Decision-making ability regarding end-of-life issues is often compromised by dementia in patients with Alzheimer’s disease. This study assessed physicians’ discussions of advance care planning with patients with mild to moderate Alzheimer’s disease. Data were collected by a survey of full-time faculty in the departments of Medicine and Family Medicine and the Center for Aging at the University of Medicine and Dentistry of New Jersey–School of Osteopathic Medicine, as well as physicians in private practice affiliated with the Kennedy Health System. Data consisted of questions that assessed whether advance care planning was provided, what specific topics were discussed, and what actions were taken if advance care planning was not offered.

Of the 271 physicians to whom the survey was sent, 63 responded, for a return rate of 23%. Of those responding, 81% indicated that they counseled their patients regarding advance care planning issues, while 19% did not. Of those who provided advance care planning for their patients (N = 51), 88% discussed living wills; 53%, the durable power of attorney for healthcare; 47%, end-of-life care; and 35%, financial planning issues. Thirty-seven percent recommended an elder law attorney, and 31% made a referral to the Alzheimer’s Association. Of those who provided advance care planning for their patients’ caregivers (N = 51), 86% discussed living wills; 78%, nursing home care; 69%, driving issues; and 47%, end-of-life care. Twenty-five percent referred their patients to an elder law attorney. Results indicate that physicians need to be more knowledgeable and proactive in their approaches to advance care planning for patients with mild to moderate Alzheimer’s disease.

(Key words: advance care planning, advance directives, Alzheimer’s disease, end-of-life issues)
The diagnosis of Alzheimer’s disease should not be considered analogous to a lack of decisional capacity, particularly in mild and moderate stages of the disease. Individuals with mild to moderate Alzheimer’s disease may lose their ability to perform complex tasks such as playing chess or financial management, but they may clearly be able to make decisions such as determining their resuscitation status or selecting a durable power of attorney for healthcare.

Autonomous decision making, a cornerstone of medical ethics, is eventually lost as Alzheimer’s disease progresses. However, effective advance care planning while the patient still has decisional capacity could ensure that the patient is a part of the decision-making process, as well as help to preserve his or her dignity. Primary care physicians are ideally situated to engage patients and caregivers in the multifaceted process of advance care planning.

Methods
A 15-item survey was mailed to primary care physicians, consisting of general internists, family physicians, and geriatricians affiliated with the Kennedy Health System, a 600-bed tridivisional, community, university-affiliated hospital system. The survey was aimed at assessing the physicians’ approach to advance care planning for patients with mild and moderate Alzheimer’s disease. Of the 271 mailed surveys, 40 were mailed to full-time faculty of the University of Medicine and Dentistry of New Jersey–School of Osteopathic Medicine in Stratford; the remaining surveys were mailed to community physicians in the private sector.

The survey sought to assess whether physicians provided advance care planning for patients with mild to moderate Alzheimer’s disease, which aspects of advance care planning were discussed with these patients, and which aspects of advance care planning were discussed with the patients’ caregivers. The survey also sought to determine which actions were taken if advance care planning for patients was not addressed. The survey was exempt from review by the UMDNJ/Kennedy Health System Institutional Review Board and was mailed with a cover letter that assured respondents that their responses would remain anonymous and confidential.

Sixty-three (23%) of the 271 subjects responded to the survey. Survey results were entered into a database using the Statistical Package of the Social Sciences (SPSS), and data were analyzed using descriptive statistics.

Results
Of the 63 respondents to the survey, 81% indicated that they counseled their patients regarding advance care planning issues, whereas 19% did not. Most (78%) physicians caring for patients with Alzheimer’s disease indicated that these patients represented less than 25% of their practice.

Table 1 illustrates the frequencies with which physicians address specific aspects of advance care planning with their patients with Alzheimer’s disease and those patients’ caregivers. Among the 51 physicians who counseled patients regarding advance care planning issues, living wills were discussed most frequently (88%), while the durable power of attorney was discussed approximately half (53%) of the time. Future plans (45%), living arrangements (57%), referral to support groups (53%), and end-of-life care (47%) were also discussed approximately half of the time, while nursing home care was discussed more frequently (67%). Items addressed less frequently were financial planning issues (35%), referral to elder law attorneys (37%), and referral to the Alzheimer’s Association (31%).
The frequencies with which physicians discussed advance care planning issues with caregivers are also shown in Table 1. Physicians were more likely to discuss living wills (86%), nursing home care (78%), driving (69%), and living arrangements (63%) with caregivers. Approximately half of the time, they discussed end-of-life care (57%), the durable power of attorney for healthcare (49%), support group referrals (51%), and comfort in making end-of-life decisions (47%). Less likely to be discussed with caregivers were issues of financial planning (33%) and consulting with elder law attorneys (25%).

Table 2 indicates physicians’ opinions regarding what caregivers of patients with Alzheimer’s disease desire from their primary care physicians. Peace of mind regarding the care the patients would receive (78%), relevant information about the illness (76%), and reassurance of continuity of care (75%) were identified most frequently. Approximately half of the time, recognition of family efforts and loss (55%), referrals to quality services (47%), and prescription for active treatment (47%) were identified. Least likely to be considered as desired by caregivers was the need for family control (29%).

Table 3 shows the frequencies with which physicians discussed specific topics with caregivers which relate to advance care planning issues. Most frequently discussed were when patients should no longer live alone (82%), where the families can get help (69%), what can be expected next (69%), effects of other illnesses and medications (69%), and where patients should live (67%). Discussed approximately half of the time were questions such as when will patients no longer recognize their families (47%) and what causes Alzheimer’s disease (49%). Less frequently discussed topics were when to assume control of patients’ finances (33%), what are the risk factors for Alzheimer’s disease (33%), who else in the family is at risk for the disease (22%), who will pay for the patients’ treatment (20%), and where can patients travel (18%).

Of the physicians who responded, 19% did not discuss advance care planning issues with their patients who have mild to moderate Alzheimer’s disease. Reasons given by these physicians for not discussing advance care planning issues were that they believe these patients lacked the capacity to make such decisions (33%), they are too busy to address these issues (33%), and they refer these patients to another source for these discussions (33%).

Discussion

For patients with Alzheimer’s disease and their caregivers, advance care planning and anticipatory guidance by primary physicians may be vital to ensure patient autonomy and to respond to the needs of caregivers. Especially important is the designation of surrogate decision makers in the form of durable power of attorney for healthcare. Yet, in this study, nearly one fifth of the respondents did not address advance care planning issues, and of those who did, only about one half discussed with either patients or caregivers the option for a durable power of attorney for healthcare. This may reflect insufficient physician time due to the pressures of managed care. Alternatively, this could represent the need for more physician education on the importance of discussing advance directives and advance care planning in general, or it may reflect primary care physicians’ reluctance to address advance directives because of a concern that patients with Alzheimer’s disease have lost decisional capacity.

Although the results of this study support previous findings that physicians are reluctant to discuss advance directives in general and more specifically with patients with mild to moderate Alzheimer’s disease, the need for discussion is still important.
The findings also indicate that similar concerns extend to other aspects of advance care planning. For example, infrequently recommended (to either patients or caregivers) were the need to consult elder law attorneys, to obtain input regarding financial planning, and to make referrals to support groups or the Alzheimer’s Association. The important role of caregivers in the lives of patients with Alzheimer’s disease has been well described, yet this survey indicates that physicians often do not discuss important caregiver issues, such as living arrangements, end-of-life care, and caregivers’ comfort in making end-of-life decisions.

Additionally, physicians frequently avoided important issues providing anticipatory guidance to caregivers, such as patients’ no longer recognizing family members, family members’ risk of having dementia, and the extent to which patients may travel. Nearly one third of the physicians surveyed indicated that they did not discuss driving safety with the caregivers. Although guidelines have been recommended to address these important legal and ethical issues through advance care planning, our data indicate that this information is not being discussed and conveyed in the primary care setting. In the current study, physicians perceived that reassurance of continuity of care is important to caregivers but that referrals to other services are less important. Perhaps this perception indicates that primary care physicians are not that knowledgeable about the multifaceted aspects of advance care planning, particularly for patients with Alzheimer’s disease.

Although this study is based on physicians’ self-reporting of their approaches to issues of advance care planning for patients with mild to moderate Alzheimer’s disease, it does not address the disparity between their perceived behavior and their actual practice. The possibility exists that the surveyed physicians may have overstated their role in advance care planning, possibly indicating an even less optimal approach to advance care planning for these patients. In addition, caution must be used in interpreting these data in light of the low response rate of this survey. Perhaps the response rate could have been improved with more than one mailing. Also, responders who readily incorporate advance care planning in the care of their patients may be more likely to respond, as they recognize its importance. This likelihood has the potential to further overstate the physician’s role.

Conclusion

Results of this study support previous reports that physicians do not adequately discuss advance directives with their patients who have Alzheimer’s disease and their caregivers. In addition, physicians are less likely to address many other important aspects of advance care planning for these patients.

More education is needed to provide physicians with a better understanding of the multifaceted aspects of advance care planning in the care of their patients with Alzheimer’s disease. Physicians also need a better appreciation for the roles of other professionals in the care of patients with Alzheimer’s disease.

More research is needed to identify interventional strategies that would result in enhanced advance care planning for patients with Alzheimer’s disease in the primary care setting, as improvements are likely to ensure patient autonomy and provide much-needed support for caregivers.

References


