

Published in final edited form as:

Am J Geriatr Psychiatry. 2010 July; 18(7): 576-585.

When help becomes a hindrance: Mental health referral systems as barriers to care for primary care physicians treating patients with Alzheimer's disease

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Abstract

OBJECTIVES—To describe structural barriers to mental health specialists and consequences of these barriers to care for patients with dementia and neuropsychological symptoms and their primary care physicians (PCPs).

DESIGN—Cross-sectional qualitative interview study of PCPs.

SETTING—Physicians' offices, primarily managed care.

PARTICIPANTS—40 PCPs in Northern California.

MEASUREMENTS—Open-ended interviews lasted 30–60 minutes. The interview guide covered clinician background, practice setting, clinical care of a particular patient, and general approach to managing patients with Alzheimer's disease or related dementias. Interviews were transcribed and themes reflecting referrals identified.

RESULTS—93% of the PCPs described problematic access to and communication with mental health specialists (in particular psychiatrists and neuropsychologists) as impediments to effective care for dementia patients. Thematic analysis identified structural barriers to mental health referrals ranging from problems with managed care and reimbursement policies to lack of trained providers and poor geographic distribution of specialists. Structural barriers compromised care for patients with dementia because the barriers limited PCP treatment options, and resources, impacted office staff and time with other patients, impeded and delayed care, and fostered poor communication and lack of coordinated care. Negative consequences for PCPs included increased frustration, conflict, and burnout.

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No disclosures to report

CONCLUSION—PCPs viewed problems created by onerous referral systems, such as mental health carve-outs, as particularly burdensome for elderly patients with co-morbid dementia and neuropsychiatric problems. These problems were cited by PCPs across different types of practice settings. PCPs managed treatment of neurobehavioral symptoms as best they could despite lack of specialist support.

Keywords

Alzheimer's disease; dementia; managed care; referrals; barriers to care; qualitative; neuropsychiatric symptoms

OBJECTIVES

Alzheimer's disease and related dementias present special challenges to the health care system because cognitive deficits and functional impairment occur in the presence of co-morbid psychological, behavioral, and medical symptoms. At some point, most patients with dementia experience neuropsychiatric and/or neurobehavioral symptoms such as depression, anxiety, agitation, delusions, or hallucinations (1–7). Although many neuropsychological symptoms may be identified and effectively managed in primary care settings, referral to mental health specialists or behavioral neurologists can be useful for differential diagnosis or management of more complex or severe symptoms (5,8–10).

An integral part of a best practices, mental health specialists or behavioral neurologists provide support for and supplement a primary care physician's (PCP's) evaluation and treatment of patients with Alzheimer's disease and related dementias, particularly for more behaviorally or diagnostically complex cases for patients with more subtle symptoms that may indicate preclinical dementia (11). Ideally, PCPs work collaboratively with the mental health specialists to whom they refer patients; shared relevant information provides patients with the most comprehensive and accurate information related to diagnosis and treatment decisions that affect them. For example, effective communication between treating physicians can minimize the negative consequences of polypharmacy and dangerous medication interactions, a particular risk for older adults, especially those with disease-related complications (12–14). Collaborative problem solving around patient care may facilitate early diagnosis and treatment, thereby helping the patient and family have the greatest opportunity for success in coping with a diagnosis of dementia as well as improving health care delivery efficiency (11,15).

Neurobehavioral symptoms (especially behavioral problems) are associated with higher rates of institutionalization and with poorer quality of life for both the person with dementia and the caregiver (11,16–19). It is estimated, however, that over half of older adults with a recognized mental health problem do not get help (20,21). Most people with dementia, even those with neurobehavioral symptoms, never see any kind of specialist (11,22) and dementia care guideline adherence to care quality guidelines is significantly less than for most chronic diseases (23). Psychiatric problems in dementia remain under-recognized, under-diagnosed and inadequately treated (10,24,25). Unmet needs for mental health services tend to be greatest for the elderly, minorities, persons with low income or no insurance, and in rural areas (10, 26–28).

When surveyed, PCPs identify numerous problems with accessing specialty mental health services for patients with dementia. In one survey, 70% of PCPs complained about problems with managed care drug plans and 28% claimed difficulty accessing dementia medication without a specialist (29). PCPs in the 1998–1999 Community Tracking Study physician survey (CTS) reported that access to mental health specialists was significantly more problematic than access to other specialists (54% versus 5% respectively); the results were similar in 2000–2001

(30). PCPs in solo and small group practices, PCPs with time constraints, and PCPs with rural practices reported the most access problems to high quality, medically necessary mental health specialists while PCPs in Health Maintenance Organizations (HMO) and large group practices reported the fewest problems. In 2004, PCPs reported that they did not use referrals for mental health specialists because there were not enough providers (59%), the health plan limited access (50%), and patients lacked adequate insurance (56%). PCPs most frequently endorsed inadequate reimbursement (61%) as the primary reason for not accepting new Medicare patients (31). Minority physicians tended to report greater difficulty accessing referrals and appropriate health care than did Caucasian physicians (32). Physicians' preferences for referrals also varied. In a vignette study, PCPs preferred to manage care for patients alone, and used specialists as consultants, while neurologists preferred using specialists for ongoing care management (33). Physicians with heavier patient loads more frequently wanted a specialist to manage care. The authors hypothesized that PCPs perceived themselves as better able to orchestrate ongoing care because dementia is so often accompanied by other chronic diseases associated with aging for which they provide primary care. Selective reporting by community and family care providers also influences PCPs' ability to provide adequate care for their elderly dementia patients with neurobehavioral symptoms (17,19,34–36).

Most studies of quality of care for patients with dementia and neuropsychiatric symptoms rely on surveys, or chart abstraction. Although useful for identifying the extent and severity of structural problems, these techniques do little to elucidate the underlying dynamics and implications for care. In prior work we identified poor access to specialists as a barrier to care for persons with dementia (37). In this paper, we examine in detail the nature of the "broken link" between primary care and mental health specialty care, and the consequences for patients, families, and providers. Specifically, we: 1) identify ways in which existing referral systems create barriers to care; and 2) examine the consequences of these barriers for primary care physicians, and patients using qualitative techniques to analyze interviews with PCPs.

DESIGN AND METHODS

We recruited PCPs identified by spouses or adult child caregivers of elderly with dementia who participated in a study of family caregivers (35,38). In this way, we knew that each physician had experience in providing care to persons with dementia. Both caregivers and the person with dementia provided informed consent (or assent with consent by the guardian if necessary). Forty out of 73 eligible physicians (55%) participated. We contacted physicians by mail and then enrolled them through follow-up telephone calls. Reasons for failed recruitment of PCPs included: unreachable (n=19), PCP refused (n=10), and family refusal/no PCP (n=4). A larger percentage of non-participants than participants practiced in HMOs (33% versus 5%). Except for two telephone interviews, we conducted most interviews in physicians' offices, usually over lunch.

Three study authors (LH, CF, YF) conducted the 30–60 minute interviews. The open-ended questions in the interview guide covered three main topics: 1) clinician characteristics and practice setting, 2) clinical care of a particular patient, and 3) general approach to managing patients with dementia. By design, the first third of the interviews were conducted in pairs, with one interviewer taking the lead and the other observing but asking questions at the end. This helped provide consistency in style and approach to the interview. We revised the interview after the first five interviews to reflect emerging themes. For instance, individual patient files were often not available or so large that review of them was untenable in the time available, so more of the interview focused on general clinical management of patients with dementia.

Data analyses occurred in two phases. In phase one, which identified barriers to care, four investigators analyzed interviews independently and created coding definitions for the derived categories of structural barriers (37). Two investigators then independently coded interviews for structural barriers with a third coder resolving discrepancies. In phase two, we focused on the implications for care of the specific barrier of referrals to mental health specialists. Three coauthors independently read all selections about mental health referrals that had been identified in phase one and identified thematic units. Using techniques based on principles of logical analysis (39), readers then examined and categorized the syntactical structure of the excerpts. For instance, impeded referrals for dementia care involved causal statements such as "it was going to take six months to see a psychiatrist, so I took care of it myself," that linked referrals and outcomes.

RESULTS

Sample characteristics and setting

This study was conducted in a 60 mile radius of an urban city in Northern California. PCPs practiced in a variety of settings, including an academically affiliated primary care network (45%), outpatient clinics at a university teaching hospital (22.5%), independent small group or individual practice (17.5%), community health centers (7.5%), a large group HMO (5.0%), and the Veterans' Affairs (VA: 2.5%). Physicians' offices were in towns with populations ranging from 3000 to a city of 1.4 million people. Physician characteristics are summarized in Table 1.

Structural, institutional and administrative barriers to care

PCPs mentioned managed care, carve outs, insurance/entitlements, and reimbursement policies as key structural barriers to accessing specialty mental health care. Although these institutional and administrative barriers impede access to specialists for most patients, PCPs felt the barriers magnified the impact for dementia patients due to the patients' fixed incomes, dependence on entitlement programs, cognitive impairment, and reliance on caregivers for transportation and assistance. For the most part, in these interviews, PCPs focused on referrals to psychiatrists or neuropsychologists (not paraprofessionals) in order to obtain assistance for complex diagnostic and treatment decisions.

For the majority of patients in this study, access to psychiatry involved a double gatekeeper system—the initial referral from the PCP to a psychiatrist, followed by a second gatekeeper (e.g., counselor, psychologist, administrative screener, behavioral health services [BHS] provider representatives) determining eligibility for care. In the large group Health Maintenance Organization (HMO), access to behavioral health was only through a physician referral to a specialist in the same system; access to a psychiatrist required that the patient first see the on-site psychologist for additional screening. PCPs in the other health care structures treated older adults with a mix of fee-for-service and multiple forms of managed care insurance with varying guidelines, administrative structures management approaches. PCPs provided mental health specialist referrals through traditional referrals or "carve-outs" to mental health benefits organizations. A carve-out is a managed care approach to cut costs for psychological or psychiatric services by separating those services from medical care services. Once the PCP requested a referral, patients scheduled their own appointments. Because mental health services were generally provided outside the PCPs' medical group, physicians reported being unlikely (or slow) to know if or when a visit occurred or with whom.

PCPs pointed to other structural problems that more directly influenced their own, or the mental health specialists' ability to effectively treat neuropsychiatric problems associated with dementia. In particular, they pointed to their own lack of geriatric and psychiatric training as

increasing their need for referrals. In addition, structural deficits in the health care system that contribute to the inadequate number or maldistribution of trained psychiatrists or neuropsychologists, particularly in rural areas, contribute to difficulties obtaining referrals.

Physicians viewed structural barriers as complicating and compromising dementia care. Moreover – due to the increased demands on patient and family—they felt structural barriers unjustly burdened the family providing care for elderly, vulnerable patients. In the next section, based on analyses of the PCP transcripts, we report on PCPs' views of the consequences of these structural, institutional and administrative barriers for persons with dementia and for the PCP. Illustrative quotations are provided in Tables 2 & 3.

Consequences of barriers to care for the dementia patient

From PCPs' perspectives, problems for dementia care arise at multiple points in the attempt to access specialty mental health referrals for assistance with complex diagnoses, psychotropic medications, and treatment planning. Structural barriers compromise care somewhat differently depending on the dyad involved (e.g., PCP/patient; patient/specialist; specialist/PCP).

Consequences arising from the PCP/patient dyad—PCPs spoke about the effect of limited resources, time, and lack of treatment options on their ability to provide care to patients with dementia and comorbid neuropsychiatric symptoms (see Table 2). For the PCPs, limited access to mental health specialists (in particular, referrals to psychiatry), meant they provided care and made treatment decisions for complex symptoms that exceeded their professional training. Patient care was additionally compromised by delays in initiating appropriate treatment caused by delays accessing mental health services; PCPs had no choice but to provide care prior to consultation with a specialist or wait while the patient (and family) suffered. PCPs also experienced the brunt of patients' and families' frustrations and worries about dementia care and the limited availability of treatments. Overall, PCPs felt overwhelmed and torn by the demands of care; "I think we are drowning with just the other patients that we have and they expect primary care to take this [dementia care] on too (1016)." However, despite the sense of extra burden, PCPs preferred to use mental health specialists for consultations, and continue overall care management themselves.

Consequences arising from the patient/mental health specialist dyad—PCPs discussed ways in which difficult and delayed access to referrals, and family attitudes toward neuropsychological symptoms compromised care for dementia patients. Depending on the patient's insurance, access to medically necessary psychiatric help could be virtually impossible and higher out-of-pocket expenses could be difficult to manage for elderly on fixed incomes, thus forcing the patient to rely on the less well-trained PCP or to delay treatment. Despite their best efforts to provide care, PCPs observed that patients and family members were often ambivalent and obstructed dementia care by failing to utilize referrals—whether due to frailty, discomfort with or minimization of neuropsychiatric symptoms, stigma, financial restrictions, cultural values, or even logistic problems such as arranging transportation to distant specialists. Family ambivalence about treatment options also influenced utilization of referrals; as one PCP said "If you're delaying the end point of the dementia by 12 or 24 months... the value of those months is completely determined by the family. Who can say how much 24 months is worth? Very valuable to some people, and not very valuable to others, especially if it's a dementia state or other problems (1034)."

When structural guidelines require that patients and families negotiate referral telephone lines, bargain with unknown and unseen administrators (especially about sensitive neuropsychiatric symptoms), and wait months to see a specialist, PCP treatment plans are put on hold. Other

studies confirm that older adults perceive less need for mental health services, and are less likely to receive referrals or utilize services for mental health care, resulting in high levels of unmet need (20,34). Even higher levels of unmet need occur among elderly minorities and elderly with lower incomes (26,28).

Consequences arising from the PCP/mental health specialist dyad—PCPs also discussed complications for patient care arising from the relationship between the PCP and the mental health specialist. These problems included poor communication, lack of feedback from the specialist following the patient visit, and lack of coordinated care. Carve-outs (which currently dominate access to mental health services), generally involve physically separate organizations. Medical records take time and effort to transfer, contributing to breakdowns in communication that may influence diagnosis and treatment. PCPs expressed the view that the use of carve-outs meant they could not direct who the patient saw, adding to discontinuity of care. PCPs remarked that they seldom received timely written or verbal feedback from the mental health specialist, so that the referrals were generally unhelpful (or too late) for managing ongoing care. In some managed care plans, PCPs relied on psychiatrists to prescribe certain medications, further limiting and hampering timely treatment. Faced with the complexities of dementia care, PCPs wanted more guidance with difficult patients but found help difficult to access; "Some times it would be nice to have somebody agree to look over things, it's not there, psychiatric backup isn't there (1017)."

In addition to these problems, PCPs felt that the gap created by carve-outs meant less potential for developing professional relationships that might improve coordinated care for patients and increase their own comfort either in treating neurobehavioral symptoms themselves or obtaining appropriate referrals. Some PCPs reflected that, in the past (before carve-outs), they were able to develop professional, synergistic relationships with other providers. In sum, PCPs viewed themselves as being trapped by the need to provide adequate care for dementia patients' neuropsychiatric symptoms at the same time as managed care increasingly regulates access to specialists.

Consequences of referral systems for PCPs

Structural barriers not only compromise care for dementia patients, they also influence other aspects of medical practice. As one PCP said: "It was part of the nightmare of knowing where to refer somebody. It was part of the game where you could never get anything done today, because you've got to have the staff go and research how you can solve a simple problem (1066)." As can be heard in the quotations presented in Tables two and three, physicians spoke with considerable frustration about their thwarted attempts to provide quality care and the resulting wear and tear on themselves, patients, and staff. Burnout, lack of control, powerlessness, and strain were all consequences of the extra time and effort created by the difficulties accessing and utilizing referrals for dementia patients with neuropsychiatric symptoms. Institutional and administrative barriers associated with referrals aroused strong responses from the PCPs over the lack of equity in medicine and the resulting sense of being in conflict with other medical professionals.

DISCUSSION

With the anticipated increase in the number of individuals with cognitive impairment and dementia in the next two decades, there is likely to be a corresponding increased rate of neuropsychiatric and neurobehavioral symptoms. PCPs expressed concern about the impact of difficult access to mental health specialists that results in delayed or inexpert diagnosis and treatment plans for elderly adults with dementia and neuropsychiatric symptoms. The views of the PCPs interviewed in the present study contribute to the sense of urgency for resolving

these systemic health care problems. These voices of frustration give rise to three questions: To whom does dementia belong? Is this the best way to provide behavioral health services to elderly with dementia? Are the consequences of compromised care tolerable?

From the perspective of the PCPs we interviewed, dementia care was, by default, their domain because of they had primary responsibility for ongoing treatment of the panoply of comorbid medical illnesses in their dementia patients. This view is consistent with that of Swarztrauber and Vickery, who found that PCPs preferred to treat dementia patients themselves, using specialists for consultation regarding diagnosis and treatment (33). However, limited resources, restricted access to specialists, and lack of geriatric and psychiatric training increased PCPs' concern about quality of care.

Can mental health services be better integrated into primary care? If we start with the idealtimely, direct access to neurobehavioral specialists coordinated by the PCP, with excellent ongoing communication between specialist and PCP-we see that systems in practice fall short of ideal in different ways. The carve-out system is most extreme because it fails in almost every possible way. There is little/no coordination, no guarantee of quality, and often no ongoing communication. Other systems do better along some of these dimensions but not others. For example, even in systems where the PCP can walk the patient down the hall, the available psychologist or counselor may not be trained, experienced or interested in the particular problem of dementia. Or a small town physician may be able to directly refer the patient to a colleague—but only if the patient can pay private rates. Carve-outs unduly impact vulnerable elderly through difficult, distant, and delayed access to care and there is not a well-developed network of psychological services outside of psychiatry (40). These structural/system barriers influence PCPs ability to provide proactive—as opposed to reactive—care for their patients with dementia who are experiencing neurobehavioral symptoms. Although interventions such as community clinics, inter-disciplinary teams, and improved physician education show mixed results, approaches that reduce barriers for elderly patients with dementia, and increase approachability and accessibility to specialty mental health services appear to improve dementia care (11,15,22,23,²⁵,²⁸,29,34,41–45). Although there is no one-size-fits-all solution to the problem of improving mental health services for elderly with dementia, physicians urge greater use of electronic medical records, advise the provision of multi-disciplinary care at primary care clinics, emphasize creating more of a consultant/collaborative care model within psychiatry, and propose use of telemedicine to improve psychiatric care in rural and other underserved areas.

Whether the consequences of often complicated and sometimes compromised care for dementia patients and the physicians who treat them are tolerable is a matter of perspective of weighing the various benefits and burdens to health care professionals, health care administrators, and the people they serve(40). Findings from the present study strongly support the need for systemic health care revision that places high priority on reducing the emotional and physical toll on patients, families, and their treating physicians through more integrated provision of mental health services. Such revision could at the same time promote reduction in care costs associated with institutionalization of inadequately treated/followed dementia patients.

Strengths and limitations

These qualitative analyses highlight the ways in which structural and systemic barriers created by onerous referral systems for mental health services contribute in different ways to compromised care for patients with dementia—as well as to increased burden for PCPs. These consequences are not evident in studies using quantitative approaches. The diversity of health care structures represented in this sample is also a strength.

There are also limitations associated with this study. First, we conducted interviews in 2002–2005; a review of health care policies, however, suggests that little has changed in managed care for elderly adults with dementia since that time. The geographic area ranged from urban to rural farmland within a 60 mile radius and with a strong presence of managed care. Thus, resources available to these PCPs may not be representative of more strictly urban or rural areas or areas with a different mix of health plans. The low participation of the HMO physicians (5% were from HMOs) may mean our results cannot be generalized to those settings, however, HMOs only provide a small fraction of care in the United States (approximately 10%). The two HMO PCPs we interviewed felt patients were well-supported by the dementia support services at their HMO; the PCPs expressed frustration, however, that they could not prescribe cognitive enhancers without specialist approval and access to psychiatry was at least one step removed. Overall, however, our sample of PCPs likely worked in more supportive settings with *better* access to mental health referrals than physicians practicing in more rural parts of the United States (30).

Finally, in a qualitative study, it can be difficult to estimate the magnitude of a problem especially when strong emotion is being expressed. Thus, although the lack of access to mental health specialists might be upsetting, we do not have a sense of how frequently lack of a mental health referral severely jeopardized patient care. In addition, despite their vocal frustrations, these PCPs preferred to manage the care of their dementia patients themselves. What was clear from the interviews is that many PCPs circumvented referrals by treating the neurobehavioral symptoms themselves or in some cases by making use of neurology, a specialty they found easier to access. Thus, the true extent of the unmet need for mental health referrals is likely to be underestimated.

Acknowledgments

Our many thanks and deep gratitude to the families and physicians who gave their valuable time to participate in this research. We also greatly appreciated the insight and wisdom of Linda Mitteness, PhD for her guidance in developing and refining the interviews.

Funding sources: This study was supported by Grants R01 AG012975, K23 AG019809, from the National Institute on Aging and an intramural grant from the UC Davis Health System to Ladson Hinton, MD. Partial support for the first author was provided by NIA AG018386 (PI: Kremen). There is no conflict of interest.

References

- 1. Lyketsos CG. Neuropsychiatric symptoms (behavioral and psychological symptoms of dementia) and the development of dementia treatments. Int Psychogeriatr 2007;19:409–420. [PubMed: 17346363]
- Lyketsos CG, Toone L, Tschanz J, et al. Population-based study of medical comorbidity in early dementia and "cognitive impairment, no dementia (CIND)": association with functional and cognitive impairment: The Cache County Study. Am J Geriatr Psychiatry 2005;13:656–664. [PubMed: 16085781]
- 3. Tschanz JT, Welsh-Bohmer KA, Lyketsos CG, et al. Conversion to dementia from mild cognitive disorder: the Cache County Study. Neurology 2006;67:229–234. [PubMed: 16864813]
- Geda YE, Roberts RO, Knopman DS, et al. Prevalence of neuropsychiatric symptoms in mild cognitive impairment and normal cognitive aging: population-based study. Arch Gen Psychiatry 2008;65:1193– 1198. [PubMed: 18838636]
- 5. Alexopoulos P, Grimmer T, Perneczky R, et al. Progression to dementia in clinical subtypes of mild cognitive impairment. Dement Geriatr Cogn Disord 2006;22:27–34. [PubMed: 16679762]
- Palmer K, Backman L, Winblad B, et al. Mild cognitive impairment in the general population: occurrence and progression to Alzheimer disease. Am J Geriatr Psychiatry 2008;16:603–611. [PubMed: 18591580]
- 7. Palmer K, Berger AK, Monastero R, et al. Predictors of progression from mild cognitive impairment to Alzheimer disease. Neurology 2007;68:1596–1602. [PubMed: 17485646]

8. Santacruz KS, Swagerty D. Early diagnosis of dementia. Am Fam Physician 2001;63:703–713. 717–708. [PubMed: 11237085]

- Alexopoulos P, Grimmer T, Perneczky R, et al. Do all patients with mild cognitive impairment progress to dementia? J Am Geriatr Soc 2006;54:1008–1010. [PubMed: 16776804]
- Wang PS, Lane M, Olfson M, et al. Twelve-month use of mental health services in the United States: results from the National Comorbidity Survey Replication. Arch Gen Psychiatry 2005;62:629–640. [PubMed: 15939840]
- 11. Banerjee S, Willis R, Matthews D, et al. Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. Int J Geriatr Psychiatry 2007;22:782–788. [PubMed: 17243196]
- 12. Jeste DV, Blazer D, Casey D, et al. ACNP White Paper: update on use of antipsychotic drugs in elderly persons with dementia. Neuropsychopharmacology 2008;33:957–970. [PubMed: 17637610]
- Sultzer DL, Davis SM, Tariot PN, et al. Clinical symptom responses to atypical antipsychotic medications in Alzheimer's disease: phase 1 outcomes from the CATIE-AD effectiveness trial. Am J Psychiatry 2008;165:844–854. [PubMed: 18519523]
- 14. Salzman C, Jeste DV, Meyer RE, et al. Elderly patients with dementia-related symptoms of severe agitation and aggression: consensus statement on treatment options, clinical trials methodology, and policy. J Clin Psychiatry 2008;69:889–898. [PubMed: 18494535]
- 15. Lessig M, Farrell J, Madhavan E, et al. Cooperative dementia care clinics: A new model for managing cognitively impaired patients. J Am Geriatr Soc 2006;54:1937–1942. [PubMed: 17198502]
- 16. Banerjee S, Smith SC, Lamping DL, et al. Quality of life in dementia: more than just cognition. An analysis of associations with quality of life in dementia. J Neurol Neurosurg Psychiatry 2006;77:146–148. [PubMed: 16421113]
- Hinton L, Haan M, Geller S, et al. Neuropsychiatric symptoms in Latino elders with dementia or cognitive impairment without dementia and factors that modify their association with caregiver depression. Gerontologist 2003;43:669–677. [PubMed: 14570963]
- Hinton L, Tomaszewski Farias S, Wegelin J. Neuropsychiatric symptoms are associated with disability in cognitively impaired Latino elderly with and without dementia: results from the Sacramento Area Latino study on Aging. Int J Geriatr Psychiatry 2008;23:102–108. [PubMed: 18058994]
- 19. Meiland FJ, Kat MG, van Tilburg W, et al. The emotional impact of psychiatric symptoms in dementia on partner caregivers: do caregiver, patient, and situation characteristics make a difference? Alzheimer Dis Assoc Disord 2005;19:195–201. [PubMed: 16327346]
- 20. Klap R, Unroe KT, Unutzer J. Caring for mental illness in the United States: a focus on older adults. Am J Geriatr Psychiatry 2003;11:517–524. [PubMed: 14506085]
- 21. Kessler RC, Demler O, Frank RG, et al. Prevalence and treatment of mental disorders, 1990 to 2003. N Engl J Med 2005;352:2515–2523. [PubMed: 15958807]
- 22. Borson S, Scanlan J, Hummel J, et al. Implementing routine cognitive screening of older adults in primary care: process and impact on physician behavior. J Gen Intern Med 2007;22:811–817. [PubMed: 17447100]
- Chodosh J, Mittman BS, Connor KI, et al. Caring for patients with dementia: how good is the quality of care? Results from three health systems. J Am Geriatr Soc 2007;55:1260–1268. [PubMed: 17661967]
- 24. Bartels SJ, Dums AR, Oxman TE, et al. Evidence-based practices in geriatric mental health care: an overview of systematic reviews and meta-analyses. Psychiatr Clin North Am 2003;26:971–990. x–xi. [PubMed: 14711131]
- 25. Van Citters AD, Bartels SJ. A systematic review of the effectiveness of community-based mental health outreach services for older adults. Psychiatr Serv 2004;55:1237–1249. [PubMed: 15534012]
- Barrio C, Palinkas LA, Yamada AM, et al. Unmet needs for mental health services for latino older adults: perspectives from consumers, family members, advocates, and service providers. Community Ment Health J 2008;44:57–74. [PubMed: 18026876]
- 27. Fang H, Rizzo JA. The changing effect of managed care on physician financial incentives. Am J Manag Care 2008;14:653–660. [PubMed: 18837643]

28. Neighbors HW, Caldwell C, Williams DR, et al. Race, ethnicity, and the use of services for mental disorders: results from the National Survey of American Life. Arch Gen Psychiatry 2007;64:485–494. [PubMed: 17404125]

- 29. Stefanacci RG. Current implications for the managed care of dementia. Am J Manag Care 2007;13 (Suppl 8):S203–205. discussion S206–207. [PubMed: 18095784]
- 30. Trude S, Stoddard JJ. Referral gridlock: primary care physicians and mental health services. J Gen Intern Med 2003;18:442–449. [PubMed: 12823651]
- Center for Studying Health System Change. Community Tracking Study Physician Survey (2004– 05). 2004–05
- 32. Hargraves JL, Stoddard JJ, Trude S. Minority physicians' experiences obtaining referrals to specialists and hospital admissions. MedGenMed 2001;3:10. [PubMed: 11549989]
- 33. Swarztrauber K, Vickrey BG. Do neurologists and primary care physicians agree on the extent of specialty involvement of patients referred to neurologists? J Gen Intern Med 2004;19:654–661. [PubMed: 15209604]
- 34. Brodaty H, Thomson C, Thompson C, et al. Why caregivers of people with dementia and memory loss don't use services. Int J Geriatr Psychiatry 2005;20:537–546. [PubMed: 15920707]
- 35. Franz CE, Barker JC, Kravitz RL, et al. Nonmedical influences on the use of cholinesterase inhibitors in dementia care. Alzheimer Dis Assoc Disord 2007;21:241–248. [PubMed: 17804957]
- 36. Kat MG, Zuidema SU, van der Ploeg T, et al. Reasons for psychiatric consultation referrals in Dutch nursing home patients with dementia: a comparison with normative data on prevalence of neuropsychiatric symptoms. Int J Geriatr Psychiatry 2008;23:1014–1019. [PubMed: 18425989]
- 37. Hinton L, Franz CE, Reddy G, et al. Practice constraints, behavioral problems, and dementia care: primary care physicians' perspectives. J Gen Intern Med 2007;22:1487–1492. [PubMed: 17823840]
- 38. Hinton, L.; Flores, Y.; Franz, CE., et al. The borderlands of primary care: Physicians and family perspectives on "troublesome behaviors" of people with dementia. In: Leibing, A.; Cohen, L., editors. Thinking about Dementia: Culture, loss and the anthropology of senility. New York: Rutgers University Press; 2006. p. 43-63.
- 39. Williams RGA. Logical analysis as a qualitative method. Sociology of health and illness 1981;3:141–187.
- 40. Committee on aging of the group for the advancement of psychiatry. Medicare managed mental health care: A looming crisis. Psychiatric Services 2005;56:795–797. [PubMed: 16020809]
- 41. Bartels SJ, Coakley EH, Zubritsky C, et al. Improving access to geriatric mental health services: a randomized trial comparing treatment engagement with integrated versus enhanced referral care for depression, anxiety, and at-risk alcohol use. Am J Psychiatry 2004;161:1455–1462. [PubMed: 15285973]
- 42. Fortinsky RH. Physicians' views on dementia care and prospects for improved clinical practice. Aging Clin Exp Res 2007;19:341–343. [PubMed: 18007110]
- 43. Lyketsos CG, Colenda CC, Beck C, et al. Position statement of the American Association for Geriatric Psychiatry regarding principles of care for patients with dementia resulting from Alzheimer disease. Am J Geriatr Psychiatry 2006;14:561–572. [PubMed: 16816009]
- 44. Robinson A, Emden C, Lea E, et al. Information issues for providers of services to people with dementia living in the community in Australia: breaking the cycle of frustration. Health Soc Care Community. 2008
- 45. Vickrey BG, Mittman BS, Connor KI, et al. The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. Ann Intern Med 2006;145:713–726. [PubMed: 17116916]

Table 1 Primary care physician characteristics and demographics

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	0–2000	9 (22.5)
	2001–4000	22 (55)
	4001-6000	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	17 (45)
	Geriatrics	2 (5.0)
Type of practice	Academic primary care network	10 (25)
	Larger group	8 (20)
	НМО	2 (5)
	Small group/solo	13 (32.5)
	University-based clinic	5 (12.5)
	Other	2 (5)

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Table 2

Consequences for patients due to institutional and administrative barriers to accessing mental health specialists

	Lack of Access to Mental Health Specialists	Lack of Coordination of Care with Mental Health Specialists
Potentially compromised care	"We don't have access to a private psychiatrist here so a lot of times we just play the psychiatrist. We don't have it here so we deal with it ourselves" (1055) "I'm like 'oh wow, you want to see a specialist? Next appointment 6 months? Well I guess we're working together for a while here until we get this taken care of or worked through and if I had more time it would be beneficial" (1012) "You end up acting like a poor man's psychiatrist many times in a situation where you recognize you probably don't have enough training to do optimally what would be in the best interest of the patient. But at least temporarily until you can make some contacts and get things rolling sometimes you end up having to temporize in that way." (1013)	"We have no control over who they see. I never get any feedback in terms of when patients are seen—I mean I don't want all the details but in terms of medications or suggestions." (1016) "There was a patient who I saw who I was concerned about one of the psych medications they were on. I called the psychiatrist because I didn't want to stop the medication without his approval and I got a phone call abox a month later after multiple calls." (1020) "They' ve stopped us from being able to refer to psychiatry. We used to be able to say 'I really want you to see someone who would be able to help, I'm going to write a referral.' Now it's like everybody's a carve- out. Somebody else now has to decide (1012)
Delayed care	"It's very hard to get psychiatric help for elderly patients, it's virtually almost impossible we have a number of psychiatrists that just take cash on the barrel. They don't want to take Medicare rates, they don't want to take HMO rates The psychiatrists—there are not that many of them—they charge full freight, and don't want to take Medicare and plus I just don't think they deal with elderly demented patients enoughthe elderly I don't think are a real interst." (1017) "Psychiatrists are more of a problem. There aren't enough of them, many of them are either committed within some program that they're working for; they're very restricted in terms of the insurances they take. For instance, I see MediCal patients, there's no way for me to directly refer a MediCal patient to a psychiatrist even if I think they have an acute need." (1073)	"I don't feel extremely qualified to make a complicated psychiatric diagnosis and sometimes I would like that hand holding and guidance and it's very tough to get (1073)." "It would be more helpful to have better backup on some of these patients that are difficult. I think doctors are loathet to declare somebody incompetent, but for their own safety sometimes you just got to do it. Some times it would be nice to have somebody agree to look over things, it's not there, psychiatric backup isn't there (1017)."

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Table 3

Consequences for primary care physicians of institutional and administrative barriers to mental health referrals.

Frustration	Burnout	Bitterness, Equity and Professional Relationships
"I cannot believe how much other medicine I do that I really don't want to do. It's not that I don't want to do thisbut there are aspects that I really don't want to do. (1012) "I can request all I want but a utilization management committee reviews everything and that's who has the final sayIf a referral gets denied then I toss it back in the hands of the utilization people and say "Sorry but this is not my field so you tell me where you want them to go."(1008)	"I think we are drowning with just the other patients that we have and they expect primary care to take this on too (1016). "It's frustrating to be primary care and not have the resources to send your patients to when you need them (1079)." "We need to have more providers here so that the work is distributedI mean the risk of burnout is always an issue, and we have a frequent turnover of physicians here." (1013)	"If you're here and having chest pain, if I think that you need a cardiologist I have the capacity to do that. If you're here and you're crying in the office, very anxious, very depressed and I say that you need a psychiatrist, I should have the capacity to do that too. There should be no approvalyou know medicine is medicine (1007)." "It doesn't foster doctor/doctor communication. I'd like to learn, get some feedback from the psychiatrists like I do in the other specialties—what I could do better with this patient in working with him. Especially since we're out in a rural area it would be nice to be the eye and ears to that doc to some extent to save the patient going down. I'd learn more if I was contacted." (1095) Now it's like everybody's a carve-out. Somebody else now has to decideSo what ends up happening is they [the patients] come to me for psychiatric care, and very quickly I get a thing from the biller. You know their insurance won't let me see them for depression, they won't give me any money." (1012)

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