

## ORIGINAL ARTICLES

# Practice Constraints, Behavioral Problems, and Dementia Care: Primary Care Physicians' Perspectives

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**OBJECTIVES:** To examine how practice constraints contribute to barriers in the health care of persons with dementia and their families, particularly with respect to behavioral aspects of care.

**DESIGN:** Cross-sectional qualitative interview study of primary care physicians.

**SETTING:** Physicians' offices.

**PARTICIPANTS:** Forty primary care physicians in Northern California.

**MEASUREMENTS:** Open-ended interviews lasted 30–60 minutes and were structured by an interview guide covering clinician background and practice setting, clinical care of a particular patient, and general approach to managing patients with AD or dementia. Interviews were transcribed and themes reflecting constraints of practice were identified through a systematic coding process.

**RESULTS:** Recurring themes (i.e., those present in  $\geq 25\%$  of physician interviews) included insufficient time, difficulty in accessing and communicating with specialists, low reimbursement, poor connections with community social service agencies, and lack of interdisciplinary teams. Physician narratives suggest that these constraints may lead to delayed detection of behavior problems, "reactive" as opposed to proactive management of dementia, and increased reliance on pharmacological rather than psychosocial approaches.

**CONCLUSION:** Physicians often feel challenged in caring for dementia patients, particularly those who are more behaviorally complex, because of time and reimbursement constraints as well as other perceived barriers. Our results suggest that more effective educational interventions (for families and physicians) and broader structural changes are needed to better meet the needs of the elderly with dementia and their families now and in the future. Without these changes, dementia care is likely to continue to fall short.

**KEY WORDS:** dementia; quality of care; barriers; qualitative.

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## INTRODUCTION

Alzheimer's disease (AD) and associated degenerative dementias are among the most common, disabling, and costly conditions afflicting older adults. Primary care treatment guidelines for dementia emphasize amelioration of cognition and noncognitive behavioral symptoms, maintaining quality of life of the person with dementia, monitoring safety issues, and supporting and educating the family.<sup>1–3</sup> Good care also entails linking patients and their families with community and social services and referral to medical specialists in more complicated cases. Behavioral disturbances are common in dementia<sup>4,5</sup> and are strongly associated with adverse outcomes, including increased disability, caregiver burden/depression,<sup>6,7</sup> higher health care costs,<sup>8</sup> and earlier institutionalization.<sup>9</sup> Thus, dementia presents special challenges for health care systems owing to the combination of cognitive and behavioral symptoms in aging adults who frequently have accompanying physical decline.

Although effective primary-care-based intervention models exist for persons with dementia and their family caregivers,<sup>10–13</sup> significant gaps in the quality of care exist. Problems include high rates of under-diagnosis,<sup>14–16</sup> long delays between symptom onset and diagnosis,<sup>17</sup> inadequate or inappropriate use of cholinesterase inhibitors,<sup>15,16</sup> and lack of referrals to the Alzheimer's Association or social service agencies.<sup>15</sup> Families often feel clinicians provide insufficient information at the time of diagnosis.<sup>17,18</sup> Understanding the genesis of gaps in quality is an essential prerequisite to improving care for patients currently in treatment as well as increasing capacity for care of the burgeoning elderly population.

Prior research has identified family and primary care provider barriers to care. Family factors include reluctance to seek help as a result of stigma,<sup>19</sup> attribution of symptoms to normal aging,<sup>20,21</sup> lack of knowledge of Alzheimer's disease,<sup>22</sup> and/or lack of access. Physician factors include lack of confidence in their dementia assessment skills, ambivalence about the value of a

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diagnosis<sup>23</sup> or pharmacological treatment.<sup>24</sup> Physician surveys show that many lack sufficient knowledge in diagnosis, treatment, and community resources.<sup>25,26</sup> Health care systems issues, particularly insufficient time, are often mentioned as barriers to diagnosis or management.<sup>23,25</sup> Whereas most studies focus on the initial assessment and management, Adams and colleagues<sup>27</sup> describe challenges primary care physicians face in the ongoing care of persons with dementia, including a shift from curing to caring, increasing reliance on the family, and ethical dilemmas. In discussing their findings, they note that dementia does not “fit well” within many physician’s practice settings.

The behavioral complexity of dementia is a major reason for this “poor fit.” Clinician recognition and management of behavioral problems is a vital but poorly investigated aspect of dementia care. Ongoing care of persons with dementia requires considerable attention to behavioral changes. These range from cognitively based problems, such as forgetting to take medications or go to appointments, to changes associated with neuropsychiatric symptoms such as agitation, irritability, depression, and psychosis. Identifying the nature and cause of behavioral changes is both challenging and time-consuming and requires caregiver involvement.<sup>28</sup> Despite the individual, family, and public health importance of behavioral disturbances, this issue remains under-studied in research on dementia in primary care settings.

This article examines barriers to dementia care based on analysis of in-depth qualitative interviews with 40 primary care physicians. Interviews elicited physicians’ perspectives on clinical management of older adults with dementia. The specific aims of this study are to: 1) explore physician views of practice constraints and how these interfere with appropriate care of persons with dementia, focusing in particular on management of behavioral and psychiatric disturbances, and 2) generate hypotheses about how these barriers impact the quality of care for persons with dementia and their families. This study addresses an aspect of dementia care that has received relatively little attention: the challenges clinicians face after the point of diagnosis, particularly with respect to the management of behavioral and psychiatric disturbances.

## DESIGN AND METHODS

Our sample comprises primary care physicians providing care to community-dwelling older adults with dementia. These physicians were recruited from a list of physicians caring for elderly persons with dementia who, along with their caregivers, were participating in a parallel study of caregiver experience and patterns of help-seeking. Elderly participants in the companion study were diagnosed with dementia, were non-institutionalized or had been institutionalized only in the prior year, and had an identified family caregiver. Elderly patients and their family members were recruited from the UC Davis Alzheimer Disease Center or through an ongoing epidemiological study of cognitive decline in older Latinos. Participants in the companion study were asked for their consent to contact their primary care physicians (PCPs). Seventy-three physicians were eligible and 40 (55%) participated. Reasons for failed recruitment of PCPs included: unable to contact PCP ( $n=19$ , 58%), PCP refusal ( $n=10$ , 30%), and family refusal ( $n=4$ , 12%). Non-participant physicians were similar to participants in

terms of gender (90% men versus 88% men respectively), but practice settings differed, with a much larger percentage of non-participants than participants practicing in HMOs (33% versus 5%). Data on gender and practice setting were missing for 3 nonparticipating PCPs. Physicians were recruited by letter with telephone follow-up. Except for 2 phone interviews, all interviews were conducted in physicians’ offices, usually over lunch.

Interviews were conducted by the study authors (L.H., C.F., Y.F.), lasted between 30 and 60 minutes, with open-ended questions structured by an interview guide. The interview include 3 broad topics: clinician characteristics and practice setting, clinical care of a particular patient, and general approach to managing patients with AD or dementia. To maintain a consistent interview style and approach, the first 15 interviews were conducted in pairs, with 1 interviewer taking the lead and the other observing, but asking questions at the end. The interview guide was revised after the first 5 interviews to reflect emerging themes.

Interview transcripts were edited to remove identifiers (i.e., names) and then entered into NVivo®, a qualitative software program (QSR International, 2002). Initially, 4 investigators independently coded a random subset of 10 interviews to identify themes related to barriers to care. A set of structural and practice barriers was defined through comparison and discussion. Next, a typology of barriers was developed. In the third and final step, the entire set of interviews was systematically coded for these structural barriers by 2 of the investigators with any disagreements between the 2 coders resolved through discussion among these 2 coders and a third investigator. All discrepancies were successfully resolved. NVivo® was used to systematically search for and retrieve all coded material for each barrier. Illustrative examples were chosen to represent each barrier. To highlight barriers experienced by a broad cross section of physicians, only barriers present in at least 25% ( $n=10$ ) of the physician interviews are discussed in detail in this paper.

## RESULTS

**Sample characteristics and setting:** This study was conducted in and around a large, urban city in Northern California. Physician characteristics are summarized in Table 1. Except for the large HMO and VA, physicians treated older adults with a mix of fee-for-service and managed care insurance. In all settings, except for the large group HMO, specialists were accessed through referral mechanisms, including both traditional referral and “carve-outs” to mental health benefits manager.

**Overview of structural and systems barriers to care:** This section describes specific structural and administrative constraints to dementia care that were recurring themes in these interviews. These constraints included insufficient time, difficulty in accessing and communicating with specialists, low reimbursement, poor connections with community social service agencies, and lack of interdisciplinary teams. Initial agreement in coding these constraints ranged from 93% (specialists) to 73% (community resources). Although each constraint is described separately, in everyday practice they

**Table 1. Physician sociodemographics (n=40)**

Physician characteristic		N (%)
Age (years)	25–45	15 (37.5)
	46–65	23 (57.5)
	66–80	2 (5)
Gender	Male	35 (87.5)
	Female	5 (12.5)
Patient panel size	0–2,000	9 (22.5)
	2,001–4,000	22 (55)
	4,001–6,000	5 (12.5)
	Does not know	4 (10)
Patients age 65 and above	0–25%	11 (27.5)
	26–50%	16 (40)
	51–75%	8 (20)
	76–100%	5 (12.5)
Race/ethnicity	African-American	2 (5)
	Asian-American	4 (10)
	Hispanic	5 (12.5)
	White non-Hispanic	27 (67.5)
	Other	2 (5)
Specialty	Family Practice	22 (55)
	Internal Medicine	16 (40)
	Geriatrics	2 (5.0)
Type of practice	Academic primary care network	10 (25)
	Larger group	8 (20)
	HMO	2 (5)
	Small group/solo	13 (32.5)
	University-based clinic	5 (12.5)
	Other	2 (5)

co-occur as cross-cutting, mutually reinforcing issues. Physician quotations are used to illustrate constraints and their impact on care of older persons with dementia. To identify the source of the quotes, physician interview numbers are placed after quotes. Themes found in fewer than 25% of the interviews are not further described. These comprised: 1) constraints in prescribing cholinesterase inhibitors caused by insurance coverage or rules for prescribing by specialists only; 2) insufficient training in geriatrics/dementia; and 3) excessive paperwork.

**“Dementia Cases Take Time:” Fitting Dementia into the “15-minute visit”**

Physicians said it was difficult to care for persons with dementia in the standard “15 minutes” typically allocated for appointments. As 1 physician told us: *Dementia cases take time, you know. It’s not like a blood pressure office visit.* (1082) Time constraints were experienced by physicians across different types of practice settings. In larger group practices, clinicians are pressured to practice in a “time-efficient” fashion and have little control over patient scheduling. In smaller group and solo practices, clinicians had more flexibility but felt compelled to see patients quickly because of economic pressures. Heavy caseloads and administrative burden (i.e., paperwork) also contributed to the time pressures felt by clinicians. Dementia created heavier paperwork demands owing to frequent need for community, social service, and specialty referrals.

Physicians related that caring for persons with dementia is more time intensive for several additional reasons. Because people with dementia have impaired recent (i.e., short-term) memory, family members or other informants are often used as a primary source of history and to assist in decision making and negotiation of treatment plans. Family involvement in the clinical visit was viewed as important but time consuming,

particularly when there were multiple caregivers with competing agendas, conflicts between the perspectives of caregiver and care recipient, or difficult behavioral problems or ethical dilemmas requiring detailed discussion and assessment.

Asked about how he manages dementia-related behavioral problems, 1 physician responded: *It [behavioral problem] isn’t something that I have to deal with clinically. Usually, the family deals with it [behavioral problems]. And that’s another problem in a 15-minute visit, is that in the same way that we don’t do an exhaustive mental exam on each visit, we often don’t talk adequately with the family in the 15 minutes.* (1058) As a result of having insufficient time to discuss psychosocial issues and behavioral disturbances, these problems may be neglected until they become severe, leading to what 1 physician characterized as “reactive care.”

Family members were perceived as having very real and sometimes intense “social and psychological” needs, requiring what 1 clinician referred to as a “lot of hand-holding”: *Most of the time when they come in to see me there may be some specific concerns like, you know, they’re [patient] wetting the bed all the time, or they’re [patient] wandering, or you know, whatever, but the majority of the visit is hand-holding and listening, that sort of thing. It takes a long time.* (1075) Clinicians felt overwhelmed by the volume of work and limited time: *I think we’re all drowning, I do. It’s, you know, we are all truly trying to keep our heads above water...These people [persons with dementia] do take a lot of time and energy and when you’re doing all the other stuff that we’re doing with all the other patients that, to be honest, sometimes it’s like, you know, you just don’t want these people in your practice cause a 15-minute visit turns into much more than that.* (1053)

**“They Don’t Count Complexity”: Reimbursement Issues**

Physicians expressed concerns about reimbursement structures that inaccurately reflected the time required to care for older adults with dementia. As 1 clinician noted: *Whether you’re self-employed or employed by a large group, they still look at your R.V.U.’s or relative value units and how much productivity and they don’t count complexity as much as they should.* (1080) Another physician said, *When you deal with a patient who has dementia, maybe depression, as well as hypertension and diabetes it’s a lot more complicated than the intact 50-year-old hypertensive diabetic but the reimbursement is the same.* (1073) The Medicare billing rules were viewed as inadequate for capturing the time-intensive nature of dementia care. One physician described the billing nuances in detail: *The big challenge that I have is [when] I bill them. There’s codes called 99214 codes which is an extended visit, there’s 99215 code, and probably these visits, for the amount of work that was involved in these visits, are probably 99215 codes, but the 15 code is really characterized for somebody who is acutely ill with a life-threatening disease that you need to swing into action and do your heroic measures on or they’ll die.* (1068) As a result of these coding quandaries, physicians may feel in a bind as the more time intensive codes best reflect the amount of time and complexity, but dementia cases are not considered to be “acute” enough to warrant this level of billing.

Other physicians noted nuances regarding coding of diagnosis that also contributed to lower payments, in particular the need to

specify a specific type of dementia: *Fortunately in geriatrics we know billing and coding better than most docs so we can usually get reimbursed for our time... I don't think many docs realize that if you put down dementia as your ICD-9 code that you're going to get reimbursed about 60% what you would get if you put down Alzheimer's 331.0, or memory impairment. (1082)* Salaried physicians also felt the pressure to translate the time required for clinical care into a "billable" code covering time spent.

### "It's a Harsh System": Access and Communicating with Specialists

Care for persons with dementia often entails consulting with or referring to specialists to assist with certain aspects of clinical care. Access to neurologists was viewed as particularly important for more complex diagnostic issues early in the illness course. After diagnosis, physicians sometimes felt the need for input of psychiatrists around the management of behavioral problems: *I do rely on psychiatry because I admit that I am not the most knowledgeable person about people with agitation and behavioral problems at home. I'm good at prescribing a little Risperdal but I get a little nervous about anti-psychotic meds and I tend to send those people to psychiatry. (1009)* Another physician said, *Usually I rely on the psychiatrist because you just get to the point there where, I don't know how to deal with all the hallucinations, the screaming and those kinds of problems. I want a second opinion too in making sure my diagnosis is correct. (1015)* Whereas some clinicians viewed the specialist as a "consultant" others preferred to have ongoing care provided by the specialist.

Yet access to specialists was often difficult because of limited availability and cumbersome referral mechanisms. With the exception of a few doctors who worked in large group HMOs in which the needed specialty consultation was often available on-site, physicians cited difficulties in accessing and coordinating specialty care as a major concern. Because of the limited number of neurologists and psychiatrists available to evaluate patients, there were often long waits before patients could be seen, as described by the following physician: *We have good neurologists, but they are generally scheduled far in advance so it takes a least a month, two months to get an appointment unless the patient's hospitalized. Psychiatrists are more of a problem. There aren't enough of them. (1073)* Further complicating access to mental health specialists were types of insurance plans in which mental health benefits were "carved-out" to a mental health care manager and which required patients themselves to call to set up their appointments: *You know the other thing with the insurance is that the carve-outs kill us because they [the patients] get an 800 number and they call and I have not had very many patients that have been successful in getting into the system and they have to be very persistent...So it is really a harsh system the way it is set up. (1016)*

Once patients were seen by specialist physicians, there was often a lack of "feedback" in the form of clinical notes and recommendations that would allow the primary care physicians to discuss the specialist's recommendations with the patient and his or her family: *It's hard, bottom line is it's hard. The feedback is slow [from specialists]...So you don't get anything and then the patient comes back and they are usually, they don't have any idea, and then they're kind of frustrated too. (1012)* As a consequence of the problematic access to specialists, physicians often felt they had little choice but to try and manage care as best they could despite a perceived lack of

time and training. Some physicians expressed frustration and even some degree of demoralization about being placed in a situation in which they felt compelled to provide care that they felt was beyond their realm of expertise.

### "I Am Not a Licensed Clinical Social Worker": Accessing Community Services

Referral of persons with dementia and their families to appropriate resources in the community, such as support groups, adult day health, meals on wheels, and in-home supportive services, is a cornerstone of quality care according to most dementia treatment guidelines.<sup>3,29,30</sup> Yet many primary care providers we interviewed felt they did not have the necessary time or knowledge to assist families in accessing these social services. One primary care provider expressed his frustration with the social service system: *Since I'm not a licensed clinical social worker and I don't know what's available in the community, and I don't know how to, nor do I have time to call up and make arrangements for meals on wheels, or call up and find out what they need for a chore-worker, or call up and find out how to access daycare. All I can do is say, you know, these things exist and here's some ways to contact them, there's a green booklet that the County put out a couple of years ago. (1075)* Other physicians emphasized the difficulty of matching up a person with resources based on their needs: *I mean, there are books that tell you who, but there's so many listings in those books it's hard to work your way through those to figure out, okay, for this person in this circumstance who are the two or three people that I need to get involved, and its confusing about who to see when, and who does what when. (1065)*

### "We Don't Have the Network We Need": Lack of Interdisciplinary Teams

Lack of interdisciplinary teams was another related concern. Physicians felt that geriatric care generally, and dementia care in particular, should be coordinated by an interdisciplinary team. Many PCPs suggested that forming these teams in primary care clinics would go a long way toward improving dementia care. One physician, for example, told us: *I just feel, I don't have the network we need, so, because for the dementia care it's a team care, dietician, social work, psychiatry, psychologist, and pharmacist...I feel I don't have this. I don't think anybody has this luxury, but the gist of care should be that. (1059)* Another physician and geriatrician saw the interdisciplinary model of care as critical not only for elderly with dementia, but for frail elderly in general: *Another thing that makes it complex and is a disincentive is that geriatrics, because it factors in psychosocial issues and acknowledges their importance, integral importance in the care of frail individuals, young or old, one often needs an interdisciplinary team. One needs access to a social worker, the nurses who are properly trained in geriatric issues. (1080)*

## DISCUSSION

These primary care physicians perceived structural realities of primary care as a formidable challenge to providing good



quality care to persons with dementia and their families. Specific non-medical constraints identified in this study include lack of sufficient time, stingy reimbursement, difficulties in accessing and communicating with specialists and social service agencies, and lack of an interdisciplinary team approach to care. These constraints are not unique to dementia and reflect more global dysfunction in primary health care.<sup>31</sup> In primary care practice, these constraints often co-occur, further complicating the management of dementia. Dementia creates acute and intensive demands because of its behavioral complexity, chronicity, the patients' growing dependence on and involvement of informal helpers and family members, and the presence of comorbid health problems that compete for the attention of providers. Our findings are consistent with prior work on physician views of issues in early diagnosis and management<sup>23,32</sup> and 1 study examining longer term issues in dementia care<sup>27</sup>.

Dementia often starts as a problem with cognition, but it almost always evolves into a problem with behavior. This study suggests several hypotheses regarding how the structural realities of primary care impact the detection and management of difficult behavioral problems. Lack of time and failure to systematically assess behavioral problems may delay their detection and management until a time of "crisis." This pattern of formal caregiving, described by 1 physician as "reactive care," may contribute to family burn-out and ultimately to the patient's institutionalization. Clinicians may rely more on medications if they are less familiar with psychosocial approaches or perceive these as potentially more time-consuming. This has important public health implications because recent data question the efficacy and safety of psychotropic medications for older adults with dementia,<sup>33</sup> making non-pharmacological approaches<sup>34-36</sup> more attractive from a risk/benefit perspective. Finally, the impact of these structural constraints is not likely to impact all elderly uniformly. Patients with fewer financial resources will have more trouble receiving adequate care. Families requiring translators may be particularly disadvantaged because translation takes even more time. In our study, few non-Latino physicians spoke Spanish or had ready access to onsite translators.

This study has several limitations. Because our qualitative method relied on participants to bring up specific barriers, this may underestimate the frequency that themes would be reported if physicians were asked about each barrier. Our physicians were drawn from 1 geographic region and are not representative of physicians nationwide. It should be noted that despite this geographic limitation, physicians were practicing in a variety of treatment settings, making it more likely that the findings will generalize across treatment settings. Third, our data are based on interviews with primary care physicians and are therefore limited by physicians' awareness and perceptions of barriers to care. Physicians, for example, with insufficient training or expertise in management of behavioral problems may not recognize solutions that could be implemented with only modest changes in resources or practice organization. Other approaches, such as ethnographic observation of treatment settings, might yield complementary or additional findings.

Our findings suggest several avenues for improving care. One avenue is to educate and support families to be more proactive in making requests for appropriate treatments, an

approach that might improve care provision within the constraints of current systems.<sup>37</sup> Quality of care might be improved by physician education around management of behavioral problems and availability of community services and agencies, as well as improve coding to more accurately capture time spent with patient/families. Community referrals are particularly important as many agencies have considerable programmatic expertise in managing behavioral problems. More ambitious reforms might include increasing reimbursement for treating patients with substantial behavioral complexity and developing incentives for health care organizations to deliver more comprehensive (and costly) care upfront to postpone as long as possible more costly "downstream" outcomes, such as institutionalization. If insurers/HMOs do not bear the costs of long-term care, they will be less motivated to invest the resources necessary to delay or prevent this outcome. An interdisciplinary team approach to dementia care in primary care settings with nurse practitioners providing more specialized dementia care has recently been shown to reduce behavioral symptoms and caregiver distress.<sup>13</sup> Alternatively, funding home-based interventions may help to augment care that occurs in the clinic. Occupational therapy or skills-building approaches delivered in the home, for example, improve outcomes for both persons with dementia and their caregivers.<sup>34,38</sup>

The barriers identified in this study highlight the need for better educational approaches for primary care practitioners as well as structural changes such as increased visit time, reimbursement and the availability of interdisciplinary teams, to better meet the needs of the elderly with dementia and their families now and in the future. Without such changes, dementia in primary care settings is likely to continue to fall short of standards of good care and to emphasize "reactive" and pharmacological approaches. As a result, persons with dementia, particularly those with difficult behavioral issues, will be unnecessarily exposed to psychopharmacological drugs and increased risk of institutionalization. Patients and their families will experience increased dissatisfaction with care and amplified suffering. Speaking of more behaviorally complex dementia cases, 1 of our physicians summed up: *those people get pushed out of those practices because they cause chaos, and so they get referred or something happens.* (1068)

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