

Navigating Without a Roadmap: Challenges of Early Alzheimer's Caregivers With Their Health Care Team

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Abstract

Caregivers of individuals with Alzheimer's disease are willing to make large sacrifices to attend to the everyday demands of their loved one's health. Many still lack the necessary skills, information, and resources from medical professionals needed to fully execute this role. The aim of this study is to explore the challenges that first-time Alzheimer's caregivers encountered with members of their health care team around a loved one's diagnosis. Four focus groups ($N = 13$) were conducted in a primary care clinic and academic setting, using a semi-structured interview format facilitated by a mental health professional. The authors used thematic analysis to generate three overarching themes regarding lack of information given about the diagnosis, complications with medication management, and level of confidence in their medical team. Medical professionals should consider educating Alzheimer's disease caregivers during the initial stage of this role, providing greater continuity of care with the family throughout treatment.

Keywords

Alzheimer's disease, caregivers, doctor–patient, medication, social support

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Introduction

Alzheimer's disease (AD) is a chronic and costly disease, with an estimated 35 million people worldwide diagnosed. AD is a significant burden upon not only those diagnosed with the disease but also those providing direct care and services to the individual (Alzheimer's Association, 2013). Caring for someone with AD not only creates an emotional toll on family members but also costs individuals time and money for their usually unpaid services (Hurd, Martorell, Delavande, Mullen, & Langa, 2013). Friends and family of individuals with AD provide an estimated 17.9 billion hr of unpaid care and services yearly. This support usually comes at a cost, however, with caregivers enduring both emotional and financial strains throughout multiple stages of this process (Brodaty & Donkin, 2009).

Daily caregiving for a parent, spouse, or close family member with AD is taxing physically, mentally, and emotionally (Kiecolt-Glaser et al., 2003). This role is often faced with the challenge of managing multiple responsibilities for their loved ones, such as medical appointments, assistance in daily living needs, shopping, and driving (Vitaliano, Young, & Zhang, 2004). In addition, caregivers of early-onset AD patients are more likely to have longer duration of caregiving, less social

support, and a heavier burden than those with late-onset dementia-related disorders. These caretakers often assume dedicated tasks for their spouse, parent, or friend with AD that are normally executed by paid health care and service professionals (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Iavarone, Ziello, Pastore, Fasanaro, & Poderico, 2014). Although caregivers provide a key role of caring for daily living functions of the individual, many often lack specific medical or diagnostic information about AD itself (Hinton, Franz, Yeo, & Levkoff, 2005).

Throughout the initial screening and assessment process of AD, an individual and his or her family may see multiple health care providers at one time. Primary care physicians (PCPs) play a pivotal role when determining a diagnosis of AD is warranted (Fortinsky, Kulldorff, Kleppinger, & Kenyon-Pesce, 2009; Hollander, Liu, & Chappell, 2009).

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PCPs are increasingly involved in post-diagnosis treatment and coordination of care, especially since the introduction of anti-dementia drugs (e.g., cholinesterase inhibitors) in the 1990s (Meeuwse et al., 2012). Primary care visits often are the first encounters where care physicians, nurses, or other providers can detect some form of cognitive or memory decline in patients. During these appointments, effective communication between the patient, family, physician, and care team is an important feature in understanding the signs, symptoms, and context of AD (Burns, Nichols, Martindale-Adams, Graney, & Lummus, 2003; Schmidt, Lingler, & Schulz, 2009). Although primary care has traditionally been the first line in detecting early symptoms or warning signs of AD, other doctors, specialists, and medical assistants are vital in recognizing and confirming the signs of cognitive impairment and memory loss in AD patients (Iliffe & Manthorpe, 2002).

Despite a greater emphasis on detection and early-treatment approaches for patients, caregivers still lack the necessary services and resources to assume this new role. Many early-stage interventions for family caregivers have focused on skills to cope with later-stage problems such as activities of daily living, family conflict, depression, and behavioral problems in individuals (Hepburn, Tornatore, Center, & Ostwald, 2001; Whitlatch, Judge, Zarit, & Femia, 2006). Although a small percentage of caregivers may seek psychological or support group services, the results have been mixed in how effective these interventions are in reducing depression, caregiver burnout, anxiety, and areas of family conflict (Pinquart & Sörensen, 2006; Thompson et al., 2007). AD caregivers do benefit from having some type of support resource or community connection early in their caregiving role. Nevertheless, providers often neglect the importance of these services for family members of AD at vital patient visits (Belle et al., 2006; Gitlin et al., 2008; Roth, Mittelman, Clay, Madan, & Haley, 2005).

To summarize, as the number of individuals with AD continues to grow globally, caregivers will increasingly be part of the medical decision making and appointments with their care team. However, many caregivers not only feel uncertain about their initial plan of action after an AD diagnosis is determined but often also feel inadequate on how to handle the continual demands of the disease over time. As a result, caregivers often feel frustrated in the quality of care received by medical professionals and lack the confidence needed to make demanding decisions for their loved ones. The purpose of this study is to explore the challenges that first-time AD caregivers encountered with their health care team during the initial stage of a loved one's diagnosis. This approach utilizes a focus group format to explore in-depth narratives and perspectives that caregivers experienced within the first 2 years of an AD diagnosis. The aim of this article is to present a consensus of themes that first-time AD caregivers encountered with their providers, where participants were viewed as the "experts" of the care provided for a loved one.

Table 1. Demographic Characteristics of Caregivers.

	N (%) Child Caregivers	N (%) Spousal Caregivers
Age range		
30–50 years old	2 (15.38)	0
51–70 years old	6 (46.15)	1 (7.69)
71–90 years old	0	4 (30.76)
Gender		
Female	6 (46.15)	4 (30.76)
Male	2 (15.38)	1 (7.69)
Ethnicity		
White	6 (46.15)	5 (38.46)
African American	2 (15.38)	0
Geographic residency		
Urban	5 (38.46)	2 (15.38)
Rural	3 (23.07)	3 (23.07)

Method

Participants and Setting

The research team recruited participants in two large metropolitan Midwest cities. Advertisements and information flyers were distributed to several primary care clinics and community-support groups in these cities. In addition, information was gathered about caregivers and their diagnosed family member via electronic health records in one of these cities. Purposeful sampling identified six participants through this clinic's health records, and convenience sampling identified seven participants through study flyers delivered at community-support groups. A total of 13 participants attended four separate focus groups (two held in a primary care clinic and two held in an academic conference room). The focus group participants consisted of three men and 10 women between the ages of 44 and 83. Eleven of the 13 participants were White and more than half lived in an urban setting (see Table 1).

Participants recruited for this study must have been both the primary caregiver and a family member of the individual diagnosed with AD. The participant did not have to reside with the individual but must have assumed the primary responsibilities of daily activities and other caretaking needs. In addition, this individual must have attended the initial medical appointments with the patient where a memory assessment or dementia screening was performed. The AD diagnosis must have been confirmed by a physician or specialist within 2 years from the start time of the focus group. This confirmation of the diagnosis was verbally communicated from the caregiver to the research team before study entry. Caregivers were excluded from the study if they either provided care for another family member or individual with AD or dementia-related disorder, or were unrelated to the patient (non-biological, non-adopted, or outside a blended family). Those who did not provide any in-home care or

services for the diagnosed individual within 6 months prior to the focus group were also excluded from participation.

Data Collection

Family caregivers attended their assigned focus group after passing initial study criteria over the phone. The facilitator confirmed that participants must be able to consent to the purpose of the study, have the capacity to recall events from the past 2 years about their loved one's diagnosis, and not be a primary caregiver for another individual with a dementia-related disorder. The study facilitator conducted four separate focus groups (approximately 90 min each group), consisting of a series of questions about the experiences of first-time caregivers within 2 years of a loved one's AD diagnosis. Before starting each group, the facilitator reviewed the consent form and group procedures, clarifying any questions or concerns from participants. All four focus groups were audio-recorded, and notes were taken by both the facilitator and a research assistant. Two institutional review boards approved the consent forms, design, and procedures for the study.

All four focus groups were conducted using a semi-structured interview guide, developed through a series of collaborative meetings with members of the research team from two academic departments. The study started with a grand tour question of, "What were your experiences as a caregiver following the initial news of your loved one's diagnosis?" The focus group facilitator allowed for consensus themes to surface in the group, with clarifying questions to confirm statements and connect group themes. Subsequent questions around the medical care provided to these participants were, (a) "How would you describe the medical care received after you heard about the diagnosis?" and (b) "What information would be helpful for medical professionals to know based on your experiences as an early Alzheimer's caregiver?" The final question of the focus groups asked participants to offer any advice that would help future AD caregivers starting out in this role. The facilitator allowed participants to share summary information about their experiences with their medical team and clarify any questions or statements raised by the facilitator. Demographic information from participants was obtained from both a review of medical records and phone screenings conducted by the facilitator.

The research team was aware of the philosophical and experiential nature of each focus group and how data collection would be approached based on group discussion. A social constructionist approach was used to frame the group conversations and experiences among all participants. The development of themes was not seen as innate in participants, but rather shared through the interactions with all group members (Creswell, 2012). Focus groups framed from this perspective tend to emphasize collaboration, achieving some type of consensus on certain issues and constructing meanings of shared experiences across many participants (Sayre, 2001). In this study, the facilitator encouraged the group to report new

insights, ideas, or knowledge that may have been previously untapped in this area of caregiving. A field researcher was present at three of the four focus groups, taking anthropological notes of the group content and non-verbal interactions.

Data Analysis

The coding and examination of the data followed the steps of thematic analysis, one that is bound to many theoretical approaches and can be used to serve different functions. It serves as a rigorous yet inductive set of procedures to examine contextual themes in a way that is transparent and credible (Braun & Clarke, 2006). A benefit of applying this approach to focus group research is that it draws out the stories and experiences voiced by participants as comprehensively as possible (Krippendorff, 2004). The authors feel that this inductive approach would fit the narrative experiences shared by each participant, gathering a rich description of how these individuals made sense of their early caregiving experiences.

Analysis of the units of data was content-driven, where the common themes throughout the review of data began to emerge. While reading through the text, a rigorous and systematic open-coding technique allowed for the researchers to explore participant narratives and form first- and second-level categories. The authors then condensed extensive raw text into a brief summary format of themes and sub-themes from all four groups. The research team combined all themes and sub-themes from participant responses, noting repeating patterns throughout the data transcripts. Similarities and differences across multiple sub-groups were also explored. In addition, Atlas ti software was utilized to generate any additional codes that were missed during the initial reviews of transcripts. The first author used an open-coding format to merge codes together, while noting side comments to document the emergence of new information. This information was then incorporated into a coding scheme graph to detail the coding process. The authors compared the details of the software-coding scheme to the open-coding procedures of transcripts.

Trustworthiness and credibility of the data were established in several ways. First, the research team conducted a consensus review at the end of each focus group to summarize and confirm the anthropological notes taken by the facilitator. The first, second, and fourth authors reported these notes to one another, comparing and contrasting the significant themes, statements, and overall tone of the groups. Second, the research team was able to contact four participants following their focus group and confirm the significant themes and topics covered in the group. Researchers allowed for any additional data or perspectives to be shared over the phone by these caregivers. Third, an independent researcher conducted a separate analysis to confirm the data were collected and transcribed in an appropriate manner. This step was performed to address reflexivity in analyzing the data and eliminate any biases that may have been interpreted by the authors.

Results

Across all four focus groups, the authors identified three significant themes about participants' perspectives of the care received after a loved one's AD diagnosis. Overwhelmingly, the challenges and initial struggles of the care received after the diagnosis and level of frustration with the overall coordination of medical care guided the tone of each focus group. The overarching themes found were as follows: (a) a lack of medical information given by providers, (b) complications with medication management, and (c) level of confidence and support in the medical team.

Lack of Medical Information Given by Providers

Diagnosis was not communicated to the patient or caregiver. One resonating theme across all four focus groups was the lack of information and reports communicated to the family at initial appointments. More than half of the participants described the ambiguity in not receiving a confirmed diagnosis from their primary care doctor, nurse, or specialist who was attending to their love one's health. The terms *Dementia*, *Alzheimer's*, or *cognitive impairment* are often never discussed or verbalized after the assessment and screening of the study participants' relatives. As a result, these caregivers were confused as to both the status of their loved one's condition and how to proceed with the necessary care following the initial appointment. A few participants mentioned that their doctor did not officially come out and deliver the diagnosis, even after multiple tests had confirmed memory loss or cognitive impairment. Their frustrations mounted from not knowing what the results meant as far as level of memory loss or severity of the patient's condition. One participant noted the initial struggles of this theme:

She had not been formally diagnosed, but I knew something is going on with her mind and my thing is just to be uhh, a little more knowledgeable about it and be able to get more information so that you can kind of be up-to-date about what to do and how to do it as far as, you know, being a caretaker.

Another participant commented on the confusion when the diagnosis was actually given and the ambiguity surrounding this conversation:

The confusion is probably on several different levels. It's not only the facts about the diagnosis, but what is it that you do as a result of what you see. And then from there, are there resources that can help with the things that you should be doing? It's also what you need to push off to the side and realize that it's just the normal course and something I have to deal with it.

Follow-up information was missing after the initial appointment. Another sub-theme that arose was how caregivers had unanswered questions after the initial appointments and were left in search of more information. The consensus among all

participants reporting this challenge was that the medical team did not provide enough answers to common AD questions. Participants had to seek additional information independent from their routine medical appointments. Specific responses on resources used by these individuals included "google searches," "Internet browsing," and "specific books on Alzheimer's and dementia." One participant spoke on the lack of resources from her medical team:

The only thing that I have been able to garner is individual research that I have done by myself. I have never really been pointed toward any resources. I have not been told that there is a great pamphlet, here is a support group, here is additional reading, here is a couple of websites to go to and read up on the latest meds that are out, that may or may not help.

Four participants from two groups expressed the lack of scheduled follow-up appointments or further conversations after the initial appointment. The time lapse between appointments was problematic because caregivers did not know what roles, skills, or duties were required of them at home. Caregivers used "confusing," "uncertainty of the future," and "dropping us as a patient" as some of the key terms to describe the lack of continuity of care. Furthermore, the anticipation that further issues may arise as a result of cognitive decline or disorientation caused further stress and anxiety from several individuals. One participant highlighted the uncertainty for his caregiving role after the diagnosis:

What is going to be left for me now? I mean I have heart problems that I'm trying to take care of . . . And uhh, you know her daughter, you know, she's nice. She says you can call anytime and then every time I call it's "oh I'm busy or I don't feel good" . . . Forget it. Looking down the line, what do I do?

Another participant commented on the long time frame between appointments and the lack of follow-up communication from care providers:

I think it is the result of the gaps. I mean, you need to be in there every two or three weeks, but the more conversations you have the more opportunities you have to get information. If you are only having that conversation every three or four months or twice a year, then you're in there and it is totally focused on other things, and there is very little opportunity to discuss anything else and then you go another four to six months.

Complications With Medication Management

Lack of competency and knowledge around medications. The topic of medications to effectively treat AD arose frequently, where issues regarding prescription details and management of their loved one's schedule were prominent struggles. Consistent among all focus groups was that learning the details of medications offered an additional challenge in caretaking for their parent or spouse. Several participants discussed the challenges in

trying to manage medications (e.g., cholinesterase inhibitors) for AD and other conditions that their spouse or parent was prescribed. Individuals ran into problems when their medical team failed to collaborate with other providers around multiple prescriptions written for the diagnosed individual. One participant commented on the continued challenges of trying to control the regime of medications:

The psychiatrist did not help at all and she put him on all the medicines and stuff. I then went to my doctor and told him this is what they've got him on. Now you tell me what he should have and shouldn't have. How and when should I give it to him? Because I was totally confused when they added all of this stuff.

Difficulties in detecting side effects. Among those with medication difficulties, some group narratives indicated that it was challenging to determine what side effects were a result of the AD medications. Participants who were trying to educate themselves on certain medications were finding more information on the Internet than getting answers from their physicians. Caregivers were uncertain about whether certain physical symptoms (e.g., fatigue, nausea) were common for the prescribed medication(s). One participant mentioned that she trusted a family member who was a Pharmacist more than the advice from her medical team, specifically the doctor and nurse providing care. The group members were in agreement that based on the reports from this participant's medical team, the family member was probably the most trustworthy person at that time:

We have a niece, who works for a pharmacy that provides drugs for various nursing homes and that sort of thing. So uh, before we came to Dr. _____, he was taking Donepezil and she said that the next thing would be to obviously talk to your doctor. But her suggestion would be to take Namenda. We trusted my niece's decision.

Another participant mentioned the unexpected symptoms that her loved one experienced while starting a new medication:

She started with one kind of medication and she was having really bad nightmares. Some real troubling sleep disturbances, so she just quit taking it but didn't tell anyone she quit taking it. And then she started taking it again then she quit taking it, but nobody had said this could happen until she came in and said I quit taking this cause of what was happening . . . and the doctor was like, Oh yeah, those things could happen.

Level of Confidence in the Medical Team

Getting a second opinion after the initial appointment. A consistent theme across all focus groups pertained to seeking a second opinion from another physician or set of specialists to confirm the AD diagnosis. Many caregivers felt that it was important to seek another opinion regardless of the knowledge

and thoroughness of their first doctor. Based on the reports from several participants, there was difficulty finding a consensus from multiple providers on the specific diagnosis or the severity of memory loss of the patient. A few participants noted that the second opinion route was recommended from outside family, friends, or others all along. These caregivers checked in with family members frequently to compare notes of multiple providers regarding support, knowledge, and thoroughness around AD. One participant specifically stated that her family's decision to pursue a second physician was simply not getting enough information from the first few appointments:

I mean, even you know practitioners. I mean, it is interesting to hear viewpoints of my father's doctors and my mother's doctors and it is the same condition (memory problems), but yet they're in some ways polar opposites in how to address the issues and communicate things.

Another participant felt very comfortable with their original physician and was unsure about their relative's decision to garner a second opinion of their loved one:

We did the second opinion thing. We got a second opinion and we stuck with the second guy. So I think we are really happy with this doctor now. Yeah, my relative also definitely wanted a second opinion on this Alzheimer's thing. I don't know the reasons why she did that though. That wouldn't have been my choice.

Mixed feelings of being supported throughout the process. Overall, the quality of the person(s) providing care for the patient and family was a common thread through many of the group conversations. Participants were mixed, however, regarding the level of support and quality of compassion received from their provider or team of specialists. A few individuals were very pleased with the interpersonal skills and awareness of the family in the care of their loved one. For example, one caregiver was impressed with their doctor, attending nurse, and overall medical team's care, trusting specifically in this doctor's knowledge throughout the entire treatment process:

When he told us (the diagnosis), he was absolutely fabulous. With the way he presented things, the good news, the bad news. He answered every question, one two or three. What could be done? What could he take to get rid of it? Dr. ____ was really great. He was . . . he just answered things . . . you know, Neurologists don't move very fast, because they take everything slowly. And that's the way he was. He answered everything deliberately, slowly so that my husband could understand.

In contrast, seven participants reported strong feelings that their physician and care team were not supportive through the initial months of the AD diagnosis. Participants expected more out of their doctor regarding ways to provide more empathy and curiosity to family. Interestingly, the

perspectives of their provider were closely tied to the number of memory tests, assessments, or questionnaires their loved one needed to complete at follow-up appointments. If the patient already had a confirmed or suspected diagnosis, several caregivers felt that there was no point giving more memory or cognitive tests at subsequent appointments.

What I need is some more guidance, like this is what you should be doing or these are things you can try doing. Or I need more guidance. It is a dark path for me . . . So that adds to the challenge but I just don't know. There's been no support. I have no idea what I am doing or what I should be doing.

One focus group member commented on the lack of support and trust from the physician at the start of this journey:

However, she (the doctor) did not think anything was wrong. She thought my mom was capable as she was 30 years earlier. You know, and don't tell her (the participant's mother) what to do. God forbid, don't do anything for my mom. And do not doubt that she's capable of doing absolutely everything.

Discussion

The purpose of this study is to use a focus group format to explore the challenges that early AD caregivers experienced with their health care team. Participants reported specific barriers regarding information communicated by their medical team, complications around medications, and the level of confidence in providers after an initial diagnosis was offered. In addition, participants described how much additional information and resources they tried to seek on their own to learn more about AD. Each focus group emphasized a high degree of ambiguity and uncertainty that exists in navigating the demands of AD following a parent or spouse's initial diagnosis. Caregivers utilized this focus group format to offer information to one another in their respective communities around medical, mental health, community, and educational resources. Several participants acknowledged that this study was one of the few times that they could connect with others experiencing similar challenges at this phase of the caregiving process.

There were a few other underlying barriers that existed for AD caregivers beyond the general study themes. Some participants felt strongly about searching for more information on the Internet about the symptoms and prognosis of AD. Re-occurring terms and sites such as "Google," "The Alzheimer's Association," and "WebMD" came up in multiple focus group conversations. Caregivers were confused, however, as to how accurate the information was on these sites and whether their physician or health care team was going to offer follow-up information. Others mentioned their personal medical and mental health history as being an additional source of stress throughout the caregiving process. Although participants differed in the severity of specific health conditions, the challenges in balancing both

their personal health with their loved one's disease were highly demanding. For instance, the oldest caregiver who participated in this study was in his late 80s and suffered from recent bypass surgery, high blood pressure, and chronic knee pain. There were no recommendations given from his medical team on how to receive outside help or services, given his physical limitations as a caregiver while suffering multiple chronic conditions. Considering that AD caregivers are more likely than non-AD caregivers to suffer from long-term health issues (Etters, Goodall, & Harrison, 2008; Fonareva & Oken, 2014), the emphasis on providers offering stress-management techniques to early caregivers is critical.

The authors identified a few surprising findings from the reports of all four focus groups. For one, more than half of the participants in this study reported that their initial doctor or medical provider did not verbalize a diagnosis of dementia. Although the majority of patients received some feedback of AD symptoms during their course of care, many caregivers were uninformed or confused as to how these providers arrived at the actual diagnosis. Because of either poor communication or lack of follow-up from their care team, caregivers felt an increased sense of ambiguity around the progression and challenges of the disease over time. It is known that physicians, nurses, and other providers often feel uncomfortable and even inadequate in how to deliver a dementia diagnosis to family members (Cody, Beck, Shue, & Pope, 2002; Downs, Clibbens, Rae, Cook, & Woods, 2002). Perhaps medical providers assumed that others on the care team would provide this diagnosis or deliver specific dementia-screening tests or assessments to confirm the AD diagnosis.

In addition, the reports of care teams as a whole were overwhelmingly critical, with far more challenges than positive narratives reported from these groups. Only two participants reported positive care from all professionals throughout their entire caregiving process. The consensus of criticism was not limited to just primary care physicians, but also Geriatricians, nurses, and care coordinators. Although the medical care experiences of caregivers was just one of three topics discussed in these focus groups, the focus on health care challenges occupied most of the conversations and narrative experiences. Perhaps early caregivers anticipated that providers would have acknowledged their struggles and challenges at some point of the care process. This lack of support and acknowledgment highlights the need for providers being "humanistic" in their care for families and viewing AD treatment as a truly systemic disease.

The essence of this focus group format was to gain a thick and rich description of caregivers' challenges with their care team and medical management around AD. The social constructionist framework of this study allowed for group members to build off of each other's experiences and compare stories of common phenomena in the caregiving process.

Caregivers shared in the “not knowing” frustrations of how to manage many of the daily medical, lifestyle, and family decisions for their loved one’s condition. Many participants expressed that they continue to be confused as to what demands their caregiving role will entail moving forward. Where previous studies (Knighting et al., 2015; Seddon & Robinson, 2015) have only reported on the challenges and needs of dementia caregivers from providers’ perspectives, this focus group venue allowed for honest and direct dialogue from AD caregivers, encouraging them to be the experts of their caregiving journey.

Limitations

There are some limitations from the study worth noting. Because there was no age range for diagnosed patients, the symptoms and severity of AD may have varied across participant experiences. For instance, older caregivers reported that increased medical conditions in their loved one complicated the caregiving process and care coordination beyond just symptoms of AD. These medical complications were not reported as frequently in younger AD individuals and their caregivers. Next, the sample for each focus group was relatively small and non-diverse with regard to ethnicity. Two participants took up much of the conversations in three of the focus groups, where larger interaction and perspectives between group members were lacking. Having a predominantly homogeneous sample missed several key aspects in caregiving such as cultural variations of caring for an older adult, influences of outside family members on the caregiving process, and access to care issues for AD services. In addition, there may have been responder bias due to participants not reporting their true emotional reactions to a loved one’s condition. Because some caregivers were still in a fragile time period and slowly transitioned into this long-term role, conveying information in a group setting may have been uncomfortable for some. Finally, caregivers who took part in the study were a mix of both children and spousal caregivers. Had the study concentrated on one type of family member, a stronger and more valid consensus of themes and experiences during the initial stage of this role may have emerged throughout the study.

Implications

Reports from participants generated clinical and educational implications for medical and allied health professionals alike to consider. PCPs and nurses would benefit from having direct talks with both the patient and caregiver about the definition of AD and the anticipated challenges that the diagnosis brings to families. The delivery of information is especially important at follow-up appointments, where caregivers continued to express their struggles in the daily routines, lifestyle adjustments, and self-care issues around their loved one’s diagnosis. An emphasis for health care providers to offer

additional resources and services for new dementia caregivers, specifically around education, stress management, and community connections is also needed. Although psychosocial support groups (Chu et al., 2011; Van Mierlo, Meiland, Van der Roest, & Dröes, 2012) have been proven effective for caregivers in decreasing depression and stress over time, more resources at the initial stage of this role is warranted. Furthermore, while most of the attention from these focus groups was given to the frustrations of physicians, little was known whether their nurse or medical assistant helped alleviate caregiver stress. Some caregivers may have assumed that physicians were the main providers to deliver a diagnosis and other pertinent medical information to the family. Future studies may benefit from exploring how nursing interventions can improve the well-being, education, and competencies of dementia caregivers in medical settings.

Conclusion

We used a focus group format to explore the challenges that first-time AD caregivers experienced with their health care team. These findings serve as an important first step in determining the frustrations that participants endured in their coordination of care with multiple providers. AD caregivers were burdened with numerous barriers and responsibilities during this initial period, sacrificing valuable time and resources to care for their loved one. The findings from this study reveal not only the critical need for early communication of the diagnosis to family members but also increasing the amount of support services and resources for caregivers at the initial stage of the disease. Based on the narratives of the study participants, many health care providers failed to include caregivers and family members in the treatment process and planning of AD on several levels. As the rates of AD continue to rise globally, it is paramount that more medical and health care clinics provide these resources and support options for caregivers after a loved one’s diagnosis is confirmed.

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