Care for Caregivers: Understanding the Need for Caregiver Support

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Most long-term care for older adults in the United States is provided by informal caregivers (Ahmad, 2012), the majority of whom experience an intense range of emotions from satisfaction to loneliness. Counselors must consider this emerging population of caretakers and learn methods to encourage clinical services to address their need for support. This article delineates experiences and challenges of informal caregivers and provides suggestions for effective clinical services for caregiver populations.

Keywords: caregiver, counseling, informal care, long-term care, caregiver wellness

The older adult population in the United States continues to increase, with projected numbers estimated at 80 million by 2040 (Administration on Aging, 2010). Older adults are living longer (Aldwin & Gilmer, 2013), often with disabilities and chronic diseases that require management and assistance. Well-documented research on caregivers states that over 43 million adults in the United States provide unpaid or informal care, and the majority (57%) of these caregivers also work full time and are responsible for their own family's needs (National Alliance for Caregiving [NAC], 2015). This combination of life circumstances offers a variety of challenges to many caregivers.

Informal caregiving may result in a great deal of strain on family members, especially the primary caregivers, bringing about feelings of being overwhelmed,

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stressed, and socially isolated (Ahmad, 2012; Grunfeld et al., 2004; Taylor & Field, 2003). Researchers have also documented that caregiving is strongly associated with depression (Mausbach et al., 2010; Schreiner, Morimoto, Arai, & Zarit, 2006) and physical illness (Segerstrom & Miller, 2004; Shaffer, Kim, Carver, & Cannady, 2017; Taylor & Field, 2003). Professional fields such as counseling, psychology, and social work have invested time into studying the stress-coping framework (Shaffer et al., 2017) and the most effective strategies to help long-term caregivers cope with stress to improve their well-being (Horvath & Mayer, 2010). Caregiver identity, stressors, and counseling implications are explored in the following sections.

TYPES OF CAREGIVERS

Definitions of caregiving are broad, encompassing a diverse population of caregivers and care recipients. Generally, a care recipient is an adult who requires assistance with personal care or household activities (Qualls, 2016). Some individuals who require care pay for caregiving services, but many rely on family members or friends for informal care. A distinction must be made between the general caregiving, or sharing of tasks, that commonly occurs in households of healthy adults and the point at which an identified family member begins to require additional assistance (Qualls, 2016).

Informal caregivers are more likely to be female than male, with an average age of 49.2 years (NAC, 2015). Informal caregivers are often adult children or spouses (Qualls, 2016), although siblings, neighbors, extended family, or friends also fulfill the role. About 35% of care recipients live with their caregiver; the remainder live independently, in long-term care settings, or with someone other than the caregiver (NAC, 2015). Care recipients in informal settings often have a prior relationship (familial or otherwise) with the caregiver. The mean age of care recipients is 69.4 years (NAC, 2015). The older a care recipient, the more likely the recipient is to be female (NAC, 2015). Although there is gender, age, and relationship diversity within the caregiver population, there are common threads to the caregiver experience, including stress, joy, and a shifting in identity.

CURRENT UNDERSTANDING

Caregiver Identity
Often as a family member or friend becomes ill, the individuals within the existing system assume the role of caregiver and then develop a new, emergent identity (Montgomery & Kosloski, 2009). Scholars have sought to better understand the development of this identity as it relates to the caregivers' role changes, self-efficacy, self-understanding, relationship shifts, life infringement, and utilization of external resources. This transition in identity has been written about in literature and identified from a theoretical perspective.

In a 2015 meta-analysis, Eifert, Adams, Dudley, and Perko isolated 23 publications from the years 1990 through 2014 that explored the role of family caregivers of adults with chronic diseases. In this analysis, they sought to understand the factors related to caregiver identity development. The results identified five recurrent themes among the published studies.

The first is the individuals' loss of self and role "engulfment" (Eifert et al., 2015, p. 360), described as relinquishing one's personal identify as the caregiver role became an all-consuming role. The second identified theme is the loss of a cocreated identity built with the individual receiving care. Most family caregivers have jointly created an identity with the chronically ill individual, and as this identity shifts from dyadic to individual, interactions, decision-making, life goals, social life, and feelings of shared history and support all change. The third theme relates to familial obligations and gender-based stereotypes, because female family members were frequently expected to adopt the caregiver role because of their gender or a societal expectation to assume wifely duty. The fourth theme identifies individuals with a previous relationship, such as a spouse or child, assuming the caregiving role as this existing relationship often serves to create an obligatory responsibility. The final theme is described by the authors as a "master identity develop[ment]" (Eifert et al., 2015, p. 363) that supersedes all former identities. As caregivers undergo the transition from individual to caregiver, individuals experience a complete change in their identity. As seen in these themes, assuming the role of a caregiver can be based on varying previous relationships but often produces a complete shift in an individual identity.

The caregiver identity theory is a specific model that addresses the career of the caretaker as it relates to identity changes. This theory originated in the study of family members caring for individuals with dementia and "outlines psychosocial processes that link particular stressors to specific forms of burden within the context of the caregiving career" (Savundranayagam & Montgomery, 2010, p. 176). Throughout the course of a caregiving relationship, the role of the caregiver continually changes based on the level of the patient's functioning. Conceptually, it is important to understand the transformation of roles as an emergence from an existing role or relationship, not the establishment of a new role or relationship (Montgomery & Kosloski, 2009). Specific role changes include things like the shift from a spousal role grounded in an established partnership into that of a caretaker wherein the individuals no longer engage in reciprocal companionship; rather, one person engages in caring for another. One of the hallmarks of this theory and the career of a caretaker is a level of variability and uncertainty, given that the length of the career is unknown, which is different from other caretaker roles, such as child rearing, which have clear expectations and delineated life transitions (i.e., turning 18). This transition into a caregiving role, along with an unclear timeline regarding this new role, can contribute to caregiver burden and stress.

Caregiver Burden and Stress

As caregivers' identities shift, they often experience their role as caretakers becoming a burden (Grunfeld et al., 2004). One can easily find a theme in research centered on the by-products of caregiver burden, particularly stress: the stress of having multiple roles; the stress of losing a companion—mentally, physically, or emotionally; the stress of financial burden; the stress of balancing schedules; the stress of not having enough knowledge and adequate resources; the stress of noninvolvement in social and family activities; the stress of noncooperation from the care recipients (Ahmad, 2012; Segerstrom & Miller, 2004; Shaffer et al., 2017; Taylor & Field, 2003), as well as many other sources and origins of perceived and actual stress (Ahmad, 2012; Givens, Mezzacappa, Heeren, Yaffe, & Fredman, 2014; Shaffer et al., 2017).

The by-product of these stressors manifests both physically and emotionally. Because caregivers often place less value on their own health, they experience lower immunity and increased risks for illness. In addition, caregivers often have higher rates of elevated blood pressures, anxiety, depression, and emotional distress (Cameron, Franche, Cheung, & Stewart, 2002; Givens et al., 2014; Joling et al., 2012; Rhee et al., 2008).

Researchers suggest that informal caregivers experience a lot of stress rather frequently as a result of handling multiple responsibilities over an extended period of time (Givens et al., 2014; Shaffer et al., 2017). Being responsible for their own families, jobs, and a care recipient creates numerous challenges, leading to the caregiver feeling overwhelmed. Besides having no respite and support from family and friends, the majority of caregivers lack professional knowledge about the specific needs of a chronically ill person (e.g., administration of medications, knowledge about diet, helping with physical or occupational therapy; Ahmad, 2012; Weinbrecht, Rieckmann, & Renneberg, 2016).

Another major complaint among caregivers is a lack of resources, support, and training. Furthermore, many times family and friends will expect new caregivers to provide a continuity of previously established roles and routines, and if expectations are not met, this can pose a significant threat to homeostasis and a shift in family dynamics (Qualls, 2016). Such demands can contribute to further conflict among the family and subsequently increase stress. Family caregivers may also be confronted with the loss of a loved one's abilities, independence, home, health, or ability to communicate effectively, which can lead to confrontation with grief (Humphrey, 2009). Finally, although professional services, such as respite care or external support, might be available, some families may be reluctant to contract such services due to societal stigmatization and cultural expectation. As is strongly documented, such psychosocial factors greatly contribute to elevated chronic stress (Weinbrecht et al., 2016).

The chronic stress of caregiving demands may lead to exhaustion and exacerbation of depressive symptoms such as isolation, lack of motivation, decreased productivity, changes in appetite, and abandonment of a healthy lifestyle (Givens

et al., 2014; Shaffer et al., 2017). Some authors report that at least one third of caregivers suffer from clinically significant depressive symptoms (Schoenmakers, Buntinx, & DeLepeleire, 2010; Schreiner et al., 2006) and that these rates are higher for caregivers whose care recipients have dementia, schizophrenia, or bipolar disorder (Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Schulz & Martire, 2004).

Current research also focuses on an examination of psychosocial risk factors longitudinally related to caregivers' physical health changes (Shaffer et al., 2017). It has been shown that chronic stress negatively affects the immune system; therefore, caregivers exposed to stress are more susceptible to infectious diseases and chronic illnesses (Fletcher, Miaskowski, Given, & Schumacher, 2012; Segerstrom & Miller, 2004; Shaffer et al., 2017). Moreover, Shaffer and colleagues (2017) found that caregivers who provided care to cancer patients for 5 years developed physical morbid conditions and those who reported chronically elevated depressive symptoms showed greater development of physical morbidity. With such documented facts, professionals should examine and implement effective strategies and interventions to support long-term caregivers. The burdens and stressors associated with being a caregiver are noteworthy but often overshadow some of the positives.

Positive Effects of Caregiving

A current trend in caregiver research is the development of a better understanding of the positive aspects of caregiving. Within this body of literature, researchers explore the range of benefits a caregiver may experience as a result of assuming the caregiving role. In one cross-sectional study by Haley et al. (2009) of 75 pairs of caregivers and stroke survivors, over 90% of caregivers reported a greater appreciation for life. They uncovered other positive attributes, including feeling appreciated (84%), needed (88%), useful (80%), and confident (81%), as well as having the opportunity to learn new skills (66%). Roth, Dilworth-Anderson, Huang, Gross, and Gitlin (2015) found that Hispanics and African Americans had more of the positive aspects of caregiving than White caregivers. Minority caregivers might feel more positive about the caregiving, and therefore might use less formal agency. In addition to ethnic identity, the perception of the caregiver role might be influenced by life circumstances, religion, socioeconomic status, and sexual orientation.

Diversity Considerations

Cultural background may influence the way caregivers experience providing care. Research explored the possible influence of moderating variables including gender and race. Middle Eastern and South Asian caregivers are less likely to use formal services. Half of the caregivers in such regions are daughters-in-law due to the cultural traditions (Ahmad, 2012). Despite the fact that caregiving in these cultures is viewed more positively with some rewarding experiences,

many caregivers still report poor sleep, difficulties administering meds, and noncooperation on the part of the care recipient (Hooyman & Kiyak, 2011; Sanders, 2005). Other reasons for not using formal services include lack of trust in formal services, restricted access, and cultural traditions or a family orientation to care for their own (Ahmad, 2012).

Despite becoming more visible, the LGBTQ (lesbian, gay, bisexual, transgender, and queer) population also faces enormous caregiving challenges. Due to experienced discrimination, victimization, and previous marginalization, older LGBTQ adults may not seek or use formal services (Fredriksen-Goldsen & Emlet, 2012). LGBTQ adults requiring assistance prefer to live independently, avoid formal care, and rely heavily on help and support from partners and/or friends to feel safe and avoid real or perceived discrimination (Fredriksen-Goldsen & Emlet, 2012). Therefore, intimate partners are the most likely caregivers (Cahill, Ellen, & Tobias, 2002), who, again, are less likely to seek formal help due to their sexual minority status.

LGBTQ caregivers are more likely to experience negative effects of caregiving, such as isolation, depression, and anxiety (Fredriksen-Goldsen, Kim, Muraco, & Mincer, 2009). As documented by Meyer and Northridge (2007), a lack of access and discrimination accelerate chronic illness and decline in mental health for both the caregiver and the care receiver. LGBTQ individuals experience challenges in staying connected with family members, social networks, and caregiving resources, especially when networks and resources are not respectful of their sexual minority status. Overall, minority caregivers might have a difficult time using formal services because of the restriction or unavailability of services, lack of sensitivity and respect for minorities, and a lack of trust due to previous experiences of discrimination. Having a greater understanding of the possible emotional benefits and challenges of assuming the caregiver role can help counselors focus treatment approaches and be effective in helping caregivers.

HOW CAN COUNSELORS HELP CAREGIVERS?

A multifaceted approach is necessary when working therapeutically with caregivers. Both practical and emotional needs should be addressed within the counseling relationship. In particular, counselors best serve these clients when addressing grief, emphasizing self-care, and recommending sources of support.

Addressing Grief
Grief is often associated with family caregiving. Humphrey (2009) discussed the concept of cumulative loss, where individuals experience a series of losses that compound and can lead to mental health issues. For family caregivers, the concurrent life transitions, required adaptations, and the impending death of a family member are a unique composite of losses. In conjunction with those losses,

family caregivers often see dramatic shifts in their own life regarding finances, free time, independence, and priorities (Grunfeld et al., 2004). Caregivers may also experience a loss of sense of self, as one's sense of self is related to connection with the important people in one's life (Chen, 2016). When those connections change, it can cause a sense of personal disequilibrium. All of this transition can lead to the experience of cumulative loss and grief. Counselors can help clients "accept and mourn inevitable limits and losses" (Chen, 2016, p. 353).

Humphrey (2009) reframed grief work as loss adaptation and provided strategies for counselors to consider. Some of the loss adaptation strategies include therapeutic writing, decisional balance sheets, and coping questions. Therapeutic writing can be structured or unstructured, spontaneous or counselor directed (Humphrey, 2009). Therapeutic writing in any format allows the client an opportunity to process emotions and information, as well as begin to make meaning of losses. This is a flexible intervention and can be tailored to the client, the counselor, and the therapeutic goals (Humphrey, 2009).

Decisional balance sheets help clients to reflect upon motivation to change and are often used in motivational interviewing, as well as in cognitive behavior therapy (Humphrey, 2009). Decisional balance sheets can take the form of worksheets divided into four sections used to allow clients to express the pros and cons of changing, or not changing, behaviors (Humphrey, 2009). Counselors can then work with clients to address how they may be "stuck" in dealing with the particular caregiving grief issue.

Coping questions, as defined by Humphrey (2009), ask clients to consider (a) how they can help themselves cope and (b) how they can use their grieving constructively. Humphrey explained that these questions help empower clients and facilitate forward progress in coping. Clients are asked to begin to take ownership of their own coping with the grief and losses associated with caregiving. The three therapeutic techniques described here are only a few of the techniques that may be useful for counselors helping caregivers work through grief.

Emphasizing Self-Care

Self-care is an important topic for counseling with a family caregiver. Counselors are in a prime position to bolster a caregiver's coping skills through exploring strengths and emphasizing self-care. Counselors can assess level of distress, coping, anxiety, grief, and depression for caregivers. The use of interviewing techniques with the primary caregiver, as well as other involved family members, can provide valuable context and extract sources of strength, meaning, and resilience on which to build (Qualls, 2016).

It is important for counselors to use a strengths-based approach to elicit self-care strategies for clients to try. Schmall, Cleland, and Sturdevant (2000) recommended that caregivers take responsibility for self-care and have realistic expectations. Furthermore, they recommended that caregivers learn to

communicate effectively, set goals, and seek help when needed. Counselors can assist caregiver clients to set realistic goals, prioritize self-care, draw upon existing strengths, and take advantage of community resources to help minimize the burden of caregiving.

Sources of Support

It is critical for counselors to be aware of local community resources. In particular, support groups for caregivers can be valuable sources of support for caregivers who feel isolated and overwhelmed. Groups can be psychoeducational and counseling focused, given that research demonstrates that psychoeducational skills-based programs help to increase coping and reduce caregiver stress (Pepin, Williams, Anderson, & Qualls, 2013). Topics of discussion can include self-care, effective communication, emotions, transitions, and decision-making. Not only are the topics interesting to caregivers, but the group setting allows for open and honest discussion regarding the often conflicting emotions associated with family caregiving.

If caregiver support groups are not an option, individual counseling and perhaps telephone support can be helpful for family caregivers. Even web-based programs can provide information and socialization for caregivers who feel disconnected and overwhelmed. Counselors can recommend ancillary services, such as respite care, care management, or volunteer home visits, to help alleviate the burden on the caregiver (Chen, 2016; Qualls, 2016). Day programs are often available for care recipients and can allow the primary caregiver time to work or engage in self-care activities (Qualls, 2016). Many times, primary care physicians and religious figures can help bridge the gap between the caregivers' needs and some available formal services. Referrals, prearranged phone calls and visits, and support groups run by professionals and lay volunteers might help facilitate the initial contact and assessment of needs and, therefore, reduce social isolation and facilitate necessary support.

The family itself is often an important resource and source of support. Family dynamics often change as a result of taking on the new roles of caregiver and care recipient (Qualls, 2016). These changes can be quite stressful for family members in that they initiate difficult conversations and force an examination of sometimes conflicting values and ethical orientations (Qualls, 2016). Counselors can help facilitate effective communication within the family unit. Considering growing diversity in the United States, counselors need to be informed, skilled, and multiculturally competent to effectively address the needs of all different populations.

Advocacy

Counselors have an obligation to help advocate for resources and support for caregivers. Currently, several legislative initiatives focus on the development of better support for caregivers and services for older adults. The Older Americans

Act Title III Programs, passed in 1965 and recently reauthorized until 2019, ensures coordination and delivery of both social and nutritional aid to older adults and caretakers. The National Family Caregiver Support Program, also under the Older Americans Act, provides support for caregivers on available services, assistance gaining access to services, mental health (e.g., individual, group), temporary respite care, and supplemental caretaking services. Last, Recognize, Assist, Include, Support, and Engage Family Caregivers Act (2017) legislation focused on providing aid for family caregivers is currently in the Senate. For counselors, having an awareness of these current movements and being active advocates for their development can subsequently help clients and their families.

IMPLICATIONS FOR FUTURE RESEARCH

To provide optimal support for caretakers, ongoing research on caregiving advancements using diverse samples is necessary. One such area of exploration is the integrated care model, which views treatment of an individual from a holistic perspective, coordinating mental and physical treatment from initial diagnosis through rehabilitation. Within this model of care, continued research is needed to better understand how the organization of services can meet the needs of the patient while reducing the burden on a caretaker. Understanding how connections to social services and providing nonmedical care can better be created, implemented, and sustained has the potential to reduce caregiver burden and the negative effects on caregivers.

Ambient assisted living is another emerging area within the field of information and communications technology, which can extend aging individuals' ability to live in their preferred environment. These technologies "combine ubiquitous information, communication, and entertainment, with enhanced personalization, natural interaction and intelligence" (Costa et al., 2009, p. 92). The capability of these technologies can range from simple push-button emergency call systems to complexly crafted systems that enable individuals to maintain their independence and live alone through GPS tracking, to prevent wandering, or "smart homes" to monitor individuals' physical and medical safety. As these technologies are developed, it is beneficial to understand how they can supplement caregivers, so they can also maintain their independence; provide better long-term support; and maintain their own physical, social, and emotional wellness.

Along more traditional lines of research, caregiver support literature would benefit from longitudinal research on counseling services. While some research looks at special populations over the course of time (Tsai, Yip, Tai, & Lou, 2015) and even combines data into meta-analyses, greater rigor, larger sample sizes, and research on counseling-specific populations would greatly advance the understanding of effective interventions for caregivers and their support

systems. Similarly, additional data on diverse samples can continue to provide a better understanding of how race, culture, sexuality, and intersectionality affect the lives of caregivers. Because of the vastly differing characteristics of individuals based on relationships, age, diagnosis, prognosis, and severity, additional understanding of the effects of each of these variables could greatly influence understanding of caregiver stressors and provide better ways to attend to this population through clinical treatment.

CONCLUSION

With a growing older adult population in the United States and prolonged life expectancy, the need for informal and formal caregiving services is on the rise. Although formal services will continue to be used, informal services such as family caregivers are expected to increase in the near future. As documented, caregivers and their situations vary greatly; therefore, as the counseling profession supports this population, it is necessary to deepen the understanding of diversity considerations, the positive and negative by-products of caregiving, avenues for advocacy, and clinical interventions. Understanding the specific needs of caregivers is essential for providing effective clinical support and focusing future research endeavors for this growing population.

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