

1-2021

Chapter 15: Family Caregiving

Anna Hammersmith
Grand Valley State University, hammeran@gvsu.edu

Follow this and additional works at: https://scholarworks.gvsu.edu/sw_books



Part of the [Social Work Commons](#)

ScholarWorks Citation

Hammersmith, Anna, "Chapter 15: Family Caregiving" (2021). *Books and Contributions to Books*. 3.
https://scholarworks.gvsu.edu/sw_books/3

This Contribution to Book is brought to you for free and open access by the School of Social Work at ScholarWorks@GVSU. It has been accepted for inclusion in Books and Contributions to Books by an authorized administrator of ScholarWorks@GVSU. For more information, please contact scholarworks@gvsu.edu.

Chapter Fifteen

Family Caregiving

Anna Hammersmith

Case Study 15.1

Joanne and Clifford are a married couple living in Holland, Michigan. Joanne just recently celebrated her 77th birthday and Clifford will turn 82 next month. Joanne is the primary caretaker for Clifford. Clifford has had Parkinson's disease for several years. As a result of the progression of his Parkinson's disease, Clifford suffers from several functional limitations. Clifford has trouble moving around the house and sometimes Joanne needs to help him up after he sits for prolonged periods. He also has difficulty with dressing and bathing. Sometimes Joanne also helps Clifford eat his meals when his Parkinson's related tremors are particularly troublesome. Consequently, Joanne typically helps him with most of these tasks. However, last week, while carrying groceries into the house, Joanne tripped and fractured her hip. Her youngest daughter Mary—who lives less than 10 miles away—rushed her to the hospital. Mary left her 16-year-old daughter Bailey to look after Clifford. At the hospital, the doctor told Mary and Joanne that Joanne will need surgery. Following surgery, the doctor recommended that Joanne to stay in a rehabilitation center for a couple of weeks. She also cautioned that even when Joanne returns home, she won't be able to return to many of her daily tasks for several more weeks, maybe even months.

Joanne knows she must have the hip surgery and give herself time to recover. However, she is worried about who will manage Clifford's care. She and her husband cannot afford long-term care nor would Clifford feel comfortable leaving the home he has lived in for nearly five decades. Joanne asks her three children to help come up with a patchwork system of care. Joanne's daughter Mary immediately offers to visit Clifford twice a day, volunteering to shorten her work hours to help out. She says she can make his meals, manage his medications, clean the house, and perform many of the other tasks Joanne typically does. Joanne does not want to

burden Mary because Mary's schedule is already stretched paper thin. Mary has three children, all of whom are still school-aged. Plus, Mary and her husband Craig both work full-time jobs. And, Joanne does not feel as though she has many other options. Joanne's other two children are also able to provide some assistance. Although her daughter Jane lives across the state in Ann Arbor. She has offered to drive to Holland on the weekends to stay with Clifford but cannot take off work on the weekdays. And, Joanne's son Paul lives in Oregon. Paul has booked a flight to fly home during Joanne's surgery and has offered to provide financial assistance to hire someone to help with some of the cooking and cleaning duties at Joanne and Clifford's home. Joanne appreciates the help offered by her children but is still worried about the mental, emotional, and financial well-being of her children and husband. Moreover, Joanne is anxious about her own recovery and is unsure how long she'll need to rely on instrumental and economic assistance from her children.

Case Study 15.2

Linda and Pamela— both in their 70s— were married for nearly five years but had been together for twenty years. Both Linda and Pamela had been in prior marriages that ended in divorce when they were in their 50s. Linda has two adult children with her ex-husband and Pamela had one daughter from her prior marriage. However, neither Linda nor Pamela had close relationships with their children. In fact, they both became estranged from their children following Linda and Pamela's announcement of their romantic relationship. Both sets of children simply could not accept that their parents were in a same-sex relationship.

Pamela had been suffering from breast cancer for several years and passed away six months ago. As Pamela's cancer progressed, Linda served as her primary caregiver. Upon learning the severity of her mother's illness, Pamela's daughter, Chelsea, would visit more often, but she rarely helped out with caregiving. To take care of Pamela, Linda stopped working her part-time substitute teaching job and often neglected her own health through cutting back on daily walks, eating more takeout meals, and even forgetting to schedule her own doctor's visits. Thus, the burden of providing care coupled with the stress of Pamela's death have both taken a toll on Linda. Now, following Pamela's death, Linda finds it difficult performing a variety of everyday tasks. For example, Linda is having trouble keeping up on chores, doing grocery shopping, keeping up on bills, and other such daily tasks. Linda is contemplating hiring a home health aide to help her with daily tasks. But Linda is worried. Since she began her relationship with Pamela, she has experienced discrimination for her sexuality. She fears such prejudices might stand in the way of receiving quality care and wonders if she'd be better off handling daily challenges on her own.

In the months right after Pamela's death, Linda's home was never empty. But as the months have passed, her friends have begun to move on and are increasingly consumed with events in their own lives. Although fewer friends drop by on a regular basis, Linda still has some close friends who she spends time with each week. Nonetheless, she often finds herself spending a lot of time alone these days. Pamela was her main source of comradery and support, even when she was ill. Linda thinks about reaching out to her children for emotional and instrumental support, but she has not spoken to them in several years. Linda also thinks about joining her local Senior Citizen Center. But again, she is worried about prejudice and discrimination if others were to find out about her sexual orientation.

Family Caregiving

The United States population aging has led to an increased need for individuals who can provide care to older adults. Often, this responsibility falls on family members. **Family caregiving** is defined as a relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition (Family Caregiver Alliance; Redfoot, Feinberg, & Houser, 2013). These individuals may be described as primary or secondary caregivers. A *primary caregiver* is an individual who takes responsibility for the bulk of an older adult's care whereas a *secondary caregiver* provides supplementary support to another care provider. This chapter will focus on family caregivers of older adults and their challenges and strains associated with care as well as social work interventions aimed at alleviating care burdens. Understanding challenges faced by family caregivers and implementing solutions will help family caregivers continue the important work they do with regards to protecting the health and well-being of the elderly.

The concept of family caregiving is not new. Prior to the introduction of social programs like Social Security in 1935 as well as Medicaid and Medicare in 1965, older people relied heavily on family as they encountered physical, financial, instrumental, or emotional difficulties associated with age (Sherwood & Schulz, 2008). Although our society offers more support to the elderly than in decades past, programs geared toward assisting older people with care needs remain limited. Thus, family members typically step in to provide care for their aging relatives; families are often the main source of home care and social support for an aging relative (Schulz & Sherwood, 2008). Today in the United States, about 41 million people provide unpaid care to an older family member for a total of 34 billion hours (AARP, 2019). Not only are many people involved in family caregiving, family caregiving has also become a significant part of our

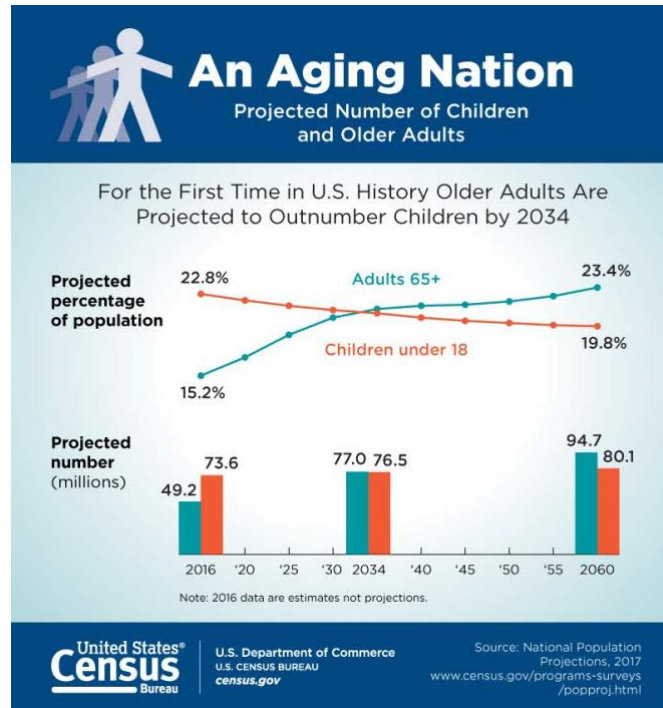
economy. If we estimate those 41 billion caregivers each provided 16 hours of care per week valued at \$13.81 per hour, this would equate to \$470 billion in 2017 alone. In context, \$470 billion dollars is more than what is spent on out of pocket healthcare expenditures or on long-term services and support in the United States in 2017 (both valued at \$366 billion). This equates to about \$1,450 per person in the USA (Reinhard, Feinberg, Houser, Choula, & Evans, 2019).

As mentioned above, family caregiving already plays a critical role not only within families, but also in our economy. It is expected that the value— social and economic—will grow in the future. Think back to Chapter 1 of this book, recall Figure 1.1., which illustrates an aging population in the United States. The **graying**—or, aging—of the population will be notable. In 2018, individuals over 65 made up 15% of the population. As we enter 2030, projections show about 21% of our population will be 65 and older. Although not all of these individuals will need care, many may require assistance. As our population becomes older, this also suggests there will be fewer young people in the United States (Figure 15.1). Figure 15.1 illustrates a steady increase in the share of the population over 65 in the United States between 2016 and 2060. The figure also depicts a corresponding drop in people under 18. In fact, it is estimated there will be more older people than younger people in the United States by 2035 (Vespa, 2018). This means that as we see more older adults requiring care, we will also encounter the dilemma of having fewer younger people who are able to provide such care.

The dilemma of the availability of caregivers is sometimes described through the lens of the **caregiver support ratio**. This is defined as the number of potential caregivers aged 45–64 for each person aged 80 and older (Redfoot et al., 2013). In 2010, the caregiver support ratio was 7:1 (Redfoot et al., 2013). This means that in 2010, there were 7 potential caregivers ages 45 to 64 for every one person who was 80 and older. By 2050, it is projected the caregiver support

ratio will shrink to 3:1, meaning there will only be 3 potential caregivers ages 45 to 64 for every older adult who could potentially require care (Redfoot et al., 2013). This demographic shift will require innovative, evidence-based social work interventions that address the challenges of a growing aging population in the face of a shrinking working age population.

Figure 15.1 An Aging Nation



Source: Vespa, J., United States Census Bureau

Who Are Family Caregivers?

Family caregivers are a diverse group. It is crucial that social workers are aware of this diversity to best engage and serve these caregivers and care recipients. The majority of caregivers are either a spouse or adult child of the care recipient (AARP, 2015). Moreover, more women are family caregivers than their male counterparts. About 2 in 3 caregivers are women (Family Caregiver Alliance, 2019). Further, many caregivers are middle aged, with an average age of 49 (Family Caregiver Alliance, 2019). The majority of caregivers in the United States are White (62%) due to relative population size, however, caregiving is more common in minority

communities. Hispanic Americans report the highest prevalence of family caregiving at over 1 in 5 providing care to a family member. African and Asian American report similar numbers whereas about 1 in 6 White Americans provide care to a family member (Family Caregiver Alliance, 2019). As for employment, about 1 in 6 Americans who work full- or part-time provide assistance to an older family member, relative, or friend (Family Caregiver Alliance, 2019). Somewhat surprisingly, when employed, family caregivers are more likely to be full-time workers (56%) rather than part-time (Family Caregiver Alliance, 2019).

Caregiving is often long-term in nature. Caregivers provide assistance for an average of 4 years, with about 25% reporting 5 years of caregiving or more (AARP, 2015). Many caregivers also expect to still provide care five years from their interview (AARP, 2015). Caregivers dedicate many hours to assisting the care recipient. On average, caregivers spend 25 hours per week providing care, with 25% providing 40+ hours of care (AARP, 2015). Caregivers who provide care for a spouse often report greater time burdens. Spousal caregivers provide care for an average of 10 years and spend about 45 hours in care per week. Spouses are also much less likely to receive outside help relative to other family caregivers (AARP, 2015).

What Do Family Caregivers Help with?

Family caregivers are integral in supporting older relatives. Two common ways caregivers provide support are through instrumental and emotional care. Instrumental care refers to assistance related to a recipient's functional limitations. For instance, many recipients face *activities of daily living limitations* (ADLs) or *instrumental activities of daily living limitations* (IADLs). ADL limitations prevent someone from performing necessary life tasks such as feeding oneself, bathing, toileting, dressing, or getting up from a chair. IADLs describe limitations that infringe upon standards for independent living, like the ability to take medication, cook oneself a

meal, drive to the grocery store, pay bills, set up doctor's appointments, and more. Note that Clifford, in Case Study 15.1, experiences some of these functional limitations. Like his wife Joanne, studies have shown that nearly 60% of caregivers provide assistance with ADL and/or IADL limitations (AARP, 2015).

Caregivers also offer emotional support. Many care recipients face limitations that may prevent them from spending much time outside of the home. In fact, research shows as age and health problems increase, so does loneliness (Dykstra, van Tilburg, & de Jong Gierveld, 2005). Thus, caregivers not only help care recipients with the tasks they can no longer complete on their own, but they also provide a source of social contact. Given the significant role that family caregivers play in care recipient's lives, identifying vulnerable family caregivers and ways to continue to support caregivers is crucial in social work practice. This chapter will discuss variation across caregivers, barriers to family caregiving, caregiver outcomes, as well as potential policy and social work interventions.

Caregiving across Race and Ethnicity

Non-Whites are more likely to be caregivers than their White counterparts (Family Caregiver Alliance, 2019). Moreover, care needs are expected to grow more for Non-Whites than Whites in the coming decades (Knight & Sayegh, 2010; McLennon, Anderson, Epps, & Rose, 2020; Pharr, Francis, Terry, & Clark, 2014). There are several reasons for this projected growth in need among Non-Whites. First, Non-White groups tend to use fewer formal care services than Whites (Ho et al., 2000; Liu, McBride, & Coughlin, 1994; Scharlach, Kellam, Ong, Baskin, Goldstein, & Fox, 2006). This could be because many minorities face structural barriers that prevent access to formal care or other support services. Structural barriers include discrimination, lack of access to transportation, language barriers, insufficient knowledge of services, cost of

services, as well as a lack of culturally sensitive services (Scharlach et al., 2006). A second barrier is many minority groups do not trust services offered by institutions supported by the government (Scharlach et al., 2006). As one example, throughout the United States' history, Native American people have faced institutionalized discrimination, prejudice, and displacement as well as social isolation and poverty, leading them to less use of government-sponsored interventions. Third, certain diseases, like Alzheimer's disease are projected to disproportionately affect Non-Whites in the USA (Chen & Zissimopoulos, 2018). Social workers should assess the diverse needs of Non-White caregivers and focus on evaluating effectiveness of current interventions across race and ethnicity to better serve the myriad needs of diverse populations (McLennon et al., 2020).

Hispanic Americans

Hispanic American family life is often characterized by "**familism**." Familism describes the responsibility that family members feel toward one another and places emphasis on the well-being of the entire family unit, rather than individual family members (Scharlach et al., 2006). Familism can help explain the sense of obligation to provide care for an older family member (Cox & Monk, 1993). Moreover, failing to care for an aging family member can negatively reflect on the entire family unit, and thus, there may be no other choice other than to provide necessary care (Scharlach et al., 2006). Although familism is an important lens through which we can view Hispanic American families, many experts have cautioned against the assumption that familism leads to more positive assessments of caregiving (Knight & Sayegh, 2010). In fact, there is evidence to discount this, including poorer coping strategies among Hispanic American caregivers relative to other groups of family caregivers (Knight & Sayegh, 2010). Moreover, other researchers have identified higher rates of depression and stress as well as a greater

manifestation of negative physical symptoms among Hispanic American caregivers relative to other caregivers (Cox & Monk, 1993; Pinquart & Sörensen, 2005). Such negative outcomes can be exacerbated by a lack of service utilization by Hispanic American caregivers (Cox & Monk, 1993). One study showed Hispanic American caregivers were less likely to use formal services. There were many reasons for this including avoiding formal services to keep problems insulated within the family, to avoid admitting caregiving was too strenuous, perceived guilty for having negative feelings about caregiving, as well as cultural barriers that hindered access (Cox & Monk, 1993). For these reasons, outreach by social workers or other practitioners may be particularly useful for Hispanic American caregivers (Cox & Monk, 1993).

African Americans

In the United States, the ways in which caregiving patterns in African American families differ from White Americans can be characterized by cultural and historical differences. The legacy of slavery and discrimination against African Americans have led to a greater reliance on family to fulfill support needs (Franklin, 1997; Dilworth-Anderson, 2005). Thus, caregiving norms are stronger in African American families than in White American families, often extending beyond immediate family to encompass others considered to be kin, such as distant relatives, friends, or neighbors (McLennon et al., 2020; Pharr et al., 2014). In fact, in a qualitative study, Pharr and colleagues (2014) found many African American caregivers described family caregiving expectations as a part of life that was “natural” or “nothing new.”

Whether the prevalence of family caregiving among African Americans leads to positive or negative outcomes on families is unclear. On one hand, studies of family members who care for someone with Alzheimer’s show African Americans experience care more positively than Whites and report lower rates of depression (Epps, 2014; Janevis & Connell, 2001; Pinquart &

Sörensen, 2005; Roff et al., 2004). African Americans are also more likely to draw on religion as a coping mechanism compared to White Americans (Epps, 2014; Haley, West, Wadley, Ford, White, & Barrett, 1995; Roff et al., 2004). In contrast, other studies suggest there are negative ramifications of caregiving in African American families. Increased feelings of obligation to provide care to an ailing family member may threaten the caregiver's health (Dilworth-Anderson et al., 2004). Moreover, others suggest reliance on family caregivers can indicate a lack of access of formal care services among African Americans that could potentially reduce caregiver burden (McLennon et al., 2020). This could indicate among African Americans, it is not necessarily true caregiving is more rewarding, but rather, there are fewer alternatives to providing care to a family member in need (Janevis & Connell, 2001; Scharlach et al., 2006).

Asian Americans

Family care provided by Asian Americans is often characterized by “**filial piety**,” which refers to taking care of or honoring one's elders. In some instances, filial piety may increase positive coping strategies among family caregivers (Knight & Sayegh, 2010; Meeks, 2020), however, similar to the discussion of familism, we cannot assume cultural values such as filial piety lead to a more positive experience among family caregivers. This is evidenced by higher depression rates reported among Asian American caregivers relative to their White American caregiver counterparts (Pinquart & Sörensen, 2005). Qualitative work by Pharr and colleagues (2014) echoes these findings. In this study, Asian American interviewees reported feeling an inability to say “no” to providing family care, no matter the circumstances (Pharr et al., 2014). Moreover, within some ethnic groups of Asian Americans, certain chronic illnesses such as dementia carry a strong social stigma, which can make the experience of caregiving more negative (Ho et al., 2000; Liu, Hinton, Tran, Hinton, & Barker, 2008).

Immigrant Groups

Immigrants in the United States come from many different racial or ethnic backgrounds, but nonetheless can be linked by the way they experience family caregiving. In many cases, upon immigrating to the USA, social support circles become more constrained (Meeks, 2020; Neufeld et al., 2002). Thus, many immigrants have fewer sources of financial, instrumental, or emotional support. Not only are social circles more constrained for immigrant groups, but also immigrants report facing barriers in accessing formalized support services that could help reduce caregiver burden. There are a few reasons for such barriers. First, many immigrants do not qualify for resources within their community that might help support care for a family member. For example, undocumented immigrants do not qualify for most types of public assistance and many legal immigrants must live in the United States for five or more years before they qualify for programs such as Medicaid, Temporary Assistance for Needy Families (TANF), Supplemental Nutrition Assistance Program (SNAP), and Supplemental Security Income (SSI), among others (National Immigration Forum, 2018). Second, immigrants often face language barriers that may prevent them from accessing help. Even when a community has agencies that provide translating services, many immigrant caregivers find their assigned translator does not know the medical terminology to adequately describe their circumstances to a health professional (Neufeld et al., 2002). Third, in many communities, there is a lack of culturally sensitive services available to immigrants. For instance, in some cultures, it is stigmatizing or inappropriate to discuss another family member's health problems at length with a non-family member (Neufeld et al., 2002). Moreover, many social services rely on Western medicine and treatments while providing few alternatives (Neufeld et al., 2002). Finally, there are several other barriers many immigrants

face, such as lack of transportation, inflexible work hours, and limited financial resources (Meeks, 2020; Neufield et al., 2002).

Caregiving in the LGBTQ Community

Only recently have researchers and practitioners focused on the unique prejudice and discrimination experienced by LGBTQ older adults who need care (Shiu et al., 2016). In fact, LGBTQ older adults are more likely to need care later in life compared to their heterosexual counterparts. This is because LGBTQ older adults are more likely to have at least one chronic illness, likely related to the accumulation of disadvantages over the life course (Baumle, 2014; Fredriksen-Goldsen, Kim, Barkan, Muraco, Hoy-Ellis, 2013). Specifically, Fredriksen-Goldsen and colleagues found the total number of lifetime discrimination and victimization experiences (e.g., loss of jobs, exposure to physical violence, etc.) were associated with poor physical and mental health outcomes as well as greater likelihood of disabilities and depression in a national sample of older LGBT adults (Fredriksen-Goldsen, Kim, Shiu, Goldsen, & Emler, 2014). Moreover, the legacy of the HIV/AIDS epidemic has left LGBTQ older adults increasingly vulnerable as HIV leads to higher morbidity and is correlated with the presence of other health limitations, possibly increasing care needs later in life (Brennan-Ing et al. 2014).

Case Study 15.2 describes chronic worry Linda has felt regarding seeking assistance from medical professionals. Linda's concerns are not unfounded. Discrimination against LGBTQ older people is pervasive in our society and extends into the healthcare system. One study found 10% of LGBTQ older adults experienced heterosexist behavior from a primary care provider and 1 in 5 utilized an advocate at a recent medical appointment to deter discriminatory behavior (Beauchamp et al. 2003). Worries of discrimination often extend to the caregiver as well. Some caregivers will not disclose their relationship to the care recipient or disclose the recipient's

sexuality out of fear of discrimination or prejudice (Knochel et al., 2011; Moore, 2002; Washington, McElroy, Albright, Oliver, Lewis, Meadows, & Elliott, 2015).

Despite the fact that LGBTQ older adults may need more care than their heterosexual counterparts, LGBTQ older people tend to have fewer sources of support to rely upon. As described in Case Study 15.2, which examined the lives of Linda and Pamela, many LGBTQ people are estranged from family members who cannot accept their sexuality or choice of partner (Valenti & Katz, 2014). Thus, LGBTQ older adults often come to rely on **families of choice**, or people to whom they are not biologically related, but feel familial duty and obligation toward (Family Caregiver Alliance). Families of choice within the LGBTQ community become apparent when examining family caregiver statistics showing 54% of LGBTQ older adults who need care receive assistance from their spouse or partner and another 24% are assisted by a close friend (Frederiksen-Golden et al., 2014). The experiences of friend caregivers can be similar to family caregivers. Friends often feel similar levels of stress and depression related to providing care relative to other family caregivers, like spouses. Caregivers of LGBTQ older adults also face other disadvantages that can make caregiving more challenging. Caregivers of LGBTQ older adults are more likely to be younger, less likely to be married, more likely to be a racial or ethnic minority, and report greater financial strain (Anderson & Flatt, 2018).

LGBTQ older adults have also been affected by the HIV/AIDs epidemic. Data from 2015 indicates about half of all people living with HIV are over 50. This number is expected to grow; by the end of 2020, it is estimated about 70% of people living with HIV will be over 50 (Karpiak & Brennan-Ing, 2016). LGBTQ older people who are HIV positive encounter more barriers to accessing care than older adults without HIV. One challenge faced by HIV positive LGBTQ older adults is **comorbidity**, or having more than one chronic condition or illness (Smith et al.

2012). This might involve coordinating several different prescriptions or treatment plans to maintain quality of life (Smith et al., 2012). Another obstacle HIV positive LGBTQ older adults encounter is lack of family support. LGBTQ older adults who have HIV are even less likely to have a spouse or children on whom they can rely on for care (Karpiak & Brennan-Ing, 2016). Thus, LGBTQ older adults with HIV may rely more heavily on friends for support. Although such families of choice are crucial in the LGBTQ community, many of these friends may also be struggling with HIV, which makes them less able to provide care or assistance (Karpiak & Brennan-Ing, 2016). Finally, not only do these older adults face a support deficit, but they are often neglected by social programs. For instance, many services geared toward helping those who are HIV positive focus on a younger population. Therefore, many older people either do not feel welcome or these services are not equipped to assist the aged (Linsk, 2000; Shippy & Karpiak, 2005). Social workers should evaluate existing interventions for effectiveness related to the diverse needs of LGBTQ+ older adults. Social workers can also work toward dismantling structural barriers, such as sources of discrimination, that might prevent LGBTQ+ caregivers or recipients from receiving support.

Caregiver Well-being

Family caregiving can have physical, psychological, social, and financial ramifications for the caregiver that social workers can help ameliorate. Consider Case Study 15.2.— Linda served as Pamela's caregiver while she fought breast cancer. Linda often neglected her own health to prioritize Pamela. After Pamela's death, Linda faced her own health problems and had few people to turn to for help.

Physical Health

Caregiving can take a toll on the caregiver's physical health. A recent study found only about half of caregivers reported good or excellent health and nearly 1/5 reported poor or fair health (AARP, 2015). Moreover, the number of hours a week devoted to care as well as years spent caregiving are linked to poorer health. Relatedly, caregivers often neglect their own health needs to prioritize the care recipient (Sherwood & Schulz, 2008). Caregivers are more likely to skip preventative health screenings and appointments compared to non-caregivers (Navaie-Waliser, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002). Not only do caregivers neglect their own health while providing care, but caregiver health is often tethered to fluctuations in the well-being of the care recipient (Crossman, London, & Barry, 1981; Jagger & Sutton, 1991; Raveis, 2000). If the recipient is doing poorly, the caregiver is even more likely to focus their attention solely on the recipient's well-being and not on their own needs.

Mental Health

There is conflicting evidence as to whether caregiving is positively or negatively related to one's mental health. In some ways, caregiving is seen as stressful and burdensome (Sherwood & Schulz, 2008). Part of the reason for increased stress is the unpredictable nature of family caregiving. Oftentimes, the types of care needed and the duration of care is out of the caregiver's control, leading to strain as the caregiver tries to balance care demands with work, family, health, and leisure (Sherwood & Schulz, 2008). Moreover, caregiving is often emotionally taxing. This is especially true when caring for someone with whom the caregiver is close, as it can be difficult to watch a loved one experience health declines (AARP, 2015). One study showed about half of individuals caring for someone with Alzheimer's, a serious mental health issue, or a long-term physical health problem experienced emotional distress related to providing care (AARP, 2015). Stress and burden felt by caregivers is exemplified in comparisons of caregivers and

noncaregivers; caregivers are more stressed, depressed, have lower levels of subjective well-being, and lower self-efficacy (or, the feeling one has control over their own life) than noncaregivers (Pinquart & Sörensen, 2003). Moreover, other studies report family caregivers feel sadness while providing care (Hammersmith & Lin, 2016).

Negative emotions experienced while providing care can follow caregivers into other daily activities. This is known as a **“spill over” effect**. Specifically, negative emotions experienced during caregiving can seep into other parts of life, like during leisure activities or while working (Bangerter, Liu, & Zarit, 2019; Stephen & Franks, 1995). Such spillover effects can lead to poorer health and well-being. In one study of **sandwiched caregivers** (those caring for children under 18 and an elderly family member, see pp. 25) exhibited lower self-acceptance and more negative affect when compared to other caregivers (Hodgdon & Wong, 2019).

As with physical health, issues pertaining to mental health often do not abate following **bereavement**, or the loss of a close loved one. Many caregivers experience **complicated grief disorder** (also called prolonged grief, traumatic grief, or unresolved grief). This is a condition in which painful emotions and intense sorrow surrounding bereavement are severe and last for such a long period of time that the bereaved have trouble moving on with their lives. About 20% of bereaved individuals experience complicated grief disorder and those who served as family caregivers are at greatest risk (Ghesquiere, Haidar, & Shear, 2011). Moreover, certain subgroups of caregivers are at an even greater risk of developing complicated grief disorder such as those who experience the sudden loss of a loved one, were very close to the deceased, or who already suffered from depression. Caregivers who have less family support, are young, report lower religiosity, have a low income and education, or are women also have a greater likelihood of developing complicated grief disorder, too (Ghesquiere et al., 2011).

Although some researchers suggest the experience of caregiving has negative ramifications for the mental health of care providers, there is a wealth of scholarship indicating the opposite (Brown & Brown, 2014; Roth, Fredman, & Haley, 2015). In one supporting study, e although 56% of caregivers reported some strain associated with caregiving, 44% reported they faced no strain at all (Schulz & Beach, 1999). In fact, as many as 83% of family caregivers feel positively about providing assistance to a loved one and sometimes reap benefits from care (National Opinion Research Center, 2014; Schulz & Sherwood, 2008). As described by some family caregivers, caregiving adds meaning to their lives, allows them to feel needed, teaches new skills, and strengthens their bond with the care recipient (Anderson & White, 2018; Bangerter, Griffin, Dunlay, 2018). In many cases, these benefits continue after the caregiving relationship has ended (Bangerter et al., 2018). However, there may be variation in the experiences of diverse caregivers. For instance, one study found women—particularly wives—and those who provide care for an aging parents may have more negative experiences overall (Lin, Fee, & Wu, 2012). It is critical to better understand why some family members derive meaning from providing care whereas others do not, especially as those who reflect positively on caregiving have better overall well-being and a lower risk of mortality (Fredman, Cauley, Hochberg, Ensrud, & Doros, 2011; Roth et al., 2015). More targeted interventions can be developed to assist caregivers who report particularly negative experiences.

Social Health

Social isolation can be a pervasive issue among care providers. Caregiving often requires assisting someone who is unable to leave their home or care facility. This suggests caregivers also spends few hours away from the home or care facility. Moreover, caregiving can be time consuming. Family caregivers report providing an average of 25 hours of care per week (AARP,

2015). Such schedules can leave care recipients with less time to spend with other family and friends (Pinquart & Sörensen, 2007) who might be crucial resources for reducing care-related burden (Bangerter et al., 2019; Choi et al., 2016). Social isolation can have serious ramifications on caregiver well-being. A lack of social support can be detrimental for family caregivers and a lack of social support can yield poorer overall health outcomes (Pinquart & Sörensen 2007).

Financial Consequences

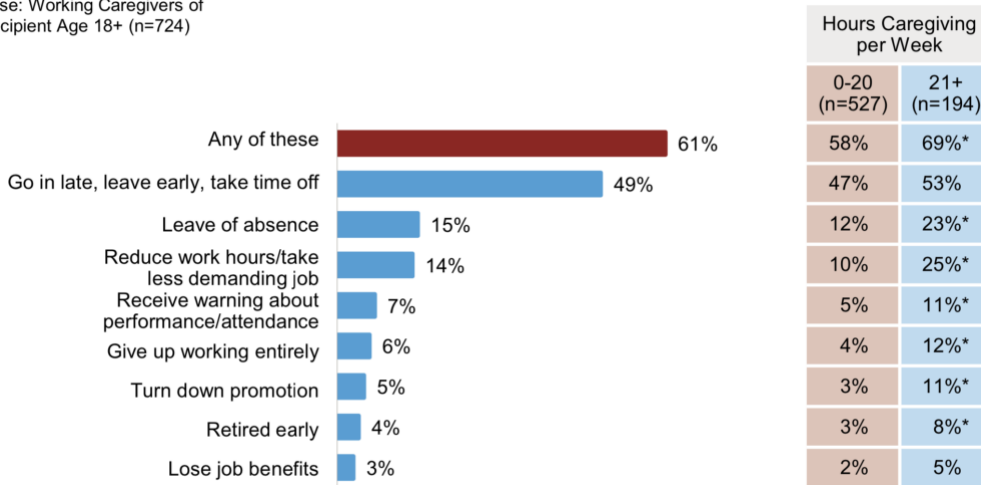
Family caregiving also comes with financial costs to the family caregiver. This is illustrated in Case Study 15.1 when Joanne's daughter Mary curtails her work hours to help care for her father, Clifford. Like Mary, many caregivers attempt to balance paid work and family caregiving and this trend is expected to continue in future decades (Feinberg & Choula, 2012; Haddock, Zimmerman, Lyness, & Ziembra, 2006; Lai, 2012). About 20% of family caregivers report financial strain due to caregiving (AARP, 2015). There are two principle ways in which family caregiving can have an economic impact on the caregiver. First, a caregiver may incur some of the expenses of providing care (Lai, 2012). Caregiving often requires medical supplies, non-prescription medications, transportation, and other expenditures that add up over time (Hollander, Liu, & Chappell, 2009; Lai, 2012). Most of these added costs are not covered by private insurance companies, leaving either the care recipient or caregiver to pay.

Second, caregivers may lose wages if they may need to rearrange their work schedules to accommodate care (Lai, 2012). Figure 12.2. shows the impact of family caregiving on workers. Almost half of all employed family caregivers have adjusted their work schedule to accommodate caregiving (AARP, 2015). Some caregivers may exit employment entirely depending on the extent of care needed. Figure 12.2 shows 6% of caregivers gave up employment and 4% of caregivers decided to retire early due to caregiving (AARP, 2015). The

effects of caregiving on the caregiver’s finances can be long-term. Studies show caregivers (particularly women) are more likely to experience poverty and a lower income later in life (Butrica & Karamcheva, 2014; Lee & Zurlo, 2014; Wakabayashi & Donato, 2006).

Figure 15.2 Work Impacts due to Caregiving

Base: Working Caregivers of Recipient Age 18+ (n=724)



Source: National Alliance for Caregiving and AARP, *Caregiving in the U.S., 2015*

Financial costs of family caregiving exist not only at the individual level, but also at the societal level. As mentioned earlier in this chapter, the economic cost of family caregiving in the United States is enormous. In 2017, it is estimated the value of family caregiving was equivalent to 470 billion dollars (Reinhard et al., 2019). Employers are also affected by family caregiving and likely suffer due to lost productivity when workers have to cut back their hours to make time for caregiving (Metropolitan Life Insurance Company, 1999).

Family Caregiving Challenges

Family caregivers and care recipients face many unique challenges. It is the responsibility of social workers to recognize these unique respond accordingly. Some of the most pertinent issues facing caregivers and recipients today are discussed below.

Socioeconomic Status

Unsurprisingly, family caregivers who classify themselves as low-income also report greater unmet need and often face unique struggles compared to higher income caregivers (Ho et al., 2000; Williams, Forbes, Mitchell, & Corbett, 2010). Specifically, low-income family caregivers may have more limited work flexibility with regards to changing schedules, missing work, or cutting back hours. This often leaves low-income family caregivers with an impossible choice between limiting the hours during which they can provide care (Lima, Allen, Goldscheider, Intrator, 2008), or risk losing one's job to make time to provide care. Moreover, these caregivers may have limited access to resources to ease the burden of caregiving and are more likely to report caregiver distress (Williams et al., 2010).

Age

There are often age differences in the experiences of family caregivers. Older caregivers may struggle to protect their own health, since older age is associated with increased prevalence of chronic illness and physical limitations. Family caregivers at midlife may also face unique struggles, such as role competition. These caregivers are much more likely to belong to the **sandwich generation**, or, are responsible for the care of a family member who is 65 or older and at least one child under 18 (Lima et al., 2008). This is a relatively common occurrence in the United States. Nearly 1/5 of family caregivers age 55 to 64-year-old also provide care to a child under 18 (AARP, 2015). Caregivers with competing role obligations often face more stress than other family caregivers (Pinquart & Sörensen, 2007).

Geographic Location

It is not uncommon for family caregivers to live in a different neighborhood or town from the care recipient, as families increasingly live spread out. In Case Study 12.1, Joanne had one child—Mary—who lived nearby and was able to step in to provide assistance. However, two of

Joanne's children could only provide limited help due to geographic distance. Although $\frac{3}{4}$ of caregivers live within 20 minutes of the care recipient, about 13% live 20 minutes to one hour away (Family Caregiver Alliance, 2019). One reason for this distance is many care recipients prefer to stay in their own home rather than move to a facility or to the caregiver's residence (Benefield & Beck, 2007). Long-distance caregivers face additional hurdles as travel creates a financial burden. Thus, family members try to employ solutions to reduce caregiver burden. For instance, siblings may use a rotating schedule to share care responsibilities. Other research suggests technology can alleviate stress related to long-distance caregiving (Benefield & Beck, 2007). Certain technologies could be used to connect the caregiver and recipient without travel. This way, the caregiver could address immediate concerns and issues experienced by the recipient while also reducing care burden (Benefield & Beck, 2007). Social networking could also be used to combat social isolation among care recipients and share crucial caregiving information to protect the recipient's health (Piraino, Byrne, Heckman, & Stolee, 2017). Practitioners should utilize new technology such as automated devices when possible to reduce caregiver burden (Benefield & Beck, 2007). Nonetheless, there is still room for more research on ways to better use technology to support family caregivers and recipients.

Living in a rural area is also quite common among older people. In fact, nearly $\frac{1}{4}$ of older adults live in an area classified as rural (Family Caregiver Alliance, 2019). Living in rural areas can limit resources older adults can use to meet their care needs (Monahan, 2013). Rural areas are also associated with a higher risk of poverty, poorer overall health, and more functional limitations among the aged (Administration on Aging, 2011; National Rural Health Care Association, 2002). Thus, family members often step in to provide care. Similarly, many family caregivers who live in rural areas or care for someone who lives in a rural area also struggle to

access supportive programs or resources (Ho et al., 2000). For example, certain social programs, such as transportation services, may not be available isolated areas of the United States.

Resources to support family caregivers are also in short supply even though evidence suggests these caregivers may have the greatest needs (Buckwalter & Davis, 2011; Monahan, 2013).

Specifically, studies indicate these family caregivers are often older on average and report poorer overall health (Buckwalter & Davis, 2011).

Parent-child Relationships

The relationship between the family caregiver and care recipient can present unique challenges. This is especially true in **intergenerational caregiving**, or when a member of one generation cares for someone in another generation. This is most often exemplified when adult children care for aging parents, similar to Case Study 12.1 in which Joanne's daughter, Mary, provides care for her father, Clifford. Research shows around age 75, elderly parents begin to receive more help from their adult children than they give (Spitze & Logan, 1992). Oftentimes, when an adult child provides care to an aging parent, they experience **role reversal**, in which they assume the role of caretaker for their parent, which is sometimes called, "parenting the parent" (Seltzer, 1990). The need to provide care to an aging parent often occurs quite slowly as parents experience gradual health declines over time (Kim, Bangerter, Liu, Polenick, Zarit, & Fingerman, 2017; Leopold, Raab, & Engelhardt, 2014). As the parent's health declines, their adult children may face increasing pressure and strain to assist their aging parent.

Caregiving can be rewarding and stressful for adult children. Providing care for parents can instill adult children with a sense of meaning through fulfillment of familial obligations (Pinquart & Sörensen, 2003; Raschick & Ingersoll-Dayton, 2004). However, providing care to an aging parent can lead to emotional, time, and financial burden. Some studies show although

caregiving can be rewarding, there are emotional consequences related to primary and secondary stressors. Primary stressors include difficulty coping with the care recipient's condition while secondary stressors are characterized by conflict related to caregiving (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). As aforementioned, these stressors can have negative consequences for the caregiver. Some studies find heightened depression among adult children who care for parents, with slightly greater consequences among daughters relative to sons (Amirkhanyan & Wolf, 2006; Bookwala, 2009; Coe & Van Houtven, 2009).

Caring for aging parents has consequences extending beyond those related to emotions or mental health. Caring for aging parents can create financial or time-related difficulties since children may feel obligated to provide care, even if their employment does not allow it. Caring for parents can be time consuming and spending more time caring for parents is linked to greater feelings of strain (Lin, Wu, & Fee, 2012; Verbakel, 2014). As mentioned above, some adult children belong to the sandwich generation, meaning they also care for their own children (under 18). Moreover, providing care for an aging parent can become especially challenging when the older adult has more than one adult child. Sometimes, children do not agree on the best course of care for the aging parent, which can foster conflict within families (Strawbridge & Wallhagen, 1991; Sutor, Gilligan, Johnson, & Pillemer, 2014). Another source of conflict can be inequitable distribution of care amongst siblings. For instance, daughters are much more likely to provide care to their aging parents (Silverstein, Gans, & Yang, 2006). It is unclear exactly why daughters provide more care than sons, although it is likely a combination of gender roles, disparities in wages or work hours, as well as caregiving attitudes (Silverstein et al., 2006).

Care Recipient Condition

Family caregivers provide assistance to older people with a multitude of illnesses, functional limitations, chronic conditions, and disabilities. Some recipient conditions can create diverse struggles for caregivers. Caregivers of those with Alzheimer's disease are often disadvantaged relative to other caregivers (Pinquart & Sörensen, 2003). Alzheimer's disease is currently the 6th leading cause of death in the United States and accounts for nearly 6% of deaths among people 65 and older (Heron, 2019). Nearly 70% of Alzheimer's patients still live at home (Alzheimer's Association, 2008), yet caregivers of individuals with Alzheimer's and other dementia-related diseases report this care as more stressful and time consuming (Schulz & Martire, 2004). This is because care recipients with Alzheimer's disease have a greater number of ADL limitations on average and are more likely to have behavioral problems including irritability, aggressiveness, or agitation (Bergvall, Brink, Eek, Gustavsson, Wimo, Winblad, & Jönsson, 2011). For caregivers, there are social consequences that come with caring for someone with Alzheimer's. These caregivers are more likely to report loss of free time and also have greater difficulty balancing work and caregiving obligations relative to others (Ory, Hoffman, & Yee, 1999). There are also health-related consequences. Caregivers of family members with Alzheimer's disease or other forms of dementia are more likely to experience fatigue, anger, social isolation, and depression relative to other family caregivers (Cox & Monk, 1993; Pinquart & Sörensen, 2003). Finally, providing care for someone with Alzheimer's is linked to greater financial burden relative to other types of care (Bergvall et al., 2011; Cox & Monk, 1993)

Recent work has also identified the unique struggles of people caring for individuals with **severe mental illness (SMI)** (Cummings & Kropf, 2015). Severe mental illness encompasses schizophrenia and schizophrenia-related disorders, bipolar disorder, personality disorders, and major recurrent depressive disorder, among others. Among caregivers of older adults with severe

mental illness, reported depressive symptoms were higher, no matter the amount of time the caregiver invested (Cummings & Kropf, 2015). As the incidence of Alzheimer's and other forms of dementia as well as severe mental illness grow in the United States, it is increasingly important to understand how to provide support to this group of caregivers.

Policy and Family Caregiving

There are a number of federal, state, and local policies that social workers and family caregivers can utilize to ease the burden associated with providing care. Medicaid and Medicare are two crucial federal programs that protect the health of older Americans. Historically, Medicare and Medicaid have not covered family caregiving costs despite one notable exception. In some circumstances of long-term care, Medicaid can be used to pay a family caregiver, although this is not common. In other circumstances, Medicaid dollars can be used for home and community-based services, such as respite care, which is a way to relieve caregiver duties for a short period of time (National Academies of Sciences, Engineering, & Medicine, 2016).

Other federal programs exist that more explicitly address the importance and needs of family caregivers. In 1965, Congress passed the *Older Americans Act*, geared toward providing home and community-based services to protect the health and well-being of older people nationwide (National Committee to Preserve Social Security and Medicare, 2018). Congress added to the *Older Americans Act* in 2000 by passing the National Family Caregiver Support Program (NFCSP), which recognized the importance of family caregivers as well as their need for support and resources (Feinberg & Newman, 2006; National Academies of Sciences, Engineering, & Medicine, 2016). Prior to the passage of NFCSP, only 7 states offered programs directed toward aiding family caregivers. After the NFCSP passed, all states were able to create and expand programs as well as resources directed toward family caregivers (Feinberg &

Newman, 2006; National Academies of Sciences, Engineering, & Medicine, 2016). Despite this progress, Feinberg & Newman (2006) report program and resource availability for family caregivers still remains disproportionate across all fifty states. In addition, there are other limitations to the NFCSP. Either the care recipient or caregiver must be 60 or older to receive assistance. Further, the allocation of funding for the NFCSP has stagnated in recent years despite steadily increasing numbers of older adults in the USA (Doty & Spillman, 2015).

Caregiving can come with consequences related to the caregiver's employment. Specifically, caregivers sometimes cut back work hours or even take a leave of absence to provide care (AARP, 2015). Policies like the federal government's *Family Medical Leave Act* (FMLA) were designed to assuage this burden. Enacted in 1993 under the Clinton administration, the FMLA provides up to 12 weeks of unpaid leave to employees who care for a sick child, parent, or spouse. Moreover, worker's jobs are protected while they are on leave (National Committee to Preserve Social Security and Medicare, 2018). Despite the benefits provided by FMLA, it is limited in scope in several key ways. First, caregivers are only covered if they provide care for a child, parent, or spouse. Families are increasingly complex in the USA and an older family member who needs care may not fit the parameters of family originally described by FMLA (National Committee to Preserve Social Security and Medicare, 2018). Second, estimates suggest fewer than 40% of workers in the United States are covered by FMLA because workers must work for their employer for at least a year and the employer/business must employ at least 50 people (National Committee to Preserve Social Security and Medicare, 2018).

These are not the only policies and programs providing assistance to family caregivers. In addition to these programs, support for caregivers and care recipients is available through the U.S. Department of Veteran's affairs, *Care, Advise, Record, Enable* (CARE) Acts (implemented

in 36 states), the National Alzheimer's Project Act, provisions in the Affordable Care Act (ACA), paid family leave acts (implemented in five states), other extensions of FMLA and other state and local efforts (National Academies of Sciences, Engineering, & Medicine, 2016).

Social Work Interventions

Caregiving can be a stressful and time-consuming obligation. Thus, a number of interventions exist with the principle goal of alleviating caregiver burden. This is critical because reducing burden is an integral part of preserving the caregiver's ability to provide high quality care to their loved one. Often caregiver interventions can be classified into two broad categories. Most caregiver interventions aim to either (1) reduce the hours spent providing care and enhance caregiver knowledge or (2) promote the caregiver's physical and emotional well-being (Sörensen, Pinguart, Habil, & Duberstein, 2002). In addition to fitting these two categories, care interventions tend to focus either on the individual or a group of caregivers. These varied features of care interventions showcase the how needs can vary across caregivers; care interventions are not a "one size fits all" model.

In fact, one group of scholars endeavored to classify the main types of care interventions (Sörensen, et al., 2002). **Psychoeducational care interventions** are quite common. These types of interventions provide caregivers with knowledge about the recipient's condition and how to respond to potential difficulties that may arise. For instance, if the care recipient has dementia, this type of intervention may educate the caregiver on how to deal with the recipient's dementia-related confusion, frustration, or anger. Psychoeducational interventions tend to be focused on the individual, although they can be supplemented with support groups (Sörensen, et al., 2002).

Psychotherapeutic care interventions are also occasionally used and involve building a relationship between a caregiver and a professional typically trained in cognitive behavioral

approaches. These professionals often teach the caregiver how to self-monitor their own behaviors as well as how to challenge negative thoughts and behaviors. The goal is to help the caregiver learn effective problem-solving strategies that are able to be tailored to the unique challenges of individual caregivers (Sörensen, et al., 2002; Sörensen, Duberstein, Gill, & Pinquart, 2006). Similar to psychoeducational care interventions, psychotherapy uses either individual or group-based intervention tactics (Sörensen et al., 2006).

A **supportive intervention** (also called **group intervention**) is another type of care intervention aimed at solving a problem. Supportive interventions often include informal support groups, which provide a space where caregivers can gather, build relationships with other caregivers, and discuss solutions to their care-related problems (Sörensen, et al., 2002). Content covered in these support groups can vary and tends to focus on the group's needs rather than issues specific to individuals within the support group. For instance, caregivers may share useful problem-solving techniques or coping strategies (Toseland, Rossiter, Peak, & Smith, 1990). These types of groups may be facilitated or led by peers or professionals. Similar to supportive or group interventions, **individual and family counseling programs** are effective at reducing caregiver stress and delaying institutionalization of the care recipient (Marriott et al., 2000; Mittelman et al., 1996; Whitlatch, Zarit, & von Eye, 1991; Zarit & Leitsch, 2001).

Respite care is another popular form of care intervention. In essence, respite care is temporary assistance that allows a family caregiver to step away from their caregiving obligations for a short period of time (Singleton, 2019). Respite care can come in the form of services like adult day care or overnight care relief. Respite care can be a life line for many caregivers. Studies of respite care provide evidence that appropriate use of respite services can stave off caregiver burnout, reduce stress, and protect caregiver well-being (Singleton, 2019;

Zarit, Bangerter, Liu, & Rovine, 2017; Zarit & Leitsch, 2001). **Adult day care** programs are a common form of respite care. Although similar to respite care, adult day care programs tend to incorporate activities, which enhance the experience for the care recipient in addition to relieving caregiver burden for the care provider (Sörensen, et al., 2002).

Although many interventions are focused on the caregiver, there are also interventions directed at the care recipient. One such type of intervention aims to increase care recipient competence. These can include memory care for dementia patients as well as activity therapy programs that can help maintain and increase the care recipient's physical functioning (sometimes combined with adult day care programs), (Sörensen, et al., 2002). It should also be mentioned care interventions do not always fit the aforementioned categories perfectly. For instance, some care interventions take a hybrid form, thus combining characteristics from two or more of the above interventions (Sörensen, et al., 2002).

Evaluation of Interventions

Just as there are many types of interventions geared at fulfilling the diverse needs of caregivers, the outcomes as well as effectiveness of these interventions can vary across caregivers with unique needs. Effects produced from interventions can vary with some resulting in specific outcomes (such as those aimed at caregiver training or problem solving) while others have non-specific results (for instance, psychotherapy). It is up to practitioners to help caregivers decide on an intervention that best suits their overall needs (Sörensen, et al., 2002). Overall, evaluations of various intervention methods show many are successful, providing positive effects that persist across about 7 months post-intervention (Sörensen, et al., 2002). Moreover, engaging in a single type of intervention method can be useful, researchers have found interventions tend to be most successful when combining several interventions at once (Sörensen, et al., 2002).

Existing evaluations have just scratched the surface in determining success of caregiving interventions. Even though recent research supports the benefits of caregiving interventions, it is crucial to further investigate how certain social groups may variably benefit from care interventions. For instance, spousal caregivers tend to benefit less from interventions than adult child caregivers. This might be attributable to a host of factors including a more intimate connection to caregiver for the spouse relative to the adult child. Such differences could also relate to financial challenges and poorer health coupled with limited social networks faced by spousal caregivers compared to adult children (Sörensen, et al., 2002). Similarly, certain care-related characteristics, like the recipient's condition, may link to intervention effectiveness. For instances, dementia caregivers notably face greater care challenges and also benefit less from existing interventions (Sörensen, et al., 2002). By determining which groups benefit less from existing interventions, we can work toward improving techniques to better serve all caregivers.

Limitations of Care Services and Interventions

There are some limitations to existing knowledge surrounding the implementation and measured effectiveness of various care-related services and interventions. When it comes to implementation, the main limitation of care interventions is the lack of use. Despite the existence of services geared toward assisting family caregivers, very few people actually utilize available assistance. Perhaps surprisingly, recent estimates suggest that only 1/4 of caregivers utilize any support services (Wolff, Spillman, Freedman, & Kasper, 2016). There are many reasons why programs and services might be underutilized such as a lack of knowledge of services, limited availability in one's own community, as well as a lack of flexibility and restrictive costs. Some solutions to the underutilization of support resources include implementing more coordination and outreach to be sure caregivers are aware of the resources available to them. Other ideas

include ensuring the flexibility of support resources and interventions to suit all circumstances and lifestyles of caregivers and care recipients (Zarit & Femia, 2008).

Successful implementation of care interventions may be influenced by the effectiveness of the intervention for the caregiver and recipient. There is scarce research on who actually benefits from care interventions. Many interventions are directed toward the care provider, however, it is unclear how often the intervention benefits extend to the care recipient as well (Zarit & Leitsch, 2001). Some limited evidence suggests individualized interventions tend to be most beneficial to the care providers whereas group interventions were most useful for improving conditions for the care recipient (Sörensen, et al., 2002). More research should be conducted with the intention of better understanding how various services and interventions are linked to care recipient outcomes and well-being.

Our knowledge surrounding effectiveness of existing services and interventions is also limited by who is surveyed, sampling mode, and the study duration. Often, studies of care interventions focus specific demographics of caregivers— in particular many studies rely on largely female and white respondents (Toseland, 1990; Toseland et al., 1990). However, the needs of family caregivers can vary widely on a host of demographic factors including socioeconomic, race, culture, and even needs of the care recipient. Programs created to support caregivers should reflect these variations. Researchers also suggest support resources be available in multiple formats (Schulz & Martire, 2004). Diversity in support resources may promote different, but equally effective therapeutic techniques that may target and alleviate multiple areas of caregiver stress or burden (Schulz & Martire, 2004; Zarit & Femia, 2008).

Many studies that examine the effectiveness of care interventions also use relatively small sample sizes. Small sample sizes make it challenging to assess whether a study's findings

would be applicable to the general population. Finally, the effectiveness of interventions may depend on the care recipient's condition. For example, caregivers of person's with Alzheimer's or other forms of dementia often face unique care challenges (Zarit & Leitsch, 2001).

Researchers and practitioners should work toward a better understanding of how effectiveness of particular interventions may vary based on the recipient's condition.

Evaluation mode also matters. Evaluation of care interventions that take place in person may be missing a subset of the caregiver population (Ploeg, Biehler, Willison, Hutchison, & Blythe, 2001; Salfi, Ploeg, & Black, 2005; Short & Saindon, 1998; Wilz & Soellner, 2016). This could be for several reasons including lack of effective transportation for themselves or their care recipient as well as time burdens and conflicts. More researchers and practitioners should assess the effectiveness of alternate approaches to interventions such as over the phone or in other virtual formats. Finally, many evaluations of current interventions focus on short-term benefits, but rarely examine if there are long-term benefits. Caregiving often involves a long-term commitment and therefore, difficulties associated with providing care might need long-term interventions (Toseland, 1990). Even if a care intervention looks promising in the short-term, we cannot know if the caregiver or recipient will reap any long-term benefits. Finally, many intervention programs focus on how to alleviate the negative consequences of providing care. However, as discussed above, there are a number of positive outcomes linked to family caregiving. Support programs should also work to promote these positive gains associated with family caregiving to enhance caregiver well-being (Cheng, Mak, Lau, Ng, & Lam, 2016).

Minority and Immigrant Populations

Care interventions are not one size fits all and there are myriad ways in which social workers can support minorities and immigrants who are family caregivers or are in need of care.

First, understanding cultural or social differences is essential. Hispanic and Asian Americans describe family caregiving through the lens of familism and filial piety, respectively (Scharlach et al., 2006). Thus, these caregivers may view caregiving as an obligation, and therefore may be less likely to seek out support programs or interventions. However, when assistance or interventions are offered, these caregivers may be more likely to take advantage of services (Cox & Monk, 1993). Similarly, many immigrant groups may have different norms surrounding family caregiving, thus, cultural competency training for social workers can be particularly useful. On the other hand, Native Americans are often wary of assistance provided by various programs and services due to a legacy of discrimination (Scharlach et al., 2006). Thus, it may be essential to build trust to spur service usage among Native Americans.

Second, developing awareness of obstacles faced by diverse families and how to tackle these dilemmas is critical. Some racial and ethnic groups in the United States have faced generations of discrimination and prejudice, which may affect interactions with programs and services. Native Americans distrust many governmental programs and services due to past discrimination and prejudice executed at the hands of government leaders (Scharlach et al., 2006). African Americans in the United States have experienced a legacy of institutionalized discrimination, which still seeps into our present-day society, creating inequality among African Americans in comparison to other minority groups. Such inequalities have led to an increased reliance on family systems (Franklin 1997; Dilworth-Anderson, 2005). Thus, more targeted interventions may be necessary to reach individuals in these groups.

Finally, it is noteworthy that what unites many minority groups together with regards to caregiving is a family-centered approach to care (Scharlach et al., 2006). In a study by Scharlach and colleagues (2006), when queried caregivers about potential programs to provide assistance,

many were more concerned about programs to support *care recipients* rather than themselves. However, in the United States, many programs and services are geared toward supporting individual caregivers— not the entire family. Thus, taking a more family-centered approach when either designing or even discussing programs and services may appeal more to minority and immigrant groups (Scharlach et al., 2006). Another potential solution to tackle could be to involve community members of different minority or immigrant groups in the creation of programs or services geared toward helping caregivers or care recipients. Moreover, existing programs and services geared toward helping family caregivers may benefit from community partnerships with another organization within the target community (Scharlach et al., 2006).

The LGBTQ Community

There are a number of ways social workers can support LGBTQ care recipients or those who provide them with care. One way can be to expand program services and provide targeted services geared toward meeting the unique needs of the LGBTQ population (Shiu et al., 2016). Through targeted services, social workers can help LGBTQ older adults and their family members understand types of assistance available to them. Moreover, social workers can provide caregivers with resources and counsel to support their own sensitivity toward the unique circumstances needs of an LGBTQ care recipient, such as hesitance or even fearfulness of discrimination in doctor's offices or at other medical appointments (Valenti & Katz, 2014).

Agencies can increase the cultural competency of their workers through cultural competency training (Fredriksen-Goldsen et al., 2014). Such trainings are valuable for many reasons. First, competency trainings can help social workers critically examine their own biases and preconceived notions of the LGBTQ community (Washington et al., 2015). Second, mastering cultural competency training can unearth how today's society is structured to

disadvantage sexual minorities. By understanding such structural barriers, social workers can work toward better assisting the LGBTQ community. Finally, such trainings are invaluable for helping social workers identify important differences between marginalized groups and the majority group. For instance, the needs of a heterosexual, transgender older adult may differ from their bisexual, cisgender counterparts.

Chapter Summary

Family caregiving fulfills an essential role in protecting older people in the United States. Many older people rely on support of family caregivers to help with everyday limitations. Caregivers devote many hours to providing care for their loved ones. Although this care can come with certain rewards, it is often performed at the expense of one's physical, emotional, social, and financial well-being. As a society, we have made strides to support family caregivers, but more attention should be paid to how to best enhance the well-being of those who provide care. This will be especially pertinent as the United States faces care-related challenges in the coming years. Most pressingly, it is expected the population of people ages 65 and older will double between 2000 and 2030 (Talley & Crews, 2007). Similar population growth is not expected for younger age groups as families become smaller and more adults choose to be childless. Although not all older adults over 65 will need care, this still means a number of people will need care while there will be a smaller number of people able to provide care. Lastly, as aforementioned, women do the bulk of caregiving. Yet, over the decades, female labor force involvement has grown steadily. Along with this, many women outearn their husbands, making them the primary breadwinner (Murray-Close & Heggeness, 2018). This may leave women with limited time to provide care to aging family members. Thus, it is essential to support family caregivers and their care recipients to make family caregiving more sustainable in the future.

Review Questions

1. Which of the following is true about family caregivers?
 - a. Family caregivers are most commonly in their 30s.
 - b. Family caregivers are typically financially compensated for providing care.
 - c. Family caregivers are more likely to be woman than men.
 - d. All of these are true.
2. The caregiver support ratio refers to:
 - a. The number of potential caregivers aged 45–64 for each person aged 80 and older.
 - b. The number of actual caregivers aged 45–64 for each person aged 80 and older.
 - c. The number of potential caregivers aged 18–64 for each person aged 65 and older.
 - d. The number of potential caregivers aged 18–64 for each person aged 80 and older.
3. The sandwich generation refers to:
 - a. A caregiver who is caring for two or more people who are over the age of 65.
 - b. A caregiver who balances paid employment and caring for an aging family member.
 - c. A caregiver who is caring for an older loved one and a child under the age of 18.
 - d. A caregiver who faces their own health problems while caring for an older adult.
4. Caregiving can be positive and negative for the caregivers. Describe some of the negative consequences encountered by individuals who provide care to an older relative.
5. What types of policy, interventions, and services are available for caregivers? If you were a policymaker, what do you think would be a useful policy or intervention to implement to help caregivers or care recipients?
6. Based on what you've learned in this chapter, describe what you think the biggest issues in family caregiving will be in the coming decade.

References

- AARP Public Policy Institute. (2015). *Caregiver profile: The typical caregiver*. Washington, DC: National Alliance for Caregiving.
- Administration on Aging. (2011). A profile of older Americans, 2011: Geographic distribution. Retrieved from http://www.aoa.gov/AoARoot/Aging_Statistics/Profile/2011/8.aspx
- Alzheimer's Association. (2008). *Alzheimer's disease: Facts and figures*. Retrieved from: www.alz.org
- Amirkhanyan, A. A., & Wolf, D. A. (2006). Parent care and the stress process: Findings from panel data. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 61(5), S248-S255. 10.1093/geronb/61.5.S248
- Anderson, J. G., & Flatt, J. D. (2018). Characteristics of LGBT caregivers of older adults: Results from the national caregiving in the U.S. 2015 survey. *Journal of Gay and Lesbian Social Services*, 30(2), 103-116. [10.1080/10538720.2018.1440681](https://doi.org/10.1080/10538720.2018.1440681)
- Anderson, E. W., & White, K. M. (2018). "It has changed my life": An exploration of caregiver experiences in serious illness. *The American Journal of Hospice and Palliative Care*, 35(2), 266-274. 10.1177/1049909117701895.
- Aneshensel, C. S., Pearlin, L. I., Mullan, J. T., Zarit, S. H., & Whitlatch, C. J. (1995). *Profiles in caregiving: The unexpected career*. San Diego, CA: Academic Press Inc.
- Bangerter, L. R., Griffin, J. M., & Dunlay, S. M. (2018). Positive experiences and self-gain among family caregivers of persons with heart failure. *The Gerontologist*, 59(5), e433-e440. 10.1093/geront/gny162

- Bangerter, L. R., Liu, Y., & Zarit, S. H. (2019). Longitudinal trajectories of subjective care stressors: The role of personal, dyadic, and family resources. *Aging & Mental Health*, 23(2), 255–262. 10.1080/13607863.2017.1402292
- Baumle A.K. (2014). Same-sex cohabiting elders versus different-sex cohabiting and married elders: Effects of relationship status and sex of partner on economic and health outcomes. *Social Science Research*. 43: 60–73. [10.1016/j.ssresearch.2013.09.003](https://doi.org/10.1016/j.ssresearch.2013.09.003).
- Beauchamp, D., Skinner, J., & Wiggins, P. (2003). *LGBTQ persons in Chicago: Growing older. A survey of needs and perceptions*. Chicago, IL: Chicago Task Force on LGBTQ Aging.
- Benefield, L. E., & Beck, C. (2007). Reducing the distance in distance-caregiving by technology innovation. *Clinical Interventions in Aging*, 2(2), 267-272.
- Bergvall, N., Brinck, P., Eek, D., Gustavsson, A., Wimo, A., Winblad, B., & Jönsson, L. (2011). Relative importance of patient disease indicators on informal care and caregiver burden in Alzheimer's disease. *International Psychogeriatrics*, 23(1), 73–85.
10.1017/S1041610210000785
- Bookwala, J. (2009). The impact of parent care on marital quality and well-being in adult daughters and sons. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 64B(3), 339-347. 10.1093/geronb/gbp018.
- Brennan-Ing, M., Seidel, L., Larson, B., & Karpiak, S. E. (2014). Social care networks and older LGBT adults: Challenges for the future. *Journal of Homosexuality*, 61(1), 21–52.
10.1080/00918369.2013.835235
- Brown, M. R., & Brown, S. L. (2014). Informal caregiving: A reappraisal of the effects on caregivers. *Social Issues and Policy Review*, 8(1), 74–102. doi:10.1111/sipr.12002

- Buckwalter, K. C., & Davis, L. L. (2011). Elder caregiving in rural communities. In R. C. Talley, K. Chwalisz, & K. C. Buckwalter (Eds.), *Rural caregiving in the United States* (pp. 33–46). New York, NY: Springer.
- Butrica B., & Karamcheva N. (April 8, 2015). *The impact of informal caregiving on older adults' labor supply and economic resources*. Washington, DC: U.S. Department of Labor; 2014. Retrieved from: <http://www.dol.gov/ebsa/pdf/impactofinformalcaregivingonolderadults.pdf>.
- Chen, C., & J. L. Zissimopoulos. (2018). Racial and ethnic differences in trends in dementia prevalence and risk factors in the United States. *Alzheimer's & Dementia: Translational Research & Clinical Intervention*, 4, 510-520. 10.1016/j.trci.2018.08.009
- Choi, K., Choi, D. R., Zang, D. Y., Park, Y. S., Kang, S. Y., Yoon, H., Lim, Y. O., Kim, Y. Nam, I., & Lee, H. J. (2016). Moderating effects of optimism and family support on the depression of family caregivers of cancer patients. *Korean Journal of Health Promotion*, 16(3), 192–202. 10.15384/kjhp.2016.16.3.192
- Coe, N. B., & Van Houtven, C. H. (2009). Caring for mom and neglecting yourself? The health effects of caring for an elderly parent. *Health Economics*, 18(9), 991-1010. 10.1002/hec.1512
- Cox, C., & Monk, A. (1993). Hispanic culture and family care of Alzheimer's patients. *Health & Social Work*, 18(2), 92–100. 10.1093/hsw/18.2.92
- Crossman, L., London, C., & Barry, C. (1981). Older women caring for disabled spouses: A model for supportive services. *Gerontologist*, 21(5), 464-70. [10.1093/geront/21.5.464](https://doi.org/10.1093/geront/21.5.464)

- Cummings, S. M., & Kropf, N. P. (2015). Predictors of depression among caregivers of older adults with severe mental illness. *Journal of Gerontological Social Work, 58*(3), 253–271. 10.1080/01634372.2014.978927
- Dilworth-Anderson, P., Goodwin, P. Y., & Williams, S. W. (2004). Can Culture help explain the physical health effects of caregiving over time among African American caregivers? *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 59*(3), S138–S145. 10.1093/geronb/59.3.S138
- Dilworth-Anderson, Peggye, Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of race on cultural justifications for caregiving. *The Journals of Gerontology: Series B, 60*(5), S257–S262. 10.1093/geronb/60.5.S257.
- Doty, P., & Spillman, B. (2015). Help for family caregivers available from government policies and programs. In J. E. Gaugler & R. L Kane (Eds.), *Family caregiving in the new normal* (pp. 153-192). Netherlands: Elsevier Science. 10.1016/B978-0-12-417046-9.00001-5
- Dykstra, P. A., van Tilburg, T. G., & de Jong Gierveld, J. (2005). Changes in older adult loneliness. *Research on Aging, 27*, 725-747. doi:10.1177/0164027505279712
- Epps, F. (2014). The relationship between family obligation and religiosity on caregiving. *Geriatric Nursing, 35*(2), 126–131. doi:10.1016/j.gerinurse.2013.11.003
- Family Caregiver Alliance. (2019). Caregiver Statistics: Demographics. Retrieved from: <https://www.caregiver.org/caregiver-statistics-demographics>
- Family Caregiver Alliance. (n.d.). Caregiver statistics: work and caregiving. Retrieved from: <https://www.caregiver.org/caregiver-statistics-work-and-caregiving>
- Family Caregiver Alliance. (n.d.). Special concerns of LGBT caregivers. Retrieved from: <https://www.caregiver.org/special-concerns-lgbt-caregivers>

- Feinberg, L. F., & Choula, R. (2012, October). Understanding the impact of family caregiving on work. Retrieved from: https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/understanding-impact-family-caregiving-work-AARP-ppi-ltc.pdf
- Feinberg, L. F., & Newman, S. L. (2006). Preliminary experiences of the states in implementing the National Family Caregiver Support Program: A 50-state study. *Journal of Aging and Social Policy, 18*(3-4), 95-113. 10.1300/J031v18n03_07
- Franklin, D. (1997). Ensuring inequality: The structural transformation of the African-American family. New York, NY: Oxford University Press.
10.1093/acprof:oso/9780199374878.001.0001
- Fredman, L., Cauley, J. A., Hochberg, M., Ensrud, K. E., & Doros, G. (2010). Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: Results of caregiver-study of osteoporotic fractures. *Journal of the American Geriatrics Society, 58*(5), 937– 943. 10.1111/j.1532-5415.2010.02808.x.
- Fredriksen-Goldsen, K. I., Emler, C. A., Kim, H.-J., Muraco, A., Erosheva, E. A., Goldsen, J., & Hoy-Ellis, C. P. (2013). The physical and mental health of lesbian, gay male and bisexual (LGB) older adults: The role of key health indicators and risk and protective factors. *The Gerontologist, 53*(4), 664-675. Editors' Choice. doi:10.1093/geront/gns123
- Fredriksen-Goldsen, K. I., Hoy-Ellis, C. P., Goldsen, J., Emler, C. A., & Hooyman, N. R. (2014). Creating a vision for the future: Key competencies and strategies for culturally competent practice with lesbian, gay, bisexual, and transgender (LGBT) older adults in the health and human services. *Journal of Gerontological Social Work, 57*(2–4), 80–107.
10.1080/01634372.2014.890690

- Fredriksen-Goldsen K. I., Kim, H.-J., Barkan, S. E., Muraco, A., & Hoy-Ellis, C. P. (2013). Health disparities among lesbian, gay, and bisexual older adults: Results from a population-based study. *American Journal of Public Health, 103*(10), 1802-1809. doi:10.2105/AJPH.2012.301110
- Ghesquiere, A., Martí Haidar, Y. M., & Shear, M. K. (2011). Risks for complicated grief in family caregivers. *Journal of Social Work in End-Of-Life & Palliative Care, 7*(2-3), 216-240. 10.1080/15524256.2011.593158
- Haddock, S. A., Zimmerman, T. S., Lyness, K. P., & Ziemia, S. J. (2006). Practices of dual earner couples successfully balancing work and family. *Journal of Family and Economic Issues, 27*, 207-234. 10.1007/s10834-006-9014-y
- Haley, W. E., West, C. A., Wadley, V. G., Ford, G. R., White, F. A., Barrett, J. J., et al. (1995). Psychological, social, and health impact of caregiving: A comparison of black and white dementia family caregivers and noncaregivers. *Psychology and Aging, 10*, 540-552.
- Hammersmith, A. M., & Lin, I.-F. (2016). Evaluative and experienced well-being of caregivers of parents and caregivers of children. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 74*(2), 339-352. 10.1093/geronb/gbw065
- Heron, M. Deaths: Leading causes for 2017. National Vital Statistics Reports; vol 68 no 6. Hyattsville, MD: National Center for Health Statistics. 2019.
- Ho, C. J., Weitzman, P. F., Cui, X., & Levkoff, S. E. (2000). Stress and service use among minority caregivers to elders with dementia. *Journal of Gerontological Social Work, 33*(1), 67-88. 10.1300/J083v33n01_06

- Hodgdon, B. T., & Wong, J. D. (2019). Influences of work and family spillover on filial and sandwiched caregivers' psychological well-being. *The International Journal of Aging and Human Development, 0*, 1-18. 10.1177/0091415019893369
- Hollander, M. J., Liu, G., & Chappell, N. L. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly, 12*(2), 42-49. 10.12927/hcq.2009.20660
- Jagger, C., & Sutton, C. J. (1991). Death after marital bereavement- Is the risk increased? *Statistics in Medicine, 10*(3), 395-404. 10.1002/sim.4780100311
- Janevic, M. R., & Connell, C. M. (2001). Racial, ethnic, and cultural differences in the dementia caregiving experience: recent findings. *The Gerontologist, 41*(3), 14. 10.1093/geront/41.3.334.
- Karpiak, S. E., & Brennan-Ing, M. (2016). Aging with HIV: The challenges of providing care and social supports. *Generations, 40*(2), 23-25.
- Kim, K., Bangerter, L. R., Liu, Y., Polenick, C., Zarit, S., & Fingerman, K. (2017). Middle-aged offspring's support to aging parents with emerging disability. *The Gerontologist, 57*(3), 441-450. 10.1093/geront/gnv686
- Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated sociocultural stress and coping model. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 65B*(1), 5-13. 10.1093/geronb/gbp096
- Knochel, K. A., Quam, J. K., & Croghan, C. F. (2011). Are Old lesbian and gay people well served?: Understanding the perceptions, preparation, and experiences of aging services

- providers. *Journal of Applied Gerontology*, 30(3), 370–389.
10.1177/0733464810369809
- Lai, D. W. L. (2012). Effect of financial costs on caregiving burden of family caregivers of older adults. *SAGE Open*, 2(4), 1-14. 10.1177/2158244012470467
- Lee Y., & Zurlo K. A. (2014). Spousal caregiving and financial strain among middle-aged and older adults. *International Journal of Human Development*, 79(4), 302–321.
10.1177/0091415015574181
- Leopold, T., Raab, M., & Engelhardt, H. (2014). The transition to parent care: Costs, commitments, and caregiver selection among children. *Journal of Marriage and Family*, 76(2), 300–318. doi:10.1111/jomf.12099
- Lima, J. C., Allen, S. M., Goldscheider, F., & Intrator, O. (2008). Spousal caregiving in late midlife versus older ages: implications of work and family obligations. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 63(4), S229–S238.
10.1093/geronb/63.4.S229
- Lin, I.-F., Fee, H., & Wu, H.-S. (2012). Negative and positive caregiver experiences: A closer look at the intersection of gender and relationships. *Family Relations*, 61(2), 343-358.
10.1111/j.1741-3729.2011.00692.x
- Linsk, N. L. (2000). HIV among older adults: Age-specific issues in prevention and treatment. *AIDS Reader*, 10(7), 430–440.
- Liu, D., Hinton, L., Tran, C., Hinton, D., & Barker, J. C. (2008). Re-examining the relationships among dementia, stigma, and aging in immigrant Chinese and Vietnamese family caregivers. *Journal of Cross-Cultural Gerontology*, 23(3), 283-299. 10.1007/s10823-008-9075-5

- Liu, K., McBride, T., & Coughlin, T. (1994). "Risk of entering nursing homes for long versus short stays." *Med Care*, 32(4), 315-327. doi: 10.1097/00005650-199404000-00001.
- Marriott, A., Donaldson, C., Tarrier, N., & Burns, A. (2000). Effectiveness of cognitive-behavioral family intervention in reducing the burden of carers of patients with Alzheimer's disease. *British Journal of Psychiatry*, 176, 557–562. 10.1192/bjp.176.6.557
- McLennon, S. M., Anderson, J. G., Epps, F., & Rose, K. M. (2020). "It's just part of life": African American daughters caring for parents with dementia." *Journal of Women & Aging*, 32(2), 168-182. 10.1080/08952841.2018.1547002
- Meeks, S. (2020). Common themes for im/migration and aging: Social ties, cultural obligations, and intersectional challenges. *The Gerontologist*, 60(2), 215-218. 10.1093/geront/gnz193
- Metropolitan Life Insurance Company. (1999). *The MetLife Juggling Act Study: Balancing caregiving with work and the costs involved*. Westport, CT: Author.
- Mittelman, M.S., Ferris, S.H., Shulman, E., Steinberg, G., Ambinder, A., Mackell, J., & Cohen, J. (1995). A comprehensive support program: Effect on depression in spouse-caregivers of AD patients. *The Gerontologist*, 35, 792–802. [10.1093/geront/35.6.792](https://doi.org/10.1093/geront/35.6.792)
- Monahan, D. J. (2013). Family caregivers for seniors in rural areas. *Journal of Family Social Work*, 16(1), 116-128. 10.1080/10522158.2012.747461
- Moore, W. R. (2002). Lesbian and gay elders: Connecting care providers through a telephone support group. *Journal of Gay & Lesbian Social Services*, 14(3), 23–41. 10.1300/J041v14n03_02
- Murray-Close, M., & Heggeness, M. L. (2018). *Manning up and womaning down: How husbands report their earnings when she earns more (SESHD Working Paper 2018-20)*. Washington, D.C.: United States Census Bureau. Retrieved from:

<https://www.census.gov/content/dam/Census/library/working-papers/2018/demo/SEHSD-WP2018-20.pdf>

National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for aging America*. Washington, DC: The National Academies Press. 10.17226/23606

National Committee to Preserve Social Security & Medicare. (2018, October 3). *Older Americans Act*. Retrieved from: <https://www.ncpssm.org/documents/older-americans-policy-papers/older-americans-act/>

National Immigration Forum. (21 August 2018). Fact Sheet: Immigrants and Public Benefits. Retrieved from: <https://immigrationforum.org/article/fact-sheet-immigrants-and-public-benefits/>.

National Opinion Research Center. (2014, May). Long term care in America: Expectations and realities. Retrieved from http://www.longtermcarepoll.org/PDFs/LTC%202014/AP-NORC-Long-Term%20Care%20in%20America_FINAL%20WEB.pdf

National Rural Health Care Association. (2002). *Setting the pace for rural elder care: A framework for action*. Alexandria, VA. Retrieved from <http://pace.techriver.net/website/download.asp?id=575>

Navaie-Waliser, M., Feldman P. H., Gould, D. A., Levine, C. Kuebris, A. N., & Donelan, K. (2002). "When the caregiver needs care: The plight of vulnerable caregivers. *American Journal of Public Health*, 92(3), 409-413. 10.2105/ajph.92.3.409

Neufeld, A., Harrison, M. J., Stewart, M. J., Hughes, K. D., & Spitzer, D. (2002). Immigrant women: Making connections to community resources for support in family caregiving. *Qualitative Health Research*, 12(6), 751-768. 10.1177/ 104973230201200603

- Ory, M.G., Hoffman R.R., Yee, J. L., & Tennstedt, S., & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *The Gerontologist*, *39*(2), 177-185. 10.1093/geront/39.2.177
- Pharr, J. R., Douglas, C. D., Terry, C., & Clark, M. C. (2014). Culture, caregiving, and health: Exploring the influence of culture on family caregiver experiences. *ISRN Public Health*. <http://dx.doi.org/10.1155/2014/689826>
- Pinquart, M., & Sörensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, *62*(2), P126–P137. 10.1093/geronb/62.2.P126
- Pinquart, Martin, & Sörensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, *18*(2), 250–267. 10.1037/0882-7974.18.2.250
- Pinquart, Martin, & Sörensen, S. (2005). Ethnic differences in stressors, resources, and psychological outcomes of family caregiving: a meta-analysis. *The Gerontologist*, *45*(1), 90–106. 10.1093/geront/45.1.90
- Piraino, E, Byrne, K, Heckman, G. A., & Stolee, P. (2017). Caring in the information age: Personal online networks to improve caregiver support. *Canadian Geriatrics Journal*, *20*(2), 85-93. 10.5770/cgj.20.271
- Raschick, M., & Ingersoll-Dayton, B. (2004). The costs and rewards of caregiving among aging spouses and adult children. *Family Relations*, *53*(3), 317–325. 10.1111/j.0022-2445.2004.0008.x

- Raveis, V. H. (2000). Facilitating older spouses' adjustment to widowhood: a preventive intervention program. *Social Work in Health Care, 29*(4), 13–32.
10.1300/J010v29n04_02
- Redfoot, D., Feinberg, L., & Houser, A. (2013). The aging of the Baby Boom and the growing care gap: A look at future declines in the availability of family caregivers. Retrieved from: https://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2013/baby-boom-and-the-growing-care-gap-insight-AARP-ppi-ltc.pdf
- Reinhard, S. C., Feinberg, L. F., Houser, R., Choula, R., & Evans, M. (2019, November). *Insight on the Issues: Valuing the Invaluable 2019 Update: Charting the path forward*. Retrieved from: <https://www.aarp.org/content/dam/aarp/ppi/2019/11/valuing-the-invaluable-2019-update-charting-a-path-forward.doi.10.26419-2Fppi.00082.001.pdf>
- Roff, L. L., Burgio, L. D., Gitlin, L., Nichols, L., Chaplin, W., & Hardin, J. M. (2004). Positive aspects of alzheimer's caregiving: The role of race. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences, 59*(4), P185–P190.
10.1093/geronb/59.4.P185
- Roth, D. L., Fredman, L., & Haley, W. E. (2015). Informal Caregiving and its impact on health: a reappraisal from population-based studies. *The Gerontologist, 55*(2), 309–319.
10.1093/geront/gnu177
- Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006). Cultural attitudes and caregiver service use: Lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work, 47*(1–2), 133–156. 10.1300/J083v47n01_09

- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*, 282(23), 2215. 10.1001/jama.282.23.2215
- Schulz, R., & Martire, L. M. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, 12(3), 240-249. 10.1097/00019442-200405000-00002
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, 108(9), 23-27. 10.1097/01.NAJ.0000336406.45248.4c
- Seltzer, M. M. (1990). Role reversal: You don't go home again. *Journal of Gerontological Social Work*, 15(1-2), pp. 5-14. 10.1300/J083v15n01_03
- Shippy, R. A., & Karpiak, S. E. (2005). The HIV/AIDS population: Fragile social networks. *Aging and Mental Health*, 3(9), 246-254. 10.1080/13607860412331336850
- Shiu, C., Muraco, A., & Fredriksen-Goldsen, K. (2016). Invisible care: Friend and partner care among older lesbian, gay, bisexual, and transgender (LGBT) adults. *Journal of the Society for Social Work and Research*, 7(3), 527–546. 10.1086/687325
- Silverstein, M., Gans, D., & Yang, F. M. (2006). Intergenerational support to aging parents: The role of norms and needs. *Journal of Family Issues*, 27(8), 1068-1084.
10.1177/0192513X06288120
- Singleton, A. (2019, September 11). *Time off for caregivers can be invaluable*. Retrieved from:
<https://www.aarp.org/caregiving/home-care/info-2019/respice-care.html>
- Smith, S. M., Soubhi, H., Fortin, M., & Hudon, C. (2012). Managing patients with multimorbidity: Systematic review of interventions in primary care and community settings. *BMJ*, 345.

- Sörensen, S., Pinguart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356-372.
10.1093/geront/42.3.356
- Sörensen, S., Duberstein, P., Gill, D., & Pinguart, M. (2006). Dementia care: Mental health effects, intervention strategies, and clinical interpretations. *Lancet Neurology*, 5(11), 961-973. 10.1016/S1474-4422(06)70599-3
- Spitze, G., & Logan, J. R. (1992). Helping as a component of parent-adult child relations. *Research on Aging*, 14(3), 291-312. 10.1177/0164027592143001
- Stephens, M. A., & Franks, M. M. (1995). Spillover between daughters' roles as caregiver and wife: Interference or enhancement? *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 50(1), P9–P17. 10.1093/geronb/50b.1.p9
- Strawbridge, W.J., Wallhagen, M.I. (1991). Impact of family conflict on adult child caregivers. *The Gerontologist*, 31(6), 770-777 [10.1093/geront/31.6.770](https://doi.org/10.1093/geront/31.6.770)
- Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health*, 97(2), 224–228. 10.2105/AJPH.2004.059337
- Toseland, R. W., Rossiter, C. M., Peak, T., & Smith, G. C. (1990). Comparative effectiveness of individual and group interventions to support family caregivers. *Social Work*, 35(3), 209-217. [10.1093/sw/35.3.209](https://doi.org/10.1093/sw/35.3.209)
- Valenti, K., & Katz, A. (2014). Needs and perceptions of LGBTQ caregivers: The challenges of services and support. *Journal of Gay & Lesbian Social Services*, 26(1), 70–90.
10.1080/10538720.2013.865575

- Verbakel, E. (2014). Informal caregiving and well-being in Europe: What can ease the negative consequences for caregivers. *Journal of European Social Policy*, 24(5), 424–441.
10.1177/0958928714543902
- Vespa, J. (2018, March 13). *The graying of America: More older adults than kids by 2035*. Retrieved from: <https://www.census.gov/library/stories/2018/03/graying-america.html>
- Wakabayashi C., & Donato K.M. (2006). Does caregiving increase poverty among women in later life? Evidence from the Health and Retirement Survey. *Journal of Health and Social Behavior*, 47(3), 258–274. 10.1177/002214650604700305.
- Washington K.T., McElroy J., Albright D., Oliver D.P., Lewis A., Meadows S., & Elliott S. (2015). Experiences of sexual and gender minorities caring for adults with non-AIDS-related chronic illnesses. *Social Work Research*, 39(2), 71–81.
<http://dx.doi.org/10.1093/swr/svu030>.
- Whitlatch, C. J., Zarit, S. H., & von Eye, A. (1991). Efficacy of interventions with caregivers: A reanalysis. *The Gerontologist*, 31, 9–14. [0.1093/geront/31.1.9](https://doi.org/10.1093/geront/31.1.9)
- Williams, A., Forbes, D., Mitchell, J., & Corbett, B. (2010). The influence of income on the experience of informal caregiving: Policy implications. *Health Care for Women International*, 24(4), 280-291. 10.1080/07399330390183606.
- Wolff, J. L., Spillman, B. C., Freedman, V. A., & Kasper, J. D. (2016). A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine*, 176(3), 372. 10.1001/jamainternmed.2015.7664
- Zarit, S. H., Bangerter, L. R., Liu, Y., & Rovine, M. J. (2017). Exploring the benefits of respite services to family caregivers: Methodological issues and current findings. *Aging & Mental Health*, 21(3), 224–231. 10.1080/13607863.2015.1128881

Zarit, S., & Femia, E. (2008). Behavioral and psychosocial interventions for family caregivers.

Journal of Social Work Education, 44(3), 49-57.

Zarit, S. H., & Leitsch, S. A. (2001). Developing and evaluating community-based intervention

programs for Alzheimer's patients and their caregivers. *Aging and Mental Health,*

5(Suppl. 1), S86–S100. 10.1080/13607860120044864

Additional Web Resources

A Day in the Life of a Caregiver

https://www.youtube.com/watch?v=bs_7jWqSeIM

A Guide to Caring for Elderly Parents

<https://www.aginginplace.org/a-guide-to-caring-for-elderly-parents/>

AARP Caregiver resources in Spanish

<https://www.aarp.org/espanol/recursos-para-el-cuidado/>

AARP's Prepare to Care Guide

<https://www.aarp.org/caregiving/prepare-to-care-planning-guide/?intcmp=AE-CAR-BB LL1>

Advocacy Starts at Home: Strengthening Supports for Low-Income Family Caregivers

https://www.justiceinaging.org/wp-content/uploads/2016/02/FINALAdvocacy-Starts-at-Home_Strengthening-Supports-for-Low-Income-Adults-and-Family-Caregivers.pdf

Alzheimer's Association

<https://www.alz.org>

As more Boomers enter old age, who will care for us?

<https://www.forbes.com/sites/jodygastfriend/2018/08/10/caregiver-shortage-who-will-care-for-us/#136cef3c532d>

Caregiving in the US: 2015 Report

https://www.caregiving.org/wp-content/uploads/2015/05/2015_CaregivingintheUS_Final-Report-June-4_WEB.pdf

Caregiving across the States: 50 State Profiles

<https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

Caregiver Fact and Tips Sheets

<https://www.caregiver.org/fact-sheets>

Caregiving for Older Family Members

<https://www.pewsocialtrends.org/2013/01/30/caregiving-for-older-family-members/>

Caregiving Research and Reports

<https://www.caregiver.org/research-and-reports>

Caregiving Resources by Health Condition

<https://www.caregiver.org/resources-health-issue-or-condition>

Caregivers and Technology: What they Want and Need

https://www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2018/caregivers-technology-needs.doi.10.26419-2Fres.00191.002.pdf

Caring for Mom and Dad, PBS (resources)

<https://www.pbs.org/wgbh/caringformomanddad/resources/index.html>

Caring for Mom and Dad, PBS (full documentary)

<https://www.pbs.org/wgbh/caringformomanddad/index.html>

Caring for the Caregivers

<https://www.youtube.com/watch?v=duhJHedj82g>

Caring for your Parents: Caring for the Caregiver, PBS

<https://www.pbs.org/wgbh/caringforyourparents/handbook/caringcaregiver/whycaregivers.html>

Coping with Caregiver Stress and Burden

<https://www.apa.org/pi/about/publications/caregivers/practice-settings/assessment/tools/stress-burden>

Definitions (of caregiving terms)

<https://www.caregiver.org/definitions-0>

Discovering the True Cost of At-Home Caregiving

<https://www.npr.org/2012/05/01/151472617/discovering-the-true-cost-of-at-home-caregiving>

Emerging Technology to Support an Aging Population

<https://www.whitehouse.gov/wp-content/uploads/2019/03/Emerging-Tech-to-Support-Aging-2019.pdf>

Family Caregiver Alliance Webinars

<https://www.caregiver.org/fca-webinars>

Family Care Navigator

<https://www.caregiver.org/family-care-navigator>

From Pyramids to Pillars: Two Centuries of Change in the U.S. Population, 1860-2060

https://www.youtube.com/watch?time_continue=2&v=PArs4CPs4JM&feature=emb_title

How to Relieve the Stress of Caring for an Aging Parent: Amy O'Rourke at TEDxOrlando

<https://www.youtube.com/watch?v=4c2grKhiKEw>

Human Rights Campaign Healthcare Equality Index

<http://www.hrc.org/hei#.Um1UOoPn9LM>

"I'm a Caregiver" Shows the Diversity Among Family Caregivers

<https://www.youtube.com/watch?v=d8pO5IReJmg>

Infographic: Caregiving in America

<https://blog.aarp.org/take-care/infographic-caregiving-in-america>

LGBT Aging Project of Boston

<http://www.lgbtagingproject.org>

Long-Term Care: Coming of Age in the 21st Century (Wisconsin Family Impact Seminars)

https://www.purdue.edu/hhs/hdfs/fii/wp-content/uploads/2015/07/s_wifis12c01.pdf

Long-term Caregiving Costs Calculator

<https://www.aarp.org/caregiving/financial-legal/info-2017/long-term-care-calculator.html>

Make yourself a Priority, Too: Tips for Caregivers

<https://www.nia.nih.gov/health/infographics/make-yourself-priority-too-tips-caregivers>

Meet Zora, the Caregiving Robot

<https://www.nytimes.com/interactive/2018/11/23/technology/robot-nurse-zora.html>

More Caregivers Needed Worldwide for the 'Oldest Old'

<https://www.prb.org/oldestold2050/>

NASW Standards for Social Work Practice with Family Caregivers of Older Adults

<https://www.socialworkers.org/LinkClick.aspx?fileticket=aUwQL98exRM%3D&portalid=0>

National Resource Center on LGBT Aging

<http://www.lgbtagingcenter.org/index.cfm>

PARO Therapeutic Robot

<http://www.parorobots.com>

Respite Care Locator

<https://archrespice.org/respitelocator>

Single? No Kids? Don't Fret: How to Plan Care in Your Later Years

<https://www.nytimes.com/2018/03/23/business/elder-orphans-care.html>

State Policy Innovations to Support Family Caregivers

<https://nashp.org/state-policy-innovations-to-support-family-caregivers/>

States Seek Financial Relief for Family Caregivers

<https://www.nytimes.com/2019/03/20/well/family/states-seek-financial-relief-for-family-caregivers.html>

Strengthening Community-Based Services for Asian Americans and Pacific Islanders Affected by Dementia

<https://www.alz.org/national/documents/strengthening-community-based-services-asian.pdf>

Technology is Transforming Caregiving

<https://www.aarp.org/caregiving/home-care/info-2018/new-wave-of-caregiving-technology.html>

The Financial and Personal Toll of Family Caregiving

<https://www.forbes.com/sites/nextavenue/2018/03/12/the-financial-and-personal-toll-of-family-caregiving/#16cac84358b8>

The New Paid Family Leave

<https://www.washingtonpost.com/business/2019/12/30/new-paid-family-leave/?arc404=true>

The Shape of Care Podcast

<http://theshapeofcare.org>

Training to Serve, Cultural Competency Trainings

<http://www.trainingtoserve.org>

U.S. Department of Labor: Leave Benefits

<https://www.dol.gov/general/topic/benefits-leave>

Veteran's Affairs: Comprehensive Assistance for Family Caregivers

<https://www.va.gov/health-care/family-caregiver-benefits/comprehensive-assistance/>

What is really means to care for grandma

<https://www.census.gov/library/stories/2018/06/eldercare.html>

Who Will Care for the Caregivers?

<https://www.nytimes.com/2017/01/19/upshot/who-will-care-for-the-caregivers.html>

Supplemental Resources

A. Caregiver Intake Report Example

University of Colorado
Colorado Springs

HealthCircle Aging Center

4863 North Nevada Avenue, Suite 321
Colorado Springs, CO 80918
office 719-255-8002
fax 719-255-8006
www.uccs.edu/agingcenter

Caregiver Intake Report (Clinician)

Date of Examination: 1/27/14, 2/4/14, 2/24/14
Referred by: A friend

Date of Report: 3/6/2014

Caregiver Identifying Information

Name: Mr. Allen Care

DOB: 1/1/1964

Place of Birth: The Philippines

Ethnicity: Filipino

Marital Status: Single

Education: Masters Degree

Occupation/Employment Status: Instructor

Living Situation: Alone

Care Recipient Identifying Information

Name: Mr. Bob Care

DOB: 2/2/1932

Place of Birth: The Philippines

Ethnicity: Filipino

Marital Status: Married

Education: High School

Occupation/Employment Status: Retired military

Living Situation: Temporarily housed in apt. on a military base in CA

Name: Mrs. Cindy Care

DOB: 3/3/1933

Place of Birth: The Philippines

Ethnicity: Filipino

Marital Status: Married

Education: Limited formal education

Occupation/Employment Status: Home maker

Living Situation: Independently in CA

IDENTIFIED PROBLEMS

Allen presented as concerned and anxious over a recent argument between his mother and father who live in California. Currently, Allen's parents are separated due to a domestic violence charge brought up against Bob in November 2013. Cindy called 911 and claimed that he hit her during an argument. Cindy has remained in their home while Bob has moved into an apartment on a military base with the urging of his sons. Since this event Allen and his brother, Doug, are angry at their mother for accusing their father of hitting her. They do not believe that this happened, instead, they think their mother was just seeking attention. Bob is confused and wants to return home despite his sons' advice to remain separated from his wife until his court date in March. In addition to the familial stress this event has created, it has also brought on financial hardships as Allen and his

brother have spent thousands of dollars bailing their father out of jail, housing him on base, and paying for a his rental car.

Allen characterized his parents as having a lifelong pattern of arguing. He reported that his mother "gets spun up" and begins to shout, calls names, and throws objects. He can remember her doing this for his whole life but indicated that over the past year these events have become more intense and have happened with greater frequency. In the fall of 2013 Cindy had threatened to call 911 when she was "spun up." This greatly distressed Allen and his brother because they did not want the police involved in their parents' arguments. Allen views threats to and the action of calling 911 as a significant increase in Cindy's anger issues. Allen described his father as having a pattern of retreating in response to his wife's angry attacks. Allen also has noticed that as he has aged, his father has spent increasing time isolating in a spare bedroom. In 2006 Allen visited his parents' home to discover that his father has been hoarding old newspapers; filling the spare room with several piles of the old newspapers so that the room couldn't even be walked through. Allen cleared out the room in 2006 and when he returned in 2007 it was filled again.

Allen has two brothers, Erick, the eldest brother and Doug, the middle child. Doug lives within an hour of his parent's home. Erick has distanced himself from the family gradually over the past years and does not have much contact with his parents by phone and rarely visits them. When Doug called Erick to report their father's arrest Erick refused to help, stating that their parents are adults and it was their responsibility to deal with this situation. Doug appears to be the main caregiver due to his physical proximity to their parents. He takes them to and from appointments and has helped his father move into his temporary apartment. While Erick has distanced himself from his family, Doug and Allen appear united in their view of this problem in several ways. Particularly in believing that the recent events are their mother's fault that their parents should remain separated until court proceedings, and that they cannot afford to give their parents more money.

Historically, Allen has temporarily cut off contact with his mother when she has had a significant angry episode. Allen described a couple of prior occasions when he discontinued phone contact with his mother after she had behaved badly. For example, she came to visit him with family and for some reason had a "tantrum" on the front lawn in his condo complex, throwing herself on the ground and screaming. Allen bought his mother a plane ticket and sent her back to California after this incident. He also described another time when she yelled at him repeatedly so he changed his phone number and it was months before he gave her the new one. He reported that this was because he was working on his dissertation and could not be disturbed by her angry tirades and name calling. Allen stated that her mother will apologize and act nice and calm, but it is only a matter of time before she gets upset and "spins up" again.

To address the most recent problem of his father's arrest, Allen and Doug bailed his father out of jail and helped him move into an apartment. They continue to convince him to remain there despite his desire to return home. Allen is not speaking to his mother currently but Doug visits her frequently.

Caregiver Medical Information

Allen characterizes himself as in good physical health.

Care Recipient Medical Information

Allen describes his mother as in good physical health.

Allen's father has numerous heart problems including a triple bypass surgery in 2005.

Problems Specific to the Caregiver:

In what ways has the situation you are in affected your everyday life?

This situation is difficult for Allen to manage in addition to his stressful job. He essentially has no social life and spends all free time talking to his brother and father. Allen has also had problems with sleep. In the past, he has struggled to balance his obligations of work and family. For example, when his father had triple bypass surgery in 2005 Allen was on a trip coaching his cadets in a competition in New Mexico. As soon as Allen heard his father was ill he left his team in New Mexico to travel to California. Conversely, Allen speaks to his family regularly but sees them less frequently (about once a year) than he would like due to work obligations.

FAMILY HISTORY

Allen denies any previous mental illness or treatment for psychological problems in his family. Allen denies any previous neurological illness or neuropsychological assessment in his family. Allen denies abuse in his family. Allen's father's recent arrest is the first instance of legal problems in the family.

Who are involved in the decision making about the care recipient and in what capacity?

Allen explained that traditionally, in Filipino families, the eldest son would be most involved in decision making for parents. However, Erick has distanced himself from this role resulting in Doug and Allen taking over this role. Doug is very involved in the day-to-day operations of caregiving including providing social support to his parents and bringing them to appointments. On the other hand, Allen is viewed by his parents as very responsible and credible, therefore he is more able to make decisions for his parents. Due to this divide in decision making power (Allen) and the ability to carry it out (Doug) they are both involved in decision making.

Concerns for CG:

What would you want to accomplish during our work together?

Allen does not acknowledge concerns for his own well being.

Concerns for CR:

Allen would like help problem solving how to manage the situation with his mother and father. He would like his father to receive the least legal punishment possible and to prevent future events like this. He would like his parents to receive counseling to work on their style of interacting when upset.

Clinical Formulation:

Allen is concerned about his parents who have a pattern of arguments which has intensified over recent years. Allen is quite committed to his parents but is unsure of how best to help his parents. One problem is that the family does not know what is causing the change in behavior of his parents. He struggles to help them retain as much independence as possible while feeling that they are at risk of making poor decisions. Allen will likely benefit from information on evaluations, strategies on obtaining a neuropsychological evaluation as well as the information provided in an assessment. Allen will also benefit from "giving himself permission" to transition into a more authoritative role over his parents, however, this will likely be a struggle for him and his family due to their Filipino culture preventing so much responsibility from falling on the youngest (which Allen is).

Problems Specific to the Caregiver:

In what ways has the situation you are in affected your everyday life?

This situation is difficult for Allen to manage in addition to his stressful job. He essentially has no social life and spends all free time talking to his brother and father. Allen has also had problems with sleep. In the past, he has struggled to balance his obligations of work and family. For example, when his father had triple bypass surgery in 2005 Allen was on a trip coaching his cadets in a competition in New Mexico. As soon as Allen heard his father was ill he left his team in New Mexico to travel to California. Conversely, Allen speaks to his family regularly but sees them less frequently (about once a year) than he would like due to work obligations.

FAMILY HISTORY

Allen denies any previous mental illness or treatment for psychological problems in his family. Allen denies any previous neurological illness or neuropsychological assessment in his family. Allen denies abuse in his family. Allen's father's recent arrest is the first instance of legal problems in the family.

Who are involved in the decision making about the care recipient and in what capacity?

Allen explained that traditionally, in Filipino families, the eldest son would be most involved in decision making for parents. However, Erick has distanced himself from this role resulting in Doug and Allen taking over this role. Doug is very involved in the day-to-day operations of caregiving including providing social support to his parents and bringing them to appointments. On the other hand, Allen is viewed by his parents as very responsible and credible, therefore he is more able to make decisions for his parents. Due to this divide in decision making power (Allen) and the ability to carry it out (Doug) they are both involved in decision making.

Concerns for CG:

What would you want to accomplish during our work together?

Allen does not acknowledge concerns for his own well being.

Concerns for CR:

Allen would like help problem solving how to manage the situation with his mother and father. He would like his father to receive the least legal punishment possible and to prevent future events like this. He would like his parents to receive counseling to work on their style of interacting when upset.

Clinical Formulation:

Allen is concerned about his parents who have a pattern of arguments which has intensified over recent years. Allen is quite committed to his parents but is unsure of how best to help his parents. One problem is that the family does not know what is causing the change in behavior of his parents. He struggles to help them retain as much independence as possible while feeling that they are at risk of making poor decisions. Allen will likely benefit from information on evaluations, strategies on obtaining a neuropsychological evaluation as well as the information provided in an assessment. Allen will also benefit from "giving himself permission" to transition into a more authoritative role over his parents, however, this will likely be a struggle for him and his family due to their Filipino culture preventing so much responsibility from falling on the youngest (which Allen is).

B. Caregiver Self-Assessment Form

Caregiver Self-Assessment Questionnaire

How are YOU?

Caregivers are often so concerned with caring for the relative’s needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, turn the page to do a self-evaluation.

During the past week or so, I have ...

- | | |
|---|---|
| <p>1. Had trouble keeping my mind on what I was doing.... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>2. Felt that I couldn’t leave my relative alone..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>3. Had difficulty making decisions..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>4. Felt completely overwhelmed..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>5. Felt useful and needed <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>6. Felt lonely..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>7. Been upset that my relative has changed so much from his/her former self..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>8. Felt a loss of privacy and/or personal time..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>9. Been edgy or irritable..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>10. Had sleep disturbed because of caring for my relative..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>11. Had a crying spell(s)..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>12. Felt strained between work and family responsibilities... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> | <p>13. Had back pain..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>14. Felt ill (<i>headaches, stomach problems or common cold</i>)..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>15. Been satisfied with the support my family has given me..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>16. Found my relative’s living situation to be inconvenient or a barrier to care..... <input type="checkbox"/>Yes <input type="checkbox"/>No</p> <p>17. On a scale of 1 to 10, with 1 being “not stressful” to 10 being “extremely stressful,” please rate your current level of stress. _____</p> <p>18. On a scale of 1 to 10, with 1 being “very healthy” to 10 being “very ill,” please rate your current health compared to what it was this time last year. _____</p> <p>Comments: <i>(Please feel free to comment or provide feedback.)</i></p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> |
|---|---|



