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ORIGINAL RESEARCH

The Experience of Transitioning to a Caregiving Role for a Family Member with Alzheimer's Disease or Related Dementia

Study findings suggest several areas for further research.

Alzheimer's disease is a chronic, debilitating illness that currently affects an estimated 5.5 million Americans,[1] with devastating consequences for those afflicted and their families. Although it's unclear how many more Americans suffer from related dementias (such as vascular dementia, dementia with Lewy bodies, and mixed dementia), the total is undoubtedly higher. The incidence of Alzheimer's disease is expected to double by the year 2050, given the growing population of people over 65 years of age.[1] The implications of this are staggering, especially when one considers that average life expectancy in this country is about 78.8 years.[2]

More than 15 million Americans currently provide unpaid care for a person with Alzheimer's disease or a related dementia, with family members providing the majority of such care.[1] These caregivers are known to have higher levels of emotional, physical, and financial burden than any other group of caregivers.[1] While providing care for any ill or disabled loved one can be overwhelming, patients with Alzheimer's disease or a related dementia present unique challenges. People so afflicted are often unaware of their limitations, and many need care for a prolonged period. Caregivers may face the daunting task of providing care for a loved one who can no longer recognize them. As the disease progresses, behavioral and psychological symptoms such as agitation, aggression, depression, anxiety, and other problems reportedly occur in almost all individuals; these can be a major source of stress and burden for caregivers.[3]

Because disease onset is subtle, caregivers often assume the role of caregiving before they quite realize they are doing so.[4] Signs and symptoms of dementia have typically been present for some time before a physician is consulted and a confirmed diagnosis obtained. Indeed, the early symptoms (such as short-term memory problems and apathy) can be confused with those of normal aging, depression, stroke, or Parkinson's disease, among other conditions. Diagnosing Alzheimer's disease and related dementias involves multiple assessments, including comprehensive physical and neurologic examinations, mental status and mood evaluations, and laboratory testing.

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ABSTRACT

Background: Alzheimer's disease is a chronic, debilitating disease that currently affects an estimated 5.5 million Americans. The majority are being cared for at home by family caregivers, who are known to have higher levels of burden than any other group of caregivers.

Purpose: The purpose of this phenomenological study was to explore the lived experiences of people who transition to the role of caregiver for a family member with Alzheimer's disease or a related dementia.

Methods: The study used purposeful sampling. Eight women and two men (mean age, 66.3 years) participated. Data were collected through in-depth semistructured interviews, along with observational field notes. Data were analyzed using a hermeneutic phenomenological approach.

Results: The average duration of caregiving reported by participants was five years. Seven themes were uncovered: something is wrong; journey to diagnosis: ambiguity and negative emotions; shifting roles and relationships: losses and challenges; seeking knowledge and support: solutions and frustrations; adapting to the topsy-turvy world of caregiving: finding purpose; preserving self without guilt; and finding a way out.

Conclusions: The study findings have implications for nursing education, research, and practice, with participants expressing needs for better communication and access to resources. The findings also suggest the importance of health care planning early in the disease process, and of raising awareness about nurses as a resource for family members.

Keywords: Alzheimer's disease, caregiving, dementia, family caregiver

Study purpose. The purpose of this qualitative study was to explore the lived experiences of people who transition to the role of caregiver for a family member with Alzheimer's disease or a related dementia. More specifically, its aims were threefold: to gain an understanding of the caregiver's experience of such a transition; to describe the meaning that caregivers attributed to their experience; and to gain an understanding of strategies that caregivers identified as effective in facilitating their transition.

METHODS

Study design. The study design was based on the hermeneutic phenomenological approach, which offers the premise that people seek to make sense of their experiences. This tradition holds that in the act of turning experiences into stories, individuals have already interpreted the meaning of those experiences.[5]

Sample. Study participants were drawn from the research database for Project ACT (Advancing Caregiver Training) at the Center for Applied Research on Aging and Health at Thomas Jefferson University in Philadelphia. Project ACT was a randomized controlled trial funded by the National Institute on Aging and the National Institute of Nursing Research. In that study, researchers tested the efficacy of a home-based intervention designed to reduce the occurrence of troublesome behaviors in people with Alzheimer's disease or a related dementia.[6, 7] The research database held a potential pool of about 140 eligible participants who could be accessed for my study.

Approval was obtained from the institutional review boards of Duquesne University, Pittsburgh, Pennsylvania, and Thomas Jefferson University before beginning the study.

Purposeful sampling was used to recruit participants who had experienced transitioning to the role of caregiver for a family member with Alzheimer's disease or a related dementia. Family caregivers who met the following inclusion criteria were eligible: self-identified as the primary unpaid caregiver of a community-dwelling person diagnosed with Alzheimer's disease or a related dementia by a physician; were 21 years of age or older; were English speaking; were responsible for the physical, emotional, and spiritual care of the care recipient; agreed to participate in the study and share their experiences; and were available for two interviews over about a two-month period.

As the researcher, I coordinated postal mailings sent to the pool of potential participants beginning in November 2006. Each mailing included a letter of introduction that explained the proposed study and let them know that I would be contacting them to invite their participation. Respondents were then screened by phone to determine their eligibility based on the inclusion criteria. The final sample of participants were offered a $10 gift certificate usable at local convenience stores or pharmacies after each interview to thank them for their participation.

Setting. Participants could choose to be interviewed in their homes or in a private setting of their choice. These options allowed participants to share their experiences in a comfortable environment, potentially without having to travel or arrange alternative care for the care recipient.

Data collection was done through interviews and the use of field notes. I conducted two interviews with each participant. All interviews were conducted from December 2006 through March 2007. At the start of the first interview, after receiving a verbal and written description of the study, each participant was asked to sign a consent form. Demographic data were also collected.

The first interview began with the question "Tell me about the day you learned about your family member's Alzheimer's disease or dementia diagnosis." Additional follow-up questions—such as "Tell me about key events that led up to the diagnosis," "Did your life change from the time of diagnosis?," "Tell me more about those changes," "How did you know what to do for your family member?," "Tell me what would have been helpful to you during this time of diagnosis and early caregiving," and "Can you describe anything that made this time of diagnosis and early caregiving more difficult?"—were used to elicit further explanation. The interview was guided by the participants. The goal was to offer them the opportunity to provide a rich, detailed account of their experiences. The first interview varied in duration from 60 to 90 minutes and ended when the caregiver had nothing more to add. All sessions were audiotaped. After each session, the tapes were transcribed verbatim by a transcriptionist, and I verified the accuracy of the transcripts.

The second interview occurred three to five weeks later and lasted from 45 to 60 minutes. It served dual purposes: it gave me an opportunity to confirm and clarify the preliminary data analysis, and it offered participants another opportunity to share more information about their experiences. Questions such as "Have you thought of any other information since I last spoke to you?" and "Is this what you meant?" were used. All of the participants completed a second interview.

Data analysis was accomplished using the phenomenological methods described by Barritt and colleagues[8] and Cohen and colleagues,[5] which are based on those originally developed by a group known as the Utrecht school of phenomenology. The process involved first reading through the data several times and extracting elements that described the experience of learning to become a caregiver. In the second phase, the data were reduced by placing similar topics together, eliminating information that was not considered relevant, and simplifying spoken language without changing its character (such as by eliminating "um" and "you know").[5] In the last phase, themes were analyzed with the goal of finding common or shared themes and the language that captured those themes.

To verify the legitimacy of the findings, peer debriefing was used with an expert in the phenomenological method. The preliminary findings, conclusions, and tentative analysis of the first three interviews were checked with this expert early on, and periodic checks continued throughout the study.

RESULTS

Participants. Saturation was achieved with a final sample of eight women and two men, for a total of 10 participants. Their ages ranged from 37 to 84 years, with a mean age of 66.3 years. Length of time in the caregiving role varied from one to 13 years, with a mean of five years. The ages of the care recipients ranged from 58 to 92 years, with a mean age of 77.1 years. Their average age at time of diagnosis was 72 years. Half of the participants had attained a bachelor's or master's degree. Nearly two-thirds (60%) lived in suburban settings. (See Table 1 for more details.)

The recruited participants were considered "veteran" caregivers in that they were already providing care for a loved one with Alzheimer's disease or a related dementia and had been doing so for some time. They were also seen as "expert" caregivers who had developed a familiarity with health care professionals and were knowledgeable about services and information that would have been helpful during their transition. Some had had experience administering medications to care recipients.

All participants chose to be interviewed in their homes. During the interviews their care recipients were either at an adult day program or, if home, in another part of the home.

Themes. Seven themes were uncovered through data analysis:

- something is wrong
- journey to diagnosis: ambiguity and negative emotions
- shifting roles and relationships: losses and challenges
- seeking knowledge and support: solutions and frustrations
- adapting to the topsy-turvy world of caregiving: finding purpose
- preserving self without guilt
- finding a way out

These themes reflected ideas mentioned by the participants in describing their experiences of transitioning to caregiving.

Something is wrong. Although the interviews started with the question "Tell me about the day you learned about your family member's Alzheimer's disease or dementia diagnosis," all of the participants began by recalling the events that preceded the diagnosis. For eight of the 10, small incidents had begun to coalesce, signaling that something other than old age or mere forgetfulness was responsible. They described events that did not initially cause alarm, but that taken together over time began to cause apprehension. These events included memory lapses, inability to complete routine tasks, disorientation to time and place, incidents that reflected impaired judgment, difficulty with communication, and inability to retain new information. Moreover, typically these abnormal behaviors had occurred over a long period of time, in some cases years. One of the most salient characteristics reported at this early stage was fear.

An 84-year-old woman caring for her 87-year-old husband recalled specific incidents that had occurred while her husband was driving. The thought of them still frightened her when she thought about their potential consequences. She spoke with distress, as though these incidents had just recently happened:

> The driving was making me a nervous wreck. Tearing across the country on the superhighways . . . he suddenly would take off and I mean the hair would stand straight up . . . and everyone is tooting horns and things like that. . . . Once I remember he was coming to an incline . . . over an overpass, and he went in the left lane and you couldn't see what was coming the other way. I can think of these things in the middle of the night.

A 49-year-old woman whose 58-year-old female partner had been diagnosed with early-onset Alzheimer's disease described her partner's "loss of common sense" and difficulties in the workplace as signals of something amiss. The partner, who was employed as a bookkeeper, had begun complaining about added responsibilities and new projects that were being demanded of her.

For two of the 10 participants, a medical event had preceded their loved one's dementia diagnosis. In neither case was dementia an expected outcome of the surgical procedures. Although the origins of dementia in both cases could be traced to sentinel events, the caregivers had been compiling evidence of deficits before the dementia diagnosis was rendered.

Journey to diagnosis: ambiguity and negative emotions. As they realized that something wasn't quite right, all of the participants described efforts to obtain answers from health care professionals. Seven participants expressed frustration with the exceedingly slow process of diagnosis, and felt that their concerns were not being heard. They also felt that the physicians were ignoring the valuable information they had to offer as firsthand observers of their loved ones' behaviors. Initial explanations offered by physicians included hearing problems, depression, and fatigue.

One 59-year-old daughter reported that her 88-year-old father had initially been diagnosed with depression. Since her mother had recently died, depression seemed a plausible cause for his difficulties. As she reflected on that time, she said:

> I really think we could have diagnosed [Alzheimer's] earlier, because I was giving them all of the information and he [the physician] was just prolonging it, saying that it was depression. . . . Thinking back on the situation, he [the father] was probably already in the Alzheimer's because, prior to my mother passing, we saw a lot of signs.

Participants were asked to speak about the day they first received their loved one's dementia diagnosis. Most perceived this event as a negative encounter

Table 1. Demographic Characteristics of Participants (N = 10) and Care Recipients

Characteristic	n	%
Caregiver–care recipient relationship		
Wife–husband	5	50
Husband–wife	2	20
Daughter–father	1	10
Daughter-in-law–mother-in-law	1	10
Partner–partner	1	10
Race of caregiver		
White, non-Hispanic	7	70
African American	2	20
Indian	1	10
Highest level of education		
High school	2	20
Some college	3	30
Bachelor's degree	4	40
Master's degree	1	10
Home setting		
Urban	4	40
Suburban	6	60
	Range	**Mean**
Age, years		
Caregivers	37–84	66.3
Care recipients	58–92	77.1
Care recipients at time of diagnosis	48–86	72
Time in caregiving role, years		
Caregivers	1–13	5

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with the health care system. Remembering this time evoked strong emotions for some participants, who became tearful when relaying their stories. Others described feelings of shock as the reality of the diagnosis sank in. A few recalled their distress at a perceived lack of empathy from health care professionals. A 76-year-old woman caring for her 92-year-old husband commented:

> When it first began it was very, very frustrating because I knew something was wrong, and I couldn't get his doctor to admit it. He [the physician] kept saying that it was his hearing and I knew it wasn't his hearing. Only the person who lives with him really recognizes it.

The woman whose female partner had been diagnosed with early-onset Alzheimer's disease reported feeling "shock and disbelief" on receiving the diagnosis. She tearfully described her reaction as follows:

> It just hits you like a ton of bricks. Everything is coming down and it doesn't seem like anything is going right . . . and the denial . . . I just wasn't sure I could handle it. I still don't think I can handle it.

One 82-year-old man caring for his 82-year-old wife still felt considerable anger toward the medical system. He expressed disappointment with the manner in which he was treated when his wife was eventually diagnosed with dementia: "I think it was pitiful, really, the way that the diagnosis was rendered. I think it was pitiful on the neurologist's part, because he couldn't . . . wait on our last trip there to get rid of her."

One 70-year-old widow reported that the physicians had been very open with both her husband and herself when the diagnosis was made. But it was her husband's reaction that she recalled most vividly. After explaining that the husband's symptoms most likely indicated the progression of Alzheimer's disease, the physician asked him if he had any comments. The wife recalled her husband's reaction:

> He turned around to me and had tears in his eyes and said, "Well I'm so sorry what my wife's gonna go through. I feel bad for my wife.". . . That's the kind of guy he was. That just devastated me terribly.

For some caregivers, the diagnosis confirmed their fears. The 84-year-old caregiver was very matter-of-fact about receiving her husband's dementia diagnosis. She stated, "It [the diagnosis] just put a name on it; I knew there was something wrong." Similarly, a 37-year-old daughter-in-law caring for her 72-year-old mother-in-law said, "We weren't surprised because I think we had seen evidence of it in the years leading up to that."

Shifting roles and relationships: losses and challenges. Participants were asked how their lives had changed since they assumed the role of caregiver. As they spoke, it was apparent that there was no distinct point at which that role was assumed; rather, it had evolved over a period of time. Some participants conveyed that their responsibilities hadn't changed or increased immediately, but had slowly become more pronounced as their loved ones' abilities diminished.

The 49-year-old woman whose partner had early-onset Alzheimer's disease reported that she'd had to attend to financial issues quickly, since her partner could no longer work. She had to apply for unemployment and disability benefits for her partner and assume the financial responsibilities for the household. She tearfully described the emotions she'd experienced:

> I just felt that I was too young, there were so many changes. I didn't really want to. . . . It's almost like you have to put your life on hold. I had no idea how long that it's going to be. I remember . . . I just told her, "Let's just go into the garage and turn the car on and just end it" . . . rather than go through it. I guess I was trying to feed her an idea. Isn't that awful?

Participants also described the manner in which the relationship with the care recipient changed. For the spouse caregivers, sorrow at the loss of their partner and the relationship they'd once shared was a common theme, as it was for the 49-year-old woman caring for her female partner. Six of the seven spouse caregivers became tearful as they spoke about this part of the story.

The 76-year-old caregiver had been married for only six years before the onset of her husband's dementia. She spoke poignantly, saying, "I have lost my companion; I am lonely. I said recently that I have the most silent house in the world. He never talks." She described her first marriage as "a very bad marriage," and said that when she met her current husband she had "found out what companionship was all about. . . . It was wonderful when we traveled. It was just such closeness; we could always just talk to each other."

The 82-year-old caregiver missed the companionship he had once shared with his wife. Aside from dementia, his wife was fairly healthy, but he was very troubled by her inability to initiate tasks and to communicate. His comments reflected that sense of lost companionship:

> That's the worst thing about this whole thing, this whole venture. I remember her [as] good for a laugh, articulate, smart and intelligent, never nasty, a wonderful mother,

> a tremendous mother. To see her now, [she's] almost like a vegetable . . . and it's sad. Of our 63 or 62 years, it's a hell of a way to end our life together.

Several participants referred to how their roles had changed from one of partner to parent. One 65-year-old woman who was caring for her 77-year-old husband had pleasant memories that sustained her, but she was now dealing with his bladder and bowel incontinence. Quite matter-of-factly, she stated, "I'm the mother and he's the child, and that's just the way I view it. I don't have a husband; I don't have a mate." She also said, "Sometimes I think I'm the maid with the cleaning him up, with the making the meals, doing his clothes, doing his laundry."

Because disease onset is subtle, caregivers often assume the role of caregiving before they quite realize they are doing so.

Seeking knowledge and support: solutions and frustrations. All of the participants reflected on their attempts to obtain information about their loved one's disease and its management when they first assumed the caregiver role. Some reported positive experiences; others spoke of the frustration they felt.

An essential strategy for all of the participants was to read anything they could find about the disease. Eight of them mentioned Mace and Rabins's book *The 36-Hour Day* (Johns Hopkins University Press, 2012) as their lifeline for information. Some had learned of the book through a support group; others found it through their participation in Project ACT. One caregiver, the 37-year-old daughter-in-law, named *The Forgetting: A Portrait of Alzheimer's* (Public Broadcasting Service, 2004), a documentary film based on Shenk's book *The Forgetting* (Doubleday, 2001), as a valuable resource. She said that watching this documentary and reading parts of the book

> [were] the wake-up call to me that made me realize that if [her mother-in-law] . . . ended up dying from pneumonia, that would be a blessing compared to dying of Alzheimer's. . . . That's what that documentary taught me. Allowing the brain to shut down on every level . . . is not the most pleasant way to go.

This knowledge also created a conflict for this caregiver with regard to future health care decisions for her mother-in-law. Faced with whether to put her mother-in-law through annual preventative examinations such as mammograms and colonoscopies, she said,

> So I struggle with that and I also think about . . . if she was diagnosed with cancer at some point. I don't see us ever taking an aggressive approach . . . my husband and I have talked about it, and of course every cancer situation is different, but I think we would be looking more for keeping her comfortable.

Seven participants attended support groups at some point during their time as caregivers. All but one believed the group was essential for their well-being. Referring to the group setting, the 76-year-old caregiver said she could share strategies that worked for her and learn new ways to deal with her husband. She said, "It's the little things that they tell us, you know, and the fibbing. You really do fib." She credited her group with giving her suggestions that ranged from how to awaken her husband in the morning to which products might work best for managing his incontinence.

One participant (the 82-year-old husband) who had not attended a support group didn't seem to know how to find information about available resources on his own. He expressed his frustration:

> You see, there's not that one kind of person . . . like the priest; you go to the priest and confess and get some counseling. I don't have that. I haven't that person in the medical field that can tell you what the better road to take is.

Adapting to the topsy-turvy world of caregiving: finding purpose. Although the focus of the interviews was on the transition to caregiving, the participants could not settle on distinct points when this role began for them, and had no sense of when it would end. All of them acquired strategies for dealing with their charges from various sources, including reading materials, support groups, the process of trial and error, participation in Project ACT, and their health care providers. Such strategies evolved over time.

Five participants spoke about finding ways to simplify hobbies or pastimes that the care recipients had once enjoyed. This allowed the recipients to participate in an activity, and according to their caregivers, in so doing they felt a sense of purpose.

Four participants had used adult day centers for their loved ones. The 37-year-old daughter-in-law decided that assisted living was not an option for her mother-in-law. She knew from her research on

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dementia that a well-managed adult day center could be an important resource. She spoke in extremely complimentary terms about the program to which she sent her mother-in-law:

> Adult day care really saved our family life. . . . I completely credit them with giving her a sense of purpose in life. She says she works there; she's going to the shop. In the evening if you ask her what she did, she said, "Well, I did piecework and patterns and you know all that stuff.". . . She just loves it and I think their formula has just worked really, really well.

Most participants felt they had acquired valuable information and advice that they wanted to share with other caregivers and health care professionals. Their participation in this study seemed to offer them a way to do that. Many of them shared specific suggestions with me. For example, the 65-year-old woman who was caring for her husband advised new caregivers to accept their loved one: "You'll never be able to change the person, so don't try. . . . They're in their own world and they're doing or not doing what they can do." She also said, "I would encourage anyone to immediately find a group close to where they live and go to it. . . . Start building a good support system around you." And the 59-year-old daughter caring for her father suggested that health care professionals immediately provide new caregivers with information about available resources and how to access them.

Preserving self without guilt. The participants reported that over time, they began to realize that self-care was essential if they hoped to continue being able to fulfill their roles as caregivers. All of them offered at least one such strategy that they employed. A common belief was that it was therapeutic to have someone to talk to about their situation. Several participants reported that being able to tell their story during this research study was invaluable. One participant said, "I mean to me, right now, this is the most wonderful thing, because I don't get people to talk to." Another remarked, "You know more about my life than anyone."

Travel was a beneficial diversion for some. Humor was another common strategy. Indeed, during the interviews, all of the participants shared humorous anecdotes related to their loved one's care. Their laughter seemed to help them handle difficult situations. One 71-year-old caregiver said that his children and friends reminded him that he needed to care for himself and not pressure himself to do everything as he had in the past:

> I feel it's selfish to do things for myself, things that would benefit me alone, because we have been doing stuff together, and I feel we should still be doing things that both of us would enjoy.

Finding a way out. Some participants expressed concerns about the future, especially with regard to potential health care decisions. These were difficult issues for them to verbalize, and there were no easy answers. Their stories reflected their anguish over the decisions they might face. Emotions such as self-doubt, confusion, ambivalence, and guilt prevailed. Some participants had already been confronted with the realities of such decisions. The 84-year-old caregiver whose husband had Alzheimer's disease shared that he had also been diagnosed with prostate cancer several months earlier. She and her sons had decided to forgo the radiation treatments that she said "would kill him"; instead he was being treated with some "hormone pills." She seemed to feel some ambivalence about the decision: "You sort of feel like you're condemning them when you decide not to go through with treatment." Another caregiver seemed to be experiencing distress and turmoil over a similar issue. While his wife appeared to be physically healthy, he felt she was suffering, as reflected by his comments:

> I said to my daughter the other day, and I know she was shocked about it, "It would be good if she would die tomorrow and not linger and go through this phase; it's going to get worse." It's not that it's affecting me personally but I don't want to see her suffering that way.

The 37-year-old daughter-in-law caring for her mother in-law summarized her conflicting emotions and the lack of definitive advice when she said,

> I understand that . . . every doctor in the practice can't be an expert on this. But there [should be somebody who] . . . has read the medical ethics issues on this and . . . has a better understanding of what it means to die when your brain is the organ that is shutting down . . . to help weigh the options. I think I'd find that helpful. That's been something that we haven't really come across. I feel like we're in a big open field as far as this subject goes.

DISCUSSION

Many of the participants in this study reported a long journey to their loved one's diagnosis. They reflected on episodes that preceded the diagnosis by long periods of time, in some cases years, and which eventually caused them to seek medical assistance. Aneshensel and colleagues have referred to this early period as the "role acquisition" stage.[4] During this stage, caregivers in this study adapted to their loved ones' difficulties by making small adjustments to normal everyday routines in areas that included household tasks, driving, and work responsibilities. They were initially unaware of the true cause and scope of the problem they were about to face.

Previous studies have reported numerous challenges to diagnosis, including barriers such as the belief that memory loss and cognitive difficulties are a normal part of aging, patients' own unawareness or minimization of their difficulties, and family members' uncertainty over how to interpret the symptoms they were seeing.[9, 10] Researchers have also reported on the challenges posed by caregivers' negative emotions as they adjusted to their new role, including frustration, anger, and doubts about their capabilities.[11] For both care recipients and their caregivers, receiving a diagnosis can mark the end of uncertainty.[12] In a recent literature review, Dubois and colleagues concluded that more research is needed on the risks and benefits of, as well as barriers to, timely diagnosis.[13]

All of the participants in this study articulated how their roles changed as they transitioned to becoming caregivers. Some mentioned having to take on unwanted responsibilities. Others described the burden that these new tasks, as well as the unfamiliar role of caregiver itself, represented. The caregiving role seemed to be one that the caregivers eventually felt captive to, and one that all participants expressed was unwanted.

As participants spoke about learning that role, reading emerged as an important source of information. For most, *The 36-Hour Day* was their "bible" for information. Seven participants found support groups to be another means of obtaining knowledge. Much has been written about support groups and their overall impact on caregivers' well-being.[14, 15] In this study, most of the participants who joined support groups spoke very highly of them. It was also striking that none of the participants mentioned any interactions with nurses during the early stages of caregiving.

All of the participants shared strategies they have implemented to manage their loved one's care. These strategies were acquired through various sources, including reading, support groups, health care professionals, and trial and error. Four participants utilized adult day care services for their loved ones. They described the research they'd performed to identify programs that would allow the care recipients to be engaged in meaningful activities. In making use of such programs, these caregivers also provided themselves with time to pursue personal interests and complete other responsibilities.

Caregiver burden has been well documented,[16, 17] and most of the participants in this study had identified at least one way to preserve their own well-being. In *The 36-Hour Day,* Mace and Rabins speak to the importance of caring for self. They stress that it's essential for caregivers to take time out or away from care recipients so that they don't exhaust their own physical and emotional resources. Caregivers need to feel empowered to address their own physical and emotional health without guilt. It's not unusual for caregivers to perceive taking such steps as self-centered. Yet failing to restore and maintain one's own resources can be manifested in physical and psychological symptoms, including anxiety, depression, and increased susceptibility to infection.[16, 18]

Several of the participants in this study expressed feelings of sadness and apprehension as they considered an uncertain future. Boss coined the term "ambiguous loss" in describing the grief that caregivers experience when their loved one is still physically present but otherwise absent.[19] Because of the insidious nature of Alzheimer's disease and related dementias, such grief has no clear beginning or ending point. Unlike grief associated with death, which at first may be overwhelming but then tends to lessen, the grief experienced with ambiguous loss can continue for a long time. In such cases, the caregiver is grieving the loss of both the person they knew and the relationship they once shared.[20] All of the participants in this study reflected on such losses.

One unexpected finding that emerged from this study was the absence of any mention of nurses.

Implications for education, research, and practice. The themes that emerged in this study suggest several areas for further research. As participants recounted their journeys to diagnosis, they spoke of impediments to timely diagnosis and difficulties in accessing appropriate services. Further investigation of the experiences and needs of family members during the early stages of a loved one's decline are warranted. And further research on acclimation to the caregiving role and on the positive aspects of caregiving may help in developing strategies that can support caregivers and their well-being.[21, 22]

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The themes of preserving self without guilt and of finding a way out suggest that these areas also warrant further exploration. The ethics involved in health care decision making were a major source of concern for some participants.

One unexpected finding that emerged from this study was the absence of any mention of nurses. As in Teel and Carson's study,[10] none of the participants identified nurses as potential primary sources of caregiver support or education. Yet in their roles as professional caregivers, educators, and patient advocates, nurses can offer family caregivers the skills, knowledge, and resources to successfully function in that role. For example, this journal has published two useful evidence-based supplements: *Supporting Family Caregivers* (http://bit.ly/2uNJnMB) and *Supporting Family Caregivers: No Longer Home Alone* (http://bit.ly/2sxg4iC).

Limitations. Because all of the participants were drawn from a research database, they might possess certain characteristics that prompted them to participate in a research study. Thus they may not reflect the larger population of caregivers of people with Alzheimer's disease or related dementias. The participants were also asked to reflect back in time—sometimes years—to the beginning of their caregiving roles; in effect they were reinterpreting their experiences from that early time. Finally, because all data coding and theme identification were done by one researcher, the possibility of bias can't be ruled out.

CONCLUSIONS

All of the study participants described their changing roles and the challenges they faced as they transitioned to becoming caregivers for loved ones with Alzheimer's disease or a related dementia. In particular, participants expressed needs for better communication and access to resources, as well as for self-care and help in facing an uncertain future. The findings also speak to the importance of health care planning early in the disease process, and of raising awareness about nurses as a resource for family members. ▼

For 57 additional continuing nursing education activities related to caregivers, go to www.nursingcenter.com/CE.

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