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Experiences of Adults Who Identify as Primary Caregivers

Tiffany M. Bordonada, Katherine A. Feather,
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The role of primary caregiver is unique. Understanding the role of the primary caregiver will better inform those in the counseling profession. The purpose of this qualitative research study was to gain a clearer perspective of the lived experiences of adults who identify as primary caregivers. The authors conducted semistructured interviews with 6 Caucasian female participants and analyzed the data using interpretative phenomenological analysis. The findings include personal perceptions and caregiver experiences pertaining to the caregiver role, caregiver mentality, professional identity, social and emotional responses, and self-care among caregivers throughout the caregiving process. Implications for counselors and future research are presented.

Keywords: adults, caregiver, lived experiences, qualitative, interpretative phenomenological analysis

According to the AARP Public Policy Institute and the National Alliance for Caregiving (NAC; 2015), 43.5 million adults in the United States spend an average of 21 hours per week providing unpaid care for a chronically ill, disabled, or aged family member or friend. Moreover, 17% of caregivers reported their physical and mental health declined as a result of caregiving (NAC, 2017). For example, clinically significant symptoms of depression have been reported by 40% to 70% of caregivers (NAC, 2017). The hardships or adverse events that caregivers experience as they provide care contribute to caregiver burden (Tan et al., 2012). Lyonette and Yardley (2003) found that caregiver stress

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increased due to feelings of guilt, duty, responsibility, and lack of choice, as well as perceived disapproval from others if they chose not to provide care for their loved one. In addition, Schure et al. (2006) reported that caregivers feel responsible to provide care, and this feeling can lead to social isolation and burnout. Research has proven that caregivers' particular situation and stressors typically dictate their coping strategies when faced with the caregiver role (Daire & Mitcham-Smith, 2006). Therefore, professional counselors must be aware of the complex, multifaceted needs of the primary caregiver.

In order for the counseling profession to understand and alleviate the negative effects of caregiving, the challenges and consequences of the caregiving role need to be addressed (Myers, 2003). Visser-Meily, van Heugten, Post, Schelpers, and Lindeman (2005) suggested that active problem-solving strategies throughout recovery are most helpful for caregivers. Moreover, Cameron and Gignac (2008) found that over time, caregivers experience a change in the level of social support needed as they provide care. More important, counselors should recognize and understand the meaning that caregivers place on the caregiving responsibilities to honor the caregivers' reality (Kralik, Visentin, & Loon, 2006; Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Furthermore, counselors and other health care professionals need to address changing caregiver needs to foster appropriate support and guidance for the caregiver. To fully understand the phenomenon of caregiving, counselors must first acknowledge the process of making sense of the caregiving experiences (Ayes, 2000). Our intention was to offer guidance for counselors working with those who identify as primary caregivers. Thus, this study explored the lived experiences of primary caregivers and how they make sense of their experiences in their role as caregiver.

PURPOSE OF THE STUDY

The purpose of this study was to gain a better understanding of the lived experiences of adults who identify as primary caregivers. Thus, we adopted a phenomenological approach for this study. Phenomenology is an extension of the constructivist paradigm that searches for a deeper understanding of everyday experiences and generates systematic, clear, and accurate descriptions of the meaning of the experience (Morrissette, 1999). Researchers explore the shared perspective across participants and seek to understand the essence of the phenomenon through the participants' lived experiences with that phenomenon (Hays & Wood, 2011). Therefore, the aim is to determine what an experience means for the persons who have had the experience and are able to provide a comprehensive description of it (Moustakas, 1994). By investigating the rich descriptions of the phenomena and the meaning caregivers make of their experiences, we hope to enhance the profession's understanding of how to better serve this ever-increasing population.

For this particular study, the main research question was, What are the lived experiences of those who identify as caregivers? Given the exploratory nature of this study, we did not determine any outcome regarding participant responses. Therefore, we analyzed the responses in great detail and identified themes derived from the data we obtained.

METHOD

Participants

The target population for this study included individuals living in the north-eastern region of the United States who identified as primary caregivers. We defined *primary caregiver* as any relative, partner, neighbor, or friend who provides a broad range of assistance without pay for an adult with chronic illness or disability (AARP Public Policy Institute & NAC, 2015). We used a snowball sampling method to access potential participants (Creswell & Clark, 2007). We initially identified two participants who met the criteria, and we solicited additional participants by asking participants to provide the names of other possible participants. Once we obtained contact information for potential participants, one member of the research team contacted each participant via phone to discuss the research purpose and process and to schedule an interview. Meanwhile, we mailed the informed consent forms to each participant. Participation was voluntary, and withdrawal from the study was permitted without undue influence.

Six Caucasian women participated in the study. Participants ranged in age from 55 to 75 years. In terms of employment while providing care, three participants reported that they were employed full-time, two participants were unemployed, and one participant was employed full-time but became unemployed due to retirement. Participants' length of time as caregivers ranged from 6 months to 12 years. Four participants provided care for their husbands, one participant provided care for her mother, and one participant provided care for her father. At the time of the interviews, two participants reported that they became widows within the previous year, one participant became a widow 2 years prior, one participant reported that her mother had passed 8 years prior, one participant was currently providing care to her father and had become his primary caregiver within the last 8 months, and one participant was currently providing care to her husband and had become his primary caregiver within the last year. Thus, four out of six participants were bereaved caregivers, and two participants were currently in the caregiver role.

Procedure

Each participant completed one interview with the first author. Five participants completed an interview via phone, and one participant completed the interview in person. A semistructured format using open-ended questions was approved

by an institutional review board at a university in the southeastern region of the United States. According to Bernard (1988), semistructured interviewing is best when the researcher interviews participants only once. Moreover, open-ended questions allow the researcher to have a general guide for the interview, as well as offer an opportunity for understanding the topic of research (Bernard 1988). Thus, a semistructured format was appropriate for this study.

The interviews were audio taped and lasted between 30 and 45 minutes. Each interview began with questions about the participants' basic demographic information, such as age, ethnicity, and the length of time providing care. The interviews were guided by semistructured, open-ended questions: (a) Tell me about your daily experiences as a caregiver, (b) What challenges have you experienced as a caregiver? (c) What motivates you to provide care? (d) How has being a caregiver affected you personally? and (e) What types of support mechanisms have you used? The fourth author transcribed all interviews verbatim. These questions permitted participants to share their personal experiences in a narrative format. Additionally, each participant chose a pseudonym, and we removed all identifiable information from the transcripts to maintain confidentiality.

Data Analysis

Interpretative phenomenological analysis (IPA) was used to analyze data from the interview transcripts. IPA suggests a small sample size of no more than 10 participants in order for the researcher(s) to retain an overall mental picture of each individual and position themes within their narrative (Smith, Jarman, & Osborn, 1999). Thus, a small sample size deemed IPA appropriate to analyze the data.

IPA is used to explore in detail the participants' view of the phenomenon and is concerned with individuals' personal perceptions or accounts of an event (Smith et al., 1999). Moreover, IPA places emphasis on understanding the participants' view with a focus on personal meaning in particular contexts (Smith, Flowers, & Larkin, 2009). Furthermore, IPA involves a thorough, case-by-case analysis of individual transcripts, and the primary aim is to examine in detail the perceptions and understandings of the specific group studied rather than make more general claims (Chapman & Smith, 2002). Additionally, IPA recognizes that the researchers' own conceptions are required to make sense of the personal world being studied through a process of interpretative activity (Chapman & Smith, 2002). Thus, we incorporated the participants' narratives to identify emerging themes and made connections between themes to better understand the lived experiences of the primary caregivers.

The method of IPA involves six specific steps to data analysis. Step 1 involves a case-by-case analysis, in which we reviewed line by line each transcript looking for concerns and understandings of each participant. Furthermore, Step 1 of the process entailed reading and rereading the transcript to attempt

to summarize and begin to identify themes. Step 2 involved looking for connections between themes. During Step 2, we made a list of emerging themes within each transcript and looked for connections between themes among transcripts. In Step 3, we created a table of themes consisting of a master list in which superordinate themes were connected to underlying themes, as well as the original annotations from the participants. At that point, we dropped certain themes and determined the number of instances of the remaining themes. Step 4 involved supervision, collaboration, and auditing to further develop coherence of participant interpretation. Step 5 involved narration or translation of themes, in which the themes were outlined and illustrated with verbatim extracts from participants. Finally, Step 6 involved personal reflection on one's own perceptions, conceptions, and processes during the data analysis process.

The research team consisted of one female Asian/Caucasian doctoral student, one female Caucasian doctoral student, one female Caucasian graduate student, and one male Caucasian faculty researcher. The Asian/Caucasian doctoral student completed the interviews with participants, both doctoral students analyzed the data, and the graduate student transcribed the interviews. The faculty researcher served as an external auditor to ensure rigor of the data analysis process, accuracy of the themes, and trustworthiness of the data during the research process. Furthermore, the Asian/Caucasian doctoral student and the Caucasian graduate student were familiar with the research topic because of personal experiences. Therefore, prior to beginning the research process, as well as upon completion of data analysis, the research team engaged in reflective commentary and discussion to address beliefs and assumptions pertaining to the phenomenon of caregiving (Shenton, 2004).

RESULTS

Data obtained from the six female Caucasian participants reflected their perceptions of the caregiver role and their experiences throughout the caregiving process. Five themes emerged from the data analysis: (a) caregiver role, (b) caregiver mentality, (c) professional identity, (d) social and emotional responses, and (e) self-care. The following sections present these themes derived from a range of codes and categories, with representative quotes for each theme. Pseudonyms were used to maintain the confidentiality of participants.

Caregiver Role

Participants described the caregiver role as one that involved making big decisions, being financially responsible, being cooperative, juggling many responsibilities simultaneously, and having a significant level of trust in one's ability to care for a loved one. Moreover, the terms *advocate* and *protector* were used to define their identity in the caregiver role. Rose stated, "It was my calling to care

for my husband, and I wouldn't have it any other way. I was happy to know I was able to care for him and so I did." Furthermore, Bridget mentioned, "I just love my husband with all of my heart. If the situations were reversed, he would have cared for me. I was confident in my ability to care for him."

Caregiver Mentality

All of the participants reported that they accepted their role as caregiver. Therefore, they described their mentality as hopeful, rewarding, determined, optimistic, and, in Bridget's words, "motivated by love." Cecilia stated, "I am his wife and so taking care of my husband is how it should be, regardless of the situation." Furthermore, Rose stated, "There's nothing more rewarding than taking care of somebody and helping them through rough times, whether it's a short-term or long-term thing." Participants who cared for their husband reported that taking care of their husband was the "natural thing to do" (Cecilia) because their marital vows were taken seriously. Additionally, the participants described their mentality as "automatic pilot" (Bridget), which meant accepting the situation and doing what needed to be done to provide care successfully. For example, Carol shared, "You [the caregiver] just try to prepare yourself for anything that could happen. And you don't know that you can prepare yourself for everything, but you sure try."

Professional Identity

The professional background varied among the participants. Four participants reported having a career in the nursing profession, one participant was an accountant, and one participant was a stay-at-home mother. Given the nursing background of four participants, all reported that having experience as a nurse assisted them during the caregiving process. According to Rose, "Being a nurse helped me because I understood what to expect as I watched my father decline due to his illness. However, the challenge was accepting what I knew would occur throughout the duration of watching my father decline." Although the participants reported their professional background and knowledge in nursing helped with the caregiving process, they consistently reported that it was still difficult and challenging providing care for their loved one, as opposed to providing care in the professional role as a nurse.

Social and Emotional Responses

All of the participants reported experiencing various social and emotional responses throughout their caregiving experiences. According to Bridget, her experiences were "multiemotional." Bridget stated, "I can go from crying, to being mad, to being happy, to yelling and screaming, and it can all be gone in 60 seconds." As for Anna, she reported feelings of guilt and stated, "When I look back, I think I could have done something else to make the situation better, or I questioned myself about everything I did." Additionally, Carol reported

feeling fearful of the future because she often thought, “If he gets worse, then I don’t know if I can manage him, and so that scares me.” Although participants reported the overall caregiving process as taking a toll on them emotionally, physically, and mentally, they still viewed the experience as a privilege to care for their loved one.

Self-Care

Participants described various mechanisms for self-care. Three of the participants discussed their place of employment as providing a sense of normalcy for them, because they could focus on other responsibilities aside from caregiving. All of the participants reported that they received support from friends and family members almost daily, whether it involved a phone call or meeting up for coffee. Moreover, Carol reported that her counselor encouraged her to maintain self-care in order to be available for her loved one. Furthermore, four participants reported feelings of relief because their adult children were so helpful. Additionally, participants identified activities such as reading, taking a walk, praying, spending time with friends, working outside the home, attending support groups, and engaging in other leisure activities such as arts and crafts as ways to maintain healthy self-care. Although the participants were able to identify supports to maintain self-care, all of them admitted to a lack of consistent engagement in maintaining self-care. However, all of the participants discussed the importance of positive self-care and acknowledged that neglecting self-care can be detrimental throughout the caregiving process.

DISCUSSION

This study provides insight into the lived experiences of six female Caucasian caregivers. In particular, four participants provided care for their husbands, one participant provided care for her mother, and one participant provided care for her father. The findings support previous research and offer new insight into the lived experiences of caregivers, which is likely to benefit the counseling profession and those engaged in the caregiving process.

All of the participants reported that they accepted their role as caregiver. Whether the participants provided care for their spouse or parent, Anna stated, “I wouldn’t have it any other way” and Rose believed, “It was my calling.” In line with a previous study, the caregivers’ experiences centered on the theme of accepting their destiny and their duty as a wife to care for their loved one (Tuomola, Soon, Fisher, & Yap, 2016). Moreover, Tuomola et al. (2016) found that caregivers experience a sense of empowerment when making decisions and conquering obstacles throughout the caregiving process. As found in this particular study, the participants reported having confidence in their ability to provide care due to the significance of the relationship with their loved

one. Therefore, they accepted their role as caregiver and felt that it was the “natural thing to do.” Moreover, the participants reported that their spouse would care for them if the roles were reversed. Although these participants acknowledged decision making and new responsibilities as a caregiver, they did not report any hesitation when accepting the role of caregiver. Lawton, Kleban, Moss, Rovine, and Glicksman (1989) defined caregiver mastery as the “positive view of one’s ability and ongoing behavior during the caregiving process” (p. P62). Thus, the findings of this study support Lawton et al.’s notion because participants reported the caregiving process to be rewarding and progressive.

The participants shared a positive caregiver mentality. However, this mentality was varied and subjective across all participants. For example, Cecelia stated, “It [caregiving] doesn’t feel like a burden at this point. . . . It’s just that my life has changed.” According to Cecelia, she accepted her role as caregiver and adopted a new perspective. Furthermore, Carol stated, “This experience makes you realize what’s important in life. . . . Things we thought were important really aren’t.” Again, this participant embraced a new outlook that influenced her attitude. Nevertheless, Anna acknowledged, “You [the caregiver] are going through the motions and trying to deal with everything ’cause it is overwhelming because mentally I went through, um, I’m OK and he’s not.” She voiced experiencing a “guilt phase” because she was healthy and her husband was declining. Like what Anna described, the strain of caring for a loved one can lead to increased levels of caregiver stress, which can be difficult to endure (Lyonette & Yardley, 2003; Tan et al., 2012). Although participants described their mentality as meaningful, hopeful, and adaptive, one’s approach to caregiving may consist of guilt, and fear of the unknown can contribute to role strain among carers (Lyonette & Yardley, 2006).

The four participants with a professional nursing background reported that having experience as a nurse helped them to provide care for their loved ones. They reported a sense of willingness and competence when providing care. This suggests that professional expertise among caregivers may contribute to successful caregiving. However, participants reported feeling fearful because of their knowledge of what could possibly occur to their loved one in the future. Although their professional expertise provided knowledge and comfort, it influenced feelings of anxiety and other emotions.

The participants reported various social and emotional responses, including feeling multiemotional and feeling helplessness during difficult times. Additionally, they reported that the caregiving process affected their family dynamic. However, many participants identified their adult children as being helpful and supportive during the process (Ampalam, Gunturu, & Padma, 2012; Fleming, Sampson, Cornwell, Turner, & Griffin, 2012). Moreover, a sense of loss, feelings of uncertainty, and an unpredictable process were used

to describe their feelings and experiences at different points throughout the course of caregiving. However, it should be noted that all of the participants viewed their role as being a privilege. They reported feeling honored to be able to provide care for their loved one, as well as a sense of hope during such a stressful and overwhelming experience. Furthermore, all of the participants reported feeling motivated by love to provide care as needed.

All of the participants mentioned coping strategies to maintain self-care. For example, taking a walk, praying, or spending time with family and friends outside the home were important to them. Additionally, employment provided a sense of normalcy (Phillips & Reed, 2010). As suggested in a similar study, caregivers should engage in physical exercise, seek religious support, and take time for themselves to avoid becoming overwhelmed (Barbosa, Figueiredo, Sousa, & Demain, 2011). Seeking professional help has been found to be beneficial to caregivers (Barbosa et al., 2011); however, only one participant reported seeking counseling throughout the caregiving process. Given the feelings of physical, emotional, and mental stress found in this study, this suggests that seeking professional help is recommended for caregivers. Daire, Torres, and Edwards (2009) recommended that mental health professionals engage caregivers in interventions around “psychoeducation, support, respite care or adult day care, psychotherapy, caregiver competence, and multicomponent approaches delivered in individual, group or mixed formats” (p. 71).

Implications for Counselors

Because of an increase in the caregiver population, it is imperative for counselors to be able to foster guidance and awareness for those who take on the role of caregiver. Many individuals will likely become caregivers at some point in their lifetime and deserve appropriate support as they engage in the caregiving process. Therefore, it is critical for counselors to fully acknowledge and understand the lived experiences of caregivers and the caregiving process.

These findings inform counselors in many ways as they offer support for caregivers. It is essential for counselors to educate caregivers on the various types of emotions they may endure throughout the caregiving process (Daire et al., 2009). These emotions may include anxiety, hope, a sense of loss, fear, stress, and even optimism. Counselors should encourage caregivers to be attentive to their daily emotions so that they can have a better understanding of themselves and their unique experiences. As caregivers become informed and aware of their variety of emotions, they can begin to accept who they are throughout the caregiving process, which in turn influences successful caregiving. Moreover, as caregivers identify their emotions, counselors can prompt them to consider triggers for particular emotions. By doing so, this can prepare caregivers throughout the process. Additionally, counselors should be aware that although the caregiving experience may be overwhelming and stressful, it

may be viewed as a privilege and consist of positive outcomes. Furthermore, counselors should identify strengths and abilities in caregivers as they process their social and emotional responses to caregiving.

The results of this study also suggest ways to properly cope with the stress of caregiving. It is recommended that counselors encourage caregivers to identify positive coping strategies, such as reading a book, taking a walk, cooking, doing arts and crafts, and spending time with friends and family, to maintain self-care. As caregivers remain consistent with self-care to manage caregiver stress, they are likely to experience success as caregivers (Daire & Mitcham-Smith, 2006). Therefore, counselors should remind caregivers to take time for themselves and take breaks from caregiving as needed. Moreover, counselors should inform caregivers about the importance of maintaining consistent self-care to be present for their loved one. It is also important to assess the level of support caregivers are receiving throughout the caregiving process to ensure that they continue to be connected to support mechanisms (Cameron & Gignac, 2008). Thus, assessment and implementation of coping strategies are beneficial to both the caregiver and the care recipient.

Additionally, counselors should consider the professional background of caregivers. As found in this study, the nursing background of some participants assisted with providing care. However, this does not imply that a caregiver with a background in the helping professions is readily prepared and aware of the caregiver role. One's professional background may offer insight into one's abilities as one provides care. Therefore, we simply recommend that counselors consider the professional background of caregivers while assessing their unique experiences during the caregiving process.

As counselors offer encouragement and identify caregiver competence, the caregiving process is likely to be successful for all involved (Daire et al., 2009). Moreover, counselors should be aware that one caregiving process is likely to be very different from another and not to generalize the process. Therefore, counselors need to consider the client's willingness to undertake the caregiving role, assess the current relationship between the caregiver and care recipient, and seek to understand the family dynamic. More important, counselors should offer consistent support and reassurance as caregivers undergo this process.

Limitations of the Study

Although qualitative research offers in-depth, personalized narratives, certain limitations exist. The scope of the study is bound to the experiences of the six Caucasian primary caregivers (Glesne, 2016). The lack of diversity among the participants limits the transferability of the findings, and the use of a snowball sampling method may have inhibited us from obtaining additional and more diverse participants (Creswell & Clark, 2007). Furthermore, because we used self-report narratives, the participants may

have responded in a socially desirable manner that influenced the findings (Creswell & Clark, 2007). Therefore, we strived to provide sufficient detail and rich description as it related to the participants' experiences and the caregiving phenomenon (Lincoln & Guba, 1985).

Areas for Future Research

This particular study provides insight into the lived experiences of Caucasian, female, bereaved caregivers. Therefore, future research is warranted to explore the lived experiences of male caregivers to gain a better understanding of how gender affects the caregiver role. New research should also include caregivers from various cultural backgrounds to better understand how particular beliefs and traditions influence the caregiving process for those from a particular cultural group. Moreover, the lived experiences of caregivers who do not have a professional background in nursing should be explored. Furthermore, the perceptions and experiences of the entire family unit should be explored to better understand how involvement of other family members influences the caregiving process.

CONCLUSION

The lived experiences of adult caregivers are unique and worthwhile. Although the caregiving process can be stressful and overwhelming, it can be a rewarding experience. As was found in this study, all participants reported caregiving as a privilege and accepted their role as caregiver for their loved one. The participants' shared feelings of optimism, hope, and love determined their motivation to provide care. Additionally, different emotions are very much a part of the caregiving role, which can lead to physical, emotional, and mental stress. However, consistent implementation of appropriate support mechanisms can alleviate burden and influence a healthy sense of well-being among caregivers. Therefore, counselors who work with this population can play an important role in providing support and guidance for individuals who engage in the caregiving process. In particular, counselors can inform individuals of the emotions, thoughts, and potential experiences that individuals may endure as caregivers. Thus, these findings can offer a sense of comfort and awareness for those who engage in such an unpredictable yet rewarding experience.

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