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## Family Experiences in the Journey Through Dementia Diagnosis and Care

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*Families caring for loved ones with dementia encounter multiple challenges. This study aimed to describe experiences of families seeking diagnosis and subsequent care and treatment for relatives with dementia. Using a descriptive qualitative approach, 14 family caregivers living in diverse areas of Kansas were interviewed regarding their experiences with dementia diagnosis and treatment. Initially uncertain about symptom interpretation, caregivers encountered marked delays in getting a diagnosis once they sought medical care. The diagnostic process often took several years and visits to numerous physicians, required considerable diligence, and ultimately resulted in feelings of mistrust toward the medical community. Caregivers described the physical and emotional strain of providing care, although support groups facilitated access to some educational and community resources. Nurses are in an opportune position to educate families about dementia and caregiving and to ease the considerable challenges they face by providing more active support during the diagnosis and care process.*

**Keywords:** *caregiving, rural, Alzheimer's disease, cognitive disorders*

The population structure in the United States is shifting to include a greater percentage of older adults than ever before. By the year 2030,

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approximately 20% of the population will be 65 years and older, with the most dramatic growth expected among the oldest old, the cohort of persons 85 and older (Administration on Aging, 2000). One of the most significant health care issues facing an aging population is the prevalence of dementia disorders. Predictions suggest that the number of older adults living with dementia in the United States—now estimated at 4 million—will continue to grow, quadrupling during the next 50 years (Brookmeyer, Gray, & Kawas, 1998).

Alzheimer's disease (AD) is the most common cause of dementia among the older population, comprising about 75% of all dementia cases (Celsis, 2000) and affecting up to half of Americans 85 and older (Cummings & Jeste, 1999; Evans et al., 1989; Leon, Cheng, & Neumann, 1998). AD causes a gradual loss of intellectual abilities with deterioration in cognition, function, and behavior. Individuals with AD become more dependent on others as the disease progresses and eventually require constant, supportive care. Cost estimates for health care expenses incurred in supporting persons with dementia have been placed at \$28.5 billion per year (Desai, Zhang, & Hennessy, 1999). More comprehensive estimates, which account for the often hidden costs for care provided by family and friends, place costs much higher, exceeding \$50 billion (Leon et al., 1998).

Diagnosis of AD is no longer made only by exclusion of other disorders (Geldmacher, 1998); AD is now considered a diagnosis of inclusion that requires the presence of memory impairment and at least one other cognitive deficit such as aphasia, apraxia, agnosia, or disturbance of executive functioning. The importance of accurate and early diagnosis of dementia is well established (Boise, Camicioli, Morgan, Rose, & Congleton, 1999; Knopman, Donohue, & Guterman, 2000; Marin, Sewell, & Schlechter, 2002; Rossor, 1999; SantaCruz & Swagerty, 2001). Using specific inclusion criteria, clinicians trained in dementia assessment can predict autopsy diagnosis with 90% certainty (Cummings, Vinters, Cole, & Khachaturian, 1998). In addition to improved accuracy, diagnosis can now be made earlier in the course of the illness (Kaye, 1998), which provides the opportunity to begin pharmacological and social interventions that may lessen the devastation of the disease for both patients and families (Ham, 1999; Marin et al., 2002). Unfortunately, however, the time

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between onset of early symptoms and diagnosis is often prolonged and may be related to underrecognition by both health care providers and families (Doraiswamy, Steffens, Pitchumoni, & Tabrizi, 1998). Family members can contribute to a delay in diagnosis by not recognizing a memory problem or not seeking medical consultation even if a problem is recognized (Knopman et al., 2000).

The purpose of this study was to describe the experience of families in seeking diagnosis and treatment for a loved one with dementia and to identify any challenges or barriers encountered in the experience that might contribute to delay in recognition and treatment of AD. Family members also were asked to identify what they wanted primary care providers (PCPs) to know about their experience of caring for someone with AD, which could provide preliminary guidance in the design of educational and practice interventions to enhance care.

## BACKGROUND

Knopman et al. (2000) reported that barriers to timely diagnosis include "low levels of ascertainment by primary care physicians" (p. 300), yet others also are unaware of recent advances in diagnosis and treatment of AD. Barrett, Haley, Harrell, and Powers (1997) reported differences in knowledge about AD among generalists and experts in four health care professions. Generalists ( $n = 179$ ) were randomly selected from professional organization listings and included physicians in internal medicine or family practice, doctorally prepared psychologists, community health nurses, and licensed social workers. Experts ( $n = 116$ ) included persons from each of the four groups selected by their AD center or geriatric education center employer as experts in AD care. Although generalist physicians and psychologists had higher mean scores than did generalist nurses and social workers, there were no differences between groups on several items, including procedures in making an AD diagnosis and causal factors of memory loss in the older population. Only 40% of generalists knew that AD is the most common cause for dementia in the older population compared with 97% of the experts, suggesting a need for more education about AD for several health care provider groups.

In focus group interviews with 78 PCPs, Boise et al. (1999) identified knowledge deficit as a barrier to diagnosing dementia but found also that negative attitudes can serve as an additional barrier. Diag-

nostic barriers included lack of recognition and response to symptoms of dementia, perceived lack of need to establish a specific diagnosis (dementia or forgetfulness versus AD), negative attitudes regarding the importance of assessment and early diagnosis, and time constraints in clinical practice.

Recognition and diagnosis of early dementia produce the opportunity for early treatment, which can improve patient function and may also slow the progression of disease (Cummings et al., 1998; Rogers et al., 1998; Sano et al., 1997; Tariot, 2001). As noted in a National Institute on Aging progress report on AD (1999), "The earlier an accurate diagnosis of AD is made, the greater the gain in managing symptoms" (p. 15). Early diagnosis also produces an opportunity for family education and preparation for caregiving responsibilities (Doraiswamy et al., 1998). Approximately 70% of patients with AD are cared for by friends and family members in the community (Ballard, 1999) who support every aspect of the affected persons' care routines in the home, from implementation of behavioral management techniques to monitoring of nutritional status. In later stages of AD, caregivers often continue care activities even after loved ones' move to nursing home settings (Haley, 1997). Caregiving can be stressful and can have negative health consequences for caregivers. Schulz and Beach (1999) found that older spousal caregivers who experienced mental or emotional strain in the caregiving role had a 63% higher risk of mortality than did noncaregiving controls.

Informed family caregivers play an essential role in supporting the care of persons with AD, yet the skills of family caregiving are not intuitive. Successfully undertaking such a vital role in the care relationship requires education and training in addition to ongoing communication and problem solving with others (Ham, 1999; Houts, Nezu, Nezu, & Bucher, 1996). Family caregivers must have knowledge about caregiving as well as the ability to put their knowledge into practice (Kelley, Buckwalter, & Maas, 1999). Education is essential.

Despite acknowledgement in the caregiving research literature about the importance of family caregivers, Kelley and colleagues (1999) outlined some of the false societal assumptions about family caregiving. These assumptions were that families do not provide enough care, families have innate knowledge about caregiving, and families have appropriate resources to provide care. On the contrary, families provide the vast majority of home care, they desperately need information about how to provide care, and they need access to

resources to help them succeed in providing home care. When education and resources are available, caregivers can assist individuals with AD in the home by using memory aids, monitoring exercise and hygiene, and assisting with overall decision making regarding treatment (Ham, 1999). An informed, supported caregiver is key to prolonging home-based care for the person with AD, and Ham (1999) noted that "keeping the patient at home for as long as possible is a vital principle of AD management" (p. S29). There are obvious personal, social, and economic advantages to prolonging home care for the person with dementia, but achieving this goal requires a better understanding of the challenges faced by families in recognizing onset of symptoms and in seeking diagnosis and treatment for their loved ones.

Early diagnosis of dementia is a desirable health service goal with potential benefits to both patients and family caregivers, but it is unclear how often the goal is achieved. No previous studies were identified that examined the role of the family in early detection or diagnosis, and the family perspective regarding timeliness of diagnosis was not identified in any previous studies. The aim of this study was to describe the diagnostic experience and to identify impediments to diagnosis and treatment as perceived by family caregivers. The research questions that guided the study were as follows: What are the experiences of family caregivers of persons with dementia with regard to getting the diagnosis and implementing care and treatment? If difficulties are encountered, what are the challenges? What do family caregivers think health care providers should know about dementia and the family caregiving experience?

## **METHOD**

The Human Subjects Committee at the University of Kansas Medical Center approved the study protocol. Following discussion and approval of the project by the three executive directors of the state's Alzheimer's Association chapters, flyers were sent to the chapter headquarters for distribution during support group meetings. Persons who were interested in participating in the interviews were invited to either contact the research team directly or have the Alzheimer's Association chapter make the contact on their behalf. Information about the study was mailed to each prospective participant

before the scheduled interview. All participants reviewed and signed consent forms prior to initiation of the research interview.

A qualitative approach was used to answer the research questions. Little is known about the phenomenon of interest, so basic qualitative description (Sandelowski, 2000) was selected to guide investigation of the diagnostic experience and articulation of barriers to diagnosis. This approach presents a descriptive summary of a phenomenon in a way that best conveys the collected data, which is concordant with the study goals.

Semistructured interviews lasting approximately 1 hour were conducted with family caregivers of persons with dementia who lived in communities of diverse size around the state. A brief questionnaire that included items about demographics and caregiving situations was completed by all participants prior to the interviews. All interviews were completed in the location of participants' choice, which was in either their home or a private room in a community center.

In an effort to support a consistent approach to the interview format, both investigators participated in the first interview. Each data collector followed the same format for all succeeding interviews, and common questions were used during each interview. For example, participants were asked to describe their experience with diagnosis and initiation of care and treatment for their loved ones with dementia. They were then asked to identify any challenges or barriers they encountered to diagnosis and treatment. The final question was to identify what they wanted health care providers to know about the families' experience with dementia caregiving.

Interviews were audiotaped for later transcription. Transcripts were then compared with the original tapes for accuracy of language and notations about additional interview features, such as voice inflection and onset of crying. Mindful of potential concerns with using computer-assisted analysis techniques, a dual strategy was used for initial data management (St John & Johnson, 2000). Each investigator conducted independent management of the interview data. Identification of meaningful data units, coding, and sorting was accomplished without computer support and by using NUD\*IST qualitative data management software. Notes written during the interviews were used to assist with coding and interpretation decisions. These independent activities were compared for consistency in selection of data units, coding, and sorting. Use of the constant comparative analysis begun during data collection continued through the

final analysis phase. Initial themes identified in peer debriefing sessions were used to guide follow-up questions asked at the conclusion of subsequent interviews, which facilitated validation of the evolving description with participants. Data unit inclusion in theme formation required its presence in at least two interviews. Collaboratively, the investigators developed a final a summary description of the phenomenon.

A total of 14 family caregivers from 11 communities across Kansas participated in the interviews. In 3 communities, the population was fewer than 5,000 residents; 3 communities had fewer than 20,000 residents; and the remaining 5 communities had populations less than 40,000. The sample was mostly female (64%) and entirely White, closely reflecting the 88% White population in the state (U.S. Census Bureau, 2001). The average age was 62 years (range = 45 to 83 years), and all but one participant were married. The educational background of the sample was diverse and ranged from 9 to 19 years of formal education ( $M = 14$  years). Income also was diverse, with half of the participants reporting an annual income of less than \$30,000. More than one third of the caregivers worked outside the home full-time, 14% worked part-time, and half were not employed (see Table 1). Although somewhat older, caregivers interviewed for this study otherwise closely represent the "typical" caregiver identified in other studies. A national survey of family caregivers found that on average, caregivers were 46 years old, female, married, and employed either full-time or part-time and had attended college (National Alliance for Caregiving & AARP, 1997).

In response to questionnaire items about the caregiving situation, participants reported having been in a caregiving role for an average of 56 months (range = 5 to 120 months) and spending an average of almost 14 hours in daily caregiving (range = 2 to 24 hours, mode = 24 hours). This caregiving intensity was determined from answers to the question, "How many hours each day do you provide care for your loved one?" Most (57%) participants were caring for spouses, and the rest were caring for parents (see Table 1). The family members with dementia were predominately female (64%), and their ages ranged from 63 to 91 years ( $M = 77$  years). Half of the participants were living in the same house with their family member at the time of interview. Four others had recently moved their loved ones to long-term care settings yet were continuing in active caregiving roles through daily visitation and assistance with feeding, grooming, and social activi-

**Table 1: Participant Characteristics and Description of Caregiving Variables**

<i>Participant Number</i>	<i>Age (years)</i>	<i>Sex</i>	<i>Education (years)</i>	<i>Income (thousand per year)</i>	<i>Work Outside Home</i>	<i>Relationship of Care Recipient</i>	<i>Living With or Apart From Care Recipient</i>	<i>Length of Caregiving (months)</i>	<i>Daily Time Spent Caregiving (hours)</i>	<i>Others Available to Help</i>
1	66	M	16	15 to 29.9	None	Spouse	With	114	24	1 to 2
2	75	M	12	15 to 29.9	None	Spouse	Apart	120	5	Agency
3	52	F	14	More than 45	Full-time	Parent	Apart	18	3	Agency
4	56	F	18	More than 45	Full-time	Spouse	With	84	24	More than 2
5	47	F	16	More than 45	Full-time	Parent	With	12	24	1 to 2
6	83	M	9	Less than 15	None	Spouse	Apart	36	4	Agency
7	79	M	19	15 to 29.9	None	Spouse	Apart	78	3	Agency, family
8	66	M	12	15 to 29.9	None	Spouse	With	36	19	1 to 2
9	52	F	16	More than 45	Full-time	Parent	Apart	60	6	More than 2
10	51	F	12	More than 45	Part-time	Parents	Apart	48	2	1 to 2
11	70	F	12	30 to 45	None	Spouse	With	30	24	1 to 2
12	68	F	16	15 to 29.9	Part-time	Spouse	With	84	24	1 to 2
13	45	F	16	More than 45	Full-time	Parent	Apart	60	4	1 to 2
14	63	F	12	Less than 15	None	Parent	With	5	24	Less than 1

ties. Three women were caring for parents still living in their own homes, which were located nearby the daughters' houses.

## FINDINGS

### Uncertain Journey Through Diagnosis

The family experience in seeking a diagnosis initially was marked by uncertainty about the appropriate interpretation or action for various symptoms that were observed. One caregiver recounted her feeling that "something wasn't just right" with her husband but initially was unsure what to do about her unrest. In retrospect, caregivers identified specific, gradual deterioration in their loved one's function, including short-term memory loss and forgetfulness; difficulties with work, finances, and driving; hallucinations; and behavioral changes such as being more argumentative and hurtful or withdrawing and expressing disinterest in previously important activities. Most caregivers noted that the deterioration had occurred during a period of several years. One daughter stated that "we can go back and say she's probably had the start of this disease maybe 15 years ago." Caregivers expressed confusion about interpreting the significance of these observed changes but noted that over time, they became increasingly uneasy about the symptoms and eventually sought medical assistance from their physicians.

Once the decision to seek assistance had been made, several common experiences were described. Most caregivers told about the hesitation of their physician PCPs in making a diagnosis and the need to consult with multiple physicians in seeking diagnosis. For many, the process took years and sometimes resulted in deducing the diagnosis from other sources. Several caregivers reported that the doctor was either unsure or did not know what the problem was. As one husband said, "I started with our family doctor, but first he said it wasn't Alzheimer's. He said it's just old age. It's a deterioration of the brain . . . just something that comes on gradual." Another caregiver described, "At first our doctor would tell her, 'You don't have Alzheimer's; you've just got a memory problem' . . . and he'd tell her that every time we'd go." Some caregivers perceived that PCPs refused to use a particular diagnostic label. One husband summed up the feeling in this way,

I think doctors are reluctant to diagnose. I think their reluctance is probably for fear of discouraging family and the patient and also that they are not sure. They can't be sure, so they're just reluctant to diagnose as Alzheimer's.

The search for a diagnosis frequently extended several years and included evaluations by several physicians. As one caregiver said,

I first took her to the doctor, and we told about what was going on with the forgetfulness. . . . Then we went to the second, then back to the first, and a neurologist, too, but he never gave us a diagnosis or anything, and then we went to a psychiatrist the last time. We were just searching for something. Did she have Alzheimer's, or was it something else?

In most other instances, families sought advice from several physicians before receiving the diagnosis from a specialist—either a neurologist or a psychiatrist. As one husband remembered, “We just went along for about 3 years without any official diagnosis, then the psychiatrist diagnosed her as Alzheimer's.” Often, the search culminated in a diagnosis from a specialist, yet for two caregivers, the neurologist did not offer a diagnosis and the families later learned about the diagnosis from the PCP. One of these caregivers said, “When the family doctor got the specialist's report back, he said that they called it Alzheimer's and that it was only going to get worse as it was going on.” Because of the limited resources in the smaller towns where some caregivers lived, visits to multiple physicians often required travel to other cities. A daughter who was caring for her father said, “We had him out of town for an evaluation, and he was diagnosed by a psychiatrist.” The referral center was several hours from their home and required an overnight stay for the testing.

Consulting with multiple providers over a period of years had significant consequences for family caregivers. They were continually uncertain about the situation, and many eventually developed concerns that doctors might be withholding information. As one husband stated,

It seems like the whole medical profession, all they want to do is talk around this—they don't want to come out and tell you this is it. They hide behind the fact that they say they can only determine a true diagnosis by autopsy. You reach a point where you don't think that they're telling you the truth.

One husband had his fears confirmed when he read the package insert from a medication that had been prescribed for his wife:

[The doctor] said you don't have Alzheimer's . . . although he put her on Cognex . . . but yet he gave me literature that showed that that was the medication for Alzheimer's, and so then we just went along for about 3 years without any official diagnosis.

Overall, the diagnostic journey began with uncertainty in how to interpret changes in a loved one's behavior. Later, getting confirmation of the diagnosis of family members' dementia required diligence in searching for an answer, which sometimes came unexpectedly and left caregivers with feelings of mistrust toward the medical community. Caregivers reported consulting with multiple PCPs and specialists in the diagnostic search, which often took several years before a diagnosis was obtained. Caregivers had to be extremely diligent in their quest and often ended up feeling mistrustful about the information they received from the physician. Notably absent from the family stories was any mention about interactions with staff nurses or advanced practice nurses in primary care or specialty roles, despite the value in nursing practice of patient and family advocacy, education, and support. Study participants described the initial experience of diagnosis only in terms of interactions with physicians.

#### **Lonely Journey Through Dementia Care**

In addition to challenges in getting a diagnosis, caregivers encountered challenges with facilitating the care and treatment of their loved ones both in home and long-term care settings. First, just understanding the caregiving role was a challenge in itself, one that included difficulties in being able to provide care within personal limits and in accessing necessary information about caregiving. Second, families described challenges in working with health care staff members who were not well informed about dementia or caring for people with AD.

Most participants commented on the difficulties of managing caregiving alone and in continuing to provide care with very limited support from others or without respite. One caregiver highlighted this concern as follows: "I just need some people that I can depend on." Regarding her mother's care, one daughter said that "my sister helps very little, she's busy with her family, she doesn't have much time for us, and my children all live out of state." Two men told of

retiring from their regular jobs to assume full-time caregiving roles for their wives. All participants cited the need for constant advocacy and the ever-changing caregiving demands as significant stressors. As a family member described, "You just never know from day to day what is going to come up next." The stressors of the role were described as unrelenting. According to one daughter, "It never gets any easier; if anything, it gets harder." Another declared, "I don't know how much longer we can do this." Yet another summarized her response to the constant stress as "most of the time you're not very happy."

In addition to the physical and emotional stressors, family caregivers noted financial worries related to providing care. A husband said, "Of course, you're paying the nursing home at the rate of \$3,000 a month plus medicine, plus clothing, plus dental bills and things like that." Another family member said, "And then there is the matter of money. This is costing a fortune. To me, it's a fortune, \$3,000 a month." One husband told of difficulties in getting care when the payment source is Medicaid, "Most doctors don't take Medicaid, so where we go is mostly doctors in training. They get through with their training and then they go set up shop some place." The caregiver described how several different PCPs had cared for his wife in the clinic and how she never saw the same physician more than once or twice.

Rather than getting information about dementia and caring for someone with dementia from physicians or nurses, families indicated that their primary information source was support groups. In this setting, they learned about dementia and tips on caring for a loved one with dementia and were able to share their frustrations, successes, and overall experiences. One caregiver described the multiple resources he used in learning about AD as follows:

I went to a number of support group meetings to find out what I could learn and what I should look forward to. I'd go to the library and read on Alzheimer's. I even went to some day care centers around the area.

One husband expressed his frustration with the limited education provided about caregiving as follows:

They tell you these things are going to happen, but there is no teaching or showing. For a man, you aren't quite used to taking care of a woman totally like a baby. This is a learning experience, and they say nobody can prepare you for it. Well, I think they can.

Secondary information sources included community educational programs, friends, family, television, books, and to a limited extent, Internet resources. The informational support from friends and neighbors was a mixed blessing for one caregiver, who expressed with sarcasm, "What really amazes me in this situation is everybody knows what to do. . . . They always have the answers." Unfortunately, caregivers reiterated that they learned nothing about dementia or about caregiving from PCPs or office nursing staff members. They also did not learn about the availability of support groups through physicians or nurses. As one daughter said,

I didn't know about the support group until Mom went into assisted care, and then I found out about it. I just didn't know. News doesn't get spread around very much. I guess there was a little notice in the paper, but I didn't know about it until I started asking. There isn't any help for us, you know.

Working with inadequately prepared providers was the second primary barrier related to care and treatment that family caregivers encountered. Many perceived a lack of expertise by PCPs in supporting both patients and caregivers after the diagnosis had been made. Several caregivers agreed with this daughter's statement, "I wish we had more good health care providers that understand dementia." Another said, "They need to understand dementia. Physicians and nurses do not." Some caregivers reported that home health and nursing home staff members were not respectful and spoke about their loved ones using inappropriate references, such as "Your mother's just nuttier than a fruitcake." A wife expressed her overall frustration with nursing home care as follows: "Everything is not all right at the nursing home. I come home every night upset about something, and mostly they're short of help." Another wife illustrated her distress by recounting a specific incident:

I tried to put his clothes on this morning, but it was 2 hours before I got his pants on. In the nursing home, they called security and they'd put them on him and they'd upset him. They just keep him upset, because if he doesn't want to put his clothes on, then they force him.

Not all caregivers reported negative experiences with nursing home care. For example, one husband's story differed in that his difficulties were with his personal response to the situation, as follows: "My

experience with the nursing home has been good, but my adjustment hasn't been that good. I guess I never thought I'd have to do it [place wife in long-term care]."

Several family caregivers also noted the presence of stigma and the need for better public education about dementia. One wife expressed her frustration in this way, "So many times when I took my husband out in public, people would come over and acknowledge me and talk to me and totally ignore him. . . . You can't just totally ignore them off the face of the earth!" Another husband said, "Maybe it's my imagination, but when I've taken her out, around groups of people, they kind of act like it's a contagious disease."

In summary, caregivers described multiple barriers to their ability to get and provide care. They described extreme burdens involved in caring for a loved one either at home or in long-term care settings. Families received limited information about caring for their loved ones from PCPs or office nurses. Many learned about caregiving from participating in support groups, while some learned by trial and error. All were frustrated by the lack of services available to support care, including the virtual absence of qualified individuals to help support in-home care in small communities. Overall, caregivers expressed frustration regarding the limited knowledge about dementia among health care providers, including physicians and nurses, and among the general community.

### **Sharing Lessons Learned From Caregiving**

Participants were asked what they wanted PCPs to know about their experiences as family caregivers. Responses to the question were consistent. They wanted to feel supported by health care providers as they struggled in their caregiving roles. One daughter complained that the PCP "hasn't given me the support I felt I've needed in dealing with Mom." Caregivers suggested several indicators they believed would provide evidence of this support, specifically, if PCPs allowed time during office visits to talk alone with caregivers; if PCPs had information available for caregivers about how to do the job of caregiving, including referrals to dementia support groups; and most important, if PCPs listened to caregivers and asked questions about the caregiving experience. One woman said, "I really wish they [PCPs] would talk to the family separately. You're not getting time to tell what's happening, but you're also not having your experiences

validated by the professional." Regarding visits to the doctor, a husband said,

There were a few times that I wrote out the problems; I would write him a note, kind of a letter and take it in so that he could read it. He would say that it's going to get worse. Maybe he had a purpose in not showing outward sympathy.

Still another said,

It would be a good thing to be more in tune with us [caregivers] . . . checking with us to see how we're doing, just simply because it can be so taxing on you. They just assume that we know, and I have to stop him and say I don't know and I need to know a little more information about what I'm doing here. I had to make a private appointment so that I could find out about Dad's medication because I had no idea. I try to bone up myself, but sometimes I just don't know enough.

Other expectations expressed by family caregivers were succinctly summarized by one participant, as follows: "Anyone who is a [professional] caregiver ought to have current information on what is happening in the drug industry, new pills, new medication, new things that are coming out—because that kind of lifts you up a little." Family caregivers were consistent in wanting all care providers to be better informed about dementia. As one daughter noted,

Hospital personnel seem to have very little understanding about Alzheimer's and how the disease affects people; they would treat her like she was a typical patient with memory and cognition. They need education about how to work with Alzheimer's patients.

Similarly, a wife reported the frustrations she encountered when taking her husband to the emergency room, as follows: "We got two different physicians, and neither one of them knew anything about how to handle dementia."

## DISCUSSION

Among 14 family caregivers from several areas of a Midwestern state, the experiences of helping a loved one seek a dementia diagno-

sis were quite similar. All were initially uncertain about the significance of early symptoms and delayed seeking medical evaluation. Once they were convinced that a problem existed, many encountered further delays before eventual identification of the problem and initiation of treatment. Most caregivers described physicians' reluctance to diagnose, which necessitated visits to multiple physicians before a diagnosis ultimately was obtained. For some, the process took years. Except for one participant, who described a situation in which his wife began receiving drug therapy even without a diagnosis, initiation of pharmacological treatment was delayed during the diagnostic search, obviating any potential benefits of early treatment. An unanticipated consequence of the prolonged search was the creation of a sense of mistrust among study participants. Several caregivers voiced the fear that they could no longer depend on their PCPs to be honest and forthcoming about their loved ones' medical conditions.

Learning about dementia and how to be a family caregiver was equally challenging for most participants. All described extreme difficulties in trying to learn this new, demanding, and ever-changing role, yet no one reported learning about caregiving from physicians, nurses, or other health care professionals. On the other hand, most participants described the helpfulness of attending support groups as a means to satisfy these learning needs. Although this finding was consistent across participants, caution is required in interpretation because participants were initially contacted primarily through support groups across the state. Few participants were active members of a support group at the time of interview, yet individuals without any link to a support group were underrepresented in the sample.

All caregivers described the overwhelming burdens of family caregiving and their frustrations when support from PCPs was perceived as minimal. Family members wanted to have separate time with physicians to discuss their concerns about caregiving situations and to receive more information about how to do the work of home caregiving. These findings are consistent with those of a recent study about communication gaps between PCPs ( $n = 500$ ) and caregivers of persons with AD ( $n = 376$ ) (Alzheimer's Association, 2001) in which caregivers reported that information they wanted about the disease, its management, and their caregiving responsibilities often was not provided by physicians. On the other hand, most physicians reported they did provide the information (e.g., 24% of caregivers said the physician recommended a support group, whereas 74% of physicians reported making the recommendation).

Study participants were not prompted during the interviews to address any particular type of health care professionals (i.e., physicians, nurses, social workers, and so forth). Perhaps because the first interview question related to experiences with medical diagnoses for their loved ones, stories focused on their experiences with PCPs without mention of nurses or nursing care. In the context of the second question relating to caring for their loved ones with dementia, participants occasionally mentioned nurses in referring to insensitive or uninformed care provided by some nursing staff members. With the potential positive effect that nurses can have on the patient-family health care encounter, this relative absence of nursing's role in the story is of concern. To demonstrate the beneficial nature of nursing interventions, nursing must be proactive in its approach to support, educate, and care for patients with dementia and their families.

Family caregivers wanted health care providers across settings to be better informed about dementia. Clearly, more education about early diagnosis, treatment, and care of persons with dementia and the needs of their family caregivers is needed for current and future practitioners. Community education efforts to raise awareness among the public about symptoms of early dementia also are needed. All study participants described feeling unsure about the significance of early symptoms of memory loss and behavioral change. Earlier recognition of these prodromal symptoms would facilitate entry into the diagnostic phase, which might then improve the likelihood of early treatment and the opportunity for delayed or slowed symptom progression.

Although little research has been conducted from the perspective of the person with dementia, Husband (2000) recently reported findings from interviews with ten persons with dementia. All study participants were worried about others finding out about their dementia and embarrassing themselves in public. On the other hand, all participants agreed they no longer worried about what the diagnosis might be. Diagnosis relieved their uncertainty about symptom interpretation. AD can be diagnosed earlier, benefiting both patients and their families (Howarth, Heath, & Snope, 1999). If, however, the diagnosis is not made or is withheld, the consequences can be devastating. Patients and families suffer from missed opportunities for treatment, education, and participation in planning for the future.

Similar challenges have been identified relative to recognizing and treating depression (Goldman, Nielsen, & Champion, 1999). Like AD, health care providers' knowledge deficit regarding diagnosis and treatment, time constraints in clinical practice, and patients' denial or

uncertainty about symptoms or fear of stigma following identification and treatment have been noted as barriers to diagnosis of depression (Goldman et al., 1999). Increasing public awareness and knowledge among professionals is suggested as a means to improve the care of persons with depression. Similar strategies would undoubtedly benefit care of persons with dementia.

Family caregivers described numerous difficulties in assisting their loved one with dementia. Challenges began with caregivers' lack of understanding about early symptoms and continued with encountering delays in getting a diagnosis and frustrations in learning how to be successful in the caregiving role. Two major points of delay in diagnosis were described, one in beginning to seek medical care and the second in getting a medical diagnosis. Both points of delay are amenable to reduction with appropriate interventions, including public education and continuing education for health care providers. PCPs are at the forefront of many health care interactions and must be knowledgeable about how to identify and treat early dementia (SantaCruz & Swagerty, 2001).

#### **Implications for Nursing of Families**

The family experiences reported in this study have several implications for practice. Nurses are in an opportune position to work more closely with families on their journey through the dementia diagnosis and care experience. A core component of nursing practice includes education for patients and families about health issues. In this case, nurses are the most appropriate educators of family caregivers about dementia and about the challenges of caregiving. Nurses encounter patients and families in myriad settings—primary care and specialty offices, hospitals, and long-term care facilities—each of which affords an opportunity for support. For example, nurses in primary care settings can address family members' needs to have time to share their caregiving experiences, to receive education about caregiving, and to have their questions answered; nurses in long-term care settings can be increasingly attentive to how staff member words and behaviors can affect patients and their family caregivers. Furthermore, nurses can act as patient advocates in educating communities about health care issues, which can lessen some of the stigma that is often attached to conditions viewed as unfamiliar to the general public. Nurses must take advantage of these opportunities to educate and support patients and families.

## SUMMARY

A descriptive summary of the experiences of 14 family caregivers in diagnosis and treatment for their loved ones with dementia has been presented. The study findings provide a rich beginning for further research in the development and testing of interventions and outreach efforts to meet the challenges described by family caregivers. From the summary of family experiences, it is evident that we need a better understanding of how nurses can contribute to the early and accurate diagnosis and subsequent treatment of dementia. For example, what strategies can nurses in primary care settings use to support earlier identification of persons with dementia? Or, how can office visits be structured to maximize opportunities for communication with family caregivers? Through active partnerships between nurse clinicians and researchers, we must identify and clarify best nursing practices for supporting and guiding patients and families on the difficult journey through dementia diagnosis and care.

## REFERENCES

- Administration on Aging. (2000). *The growth of America's older population*. Retrieved May 9, 2002, from <http://aoa.dhhs.gov/May2000/FactSheets/Growth.html>
- Alzheimer's Association. (2001). *Alzheimer's disease study: Communication gaps between primary care physicians and caregivers*. Retrieved February 6, 2002, from <http://www.alz.org/media/news/current/alzheimerreport.pdf>
- Ballard, E. L. (1999). Social work perspectives: Issues in caregiver research: The family. *Alzheimer Disease and Associated Disorders*, 13(Suppl 1), S88-S92.
- Barrett, J. J., Haley, W. E., Harrell, L. E., & Powers, R. E. (1997). Knowledge about Alzheimer disease among primary care physicians, psychologists, nurses, and social workers. *Alzheimer Disease and Associated Disorders*, 11, 99-106.
- Boise, L., Camicioli, R., Morgan, D. L., Rose, J. H., & Congleton, L. (1999). Diagnosing dementia: Perspectives of primary care physicians. *Gerontologist*, 39, 457-464.
- Brookmeyer, R., Gray, S., & Kawas, C. (1998). Projections of Alzheimer's disease in the United States and the public health impact of delaying disease onset. *American Journal of Public Health*, 88, 1337-1342.
- Celsis, P. (2000). Age-related cognitive decline, mild cognitive impairment or preclinical Alzheimer's disease? *Annals of Medicine*, 32, 6-14.
- Cummings, J. L., & Jeste, D. V. (1999). Alzheimer's disease and its management in the year 2010. *Psychiatric Services*, 50, 1173-1177.
- Cummings, J. L., Vinters, H. V., Cole, G. M., & Khachaturian, Z. S. (1998). Alzheimer's disease: Etiologies, pathophysiology, cognitive reserve, and treatment opportunities. *Neurology*, 51(Suppl 1), S2-S17.

- Desai, M. M., Zhang, P., & Hennessy, C. H. (1999). Surveillance for morbidity and mortality among older adults—United States, 1995-1996. *Morbidity and Mortality Weekly Report*, 48(SS-8), 7-25.
- Doraiswamy, P. M., Steffens, D. C., Pitchumoni, S., & Tabrizi, S. (1998). Early recognition of Alzheimer's disease: What is consensual? What is controversial? What is practical? *Journal of Clinical Psychiatry*, 59(Suppl 13), 6-18.
- Evans, D. A., Funkenstein, H. H., Albert, M. S., Scherr, P. A., Cook, N. R., & Chown, M. J., et al. (1989). Prevalence of Alzheimer's disease in a community population of older persons: Higher than previously reported. *Journal of the American Medical Association*, 262, 2551-2556.
- Geldmacher, D. S. (1998). Office diagnosis and management of Alzheimer's disease. *Mediguide to Geriatric Neurology*, 2(4), 1-8.
- Goldman, L. S., Nielsen, N. H., & Champion, H. C. (1999). Awareness, diagnosis, and treatment of depression. *Journal of General Internal Medicine*, 14, 569-580.
- Haley, W. E. (1997). The family caregiver's role in Alzheimer's disease. *Neurology*, 48(Suppl 6), S25-S29.
- Ham, R. J. (1999). Evolving standards in patient and caregiver support. *Alzheimer Disease and Associated Disorders*, 13(Suppl. 2), S27-S35.
- Houts, P. S., Nezu, A. M., Nezu, C. M., & Bucher, J. A. (1996). The prepared family caregiver: A problem-solving approach to family caregiver education. *Patient Education and Counseling*, 27, 63-73.
- Howarth, D. F., Heath, J. M., & Snope, F. C. (1999). Beyond the Folstein: Dementia in primary care. *Primary Care*, 26, 299-314.
- Husband, H. J. (2000). Diagnostic disclosure in dementia: An opportunity for intervention? *International Journal of Geriatric Psychiatry*, 15, 544-547.
- Kaye, J. A. (1998). Diagnostic challenges in dementia. *Neurology*, 51(Suppl 1), S45-S52.
- Kelley, L. S., Buckwalter, K. C., & Maas, M. L. (1999). Access to health care resources for family caregivers of elderly persons with dementia. *Nursing Outlook*, 47, 8-14.
- Knopman, D., Donohue, J. A., & Guterman, E. M. (2000). Patterns of care in the early stages of Alzheimer's disease: Impediments to timely diagnosis. *Journal of the American Geriatrics Society*, 48, 300-304.
- Leon, J., Cheng, C. K., & Neumann, P. J. (1998). Alzheimer's disease care: Costs and potential savings. *Health Affairs*, 17(6), 206-216.
- Marin, D. B., Sewell, M. C., & Schlechter, A. (2002). Alzheimer's disease: Accurate and early diagnosis in the primary care setting. *Geriatrics*, 57(2), 36-40.
- National Alliance for Caregiving & the AARP. (1997). *Family caregiving in the U.S.: Findings from a national survey*. Washington, DC: Author.
- National Institute on Aging. (1999). *Progress report on Alzheimer's disease* (National Institutes of Health Publication No. 99-4664). Bethesda, MD: U.S. Department of Health and Human Services.
- Rogers, S. L., Farlow, M. R., Doody, R. S., Mohs, R., Friedhoff, L. T., & the Donepezil Study Group. (1998). A 24-week, double-blind, placebo-controlled trial of donepezil in patients with Alzheimer's disease. *Neurology*, 50, 136-145.
- Rossor, M. N. (1999). Early diagnosis of dementia. *Journal of Neurology*, 246, 4-5.
- Sandelowski, M. (2000). Whatever happened to qualitative description? *Research in Nursing & Health*, 23, 334-340.
- Sano, M., Ernesto, C., Thomas, R. G., Klauber, M. R., Schafer, K., & Grundman, M., et al. (1997). A controlled trial of selegiline, alpha-tocopherol, or both as treatment for Alzheimer's disease. *NEJM*, 336, 1216-1222.

- SantaCruz, K. S., & Swagerty, D. (2001). Early diagnosis of dementia. *American Family Physician*, 63, 703-713, 717-718.
- Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association*, 282, 2215-2219.
- St John, W., & Johnson, P. (2000). The pros and cons of data analysis software for qualitative research. *Journal of Nursing Scholarship*, 34, 393-397.
- Tariot, P. (2001). Maintaining cognitive function in Alzheimer disease: How effective are current treatments? *Alzheimer Disease and Associated Disorders*, 15(Suppl 1), S26-S33.
- U.S. Census Bureau. (2001). *Population by race for the United States 2000, Table 3*. Retrieved May 9, 2002, from <http://www.census.gov/population/cen2000/phc-t6/tab03.pdf>

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