circumstance, and involvement of young adult and other-aged caregivers, was partially supported by a mixture of significant and non-significant differences. Young adult caregivers report taking on similar degrees of responsibility in terms of how long they have provided care, how many hours of care they provide weekly, and number of ADLs and IADLs performed. However, young adult caregivers were less likely to live in the same home as the care recipient, requiring higher rates of commuting to provide care. Young adult caregivers report additional stressors such as simultaneously providing childcare and experiencing higher levels of uncertainty with respect to their future role as a caregiver. Nevertheless, young adult caregivers report equivalent impact on their physical, financial, and emotional wellbeing, and are more likely to have a choice in their original decision to become a caregiver.

While some age differences were pronounced and may contribute to a better understanding of young adult caregivers as a unique group, other times young adult caregivers and one different-aged group were more similar than the remaining age group. These mixed differences support the notion that current interventions may, in some ways, suit the needs of young adult caregiver at least with respect to intervention content. For example, young adult caregivers and middle-aged caregivers were both less likely to be a primary caregiver compared to older adult caregivers, whereas young adult caregivers and older adult caregivers were less likely to request additional support managing challenging behaviors and to discuss financial needs with a healthcare professional compared to middle-aged caregivers. With respect to the

development of young adult caregivers, results indicate that they are more likely to obtain a college degree, be self-employed, report working part-time, and report lower yearly income compared to non-caregiving peers; however, these groups report similar instances of being single, cohabitating, or married.

These findings advance our understanding of young adults who care for a loved one with dementia. The sparse existing evidence has not directly compared young adult caregivers to other-aged caregivers, leading to shortcomings in our understanding of the role, functioning, and needs of these individuals. Findings further support the hypothesis that young adult caregivers experience unique stressors, which may inform future interventions. For example, half of young adult caregivers reported simultaneously caring for a child while caregiving, while only a quarter of middle-aged and less than a tenth of older adult caregivers do the same. Considering young adult caregivers often work, care for a child, and commute to their care recipient, it is surprising that these individuals also report equal or lower burden levels and health impacts compared to other caregivers. Nevertheless, this resilient group may benefit significantly from support services to prevent caregiver burnout due to their increased number of potential stressors. Unfortunately, results suggest they may balance a larger number of competing goals, and thus may have less time to attend to their own needs in this regard. Future research should examine the relationship between caregiver age and use of coping behaviors, social support, and the interactive effects on objective measures of health status and well-being.

Developmentally, young adulthood is a time of complex development transition in which successes or setbacks will influence well-being in later-life. While this study found that young adult caregivers may obtain college degrees at higher rates than their non-caregiving

counterparts, it also found young adult caregivers are more likely to work part-time jobs, be self-employed, and earn a smaller annual income. One interpretation of these findings is that young adults with fewer occupational demands are more likely than full-time employees to assume caregiving responsibilities. This pattern may also reflect the greater opportunity cost associated with non-remunerative activities encountered by those with more professional credentials and higher incomes. An alternate interpretation is that caregiving responsibilities create barriers to involvement in remunerative occupational activities. The later interpretation is supported by other work suggesting that caregivers reduce labor force participation in response to escalating caregiving demand, but not as a function of personal preferences to do so (Paulson, Bassett, Kitsmiller, Luther, & Conner, 2017). Nevertheless, under one-fifth of young adult caregivers report a household income over \$75,000, while their peers are twice as likely to earn the same. This lower access to financial support may be magnified by the resource and time needs of caregivers, especially those with children to care for as well. Future research should further explore this relationship in addition to the direction of career choices.

The primary limitation of this study is the use of pre-existing data, which limited the ability to answer important questions such as utilization of other health behaviors related to burden resilience and important developmental questions such as social involvement, career progress and impact, and familial relationships. Secondly, while this sample is one of the largest of its kind available, there still exists an issues in the sampling of young adult caregivers, further underscoring the need for future work with this population. Samples of young adult caregivers are infrequent, and are minimal to nonexistent within the support intervention literature. The lack of sample size in this study precluded analysis of rare events among young adults such divorce

and death of spouse. Thirdly, available variables such as marital status may be underrepresented in members of the LGBT community due to the recency of nation-wide marriage equality, thus relationship status may not be an accurate representation of an individual's plans or desires. It is interesting that CUS survey respondents reported LGBT identity at double the rate of the overall population. This suggests that future research should seek to better understand the influence of sexual and gender diversity on outcomes among young adult caregivers. Finally, this study compared a range of differently-aged caregivers, which may conflate developmental and cohort effects. For this reason, areas in which young adult caregivers differ from middle-aged and older adult caregivers may be better accounted for by social or cultural norm shifts within age groups as opposed to direct age or developmentally related dissimilarities. Future research may build on these findings using longitudinal designs.

One possible implication of this study is to the role caregiving plays in risk of long-term poverty outcomes and its contribution to a reduction in intergenerational economic mobility. The notion that caregiving in earlier life may contribute to poverty rates in later-life has been supported by previous research on women caregivers (Wakabayashi & Donato, 2006). The present study extends these findings to support the notion that both male and female young adult caregivers are at risk of working fewer hours and earning substantially less than their non-caregiving peers. Further, the notion that economic mobility between generations is more pronounced than our other first-world counterparts (Corak, 2013) and the role caregiving may play in creating a cycle of lower income and stability have been documented in review and experimental studies (Lee, Tang, Kim, & Albert, 2014). And while caregiving is not a unique phenomenon to the United States, understanding how it may contribute to these detrimental

circumstances is vital to informing future policy, cross-cultural examination of caregiving impact, and creating supportive interventions to reduce caregiver burden.

This study emphasizes the presence of young adult caregivers as a significant proportion of those providing informal care and underscores similarities and differences between young, middle-aged, and older adult caregivers. It remains unclear why young adult caregivers are not being represented in interventional research, but perhaps future research may address this disparity. Similarities between caregivers of varying age groups suggest that young adult caregivers may similarly benefit from interventions such as REACH or Savvy Caregiver. However, differences between these groups suggest that young adult caregivers may have limited time and resources to pursue such interventions. Clarifying young adult caregivers' desire for, needs within, and response to support services is an integral next step in assuring that this population does not remain a forgotten segment of those providing substantial care to loved ones.

CHAPTER 5: FACTORS CONTRIBUTING TO THE NON-INVOLVEMENT OF YOUNG ADULT CAREGIVERS

Methods

Study 2 involved the collection and comparison of data from an online nation-wide sample of caregivers of individuals with dementia-related difficulties. This study served two purposes: to explore young adult caregivers' use, interest, and barriers to supportive interventions, and to compare the past utilization, desired needs, and interest in future interventions between caregivers of different age groups. It is hypothesized that when compared to other-aged caregivers, young adult caregivers will report 1) more numerous barriers to care, 2) lower interest and intervention expectancy, and 3) different caregiving support needs.

Participants

The collected sample contained young adult (n=51), middle-aged (n=50), and older adult (n=50) caregivers who had provided care within the last five years. An individual was defined as a "caregiver" if they met the operational criteria of: providing or helping obtain care for a friend, relative, or loved one to aid/supplement Activities of Daily Living (ADLs) and/or Instrumental Activities of Daily Living (IADLs). Caregivers were asked to report primary difficulties experienced by the care recipient to assess for dementia or dementia-related difficulties. Participants were recruited through Amazon Mechanical Turk and were monetarily compensated \$0.30 for their participation. Participants were excluded from the study if they did not meet the above criteria as a caregiver, if they were under the age of 18, and if they did not reside within the United States.

Measures

Due to the lack of literature assessing non-patient-related barriers to care, self-efficacy, and support service interest/needs, several validated measures were adapted to properly address caregiving support interventions. All effort was given to minimize alterations within pre-existing measures. Psychometric properties reported reflect the original measures and should not be considered fully applicable due to phrasing and/or structural changes.

Caregiver Screener

Participants were asked a series of initial questions regarding the demographics of the caregiver and care recipient (see Appendix A). The screener covered a range of possible conditions experienced by the care recipient. The first purpose of this 5-question screener was to identify individuals who fit study criteria. The second purpose of the screener was to control for possible low-quality or disingenuous respondents via the Mechanical Turk survey system.

Caregiver Relationship

Participants were asked several questions regarding how they became caregivers, frequency and type of caregiving being provided, utilized support, and caregiving expectancies. Caregiver relationship questions were modeled after similar Young Adult Caregiver surveys (Dellmann-Jenkins & Brittain, 2003).

Caregiving Burden

Participants completed the Level of Care Index (National Alliance for Caregiving, 2005, 2009; National Alliance for Caregiving (NAC) and AARP Public Policy Institute, 2015; Persons,

1997). The Level of Care index contains several questions that assess number of ADLs and IADLs performed by the caregiver, hours spend providing care each week, and total time spent as a caregiver. Additionally, questions to assess the subjective burden associated with these caregiving activities were asked.

Caregiver Support

Several questions were asked to assess what support caregivers had previously sought, where this information was obtained, and what further information was desired. Listed support services reflected common areas of support addressed by caregiver interventions and surveys. Additionally, participants were given the option to freely note any unlisted responses.

Barriers to Access and Care

Barriers to care were measured using an adapted version of the Barriers to Care Evaluation (BACE-3; Clement et al., 2012). The BACE-3 is a 30-item self-report measure which covers a range of possible barriers to accessing mental healthcare, including attitudinal, structural, and stigma barriers (Clement et al., 2012). The BACE has been found to have good overall test-retest reliability (κ [0.61, 0.80]), subscale internal consistency ($\alpha = 0.89$), and convergent validity with similar scales (Clement et al., 2012). Development of the BACE included focus groups to ensure high content validity, and readability understandable by individuals 11 to 12 years of age (Flesch-Kincaid Grade level = 5.9; Clement et al., 2012; Kincaid, Fishburne Jr, Rogers, & Chissom, 1975). As stated previously, there exist no current options to assess barriers to care for support services such as caregiver support groups. For this

reason, the BACE was repurposed to include language reflective of a caregiver's circumstances and not the circumstances of an individual currently seeking mental health treatment.

Caregiver Self-Efficacy

Participants were given a 6-question measure confidence in caregiving tasks. These areas of caregiving reflected areas of caregiving associated with caregiver support interventions. Caregiver self-efficacy was assessed to explore possible efficacy-related disinterest in support services.

Intervention Expectancy/Credibility

Participants were given an adapted version of the Credibility/Expectancy Questionnaire (CEQ; Devilly & Borkovec, 2000). The CEQ is a 6-item self-report measure that addresses credibility in the form of how an individual thinks an intervention will work and expectancy based on how the same individual feels the intervention will work (Devilly & Borkovec, 2000). CEQ-based questions were asked to assess caregiver support group credibility and expectancy. The original CEQ was given to individuals in the initial stages of treatment; however, due to the prospective nature of this study, participants based their ratings on a short description of a caregiver support group format and content (see Appendix E).

Intervention Preferences

Participants were asked to provide information regarding intervention modalities of interest (i.e., group, online, support, or psychoeducation-only). Additionally, questions addressing overall interest in receiving services were asked.

Demographics

In addition to measures establishing various caregiving variables, additional basic demographic information was gathered (i.e., gender, ethnicity, age) in addition to idiographic information (i.e., education, marital status, number of children, employment, and income/socioeconomic status).

Procedures

Following IRB approval, the study was opened within the Amazon Mechanical Turk System. Participants were directed via URL to a Qualtrics-based online survey. After consenting to participation in the study, participants were directed to the survey. Completion time of the full survey varied between 10 to 20 minutes. At completion of the survey, participants were compensated as listed above [see Chapter 5 – *Participants*].

Statistical Methods

Due to the novel sample and exploratory nature of this study, power analysis could not be used to determine appropriate sample size. In an attempt to allow for effect size estimates to be obtained, a sample of 50 participants per age grouping (N=151) was collected. Further, based on previous national sampling attempts, samples larger than 150 individuals may have been difficult to obtain. Data collected for Study 2 analyzed differences in intervention preferences between caregivers based on age group. Chi-square and ANOVA analyses were utilized to explore these

differences. Additionally, specific intervention preferences and barriers to care reported by young adult caregivers were explored using frequency and descriptive statistics.

Results

Caregiver Circumstances

Participants were recruited over a four month period using the Amazon Mechanical Turk survey system. Demographic and individual differences between participants are provided in Table 5. Caregivers within this sample were on average 48 year old ($SD = 5.23$) white (78.8%) females (70.2%), nearly half of whom had completed college or technical school (74.2%). Average age of the overall sample was 48.04 years ($SD = 17.11$). To be expected, specific demographic variables, such as marital status and employment, differed between categorical age groups and are noted in the demographics table. Young adult caregivers were more likely to be single and never partnered (37.3%) compared to middle-aged (14.0%) and older adults (8.0%). However, overall the number of caregivers married or with a partner and those single or without a partner due to divorce, death, or separation were similar between age groups. With respect to employment, young adult caregivers were more likely to be employed full-time (52.9%) and part-time (43.1%) than middle-aged (40.0% full-time and 30.0% part-time) and older adult (3.9% full-time and 30.0% part-time) caregivers. Of those who were employed, older adults were the most likely to be self-employed (40.0%) when compared to young adult (16.3%) and middle-aged (17.1%) caregivers. Additionally, racial and ethnic background differed between groups. As is reported in Table 5, middle-aged caregivers were more predominantly white (90.0%) compared to older adult (78.0%) and younger adult (68.6%) caregivers.

Of interest, there were significant differences in gender distribution between age groups ($\chi^2(4, N = 151) = 10.22, p = 0.037$). Older adults were the most evenly distributed with 58.0% being female, young adults were comprised of 66.7% female caregivers, and middle adults were 84.0% female. There were unexpected differences in religious distribution of caregivers. The current study found that non-religious respondents made up 37.2% of younger adults, 34.0% of middle-aged adults, and 37.7% of older adults. Further examination of the older adult caregivers indicated that 24% were Catholic, 30% other denominations of Christianity, 2% Jewish, and 2% “other” religions. Additionally, LGBT status was disproportionately represented in certain caregiver age groups. Young adult caregivers identified as a member of the LGBT community most frequently (24.6%), followed by middle-aged adults (16.0%), and older adults (6.0%).

Caregivers reported similar circumstances regardless of age group. Reports of caregiver circumstances and burden can be found in Table 6. Caregivers did not significantly differ in terms of length of time providing care, time expecting to continue caring for recipient, hours spent providing care each week number of ADLs and IADLs performed. Of interest, when asked how difficult it was to complete caregiving tasks, there was a small non-significant trend towards young adult caregivers reporting lower levels of subjective burden. Young adult caregivers reported similar ratings of difficulty performing ADLs ($M = 2.71, SD = 1.64$) compared to middle adult ($M = 3.22, SD = 1.27$) and older adult caregivers ($M = 3.16, SD = 1.23$; $F(2,148) = 2.66, p = .073, \eta^2 = 0.03$). Similarly, there was a small non-significant trend for young adult caregivers in terms of difficulty performing non-ADL/IADL tasks ($M = 2.67, SD = 1.19$) when compared to middle adult ($M = 3.22, SD = 1.30$) and older adult caregivers ($M = 3.07, SD = 1.20$; $F(2,148) = 2.71, p = .070, \eta^2 = 0.04$). Caregivers did not differ in terms of reported

difficulty performing IADLs ($F(2,148) = 1.59, p = .208, \eta^2 = 0.02$). Additionally, caregivers reported similar rates of taking on the role of primary caregiver, equally sharing caregiving responsibilities, or having someone else serve as the primary caregiver. However, older adults were more likely to live with the care recipient (58.0%) compared to middle-aged (46.0%) and young adult (31.4%) caregivers ($\chi^2(4, N = 151) = 9.53, p = .049$).

All caregivers endorsed few barriers to care on the Barriers to Access to Care Evaluation for Caregivers (BACE-CG). Results of these comparisons are reported in Table 7. Considering the Likert-style scale ranging from not at all (0) to a lot (3), caregivers did not differ in overall average endorsement of barriers to care ($F(2,148) = 1.405, p = .249; \eta^2 = 0.02$). Similarly, caregivers did not differ in rates of instrumental ($F(2,148) = 0.108, p = .898; \eta^2 = 0.001$) or stigma-related barriers to care ($F(2,148) = 1.168, p = .314; \eta^2 = 0.02$). Of interest, there was a small non-significant trend towards a difference in attitudinal barriers to care ($F(2,148) = 3.019, p = 0.52; \eta^2 = 0.04$). Specifically, young adult caregivers ($M = 1.01, SD = 0.65$) endorsed more attitudinal barriers to care than middle adult ($M = 0.75, SD = 0.48$) and older adult ($M = 0.79, SD = 0.56$) caregivers.

Interest in Support, Information, and Intervention

Interest in support groups was measured in several metrics including overall interest, ratings of importance for, and different forms of groups available. There were no significant differences between age groups in terms of overall interest in a caregiver support group, rating the importance of support groups, and attending in-person support groups, individual therapy, online educational services, or online support groups. Results for these comparisons are reported in Table 8. On a Likert-scale of one to five, caregivers were generally in favor of treatment. All

caregivers reported interest in support groups ($M = 3.42, SD = 0.91$). Additionally, they rated support groups as highly important ($M = 4.04, SD = 0.79$). Caregivers did not differ in preference of support format across age groups. Several paired-sample t-tests were conducted to examine whole-sample preference for support format. Caregivers found online caregiver education services to be more appealing ($M = 3.60, SD = 1.179$) than in-person support group ($M = 3.26, SD = 1.284; t(150) = -2.621, p = .010$) and individual therapy ($M = 3.26, SD = 1.315; t(150) = -2.545, p = .012$). Similarly, caregivers found online support groups to be more appealing ($M = 3.55, SD = 1.209$) than in person support group ($t(150) = -2.540, p = .012$) and individual therapy ($t(150) = -2.226, p = .028$). There were no significant differences between the two in-person support formats or the two online support formats.

With respect to treatment expectancy, there were no significant differences between caregivers of different age groups. On a scale of one to nine, caregivers found that a support group was logical ($M = 5.97, SD = 2.38; F(2,148) = 0.512, p = .600; \eta^2 = .007$), useful ($M = 5.35, SD = 2.39; F(2,148) = 1.702, p = .186; \eta^2 = .02$), would recommend it to a friend ($M = 6.17, SD = 2.17; F(2,148) = 0.878, p = .418; \eta^2 = .01$), and felt that it may reduce caregiving difficulties ($M = 4.70, SD = 2.50; F(2,148) = .371, p = .691; \eta^2 = 0.005$). Additionally, when asked what percentage of improvement a caregiver support group may result in, they expected to see a 41.72% ($SD = 25.94; F(2,148) = .792, p = .455; \eta^2 = .01$) improvement in stress and 38.79% ($SD = 26.99; F(2,148) = .648, p = .525; \eta^2 = .009$) improvement in caregiving difficulties. Finally, caregivers were asked about their self-efficacy in performing caregiving tasks. There were no significant differences between groups in terms of self-efficacy across tasks or in total.

A series of Chi-square analyses were conducted to explore differences between caregivers with respect to their sources of support, caregiving information, kinds of support utilized while caregiving, desired support while caregiving, information they sought out when taking on their role as a caregiver, and information they desired to have as caregivers. Percentage of endorsement for each category is reported in Figures 2 through 7.

Figure 2 reports the sources of support for all caregivers in the sample. Young adult caregivers reported family (94.1%) as a source of support significantly more frequently than middle adult (72%) and older adult caregivers (78%; $\chi^2 (2, N = 151) = 8.77, p = .012$). Caregivers did not differ significantly in reports of other areas. Combined frequency of support sources of all age groups are reported following: the most common source of support was family (81.5%), followed by professional care services (33.1%), friends (30.5%), non-profit care services (7.9%), and finally work (2.6%).

Figure 3 reports sources of caregiving information. Of the several sources of caregiving information, friends were more commonly used by young adults (47.1%) compared to middle adult (40.0%) and older adult caregivers (26%; $\chi^2 (2, N = 151) = 4.93, p = .085$). However, young adults (35.3%) were the least likely group to receive caregiving information from a primary care doctor or other physician, compared to middle-aged (62.0%) and older adult caregivers (54%; $\chi^2 (2, N = 151) = 7.605, p = .022$). Caregivers did not differ in terms of sources of support, overall frequency of endorsement across age groups follow: the most common source of information was the internet (61.6%), followed by a primary care doctor or physician (60.3%), family (52.3%), friends (37.7%), books (33.1%), community groups or organizations (20.5%), support groups (18.5%), and finally religious organizations (5.3%).

Figure 4 reports information on the types of support utilized by participants during their time as caregivers. Support utilization differed between groups in two areas: transportation aids and house modifications. Middle-aged caregivers (28%) more frequently used transportation aids compared to young adult (17.6%) and older adult caregivers (4.0%; $\chi^2(2, N = 151) = 10.49, p = .005$). Additionally, middle-aged caregivers (38%) were more likely to have modifications to the care recipient's house installed compared to young adult (27.5%) and older adult caregivers (12%; $\chi^2(2, N = 151) = 8.93, p = .012$). Caregivers did not differ in terms of sources of support, overall frequency of endorsement across age groups follow: caregivers most frequently reported utilizing friends of family members to provide care (51.0%), followed by friend or family members for "other" (unlisted) forms of support (41.1%), friend or family transportation (35.1%), professional care services (31.8%), house modifications (25.8%), support group (19.9%), transportation aids (16.6%), respite care or adult daycare services (12.6%), and finally financial counseling (5.3%). Caregivers were also asked which types of support they wished to have during their time as a caregiver. These results are reported in Figure 5. There were no significant differences between groups in terms of desired support while caregiving. Most frequently, caregivers reported a desire for professional care services (49.0%), followed by care provided by a family member or friend (36.4%), "other" (unlisted) support by a family member or friend (29.8%), caregiving support group (29.8%), respite services or adult daycare (29.1%), transportation provided by family or friend (26.5%), transportation aids (25.8%), house modifications (23.8%), and finally financial counseling (21.9%).

Finally, caregivers were asked what information they sought out when serving as a caregiver, as well as what information they wished they had as a caregiver. Figure 6 reports

information sought out by caregivers. There were no significant differences between caregiving age groups in any categories. Overall, caregivers most frequently sought out education about the diagnosis of the care recipient (69.5%), followed by ways to manage their own emotional or physical stressors (39.7%), education about community services (33.3%), stress management skills (30.5%), emotional or community support (29.8%), ways to manage difficult behaviors of their care recipient (21.9%), and finally professional counseling or treatment (17.9%). With respect to information caregivers wished they had during their time as a caregiver, there were no significant differences between groups. Figure 7 reports these findings. Caregivers most frequently desired education about the diagnosis of the care recipient (57.6%), ways to manage their own emotional or physical stress (42.4%), stress management skills (41.1%), education about community services (35.8%), skills to manage difficult behaviors (31.1%), and finally professional counseling or treatment (25.2%).

Discussion

This study surveyed a national sample of caregivers who ranged from age 18 to 77 and contrasted those who were young, middle-aged, and older adults. Results indicate that young adult caregivers experience similar levels of burden, role, and impacts from caregiving. Despite being in drastically different stages of life, caregivers were shown to typically present with more within-group than between-group variation. However, young adult caregivers were unique in several ways. Young adult caregivers tended to report lower subjective impact from caregiving activities; they were the least likely to live with the care recipient, and thus most likely to commute to provide care; they endorsed more attitudinal barriers to care; and they were more

likely to ask friends and family for help when acting as a caregiver, yet were the least likely group to receive caregiving information from a medical professional. Similarities between groups are also important to note. Young adult caregivers reported similar utilization of services, needs, and sources of support, were just as likely to report attending a caregiver support group as other-aged caregivers, and found support groups similarly of interest and importance.

Two demographic anomalies were present in the collected sample. It is unclear if these are a result of sampling, random chance, or representative of caregivers. First, there were unexpected differences in religious distribution of caregivers. Non-religious caregivers were more represented in the sample than would be expected from previous nation-wide sampling. Surveys from the Pew Research Center (2014) report that non-religious individuals make up roughly 36% of adults ages 18-29, 25% of adults ages 30-49, 17% of individuals ages 50-64, and 12% of adults aged 65 or older, while the present study found that non-religious respondents made up 37.2% of younger adults, 34.0% of middle-aged adults, and 37.7% of older adults. When reviewing other faith backgrounds, it appears that the discrepancy existed in a lack of Protestant Christian respondents. The present study included 30% Protestant Christians, whereas national samples estimate roughly 59% of older adults to fit into this category. Secondly, LGBT status was disproportionately represented in this sample. National surveys on sexual orientation and gender report 4.1% of all adults identify as LGBT (Gates, 2017). In the present study, young adults were about six times more likely to identify as LGBT, middle aged-adults were about four times as likely, and older adults were about one and a half times more likely. Further exploration as to the representativeness of these findings is warranted, particularly in addressing support systems and unique difficulties that individuals in these groups may differ.

The first hypothesized difference between young and other-aged caregivers was partially supported. While all caregivers reported few barriers to care, young adults reported several more attitudinal barriers to care. Attitudinal barriers include notions such as: wanting to solve my own problems; thinking that professional care probably would not help; or preferring to get help from friends or family instead. These notions fit with young adult caregivers' more frequent utilization of friends and family as sources of support. Paired with young adults being the least likely group to speak to a medical professional about caregiving, this also leaves young adults vulnerable to receiving inadequate or information not based in empirical study – both for caregiving duties and for self-care.

The second hypothesis posited in this study, that young adult caregivers would report lower interested and intervention expectancy, was rejected. Young adult caregivers, along with other-aged caregivers, reported neutral to positive views on the importance of caregiver support interventions. However, while realistic, caregivers reported low levels of expectancy for stress or caregiving difficulties improvement as a result of support interventions. Finally, when surveyed about what form of support caregivers would prefer, all favored online-based education or support groups above in-person groups or individual therapy. Type of online support (i.e., education-only or support group) did not significantly differ between caregivers.

The third and final hypothesis, that young adult caregivers would report dissonant caregiving needs, was partially supported by a mixture of significant and non-significant results. Young adults were similar to other-aged caregivers in the majority of desired caregiving information or support; however, middle-aged caregivers reported higher frequency of transportation usage and house modifications when compared to young adult and older adults.

While there still remain gaps in our understanding of young adult caregivers, these findings highlight three major areas of focus. First, young adult caregivers mirror middle-aged and older adult caregivers in the majority of caregiving responsibilities, burden, and impact. However, they take on additional roles such as parenting and employment at much higher rates. This means that young adult caregivers are more restricted by their lack of time and potential lack of financial support. Second, young adult caregivers report utilization of caregiver support services at similar rates to other caregivers; however, research samples of caregivers continue to lack this significant portion of caregivers. Young adult caregivers reported similar or more barriers to care, particularly in attitudinal barriers (i.e., belief that the stressor will resolve itself or the treatment would not create change), and all caregivers reported greater interest in online-based interventions compared to in-person interventions. Though significant, the difference in attitudinal barriers was not large. Due to the similarities between caregivers across age groups, it is still unclear why interventionistic samples tend to lack younger adult caregivers. Barriers to care and interest in such support do not account for the non-participation of young adult caregivers; thus, researchers themselves may need to reevaluate recruitment methods and inclusion criteria between research protocols. Third, caregivers across the spectrum had medium to low expectations for the efficacy of support groups, but did prefer online modes of support. While this may be due to a sampling bias caused by surveying caregivers online, these findings also suggest that an online caregiver support group may be an attractive option for caregivers, thereby facilitating recruitment and retention.

The main limitations of this study were three-fold. First, it utilized an online sample of caregivers who may disproportionately prefer online formats of support and use the internet as a

source of information. Despite these potential limits to validity, these results were consistent with other samples of caregivers, such as the CUS 2015 sample. Future research may attempt to sample community-based caregivers and compare them to online-samples of caregivers to evaluate the bias – if any – between samples. The second limitation of this study is the inherent cohort effect carried by comparing age groups at a single time point. For example, young adult caregivers reported more attitudinal barriers to care (e.g., “I want to solve the problem on my own” or “I think the problem will get better on its own”). Due to the possible cohort effect, it is difficult to differentiate between this being due to maturation differences or social/cultural shifts specific to this group of caregivers. Finally, numerous findings with marginal, but non-significant p-values suggests that the study was underpowered. Future studies may benefit from increasing sample size, or attempting to conduct a meta-analysis across samples of caregivers to achieve higher statistical power.

The two presented studies prompted several actionable pieces of information for clinicians and researchers. With respect to research endeavors, findings indicate that young adult caregivers desire support as much as other-aged caregivers. While young adult caregivers may take on additional time-consuming burdens (e.g., childrearing and employment), the gap between the number of caregivers in the population and those included in research is drastic and results in an almost non-existent sample of young adults. Sampling methodology may be enhanced by taking this population into account when considering location of recruitment materials, language used in flyers, time and location of the support group, and utilizing location-based online advertisements. For example, the REACH II inclusion criteria limited participants to those who were white, black, or Hispanic, over the age of 21, and a caregiver who lived with or shared

cooking facilities with the care recipient (Czaja et al., 2006). It is unclear if preference was given to spouses or older caregivers; however, given the likelihood for young adult caregivers to share caregiving responsibilities or not label themselves as a primary caregiver (while still providing similar levels of care), this exclusion criteria may have disproportionately limited the ability of young adult caregivers to participate. While this is not a criticism of the methodology of this caregiver intervention, it serves as an example of how current recruitment methods may artificially limit the presence of young adult caregivers during the creation and implementation of support interventions. With respect to actionable changes to interventions, young adult caregivers may have greater need for content addressing work-related stressors and balancing parenting and caregiving needs. Of significance, young adult caregivers were half as likely to receive information from primary care doctors when compared to other-aged caregivers. Educating physicians of this discrepancy may help close the gap in medically relevant caregiving knowledge, and add another source of support to this potentially overlooked population.

These results may be informative to the development, refinement, and delivery of caregiver support interventions. While young adult caregivers appear extremely similar to other-aged caregivers, they remain scarce in research samples. Re-assessment of research protocol in both recruitment and inclusion criteria is warranted. Young adult caregivers may have more restricted schedules due to work or childrearing obligations, may be less fiscally stable, and may hold the opinion that support is unnecessary. One promising finding of this study, however, is that online-based interventions appear to be acceptable, welcome, and well-suited to address the time and financial constraints experienced by all ages of caregivers. While such interventions are being developed across the country (e.g., SAVVY Caregiver; Lewis, Hobday, & Hepburn,

2010), this area remains open for innovation and research. Future research, especially those developing online caregiving interventions, should ensure that they achieve an adequate sample of young adult caregivers to ensure that this group is no longer overlooked.

APPENDIX A: IRB APPROVAL LETTER



University of Central Florida Institutional Review Board
Office of Research & Commercialization
12201 Research Parkway, Suite 501
Orlando, Florida 32826-3246
Telephone: 407-823-2901 or 407-882-2276
www.research.ucf.edu/compliance/irb.html

Approval of Exempt Human Research

From: UCF Institutional Review Board #1
FWA00000351, IRB00001138

To: Nicholas T. James

Date: October 10, 2017

Dear Researcher:

On 10/10/2017, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination
Project Title: Caregiver Treatment Preferences
Investigator: Nicholas T. James
IRB Number: SBE-17-13430
Funding Agency:
Grant Title:
Research ID: N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the Investigator Manual.

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

A handwritten signature in black ink, appearing to read "Gillian Morien".

Signature applied by Gillian Morien on 10/10/2017 10:54:20 AM EDT

IRB Coordinator

APPENDIX B: MATCH SAMPLE CRITERIA TABLE

Match-Sample Criteria	
CUS Variable	ACS PUMS Variable
Age Numerical	Age Numerical
Gender Options: M/F	Gender Options: M/F
Race/Ethnicity (single-shot) Options: White Black Asian Other Hispanic	Race/Ethnicity + Hispanic status (HISP) Recoding done to match CUS variables with lower specificity
English Speaking Participation only available to those able to speak English fluently.	English Speaking: Ability to speak English Removed if responded “not at all”

**APPENDIX C: MATCHED-DATASET VARIABLES OF ANALYSIS
TABLE**

Match-Dataset Variables of Analysis		
CUS Variable	ACS PUMS Variable	Re-coded Variables
<p>Education:</p> <p>Options:</p> <ul style="list-style-type: none"> • Less than high school • High school grad/GED • Some college • Technical school • College grad • Graduate school / Grad work 	<p>Education:</p> <p>Options:</p> <ul style="list-style-type: none"> • No schooling completed • Nursery school, preschool • Kindergarten • Grade 1-12 [each individually listed] • 12th grade - no diploma • Regular high school diploma • GED or alternative credential • Less than 1 year of college • 1 or more years of college credit, no degree • Associate's degree • Bachelor's degree • Master's degree • Professional degree beyond a bachelor's degree • Doctorate degree 	<p>Re-code ACS data to fit less stringent CUS data</p> <ul style="list-style-type: none"> • Less than high school = Grade 12 no diploma and those under. • High school grad/GED = Regular high school diploma + GED or alternative credentials. • Some college = Both “some college” variables. • Technical school and College Grad merged in CUS = AA+BS. • Graduate school/grad work = MA+ all above.
<p>Household income: Caregiver Household Income</p> <p>Options:</p> <ul style="list-style-type: none"> • Under \$15,000 • \$15,000 to \$29,999 • \$30,000 to \$49,999 • \$50,000 to \$74,999 • \$75,000 to \$99,999 • \$100,000 or more • Less than \$50,000, not fully specified • More than \$50,000, not fully specified 	<p>Household income (past 12 months)</p> <p>Option: Numerical response</p>	<p>Re-code ACS dataset into same categorical groupings as CUS.</p>
<p>Hours worked per week: About how many hours a week, on average, do you work?</p> <p>Option: Numerical response</p>	<p>Hours worked per week: Usual hours worked per week past 12 months</p> <p>Option: Numerical response</p>	<p>No change</p>

<p>Employment: “Are you currently employed?” Options: Y/N</p>	<p>Employment: Employment Status Recode Options: <ul style="list-style-type: none"> • Civilian employed, at work • Civilian employed, with a job but not at work • Unemployed • Armed forces, at work • Armed forced, with a job but not at work • Not in labor force </p>	<p>Recode ACS for employed or not currently Options: Y/N</p>
<p>Leave of Absence: Took a leave of absence – as worker/caregiver Options: Y/N</p>	<p>Leave of Absence: Temporarily absence from work Options: Y/N/NA</p>	<p>No change</p>
<p>Self-Employment: Currently/were self-employed or own business? Options: Y/N</p>	<p>Self-Employment: Class of worker Options: 6-7 (Self-employed...)</p>	<p>Recode ACS variable to only show 1-5 (N), 6-7 (Y), 8-9 (N)</p>
<p>Military: CG served military active duty? Options: Y/N</p>	<p>Military: Military Service Options: <ul style="list-style-type: none"> • Now on active duty • On active duty in the past, but not now • Only active duty for training in Reserves/National Guard • Never served in the military </p>	<p>Recode ACS for only active duty (Y) and non-active/no service (N)</p>
<p>Relationship: Caregiver marital status Options: <ul style="list-style-type: none"> • Married • Living with a partner • Widowed • Separated • Divorced • Single, never married </p>	<p>Relationship: Marital status Options: Married Widowed Divorced Separated Never married PARTNER variable 1-4 = Living with partner will have to do some coding magic to make this fit, but basically if someone reported 1-4 they are cohabitating, else if use marital status answer</p>	<p>No change to Married No change to Divorced No change to Separated No change to Widowed No change to Living with Partner ACS PUMS create Cohabitation variable (“Living with a partner”)</p>

APPENDIX D: ONLINE CAREGIVER SCREEN

1. What is your current level of comfort reading/writing in the English language?
 - a. Comfortable, I am fluent in English
 - b. Mostly comfortable, I am almost fully fluent in English
 - c. Somewhat comfortable, I am somewhat fluent in English
 - d. Not comfortable, I can understand little English
 - e. I do not understand English
2. What is your age?
3. In any time in the last 5 years, have you provided unpaid care to a friend, family member, or loved one over the age of 18?
 - a. Yes
 - b. No
4. Thinking of the individual you care for, please mark all responses which describe their condition:
 - a. Short-term physical condition
 - b. Long-term physical condition
 - c. Emotional or mental health problem
 - d. Developmental or intellectual disorder or mental retardation
 - e. Behavioral issue
 - f. Memory problem
5. Thinking of the individual you care for, which best fits the main problem or illness they experienced?

<ol style="list-style-type: none"> a. Alzheimer's, confusion, dementia, forgetfulness b. Arthritis c. Back problems d. Blood pressure, hypertension e. Brain damage or injury f. Broken bones g. Cancer h. Developmental or intellectual disorder, mental retardation, Down syndrome i. Diabetes j. Feeble, unsteady, failing k. Hearing loss, deafness l. Heart disease, heart attack 	<ol style="list-style-type: none"> m. Lung disease, emphysema, COPD n. Mental illness, emotional illness, depression o. Mobility problem, can't get around p. Old age, Aging q. Stroke r. Substance, drug, alcohol use s. Surgery, wounds t. Vision loss, blindness, can't see well u. Other [Specify] v. Not sure. . .
--	---

APPENDIX E: ONLINE CAREGIVER SURVEY

Throughout this survey the individual you care or cared for in the past will be referred to as the “care recipient.” Please answer each question to the best of your ability thinking of the time you provided unpaid assistance to this individual with dementia or dementia-related difficulty.

1. What is your biological sex?
 - a. Male
 - b. Female
2. What is your gender?
 - a. Male
 - b. Female
 - c. Transgender
 - d. Gender non-conforming
 - e. Prefer not to answer
 - f. Other (Please specify):
3. Which race and/or ethnicity best describes you? (Please check all that apply)
 - a. Asian
 - b. Black or African American
 - c. Hispanic/Latina(o)
 - d. Native American
 - e. Native Hawaiian/Pacific Islander
 - f. White
 - g. Other (Please specify):
 - h. Prefer not to answer.
4. Which country were/are you living in while providing care?
[List of countries]
5. What is your current relationship status?
 - a. Married
 - b. Divorced
 - c. Separated
 - d. Widowed
 - e. Living with a partner
 - f. Single, never married
 - g. With a partner, not living together
6. What is sexual orientation?
 - a. Straight
 - b. Gay or lesbian
 - c. Bisexual
 - d. Pansexual
 - e. Asexual
 - f. Other (Please specify):
7. What is your current religious identification?
 - a. Agnostic

- b. Atheist
 - c. Buddhist
 - d. Catholic
 - e. Hindu
 - f. Muslim
 - g. Non-religious
 - h. Other (Please specify):
8. What is your educational level?
- a. Elementary school
 - b. High school
 - c. GED
 - d. Bachelor's Degree
 - e. Trade/Vocational degree
 - f. Master's Degree
 - g. Professional degree (Ph.D., M.D., D.O., J.D.)
 - h. Other (Please specify):
9. How many adults do you provide unpaid care for? (Qualtrics: give options based on number) _____
10. What is the gender of this care recipient? (funnel #3 by gender)
- a. Male
 - b. Female
11. What is your relationship to the care recipient?
- | | |
|---|--|
| <p>(Male options)</p> <ul style="list-style-type: none"> a. Brother b. Brother-In-law c. Companion/Partner d. Father e. Father-In-Law f. Grandfather g. Grandfather-In-Law h. Grandson i. Husband j. Nephew k. Same-sex partner l. Son m. Uncle n. Other relative [Specify] o. Foster child p. Friend q. Neighbor r. Other non-relative | <p>(Female Options)</p> <ul style="list-style-type: none"> s. Aunt t. Companion/Partner u. Daughter v. Granddaughter w. Grandmother x. Grandmother-In-Law y. Mother z. Mother-In-Law aa. Niece bb. Same-sex partner cc. Sister dd. Sister-In-Law ee. Wife ff. Other relative [Specify] gg. Foster child hh. Friend ii. Neighbor jj. Other non-relative |
|---|--|
12. What age is/was the care recipient? _____
13. Where does/did the care recipient live in relation to you?

- a. In the same household
 - b. Within twenty minutes of your home
 - c. Between twenty minutes and an hour from your home
 - d. One or two hours from your home
 - e. More than two hours away
14. [Funnel if not in the same household] On average, how often do/did you visit the care recipient?
- a. 5+ times a week
 - b. 3-5 times a week
 - c. 2-3 times a week
 - d. Once a week
 - e. A few times a month
 - f. Once a month
 - g. Few times a year
 - h. Less often
15. How long have/had you been providing care to this individual? (Please give your best estimate in months and years)
- a. [Qualtrics entry bars for months and years]
16. Which, if any, caregiver support programs do/have you used? (Please check all that apply)
- a. Caregiver support groups
 - b. Professional care services
 - c. Financial counseling
 - d. Respite services / Adult day care
 - e. Transportation aids
 - f. Home modifications to house or apartment to make things easier for care recipient
 - g. Friend/Family providing care
 - h. Friend/Family providing transportation
 - i. Friend/Family providing other support
 - j. Other (Please specify):
17. Sources of Caregiving Support (check all that apply):
- a. Family
 - b. Friends
 - c. Work
 - d. Professional caregiving groups or services (i.e., nursing home, at-home nurse)
 - e. Non-profit caregiver support services
 - f. Other (Please specify):
18. Desired Support (check all that apply):
- a. Caregiver support groups
 - b. Professional care services
 - c. Financial counseling
 - d. Respite services / Adult day care
 - e. Transportation aids
 - f. Home modifications to house or apartment to make things easier for care recipient
 - g. Friend/Family providing care

- h. Friend/Family providing transportation
 - i. Friend/Family providing other support
 - j. Any other support not yet listed: [Open response]
19. Caregiving information sought out when preparing to/became a caregiver
- a. Education about care recipient's condition/diagnosis
 - b. Emotional/community support from others in similar circumstances
 - c. Stress management skills
 - d. Managing own emotional or physical stress
 - e. Professional counseling/treatment
 - f. Behavioral management for difficult care recipient behavior
 - g. Education about other community services (such as transportation, professional care, financial counseling, information on end-of-life decisions)
 - h. Other (Please specify):
20. Primary source of Caregiving Information:
- a. Friends
 - b. Family
 - c. Books/Periodicals
 - d. Support group
 - e. Primary care doctor of care recipient
 - f. Other medical professionals
 - g. Internet
 - h. Community group/organization
 - i. Religious group/organization
 - j. Other (Please specify):
21. Desired information:
- a. Education about care recipient's condition/diagnosis
 - b. Emotional/community support from others in similar circumstances
 - c. Stress management skills
 - d. Managing own emotional or physical stress
 - e. Professional counseling/treatment
 - f. Behavioral management for difficult care recipient behavior
 - g. Education about other community services (such as transportation, professional care, financial counseling, information on end-of-life decisions)
 - h. Other services/support you would have wanted: [Open response]

Level of Caregiving Burden

22. Which of these do/did you help this individual with?
- a. Getting in and out of bed and chairs
 - b. Getting dressed
 - c. Getting to and from the toilet
 - d. Bathing or showering
 - e. Dealing with incontinence or diapers
 - f. Feeding him or her
 - g. Giving medicines like pills, eye drops, or injections for his/her condition.
23. How difficult is/was it for you to help with these kinds of tasks?

- (Not difficult at all) 1 2 3 4 5 (Very difficult)
24. Which of these do/did you help this individual with?
- Managing finances, such as paying bills or filling out insurance claims
 - Grocery or other shopping
 - Housework such as doing dishes, laundry, or straightening up
 - Preparing meals
 - Transportation, either by driving him/her, or helping him/her get transportation
 - Arranging outside services such as nursing, home care aides, or meals-on-wheels
25. How difficult is/was it for you to help with these kinds of tasks?
- (Not difficult at all) 1 2 3 4 5 (Very difficult)
26. And do/did you provide help with:
- Advocating for him/her with health care providers, community services, or government agencies
 - Monitoring the severity of his/her condition so that you can/could adjust care accordingly
 - Communicating with healthcare professionals like doctors, nurses, or social workers about his/her care
27. How difficult is/was it for you to help with these kinds of tasks?
- (Not difficult at all) 1 2 3 4 5 (Very difficult)
28. Thinking now of all the kinds of help you provide/provided for this individual, about how many hours do/did you spend in an average week, helping? [Numerical response between 0-168 (will code anyone over 40 as full time.)]
29. Has anyone else provided unpaid help to this individual during the last 12 months?
- Yes, a friend/family member
 - Yes, a professional caregiver
 - Yes, another unlisted individual: [Open response]
 - No
30. Who would you consider to be the person who provides most of the unpaid care for this individual?
- I am the primary caregiver
 - Someone else is the primary caregiver
 - We split caregiving work equally
31. Please think about all the health care professionals or service providers who (give/gave) care or treatment to this individual? How easy or difficult (is/was) it for you to coordinate care between those providers?
- (Not difficult at all) 1 2 3 4 5 (Very difficult)
32. Do you expect to have some responsibility for the care of this individual or another friend/family member, or loved on in the next five years?
- Yes
 - No
 - Uncertain

Employment Question Block

33. Are you currently employed?
- Yes

- b. No
- 34. Have you been employed at any time in the last year while you were also providing care?
 - a. Yes
 - b. No
- 35. Thinking of when you work, how many hours a week, on average, do you work?
 - a. [Numerical 1-80]
- 36. Are you currently self-employed or do you own your own business?
 - a. Yes
 - b. No
- 37. [Funneled if provided past care] When you were last working and providing care, were you self-employed or did you own your own business?
 - a. Yes
 - b. No

Plan / Health

- 38. Do you, the other care providers, or the individual have plans in place for his/her future care, such as instructions for handling financial matters, healthcare decisions, or living arrangements?
 - a. Yes
 - b. No
- 39. Do you have your own plans for future care, such as handling financial matters, healthcare decisions, or living arrangements?
 - a. Yes
 - b. No
- 40. If you are currently providing care, how long do you expect to continue providing it?
[open response days, months, years)
- 41. How would you say taking care of this individual has affected your health?
 - a. Made it better
 - b. Not affected it
 - c. Made it worse

Barriers to Access to Care Evaluation **BACE-CG** (Care Giver Version)

Instructions:

Below you can see a list of things which can stop, delay or discourage people from getting professional care for mental or physical stressors related to caregiving.

By professional care, we mean care from staff such as a GP (family doctor), member of a community mental health team (e.g. care coordinator, mental health nurse or mental health social worker), psychiatrist, counsellor, psychologist or psychotherapist. Care for stressors may include support groups, educational classes, individual counseling, and other support options.

Have any of these issues ever stopped, delayed or discouraged you from getting, or continuing with, professional care for caregiving-related stressors?

	Please circle one number on each row to indicate the answer that best suits you. For 'not applicable' please cross the 'not applicable' box.	This has stopped, delayed or discouraged me:			
		not at all	a little	quite a lot	a lot
1	Being unsure where to go to get professional care.	0	1	2	3
2	Wanting to solve the problem on my own.	0	1	2	3
3	Concern that I might be seen as weak for having this problem.	0	1	2	3
4	Fear of being put in hospital against my will.	0	1	2	3
5	Concern that it might harm my chances when applying for jobs. <input type="checkbox"/> not applicable	0	1	2	3
6	Problems with transport or travelling to appointments.	0	1	2	3
7	Thinking the problem would get better by itself.	0	1	2	3
8	Concern about what my family might think, say, do or feel.	0	1	2	3
9	Feeling embarrassed or ashamed.	0	1	2	3
10	Preferring to get alternative forms of care (e.g. traditional/religious healing or alternative/complementary therapies).	0	1	2	3
11	Not being able to afford the financial costs involved.	0	1	2	3
12	Concern that I might be seen as 'crazy'.	0	1	2	3
13	Thinking that professional care probably would not help.	0	1	2	3
14	Concern that I might be seen as a bad caregiver. <input type="checkbox"/> not applicable	0	1	2	3

Barriers to Care Evaluation (BACE-3) scale © 2011. Health Service and Population Research Department, Institute of Psychiatry, King's College London.
Contact: Dr Sarah Clement, sarah.clement@kcl.ac.uk, Professor Graham Thornicroft, graham.thornicroft@kcl.ac.uk
Clement S, Brohan E, Jeffery D, Henderson C, Hatch SL, Thornicroft G. Development and psychometric properties of the Barriers to Access to Care Evaluation scale (BACE) related to people with mental ill health. BMC Psychiatry. 2012; 12:36.

Barriers to Access to Care Evaluation (Care Giver Version)

BACE-CG
Page 2

	Please circle one number on each row to indicate the answer that best suits you. For 'not applicable' please cross the 'not applicable' box.	This has stopped, delayed or discouraged me:			
		not at all	a little	quite a lot	a lot
15	Professionals from my own ethnic or cultural group not being available.	0	1	2	3
16	Being too unwell to ask for help.	0	1	2	3
17	Concern that people I know might find out.	0	1	2	3
18	Dislike of talking about my feelings, emotions or thoughts.	0	1	2	3
19	Concern that people might not take me seriously if they found out I was having professional care.	0	1	2	3
20	Concerns about the treatments available (e.g. medication side effects).	0	1	2	3
21	Not wanting a mental health problem to be on my medical records.	0	1	2	3
22	Having had previous bad experiences with professional care for mental health.	0	1	2	3
23	Preferring to get help from family or friends.	0	1	2	3
24	Concern that the care recipient may be taken into care or that I may lose access or custody without my agreement. not applicable <input type="checkbox"/>	0	1	2	3
25	Thinking I did not have a problem.	0	1	2	3
26	Concern about what my friends might think, say or do.	0	1	2	3
27	Difficulty taking time off work.	0	1	2	3
28	Concern about what people at work might think, say or do. not applicable <input type="checkbox"/>	0	1	2	3
29	Having problems with care recipient monitoring while I receive professional care. not applicable <input type="checkbox"/>	0	1	2	3
30	Having no one who could help me get professional care.	0	1	2	3

Barriers to Care Evaluation (BACE-3) scale © 2011. Health Service and Population Research Department, Institute of Psychiatry, King's College London.
Contact: Dr Sarah Clement, sarah.clement@kcl.ac.uk, Professor Graham Thornicroft, graham.thornicroft@kcl.ac.uk
Clement S, Brohan E, Jeffery D, Henderson C, Hatch SL, Thornicroft G. Development and psychometric properties the Barriers to Access to Care Evaluation scale (BACE) related to people with mental ill health. BMC Psychiatry, 2012 12:36.

31. Are there any barriers to seeking out or continuing services which were unlisted? Please use the space below to describe these barriers: [Open response]

Intervention Expectancy Questionnaire - Modified

Below is a description of a caregiving support intervention. We would like you to indicate how much you believe that receiving this therapy would help you. Belief usually has two aspects to it: (1) what one thinks will happen and (2) what one feels will happen. Sometimes these are similar; sometimes they are different. Please answer the questions below. In the "first set, answer in terms of what you think. In the second set answer in terms of what you really and truly feel.

Brief Caregiver Support Description

Caregiver support groups are a common means of improving caregiving ability, increasing education about your situation as a caregiver, and reducing life stressors during this difficult period. Often, caregiving support groups contain several key components to reach these goals. For example, a support group will typically include: group discussion between caregivers and professionals, educational content about specific difficulties the care recipient may be experiencing, methods to reducing stress and fighting caregiver burden and burnout, behavioral management skills to cope with difficult behavior some care recipients experience, and connection to other community services for caregivers. Support groups typically meet for 1-2 hours on a weekly or bi-weekly basis.

Set I

1. At this point, how logical does the support group offered to you seem?
1 2 3 4 5 6 7 8 9
not at all logical somewhat logical very logical
2. At this point, how successfully do you think this support group will be in improving your caregiving situation?
1 2 3 4 5 6 7 8 9
not at all useful somewhat useful very useful
3. How confident would you be in recommending this support group to a friend who experiences similar problems?
1 2 3 4 5 6 7 8 9
not at all confident somewhat confident very confident
4. By the end of the support group, how much improvement in your stress symptoms do you think will occur?
0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Set II

For this set, close your eyes for a few moments, and try to identify what you really feel about the support group and its likely success. Then answer the following questions.

5. At this point, how much do you really feel a support group will help you to reduce your caregiving difficulties?
- 1 2 3 4 5 6 7 8 9
 not at all somewhat Very much
6. By the end of the support group, how much improvement in your caregiving difficulties do you really feel will occur?
- 0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Desired Intervention Components

Based on the previous description of a caregiving support group, please rate the following components in importance to you.

7. Education about care recipient condition
- 1 2 3 4 5
8. Support and discussion with others in similar circumstances.
- 1 2 3 4 5
9. Stress management skills
- 1 2 3 4 5
10. Behavioral management skills to cope with difficult behavior symptoms
- 1 2 3 4 5
11. Education and connection to other community services (such as transportation, meal, respite care, financial counsel, and others)
- 1 2 3 4 5

Based on the previous description of the support group, please rate your interest in the following formats of caregiver supportive services:

12. In-person support group
- 1 2 3 4 5
13. In-person individual therapy
- 1 2 3 4 5
14. Online education-only service
- 1 2 3 4 5
15. Online support group (education and supportive discussion)
- 1 2 3 4 5

Caregiver self-efficacy

Please rate your current level of comfort acting as a caregiver

16. I understand the issues/conditions that I provide care for.

1 2 3 4 5
17. I know of community/government resources to aid in my work as a caregiver.

1 2 3 4 5
18. I have good coping methods to deal with the stress of being a caregiver.

1 2 3 4 5
19. I have the skills needed to manage difficult behavior the care recipient currently/may in the future experience.

1 2 3 4 5
20. I have a strong support system to aid me in my work as a caregiver

1 2 3 4 5
21. I have a strong support system to share my needs and experiences with

1 2 3 4 5

Open response to services section

22. We'd like to hear from you about your needs as a caregiver. In the space provided below please list or describe what would be important in a caregiver support group to you: [Open response]

23. Are there any other comments you have about your status as a caregiver or about this survey that you feel are important? [Open response]

Thank you for your participation in this survey.

APPENDIX F: TABLES

Table 1: Sample Characteristics for all CUS Participants

	Total Sample (n = 285)	Young Adult (n = 45)	Middle Adult (n = 164)	Older Adult (n = 76)
Variable	M (SD)	M (SD)	M (SD)	M (SD)
Age	55.25 (14.26)	29.98 (5.26)	54.87 (6.16)	71.03 (5.97)
Percentage of Sample: n (%)				
Gender				
Male	122 (42.8)	13 (29) ^a	79 (48.2)	30 (40)
Female	136 (57.2)	32 (71)	85 (51.8)	46 (60)
Member of LGBTQ Community				
Identifies as LGBTQ	21 (7.4)	4 (9)	14 (8.0)	4 (5)
Does not identify as LGBTQ	264 (92.6)	41 (91)	150 (92.0)	72 (95)
Race/Ethnicity				
Caucasian	173 (60.7)	19 (42)	102 (62.2)	52 (68)
Black/African American	48 (16.8)	11 (24)	25 (15.2)	12 (16)
Hispanic	36 (12.6)	11 (24)	18 (11.0)	7 (9)
Asian	21 (7.4)	4 (9)	13 (7.9)	4 (5)
Other	7 (2.5)	0 (0)	6 (3.7)	1 (1)
Marital Status				
Married	173 (60.7)	22 (49)	97 (59.1)	54 (71)
Cohabiting	22 (7.7)	5 (11)	15 (9.1)	2 (3)
Single / never married	37 (13.0)	16 (36)	16 (9.8)	5 (7)
Separated, Divorced, Widowed ^b	53 (19.6)	2 (4)	36 (22.0)	15 (19)
Education				
Less than high school	19 (6.7)	4 (9)	10 (6.1)	5 (7)
High school / GED	74 (26.0)	13 (29)	38 (23.2)	23 (30)
Some college / technical school	81 (28.4)	9 (20)	49 (29.9)	23 (30)
College degree	60 (21.1)	15 (33)	34 (20.7)	11 (15)
Graduate degree	51 (17.9)	4 (9)	33 (20.1)	14 (18)

a. Percentage of samples with less than 100 individuals reported without decimal places b. Variable combined due to low-cell size, not included in frequency count for other relationship groups; LGBTQ = Lesbian, Gay, Bisexual, Transgender and/or Questioning

Table 2: Level of Care Index – Burden

Variable	Young Adult (n = 45)	Middle Adult (n = 164)	Older Adult (n = 76)	ANOVA
	M (SD)	M (SD)	M (SD)	
Length of time provided care	3.26 (3.83)	4.94 (7.25)	4.41 (5.11)	$F = 1.29$ $p = .278$ $\eta_p^2 = .009$
Hours providing care weekly	21.06 (28.18)	29.06 (30.58)	30.45 (30.80)	$F = 1.46$ $p = .232$ $\eta_p^2 = .010$
ADLs Performed	2.20 (2.26)	2.24 (2.09)	2.13 (2.16)	$F = .072$ $p = .931$ $\eta_p^2 = .001$
IADLs Performed	4.24 (1.90)	4.74 (1.99)	4.67 (1.97)	$F = 1.15$ $p = .319$ $\eta_p^2 = .008$
Level of Burden Index	2.77 (1.43)	3.25 (1.44)	3.16 (1.56)	$F = 1.803$ $p = .167$ $\eta_p^2 = .013$

ADLs = Activities of Daily Living; IADLs = Instrumental Activities of Daily Living

Table 3: General Caregiver Burden Factors

Variable	Young Adult (n = 45)	Middle Adult (n = 164)	Older Adult (n = 76)	ANOVA		
	M (SD)	M (SD)	M (SD)			
Physical Strain	2.47 (1.22)	2.83 (1.30)	2.87 (1.27)	$F = 1.68$ $p = .188$ $\eta_p^2 = .012$		
Financial Strain	2.09 (1.13)	2.39 (1.30)	2.30 (1.31)	$F = 0.995$ $p = .371$ $\eta_p^2 = .007$		
Emotional Stress	3.16 (1.13)	3.57 (1.19)	3.44 (1.16)	$F = 2.25$ $p = .108$ $\eta_p^2 = .016$		
Current Health	3.44 (0.99)	3.26 (1.02)	3.22 (0.89)	$F = 0.78$ $p = .458$ $\eta_p^2 = .006$		
Work Impacts ^a	1.29 (1.61)	1.17 (1.35)	1.47 (1.68)	$F = .393$ $p = .676$ $\eta_p^2 = .005$		
	¹ Young Adult (n=45)	² Middle Adult (n=164)	³ Older Adult (n=76)	ANOVA	Comparison Group	Post hoc p-value
Impact on Health	2.11 (0.54)	2.35 (0.56)	2.25 (0.55)	$F = 3.47$ $p = .032^*$ $\eta_p^2 = .024$	1 Vs 2 1 Vs 3 2 Vs 3	.011* .186 .195
	n (%)	n (%)	n (%)	Chi-Square	p-value	
Child/Grandchild present in home	23 (51.1)	27 (23.0)	5 (6.7)	31.25	<.001***	

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$; a. Workplace impacts contained only working individuals, therefore each group was reduced Young adult (n=34), Middle adult (n=115), Older adult (n=19).

Table 4: Young Adult Caregiver and Non-Caregiver Relationship, Education, and Employment Comparisons

Variable	Total Sample (n = 270)	Young Adult Caregiver (n = 45)	Young Adult Non- caregiver (n = 225)
Education Level	n (%)	n (%)	n (%)
Less than high school	31 (11.5)	4 (8.9)	27 (12.0)
High school / GED	68 (25.2)	13 (28.9)	55 (24.4)
Some college / technical school	83 (30.7)	9 (20.0)	74 (32.9)
College degree	64 (23.7)	15 (33.3)	49 (21.8)
Graduate degree	24 (8.9)	4 (8.9)	20 (8.9)
Relationship Status			
Married	136 (53.8)	22 (51.2)	114 (54.3)
Living with a partner	17 (6.7)	5 (11.6)	12 (5.7)
Single, never married	100 (39.5)	16 (37.2)	84 (40.0)
Employment Status*			
Employed Full time	164 (60.7)	21 (46.7)	143 (63.6)
Part-time	45 (16.7)	13 (28.9)	32 (14.2)
Unemployed	61 (22.6)	11 (24.4)	50 (22.2)
Self-Employment**			
Self-employed	24 (11.5)	9 (27.3)	15 (8.6)
Employed by other	184 (88.5)	24 (72.7)	160 (91.4)

* $p < 0.05$; ** $p < 0.01$

Table 5: Sample Characteristics Online-Participants

	Young Adult (n = 51)	Middle Adult (n = 50)	Older Adult (n = 50)
Variable	M (SD)	M (SD)	M (SD)
Age	28.10 (5.58)	48.92 (7.53)	67.50 (2.58)
Percentage of Sample			
Gender			
Male	31.4	16.0	42.0
Female	68.6	84.0	58.0
Race/Ethnicity			
Caucasian	68.6	90.0	78.0
Black/African American	11.8	10.0	8.0
Hispanic / Latino(a)	5.9	0	6.0
Asian	2.0	0	4.0
Native American	2.0	0	2.0
Bi-Racial	9.8	0	2.0
Employment Status**			
Employed Full time	52.9	40.0	26.0
Part-time	43.1	30.0	44.0
Unemployed	3.9	30.0	30.0
Self-Employment*			
Self-employed	16.3	17.1	40.0
Employed by other	83.7	82.9	60.0
Marital Status			
Married / Partnered	60.8	58.0	62.0
Single, never married	37.3	14.0	8.0
Separated, Divorced, Widowed ^a	2.0	28.0	30.0

**p < 0.05; **p < 0.01; a. Variables combined due to low-cell size, not included in frequency count for other relationship groups*

Table 6: Caregiver Circumstance & Burden

Variable	Young Adult (n = 51)	Middle Adult (n = 50)	Older Adult (n = 50)	ANOVA
	M (SD)	M (SD)	M (SD)	
Length of time provided care	3.05 (3.63)	3.06 (2.89)	4.39 (4.61)	$F = 2.09$
Time expecting to provide care	2.74 (4.15)	3.17 (5.71)	3.72 (5.00)	$F = 0.49$
Hours providing care weekly	24.0 (25.25)	34.42 (37.95)	38.72 (34.57)	$F = 2.66^{\Psi}$
ADLs Performed	4.04 (2.19)	4.02 (2.32)	3.14 (2.08)	$F = 2.74^{\Psi}$
IADLs Performed	3.86 (1.64)	4.32 (1.60)	4.38 (1.46)	$F = 1.65$
Subjective Difficulty Performing ADLs	2.71 (1.19)	3.22 (1.27)	3.16 (1.23)	$F = 2.66^{\Psi}$
Subjective Difficulty Performing IADLs	2.84 (1.24)	3.24 (1.26)	3.10 (1.26)	$F = 1.59$
Subjective Difficulty Performing Other Caregiving Tasks	2.67 (1.19)	3.22 (1.30)	3.07 (1.20)	$F = 2.71^{\Psi}$
	Percentage of Sample			Chi-Square
Role				
Primary Caregiver	43.1	50.0	66.0	$\chi^2 = 7.26$
Equally Shared	19.6	24.0	10.0	
Non-Primary	37.3	26.0	24.0	
Housing*				
Lives with CR	31.4	46.0	58.0	$\chi^2 = 9.53^*$
Lives within 20 minutes	52.9	34.0	34.0	
Lives 20+ minutes away	15.7	20.0	8.0	

* $p < 0.05$; $^{\Psi}p = .07$; ADLs = Activities of Daily Living; IADLs = Instrumental Activities of Daily Living

Table 7: Barriers to Care Evaluation for Caregivers (BACE-CG)

Variable	Young Adult (n = 51)	Middle Adult (n = 50)	Older Adult (n = 50)	ANOVA
	M (SD)	M (SD)	M (SD)	
Average Overall Barriers to Care	0.82 (0.64)	0.63 (0.45)	0.68 (0.55)	$F = 1.405$
Average Instrumental Barriers	0.77 (0.64)	0.72 (0.50)	0.74 (0.56)	$F = 0.108$
Average Attitudinal Barriers	1.01 (0.65)	0.75 (0.48)	0.79 (0.56)	$F = 3.019^{\Psi}$
Average Stigma-Related Barriers	0.69 (0.71)	0.50 (0.56)	0.56 (0.65)	$F = 1.168$

^Ψ $p = .05$; Barriers to care scale based on a 0-3 Likert-type response

Table 8: Interest in Support Group

Variable	Young Adult (n = 51)	Middle Adult (n = 50)	Older Adult (n = 50)	ANOVA
	M (SD)	M (SD)	M (SD)	
Interest in Support Group	3.45 (0.92)	3.45 (1.00)	3.37 (0.83)	<i>F</i> = 0.13
Importance of Support Groups	3.87 (0.84)	4.15 (0.75)	4.10 (0.76)	<i>F</i> = 1.73
Interest in In-Person Support Group	3.27 (1.33)	3.20 (1.37)	3.32 (1.68)	<i>F</i> = 0.11
Interest in Individual Therapy	3.33 (1.32)	3.16 (1.41)	3.30 (1.23)	<i>F</i> = 0.24
Interest in Online Education-Only Services	3.53 (1.21)	3.78 (1.23)	3.48 (1.10)	<i>F</i> = 0.93
Interest in Online Support Group	3.65 (1.16)	3.64 (1.24)	3.36 (1.23)	<i>F</i> = 0.92
Self-Efficacy in Caregiving Ability	3.75 (0.76)	3.70 (0.87)	3.77 (0.78)	<i>F</i> = 0.123

APPENDIX G: FIGURES

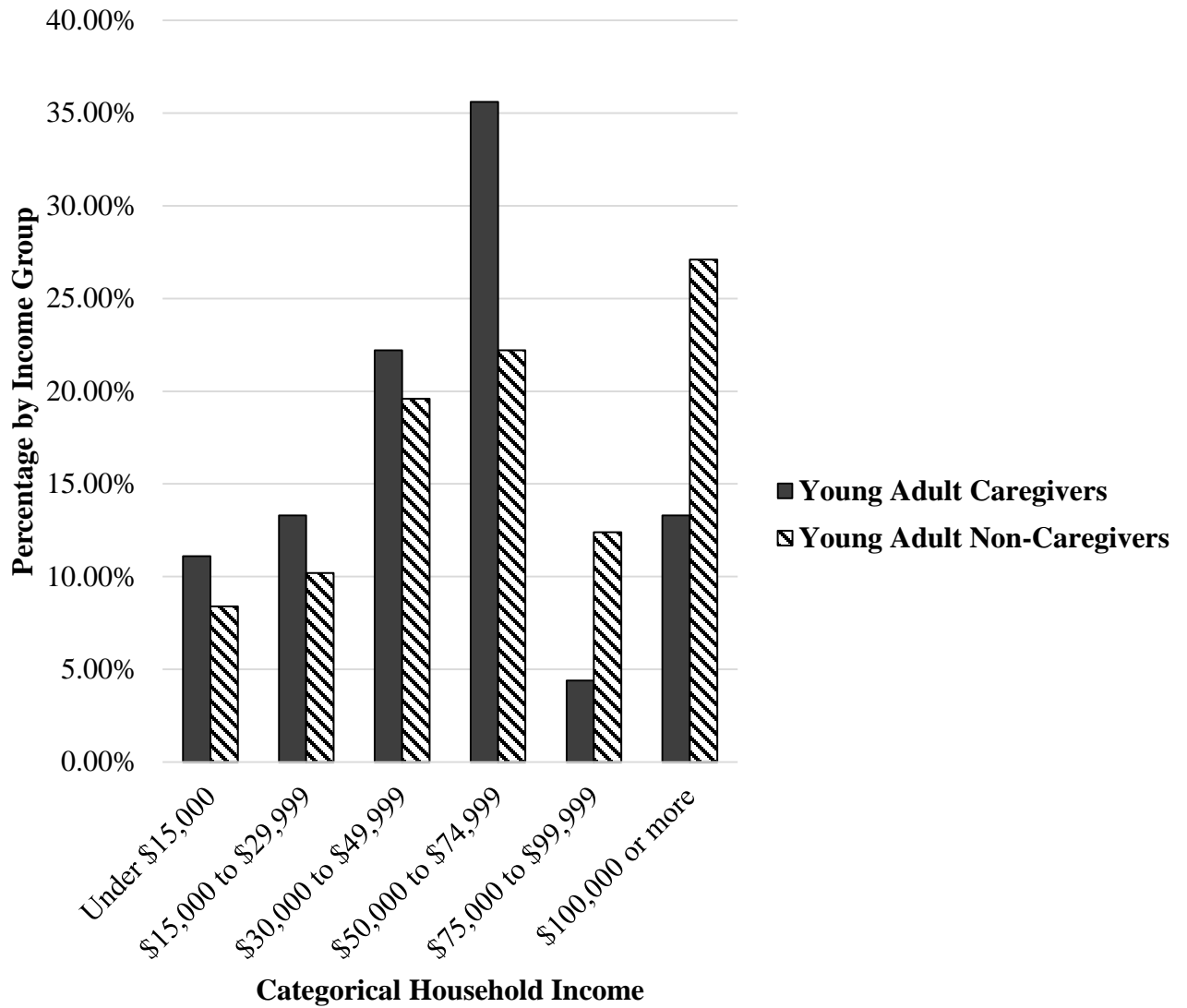


Figure 1: Yearly income of caregiving and non-caregiving young adults

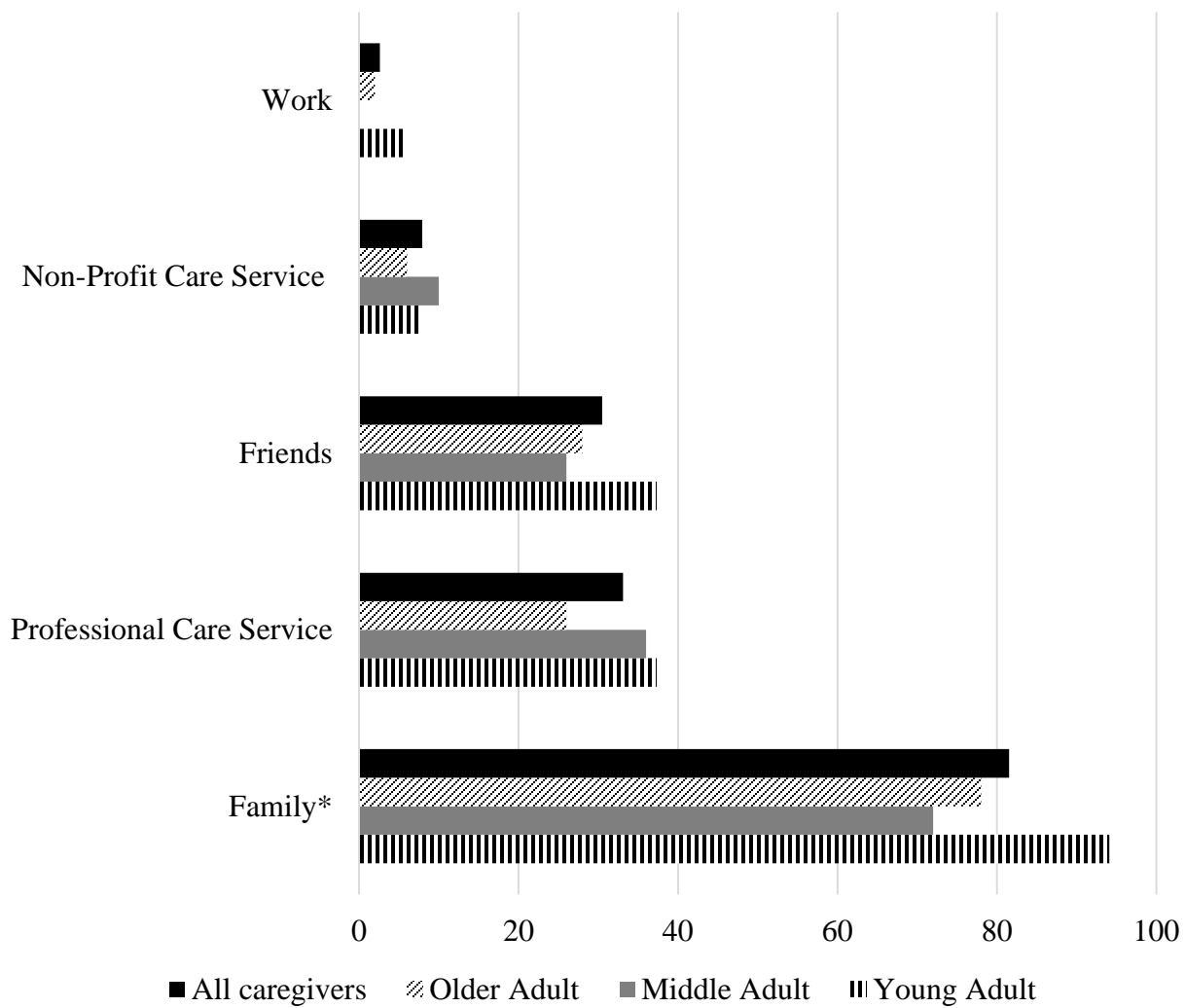


Figure 2: Sources of support while caregiving

* $p < .05$

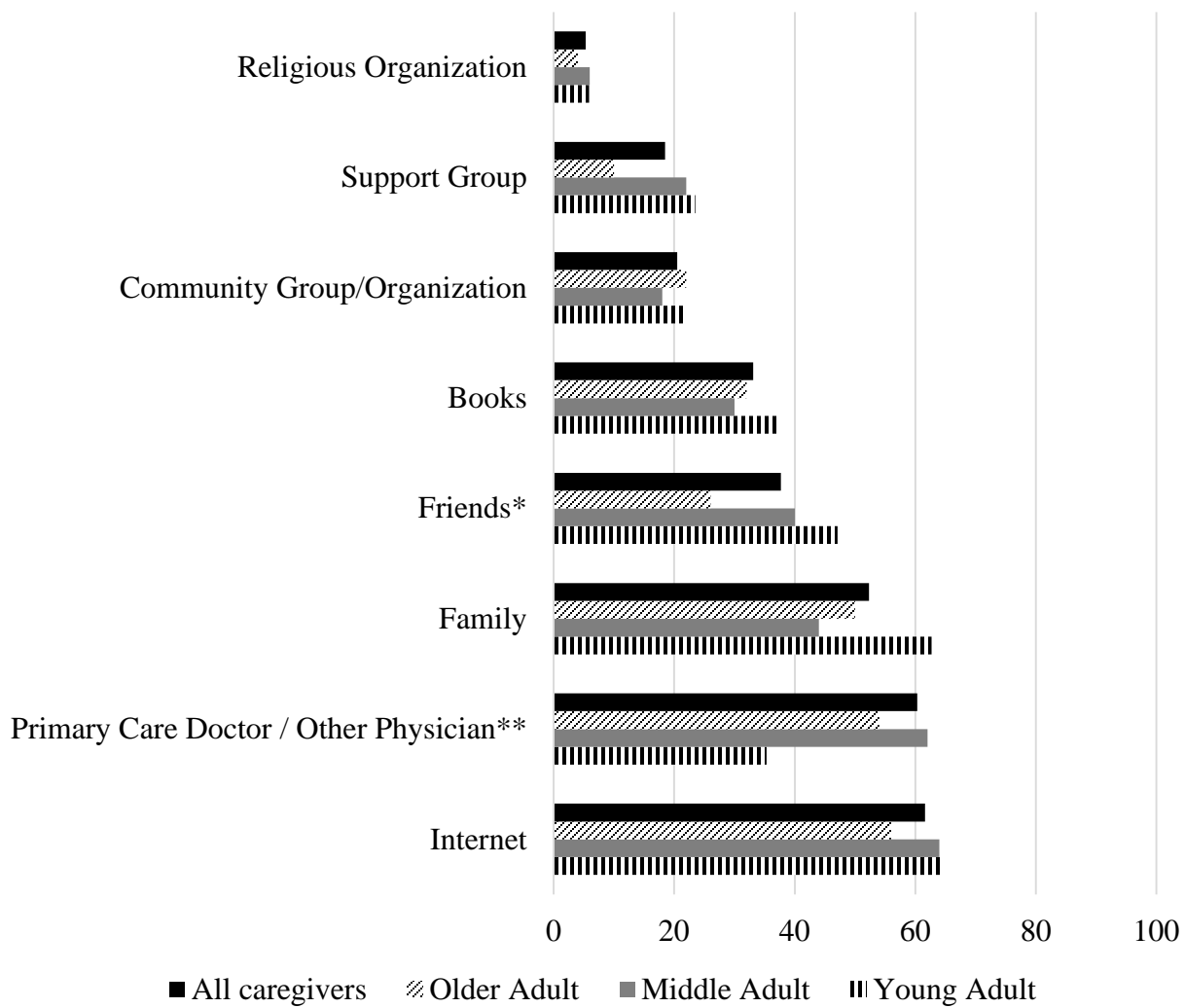


Figure 3: Sources of caregiving information

* $p < .05$; ** $p < .01$

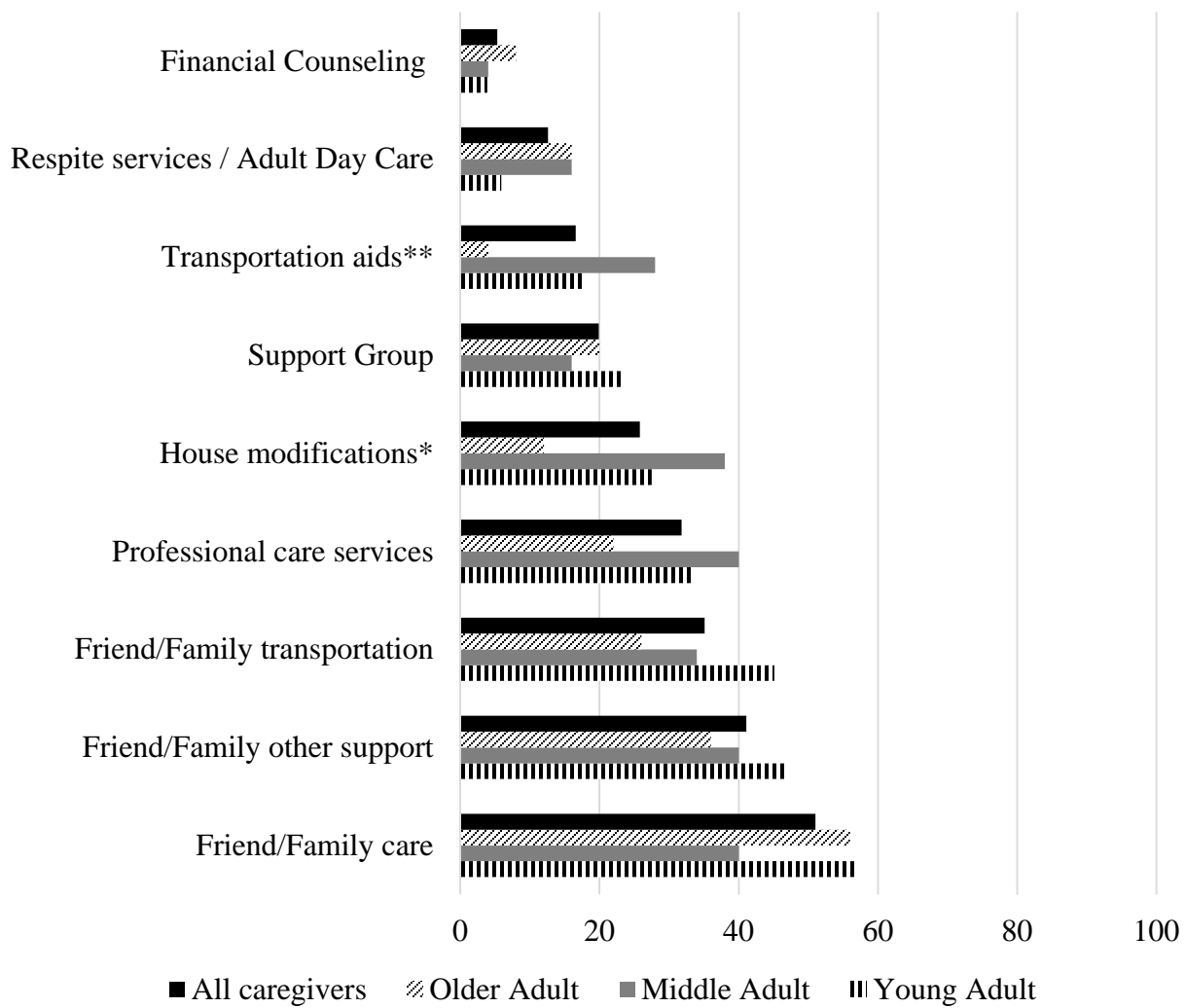


Figure 4: Support utilized while caregiving

* $p < .05$; ** $p < .01$

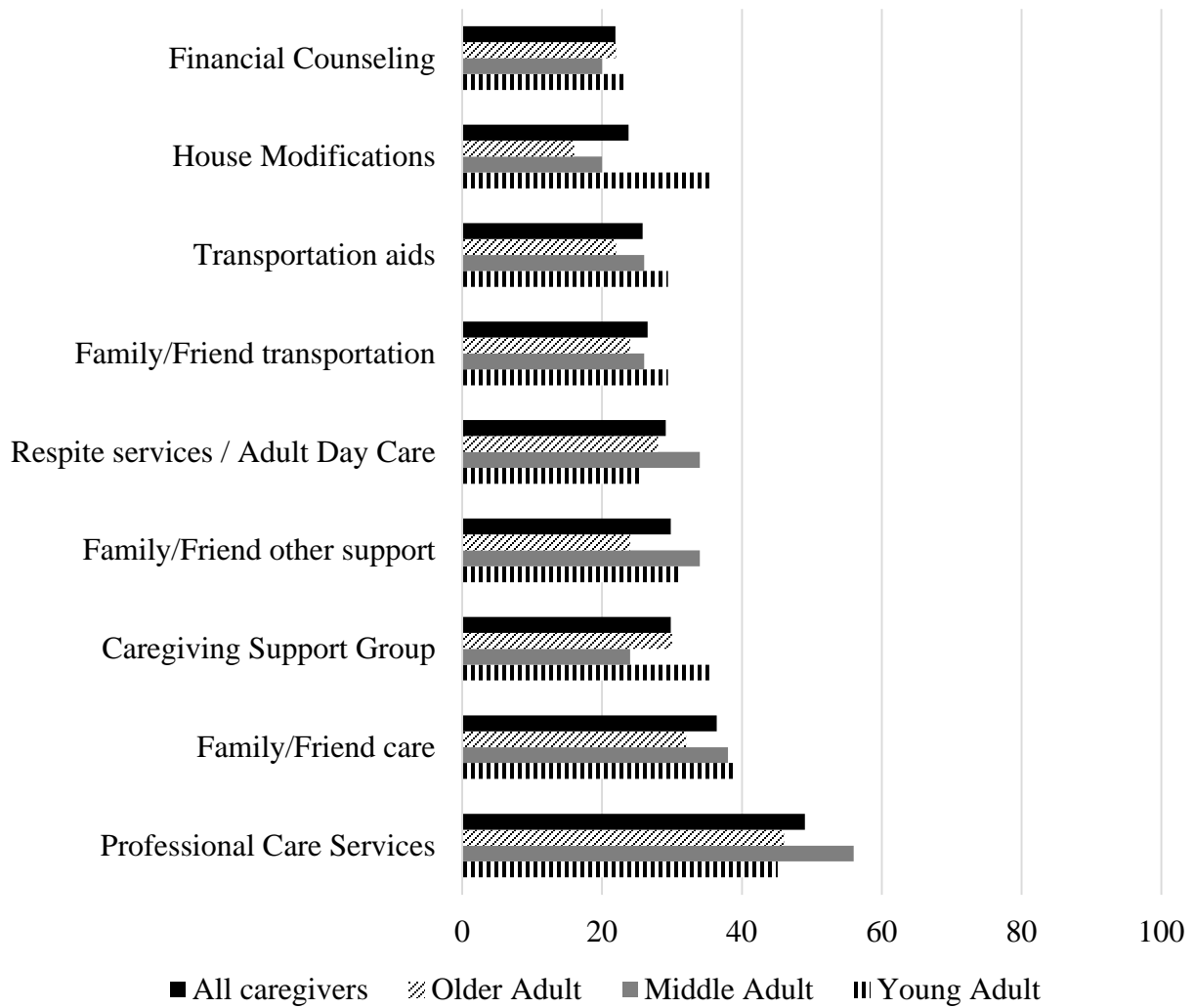


Figure 5: Desired support while caregiving

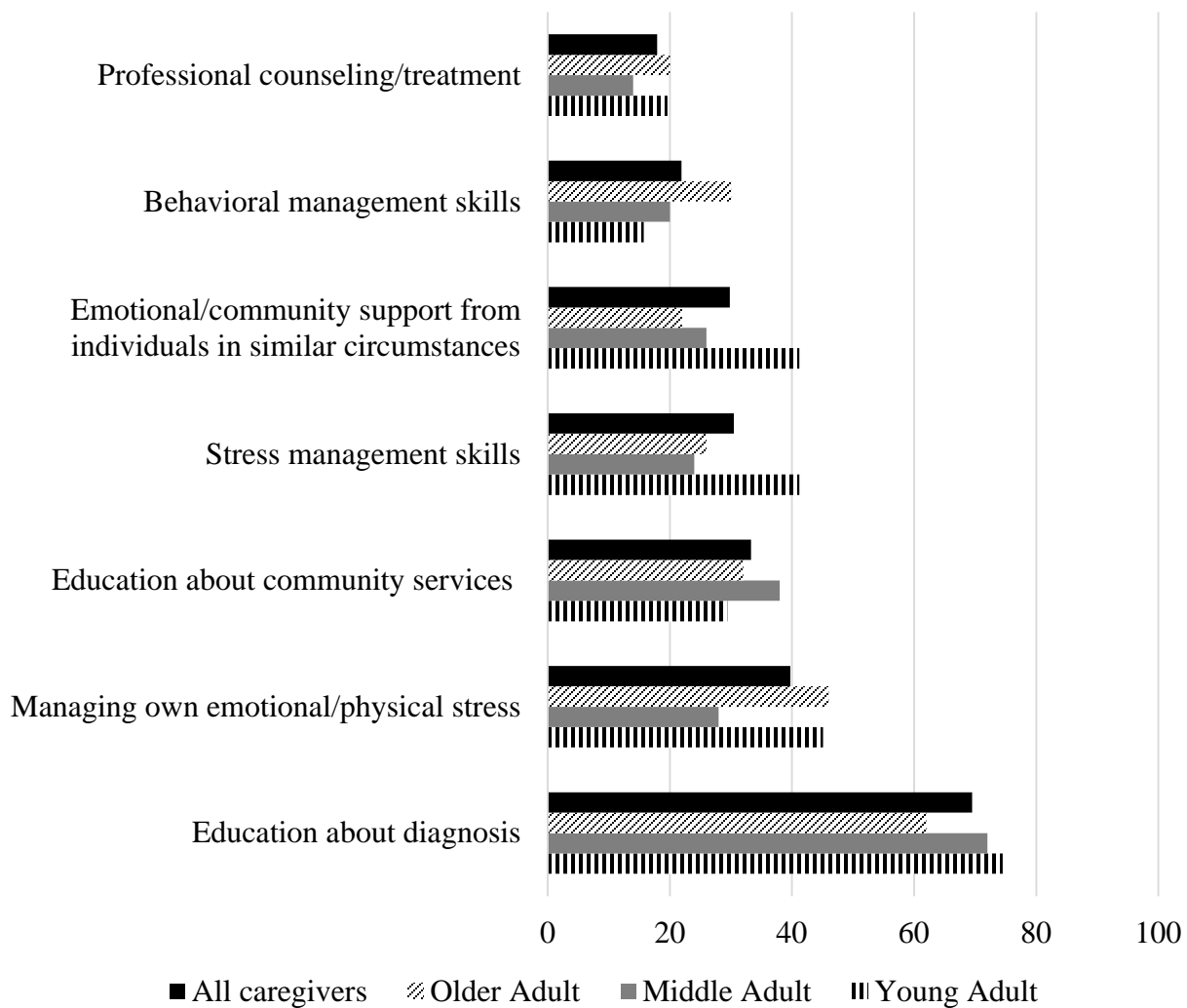


Figure 6: Information sought out when beginning caregiving

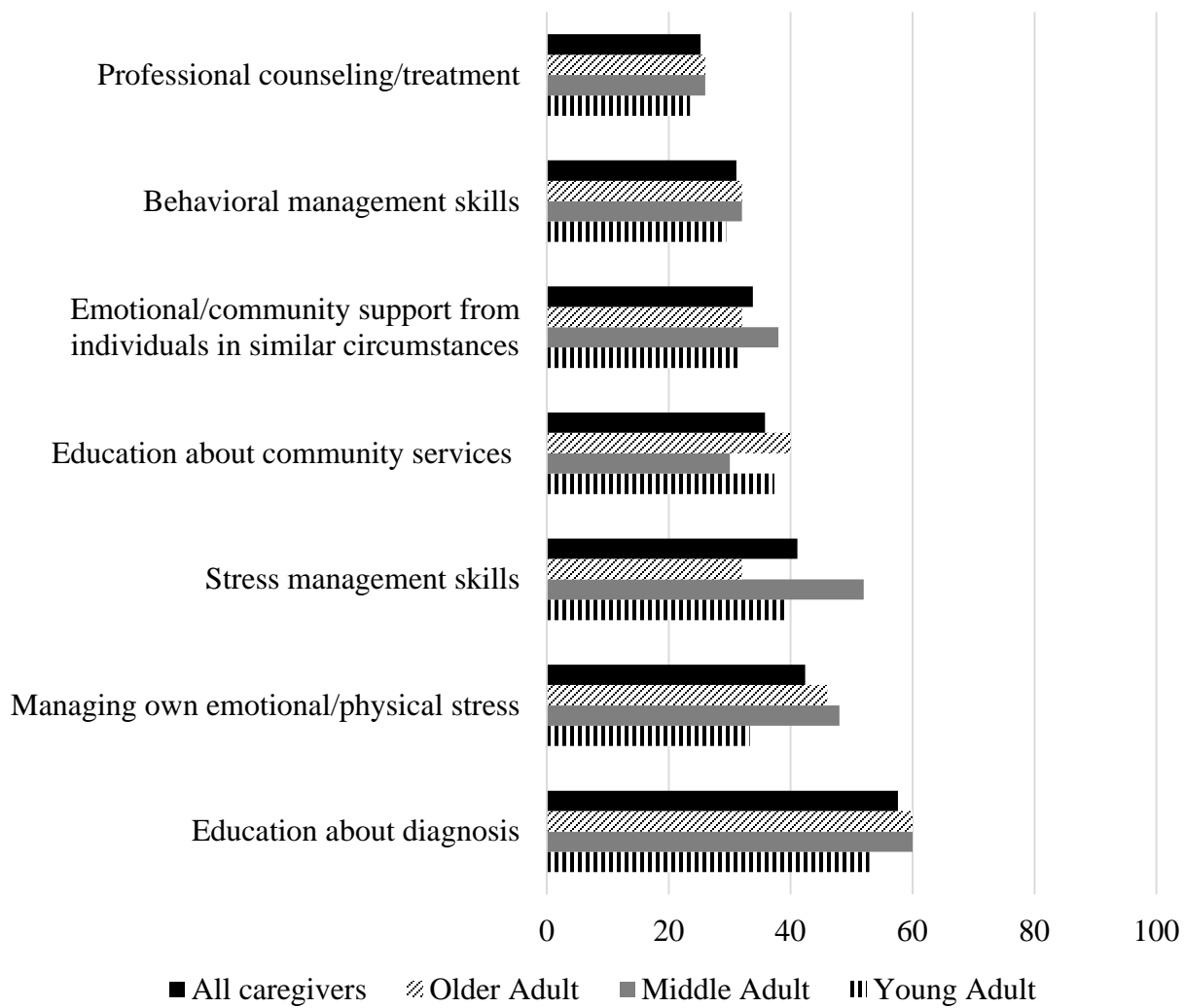


Figure 7: Information desired while caregiving

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