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Becoming a Caregiver: Experiences of Young Adults Moving into Family Caregiving Roles

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Abstract

While the vast majority of family caregivers struggle to find balance between different roles in their lives, young adult caregivers are faced with the atypical challenge of caring for family member while simultaneously accomplishing developmental tasks typical of this stage in life (e.g., establishing career, developing romantic relationships). This exploratory, qualitative study examined strategies used by young adults to adopt family caregiving roles. These strategies can be described as embracement, compromise, and integration. While each approach allowed for the young adult to facilitate their caregiving role, additional research is needed to understand how the strategy affects the emerging adult's development.

Keywords

young caregivers; caregiving role; role theory; development; young adults

National caregiving data indicate that although the mean age of caregivers is 49 years, almost a quarter are between the ages of 18 and 34, and another 23% are aged 35 to 49 (National Alliance for Caregiving [NAC] & AARP Public Policy Institute, 2015). One report from AARP found that a third of people under age 40 in the U.S. have cared for an older friend or relative and another third expect to become caregivers within the next five years (AARP, 2018). Yet another recent report reveals that one in four caregivers is a millennial (Frank, 2018). While often not primary caregivers, instead serving in secondary roles, these young adults typically have additional obligations besides caregiving (AARP 2018; Stelle et al., 2010). Most younger caregivers (75%) spend less than 10 hours a week providing care,

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compared with caregivers 40+, who provide at least 10 hours of unpaid care a week (AARP, 2018). Despite putting in fewer hours, younger caregivers are more likely (80%) than older ones (67%) to say their care responsibilities are at least moderately stressful (AARP, 2018).

The older population is expected to double by 2030, representing 20% of the U.S. population (Vespa, 2018). As the social profile of the U.S. continues to change, with delayed childbearing and smaller families, it is anticipated that care recipients will be even older than they are now, and caregivers will be even younger (Bureau of Labor Statistics, 2017; Jenkins, 2018). Although young adults are intermittently represented in the expanse of caregiving literature – there is a limited understanding of how young adults go about assuming family caregiving responsibilities and the resultant effects on their lives. There is a need to systematically describe and understand the effect of caregiving on young adults' lifespan development. Given that individuals do not provide caregiving in isolation from the other roles and responsibilities, we expected that participants' personal lives — as spouses, parents, employees, students — would intersect with caregiving at different times and in various ways. The purpose of this present study is to explore the experience of young adult caregivers in adopting their caregiving role.

Review of the Literature

Despite many commonalities, the experience of family caregiving – and caregiving roles and responsibilities in particular – are unique and variable to every caregiver and each caregiving dyad. The diversity of families, timing of entry into the caregiving role, duration of the caregiving responsibilities, and care transitions experienced over time all shape the nature of the caregiving (Dellmann-Jenkins & Brittain, 2003; Koumoutzis, Cichy, Dellmann, & Blankemeyer, 2021; McLaughlin et al., 2019; Wolff & Kasper, 2006; Yu, Cheng, & Wang, 2018). When care recipients become increasingly impaired over time, such as with Alzheimer's disease, intensity of caregiving tasks often increases accordingly. When care recipients experience brief or episodic periods of impairment, such as with heart failure or bouts of psychosis, the caregiving role is expected to be short term, but intense – or it may wax and wane over time.

Role strain occurs when one is unable to meet the expectations and obligations of multiple roles. Role theory speaks to the many identity roles we carry at any given point (i.e., spousal/partner, parent, child, employee) and describes the rights, duties, expectations, or obligations individuals have to fulfill within these various roles (Biddle & Thomas, 1966; Campbell, 2014). When different roles create competing demands, then role conflict may result. Role conflict can lead to role strain, where individuals experience burden, exhaustion, and tension due to requirements of their various roles (Gordon et al., 2011). Role conflict occurs when one experiences incompatible and conflicting demands (e.g., working full time, spending time with a partner, finishing college, and caring for a family member) (Aazami et al., 2018; Campbell et al., 2014; Conway et al., 2010; Li & Lee, 2020). These responsibilities may also create role overload where competing demands overwhelm the person's ability to carry out their roles (McLaughlin et al., 2019; Li & Lee, 2020). Research on how young adults adopt and adapt to caregiving roles and reduce caregiver role strains continues to diversify in the caregiving literature (D'Amen, Socci, & Santini, 2021).

There is a growing body of research on emerging adults (ages 18 to 25) and young adults (ages 26 to 40) who serve as caregivers to older adults with disabilities, chronic illness, or terminal illness (e.g., Alexander, 2019; McLaughlin et al., 2019; Pope, Baldwin, & Lee, 2018; Fruhauf & Orel, 2018; Shifren & Chong, 2012). More than 15 years ago, Shifren and Kachorek (2003) surveyed young adults about their experiences as child caregivers and found significant impacts to be in the areas of reduced time for family and friends (36%), and giving up hobbies and social activities (43%). This subpopulation of caregivers is providing care at a time of tremendous developmental activity. Caregiving in young adulthood is considered non-normative and can result in challenges for people accomplishing developmental tasks typical of this stage in life (e.g., separation from family of origin, establishing close relationships with friends and intimate partners, and career development) (Greene et al., 2017). One study of grandchildren caregivers found that caring “took them away from school endeavors, career advancement, their friends, and from dating” (Fruhauf & Orel, 2008, p. 225). When compared to older adult caregivers (60-80 years old), young adult caregivers demonstrated similar caregiver burdens and financial stressors and yet, all groupings of caregivers (young, midlife, and older adults) revealed consistent emotional and physical stress (Koumoutzis et al., 2020).

Compared with their middle aged and older counterparts, young caregivers are more likely to have to work while caring (Flinn, 2018), need to make more workplace accommodations such as going in late, leaving early, and taking time off during the day because of caregiving responsibilities (NAC & AARP Public Policy Institute, 2009; 2015), and experience more financial strain than family caregivers in midlife or later life (McLaughlin et al., 2019). Hindrances that younger caregivers face in pursuing higher education, career advancement, and establishing social relationship might put them at risk for accumulated social disadvantages over the life course.

Social media is one of the more recent strategies that young caregivers of cancer patients are employing with some mixed results. In the United States, approximately 88% and 97% of young caregivers have begun using social media for a couple of reasons (Smith & Anderson, 2018; Villanti, et al., 2017). The primary focus of the social media usage was to keep family and friends updated about the progress of the cancer patient, and secondly, for the purpose of soliciting social support (Warner et al., 2020). While posting on social media offered different types of social support, such as connecting with others through shared experiences, there were some negative results where caregivers’ experiences were minimized or misinterpreted (Warner et al., 2020). Although there is strong potential for encouraging connection and social support through social media, it is important to acknowledge that the digital divide inequity exists and accessibility to and ability to utilize social support via the internet will vary among different caregiver groups.

This pilot study aims to shed light on a group of caregivers not well-represented in the caregiving literature – young adult caregivers. To date, it has not yet been fully discerned how caregiving impacts young adults or how young adults assume their caregiving role.

Methods

This study utilized a basic interpretive qualitative design (Merriam & Tisdell, 2016) given that the purpose of the study was to help make sense of the experiences of young adults in family caregiving roles. Merriam and Tisdell (2016) suggested that qualitative methods best fit if the aim of a study is to describe the experiences and perspectives of a specific group of people at a particular point in time and in a particular context.

Data presented in this paper come from a larger project focused on the lived experiences of young caregivers, more specifically the ways these young adults perceived the caregiving role to have affected their education, employment, and current and potential social relationships. In this study, we were especially interested in how young adults described changes in their everyday lives in areas such as financial strain (Kang, 2021; Lai, 2012), compromised work opportunities (Dellmann-Jenkins & Blankemeyer, 2009; Flinn, 2018; Fruhauf & Orel, 2008), decreased social life (Shifren & Kachorek, 2003), and negative psychological effects (Kang, 2006; Pinquart & Sörenson, 2003) after assuming family caregiving roles. This research was conducted following IRB approval from the two supporting universities involved in this study.

Recruitment and Sampling

Study participants included current and former young adult caregivers. When the study began, only current caregivers were interviewed. During the first 5 months of data collection, the study yielded only six participant interviews, after which the study sample was expanded to include individuals who had previously been caregivers in young adulthood. Given existing evidence that what people recall about an event or experience is considered as valid as people going through the event at present (Lackey & Gates, 2001), we concluded that the inclusion of former caregivers was acceptable. Participants had to meet the following inclusion criteria: (1) currently (or within the past 3 years) caregiving for a family member with a chronic illness, disability, or terminal illness; (2) spending at least 10 hours a week on caregiving duties, and (3) between the ages of 18 and 40 – defined as young adulthood by developmental researchers – (Schaie & Willis, 1996) at the time of their caregiving.

Multiple recruitment strategies were employed to locate participants. Online advertising was employed and included postings on university and college listservs, Facebook, and Research Match. Snowball sampling, personal and professional contacts were used to recruit potential participants. A third strategy involved working with a program coordinator of a local Area Agency on Aging to identify caregivers between the ages of 18 and 40 who were receiving support services. Recruitment fliers were mailed directly to individuals who met study criteria and gave permission for their address to be provided to partner agencies.

Twenty-two individuals who were (or had previously been) caregivers while in young adulthood comprised the final sample (see Table 1). Eighteen participants were women and four were men; the sample ranged in age from 18 to 39. Most of the sample were single (59%), as compared to partnered or married (41%). About a third of our participants had dependent children while caregiving and about 68% of our sample were primary caregivers who received little to no support from family and friends. Fifteen of the participants (68%) were White, and within this subset, one participant identified being of Bosnian decent and one of Puerto Rican descent. Of the non-White participants, two were Black and five were Asian. All of the participants lived in the US, residing in Georgia, Washington, DC, Kentucky, North Carolina, Oregon, California, Ohio, and Michigan. Care recipient diagnoses varied and included Alzheimer's disease and other dementias, diabetes, bipolar disorder, Lou Gehrig's disease, and rheumatoid arthritis.

Data Collection

Over a 15-month period (in 2014 – 2015), data were collected through individual semi-structured telephone interviews lasting between 31 and 102 minutes (average length = 57 minutes). Telephone interviews, rather than in-person interviews, were used for several reasons. First, phone interviews allow for increased access to participants across geographic locations (Sturges & Hanrahan, 2004; Sweet, 2002) and are relatively cost-effective (Chapple, 1999). Since the researchers conducting this study were in different locations (i.e., Kentucky and Oregon), telephone interviews allowed them equal access to potential participants. Recruitment was not limited to a particular geographic region, which resulted in a sample drawn from across the US. Lastly, phone interviews allowed flexibility in scheduling (Holt, 2010), which was critical for those working jobs, attending college, raising children, and maintaining personal relationships, while also providing care for a relative. Participants were not provided an honorarium or compensation for their time.

An interview guide was used to help ensure the interviews addressed the research questions while allowing participants to share information that was significant to them (Patton, 2015). Examples of interview questions are provided in Table 2. Consent was obtained verbally over the phone. Interviews were digitally recorded, transcribed verbatim, and checked for accuracy; participants were also assigned a pseudonym to protect their identity. Initial interviews were transcribed by the first two authors. The first and second authors conferred regularly in the early stages of data collection, which helped refine and adjust the interview guide.

Data Analysis

The first and second author collaborated on analysis utilizing the grounded theory techniques of open coding, focused coding, memo writing, and constant comparison (Charmaz, 2014). During the first round of coding, about 20% of the interviews were read in their entirety and open coding and memo writing were used to generate codes from the data.

Over a period of six weeks, initial codes were compared and discussed; this was followed by focused coding, which involved making decisions about which codes were most relevant to the research questions, eliminating irrelevant codes, and combining similar or redundant codes. After completing open and focused coding, a preliminary codebook was developed that contained the most recurrent and salient initial codes and categories (Charmaz, 2014). This codebook was then used by the first and second author to separately code another 20% of the interviews, after which the coded transcripts were compared, and disagreements were resolved related to code definitions and coding protocols. The iterative process helped establish a well-defined codebook that the first author used to independently code the remaining transcripts. In addition, investigator and interdisciplinary triangulation throughout all aspects of the study (e.g., data collection, analysis) added to the rigor of the study (Barbour, 2013; Merriam & Tisdell, 2016; Padgett, 2008). Once the codebook was finalized, transcripts were uploaded to MaxQDA12, a qualitative computer software program that assists with data analysis and management. The first author utilized the constant comparison technique to search for similarities and differences in categories across the transcripts; comparisons were made based on demographic or social characteristics of participants as well as inductive differences (e.g., participants who were partnered and those who were single). Memo writing was used throughout the analytic process to encourage conceptual thinking about the data (Charmaz, 2014).

Findings

For participants in this study, caring for a relative with chronic illness, terminal illness, or disability brought about significant changes in how they experienced daily life. To some extent, becoming a caregiver in young adulthood interrupted their life in a real, tangible way. They were progressing in higher education or careers and investing in social and romantic relationships when they assumed caregiving responsibilities. Erika, a single 32-year-old with no children, discussed the initial shock of becoming a caregiver for her aunt with bipolar disorder: “Being someone who had never been in a situation like this before, and no one in my immediate circle of friends had either. It was just hard. It was a life-changing event. It changed my lifestyle, like everything.” For Erika and others, there was not one area of their life that remained unaffected upon assuming their new caregiving role. Tushar, a young man providing care to his mom with Normal Pressure Hydrocephalus (NPH), detailed the chaotic reality of his work and personal life:

> The first year and a half—I was like just like a juggler. I was doing everything myself. I was [doing the] cooking, cooking, cleaning, pharmacy. Then going to pay the bills and then going to client’s house and doing all the estimates. Then from the estimates to getting the projects done and installed.

By and large, participants interviewed for this study described their start to caregiving as an initial disruption, especially related to their home life, career, and relationships. Analysis revealed that young caregivers responded to this adoption of the caregiving role in one of three ways: embracing, compromising, and integrating.

Embracing the Caregiver Role

Some young adult caregivers embraced the life changes that came from caregiving. They embraced their disrupted life and created a new situation where they prioritized the needs of their relative above their own. Gary, a single man who left a lucrative job in Arizona to move back to Kentucky, described his day-to-day life as one that seemed to revolve around his mother’s care. As the sole caregiver for his mom with dementia and diabetes, Gary had few friends and no reliable respite help. When asked about what his future might look like in terms of his career, Gary said:

> While mom needs me, I think it's best that I give her as much attention and the care that she needs…I do some [work] from home, but my job is taking care of mom…The way I look at that is she took care of me and that she raised me. It's my turn now to make sure she's got what she needs and to take care of her.

Gary fully embraced his role as primary caregiver for his mom, but from our analysis, he seemed socially isolated and prioritized his mom at the expense of his own needs. He did not utilize respite, rarely left the house, and had few friends.

Like Gary, Peter was completely committed to caregiving, making many personal sacrifices on behalf of his terminally ill parents, whom he cared for during two separate stints. Unlike Gary however, Peter expressed regret about neglecting aspects of his own development because he was so absorbed in caregiving:

> I wish I would have worked a little bit harder on developing relationships, but I didn't. Sometimes as a caregiver, if you're weak as far as talking and developing relationships, you use it as an excuse, "Well, I got to take care of my parents and I'll do that afterwards." Well, you can never go back in time. You don't experience things the same as when you're a teenager or in your 20s. You only feel that way when you're that age. So, make sure you leave some time to experience dating in your teens or whatever the hell you do when you're 20, because…if I'm trying to go back and live stuff that I didn't get to do in my teens, 20's and 30's. It isn't the same. It's just weird—because I'm 40 and I need to act like a 40-year-old.

While the perspectives of Gary and Peter may seem contradictory, Peter—formally a caregiver—has had significant time and distance for self-reflection. Gary was interviewed, however, while occupying his caregiving role, perhaps limiting his ability to view his experience with any objectivity or perspective.

Many of the young caregivers interviewed seemed able to postpone their own dreams and plans willingly because they acknowledged that the interruption was temporary. Shane, age 28, readily admitted to not having much of a romantic life while living with his grandmother for the past four years. Although it was not ideal, Shane acknowledged his circumstance as a momentary sacrifice he was willing to make for the woman who helped raise him: "I know this isn't a long term forever [thing]." Luna, who began caregiving while still in high school, discussed how her priorities shifted and became radically different than her classmates. While not glossing over the impact caregiving had on her life, Luna – like Shane – viewed her care responsibilities as temporary, but something she willingly embraced:

> It's like you have to make some choices. I know there are times where you're like you want to watch that TV show [or] you want to go to that game…or you want to go hang with that friend…And it will be frustrating, but you need to complete what's more important and you can make time for your friends later.

In sum, some young caregivers interviewed for this study assumed the new situation brought on by caregiving. They adopted this different routine, moving forward, and dealing with changes that occurred in their day-to-day lives (i.e., home life, career, relationships).

Compromising for the Caregiving Role

Compared to situations involving a drastic disruption in everyday life that persisted, even years into their caregiving career, some participants were able to find a compromise where they considered the needs of their relative, and yet maintained their own sense of self and identity while caregiving. These young caregivers made modifications to their lifestyle in the beginning to accommodate the care recipient, only to modify these changes later – settling into a more balanced way of meeting their own needs while also attending to the needs of their relative. Erika, who cared for her aunt with mental illness, initially stopped inviting friends to her house when her aunt became distressed around unfamiliar people. “Nobody came over because [my aunt]…didn’t want to be around anybody so I was trying to protect her…so that she could feel comfortable in her own house and wouldn’t have to feel confined to one bedroom.” Five months into caregiving, however, Erika adapted her approach:

> [She] and I had a conversation…I started realizing that I wasn’t helping her. I was kind of enabling her by not wanting to be around people in [my apartment]. I’m altering my life to make things comfortable for her, whereas she really was just going to have to adjust. People weren’t going anywhere, they’re always gonna’ be around. We were going to have to figure out how to make it work.

Other efforts discussed by participants to find balance between meeting their own needs and the needs of their relative included exploring the use of institutional care, utilizing respite care, and eliciting help from family. One caregiver, Melanie had mixed feelings about recently hiring an elder care consultant to advise her on potential nursing home placements:

> I can’t believe I’m talking about it, [but] at the same time, we want to have more kids. We can’t, because Mom is [living] here and I’m just emotionally and physically worn out. It’s been a year, and I’m just, done.

Kendra was another caregiver who described compromises made in order to sustain caregiving while negotiating multiple roles and responsibilities in her life. When she assumed care for her grandmother, she was a graduate student, mother of two young girls (ages 1 and 3), and partner to a medical student completing his medical residency. Kendra attended classes two nights a week and then she and her children would drive to her grandmother’s home to stay from Thursday night to Monday. This routine interfered with her children’s ability to sleep through the night and her oldest daughter’s dance lessons; she rarely saw her husband who had a demanding schedule as well.

> After a couple months of that, I physically couldn't do it anymore. I was having to drag two little girls a hundred miles and just be back and forth. I wasn't getting any sleep at all between trying to study, driving 200 miles a week and just it was not working.

Kendra eventually moved her grandmother into her home; compromises like this helped her sustain caregiving:

> It has gotten a lot easier…especially once grandma came up here. I know it's harder on her because she would like to be home. I fully understand her wanting to be home but there was just no way I could keep going the way that we're going. Physically, mentally, I was worn very thin.

Stories like those from Kendra, Erika, and Melanie illustrate how participants whose lives were initially disrupted due to caregiving made intentional choices to modify their lives, making compromises to their other roles and routines to continue caregiving.

Integrating Caregiving into Existing Roles

In contrast to young caregivers who described complete disruptions to their daily life and compromises made, some participants described changes in daily life where their role as caregiver appeared more minimal. Although these young caregivers made some adjustments for their relatives, they seemed more able to naturally integrate caregiving responsibilities into their existing responsibilities. They did not describe a life put on hold due to caregiving tasks, but their narratives seemed to illustrate more of a gentle adjustment in everyday life. These participants had an easier time incorporating their relative into their daily routine. For example, some caregivers included relatives in their leisure time and social life. When asked about spending time with friends, Carla, who lived with her toddler and 68-year-old mother with rheumatoid arthritis, said casually, “If mom wants to go with me, I take her.” Likewise, Anne, a 35-year-old, who worked full time while finishing a graduate degree, mentioned bringing her mom along on outings with peers:

> I don’t have too big of a social life. Just from the amount of work and stuff I do. I guess my social life has been homework. But I have a few close friends that I still stay really close with…Usually I try to find time and sometimes mom just comes with me (laughs)

Both of these young women chose to integrate their mothers into their daily activities, yet their caregiving needs varied greatly. Anne’s mother (age 74) had early onset Alzheimer’s disease which was fairly debilitating, compared with Carla’s mom who was dealing with the effects of rheumatoid arthritis.

Another young caregiver, Rachelle, a 20-year-old who lived in her grandmother’s home while in college, shared proudly how her grandmother influenced the way she and her friends spent their time.

> [My grandmother] got me really connected with older adults in the church that we attended. Like when they…would…end up…in the hospital…she and I would go visit them. Even when she wasn’t doing well, she would write a card or something and have me take it. It ended up becoming like a routine that my friends and I did…. And that started before I moved in with her. So, once I moved in with her, every Friday night…when everyone got off work, we would all go to the nursing home.

In closing, participants interviewed in for this study varied in their response to the demands of being a caregiver. Compared with young caregivers who described a period of time of embracement and compromise, others described a disruption due to caregiving as much less intense, one of integration. These participants naturally and organically wove their caregiving responsibilities into the existing fabric of their lives. They more easily fit their work and social life around the needs of the care recipient.

Discussion

Data in this paper stem from a larger research study focused on the lived experiences of young caregivers, giving particular attention to how young adults perceived the caregiving role to have affected their education, employment, and current and potential social relationships. As expected, caregiving activities had a significant impact on the day-to-day lives of these 20 and 30-something year olds. Participant narratives described how they had adopted their caregiving role and how caregiving responsibilities intersected with their development as young adults.

Of the three responses (i.e., embracement, compromise, and integration), participants who embraced caregiving placed a higher priority on caregiving as compared to other roles they inhabited. These caregivers gave primacy to the needs of the care recipient and adjusted other roles (e.g., as an employee) so they could fulfill their caregiving role and responsibilities. Factors such as severity or temporality of the care recipient's needs may account for this varied response to role adoption. For young adults providing care to terminally ill parents, Goldblatt and colleagues (2018) found that "the ability to the ability to put their life on hold temporarily allowed them to be present in the here and now" for this formative experience (Goldblatt et al., 2018, p. 7). In the present study, care recipient needs seen as being severe may have influenced why young adults decide to prioritize caregiving above other aspects of their life. If a caregiving role was seen as being temporary, this also might have prompted some to more easily assume their caregiving duties.

Many participants who embraced the caregiving role expressed feeling personally responsible to provide care out of familial obligations or expectations. Existing research supports the notion that values about family caregiving can shape how one approaches their caregiving role and their attitudes about fulfilling this role (Gibson, Holmes, Fields & Richardson, 2019; Pharr, Francis, Terry & Clark, 2014). Luna described family as being more important than her social life; she asserted that there would be opportunities to "spend time with friends later." In addition to values about caregiving, the presence (or not) of outside support may also influence how a young adult assumes the family caregiving role. When there is a lack of informal support (e.g., family members to help provide care) and/or formal support (e.g., respite services), young caregivers might think they should assume all the caregiving, feeling that if they do not do it, then no one else will. For young adults assuming care of grandparents, they are likely to be motivated by feelings of attachment (as opposed to obligation) (AARP & NAC, 2020; Bradley Bursack, C., 2021; Dellmann-Jenkins & Blankemeyer, 2000) and tend to provide more care when their parents experience a greater care burden (Hamill, 2012).

For participants like Gary, who have left paid work, questions remain on how such actions might influence opportunities in later life. There is some evidence to suggest that for young adults, the caregiving role can interfere with paid employment in ways such as missing out on job promotions and having insufficient support at work (Dellmann-Jenkins & Blankemeyer, 2009; Flinn, 2018; Fruhauf & Orel, 2008). Compared to middle-aged and older caregivers, young adult caregivers report more financial strain (Koumoutzis et al., 2021; McLaughlin et al, 2019). Future studies should explore what factors contribute to young adults embracing the caregiving role, as well as the implications of how such actions affects young adult caregivers longitudinally. For example, for young caregivers, there can be a significant physical toll, including impaired sleep quality, leading to the diminished health of the caregiver (Hoyt, Mazza, Ahmad, Darabos, & Applebaum, 2021). Studies might examine how prioritizing family caregiving in young adulthood might affect one's ability to engage in developmental activities such as establishing intimate relationships, becoming a parent, or re-entering the workforce following the conclusion of their caregiving role.

Compared with embracing caregiving responsibilities, participants who compromised were able to meet the needs of their relative while also maintaining their own sense of self and identity. Compromise seemed to allow these young caregivers to inhabit multiple roles simultaneously. For most participants, compromise was a reaction to over-embracing the caregiver role initially. This was the case for Kendra who made a long commute to care for her grandmother, but later opted to have her grandmother move in with her. Our data suggests that compromise may be a strategy for young adults to intentionally prioritize their own development while also being available to provide care for a family member with functional impairment. Although some participants, like Kendra, had found a balance in their many roles and responsibilities, young adult caregivers do often have to give up time participating in social activities and spending time with friends (Associated Press - NORC Center for Public Affairs Research, 2018; AARP & NAC, 2020).

Compromise may also allow for young caregivers to cope with role strain and prevent burnout from caregiving. Making compromises like the ones detailed in this paper may allow caregivers to sustain caregiving in times of stress from role strain. Such compromises might be compared to personal self-care, but more aptly describes making accommodations so that young caregivers can still progress in development tasks typical of their age. In the case of caregivers like Melanie, compromising via use of external support enabled her to expand her family while still ensuring her relative has adequate care. Whether young, midlife, or older adult caregivers, the stressors are similar (Koumoutzis et al., 2020), but the importance of life span interruption, whereas the young adults are still in their formative life stages, cannot be discounted. Young caregivers' life stages create different challenges as they juggle their caregiving roles and their economic and work status make them more vulnerable to the stressors of caregiving (McLaughlin et al., 2019). Future studies might explore how making compromises in the process of caregiving affects younger adult caregivers' resilience as caregivers and their ability to meet developmental milestones.

This third response to assuming the caregiving role is one of integration; these young caregivers naturally and organically wove caregiving responsibilities into the existing fabric of their lives. Often perceived to be more minimal and less disruptive, integration of caregiving role allows the caregiver to fulfil their caregiving obligations through other, pre-established roles. Both Carla and Anne brought along their mothers to outings with their friends, thus merging the interaction of the two roles (caregiver and friend). Some caregivers seem able to accommodate the needs of care recipients in ways that require few major changes in their lives (Matthews, 1985), yet there is wide variability in this based on the trajectory of relatives' care needs (Pressler et al., 2013; Tsai et al., 2015). While most of our participants appeared to provide care to a relative that had less severe care needs, further research is needed to explore if integration can be accomplished for a care recipient with more advanced care needs. Further it is unclear to the extent integration has on caregivers' subjective burden.

As with any study, findings should be considered in the context of study limitations. Although generalizability is not the purpose of qualitative inquiry, we recognize that a small sample size has limitations to the degree to which findings can be applied to other young adult caregivers. About one-third of our participants (28%) had dependent children concurrent to caregiving, which is comparable to a national sample of family caregivers indicating 28% of family caregivers have children or grandchildren in their household (NAC & AARP Public Policy Institute, 2015). Unlike typical young adult caregivers who serve in secondary caregiving roles (AARP 2018; Levine et al., 2005), 68% of our sample were primary caregivers and received little to no support from family and friends.

Another limitation is the inherent challenge with telephone interviews in terms of rapport building and inability to see nonverbal communication. However, we determined the advantages of conducting interviews via phone (i.e., increased access to participants, flexibility in scheduling) outweighed the disadvantages. Lastly, although we used purposive sampling with specific inclusion criteria, the nature of caregiving dictates that every situation is going to be unique and variable (e.g., care recipient diagnosis, relationship dynamics, duration of caregiving, presence of social support). We acknowledge that participants' perspective might have differed based on specifics of the caregiving situation.

Despite these limitations, this study's findings contribute to the understanding of a subgroup of family caregivers who have received little attention – young adult caregivers. Not unlike most family caregivers, young adults struggle to find balance between caregiving demands and other areas of their lives, such as work and family. Millennial family caregivers (those aged 23 to 38 in 2019) however, are the most likely of any generation (compared to Generation Xers and Boomers) to also be employed while caregiving (Flinn, 2018). Additionally, younger caregivers are establishing a series of new roles typical of young adulthood (e.g., first job, intimate relationships, parenthood). Young adults providing care to an ill or disabled relative must often find ways to continue their studies, begin their careers and/or families, while simultaneously taking on caregiving duties. The stress of balancing these demands can overwhelm a mature adult, let alone a younger person who is just beginning to establish themselves. Our findings suggest that young adult caregivers responded by embracing, making compromises, and integrating the caregiving role into their existing roles.

Conclusion

The results of exploratory, qualitative study suggest that there are three approaches to adopting the caregiving role among young adult caregivers - embracement, compromise, and integration. Certainly, the objective aspects of the caregiving situation will shape participants' perspectives (e.g., subjective burden). Further, some participants were caring for someone with less functional disability and therefore there may be more of an ability to integrate caregiving into their day-to-day life because the person's needs are less intense.

Whether an individual feels they had a choice in assuming the caregiving role may also make a difference. Nearly half of all caregivers report that they had no choice in taking on the caregiving role and lack of perceived choice is associated with increased levels of role strain, burden, and overall well-being (Li & Lee, 2020; Reinhard et al., 2012; Schulz et al., 2012). Further exploration in two areas is needed: 1) the value of social media support is needed as the 24-hour internet access to support and information may be a positive outlet for the caregivers if the potential negative side effects can be offset (Villanti et al., 2017; Warner et al., 2020), and 2) the physical impact on the young caregivers (Hoyt et al., 2021).

In summary, additional research into the needs of young adult caregivers is warranted. Understanding if these distinct approaches to adopting caregiving roles relate to the personality or motivation of the participants, or if adoption of these strategies is based primarily on their caregiving situation and extraneous circumstances (marital status, presence of children, etc.), further research is needed. Additionally, given that the caregiving role has the potential to disrupt individuals' other roles and exacerbate one's role strain, studies should examine how these different approaches affect individual's development.

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Table 1

Participant Characteristics

Participant	Age	Race/ Ethnicity	Care Recipient	Care Recipient Diagnosis	Care Recipient Age	Marital Status	Children	Employment/ School Status	Length of Time Caregiving	Current/ Former Caregiver
Kayla	32	White / Non-Hispanic	Spouse	Glaucoma, kidney problems, mood disorder	33	Married	Daughter, 3	FT graduate student	7 years	Current
Erika	32	Black	Aunt	Bipolar disorder, depression	50	Single	None	Employed FT	14 months	Current
Dana	24	White / Bosnian	Grandmother	Diabetes, heart & kidney problems	85	Engaged	None	Employed FT	2 years	Current
Gary	37	White / Non-Hispanic	Mother	Multi-infarct dementia, diabetes	73	Single	None	Not employed or in school	13 years	Current
Melanie	37	White/ Non-Hispanic	Mother	Early-onset Alzheimer’s, CHD, depression	66	Married	Son, 3	Stay at home mom	18 months	Current
Luna	18	Asian/ Filipino	Grandparents	Diabetes, stroke	71	Single	None	FT student	4 months	Current
Carla	32	White / Non-Hispanic	Mother	Rheumatoid arthritis & fibromyalgia	68	Separated	Son, 4	Employed FT; PT student	4 years	Current
Lacy	39	White / Non-Hispanic	Father	Lung cancer, emphysema	69	Married	Daughter, 7Daughter, 10	Employed FT	11 months	Current
Rachelle	20	White / Non-Hispanic	Grandmother	Rheumatoid arthritis	67	Single	None	FT undergraduate student	2 years	Former
Anne	35	White / Non-Hispanic	Mother	Early-onset Alzheimer’s	62	Partnered	None	Employed FT; PT graduate student	5 years	Current
Natasha	25	White / Non-Hispanic	Father	Lou Gehrig’s disease	62	Single	None	FT graduate student	15 years	Current
Tamara	22	Black	Mother	Lung Cancer	unknown	Single	2 sons	FT student	7 years	Former
			Uncle	TBI						
			Aunt	Multiple Sclerosis						
Peter	21	White / Non-Hispanic	Mother	Type I Diabetes, heart problems	62	Single	None	Employed 2 PT jobs	18 months	Former
			Father	Dementia, peripheral artery disease, kidney problems	78				7 years	
Jasmine	31	White / Hispanic	Mother	Early-onset Alzheimer’s	74	Single	None	Employed 2 PT jobs	1 year	Current
Kay	27	White / Non-Hispanic	Great Grandmother	Dementia	99	Single	None	FT undergraduate student, employed PT	2.5 years	Former
Ravi	33	Asian/ East Indian	Father	Early-onset Alzheimer’s, Parkinson’s, epilepsy	61	Married	None	Employed PT	3 years	Current

Participant	Age	Race/ Ethnicity	Care Recipient	Care Recipient Diagnosis	Care Recipient Age	Marital Status	Children	Employment/ School Status	Length of Time Caregiving	Current/ Former Caregiver
Kendra	30	White / Non-Hispanic	Grandmother	Congenital heart defect, stroke, diabetes	74	Married	Daughter, 1Daughter, 3	Employed PT; PT graduate student	15 months	Current
Regina	26	White / Non-Hispanic	Husband	COPD, emphysema, narcolepsy, diabetes, cervical stenosis	47	Married	None	Employed FT, PT student	1 year	Current
Chithra	24	Asian/ East Indian	Grandmother	Alzheimer’s	79	Single	None	FT student; employed PT	7 years	Current
Tushar	36	Asian/ East Indian	Mother	Normal Pressure Hydrocephalus	63	Single	None	Employed FT	3 years	Current
Shane	28	White / Non-Hispanic	Grandmother	COPD, lung problems	83	Single	None	FT graduate student	4 years	Current
Ramona	28	White / Non-Hispanic	Husband	Hodgkin’s Lymphoma	28	Married	None	Employed FT	9 months	Former

Note: For current caregivers, their information (e.g., age) pertains to the situation at the time of the interview. For former caregivers, their information pertains to the time their caregiving began. For caregivers (e.g., Peter) who have cared for more than one family member, information on all caregiving experiences is reported.

Table 2

Examples of Interview Questions

- How did you come to be taking care of your relative?
- How long have you been caring for him/her?
- What kind of care do you provide to your relative?
- Sounds like a pretty big transition in your life, what was that like for you?
- What are some plans or goals you have about your education/schooling?
- In what ways do your caregiving responsibilities impact your plans/goals around education?
- How have things with school been different since you’ve been caring for your relative?
- Tell me about your current job situation.
- How are things with your job different since you’ve been a caregiver?

Table 3

Examples of Themes and Exemplar Data

Theme	Central Idea	Data Extract
Embracing the caregiving role	Prioritized needs of care recipient above their own Extensive disruptions to daily life	“While mom needs me, I think it’s best that I give her as much attention and the care that she needs…I do some [work] from home, but my job is taking care of mom.” (Gary)
Compromising for the caregiving role	Adopted a balanced way of meeting their needs while also meeting care recipient’s needs Intentional modifications in order to sustain caregiving long-term	“After a couple months of that, I physically couldn’t do it anymore. I was having to drag two little girls a hundred miles and just be back and forth. I wasn’t getting any sleep at all between trying to study, driving 200 miles a week and just it was not working…. It has gotten a lot easier…especially once grandma came up here.” (Kendra)
Integrating caregiving into existing roles	Natural incorporation of caregiving responsibilities into their daily lives Assumption of caregiving seemed more effortless of a transition	“But I have a few close friends that I still stay really close with… Usually I try to find time and sometimes mom just comes with me” (Anne)