Thinking About Dementia
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Midway through our interview, Mrs. Jones, whose husband was diagnosed with Alzheimer’s disease two years earlier, began talking about a change in her husband that distressed her—his forgetfulness. My immediate association was to short-term memory loss, a core part of the professional criteria of dementia. She then told us a story about his inability to set the alarm in their house in response to her admonitions to do so. Again, her description appeared to conform to the clinical criteria for dementia, which include functional decline and difficulties with higher-order cognitive tasks that require planning and sequencing (executive functioning). At this point, her story seemed off the central focus of our research: how families understand, manage, and seek help for the behavioral changes of a person who has been diagnosed with dementia. What followed next, however, surprised me. Mrs. Jones described how her husband became frustrated when he was unable to set the alarm, and then proceeded to “vent at her,” which she described as his getting very angry and pounding on the walls of the house. These outbursts occurred often and represented a change from how he had been before he was diagnosed with Alzheimer’s disease. We later learned that despite being very involved in her husband’s medical care, she had yet to mention these violent outbursts to his primary care physician. While the reasons for not telling his physician never became entirely clear, her own nonmedical, psychosocial explanation of his distress, a sympathetic physician who reinforced her interpretation of his behavioral changes, and the realities of a very constrained health-care system all played important roles.

This vignette highlights some of the core issues that will be explored in this chapter, which focuses on the behavioral changes of people with dementia as observed and responded to by families and primary care providers. We use the
term **behavioral changes** to refer to the diverse set of noncognitive symptoms (for example, depression, irritability, psychosis, wandering, agitation, aggression) that fall outside the formal diagnostic criteria for dementia (which emphasize cognitive symptoms and functional decline), yet are common clinical manifestations and are cited by family caregivers as among the most challenging aspects of living with a person who has been diagnosed with dementia (Chappell and Penning 1996; Chenoweth and Spencer 1986). For those interested in the anthropology of senility, primary care settings are important sites for study because that is where most people who suffer from dementia are diagnosed and treated (Small et al. 1997). Yet despite the enormous public-health significance of Alzheimer’s disease, “underdiagnosis” and “undertreatment” of dementia is ubiquitous in primary care (Boise et al. 1999; Callahan, Hendriel, and Tierney 1995). This lack of medicalization is striking because it occurs against the backdrop of clinical guidelines highlighting the need for early diagnosis and of considerable optimism among scientists and clinical researchers about the ability of pharmacological and nonpharmacological interventions to delay the progression of cognitive decline and ameliorate behavioral symptoms (Doraiswamy 2003). This disjunction between “expert” knowledge and routine clinical practice raises intriguing questions about how behavioral changes in persons with dementia are valued and responded to in primary care settings, where older adults, their families, and physicians come together. Anthropological perspectives may help us to understand how social and cultural processes influence the occurrence and timing of medicalization of cognitive decline, functional impairment, and behavioral change in older adults who meet criteria for dementia.

This chapter is based on early analysis of interviews conducted with families and primary care physicians who provide care to a person who has received a formal diagnosis of some type of degenerative dementia (such as Alzheimer’s disease). To frame our analysis, we use the concept of borderlands. Our use of this concept developed from the observation that clinical encounters in primary care have the potential for intimacy and supportive intervention as well as conflict, misunderstanding, and unnecessary or even dehumanizing medicalization. The concept of borderlands, which was developed in postcolonial feminist discourse, holds together the dual aspects of these settings that are so important to the experience and actions of families and primary care providers. Gloria Anzaldúa describes borderlands as “physically present wherever two or more cultures edge each other, where people of different races occupy the same territory, where under, lower, middle, and upper classes touch, where the space between two individuals shrinks with intimacy” (1987, 19). Her writing, which derives from her own experience growing up as a Latina woman on the Texas-Mexico border, highlights the psychological meaning of living between two cultures. Among other things, this postcolonial situation requires of those who live
in it a tolerance of the ambiguity that results from contact with multiple, sometimes contradictory cultural frames.

The concept of borderlands is relevant to our examination of behavior change among people with dementia and primary care settings in at least three ways. First, behavioral aspects of dementia have occupied a borderland in the history of the professional description and diagnostic criteria of dementia. After years of languishing in the shadows of cognitive symptomatology, there is now a flourishing scientific discourse and debate about dementia behavioral symptoms, their etiology, and their management. Second, in routine primary care settings, “troublesome” behaviors often elude formal medical intervention because of their ambiguous nature. Families and primary care clinicians struggle to clarify, understand, and negotiate care for these changes, highlighting what Sharon Kaufman (1993) has referred to as the boundaries of professional authority. Third, primary care settings can be viewed as contested spaces. They are contested because of the sometimes competing agendas of patients, families, primary care providers, insurance companies, and health systems. Within these borderlands of primary care, families and primary care providers are not passive, but actively resist what they view as oppressive bureaucratic structures or inadequate care.

In this chapter, we will describe two cases that differ substantially in the degree of intimacy and trust that is achieved between family and primary care physician. Despite their differences, each case shows the relevance of borderlands to the experience of families and primary care physicians, with particular attention to how these clinical and interpersonal processes of care are influenced by larger structural forces (health-care bureaucracies, political economy of health care, physician education), which operate somewhat in opposition to “expert” discourse on the diagnosis and management of Alzheimer’s disease and related dementias. Our attention to the structural and cultural contexts of care is influenced by the work of Cohen (1995), who emphasizes the need to examine multiple perspectives, including those of biology, culture, and political economy, in relationship to local contexts and politics of communities and families in order to account for medicalization of senility. The importance of structural constraints in the management of chronic illness in contemporary American health-care settings has been highlighted by others (Good 1998; Kaufman 1993; Kleinman 1998; Mitteness and Barker 1995). These structural constraints, combined with the lack of formal training for primary care providers in the care of persons with dementia and the latter’s skepticism of “expert” knowledge, converge to make the medicalization of noncognitive, behavioral changes less likely. The outcomes are varied, and they are complicated by cultural, gender, and age differences in the clinical encounter. Before discussing the case material, we review historical and contemporary perspectives on dementia behavioral symptoms to highlight their borderland status.
Nosological Borderlands from Past to Present

In this section we focus on the marginalization of behavioral symptoms in diagnostic criteria for dementia, despite ample data showing that they are common clinical features, and then turn to a description of the reemergence of behavioral symptoms as an area of active scientific interest in dementia research. We will not review the critique of the construction of Alzheimer’s disease and other forms of dementia as distinct disease entities (Gubrium 1986; Lyman 1989). Clinical diagnostic criteria for dementia emphasize cognitive symptoms and deemphasize noncognitive, behavioral symptoms. For example, according to the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), the most widely used diagnostic manual in American psychiatry, dementia is a clinical syndrome characterized by cognitive impairment that represents deterioration from a previous state and is associated with functional decline (American Psychiatric Association 1994). Cognitive impairments are further defined as short-term-memory loss and at least one additional domain of cognitive impairment, such as apraxia, agnosia, aphasia, or loss of executive functioning. There are multiple diagnoses (based on presumed etiologies) that fall under the general rubric of dementia, including a cluster of what are commonly referred to as the degenerative dementias: Alzheimer’s disease, vascular dementia, and frontotemporal dementia. The first two dementia subtypes are much more elaborated in DSM-IV, and behavioral symptoms are not part of the core description of either. Clinicians are, however, encouraged to subtype, specifying predominant behavioral symptoms (that is, with delusions, with depression, or with behavioral disturbance), although this is not essential for diagnosis or billing purposes. While frontotemporal dementia does not have explicit diagnostic criteria in DSM-IV, its clinical description does include an emphasis on changes in personality and behavior (Miller and Gustavson 2000). It is worth noting that one of the core diagnostic criteria for dementia with Lewy bodies, which is not included in DSM-IV but will likely emerge as a diagnostic category in DSM-V, is the presence of visual hallucinations.

The omission of behavioral symptoms from the description of Alzheimer’s disease can be traced to the early part of the twentieth century. In a historical review of the social and scientific construction of the Alzheimer’s disease category, Cohen (1995), citing Berrios (1990), demonstrates how behavioral symptoms moved to the periphery of the diagnostic criteria for this particular subtype of dementia. Alois Alzheimer’s initial description of a patient with Alzheimer’s disease in 1906 gave equal weight to both cognitive (memory loss) and behavioral (hallucinations, delusions, depression) symptomatology. Several years later, Emil Kraepelin used this clinical description as the basis for the creation of a disease category bearing Alzheimer’s name, distinguishing it from senile dementia, which was first described several decades earlier byBinswanger. As reviewed by Fox (1989), the distinction between senile dementia...
and Alzheimer’s disease was much debated at the time and over the ensuing years. Fox makes the point that technological developments, particularly the development of the electron microscope, which allowed more detailed study of brain neuropathology, were critical in the elimination of the word *presenile* from the definition of Alzheimer’s and paved the way for its description in DSM-III and beyond. However, as highlighted by Cohen (1995) and Berrios (1990), the DSM retained Kraepelin’s emphasis on cognitive symptoms in his description of Alzheimer’s disease and deemphasized the noncognitive symptomatology that was so carefully documented and emphasized by Alzheimer himself. While DSM-III did include “personality change” as one of the core criteria for dementia, this was subsequently dropped in DSM-IV.

Although behavioral changes are not part of the criteria for Alzheimer’s disease and vascular dementia, clinical and social gerontological literature over the past twenty years has continued to highlight their importance. In one of the earliest clinical epidemiological studies, Reisberg and colleagues (1987) found that 58 percent of Alzheimer’s patients had significant behavioral symptomatology, with delusions, agitation, day-night disturbance, motor restlessness, and violence among the most common symptoms. Community-based epidemiological studies have also found that mental and behavioral disturbances are much more common in people with dementia compared with their nondemented or mildly cognitively impaired counterparts (Hinton et al., forthcoming, Lyketsos et al. 2000). Early on, studies of families revealed that what was often most disturbing to them was not the extent of cognitive impairment or disability, but the disruptive behavioral symptoms, such as hallucinations, delusions, and agitation (Schulz et al. 1995). Subsequent studies found that these symptoms are associated with elevated caregiver depression and felt burden, increased rates of hospitalization, early institutionalization, excess disability, and higher health-care costs (Beeri et al. 2002; Donaldson, Tarrier, and Burns 1997; Finkel et al. 1998; Norton, Malloy, and Salloway 2001; O’Donnell et al. 1992; Schulz et al. 1995).

Current scientific discourse on behavioral symptomatology contains two alternative sets of theories about etiology. From the perspective of neuropsychiatry and neurology, there is a strong tendency to view these symptoms as brain based, that is, a result of pathological changes in the brain, particularly in neurotransmitter systems such as acetylcholine, dopamine, serotonin, and norepinephrine. In an example of this approach, Jeffrey Cummings has recently published an article speculating that acetylcholine deficiency, which has long been considered a factor in the development of cognitive deficits, is also implicated in the development of neuropsychiatric symptoms (Cummings and Back 1998). This medical approach to behavioral symptoms leads to an emphasis on pharmacological substances as a treatment. In contrast, perspectives on the etiology of behavioral disturbances from a social work and nursing perspective...
give greater emphasis to environmental and psychological factors. Cohen-Mansfield (2001), in a recent summary of research, highlights three alternative formulations: (1) behavioral problems as signs of underlying unmet needs or, essentially as idioms of distress; (2) stress/vulnerability causing behavioral problems as a result of a process in which dementia lowers the threshold at which environmental stimuli influence behavior (for example, overstimulation); and (3) learning/behavioral models. This formulation of behavioral problems underpins a set of nonpharmacological approaches to treatment.

To the critical eye, much remains ambiguous about behavioral symptoms. While symptoms such as hallucinations are abnormal, where one draws the line between normal and pathological levels of other neuropsychiatric symptoms, such as depression or aggression, remains unclear. Reflecting this, existing instruments that measure behavioral symptomatology (Cummings 1997; Reisberg et al. 1987) are continuous and do not clearly demarcate “normal” from “abnormal,” leaving uncertainty about where this boundary lies. When symptoms are present, clinicians must rely heavily on the statements of family caregivers, whose reports are filtered through the lens of their own emotional states, biases, and agendas, making older adults with dementia more vulnerable to the medicalization of behavior in response to caregiver distress. Finally, pharmacological and nonpharmacological interventions for behavioral problems, while clearly helpful in some clinical situations, have modest effects overall (Bourgeois, Schulz, and Burgios 1996; Trinh et al. 2003). Nonpharmacological interventions remain underused, perhaps reflecting a bias in research toward a neuropsychiatric (brain-based) view of symptomatology.

The Larger Project

The case studies that follow are drawn from a larger, ongoing study whose overall goal is to better understand patterns of help-seeking and barriers related to behavior changes in people who have received a formal diagnosis of some type of degenerative dementia. Interest in the role of sociocultural factors, specifically gender and ethnicity, led to a comparative focus on Latinos and Anglos. Thus, our study focuses primarily on the social responses to behavior changes after the point of diagnosis through in-depth qualitative interviews with both families (spouses or adult children) and primary care providers (PCP). Families were selected from two sources: a memory-loss clinic at a major university hospital and an ongoing epidemiological study of older Latinos. Interviews are conducted first with family members and then, with the family’s permission, PCPs. Family interviews focus on the caregiver’s experience of caregiving; the challenges they face in day-to-day care, including any behavioral difficulties; their patterns of help-seeking (both formal and informal); and their experience of care in primary care settings. The interviews with PCPs focus on their experi-
ences in the diagnosis and management of dementia and on their care of the specific person with dementia through whom they were identified.

**The Contexts of Primary Care**

As documented by Fitzhugh Mullan (2002) in *Big Doctoring in America*, the field of primary care has undergone dramatic changes in recent years, largely as a result of managed care. Many physicians have given up solo practices to become members of larger groups in an increasingly competitive health-care marketplace. Our data were gathered in a major metropolitan area in Northern California, where a higher percentage of elderly opt for managed-care plans, which restrict choice but often offer enhanced coverage for medications. Most of the clinicians we have interviewed thus far are internists or family practice physicians who work in outpatient clinic settings with typical patient loads averaging twenty-five hundred patients. The percentage of elderly patients on individual physician panels varied widely, from a low of 10 percent to more than 50 percent. Few physicians received specialty training in geriatrics, with most learning “on the job.”

There is great variation across health systems and primary care clinics in the support systems provided for clinicians in their management of patients with dementia and their families. Since few of the PCPs have particular expertise in dementia or psychiatry, the availability and accessibility of referrals to specialists, particularly neurologists and psychiatrists or other mental health professionals, is a major concern. Although neurologists are generally perceived to be available, providers consistently complain about linkages with mental health, and psychiatry in particular. In one system, there is significant integration of physical and mental health care, with a behavioral mental health specialist available on site to assist clinicians. At the other sites, mental health remains more of a “theoretical” than a real resource and is marginalized in these stories except as the object of considerable complaint.

As a result of this, patterns of specialty referral for dementia are heavily tilted toward neurology, with the burden of recognition and treatment for psychiatric problems falling on the PCP. There are also emerging differences between PCPs in urban and rural areas, where access to resources such as specialists; translators; and social and medical programs for the elderly with dementia and their families, such as day care, visiting nurses, and support groups, is much sparser. The lack of access to specialists, combined with problems in finding additional time to deal with both the physical and psychological health of these elderly patients, difficulties in billing for behavioral problems, and limited and expensive pharmaceutical arsenals for treating dementia patients, plus the reams of paperwork and forms required to allow the family to access support, places a heavy burden on the PCP.
The overall approach to managing behavioral problems that we are finding is what one PCP refers to as “reactive care” in which the family is relied upon to seek out help for these “problems.” The primary care office can be viewed as the borderland to which patients, caregivers, and physicians bring their respective cultures—personal, social, and structural—to bear on providing care for the elderly with dementia. Within clinical encounters, families and primary care clinicians often share intimacy and caring at the same time that they struggle to clarify, understand, and negotiate care for the ambiguous nature of behavioral changes, highlighting the borders of professional authority and personal responsibility.

The Jones Family and Dr. Henry

Surveys find that Americans are quite critical of physicians generally, but they tend to hold their own personal physician in much higher regard. Satisfaction and a degree of closeness would seem to characterize the relationship of a number of family caregivers and PCPs we interviewed, including the Joneses and Dr. Henry. Mr. and Mrs. Jones, both retired professionals, are healthy looking, energetic adults in their mid-seventies and have lived in their current home, which is located in the suburb of a major metropolitan area, for nearly as long as they have been married, fifty years. Although they are still active as a couple in many volunteer organizations, in travel, and in social events, Mr. Jones has become more dependent on his wife for initiating and maintaining these activities. More recently, Mrs. Jones took over the finances of the family. With no local family members to help care for Mr. Jones, Mrs. Jones pays caregivers to help out so that she can maintain some semblance of the autonomous active lifestyle to which she was accustomed.

When Mrs. Jones first noticed her husband’s memory loss two years ago, she was distressed by the cavalier attitude of her husband’s PCP in making the diagnosis and felt that the physician was not thorough enough in his assessment. A self-described “go-getter” who is heavily involved in her husband’s care, she sought a second opinion through a memory-loss clinic and had her husband switch doctors to Dr. Henry, in that order. She is quite complimentary when speaking about Dr. Henry, her husband’s current PCP, who accurately diagnosed her husband’s heart condition one year ago, enabling him to get a pacemaker that may well have saved his life. At the same time, she expects relatively little from him with regard to dementia care, in part because she views the neurologist as being “first” (in order of involvement with her husband’s dementia care) and as more of an expert.

MRS. JONES: Dr. Henry seems to want to get on top of all the little minor things before we hit a big problem. He’s got too many patients. I can never keep
him there long enough. But he’s the one that if he doesn’t know, he’ll find out before we come back the next time. He doesn’t know about medications. See this Aricept and Exlon and all that. He didn’t know much about that—nothing in fact—but he does now.

INTERVIEWER: Dr. Henry didn’t know anything about those at all?

MRS. JONES: No. I mean he’s a GP [general practitioner].

On the surface, Mr. Jones suffers from what would be characterized clinically as “mild” dementia; he appears quite normal—is extroverted and jovial—and is able to interact in a socially appropriate ways with others. In addition to the dementia, he suffers from heart disease, diabetes, and hearing loss. Despite his apparent cheerfulness, Mr. Jones can become quite irritable and—in the past six months—more physically aggressive. These episodes tend to be triggered by Mrs. Jones’s attempts to get him to do things around the house, such as setting the house alarm, or taking his own medications.

MRS. JONES: Like his pills, he said, “I don’t know where you keep them.” “Take your pills now.” I have a card there that tells him exactly what to do in the morning. Turn it over, exactly what to do at night. “Where are they, where are my pills?” “Same place they were yesterday: in the basket on the table.” He would get so mad at me when he can’t remember how to do his blood count.

INTERVIEWER: And he gets frustrated?

MRS. JONES: Terribly, I really don’t think that I should help him step by step because the more I help him, the more he expects me to help him. . . . Right now the big thing that we got going, we have an alarm system in the house and I make him set it every night. It’s four digits, which is our secret code, and then two other things that he has to push. I make him undo it in the morning when he gets up. If he doesn’t, then he sets off the thing and it’s awfully loud. I told the neurologist that’s what I was doing, and he says “Fine, that’s great,” so I feel that the more I make him think, the better off he’s going to be. Maybe I’m wrong.

INTERVIEWER: How do you deal with that when he, you know, gets frustrated or angry? How do you . . . ?

MRS. JONES: I don’t hit the wall like he does sometimes. Going down the hallway there, pow! I don’t do that. I just say, “Now think, think.”

INTERVIEWER: How often does that happen?

MRS. JONES: (Crying) Every day now . . . ’cause he takes pills twice a day.

Although initially Mrs. Jones seemed to downplay the extent and intensity of her husband’s irritability, it is apparent here that these episodes are both
frequent and quite upsetting to her. As she put it, “He vents at me.” She under-
stands his frustration and anger as a psychological response to his problems
with memory and functioning and his growing dependence on his wife. Reflect-
ing on his difficulties, she says, “Well, I know what causes it. It’s that he doesn’t
want to give up his man-in-charge and he has had to.”

Mr. Jones is under the care of both a neurologist and his PCP, yet Mrs. Jones
says that she has not discussed the seriousness of these episodes of agitation
with either of them. His neurologist sees him infrequently and the visits are
brief. Asked why she does not talk to Dr. Henry about it, she drew the distinc-
tion between “physical” and “mental” health issues and emphasized that he is
the expert in the former, rather than the latter.

INTERVIEWER: And would there be any reluctance to mention the moods, or the
irritability, or the swearing to Dr. Henry?
MRS. JONES: Oh no, I could do it, but I don’t know what good it would do. I don’t
think he would appreciate me saying anything because his interest in [Mr.
Jones] is in the physical part of him, not in the mental part of him.

Although Mrs. Jones clearly has high regard for Dr. Henry, she does not feel
that he is “knowledgeable about the disease,” and her husband has enough
physical health problems. This attitude was somewhat surprising, as our initial
sense of Mrs. Jones was that of a very agentic (that is, assertive and aggressive)
caregiver. It is as if she does not want to jeopardize the satisfactory medical care
she receives for her husband by being too demanding of the PCP regarding de-
mentia or emotional care.

In important respects, Dr. Henry, a young family-practice physician, agrees
with Mrs. Jones’s assessment. Dr. Henry does note that the primary behavioral
problems are “essentially surrounding fatigue types of issues and lack of want-
ing to do very many things, sort of being semiwithdrawn . . . the wife also noted
a few instances of a short temper, agitation types of things.” However, he has
not seen the Joneses in more than six months—the period during which Mrs.
Jones said the venting became worse. He admits he does not really know how
severe the “agitation” is, in part because Mr. Jones totally downplays it. He doesn’t really see it as a problem and I don’t know if
it actually is a problem or if it’s just normal spouse conversation. Yeah, I
didn’t think that it was something that was concerning enough for me to intervene.

As a participant in this borderland, Dr. Henry has alternatives that are limited not only by structural constraints but also by the limits of what he observes or is told. In this relatively brief two-year relationship, the differences in age, experience, training, and agendas as well as the structural constraints of the medical system both benefit and interfere with adequate treatment of Mr. Jones.

Dr. Henry describes his role as a PCP as that of being an “anchor” for his patients and a conduit for the opinions and recommendations of specialists, which he can interpret for families:

DR. HENRY: I think that my primary role is an anchor, OK? And that is having good communication with the family members or caregiver for that particular patient and then making sure that they’re associated with a neurologist. Also having close follow-up—which I haven’t had with him yet—close follow-up with him, keeping an eye out for any changes, also as a person that the family can feel comfortable coming and saying, you know, I went and saw this doctor, they prescribed me this type of medication, I have this question regarding this medication. I have a little bit more time on my hands and little bit more follow-up capacity to be able to let me pull up a couple of articles on this particular treatment regimen and I can review that with you sort of like an educator as well.

However, in his practice, this integrated model does not work well when mental health specialists are needed, though it is unclear that this is an option he has ever considered for the Joneses. Access to specialty mental health is particularly difficult because for many patients, including Mr. Jones, benefits have been “carved out” to a group of mental health providers separate from the providers of the rest of his health care. He described at length how cumbersome and difficult it is to refer patients for mental health treatment as a result of the presence of mental health carve-outs. As a result of the long delays in getting patients referred, he often finds that he is left to manage the mental health problems at least for a while; the phenomenon he describes, mental health carve-outs, have become much more common over the past ten years with the spread of managed care. They were introduced in response to mental health parity legislation largely because major health maintenance organizations (HMOs) were concerned that they would not be able to contain the mental health costs. Mental health benefit is carved out to another bureaucratic entity, which is subcapitated to care for the mental health care at a certain level of benefit, for the specified populations. In the context of mental health carve-out, Dr. Henry often finds that when patients do receive mental health treatment,
the communication from the providers of mental health care back to the PCPs is inadequate; care becomes fractured. The relative lack of access to mental health specialty care has changed Dr. Henry's strategies for managing mental health issues so that he relies much more heavily on neurologists and himself, even for problems that he considers to be psychiatric.

**Discussion of the Jones Family and Dr. Henry**

What is most striking in this case is the failure to “medicalize” Mr. Jones’s behavioral symptoms. Dementia is a chronic illness, and there is often considerable “uncertainty” about the cause of “changes.” Are they essentially expressions of interpersonal distress in response to his wife’s efforts to keep him mentally active, a psychological reaction to his growing dependence on his wife, or signs of underlying brain disease? Mrs. Jones settles on an explanation that attributes Mr. Jones’s irritability and aggression to marital discord triggered by the difficulties in adjusting to his increased dependence on his wife and to her prodding that he does more. From Mr. Jones’s perspective, these outbursts are understandable responses to a tragic loss of ability to function as he once had; his increasing reliance on his wife; and role reversal, which threatens his sense of self and manhood. Even with us, Mrs. Jones seemed to downplay the significance of his “venting” episodes and has yet to speak with physicians about the worsening venting and wall banging. Interestingly enough, even though Mrs. Jones says that she has not spoken with Dr. Henry in detail, Dr. Henry apparently has observed some of these spousal dynamics in his office visits. While hedging his bets somewhat, he basically views their difficulties as “normal spouse conversation” and thus outside his domain. For Mrs. Jones, what is clearly at stake in the issue of whether her husband’s irritability is caused by psychosocial stress or his Alzheimer’s are issues of loss, personhood, and identity that go very much to the core of their marriage. The alternative of medicalization of the irritability, though potentially providing relief from the strain of coping with these problems, is to let the disease enter further into their personal lives. In addition, she does not view Dr. Henry as a resource for these types of problems—only for physical health issues. Dr. Henry, by contrast, appears to be doing his best to mediate the problem away, considering each person’s opinion in an egalitarian fashion and attempting to do his best to negotiate a solution, much as if he were providing marital counseling. While Dr. Henry values Mr. Jones’s perspective, there is a tacit assumption that Mr. Jones’s “voice” needs to be balanced with that of his wife, reflecting his diminished autonomy personally and his ability to make medical decisions for himself. While Mrs. Jones has sought expert help both for Mr. Jones’s physical health problems and for his dementia diagnosis, that same energy has yet to be used in regard to the behavioral problems.
The multitude of constraints revealed in our interview with Dr. Henry suggests a somewhat different yet complementary reading. For patients who have been diagnosed with dementia, the reality is that PCPs and systems of care are often poorly equipped to provide the type of care that is described by experts. In the case of Mr. Jones, Dr. Henry sees him once every four to six months, mainly for management of Mr. Jones’s physical health problems. Mrs. Jones and Dr. Henry mutually allow care of his dementia to be performed by a neurologist, who allot fifteen to twenty minutes for office visits every six months or so. Although mental health specialty care is a theoretical possibility, it is not even under consideration yet by either the family or the physician. In any case, it is for all practical purposes out of reach, because of maddening layers of bureaucracy, which severely limit access and disrupt continuity. Mrs. Jones and Dr. Henry agree that the latter has little expertise in managing the “mental health” aspects of care; they also persist in viewing Mr. Jones’s emotional problems as constituting a marital style as opposed to a concomitant of dementia. These constraints may tacitly operate to direct efforts at help seeking away from the formal health care system and toward other sources, such as Mrs. Jones’s network of female friends. Thus, in this case, the medical office becomes a borderland where personal, marital, medical, and psychiatric issues collide, yet remain unresolved, if not unrecognized. Finally, we are left to wonder if Dr. Henry’s resistance to medicalize is shaped by his own reluctance to engage “mental health issues” in his practice, to keep a lid on this Pandora’s box.

The Garcia Family and Dr. Paul
The systemic constraints and challenges that physicians face in the delivery of services to patients who have been diagnosed with dementia is furthered nuanced by linguistic and cultural differences between physician, family, and patient. The intimacy needed to forge a treatment alliance of family members, patient, and physician is difficult to achieve when the physician misunderstands or lacks the cultural knowledge to contextualize the patient’s idioms of distress.

Mr. Garcia and his wife live in a small modest house located in an alley between two streets. Both were born in Michoacan, Mexico, and moved to the United States more than fifty years ago. They have been married for fifty years and are both in their seventies. Mr. Garcia is a retired farmworker and is monolingual Spanish speaking. They have four children; two live in the Sacramento area. While Mr. Garcia lives with his wife and cares for her day to day, their oldest son, José, manages his mother’s health care, in a pattern that is quite common among immigrant Mexican families. At this point in time she is basically nonverbal, yet is still able to perform some basic care. A social worker comes to the home once every few months to evaluate her condition, and the
family has hired a caregiver to help out for a few hours a day, to provide additional support for Mr. Garcia.

For the past four years Mrs. Garcia has experienced multiple health problems. In addition to suffering from her ongoing diabetes, high blood pressure, heart condition, recent stroke, and memory loss, in 1999 she was hospitalized for six months because of sepsis—at one point falling into a coma. The resulting weight loss, decrease in appetite, and continued extreme pain, as well as her increased distress, depression, and anxiety, spurred José to become aggressively involved in his mother’s health care. He changed health systems in late 1999, leaving the mother’s long-term physician for a new PCP and also searching for better solutions to his mother’s depression, anxiety, and hallucinations.

The central theme of the interview with the Garcias, told primarily from José’s perspective, is the struggle to obtain an accurate diagnosis and treatment for his mother’s behavioral symptoms. Their story is an interesting one, because it begins with her development of feelings of depression, anxiety, and memory problems while she was also suffering from a number of other health problems. Later, the mother started having visions of her deceased mother and father. When the son brought these symptoms to the attention of her PCP, the latter diagnosed her with depression and prescribed an antidepressant. José was not satisfied with the diagnosis, because his mother’s visions signaled to him that her troubles could not be explained just as depression or nerves: “The most alarming sign was when she said she saw her father or mother. I was sure this was not part of her depression.”

José discussed these symptoms with her PCPs and complained over and over again that her symptoms could not possibly be attributed to irritable bowel syndrome or depression alone, yet the PCP continued to maintain that all these things were part of the depression and part of the aging process itself.

MRS. GARCIA’S SON: She was in the care of a doctor, but the doctor would always say that it was due in part to her age, and in part to a problem—ah, she was very depressed and had a lot of problems with anxiety. And the doctor attributed those mental problems to that. I would tell the doctor that it wasn’t OK, that her behavior was not OK, her behavior was not in accordance with a depressed person, with a person with anxiety.

After about a year, Mrs. Garcia’s new PCP left the clinic and she came under the care of her current PCP, Dr. Paul, who also spoke some Spanish. When José approached the new doctor, however, he felt that he received a similar response to his concerns about this mother’s behavioral symptoms.

MRS. GARCIA’S SON: Well, this doctor left and we got another one. Then when we got the other doctor we spoke to him about the same problem. And this doctor was almost—I don’t know why they have the same mentality—he
said something similar to what the other doctor had said, but . . . I would always tell him that it wasn’t logical, their explanations.

He also requested that his mother be seen by a psychiatrist, but felt that his doctor stonewalled and was very defensive because his authority had been challenged. About the same time that Mrs. Garcia switched health systems, José set out to research the Internet for answers. He had learned about Alzheimer’s disease on the television show 20/20 and felt that his mother exhibited many symptoms of that condition; he then went online to research information, finally finding the Web site of a memory-loss clinic. He arranged for his mother to be evaluated there, and she was diagnosed with Alzheimer’s disease. This provided him with an explanation that made sense. Armed with a diagnosis of Alzheimer’s and recommendations from the memory-loss clinic, which included treatment of the hallucinations, José was finally able to get his PCP to prescribe an antipsychotic medication for his mother’s hallucinations. While her depression, anxiety, and hallucinations have stabilized, José feels quite bitter about his experiences in the health-care system and continues to search for an alternative site of health care for his mother.

Although the Garcias’ journey to finding care for Mrs. Garcia has been riddled with difficulties, her son, wanting answers, fought his way through a nonsupportive system to find them. He has been relentless in finding a doctor or clinic that would give him “logical answers” to his concerns. He challenged doctors’ diagnoses to the point of arguing with them. He explained that living in this country means fighting for answers, for the things that you need. His father, by contrast, has a more accepting, passive approach to medical care. This includes a much more deferential stance toward doctors, through the belief that they must know what they are doing. It is clear that neither approach has yielded optimal care for Mrs. Garcia’s complicated comorbid medical and behavioral problems.

This case shows us how the approach to health care of an educated bilingual adult child differs from that of a monolingual immigrant farmworker. This is not to say that all migrant monolingual farmworkers would take this passive approach, yet we have had similar cases in which adult children are the ones taking the lead in their parents’ health care. They are more aggressive about getting answers to their questions. They do not have the cultural value that a doctor must know what he or she is talking about and is not questioned. Furthermore, knowledge of English, the ability to converse directly with physicians, and the capacity to seek answers by using technology facilitated José’s search for a solution to his mother’s illness. Mr. Garcia, however, was hesitant to challenge the medical status quo. In fact, he was guarded about the interview itself, expressed hesitancy in challenging the doctor, and was uncomfortable with his son’s assertiveness. In Mrs. Garcia’s case, without her son’s intervention, she
would still be undiagnosed, suffering from hallucinations, depression, and anxiety and not receiving the appropriate treatment. Since her diagnosis, she has been given medication for Alzheimer’s disease and for the hallucinations, which ceased shortly after she began taking the medicine.

This case reflects some common patterns of caregiving among Latinos. While the spouse was involved in the day-to-day care of his wife, it was the adult child who negotiated the health-care system. In other families we have interviewed who have several adult children, most if not all are involved in supporting the ill parent by taking him or her to the doctor, searching for information and treatment, and supporting the spouse by taking on these tasks. Moreover, we have noted significant differences in how immigrant compared with U.S.-born children negotiate the barriers to health care. Mexican-immigrant adult children appear to feel less comfortable challenging, confronting, or even questioning physicians. It must be noted that most of the caregivers we have interviewed primarily migrated from rural Mexico, have less education, and may have had less access to health care while in Mexico. Therefore, as a result of these demographic characteristics, they may appear to have less agency. The pattern of deferring to authority may be exacerbated postmigration, as they are not able to negotiate the health-care system without adequate English-language skills.

Dr. Paul is a young family-practice physician who presented himself as a caring, but naive and overwhelmed, physician, unprepared for the challenges of dementia care. Even before we were through the consent process, he began talking about the terrible impact of mental health carve-outs on clinical care. This was a major theme throughout the interview, as he described the enormous difficulties involved in referring patients for mental health evaluation—something that often places him in the position of having to manage patients. He says that his patients’ mental health services are constantly being carved out to new sets of providers. This has several effects. For patients who are on cognitive enhancers, for example, a new insurance company may require a lengthy prior-authorization process before the patient is allowed to get the medication. This results in a period of time when they do not take the medication, because their prescription from the old insurance has run out but they are not yet approved by the new insurance company. Some of these patients go “downhill” when they are taken off the medication. This is such a problem that Dr. Paul is inclined to prescribe cognitive enhancers less readily. He says that his patients’ insurance is changing “all the time.” Another problem is that in the current system, he has to wait for a long time before he can arrange for his patients to see specialists, particularly mental health specialists. While he often finds himself forced to see them, he then faces the hurdle of billing for the services, as the insurance company will often not allow him to charge under psychiatric diagnostic codes.

He described Mrs. Garcia’s case in some detail, particularly the family dynamics. Clearly, this was a challenging and frustrating case, one that caused the
clinic to take the extreme position of limiting office visits, because of the high frequency of these visits, which included the family’s often showing up unannounced. Dr. Paul felt that their pattern of help-seeking was driven by Mrs. Garcia’s son, who, he believed, had unrealistic expectations about the extent to which his mother would recover. Interestingly, the issue of dementia was rarely discussed in the background of that conversation, with more emphasis being placed on family dynamics. There was relatively little discussion from him of the dementia diagnosis. However, he also tells us that the focus of the family was less on dementia symptoms and more on her physical ailments—in particular her abdominal pain. He readily admits that he does not have either the time or the training to manage many medical issues in his practice, including dementia and mental health issues:

**DR. PAUL:** I’m not the best, I’m not the best qualified. And I don’t have enough time, and that’s tough, it really, you know, it is very hard to know, I cannot believe how much other medicine that I do, that I really don’t want to do, and it’s not that I don’t want to do this, but there are some aspects I really don’t want to do, and I’m like, oh, wow, want to see a specialist, next appointment, six months, well I guess we’re working together for a while here until we get this taken care of or worked through.

As the interview moves to a description of the patient, it is interesting that dementia is so much in the background of this case. This may have some important consequences for care. For example, Dr. Paul describes his exasperation at the inconsistencies in his patient’s presentation—when she is in the room alone and when she is in the room with her son. However, he suggests that this may be a result of her loss of verbal abilities as well as cultural differences between himself and the family. The difficulties of communication with the family, since the patient is not a reliable source of information, may make it much more difficult to identify and treat behavioral symptoms, particularly when the family is labeled as a “problem” family:

**DR. PAUL:** This is the tough part, because I think he went overboard and then it was very hard to then figure out where the compromise was, because you’d really rather have somebody say, “Something’s different,” as opposed to the same thing over, and over, and over again. Something’s different then, then, oh, now I got to pay attention. Maybe now there’s something wrong that we can try to address, and that was hard.

**INTERVIEWER:** In this family did you feel that the family dynamics contributed to good or better care for her, that the son was as involved as he was, or did you think that the family dynamics, did the son and the father agree basically? Did they have the same agenda?

**DR. PAUL:** I don’t think they had the same agenda. The son’s agenda was to get
her back [to] how she was. She’s not the same, get her back, and the husband’s agenda was not that. He just wanted her to feel comfortable. He didn’t want her to be in pain for sure, but I think he understood when there was nothing wrong, he was like, OK, there’s nothing really wrong. OK, he was much more accepting, right from the get-go.

At the same time as Dr. Paul had some insight and appreciation for the plight of the Garcia’s, he seemed particularly limited—both in his professional training and in the health-system bureaucracy in providing care for them.

**Discussion of the Garcias and Dr. Paul**

This case exemplifies the inherent difficulties of delivering medical services to the elderly with dementia while needing to negotiate managed care, carve-outs, and the challenges of a cross-cultural medical encounter. Dr. Paul experienced the family and the case as a difficult one. Despite his feeling that he was culturally aware, and that his Spanish benefited the interactions that he had with the family, Dr. Paul appeared unaware that somatization of behavioral and psychiatric symptoms is common among Latinos and may well have explained Mrs. Garcia’s presentation. He also appeared not to be aware of the highly interdependent nature of many Mexican-immigrant families or the role of adult children as linguistic and cultural interpreters or brokers for the parents and, instead, problematized José’s effort to help. What we were unable to ascertain was whether the conflicts arose from the extreme differences in agendas—José’s to bring his mother back to her original health, alleviate her pain, and treat her depression and hallucinations; Dr. Paul’s to care for this frail elderly patient with multiple health problems at the same time as he conformed to the bureaucratic demands of his clinic and colleagues.

Dr. Paul’s self-admitted lack of training and experience in assessing and treating people with dementia and his limited cultural awareness appeared to create a frustrating and unsatisfactory relationship for both him and the Garcias. Once the family was labeled problematic, and their contact with the clinic was significantly constrained, the medical encounter became a contested borderland for both, one where the doctor and clinic staff were viewed as excessively controlling, if not denying, care to Mrs. Garcia. The family felt no connection to the doctor and the doctor appeared to feel burdened by the family’s demands, precluding the development of the intimacy, respect, and cooperation that Latinos value in their interactions with doctors.

**Conclusion**

The extent to which these borderlands of primary care are constrained by economic and bureaucratic structures needs to be highlighted. Lack of adequate
training in geriatrics and mental health for PCPs, large patient panels and relatively short office visits, very limited access to specialists for anything other than consultation, and lack of continuity in formal services are just some of the structural barriers that limit the options available to families and physicians in managing the sometimes “troublesome” behaviors of people with dementia. When resources are very limited, the expectations of both patients/families and PCPs may be realistically lowered with respect to the nature and type of care for behavioral symptoms. The situation described here for behavioral change in dementia is similar to what Sharon Kaufman described in her study of people rehabilitating from stroke. She notes that “the structure of social services and health care delivery, as well as their limits, creates the facts, the only knowledge that patients and families have as a basis for decision making and coping with long-term disability” (1988, 339). These constraints make nearly impossible, for many families, the careful biopsychosocial assessment that would lead to careful consideration of behavioral symptoms of environmental, interpersonal, and biological causes of behavioral change; prioritization of early nonpharmacological interventions, and the use of medications only as a last resort. Instead, the constraints of primary care in many cases dictate that there will be, at best, careful use of pharmaceutical agents to ameliorate symptoms that are presented by families, often at the point of “crisis.” Ultimately, this reflects the larger problem of a health-care system that has long excelled at handling acute illness, but that fails, often miserably, in the management of illness that is chronic.

These forces powerfully shape the experiences of PCPs and families, who, however, are far from passive. In these cases we can see the extent to which behavioral changes remain a borderland in the diagnosis and treatment of dementia by going unrecognized, misunderstood, or undiscussed in the primary care office. Within these borderlands, the influence of ethnic/cultural and gender differences and the power inherent in the role of the physician, caregiver, and health system can be acknowledged, recognized, and renegotiated to create sites for collaborative partnership in healing and support, as in the case of the Joneses, or a failure to treat adequately, as in the case of the Garcias. In some instances families and physicians can be seen actively resisting systemic pressures, trying their best, sometimes heroically forging humane and decent care for older adults who have been diagnosed with dementia and their families. Otherwise, these borderlands, as is especially apparent in the case of the Garcias, can be characterized by deep interstices within which the human connection that fosters healing can be lost. We suggest that these borderlands need not be sites of respite from marginalization (Alarcon 1998; Anzaldúa 1987), but also as active terrain where physicians, patients, and patients’ families can form partnerships that contest the influence of bureaucracy and unnecessary medicalization. We argue for a closer analysis of systems issues and of the impact of these on providers, families, and patients.
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