Attitudes Toward the Diagnosis and Disclosure of Dementia Among Family Caregivers and Primary Care Physicians

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Purpose: This study examined attitudes of caregivers and physicians toward assessing and diagnosing dementia, with an emphasis on how a diagnosis is disclosed. Design and Methods: Seventeen focus group interviews were conducted with caregivers or physicians from three sites; 52 caregivers participated in nine interviews (three each at the three sites), and 39 physicians participated in eight interviews (three each at two sites; two at one site). Structured interview protocols were used to assess diagnostic disclosure, first reactions, and suggestions for improving the diagnostic process. Results: Caregivers recounted a highly negative emotional response to the disclosure, whereas many physicians reported that families handled the information well. Caregivers expressed a range of preferences for how the diagnosis should have been disclosed, from a direct approach to having the physician ease them into the results. Implications: Whenever possible, physicians should consult with the patient and family at the outset of the diagnostic process to better understand their preferences for diagnostic disclosure.

The benefits of obtaining a specific diagnosis of a dementing illness from the perspectives of family caregivers and primary care physicians have been documented. For family caregivers, benefits include providing a sense of relief by letting them know what is wrong, ruling out other reversible causes of memory or behavior problems, facilitating access to community-based information and support services, promoting adaptation and coping, helping to plan for the future, and enhancing communication during health care visits (Connell & Gallant, 1996). For physicians, a specific diagnosis can increase certainty about treatment options and possible illness complications as well as assist in planning for future care based on the known clinical course of the illness (Foster, 2001).

Caregivers also encounter barriers when seeking a diagnosis, including the time-consuming and expensive nature of the process, not knowing where to turn for help, the patient’s reluctance to go to a doctor, and a lack of consensus among family members about how to proceed (Boise, Morgan, Kaye, & Camicioli, 1999). Physicians also report obstacles to providing a diagnosis of a dementing illness, including not having enough time for a comprehensive assessment during a typical office visit (Boise, Camicioli, Morgan, Rose, & Congleton, 1999) and being inexperienced in dealing with diagnostic uncertainty (Beisecker, Chrisman, & Wright, 1997; Foster, 2001).

Relatively few studies have focused on the process of disclosing a dementia diagnosis (Downs, 1999). In a qualitative study of 14 patients and 40 of their family members, Smith and Beattie (2001) concluded that...
disclosure of a dementing illness is generally beneficial because it provides a sense of relief, but that there are great variations in caregivers’ level of understanding of the diagnostic information. Maguire and colleagues (1996) report that caregivers generally feel that their family member should not be informed about their diagnosis, in large part because of their concern that the disclosure would trigger depression in the patient. In one of the few published studies of the diagnostic process in which paired interviews were conducted with physicians and dementia caregivers, family members reported being more satisfied with physicians’ diagnostic skills than with their attention to psychosocial issues (Glasser & Miller, 1998). Caregivers reported that physicians could have done a better job of listening to their concerns, making them feel understood, and checking to see how they were coping with the stress of the role. Overall, physicians tended to evaluate their own efforts more highly than did caregivers (Glasser & Miller, 1998).

The purpose of this collaborative study among three Alzheimer’s Disease Centers (ADCs) was to examine attitudes of family caregivers and primary care physicians toward assessing and diagnosing dementia, with a particular focus on how a diagnosis is disclosed. Unlike previous qualitative research in this area, parallel open-ended questions were asked of caregivers and primary care physicians to provide an in-depth examination of these issues. Comparing perspectives may inform strategies for disclosing a diagnosis of a dementing illness and developing educational interventions for both caregivers and physicians.

Methods
Participants

The three ADCs that participated in the study were located at the University of Michigan (UM), University Hospitals of Cleveland/Case Western Reserve University (UHC/CWRU), and the Oregon Health & Sciences University (OHSU). We recruited participants from three sites for the study to increase the generalizability of the findings in terms of geography and practice and care settings. Caregivers were required to be caring for a patient who was diagnosed with a dementing illness within the past 2 years and had to be willing to discuss the general issues of the doctor–patient relationship. Participants were recruited in collaboration with a local chapter of the Alzheimer’s Association (UM), through a research registry and a local chapter of the Alzheimer’s Association (UHC/CWRU), and from a local senior center and two residential care facilities (OHSU).

A total of 52 caregivers participated in nine focus-group interviews (three each at the three sites). The groups included from 3 to 10 caregivers each. Participants ranged in age from 40 to 85 years, with a mean age of 63. The majority of participants were female (76.2%), White (85.7%), and the spouse (52.4%) or daughter (23.8%) of the family member with a dementing illness. In the majority of cases, caregivers reported that the diagnosis they received was probable Alzheimer’s disease (61.9%), followed by dementia (28.6%), diffuse Lewy Body disease (4.8%), and frontotemporal dementia (4.8%).

Each ADC recruited physicians in family medicine, internal medicine, and general practice from managed care organizations and group practices. Primary care physicians were included in this study because they are typically the first resource that families contact when facing symptoms of dementia, particularly for those in rural areas where specialist care is not readily available (Council on Scientific Affairs, 1993; Heagerty & Eskenazi, 1994; Maslow, 1990; Silliman, 2000). Physicians were recruited from a health maintenance organization for seniors (UM), with assistance from a local physician (UHC/CWRU), and from a private group practice, a health maintenance organization, and the director of an osteopathic organization (OHSU).

Across the three study sites, a total of 39 physicians participated in eight focus-group interviews. The groups ranged in size from 3 to 8 participants. Physicians ranged in age from 28 to 54, with a mean age of 41 years. Two thirds of the participants were male; 82% were White. Of the physicians, 34% were specialists in family medicine, 53% in internal medicine, and 13% in geriatrics. On average, the physicians had been in practice for 10 years and saw 73 patients with dementia in the last year.

Procedure

We developed semistructured interview protocols for the caregiver and physician focus group interviews. The questions in each were designed to be parallel, to move from general to more specific topics, and to examine attitudes toward diagnosing and disclosing the diagnosis of a dementing illness. Staff at each ADC who were experienced in qualitative data collection conducted the focus group interviews (conducted separately for caregivers and physicians). The interviews were audiotaped, with the permission of participants, and transcribed verbatim. On average, the interviews lasted 1.5 hr. As part of the interview process, participants completed a brief survey to assess demographic characteristics and other descriptive information. All research procedures were approved by the Institutional Review Boards at the three sites.

Caregiver Interview Protocol

After caregivers described the symptoms they first noticed in their family member, interviewers asked them how the first physician they consulted noticed the problem, and to describe the process of the physicians and other family members involved. Interviewers then asked caregivers if they had seen a neurologist, psychiatrist, or other specialist. Next, interviewers asked for a description of the initial diagnostic evaluation. Caregivers were asked to describe the first physician’s evaluation and whether they were satisfied with the diagnosis.

Caregivers then described the process of the initial diagnostic evaluation. Interviewers asked caregivers to describe the process of the initial diagnostic evaluation and whether they were satisfied with the diagnosis. Caregivers were asked to describe the first physician’s evaluation and whether they were satisfied with the diagnosis.
the specific words their physician used when giving the diagnosis and to whom it was given. The next set of questions included: (a) How would you like to have been told the diagnosis? and (b) How did you first react to the diagnosis and how did your physician respond? Interviewers also asked caregivers whether their physician provided information and referrals to other services and discussed treatment options. Finally, interviewers asked caregivers: What advice do you have for physicians to make the process of dealing with a dementing illness less stressful for patients and family members?

**Physician Interview Protocol**

In the first part of the interview protocol, interviewers focused on the disclosure process. The questions included: (a) What specific words do you use and avoid using?, (b) To whom do you usually tell the diagnosis?, (c) How do patients and family members react?, and (d) How do you respond? Next, interviewers asked physicians whether they provide information and referrals to other services and discuss treatment options. Finally, interviewers asked physicians whether they had any suggestions for making the process of getting and disclosing a diagnosis less stressful for family members and physicians.

**Analysis Strategy**

We first analyzed data collected during the focus group interviews, aggregated across the three sites, separately by group (caregiver and physician). Our data-analysis strategy involved multiple steps using a constant-comparison approach to identify major themes. First, two researchers at the UM analyzed each transcript line by line. Next, they compared and discussed the classification schemes they used as a form of analytical triangulation. A series of code categories, based on the research objectives and reflected in the interview protocol were created as the basis for organizing the data, as recommended by Miles and Huberman (1994). Because the initial protocol-based codes were broad, we further refined them as the analysis progressed. For example, we further categorized “first reactions to the diagnosis” as including both positive responses (e.g., relief or validation) and negative responses (e.g., shock, devastation, or sadness). Next, we assigned segments of data either a preexisting code, a new, emergent code suggested by the data, or both.

Our analysis was facilitated by the use of ATLAS.ti software (Scientific Software Development, Berlin, Germany). This software provides tools to retrieve all quotations in a code category for comparison and refinement and to write memos, which were linked to codes and quotations. Early in the analysis, we used memos to explore emerging themes. Later in the analysis, we used memos to link codes across the caregiver and physician groups. These tools were especially helpful given that two researchers were involved in a collaborative process of analyzing the data.

Major themes, organized by subheadings, are provided in the subsequent section, followed by illustrative quotes.

**Results of Caregiver Focus Group Interviews**

**The Process of Getting a Diagnosis**

Caregivers reported that they met with resistance from physicians when they tried to obtain a dementia assessment and were sometimes told that their family members’ symptoms were due only to aging.

“I first noticed symptoms in my husband about 5 years before I could convince the doctor that there was anything wrong.”

“Mother’s family doctor did not describe anything. He just said flat out it was due to aging, just memory loss due to aging, and that there wasn’t anything that could be done.”

**Advantages of Receiving a Diagnosis**

A number of caregivers described feelings of regret that they didn’t receive a diagnosis earlier than they did. With a diagnosis, they felt that they would have been more patient, understanding, and less apt to blame their family member for his or her actions, as illustrated by the following quotes.

“Well, if I had known that the man was sick, first of all, he wouldn’t have been left alone as long as he was. Second of all, I wouldn’t have blamed him for his actions. I would have known it was the disease. We did a lot of damage emotionally to him as well as to ourselves, and there’s a lot of guilt associated with what we had done, so I think diagnosis as early on as possible is the best possible thing that can happen.”

Caregivers also reported that the diagnosis provided an incentive to take the initiative to make decisions and assume responsibility for their family members.

“... it was a relief to have the diagnosis because as decisions had to be made ... we had to take the leadership.”

**The Disclosure of a Diagnosis**

Some caregivers were told that their family member had dementia. More frequently, caregivers were told that their family member had Alzheimer’s disease. Although caregivers generally reported that
they appreciated knowing what was wrong with their family member, many reported that they weren’t sufficiently prepared to hear the words Alzheimer’s disease and that the diagnosis was presented in a manner that was too direct and insensitive.

“He told her point blank . . . you have Alzheimer’s.”
“I think if he had just sat us down and said, ‘You know, all signs are beginning to point this way’ . . . in other words, . . . ease us into it. I think that’s better than coming right out and saying you’ve got it.”
“. . . he did say the word Alzheimer’s . . . I was so afraid of the word and I didn’t know how my mom would react because she still had enough of her faculties to know . . . that this was a very, very bad thing . . . the worst of all possible diagnoses.”

Other caregivers preferred the direct approach. They appreciated being confronted with what the symptoms were suggesting.

“I really appreciated it when she just came right out and just told me what it was.”

First Reactions

Although first reactions to hearing the diagnosis included shock, embarrassment at having not recognized the problem earlier, devastation, and anger, caregivers also reported relief and validation.

“The first thing was . . . a shock that I didn’t recognize the problem. I think that hit me harder than anything that, for some reason, I had not recognized this problem.”
“I kept that to myself that I didn’t recognize what was happening to my wife. It was a bit of an embarrassment.”
“I knew there was something wrong. I suspected it was . . . Alzheimer’s, but when I heard the word from the neurologist, I was devastated. It pushed me over the edge.”
“I was angry. I didn’t want her to be sick. I didn’t want to have to take care of her. I was still taking care of my kids and my grandchildren.”
“I felt very relieved when we finally got the diagnosis . . . I just felt validated that finally someone knew what we knew.”

What Happened After the Diagnosis?

For the most part, caregivers reported that they did not receive adequate information and referral after they received the diagnosis. Many reported that their physician did not discuss next steps or provide current information about community-based services.

“I don’t think that any of the doctors that we were involved with ever offered any help as far as what to do next.”

“I ran into the problem that they give you the information, but they don’t keep it current and up-to-date. You call places . . . and you get answering machines or you get disconnected or get told ‘we don’t do that service anymore’ . . . that’s kind of frustrating.”

Some caregivers were disappointed that their physician did not suggest a return visit to follow-up and monitor their family member’s conditions.

“I just can’t understand that some disease that you’re going to have for 4 to 6 years, you don’t need to go back ever and see them.”

Most caregivers reported that they received either no or only limited information about treatment options. Caregivers often reported that the burden was on them to initiate any discussion of medications for their family member.

“In every case, I was the person coming up with the treatment . . . and the family doctor would say, ‘Well, alright. We can try that.’”

Any Advice for Physicians?

Caregivers suggested that physicians take the time to listen to their concerns.

“Listen to the people close to the person because even if you (physician) have known that patient for a long time, . . . no one can tell quicker than the family . . . that there is something drastically wrong . . .”

Caregivers reported that they would have liked to have the diagnosis disclosed in a compassionate and gentle manner and to include the patient in the office visit in a way that preserves their dignity and a sense of hope.

“He took the time to explain it and treat her like a human being.”
“Right or wrong, give the patients and their families some hope . . . I think it’s more compassionate.”

Results of Physician Focus Group Interviews

Challenges to Providing a Diagnosis

Although caregivers reported that the physicians they consulted often seemed reluctant to provide a diagnosis, physicians presented another view. One physician reported feeling pressured into making a diagnosis, as illustrated by the following quote:

“In the last 5 to 10 years, there has been so much in the media about it, that . . . they are demanding the
One of the challenges faced by physicians is the limited amount of time they have to spend with people with dementia and their family members. "On the brief visits that we do nowadays ... when these people come in not for dementia but to have their blood pressure medication refilled ... in the 10 or 15 minutes you have, ... you don’t get in depth enough to pick up some of these subtle or mild dementias."

Other physicians mentioned the challenge of disclosing a diagnosis of a dementing illness. "It’s difficult ... everyone feels uncomfortable telling somebody bad news."

Finally, physicians mentioned the challenges in maintaining a balance between patient confidentiality and keeping the family fully informed. "The difficult issue here is the underlying respect for the patient’s confidentiality that you have to violate because of their inability to understand."

### Advantage of Receiving a Diagnosis

Physicians reported that the primary advantages of receiving a diagnosis are that family members could find out what is wrong, begin planning for the future, and be referred to services. "Once they know, they can avail themselves of the services that are available, the medication, research, whatever. ..."

### The Disclosure of a Diagnosis

Physicians use a variety of terms when disclosing a diagnosis, including memory loss and dementia. Others use the term Alzheimer’s disease, although some physicians do so only if family members are with the patient during the visit.

"I use the term dementia and try to explain what that means in terms of a loss of brain function."

"Once I feel fairly comfortable with my workup ... I bring that patient back in and say, ... you probably have early Alzheimer’s disease."

"I use the term Alzheimer’s a lot more with family members and not with the patient."

A number of physicians reported that they avoided the terms dementia, senility, and/or Alzheimer’s disease when disclosing a diagnosis. "... so I’ll kind of soft touch the diagnosis ... and focus more on their memory rather than saying you’ve got Alzheimer’s."

"I guess I probably tend to hedge a little bit and say your mom/or you is not able to go home and live safely by yourself. I guess I go down that road rather than saying you have dementia."

"Alzheimer’s is such a ... familiar word now and people frequently associate it with disaster ... it’s a powerful choice of words."

Physicians rarely disclose the diagnosis to a patient not accompanied by a family member unless they are in a very early stage of the disease. Instead, as reported by caregivers, the diagnosis is usually disclosed to both the patient and the family members together. At times, the physician chooses to tell the family before he or she informs the patient.

### First Reactions

A few physicians reported that the first reactions of caregivers included shock, denial, and frustration. More frequently, however, physicians reported that family members respond well to the news. "Families have seemed ... pretty accepting, understanding ... especially if the person is old."

"I haven’t had any problems with anyone getting too emotional and excited or distraught."

Physicians also reported that family members weren’t surprised to hear the news. "It confirms what they suspect."

### What Happens After the Diagnosis?

Some physicians reported that they do not schedule a return visit in cases of dementia. "I don’t ... have them follow up on a regular basis because of the dementia ... but for some other chronic disease...."

Other physicians described the advantages of follow-up to both the patient and family members. "They’re going to have a bunch of questions ... having ... that appointment slip ... so next week they can come back ... having that connection ... seems to make a difference."

Physicians reported that they provide information and referral to community-based services. "You try and tap them into resources, things they can read ... whether it’s an 800 number, the Alzheimer’s Association, Agency on Aging, or the 36-Hour Day, something they can take home and..."
learn a little bit about the experience and plan ahead.”

Physicians also reported challenges to providing up-to-date information and referral to services, particularly in light of the public’s access to the Internet.

“My patient . . . lives in a rural small town . . . I don’t know what the community agencies there are.”

“You have to keep up with what’s on the Internet too . . . families come in . . . with the most crackpot stuff. You have to be aware of that and . . . know what’s coming.”

Some physicians present treatment options to patients and their family members but they also reported reservations about their effectiveness.

“Even though they’re not cures by any means, we . . . have the obligation to at least mention that there are a number of current interventions that . . . slow down progression.”

Suggestions for Improving the Diagnostic Process

Physicians suggested several strategies for improving their ability to make a diagnosis, including building consensus regarding a specific diagnostic protocol for dementia, offering additional training to improve diagnostic skills, and increasing the amount of time available to spend with patients and their family members. Physicians also suggested involving family members as a source of support and contact.

“Having a point person for the family makes our job a lot easier. That person can gather all the family’s concerns, have the questions written down, make sure they get addressed.”

“Having all the interested family members there while you’re discussing it at the same time . . . is really helpful. That way, they’re hearing the same thing at the same time.”

Physicians described several strategies for disclosing a diagnosis in an appropriate manner, including taking a slow and cautious approach, being compassionate and sensitive, and being direct in an effort to help families plan for the future.

“Take your time . . . don’t feel that you have to give them the diagnosis on the first visit. Do the workup, develop a relationship with this patient . . . and family. The more time you’ve spent, several months down the road when the Alzheimer’s really comes out, it’s going to be a lot easier for everybody.”

“When they first come into the process of memory loss, I go through all the alternatives it could be . . . I get this planted in their mind before I see them the next time.”

“I don’t think there is a way to make it easy for someone to find out that a loved one has a chronic, incurable progressive disease. So, I try to be compassionate, understanding, and available. I don’t know if there’s more that . . . can be done to make it less upsetting.”

Discussion

The present study provides an in-depth qualitative examination of the perspectives of both caregivers and physicians about their experiences in the assessment and diagnostic disclosure process. Results suggest areas of both convergence and contradiction in the attitudes and experiences of the two groups. For example, caregivers reported that one of the major benefits of obtaining a diagnosis was that it helped them to be more patient and understanding with their ill family member and enabled them to make decisions on their behalf. In fact, many caregivers expressed regrets that they did not obtain a diagnosis sooner. Physicians, in contrast, tended not to mention the psychosocial impact of the diagnosis. Instead, they endorsed the tangible benefits, including enabling family members to start making plans and get information about community-based services and treatment options.

Some caregivers conveyed a sense of urgency about their need to obtain a dementia assessment and, at times, frustration with what they perceived to be resistance from physicians. In some instances, caregivers reported that they were unable to convince their physician that something was wrong with their family member (also reported by Boise, Morgan, et al., 1999). In contrast, physicians reported that they sometimes felt pressured by caregivers to make a diagnosis, in part because of the heightened awareness of dementing illnesses among the general public due to increased media attention.

In terms of the actual disclosure of the diagnosis, caregivers recounted a wide range of experiences and reactions to what was said and how the news was delivered. Some caregivers appreciated a direct approach—having the physician come right out and tell them the results of the assessment. Other caregivers, however, felt that the patient would be devastated if they heard the words Alzheimer’s disease. Physicians reported that they use the terms dementia or Alzheimer’s disease, but a substantial number chose to discuss memory problems or safety concerns rather than offer a definitive diagnosis. These physicians may have been concerned about the negative impact of certain words (e.g., Alzheimer’s disease) or were not convinced of the benefits of disclosure in the case of dementia (Drickamer & Lachs, 1992).

Caregivers also stressed the importance of having the diagnosis disclosed in a compassionate and sensitive manner and in such a way as to preserve a sense of dignity and hope for both the patient and family members. Many caregivers wanted physicians...
to ease them into the bad news rather than use the words Alzheimer’s disease (also reported in Connell & Gallant, 1996). Some physicians recognized the significance of the timing of the disclosure. For example, one physician was quoted as saying, “Take your time … don’t feel that you have to give them the diagnosis on the first visit.” Other physicians were reluctant to disclose the diagnosis in front of a family member without the patient’s explicit consent because it would represent a breach of his or her confidentiality.

Results suggest that, when a diagnosis of dementia is disclosed, the best situation is when the expectations and preferences of the family are acknowledged and understood by the physician. For those family members who prefer the direct approach, having a physician offer anything less than a definitive diagnosis is likely to be unsettling. Alternatively, disclosure by a physician who “tells it like it is” might be very threatening to a patient and caregiver who need time to warm up to the reality of the diagnosis. Similarly, the term dementia might be most appropriate for those patients and family members who prefer a cautious approach to disclosure whereas Alzheimer’s disease might be a better term for those who are ready to confront the diagnosis in a more direct fashion. Whenever possible, physicians should consult with the patient and family members at the outset of the diagnostic process about their preferences for how the diagnosis should be discussed (Moniz-Cook, Agar, Gibson, Win, & Wang, 1998; Smith & Beattie, 2001). For example, patients should be asked if they want to have a family member present when they learn about the results of their evaluation or if they would prefer to hear the news privately first.

The caregivers and physicians differed in their reporting of the reactions of family members to the diagnosis. Although some caregivers expressed relief, most described their first reactions to hearing the diagnosis in highly negative and emotional terms. In contrast, most physicians reported that the diagnosis confirmed what had been suspected and that family members responded well to the diagnosis. This difference in perspectives is intriguing and may be due, in part, to the fact that family members may feel obligated to adhere to an unwritten social protocol that dictates they be stoic, polite, and unemotional in the context of a doctor’s visit. In contrast, some family members may prefer to contain their emotions in the context of the office visit in the presence of the patient. These results suggest that even when families receive the news of a dementia diagnosis with equanimity, their underlying reaction may be great shock and sadness.

Caregivers and physicians also differed in their descriptions of what happens after the diagnosis is disclosed. Family members reported that they received little or no help or that the help they received was not what they needed. In particular, caregivers mentioned that they received little information about the diagnosed disease and its expected progression, a finding that has been reported extensively in the literature (Connell & Gallant, 1996; Fortinsky, 1997; Glasser & Miller, 1998). On one hand, most caregivers reported that their physicians did not initiate a discussion of treatment options; rather, the burden was on them to bring up the subject if they wanted information or advice. Physicians, on the other hand, reported that they tried to provide information about community-based services and treatment options, although they acknowledged that they rarely had up-to-date information about their availability.

Several study limitations should be noted. For the caregivers in this study, recall bias may have influenced responses, especially if more than a few months elapsed since the diagnosis. Primary care physicians’ responses are based on reflections across their patients with dementia, independent of the length of their relationship. In addition, results are based on a nonrandom sample of caregivers and physicians. The caregivers in the study may be unique because they were motivated to seek a diagnosis and willing to participate in research. The physicians who completed the interviews may treat more patients with dementia or be more aware of issues surrounding a dementia diagnosis than physicians in general. Nevertheless, major themes were confirmed across three sites representing different geographic areas and recruitment strategies.

Future research in this area should include those who have not sought a diagnosis, as well as paired interviews so that family members and physicians could discuss their unique experiences of the same interaction. In addition, both the caregiver and physician samples were predominantly White. Diverse groups of caregivers should also be recruited to participate in future research, as culture, race, and ethnicity affect the decision to seek an early diagnosis, issues in diagnostic disclosure, and doctor–patient interactions (Brotzman & Butler, 1991; Connell, Shaw, Holmes, & Foster, 2002; Janevic & Connell, 2001). Including the patient perspective would also enhance understanding of the diagnostic process (Cotrell & Schulz, 1993; Fortinsky, 2001; Husband, 1999). Finally, expanding the focus of this research to other chronic illnesses (particularly a dreaded disease such as cancer) would better position this work in the broader literature on doctor–patient relationships (Haug, 1994).

Despite these limitations, these results offer insights into the process of diagnosing dementia and suggest a number of implications for practice. First, physicians would benefit from clear and consistent delineation of standardized protocols for the assessment and diagnosis of dementia. Innovative outreach programs are also needed to better inform both caregivers and physicians about available community-based services and treatment options (Fortinsky, 1997).
Both caregivers and physicians offered suggestions for improving the diagnostic and disclosure process that could be incorporated into physician education. Caregivers suggested that physicians take the time to listen to their concerns, devote more time to discussing the diagnosis and what it means, and include the patient in the context of the office visit, even if he or she might not understand the implications of the diagnosis. Previous research has documented that these factors are directly linked to caregiver satisfaction with the triadic relationship (patient–physician–caregiver) that is typical in cases of dementia (Beisecker et al., 1997; Fortinsky, 2001).

Physicians suggested the need for a specific protocol for diagnosing dementing illnesses to help less-experienced physicians and ensure that “things don’t fall through the cracks.” Another suggestion was to increase the amount of time available to spend with patients and their caregivers, which is supported by a recommendation by the Council on Scientific Affairs of the American Medical Association (1993) that physicians be reimbursed for time spent providing education and counseling for caregivers. An emphasis on diagnostic-disclosure techniques could become a standard component of physician-education programs on dementia. Such techniques could increase familiarity with the emotional and psychological needs of patients and family members inherent in the diagnostic process and the importance of disclosing the diagnosis in an informative and compassionate manner. These approaches could go a long way toward helping families and patients as they face the potentially profound impact of receiving a diagnosis of a dementing illness.

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