

Physicians' Perspectives on Caring for Cognitively Impaired Elders

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Purpose: This study aims to develop an in-depth understanding of the issues important to primary care physicians in providing care to cognitively impaired elders. **Design and Methods:** In-depth interviews were conducted with 20 primary care physicians. Text coded as "cognitive impairment" was retrieved and analyzed by use of grounded theory analysis techniques. **Results:** A patient's impaired ability to provide an accurate history and to participate in self-care hindered the usual process of care, often resulting in greater medical uncertainty and feelings of inadequacy and frustration for the physician. Shifting the goal of care from "curing" the patient's illness to "caring" for the patient's quality of life was also problematic. The doctor-patient relationship changed dramatically as others became involved in care, often with attendant ethical dilemmas related to patient autonomy and the locus of decision making. Many physicians described a deep sense of loss and grief as the personhood of patients faded. The increased complexity and prominent social and emotional issues were difficult to manage in the context of the current model of practice. **Implications:** Profound changes occur in the process of care with cognitively impaired patients. The increased complexity mandates an expanded model of care that addresses the prominent psychosocial and ethical aspects of care as well as the medical ones.

Key Words: Primary health care, Cognitive impairment, Geriatrics

Cognitive impairment is extremely common in old age, with 40–50% of people over the age of 85 affected (Aevarsson & Skoog, 1996; Bachman, Wolf, & Linn, 1993; Evans et al., 1989; Unverzagt et al., 2001). As the Baby Boom generation ages, general internists and family physicians will see increasing numbers of cognitively impaired patients. In order to meet these patients' needs, physicians must have the appropriate skills not only to diagnose and treat the illnesses that cause cognitive decline but also to provide ongoing care for the majority who will have a relentless progressive course. Although there are studies of primary care physicians' recognition and diagnosis of dementing illnesses (Boise, Camicioli, Morgan, Rose, & Congleton, 1999; Brodaty, Howarth, Mant, & Kurrle, 1994; Callahan, Hendrie, & Tierney, 1995; Wind, Van Staveren, Jonker, & Van Eijk, 1994), there is little research on what is involved in the ongoing process of primary care for patients who suffer from them. In order to train physicians to provide care for these patients, we need to understand the process of their care and what skills physicians need to provide this care.

Cognitive impairment does affect medical care. It has been shown, for instance, that cognitively impaired patients are more likely to be hospitalized and to have lengthier hospital stays than older adults without dementia (Albert et al., 1999; Lyketsos, Sheppard, & Rabins, 2000). What underlies such phenomena, however, has been studied very little. Although it seems obvious that deficits in memory, language, and other cognitive processes must affect the process of medical care, there is a dearth of information regarding the primary care needs of these patients and their physicians. For example, previous studies have explored the "triad" relationship in geriatrics, in which third parties become involved in patient care, but these studies have largely omitted the extremely prevalent problem of cognitive impairment (Adelman, Greene, & Charon, 1987; Greene, Majerovitz, Adelman, & Rizzo, 1994; Silliman, 1989). In the American College of Physicians' quality indicators for dementia care, only 2 of the 14 recommendations involve treatment

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COGNITIVE IMPAIRMENT

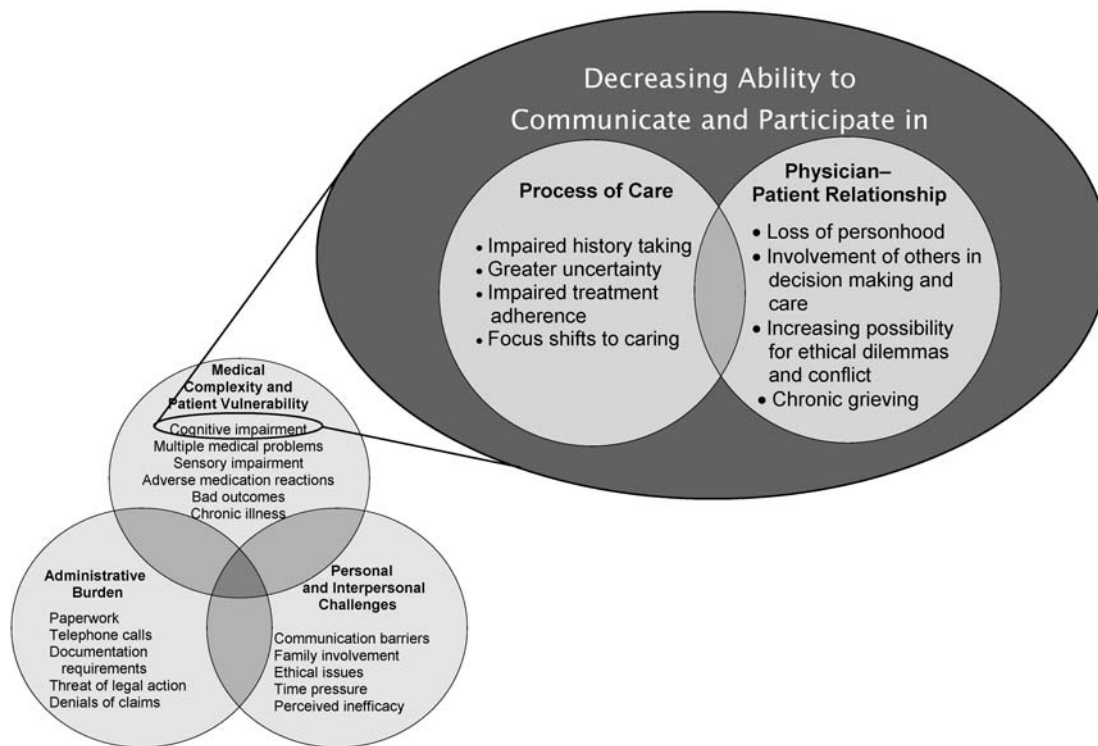


Figure 1. Process of care with geriatric and cognitively impaired patients.

or management of the dementia (Chow & MacLean, 2001). Without understanding the issues that primary care physicians face in providing ongoing care for these patients, medical educators may not be providing them with the skills they need to provide optimal care to cognitively impaired elders.

In a qualitative study exploring physicians' perceptions of geriatric primary care, we (Adams et al., 2002) found this:

[Although physicians] enjoyed their interactions with elderly patients . . . the high prevalence of multiple medical problems and declining physical and cognitive functioning . . . gave rise to interacting medical, interpersonal, and administrative difficulty. Physicians struggled to deal with the difficulty in a practice environment that was not set up to provide the support and resources these patients needed (p. 841).

The left-hand portion of Figure 1 illustrates our findings of the specific issues that physicians raised in geriatric primary care. We noted, however, that their descriptions of trying to care for cognitively impaired patients contained deeper overtones of frustration and uncertainty than their descriptions of coping with other types of problems seen in the elderly population. This difference and the subtle professional and emotional difficulties that seemed to be associated with it provided the impetus for our further examination of this subset of the data. Our intent was to develop a more detailed understanding

of the issues faced by physicians in providing primary care for cognitively impaired patients, and to explore how these affect the process of primary care.

Methods

Design and Participants

We conducted a qualitative in-depth interview study with a sample of 20 practicing general internists and family physicians. Unlike quantitative research in which the intent is to gain a representative sample, we were interested in obtaining data on the widest possible range of practice types and physicians providing primary care. To do this we used an iterative maximum variation sampling strategy rather than a random sampling strategy (Kuzel, 1999). In the first step, using a database maintained in the chancellor's office at the University of Nebraska Medical Center, we compiled a list of physicians practicing in the vicinity of Omaha, Nebraska. This list contained men and women, internists and family practitioners within a wide age range. We sent introductory letters describing the study to these physicians, informing them of the study and asking them to participate. We then made telephone calls to physicians on our list who fit the categories already noted, with a goal of interviewing 15 physicians. When the first few interviews suggested that geriatrics training and rural versus urban location might be important variables to consider, we expanded our sampling strategy to

include two fellowship-trained geriatricians in private practice in Omaha and three rural physicians within 50 miles of Omaha. In all, we contacted 141 physicians to recruit 20 physicians for our interviews.

Table 1 identifies the characteristics of our sample. Of the 20 participants recruited, 19 were White and 1 was Hispanic. Seven were women. Ages ranged from 32 to 70 years. Of the participants, 10 were internists and 10 were family physicians. Three respondents limited the number of elderly patients they accepted into their practices; all three were busy internists with a high volume of elderly patients. In this report, we have randomly assigned a code letter to identify participants.

Procedure

Two investigators, both physicians, conducted in-depth interviews (Crabtree & Miller, 1999) with the participating physicians in their practice settings. The average interview lasted 50 min, with a range from 30 to 120 min. The questions were broad and open ended. We invited the participants to relate personal narratives regarding experiences with geriatric primary care with the initial “grand tour” question: “Please tell me about some of your experiences taking care of elderly people.” We then asked the participants to relate both satisfying and frustrating experiences.

Because one of the interviewers was previously acquainted with two of the participants, we examined interview content for both systematic differences in responses to the different interviewers and for possible differences related to previous acquaintance. Specifically, during the group analysis sessions for each interview, the analysis team looked for any significant differences in the content of the physician’s answers, in the phrasing or implied content of the questions, and in the respondent’s relational response to the interviewer. We detected no differences in response content between interviewers.

As a result of the iterative nature of data collection and analysis in this study, the analysis team determined after the first few interviews that cognitive impairment was a very important issue. At that point we modified the interview script to ask subsequently interviewed physicians to specifically comment on their experiences with cognitively impaired patients, if this topic did not come up spontaneously.

Analysis

Interviews were audiotaped and transcribed verbatim. For the original analysis a multidisciplinary team used a three-stage coding process derived from the sociologic tradition of grounded theory (Strauss & Corbin, 1998). In the open-coding stage, each team member independently read each transcript and marked key phrases, terms, or sentences. We then discussed these as a group, sharing insights from our

Table 1. Characteristics of Participants

Characteristic	Internists (n = 10)	Family Physicians (n = 10)
Mean age (range)	44.9 (32–69)	49.5 (35–70)
Mean years since board certification (range)	14.1 (2–37)	14.7 (4–26)
Percent female	60	10
Percent urban location	90	70
Mean percent of practice aged 65 or older (range)	57 (25–100)	32.8 (15–65)
Size of group		
Solo practice	1	2
2–5 physicians	5	2
> 5 physicians	4	6
Percent who do nursing home practice	60	70
Percent who are nursing home medical directors	40	10

various disciplines and assigning topical codes to the text of the interviews. We grouped these codes into categories as it became evident which concepts were emerging as keys to understanding physicians’ perspectives on primary care with elderly patients. We compared the content of each new interview to the existing categories and modified the coding accordingly. In the axial-coding phase, we developed the categories further and began to define the relationships among them and their possible implications. In the final selective-coding process, we developed a conceptual model (Adams et al., 2002).

For the analysis on which we report in this article, we used QSR NUD*IST software to identify all text previously coded as “cognitive impairment.” This text was retrieved, printed, and distributed to each of us by the first author. Using the three-stage process previously outlined, we coded all the text and developed categories identifying issues that arise in primary care with cognitively impaired elders and exploring how these affect the process of primary care.

Results

Overview

In reanalyzing the interviews of these 20 primary care physicians, we found that a common set of issues emerged that made primary care for cognitively impaired elders qualitatively different from usual geriatric primary care. Figure 1 illustrates the nature of these differences. Physicians described profound changes in both the process of medical care and in the doctor–patient relationship. Unlike most other chronic illnesses, those causing cognitive impairment immediately affect the patient’s ability to participate in the process of medical diagnosis and treatment. As a result of patients’ increasing inability to provide an accurate medical history or follow through with instructions consistently, physicians

found diagnosing and treating concurrent conditions more challenging, and they experienced a greater sense of medical uncertainty. Physicians described feelings of inadequacy and frustration as their ability to apply their medical knowledge was thus hindered. Cognitive impairment also had a profound effect on the doctor–patient relationship. As patients became less able to participate actively in decision making, the involvement of family members and others increased the complexity of the relationship. Ethical dilemmas regarding patient autonomy and the locus of decision making were common. As the condition progressed and patients became unable to care for themselves or remain in their homes, additional difficult issues emerged. The focus of care shifted from “curing” to “caring”; nursing home placement with all of its emotional and financial implications for the family and administrative restrictions for the physician came into play. In addition, physicians sometimes felt frustrated by problems caused by personality changes, and they experienced a profound sense of loss and grief as the cognitive abilities of their patients declined and they lost their sense of the patient as a person.

For clarity of presentation, we describe medical and relational issues in separate categories. In practice, these issues overlap and intertwine, resulting in a tremendous increase in the complexity of the primary care process. In the following paragraphs we use quotations from the physician interviews to illustrate these points.

Impact on Medical Care

Cognitive impairment affected medical care by rendering physicians’ usual ways of obtaining information and implementing treatment less effective. Because dementing illnesses progress relentlessly, curing as a measure of success and accomplishment is not an option. In response, some physicians adopted a more comfort-oriented approach to care, but not all found this meaningful.

Impaired History Taking.—Because patients do not usually bring complaints of cognitive impairment to the physician’s attention, recognition of the cognitive impairment itself is challenging. One physician discussed the insidious onset of dementia and the difficulty of detecting it within the time allotted for office visits:

It’s usually so subtle that before I have noticed it, it’s usually been, you know, the family and friends who have brought it to my attention Personally I find it difficult to really recognize it in a 15-minute interview or, you know, appointment every 2 or 3 months. (Dr. J.)

None of the physicians regularly screened patients for cognitive impairment. Often dementia was not

recognized until a third party brought it to the physician’s attention because of safety issues:

You know when they get to the point that they do things dangerous. They leave the stove on . . . or they start wandering into the living room naked and things like that, you know, then it’s clearly, “We’ve got a problem,” and they [the family] get people involved. (Dr. J.)

As patients became progressively less able to give a reliable history, diagnosing concurrent illnesses also became more difficult for the doctors. Physicians had less certainty in the accuracy of their diagnoses and had to look elsewhere for the information they needed to diagnose concurrent illnesses. This was time consuming and frustrating if the information was not readily available: “They can’t really tell you their history, so a lot of times, they take longer and I’ll have to look through the chart more and just try to gather information” (Dr. P.).

Physicians’ uncertainty about the medical history also can lead to increased use of diagnostic tests:

[I’m] doing more laboratory–x-ray medicine than clinical medicine sometimes because I don’t get as much feedback. I don’t know what’s going on in their mind. I don’t really particularly care for that part of my practice I want them to be able to talk to me, tell me what’s going on. (Dr. E.)

As cognition declined, alternative informants became increasingly necessary. As one physician described,

[Cognitively impaired patients] won’t tell you that they’re having problems or they just don’t realize that they’re having problems functioning and you need a family member to tell you that they’re not eating or that they eat candy all day long. (Dr. P.)

One physician developed a creative response to a patient’s impaired ability to give a medical history:

There was one lady I had once . . . the responses you got bore no relationship to anything useful, except I discovered that no matter what else was going on, you could get a bowling score out of her. She’d been on a bowling league and she’d always go bowling and so in the margin of the chart and my notes . . . we always listed bowling scores. And I discovered if her bowling score fell off significantly, something was wrong One of my partners one time was seeing this patient [and asked], “What are all the bowling scores?” I said, “It’s sort of like a sedimentation rate.” (Dr. N.)

Impaired Treatment Adherence and Cooperation.—Cognitively impaired patients’ difficulty remembering to take medications or to follow other instructions interfered with the potential effectiveness

of treatment and was sometimes frustrating. One physician described a situation with an older couple:

Neither of them could remember what medicine she was taking. It was incredibly frustrating and you know, most of it was just because they weren't able to cooperate with bringing in their medications or staying on the medications you asked them to. (Dr. G.)

Another remarked, "I get a lot of that happening where I just try one thing and then they don't end up doing it right and we end up taking two steps back instead of two steps forward" (Dr. I.).

When dementia was severe, patients were sometimes actively resistant to care: "Granted, it's frustrating when somebody's really sick and they're, you know, striking out at you or hitting at you and you can't get the appropriate history" (Dr. A.). As another physician described, this is not a pleasant situation: "They hit you. They bite you. They spit in your face. I mean, you know, it's hard to do that day in and day out" (Dr. P.).

Despite the increased difficulty, however, there can be satisfaction in getting to a diagnosis without all the usual information. One geriatrician related, "In a way, it gives you a sense of accomplishment if you can figure out what other things are going on with them, despite them having dementia" (Dr. A.).

Curing Versus Caring.—Several physicians expressed feelings of futility about their inability to cure or alleviate patients' dementia. One physician, when asked about the adequacy of his education regarding dementia, responded,

The problem is, we still don't have any good treatments, so using what we know is the latest and most comprehensive information on it, you do feel like you're well educated well enough and you recognize the fact that there's not a good treatment out there for it. (Dr. K.)

Another commented, "Cognition, you know... in general, there's not a lot that medicine can do about that." (Dr. L.)

Many came to embrace a different, more comfort-oriented approach to caring for dementia patients. This required a shift of focus away from the biomedical model they learned during their training. As one geriatrician described, "In a good training program, you're taught to make a diagnosis and treat the underlying cause. Well, sometimes you just can't. Sometimes that's hard, but it's just one of the things you have to learn to deal with" (Dr. T.).

In many interviews, there was a tone of reluctant acceptance of this caregiving role. As one physician remarked,

So you kind of just find yourself doing a little more patting on the back, handholding, and being

pleasant and cheerful. And you know, I think there's some value to that ... that they know that there's somebody there who's interested in them and cares about them. (Dr. L.)

In the case of severe dementia, it may be easier to accept a comfort care approach. One physician described his change in attitude toward the care of patients as they become more demented:

When they're more demented, I feel less ... I shouldn't say less responsible, ... I feel less pressure to make them well, to have to perform, because "death is an acceptable outcome," as one of our partners likes to say. And for people that are really demented, sometimes it's just a blessing when they go. (Dr. E.)

Impact on the Doctor–Patient Relationship

As dementia progressed, the doctor–patient relationship underwent a major transformation. When patients became unable to care for themselves independently, the relationship changed from a direct, one-on-one interaction to an expanded relationship with several parties. The new relationship usually included family members, but sometimes it also involved friends, home health agency staff, and eventually nursing home staff. This gave rise to many interpersonal and ethical challenges. In addition, several physicians described a deep sense of loss as the patients' personalities faded.

The Triad Relationship.—Several physicians described the effort required to maintain a kind and respectful relationship with their cognitively impaired patients while also involving a third party. One physician worried, "You end up sometimes examining the patient, then addressing somebody else almost to the point where you might even be slighting them" (Dr. H.). Another related, "The patient's coming in to see me and if I do all my talking to the noncognitively impaired individual then the patient feels left out" (Dr. C.). Another described using "body language things you can do to include the patient" (Dr. T.). Although it was difficult to negotiate this triad, it was deemed necessary, both for diagnostic purposes ("they really can't keep track of how many times they've had chest pains, so the caregiver has to say that"—Dr. T.), and for therapeutic purposes ("you just need to make sure that you have the son, daughter, caregiver, whoever it is, actually be in the room. Otherwise, you end up explaining the same thing twice because the patient doesn't remember"—Dr. K.).

Physicians also were involved in the struggle to maximize patients' safety while still respecting their autonomy. The most challenging issues seemed to be

restriction of driving and independent living. One physician described,

The patient becomes a hazard to themselves and it becomes more difficult for the family, . . . especially when you try to take away driving privileges. That's where you get into the biggest arguments between patient and family. That and actually having to go from the home to a nursing home. (Dr. K.)

As a patient's cognitive abilities declined, the locus of decision making shifted increasingly toward third parties. Often various parties had different perspectives on what the best course of action was. The physician and family sometimes disagreed on when an alternative decision maker was needed. For example, one family physician described a situation with adult children from out of town who felt their parents should not live independently: "As I tried to tell the kids, [your parents] were smart enough to take care of you and put you where you are; they're probably smart enough to make a few decisions as to their care now" (Dr. M.). Conflict also sometimes occurred when family members did not accept the cognitive impairment or persisted in expecting a cure. "The husband would say, 'Look, she can't remember anything, you know. We've got to do something.' And it was like it was my fault, and he didn't get it" (Dr. G.). In the hospital or nursing home, other people involved in the care also sometimes had expectations about what was appropriate: ". . . and then it carries over into the staff at the facility. The nurses say, 'Doctor, why aren't you having the family do this instead of what they're doing?'" (Dr. L.).

Decisions about aggressiveness of care at the end of life were often a source of conflict between families and physicians. Physicians sometimes felt they were being pulled in many different directions and were uncertain whether they were most accountable to the patient or the family. There were sometimes wrenching situations in which the designated decision maker did not seem to have the patient's best interests at heart. One physician described,

I have a patient now out at [local nursing home] who has recurrent aspiration pneumonia, he has Parkinson's dementia, does not talk, does not communicate with the world around him, but his wife has nothing else in the world except her husband and she wants everything done to this fellow . . . I'm doing OK with that particular case, but I've not had success with other families in similar situations, when they, I simply can't do what they want me to do, I just don't have it in my heart to do it. (Dr. C.)

When there was not a designated decision maker, different challenges arose and sometimes legal intervention was required:

I think one tragedy is that people will not have made it clear to their families and/or maybe they really don't have any family around here any more and there is no one to speak for them. I mean, decisions need to be made. Maybe it's not end of life care. Let's say they develop breast cancer . . . Maybe some people would want a lumpectomy and maybe some Tamoxifen orally or some people may say, "Don't do anything." But you may end up going through trying to get a court-appointed guardian fast. You know, it doesn't always help you out very well because sometimes you need decisions faster than the courts. (Dr. N.)

Physicians were often able to adapt the way they handled decision making, however, keeping the patients' wishes as much in the forefront as possible. Some described making considerable efforts to make a good decision:

I can remember one lady . . . if you asked her the same question more than once on successive days you always got the same answer, whether she remembered it or not. It was very clear that she didn't want [nasogastric feeding]. So sometimes even if somebody is not competent, they can still make a decision. In that case, I could provide information like that to this friend who had reluctantly agreed to be guardian: "You have to make the decision, but this is what she's telling me." (Dr. N.)

Loss of Personhood.—As dementia progressed and communication became more and more limited, the doctor–patient relationship became less satisfying. One physician related, "You have to tell them the same thing every visit. And they don't remember you. It eliminates some of the camaraderie, if you will, with the patient. That's inevitable" (Dr. L.). Another expressed, "Probably the relationship isn't quite as close, probably more of a feeling like you're doing your part for society to help with this individual" (Dr. G.). Many physicians also expressed a decreased sense of meaning when caring for severely impaired people, since they can no longer connect in the usual way. "When I'm taking care of [those with dementia], depending on how demented, obviously, I feel more like I'm doing medicine to them instead of working with them toward something" (Dr. E.).

Many regarded severely demented people as having lost what made them human. One physician described, "Whatever is the essence of their humanity is long since gone and I'm tending to a body which has no hope of recovery and it's hard for me to get real excited and enthusiastic in that setting" (Dr. B.). Another put it this way: "You know you're not reaching them. You know, you're talking to them but you're not talking to a person" (Dr. J.).

Several physicians related the deep sadness they felt when caring for a person they have known for some time as that person loses cognitive function. One described chronic grieving:

The family deals with that all the time, but you also deal with it as a physician When they continue to live but you can't communicate with them anymore, that's a chronic grieving type of thing. It's more difficult to deal with I think. (Dr. J.)

Another put it this way:

I do know it is quite sad when you get somebody in end stage organic brain syndrome Having cared for that person for a decade, known what they wanted to do, that is very sad. Not quite as bad as when the babies die, but that is very sad. (Dr. N.)

And lastly,

Especially when you've known the patient before and you watched them before your eyes deteriorating, there's nothing you can do about it It just steals the person. It's just an empty shell kind of situation and definitely a very sad, sad thing. (Dr. D.)

Discussion

In this study, we found that physicians experience extremely challenging problems in providing primary care for cognitively impaired elders. Physicians must diagnose and treat concurrent illnesses without the usual diagnostic clues and cannot have confidence in the patient's ability to follow through with instructions. The doctor-patient relationship transforms as third parties become involved in decisions about appropriate care. Families expect doctors to address ethical concerns about balancing patients' autonomy with the need to consider their safety. Physicians also must deal with their own sense of loss as patients' cognition declines. In contrast to these prominent issues facing physicians, the focus of most previous research and of medical education programs has been on recognition and diagnosis of dementia. Our study clearly demonstrates that there are skills and resources physicians need beyond the diagnostic workup and pharmacological treatment they learned in their training.

Skills physicians need that are not currently emphasized in medical education include alternative strategies for history taking, knowledge of resources available for improving medication compliance, and understanding of community resources for coping with the issues presented by cognitively impaired patients and their families. For example, when the usual way of getting a history doesn't work any more, having caregivers keep symptom diaries can be extremely useful. When medication compliance is

questionable, simple devices to keep medications orderly or pharmacy-delivered "blister packs" may suffice; in other cases more direct supervision is needed. Physicians also need greater knowledge of and expertise in mobilizing family and community resources for care. It was surprising, for instance, that none of the physicians mentioned referring caregivers to Alzheimer's Association courses or support groups. Medical school workshops on balancing safety and autonomy and promoting a "team" concept of care could be helpful to physicians in learning to address the many psychosocial issues involved in dementia care.

In the situations these physicians encountered with cognitively impaired patients, the processes of diagnosis and treatment were not straightforward; social and emotional issues were often more prominent than the medical ones; and cure or even improvement was not possible. Cognitive impairment is a condition that doesn't comfortably fit in the usual model of primary care, in which the physician is expected to take a history, perform the needed exam, and provide treatment as well as education and counseling efficiently in a 15- to 20-min block of time. It seems likely that unmet patient and caregiver needs generated by trying to fit this increased complexity and difficulty into the normal model contribute to the more frequent hospitalizations and lengthier hospital stays that these patients experience (Albert et al., 1999; Lyketsos et al., 2000). Table 2 illustrates ways in which cognitive impairment shifts the reality of primary care and causes physicians to need new skills and resources. Other health professionals who care for older adults with dementing disorders face similar challenges. Disciplines such as nursing and social work may also be able to build on our findings in future research efforts and treatment plans.

An alternative model that would allow for addressing the expanded needs of these patients is necessary. Much work has already been done to develop such a model. Engel (1977) introduced the "biopsychosocial model." Geriatric assessment clinics have employed multidisciplinary teams to address psychosocial as well as biomedical aspects of care with some success, largely in academic institutions (Boult et al., 2001; Burns, Nichols, Martindale-Adams, & Graney, 2000; Cohen et al., 2002). Recently, the Institute of Medicine called for a multidisciplinary team to be the paradigm for optimal primary care (Scheffler, 1999). In spite of such efforts, however, reimbursement policies remain defined by the usual model of care. Reimbursement for nonphysician team members is minimal and the pressure for primary care physicians to shorten patient visits in the face of shrinking reimbursement is ever present. These forces make multidisciplinary teams nearly impossible to implement in primary care practice. In order to provide the care our cognitively impaired elders need, it is

Table 2. Skills Needed for Primary Care With Cognitively Impaired Elders

Feature of Primary Care With Cognitively Impaired Elders	Additional Skills and Resources Physicians Need
Patient is unable to give reliable medical history	New strategies for history taking (e.g., teaching caregivers what information to report; using symptom diaries)
Patient is unable to take medicine or follow instructions reliably	Education on options to improve medication safety for patients unable to follow through Training on how to mobilize family and community resources
Patient becomes unable to make good decisions about care	Training in negotiating the new relationships
Physician may need to restrict autonomy	Reimbursement for time spent in caregiver counseling
Care is complex and time consuming	Training in team care
Problems not considered "medical" have major impact on medical care	Knowledge of community social services Reimbursement for nursing, social work, and other nonphysician team members
Patient has chronic progressive illness	Improved education on process of care for dementia
Focus is on care; cure is not possible	Improved reimbursement for nonprocedural care Outlet for feelings of discouragement and grief

essential that those who are involved in planning and providing care recognize the need for an expanded model of medical care and reimbursement for these patients.

This study has both strengths and limitations to consider. The open-ended qualitative format and the sample of physicians in private practice allowed new information to come to the fore regarding the issues that are important to primary care physicians. Because of the intensive nature of qualitative research, however, the number of participants in the sample must remain small. The main themes were very consistent across interviews, but it is possible that our participants were systematically different from nonparticipants or from physicians in other locales. It is very clear, however, that further research in this area is needed.

In conclusion, primary care for cognitively impaired elders is much more complex than usual primary care, with profound changes in the process of medical care and the doctor-patient relationship. The model of care predominant in medical practice does not address important aspects of the care cognitively impaired elders need. The physicians who care for these patients need additional skills and resources. Future research must emphasize the process of ongoing care for elders with progressive neurodegenerative disorders, further develop a paradigm for optimal care, and help physicians develop the skills they need to manage this extremely common condition.

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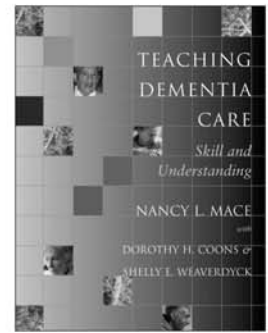
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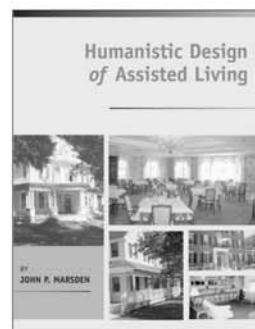
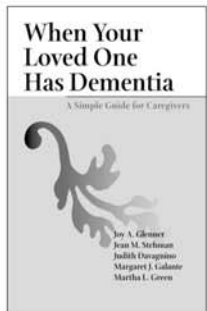
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