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Feature Article

Caregiver decisions along the Alzheimer's disease trajectory

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ABSTRACT

Despite the rising prevalence of Alzheimer's disease (AD), there is limited systematic evidence about disease specific decisions. The aim of this qualitative descriptive study was to identify decisions across the AD trajectory using focus groups of past and present caregivers. Qualitative content analysis revealed three main categories with corresponding categories and sub-categories. *Main Category One*—Decisions pertaining to self—yielded two categories: decision pertaining to the offering of self and care for the caregiver. *Main Category Two*—Decisions pertaining to the patient—yielded three categories: decisions about care and treatment, living arrangements, and protecting the patient from harm. *Main Category Three*—Communication and relationships in decisions—yielded two categories: navigation and negotiations. The results of this study will inform healthcare providers and caregivers as they work together to anticipate, prepare, and plan for care management decisions over the AD trajectory.

Alzheimer's disease (AD), a progressive disease associated with cognitive and functional decline, affects 47 million people worldwide.[1,2] Alzheimer's disease is highly individualized and variable in presentation from the initial appearance of signs and symptoms and throughout disease progression. The complexity of AD requires patients and informal caregivers, many of whom are family members, to make care management decisions across the disease trajectory, including diagnostic and treatment decisions and those related to palliative and end of life care.[3,4] As cognitive decline becomes pronounced, the patient's decision-making also declines, leaving caregivers as the primary decision-makers.[5,6]

A diagnosis during the early stages of AD affords healthcare providers with both opportunities and challenges. Opportunities arise when patients have the cognitive ability to participate in discussions about present and future decisions. This allows patients to share with their healthcare providers and caregivers their anticipated desires, thereby facilitating early planning and shared decision-making.[7,8] Early diagnosis offers healthcare providers the opportunity to educate patients and caregivers about AD and the disease trajectory. This knowledge can heighten patients' and caregivers' awareness of the types of decisions they may face while offering an opportunity to anticipate, prepare, and plan.[9,10] Challenges occur when the patient and/or caregiver is aware of AD but not ready to engage in early discussions about care management, is unaware of the trajectory of AD and the significance of early decision-making, or lacks resources and access to healthcare providers who can introduce and guide these discussions. Caregivers may find themselves making decisions for the patient unaware of the patient's preferences, thereby creating uncertainty.[5,11]

Preventing and addressing uncertainty requires knowledge about the types of disease specific decisions caregivers face. Decisions vary across the AD trajectory according to patients' physical, mental, emotional, and financial needs, values, and preferences.[10] The recognition of the disease specific decisions in AD provides the necessary information that caregivers and healthcare providers need to know to engage in anticipatory discussions, preparation, and planning for future care management.[12] Despite the prevalence of AD, there is limited research about the specific decisions that present themselves across the AD trajectory.

Aim

The purpose of this study was to identify AD specific decisions that past and present caregivers faced over the disease trajectory.

Methods

Design

This study used a qualitative descriptive design using the Krueger and Casey[13] systematic focus group interview method. The study was reviewed and approved by the Institutional Review Board (IRB) at the authors' university. Consent from the agency where data were collected was also obtained. Information regarding the study aims and focus group process was provided to all participants in advance and informed consent was obtained. Participants received a $25.00 gift card.

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Participants

A convenience sample of caregivers ($n = 13$) was selected through a partnership with an AD support agency located in a large northeastern city in the US. Two focus groups consisted of past caregivers ($n = 7$) who offered information about their experiences. A third focus group consisted of present caregivers ($n = 6$) to offer insights into the ongoing decisions they were making during the process of day-to-day care. Comparing and contrasting interview data across both groups of participants lead to the identification of disease specific decisions.

Data collection

Focus groups took place July, September, and November 2017 at the support agency. Each session was 90 minutes long and was recorded. An IRB approved transcriptionist transcribed the audiotapes from the meetings. The first author (MTL) led the focus group interviews using an interview guide (Table 1). The second author (JTS) took field notes. Each session began with an introduction and a broad opening question to stimulate discussion, followed by focused questions. The investigators debriefed after each session to review notes and reflect upon the points learned, unexpected observations, and insightful participant quotes. The debriefing sessions also served as a means to generate new questions for upcoming groups.[13]

Data analysis

Qualitative content analysis was applied using a multi-step process.[14] Past and present caregivers provided data of a heterogeneous nature; therefore, the two groups of participants were separately analyzed. First, both investigators independently read each transcript. During the initial reading, investigators documented notes on the transcript, known as coding, using actual phrases from participant.[14] The investigators were mindful of the frequency of topics raised, the extensiveness of certain topics, and the emotions displayed. Second, the investigators discussed their codes and merged them. Third, the investigators worked independently with the final list of codes identifying categories and sub-categories. Fourth, the investigators shared the final categories and sub-categories for consensus. The data were then collapsed into final sub-categories, categories, and main categories identifying specific decisions along the AD trajectory.

Results

A total of 13 caregivers participated in three focus groups. Table 2 offers a description of participants. Focus group analysis yielded three main categories with corresponding categories and sub-categories (Table 3).

Decisions pertaining to self

Participants identified that throughout the AD trajectory they faced decisions pertaining to themselves. Two categories emerged: offering of self and care of self.

Offering of self. Past and present caregivers identified decisions they made that dealt with the offering of themselves. This involved giving back and advocating in some way to others with AD, caregivers, and to organizations. The extent and depth of the discussion was greater in past caregivers who expressed a need to give back a total of 10 times compared to 2 times for present caregivers. The action of giving back was described as a form of healing as in "*making sense of a horrible experience*" and was a coping strategy. Specifically, participants noted:

> I go and sing with Alzheimer's people and I speak to relatives. I do everything because I know that if there is anyone out there who I can help I will. . .

> I feel like participating in these kind of things in activist ways. I have been to Washington DC, Albany and to the Alzheimer's National Conference. . . .for me it is a way to carry on the fight for my husband and for my mom.

Care for the caregivers. Both groups identified the need to make decisions about how to care for themselves so they could be an effective caregiver. Care for self was discussed 13 times by past caregivers and 19 times by present caregivers. The emotions associated with the discussion on care for the caregiver were intense. Participants realized that in order to continue to be a caregiver they needed some type of support to manage ongoing challenges. For example, one participant noted, "*I'm at my wits end,*" when she realized she needed help. Another noted:

> *There were many times when I did not know what to do . . . I would call the 800 help number and I would say, 'I do not know what to do. She is freaking—I am freaking out—and I do not know how to handle this.' . . .There was always somebody there to answer the phone.*

The awareness of needing help came as others introduced the idea to caregivers, such as a professional, friend, or family member. For example, one participant noted:

> The focus is so much on the person—the patient. When is it that you finally say I need help? . . .I was still working full time and my husband was not. I crumbled at my desk at work and my boss said 'Okay you need help; something is wrong.'

> There is a social worker, and from the very beginning, she kept saying—'How are you going to take care of yourself?

> What are you going to do for yourself?' That was her mantra. The question for me then was—am I going to take care of myself?

Participants in both groups also identified the need to find out more information as a means to care for themselves so that they could make necessary decisions for the AD individual. For example, a participant identified the frequent need to talk to someone about medical

Table 1
Focus group interview guide.

Past caregivers	Present caregivers
Broad opening question:	**Broad opening question:**
• Reflect upon the time in which you were a caregiver. What specific decision did your face as you cared for the individual with AD?	• Reflect upon the care that you provide every day. What specific decision do your face as you care for the individual with AD?
Example of focused questions:	**Examples of focused questions:**
• What did you do as you faced these decisions?	• What do you find yourself doing as you face these decisions?
• Who did you go to for information and support?	• Who do you go to for information and support?
• How did you feel as you faced these decisions?	• How do you feel as you face these decisions?
• What were the most difficult decisions that you had to make?	• What are the most difficult decisions that you find yourself facing?
• What have you learned that you could share with other caregivers?	• What are you learning that you would like to share with other caregivers?

Table 2
Participant characteristics (n = 13).

Participants	Female	Male	Relationship to patient	Length of time as caregiver
Past caregivers	5	2	5 female participants • 4 caring for mother • 1 caring for husband 2 male participants • 1 caring for mother • 1 caring for wife	1–15 years
Present caregivers	6	0	6 female participants • 3 caring for mother • 2 caring for husband • 1 caring for father	Length of time to date: 1.5–8 years

decisions, stating "*so who can I call to help me with this*." In these situations, caregivers explained their need to search for and access programs that would provide information they needed to make informed decisions, thus alleviating a burden and therefore caring for self.

> I did not know what this disease was about. I had to learn as much as I could and that is how I found my support groups, looking for the information.

Social isolation was another topic identified by both groups. As one participant noted, there is "*the destruction of one's social life as more people become uncomfortable*." Participants identified the decision to become a member of a social support group as a way of alleviating isolation. Participants also described their decisions to access various forms of social media as a strategy for seeking and delivering educational information while relieving social isolation.

Participants in both groups came to a decision that they had to find alternative ways to live their lives, care for themselves, and openly engage in self-care in order to achieve and sustain their own health.

> When my father was diagnosed I started taking antidepressants because there was just no way that I was able to get up out of bed and go to work and leave my mother. . . .I stopped taking them. I just find other ways of dealing with it. I like to exercise and write and that is pretty much it because you cannot be on those types of medications for a long time.

Self-awareness and acknowledging one's own need for help was an antecedent for participants who made decisions to seek help. Both groups identified how the burdens and stress of caregiving, along with corresponding emotions, had negative physical and mental

Table 3
Analysis-sub-categories, categories, and main categories.

Sub-categories	Categories	Main category
• Giving back to present caregivers • Giving back to those diagnosed with AD	Offering of self	**Main category one: decisions pertaining to self**
• Giving back to organizations • Acknowledging the need for help • Seeking information • Support groups • Social isolation	Care for the caregiver	
• Seeking help with initial signs and symptoms • Accept the diagnosis	Care and treatment	**Main category two: decisions pertaining to the patient**
• Treatments options including end-of-life care • Home care	Living arrangements	
• Skilled nursing placement • Assisted living placement • Limiting independence, and autonomy	Protecting from harm	
• Who tells the patient the diagnosis? • What to tell others • Creative lying • Legal and financial matters		
• Creative solutions for difficult situations • Navigating providers • Navigating organizations and systems • Navigating family • Navigating through day to day operations	Navigation	**Main category three: communication and relationships**
• Negotiating providers • Negotiating organizations and systems • Negotiating family • Negotiating through day to day operations • Negotiating with self	Negotiation	

health consequences, and described the decisions to finding help for themselves was essential for them to care for others.

Decisions pertaining to the patient

Participants identified three categories of decisions pertaining to the patient: decisions about care and treatment, living arrangements, and protecting the patient from harm.

Decisions about care and treatment. Decisions about care and treatment over the disease trajectory were discussed by present caregivers seven times and four times by past caregivers. Both groups noted that initial decisions on care and treatment came with the realization that they needed to seek help because of presenting signs and symptoms. Participants stated that while the signs and symptoms of AD were present and they knew "*something was wrong*," the decision to seek care did not happen immediately. When the decision was made "*it was a big step*."

> It was so insidious and change happened subtlety over time. . . .If you take two steps back you look you can see mild changes but day-to-day you might not realize.

> We saw signs early but once his business went into foreclosure because he stopped paying bills we were like—well it is time to go to the doctor.

Participants noted that a delay in seeking assistance might be because the signs and symptoms were subtle at first; however, it was also identified that the delay may be due to an "*adjustment*" a person may need to make prior to "*acknowledging*" that something may be wrong and "*seeing the loss.*"

Once caregivers acknowledged that something was wrong and sought a diagnosis, decision-making about care and treatments did not happen immediately. Participants spoke about the need to accept the diagnosis before any other decisions could occur. Questions asked included: What is this disease? What does it mean? What does it mean for our relationship? How will it change our life? Once there is acceptance and understanding of the disease, then the process of decision-making involving anticipation, preparation, and planning could ensue. As one participant noted, this is when "*action*" could take place.

Who was responsible for telling the patient and informing others was another early decision. How and who informed the patient varied. For example, a participant noted:

> I told my wife. I did it for her because I knew that this was what needed to be done.

As the trajectory progressed, decisions about types of care, treatment options, medications, and clinical trials began to surface. For example, a participant noted:

> What medical treatment do you continue? What about current medications for certain conditions? Do you continue to do those? Is there a point where it does not make sense anymore? . . .it is like a balancing act.

Still for others, decisions about end-of-life care were especially difficult and were compounded by loss and grief. Participants echoed these emotions in the following statements:

> You knew what they were going to do was kind and gentle. . . .they were not going to die in trauma. . . . the end of life would be as peaceful as possible.

> To me it was hard because it was acknowledging—oh my God we are at the end, right?

Still other decisions created uncertainty in the caregiver. An example of this was care decisions of an ethical nature, such as:

> My mother's health proxy says she does not want to be hand fed by anyone. . . .And, if she is in a nursing home and they do allow it, well there is a pit in my stomach, will I go through with it?

Decisions about living arrangements. Decisions about living arrangements encompassed care in the home, assisted living, and nursing home placement. Past caregivers embarked upon these discussions 11 times and present caregivers five times. Participants in both groups identified how difficult it was making decisions about living arrangements. For some the decision was difficult because they felt that it was their responsibility alone. For other caregivers the emotion of making decisions about assisted and long-term care was challenging because they did not know if the decision was the "*right*" decision.

> It took two years for me to overcome my feelings that I had the primary responsibility to take care of my wife. They had to give me permission to engage this wonderful caregiver. And, that changed my life. I had somebody.

> Towards the end, it was moving him to a nursing home. That decision was the hardest.

Decisions about living arrangements were challenging and emotionally charged. These decisions were a continual reminder of the ongoing decline of the patient facilitating feelings of chronic loss and grief. Furthermore, caregivers often experienced regret at not being able to provide the type of care necessary for the patient to remain in the home, compounding guilt. Some caregivers initially experienced a sense of relief with placement; however, the relief was short lived as caregivers experienced renewed guilt because of the relief they felt. Placement, however, often brought other challenges. For example, caregivers expressed the need to be ever vigilant over the care rendered in long-term care to ensure the AD patient was well cared for, which too signaled decisions on protecting the patient from harm.

Protecting from harm. Both groups of caregivers expressed the need to protect the AD patient from harm. Past caregivers discussed this category 13 times while present caregivers offered five examples. Protecting the patient from harm included enhanced vigilance and taking action to protect the patient from others who may inadvertently cause discomfort to the patient. For example, participants noted:

> You could sit in the courtyard. . . .But then the question is, would she have wanted people to see her in this debilitated state? . . .At what point do you say, she looks so awful, you know, or that if she knew about this she would be horrified.

> It goes back to protecting their dignity and how I did not want him to feel embarrassed about this or to feel like it was something shameful. . . .And, at the same time wanting to protect his right to dignity and his right to disclose what he wanted to disclose.

The concept of dignity and how to maintain the patient's dignity was a concern for participants especially when decisions were taken away from the patient. For example:

> We were talking to the doctor and he said . . .'You can no longer continue your psychoanalytic practice.' . . .So, it was no longer about yourself it was about your work, who you are, and your identity.

As the AD trajectory continued, caregivers found themselves making decisions that limited the patients' independence and autonomy in an attempt to protect them from harm or causing harm to others, thus compounding their experience of loss, guilt, and grief. For example:

> . . . she was able to go to places that she was familiar with like the doctor, the dentist. . . .And, she did that alone until one day, the police came—when they found her wandering. . . .How much do you allow them to do because on the one hand, you do not want them to be shut in beyond what is necessary but you also do not want to risk it?

> What do we do about driving? There was no way that I was going to be able to figure this out!

Participants expressed an awareness and mindfulness of the AD patient as a person who needed to be treated with respect, particularly when making decisions perceived as taking away their autonomy. For these caregivers, decision-making required an ongoing balance to ensure outcomes were not only beneficial but mindful of the patient as a unique individual.

Communication and relationships

Both groups of participants described the importance of communication and relationships for decision-making, including the ability to navigate and negotiate to meet their needs and those of the patient.

Navigation. Navigation was a category discussed six times by past caregivers and 15 times by present caregivers, whose discussions were in greater depth and very emotionally charged. Participants discussed the need to navigate the healthcare system, the diversity of providers, family, and conversations with the patient. The process of navigation began with an awareness of a particular need and a corresponding goal. Reaching the goal takes skills to navigate a complex terrain that requires decisions about what direction to take and who to contact, as well as evaluation skills that informed the caregiver whether or not the navigation was successful or if there was a need to make alternative detours. Participants noted that while they were navigating the terrain, communication and relationship building was essential for successful outcomes:

> My mother was an old black woman; I knew that she needed to have a black physician. How many black geriatricians do you know. . .? Fortunately, through asking questions of my friend, who had another friend, I received the name of a black geriatrician.

> It is making connections and building relationships with places that you never know if you are ever going to need.

Participants further described that navigation was also essential in the family system:

> If you are the dominant family member then you are probably going to be the one who does this on your own and because you are going to discuss this with the family there is going to be confusion and you just have to find out what you need to find out.

Another example was the caregivers need to navigate the complex communication that took place with the patient especially as the disease advanced. Participants identified that staying connected was important and they had to decide how to navigate these conversations.

> Even just keeping a conversation going is difficult. Therefore, I keep asking her the same question every morning. . . .It is not even so much what she says—just that we somehow stay connected.

Communication with the patient also included requests that gave the appearance of being mundane yet were challenging to navigate to reach a reasonable decision. Other situations appeared impossible to navigate. For example, participants noted:

> My father loves sweets and we noticed when he has ice cream he is up more during the night. . . .do we give him the dessert and then we know he will not sleep. . . .It is hard because we want him to feel included but also, we want to sleep.

> Mom complains about her wisdom teeth. Is this real? Is this not real? Do I take her to the dentist? Do I let it go because I think it is in her head? Am I supposed to do something with this?

Finally, participants discussed how they needed to navigate exhausting day-to-day decisions.

> How many hours can I leave him alone? . . . He has not wandered and he does not set fires. He does not lock himself out of the house, so I figure four. . . . I am going to dinner so that will be another two hours. So how do I do all of this?

Negotiation. Navigating the day requires ongoing decision-making. As the caregiver navigates the tenuous terrain, the skill of negotiation was essential for decision-making. The topic of negotiation was discussed 16 times by past caregivers and 18 times by present caregivers. Negotiation generally took place as a discussion between the caregiver and another person or system. There were also times when the caregiver self-negotiated while self-reflecting, for example when deciding when to visit the patient and how long to visit. Caregivers negotiated with themselves to come to a decision they felt comfortable with.

> I think each of us sort of figures out a comfortable spot. And, it takes a little time adjusting. When I was working, I would see mom once a week. . .. And, I can't spend more than an hour and a half and I decided that meals are better because there is a focal point—food.

Negotiating also took place between the caregiver and the patient when patients made decisions that had potentially harmful consequences. This offered a challenge to caregivers as they negotiated with the patient to come to a more acceptable and safe decision. Caregivers spoke of the need to maintain the patient's independence and autonomy in these negotiations in an attempt to minimize confrontations and maintain dignity. Participants offered these examples:

> I was taking my wife home from dinner one evening . . .we were two blocks north from our home and she said we live south. And, I said no we live north and she insisted we lived south. I said let's walk one more block and then she realized it.

> . . . we do not want to have an argument, we do not want to have a confrontation and we want them to see that, yes, they can still make decisions maybe they just need a little help in order to make these decisions.

Participants also noted the need to be creative in these negotiations. An example of this creativity is seen in the following comment:

> I got my mom a [identification] bracelet and she did not want to wear it. I got one for myself as well. And, I said, 'Mom I got this because if something happens to me, I am alone and there is a code on the back so someone will know to call you. And, she said okay. . . .I knew that if I pushed her she would never do it. And, I know that I had to frame it in such a way that it was about me.

Many times negotiation took place between the caregiver—if that person is a family member—and other family members:

> My sister and I try the best we can to help our mother and relieve her but it is hard because her and I both have full time jobs and our own lives and she does not want us to miss out on that because that is her husband but he is also my father. . .

Caregivers may also find that they need to negotiate with a healthcare system:

> The hospital was no help, and I got aggravated with all of them and finally I had to call a meeting between all the doctors because I could not get anyone to give me any answers.

The concept of renegotiation also surfaced. Caregivers caring for a parent, who had a difficult past relationship, identified the need to renegotiate their relationship and the associated decisions that went into this. For example:

> I didn't fall in love with my mom until after she became ill. . . . My mother was tough love also. . . .I said to her, Ma I want to apologize for all of the times I opened a big mouth to you and that we did not get along and that we clashed. . . .So all of a sudden, she opens her eyes and smiles at me and says I love you.

Caregivers offered many examples of trying to figure out how to negotiate care for the patient and reach a desired goal. The notion of figuring out this care began with an awareness of an unmet need, identifying a goal to meet that need, and identifying the resources available to meet that need, followed by the caregiver's ability to gain access to these resources. This process of figuring out and knowing how to access resources is achieved by the caregiver's ability to navigate and negotiate through complex systems as well as the diversity of providers within those systems and family members.

Discussion

The purpose of this study was to identify disease specific decisions across the AD trajectory. An understanding of these decisions is necessary to guide healthcare providers' education of caregivers and to increase caregivers' awareness of potential decisions. This increased awareness enables healthcare providers and caregivers to work together as they anticipate, prepare, and plan for decisions-making that is shared and patient-centered.[15,30] The comparison of the frequency of topics offered by past and present caregivers provides evidence of the lived experience. Individuals presently involved with caregiving offered greater depth with strong emotional overtones of loss, guilt, and grief when discussing the challenges associated with decision-making where past caregivers had time to reflect on their experience and decisions made, come to terms with emotions experienced, and offer themselves in support of current caregivers.

Caregiver burden is an experience caregivers live with on a daily basis as they question if the decisions made are congruent with the patient's ideas, values, and beliefs.[16] Caregivers who experience guilt over decisions they made or have failed to make may reflect upon those decisions and see themselves as committing a transgression upon the patient.[17-19] Guilt is also compounded when caregivers believe they are to blame for not carrying out their caregiver tasks as they should, blame themselves for not taking needed actions, or perceive that decisions made were not beneficial.[19] The decision to give back, therefore, can be a way to begin a process of self-forgiveness and growth for the caregiver as they work through their guilt.[18,19] Advocacy and giving back are ways of fighting this debilitating disease and in doing so enhancing one's self-capacity and fulfillment.[20] Offering of self occurs more in past caregivers compared to present caregivers for varied reasons. Present caregivers are overwhelmed, challenged by day-to-day decision-making, and have not yet had the time to contemplate their own feelings about their caregiver experience. Furthermore, there is evidence that self-forgiveness is linear and increases over time along with a decline in guilt.[17]

All caregivers identified the need to take care of themselves in many ways. For example, there was the need for information so that caregivers could make important medical, legal, and financial decisions.[11,21,22] Participants all noted how support groups and social media networks were a life-saving means of finding additional information and supporting others who were living through the same experiences.[23] These same support groups also helped caregivers deal with social isolation.[24,25] Care of self, therefore, is a buffer to caregiver burden and stress by enhancing coping.[24-26] Participants expressed that care of self was essential to maintaining health so that they could continue to be an effective caregiver.[27]

Participants identified many decisions related to the care management and living arrangements of the patient that required the ability to navigate and negotiate with the patient, family, healthcare providers, and systems. Caregivers are often unfamiliar with formal healthcare delivery systems or do not understand how these systems work thus compromising their navigation abilities.[28] Part of navigation is monitoring progress and knowing how to find needed information to make decisions. As caregivers navigate through the complex terrain, they need to communicate and ask questions. With each question the knowledge gap closes, "ambiguity lessens" and questions become more "refined" until unmet needs are met and goals achieved.[2] At times, caregivers must challenge the healthcare system, providers, family, or patient using negotiation strategies. Negotiation occurs as caregivers interact with others, influence others, come to an agreement about certain decisions, and take a particular course of action to reach a desired goal.[29]

The concept of renegotiation as a decision was also introduced, particularly when a parent was requiring support.[30] Renegotiation between the child as caregiver and parent may be needed when there where difficult past relations. The AD trajectory and the caregiver process creates the context for renegotiation of the caregiver/patient relationship allowing for a working through of past difficulties and finding ways to appreciate one another.

Caregivers are often unable to visualize the AD trajectory and decisions they may face. Healthcare providers should begin discussions early in the disease trajectory when patients are able to participate. The patient's ability to participate in these discussions is beneficial as these discussions may reduce conflict and uncertainty by offering direction for caregivers.[7] Many AD patients have not been invited into these discussions or are not ready to begin the anticipatory preparing and planning processes.[7,31] There are many reasons for delayed conversations including whether or not the AD patient perceives these discussions as necessary along with denial and fear about the diagnosis and readiness to look to the future. The lack of discussions has also been linked to barriers associated with family/caregiver and healthcare provider willingness to begin discussions.[8]

Limitations

There are several limitations to this study. A small convenience sample of caregivers who utilized an AD support agency located in an urban area participated in this study. These caregivers may not be representative of the total population; therefore, the results are not generalizable. Caregivers in different settings, without access to an AD support agency, or from other geographic areas may have different experience.

In this study, past caregivers had the opportunity to reflect back and identify important decisions that they had struggled with coming to resolutions and acceptances as to the types of decisions they made. Present caregivers focused on day-to-day challenges experienced and how to meet these challenges. By comparing and contrasting data from both groups, disease specific decisions were identified. While saturation was reached in the past and present caregiver focus groups, the AD trajectory is highly individualized and different caregivers may have diverse experiences not encountered by those participating in this study. In addition, patients with AD were not included in the focus groups. Understanding patient preferences and goals for decision-making earlier in the disease trajectory might have yielded additional insight into the decision-making process.

Conclusion

This research offers evidence as to the types of decisions the caregiver may encounter over the AD trajectory. Healthcare providers can educate caregivers about present and future decisions thus raising caregiver awareness and creating an environment for open discussion and working together on how to anticipate, prepare, and plan. Healthcare providers also guide, counsel, mentor, and advocate for caregivers as they navigate and negotiate the challenges of decision-making together. An awareness of AD specific decisions is an opportunity for healthcare providers to work with caregivers and share in the process of decision-making.

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