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Curing and Caring: The Work of Primary Care Physicians With Dementia Patients

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Abstract

The symbolic framework guiding primary care physicians' (PCPs) practice is crucial in shaping the quality of care for those with degenerative dementia. Examining the relationship between the cure and care models in primary care offers a unique opportunity for exploring change toward a more holistic approach to health care. The aims of this study were to (a) explore how PCPs approach the care of patients with Alzheimer's disease (AD), and (b) describe how this care unfolds from the physicians' perspectives. This was a cross-sectional study of 40 PCPs who completed semistructured interviews as part of a dementia caregiving study. Findings show that PCPs recognize the limits of the cure paradigm and articulate a caring, more holistic model that addresses the psychosocial needs of dementia patients. However, caring is difficult to uphold because of time constraints, emotional burden, and jurisdictional issues. Thus, the care model remains secondary and temporary.

Keywords

Alzheimer's disease; emotions / emotion work; empathy; health care; primary; health care professionals; holistic care; interviews; semistructured; medicine; practice guidelines; psychosocial issues; qualitative analysis

Once Alzheimer's starts, there's practically not much you can do. (Primary care physician)

Scholars have amply documented significant changes in U.S. medical care because of managed health care, unprecedented advancements in health technology, and the increasing rationalization of services (Marmor, 1998; Mechanic, 2006, 2008; Starr & Marmor, 1984). The field of medicine has changed as a social institution and at the level of physician practice (Freidson, 1986; Starr, 1982). For example, family doctors historically had limited technical and interventionist skills, and their work involved primarily being with patients rather than doing something to them (Freidson, 1989). A rather different set of expectations characterizes physician work in the United States today, which routinely involves technical intervention with the intent to cure. By cure we mean to eradicate, alter, or reverse physical conditions identified as pathological, mainly through standardized technical, individually focused pharmacological, surgical, and/or behavioral interventions. This dominant biomedical model is embedded in physician training and practice, and impacts the patient

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illness experience (Apker & Eggly, 2004; Hyde, Nee, Howlett, Drennan, & Butler, 2010; Hyde et al., 2010; Mishler et al., 1981).

The meaning of cure in today's clinical practice is central to U.S. physicians' collective identity, and many questions arise when biomedical interventions are futile or inadequate—something that challenges physicians' historical claims to a special status vis-à-vis other health-related occupations. How is the symbolic power of cure, as embodied in physicians' technical interventions, negotiated in daily practice when such actions are negligible? What happens when physicians cannot live up to the scientific ethos of cure, and must face a patient whose physical and mental decline is inevitable? How do they care for such a patient, given their training? How do they view this endeavor in the long term? We explore these questions by analyzing primary care physicians' (PCPs') work with dementia patients.

Unpacking physicians' views of these issues is relevant in several domains, such as standards of medical training, recommendations for clinical interventions, and health care policy. This is also important for understanding the functioning and financing of the welfare state as chronic and degenerative diseases place greater burdens on caregivers, communities, and support systems. All of these issues are magnified as aging baby boomers present an unprecedented challenge to health care delivery and medical practice. An analysis of PCPs' views and practices has broad-ranging implications for those providing as well as those receiving health care services in the United States.

Curing and Caring in Medicine

Social science scholars writing from a critical perspective have characterized medicine's approach to health as informed by a cure model that emphasizes biomedical interventions based on scientific principles. Cure has been contrasted to a care model, which is depicted as a more humane, holistic, and nurturing approach to healing and well-being (Abbott & Meerabeau, 1998; Apesoa-Varano, 2007; Benner, Tanner, & Chesla, 1996; Cancian & Oliker, 2000; Clarke & Quin, 2007; Davies, 1995b; Folbre, 2001; Holmes, 1989; Kumpers, Mur, Maarse, & van Raak, 2005; Melosh, 1989; Reverby, 1987).

Much controversy has ensued for decades about the cure/care divide, and there are two main schools of thought about how these models crystallized. Feminist scholars have identified patriarchy as a social system and sexism as a process of exclusion shaping the structure, ideology, and culture of the medical profession. Western science, with its emphasis on objectivity, standardization, and measurable interventions, is the basis of physicians' clinical and scientific enterprise (Acker, 1990; Witz, 1992). Because they involve the affective, relational, and expressive (Cancian & Oliker, 2000; Davies, 1995a, 1995b; Harrington Meyer, 2000; Kaplan Daniels, 1987; Waerness, 1984), caring-related activities in medicine are feminized and devalued; thus, the responsibility of women and women-dominated occupations such as nursing (Cassell, 2004; Elwer, Alex, & Hammarstrom, 2010; Norberg & Uden, 1995; Walby, Greenwell, Mackay, & Soothill, 1994). From this perspective, the divide between cure and care is vast, and it reflects larger social structures whereby gender inequality is reproduced.

Another approach emerges from research on work and professions in which the cure and care models in health are related to social class and professionalization processes (Coburn & Willis, 2000; Ehrenreich & Ehrenreich, 1979; Freidson, 1970a, 1970b; Kimball, 1992; Sarfatti Larson, 1990; Wolpe, 1985). The persistence of the cure/medicine and care/supportive occupations is closely tied to socio-economic processes by which professions have become powerful state actors. As such, these groups (or social classes) have protected their collective interests, primarily by monopolizing esoteric knowledge and technical skills to assert their privileged market positions (Derber, 1982; Leicht & Fennel, 2001). The

outcomes of these “professional projects” are varied, with medicine continuing to be located at the top of a highly stratified expert division of labor based on its claims to diagnose, reverse physiological phenomena and, more recently, manage chronic disease (Light & Levine, 1998; Wolinsky, 1993).

The cure and care models have played an important role in shaping the trajectories of health care occupations, health systems, and the symbolic repertoire of health practitioners; however, neither model is without shortcomings. Scholars have argued that the cure model privileges biomedical interventions at the expense of other approaches as the end-all of the healing process, often leading to medicalization (Conrad, 1992; Gill, 1998; Waitzkin, Britt, & Williams, 1994; Warshaw, 1989; Zussman, 1997). It has also been asserted that the cure model is individualistic and devoid of sociocultural, experiential, affective, and interpersonal dynamics (Cohen, 2003; Conrad, 1988; Davis & Webster, 2002; Fox, 2006; Fox Keller, 2003; Good, 1994; Gordon, 1988; Kleinman, 1999; Nasser, Walders, & Jenkins, 2002; Petersen & Seear, 2009; Speraw, 2009). In the United States, many have seen this focus as deleterious in conjunction with managed care’s rationalization of services (Campbell, 2007; Casalino, Pham, & Bazzoli, 2004; Derber, 1982; Diamond, 1992; Dingwall & Fenn, 1992; Gawande, 2007; Groopman, 2000, 2004, 2007; Hacker, 1998, 2002; Mechanic & Rochefort, 1996). The care model, conversely, is unable to move beyond its claims to holism and emotional labor, frequently getting bogged down in interpersonal dynamics and conflict. Furthermore, it can also promote an individualistic ethic based on the perceived moral virtue of practitioners, whereby caring about is seen as intrinsic to caring for someone (Held, 2006). This conflation assumes “states of character of individuals,” and when caring is understood as a matter of individuals’ motives and attitudes, it neglects “unduly the labor and objective results of caring” (Held, p. 20).

Cure and care have thus been contending perspectives in health care, often becoming more ideological weapons than analytical distinctions (Chambliss, 1996; Davies, 1995a, 1995b; Foner, 1994). Jecker and Self, calling for an end to the cure vs. care debate, have argued that there are four models of health practice: “1) health professionals who care for and about their patients, 2) health professionals who care for, but not about their patients, 3) health professionals who care about, but not for their patients, and 4) health professionals who care neither for nor about their patients” (1991, p. 294). Thus, the crucial distinction is whether practitioners care about and/or care for their patients. Caring about means to be in a “subjective state of concern about something,” whereas caring for involves “the exercise of a skill . . . with or without a particular . . . feeling toward the object upon which the skill is exercised” (Jecker & Self, p. 294).

Though appealing, these four models still pose challenges. For instance, Models 2 and 3, above, emphasize either cure or care, therefore still reproducing the dichotomy. Model 4 assumes that those in management and administration do neither, even when they might consider their jobs as much a “calling” as those on the front lines. Model 1 holds promise in incorporating both cure and care, but unfortunately Jecker and Self (1991) provided no clear prescription as to how this might be accomplished. Likewise, Jecker and Self did not consider how the cure/ care debate might be culturally bound. For instance, in recent decades there has been a large influx of ethnic minorities in health care who provide many medical services (Fisher & Wallhagen, 2008). Do these groups similarly dichotomize the cure and care models? What set of principles guide their everyday practice? How are formal training, work experience, and cultural factors related to the adoption of a cure and/or care model? There is more to be uncovered about the relationship between cure and care, given the complexities of health care and the diversity among those practicing it.

An in-depth look at PCPs' work with dementia patients provides a unique opportunity to examine how cure and care relate to each other in daily medical practice. Here, we offer a grounded analysis of PCPs' experiences with dementia patients to illuminate whether these models, curing and caring, are reconciled in light of the imperfect and tenuous enterprise of health—something that might push PCPs to reflect on their own practice and professional identity, and reexamine their views on health care.

Current Guidelines for Dementia

There are many different types of degenerative dementia, of which Alzheimer's disease (AD) is the most common and probably the most referred to in popular culture. AD is an incurable, "progressive neurodegenerative disorder that is clinically characterized by loss of memory and progressive deficits in other cognitive domains" (Reichman, 2003). Commonly associated with AD are changes in behavior such as aggression, disinhibition, and hallucinations. The progression of dementia leads to a person's inability to conduct activities of daily living, requiring around-the-clock caregiving (Hogan, 2008; Hogan et al., 2008). U.S. guidelines promote the use of cognitive enhancers as standard treatment to address the loss of "brain cells" responsible for cognitive decline (Allain, Akwa, Lacomblez, Lieury, & Bentue-Ferrer, 2007; Reichman). A group of medications, often referred to as cognitive enhancers, have been developed to treat AD, and have been incorporated into clinical treatment guidelines. These medications, which include cholinesterase inhibitors and one medication that targets glutamate receptor in the brain, do not treat the underlying cause(s) of AD, but have been shown in some clinical trials to improve cognition and functioning in a subset of persons (Farlow & Cummings, 2007). For behavioral problems, U.S. guidelines establish (a) nonpharmacological treatments, including caregivers' education (Hinton et al., 2007); and (b) medications for neuropsychiatric symptoms such as depression and agitation (Cummings, 2004).

Because of the incurable nature of dementia, researchers in U.S. biomedical fields often talk about the "management" of its symptoms, mainly to occur in primary care settings (Adams et al., 2002; Boustani et al., 2005; Boustani, Peterson, Hanson, Harris, & Lohr, 2003; Boustani, Sachs, & Callahan, 2007; Hinton, Franz, & Friend, 2004; Hogan, 2008; Olafsdóttir, Foldevi, & Marcusson, 2001; Vickrey et al., 2006). Specifically, PCPs are to assess a patient's cognitive function, medical and nutritional status, and start (and evaluate the effectiveness of) pharmacologic treatment in slowing disease progression (Boustani et al., 2003; Fillit et al., 2006). With regard to behavioral problems, recommendations also emphasize the use of drug therapies to be increased through ongoing physician follow up (Lieberman, 2003).

The evidence is mixed regarding the effectiveness of approved medications for slowing the progression of dementia, with much debate over what constitutes clinically meaningful outcomes (Cummings, 2004; Jones et al., 2009; Kaduszkiewicz, Zimmermann, Beck-Bornholdt, & van den Bussche, 2005; Pelosi, McNulty, & Jackson, 2006; Standridge, 2004). Although questions persist about their merit, based on studies in the United States and Canada, 60% of dementia patients receive acetylcholinesterase inhibitors, particularly White patients (Hillmer, Krahn, Hillmer, Pariser, & Naglie, 2006; Maneno et al., 2006). The data on efficacy are even weaker when it comes to psychiatric symptoms such as agitation, global disturbance, and psychosis. These symptoms are widely treated with atypical antipsychotics, the latest pharmacologic agents in the management of behavioral problems in dementia, "although studies have not always found significant advantage over placebo" (Jeste et al., 2008, p. 958; see also Katz, 2008; Kindermann, Dolder, Bailey, Katz, & Jeste, 2002; Schneider et al., 2006; Sink, Holden, & Yaffe, 2005).

The costs of drug therapies for both cognitive and psychiatric symptoms of dementia are many, including being highly expensive, increasing risk of mortality, and causing undesirable side effects in the elderly (Gill et al., 2005; Valiyeva, Herrmann, Rochon, Gill, & Anderson, 2008). Recommendations to use nondrug therapies such as caregiver education or behavior modification to address dementia patients' long-term cognitive decline and behavioral problems remain elusive. Other systemic problems exist in access to adequate consultation and support in formal health care settings and the community. U.S. physicians face great gaps in social service availability and organizational pressures that curtail their ability to take the time needed to deal with the complexity of psychosocial issues presented by dementia patients (Franz et al., 2010; Hinton et al., 2004; Hinton et al., 2007). Amidst controversies about their cause and the efficacy of available treatments, AD and other degenerative dementias are conceptualized as biomedical phenomena associated with pathophysiological processes.

Medical science continues to expand on the biomedical aspects of the disease, yet we know little about physicians' work with dementia patients on the front lines. Given limited technical (i.e., drug) and behavioral interventions to cure or even ameliorate symptoms, how do physicians care for dementia patients? What are the set of overarching principles guiding physician practice when "cure" is not apparent? It is exactly these questions that underpin this article.

Methods

This was a cross-sectional, qualitative study of primary care physicians (PCPs). The aims of the study were to (a) explore how PCPs experience and approach the ongoing care of patients with Alzheimer's disease (AD), and (b) describe how this care unfolds from the physicians' perspectives. To this purpose, we performed secondary analyses of existing semistructured interviews with primary care physicians that were conducted as part of a larger, mixed-method dementia caregiving study in a large urban area in northern California. All study procedures were institutional-review-board-approved before data collection commenced and complied with all ethical standards of the sponsor institution (University of California, Davis). Informed consent was obtained from each patient's legally responsible caregiver and the participating PCPs, and all participants' rights to privacy and confidentiality protected.

The physician sample ($N = 40$) was recruited from a list of 73 eligible clinicians providing services to community-dwelling older adults with dementia, who along with their caregivers, participated in the larger dementia caregiving study. Caregivers (family members in all cases) were asked for their consent to contact the patients' PCPs. Physicians were contacted by letter with a telephone follow up. Thirty-eight PCP interviews were conducted in person in physicians' offices, typically over lunch, and two interviews were done by phone.

Interviews were conducted by Ladson Hinton and two other researchers who were part of the larger dementia caregiving study. To ensure consistency in interviewing style and approach, the first 15 interviews with PCPs were conducted in pairs, with one person leading the interview and the other researcher observing and then asking questions at the end. The interviews consisted of open-ended questions in a structured interview guide utilized with all physician respondents. This interview guide was revised after the first five interviews to reflect emerging themes. PCP interviews covered three broad topics: clinician characteristics and practice setting, clinical care of a particular patient, and general approach to managing patients with AD. Interviews ranged from 30 to 60 minutes in duration, and verbatim transcriptions were produced for analysis. All transcripts were fully deidentified to remove all personal information. Transcripts were not returned to participants for comments,

and other analyses of these data have been published in peer-reviewed journals by authors participating in the larger dementia caregiving study (Franz et al., 2010; Franz et al., 2007; González, Hinton, Haan, & Ortiz, 2006; Hinton et al., 2006; Hinton, Chambers, Velásquez, Gonzalez, & Haan, 2006; Hinton, Flores, Franz, Hernandez, & Mitteness, 2006; Hinton et al., 2007; Hinton, Zweifach, Oishi, & Unützer, 2006; Kravitz et al., 2006).

Analyses of data for this article were performed from a grounded theory perspective using standard qualitative techniques (Coffey & Atkinson, 1996; Miles & Huberman, 1994; Starks & Brown Trinidad, 2007), assisted by NVivo qualitative computer software (QSR International, 2009). First, all three authors read interviews, conducted open coding of the transcripts to identify main themes, and agreed on three emerging central thematic categories: (a) diagnosis (when and how PCPs concluded the patient had dementia); (b) treatment/management per guidelines (how they proceeded and what they did after they concluded a patient had dementia); and (c) relational/emotional work (nonclinical, psychosocial, and other tasks outside of their clinical purview physicians described performing with dementia patients). In a second stage of analysis, the primary author (Apesoa-Varano) conducted iterative, systematic, finer-grained coding within these three agreed-upon categories. Then all authors discussed the results until all were satisfied that data saturation and reliability had been achieved. Apesoa-Varano was responsible for producing the manuscript for the article, which coauthors Hinton and Barker commented on and edited closely over an extended period of time.

Results

Sample Characteristics

Approximately half (57.5%) the interviewed PCPs were between 46 and 65 years old; most (87.5%) were men, and two thirds (67.5%) were White non-Hispanic, with others identifying as Hispanic (12.5%), Asian American (10%), African American (5%), and “Other” (5%). The largest proportion (37.5%) of physicians practiced in academic/university-based clinics, followed by those working in small group/solo practice (32.5%) and large groups (20%), with the remaining PCPs working in health maintenance organizations (HMOs; 5%), community health clinics, and other settings (5%). Just over half (55%) reported being family practice physicians, 40% internal medicine physicians, and 5% geriatrics. The majority (55%) of PCPs had between 2,001 and 4,000 patients in their panels, whereas 22.5% had smaller panels (< 2,000), 12.5% had a patient panel of 4,000 or more, and 10% did not know their patient panel size. Most physicians (74%) did not have specialty training in geriatrics, yet approximately 35% of their patients were aged 50 or older. As the sample characteristics make clear, the lack of better representation of women and ethnic minority physicians is a limitation of the current study. Although we are not presenting a gender or cross-ethnic analysis, gender and ethnicity issues raise important questions to be examined in future inquiries.

Curing Dementia: PCPs' Biomedical Narratives

Diagnosis—Most PCPs were readily able to outline the protocol they followed in diagnosing dementia. They relied on their initial suspicions, on lay caregivers' accounts, on medical evidence such as laboratory tests, on clinical assessments of cognitive function based on measures such as the Mini Mental Status Exam (MMSE; Folstein, Folstein, McHugh, & Fanjiang, 2010), direct observation of patient behavior, and imaging tests (i.e., computed tomography [CT], magnetic resonance imaging [MRI]). Physicians identified memory loss as the main symptom triggering their inquiry into a possible dementia diagnosis. They constructed the diagnosis of dementia over an extended period of time. One of them said,

I'd seen him [patient] for a checkup in August. He did make mention [of] many areas of his memory being somewhat off, didn't seem like any big deal but again it was brought up by him in such a manner as, "Why have I got a problem here?" Then a visit was scheduled January 2001, and he says that for at least 10 years he's had a poor memory that's more noticeable lately.

This process involved negotiation and sorting, dealing with conflicting pieces of information, and evaluating the impact of other medical conditions that were affecting the patient (Brown, Ahmed, Gary, & Milburn, 1995; Brown, 1987; Halpern, 1990; Jutel, 2009). A PCP described this process:

I check the medicines that they're taking. I do quite a few mini mental status exams for diagnosis and for baseline for patients to feel a little bit more reassured. Then I'll, depending on how they do on the test and whether I really feel that they just need to be reassured, I continue testing.

Often symptoms did not fit or could not be solely attributed to dementia, and the PCP would ask for a specialist's opinion. A physician spoke about one of his patients:

I sent him to the neurologist right about when I started seeing him about the aphasia and some of the other symptoms, and then she [neurologist] diagnosed a dementia, after the CT. In the year 2000, I sent him to the neurologist with worsening confusion and aphasia, 'cause it was a hard diagnosis to make, so that's how it happened.

PCPs commonly spoke of not being able to distinguish dementia symptoms (i.e., emotional withdrawal) from other psychiatric conditions such as depression. "She [patient] started back in the year 2000 with symptoms, no energy, poor concentration," explained a physician. "They were kind of confused between whether it was dementia or it was depression." Even specialists confused the onset and presentation of symptoms. "This psychiatrist wanted to treat her for her anxiety and depression," recalled another physician. "He's a good psychiatrist, [but] he didn't see the whole picture to realize that this patient was really demented." Eventually, most PCPs would refer the patient to a specialist such as a neurologist, and less frequently to a psychiatrist. In this process, PCPs typically played the roles of coordinators, mediators, and generalists treating the patient for a miscellany of diverse health issues, with the specialist focusing on confirming the diagnosis and supervising pharmacologic treatment (see also Franz et al., 2010; Hinton et al., 2007). Because of their frequent contact with patients, however, PCPs often initiated medications. They actively managed the condition themselves, with specialists weighing in at strategic times on the PCPs' medical decisions.

All in all, arriving at a diagnosis required careful construction of data over time, because some dementia symptoms could be attributed to other pathologies, both physical and mental, and because PCPs were cognizant of the symbolic power and stigma associated with this diagnosis. Even though PCPs had a theoretical understanding of the disease protocols, the actual diagnostic process was far more tentative and discretionary than textbook depictions and guidelines suggested. Not only did the dementia diagnosis have to make sense to PCPs themselves, but also to their patients, families, and other professionals such as neurologists and psychiatrists. PCPs said they felt competent about diagnosing dementia despite the uncertainty involved in this process.

Treatment—Once they verified the dementia diagnosis via medical evidence and the authority of a specialist, most PCPs were likely to offer pharmacologic treatment (i.e., cognitive enhancing drugs). Some PCPs, however, expressed that they almost felt compelled

to prescribe medication, despite contradictory scientific evidence and their own unsatisfying clinical experiences. One of them said,

First of all, we don't have very good treatment for Alzheimer's disease, and there's somewhat of an ethical problem in that realm, as well. That is, giving something like Aricept, the data is not strong, the amount of benefit is not great, where one wonders, "Is it truly, truly beneficial, or are we just literally grasping at straws [be]cause we have nothing else?" One feels a bit pushed to provide something. I wonder sometimes with the anticholinesterase inhibitors how much we're being driven by the tremendous concerns of the family, and the clinical trials that are funded by the pharmaceutical companies showing absolute miniscule benefit. . . . Everybody's jumping on the band wagon and providing these medications, which in truth may not provide a whole lot of benefit for the patient. There's a little bit of a dilemma. . . . There is really lousy data to support the use of the medication.

PCPs expressed reservations about the pharmacologic treatment they prescribed, given the many side effects of dementia medications. "I hate giving an old person something that makes them puke," one PCP lamented. "Some of these things [medications] that are recommended [now], in three years won't be anymore. In fact, [medications] will be shown to hurt people, and we hate that." Few PCPs were willing to let their patients go without medication, even when they thought pharmacologic intervention would not help them and could even discomfort them with side effects. "My impression is that 90 percent of the time," a PCP candidly explained, "we're just hoping to help and we're not significantly helping." Commonly, PCPs justified prescribing these questionable drugs by pointing to the likelihood that most patients and families would receive the dementia diagnosis as a "death sentence."

It is unclear whether PCPs exclusively prescribed these medications as a response to the patient/family's request, or because of their own sense of inadequacy or "wishful thinking" that they could reverse the condition (Franz et al., 2007; Hinton et al., 2007). However, it was evident that they felt they had an ethical imperative and hoped they had also the technical tools to help their patients address their cognitive decline in the context of current guidelines recommending pharmacologic intervention. PCPs made rare exceptions when a patient/family refused the medication, when the patient experienced severe adverse reactions to it, or when a patient's physical health took a precipitous decline. In the end, PCPs struggled with the realization that there was not much they could do to reverse dementia symptoms; pharmacologic treatment constituted the default medical practice.

PCPs' narratives about how and why they treat dementia patients by giving them medications makes sense in the context of the dominant cure model (Conrad, 1992; Mechanic & Rochefort, 1996); however, they recognized the limitations of this approach. When they hoped to medically alter dementia symptoms, yet failed, PCPs articulated an alternative approach that emphasized caring for the emotional and social dimensions of the illness. How do PCPs make sense of this alternative model, given the symbolic power of cure? When does curing transition to emotional and social support?

Caring For Dementia Patients: PCPs' Relational Work

A difficult alternative—Dementia patients pose a challenge, given PCPs' inability to alter the progression of the illness. According to those interviewed, standard medical training continues to emphasize diagnosis and treatment as defined by the dominant cure model. This approach betrays them, especially when they encounter older patients with dementia who present illness symptoms differently, and whose priorities, needs, and health outcomes are distinct from younger populations. "The problem [with the aging population] is that most

problems require longitudinal assistance,” explained a physician. “The very reason why people are coming to us, or we would be referring them . . . would be for ongoing, longitudinal assistance with those problems.”

Primary care physicians readily recognized the dominance and shortcomings of the cure perspective. Consequently, they also engaged in a parallel discourse emphasizing caring for patients beyond their purely medical needs. In an attempt to articulate this tension, a physician indicated that the cure model is dominant, but that there are some alternative approaches, such as that of the geriatrician:

[In geriatrics] we are treating the whole patient . . . their LDL [low-density lipoprotein] cholesterol number is usually just immaterial to us. [Our concern is], are they enjoying their life? Are they thriving? Are they safe? Is anyone abusing them? Do they have access to good nutrition and transportation? Is anybody looking at their ability to manage their own affairs? . . . So it’s not “the enlarged prostate in Room 3.” It’s more of a holistic approach to medicine, very difficult for many of the residents to accept [because of their training and other specialties]. . . . I just say, “Calm down. Let’s look at his [elderly patient’s] life.”

Most PCPs found that a psychosocial care model was best suited to address the needs of dementia patients in the long term. They described it as a more holistic approach that did not exclude medical intervention but that fundamentally embraced a humanistic ethos that valued nonbiomedical interventions. Explaining what this meant, a physician said,

Taking care of the whole person, taking care of the person in the context of their family and their community . . . seeing it as sort of an organic whole, not little units of organs . . . but how grounded they are in a good support system. . . . And I think more than anything, the doctor [who] does that determines how well you [patient] do.

Another PCP described this care model as “all encompassing” of a patient’s life:

They [dementia patients] need more attention to aspects of care that are important to the patient but are not part of the normal span of medical care. We always assume that medical care’s purpose is to optimize functional status, but we are taught to think in terms of categorizing diseased organ systems rather than thinking holistically. So functional status is a product of not just medical care or diseased organ systems but a product of [a] patient’s culture, socio-economic status, income, caregiver support, and the environment in which they live.

When articulating the care model, some PCPs went as far as framing it in empathic terms. One of the physicians described a past mentor as an ideal he tried to emulate in his daily practice: “Dr. M [mentor] was a very good physician. I would say he care[s], has a spiritual heart.” Reflecting further on this approach, the physician said,

As a human being my feeling is, everybody has grandparents and everybody has an elderly father and mother. So I don’t look for the cure for them, but I want them to enjoy their [life], they [have] left over a couple of years. . . . I just want to make him [patient] happy, smooth [things] until he finishes his life.

It is clear that this switch to managing beyond the biomedical occurred at the point where PCPs’ standard (i.e., pharmacologic) interventions no longer made a difference— even a minimal improvement—or when “basically you cannot change them [symptoms].” At this juncture, PCPs struggled to reconcile their belief in cure with what they could actually do.

Even though physicians expressed a caring alternative, it was difficult for them to enact as they described it. Thus, the care model often remained elusive, idealistic, and constrained by

disclaimers about how “problematic” it is to care for patients in that way routinely and systematically. According to PCPs, one reason caring was hard to perform was because it required emotional labor at both the professional and personal levels. “Dealing with a demented patient is very tough,” said a physician. “It’s your mom, you know.” PCPs frequently spoke of this emotional labor as a burden and a test of their will and persistence. “He [patient] definitely has become more childlike,” recalled one of the physicians. “It was dragging her kicking and screaming to get her there” (to the point of accepting his recommendation). “That’s when I saw what Ms. M [patient] was up against,” another physician lamented, when summarizing his experience. “It was distressing really to her, to me. . . . She couldn’t really remember how to walk because of the dementia.” Adopting a caring model meant more emotional involvement, such as dealing with patients’ anger, frustration, fears, anxiety, and physical decline which, in turn, could take a toll on physicians themselves.

In addition to the emotional toll as a reason for shying away from the care model, PCPs viewed the complicated interactions with patients’ families as troubling. “There’s been quite a tug of war going on,” recalled a physician about the interactions between a patient, her family, and himself. Another physician said,

Because it is the interaction between family members that sometimes plays against what you recommend, and sometimes the family members agree with you wholeheartedly but you have a patient who is not quite to the stage where they cannot make their own decisions. You get caught in the middle sometimes.

Finally, one PCP summarized the challenge of caring, especially when the family had trouble with the situation:

Well, you have to deal with being between people, and that is not an easy thing to do. [There are] the patients that are old and still coherent who are physically having difficulties being on their own, and family concerns. Then you have the ones that are mentally not able to manage for themselves. Sometimes, you have good family members and sometimes you don’t . . . and that becomes an issue.

Caring beyond the medical, managing more holistically, required that PCPs deal with a complicated web of social relationships between patient, family, direct caregivers, and/or even other specialists whose actions and opinions could also bring about conflict. PCPs were caught in the middle, mediating these interactions while trying to decide what was best for all parties involved, including for the physician her- or himself. In this context, they were pushed to become “brokers,” much like nurses are in the hospital setting (Apesoa-Varano, 2008)—something PCPs felt highly conflicted about.

Beyond the emotional demands, a majority of PCPs pointed to structural and organizational obstacles that detracted from caring. One of the physicians reflected,

Some doctors don’t like to deal with emotional stuff. It takes your time and you’re supposed to spend just fifteen minutes per visit. . . . Sometimes they [physicians] don’t want to do it so they just ignore it. . . . If they [physicians] get a hint of that [emotion] they ignore it, won’t talk about it, turn it off, and then the patient has to find it someplace else, or they [physicians] will refer them if they’re aware, and right away it gets dealt with that way.

PCPs readily identified time constraints as hindering their care for dementia patients beyond established guidelines. They expressed regret when recognizing their failure to care because of organizational constraints. “Sometimes I really want to spend more time with the patient and family,” a physician lamented, “so I really want to take care of everything, but I don’t

have the time in this kind of situation.” Reflecting on organizational issues and the bureaucratization of medicine, another physician said,

They [administrators] push us to be more and more efficient. I am not very much efficient anyway; I talk too much, I listen too much, so I am always behind. It kind of annoys me at times when I just get further behind. . . . I don’t like being behind, and it seems to be a lot [of the time].

Physicians overwhelmingly saw the lack of time, the structure of the health care system, and prevailing HMO directives as the main reasons for why they could not provide the kind of caring they would have liked (Hinton et al., 2007). It is indisputable that the conditions under which PCPs (and other health practitioners) work are not optimal, potentially putting at risk the quality of care dementia patients receive. It is equally indisputable that in the absence of biomedical interventions, dementia patients also pose a particular challenge because they push PCPs to consider an alternative worldview. Even though PCPs found a caring alternative that emphasizes the psychosocial and emotional aspects of health, they struggled to integrate it as part of their medical practice. How do PCPs resolve this dilemma? What set of principles ultimately prevails?

The reproduction of cure?—In further analyzing physicians’ views of caring, it became apparent that in the end the dilemma was resolved by relegating the care model to second place. For instance, most physicians viewed caring as someone else’s job. Thus, they referred patients to other health practitioners, particularly nurses and social workers whom PCPs thought “[we]re there” for that purpose. PCPs frequently explained that nurses and social workers are “better” at caring, and hence they ought to be the ones fulfilling this role. Extrapolating from his experience in the hospital, a physician said,

If somebody’s in the hospital and making all kinds of trouble when the nurse finally realizes [there is a psychosocial or emotional need]. They’re [nurses] more comfortable with themselves, and with what they’re doing for the patient.

By implication, PCPs felt uncomfortable about caring because they not only lacked the time to do it, but they also did not know how to do it. That is, they cared about but did not exactly know how to care for their patients with dementia. PCPs did not feel competent about deploying interventions outside of the biomedical realm. As a physician put it,

Well, I have stuff I carry in my pocket, so I have a person that I refer these folks [patients and families] to that I know who can do it. . . . Either I get the social worker involved, depending on sort of what I think they need . . . or I’ll just give them the contact numbers and say, “Call this person.”

Ultimately, PCPs resolved the struggle they experienced over caring by reaffirming their belief that their professional jurisdiction did not include managing dementia patients beyond the medical. Moreover, some resented the fact that they were put in a position of having to attend to the psychosocial and emotional needs of their patients and their families. Summarizing this view, a physician said adamantly,

But I’m not a social worker! I’ll be honest, I continually in my entire practice get pulled into the psychosocial issues because of—I sound like a broken record—the dismal state of affairs in our mental health system is horrible. So I am the psychiatrist and the therapist for a number of people.

The devaluation of this mode of caring for patients is only partially related to the emotional toll PCPs initially described and/or the structural barriers they identified. PCPs did not adopt this care model precisely because the kind of work it entailed was outside of their medical purview: caring did not readily lend itself to the evidence-based principles and

standardization procedures that dominant medical science espouses. Neither did caring easily fit in the context of mainstream dementia management guidelines PCPs were likely to follow. Another physician said,

The easiest thing that we have to do is prescribe a pill, because there's a whole infrastructure out there that allows me to write a prescription on a notepad, and there's a standard format and I just write it down. I hand it to the patient, the patient has a place to go to get that filled. I have a standard product that they get that I know what they're going to get, and that's all quality controlled and tested, and it takes me a moment to do that, and it's my belief that all this other stuff [providing social, emotional support, comfort] has to be coordinated in the same kind of way that I can write that. Which is why I [don't] have a prescription for Easter Seals that I can write just like a pill, until I get to the point where I can do that as rapidly as I write a pill [then I'll do it].

When asked about what she would like or hope for, one of the physicians commented,

A miracle medical cure for dementia, so we could all read the *New York Times* until the moment we die, or something! In the absence of having a cure for dementia, I am absolutely terrified of what's going to happen when each of us in turn could be ninety years old. Twenty years from now there's going to be ten times as many ninety year olds as there are today. Fifty percent of them are still going to be demented. Where [are] they going to go?

Discussion

The quote above points to “the writing on the wall” as the baby boomers age and the U.S. health care system faces a “perfect storm,” where the losses are potentially great for those at the receiving and providing ends. To assume that cure is the ultimate solution is equally troubling, as great burdens are placed on practitioners and health systems to continue managing larger numbers of those living longer with chronic illnesses, even if dementia were to be eradicated. The quote is also testament to the persistent, symbolic power of “cure,” even when its purpose and utility prove inadequate and when alternatives might exist. The issue is not whether physicians care about their patients, for they do, but how they care for them when biomedicine falls short and when the needs of patients and families reach beyond physicians' prescriptive practices. This has ramifications for the gap between physicians' ideas about what constitutes “proper” medical work, and their patients' needs.

The alternative differed from the mainstream cure model, and it involved a greater emphasis on the psychosocial and emotional dimensions of health and patient experience (Benner et al., 1996; Cancian & Olicker, 2000; Davies, 1995a, 1995b; Ungerson, 1990; Waerness, 1984; Watson, 1985). Essentially, the care alternative encompassed concerns for a patient's quality of life and well-being, expanding the clinical imperatives of the physician role (Waitzkin & Britt, 1989). This dissonance required symbolic work as physicians were pushed to accept the value and meaning of comfort, psychosocial emotional support, and “unskilled” work as part of their practice and professional identity. We found that PCPs reconciled the dilemma posed by dementia patients by relinquishing jurisdiction of caring to other health practitioners, and only a notable minority of PCPs effectively combined these two models. In short, PCPs collectively reinforced what has historically constituted claims to medical expertise by underscoring the preeminence of their technical interventions vis-à-vis caring more holistically. In so doing, they infused new life into the cure/care divide. The call to end the cure vs. care debate, as Jecker and Self (1991) proposed, remains an ideal.

As we have shown, revising the guiding values central to PCPs' practice will not come easy. This challenge must be understood in a larger social context where organizational,

structural, and ideological dynamics take place. For instance, cure has historically served medicine well in advancing collective (occupational) interests, yet perhaps not against the encroachment of HMOs over the last 60 years. These structural changes in the delivery of health services have impacted primary care, which declined in status vis-à-vis increasing technical specialization. In particular, primary care has moved toward triaging and resource coordination, focusing mostly on common illness treatment and leaving the “fancy” stuff for specialists. Additionally, PCPs are among the lowest paid physicians in medicine (for a related argument, see Kim & Sakamoto, 2008). Over the past decades there has been a continuing decline in the number of medical students entering primary care, an issue that has prompted much research and many campaigns to improve recruitment (Bodenheimer & Pham, 2010; Tu & Ginsburg, 2006; Walker et al., 2010). Likewise, the unprecedented health care demands following legislative reform and a diverse aging population will further test already strained resources and the practitioner–patient relationship. In short, PCPs have become the front line of health care reform. They are “in the trenches,” where much is at stake; where symbolic struggles over professional identity and practice have important material and territorial consequences.

We do not suggest that PCPs should be an “all-in-one” practitioner, holding the expertise of others such as nurses, social workers, or psychologists. Rather, we see the caring challenge faced by physicians working with dementia patients as underscoring the vulnerable yet potentially transformational position of primary care in the decades to come. Regarding this transformational capacity, some have proposed a participatory or partnership approach between physician and patient, a patient-centered model in which patients/families become integrally involved in the health care decision-making process. Scholars such as Davies (1995b) have also called for a “new professionalism” in which different types of knowledge and approaches to health and healing are equally valued to advance the well-being of patients and improve the collaboration of health care practitioners (see also Holmes 1989; Hugman, 1998a, 1998b, 2005). Calls for a new model of health care practice require “a process of situated reflection on expertise and experience which attends to the uniqueness and the uncertainty of the specific situation” (Davies, 1995b, p. 139). Bridging curing and caring entails rejecting the hegemony of the biomedical model and focusing on a more balanced view of health provision that is based on genuine collaboration among different health care practitioners, and among practitioners, patients, families, and the community.

Because the evidence remains inconclusive on the efficacy of drug therapies for dementia, the promise of the new professionalism and/or a patient-centered model leading to the reconciliation of cure and care are equally mixed. The playing field in health care remains embedded in a hierarchical system characterized by distinctively stratified work-places where health services are provided (Apesoa-Varano, 2008), and some models of health care practice carry more weight than others. The persistence of power differentials is still evident not only in the division of labor in health institutions but also in the relationship between “experts” and “clients,” physicians and patients, and among health practitioners themselves (Gill, 1998; Waitzkin, 2000, 2001; Waitzkin, Britt, & Williams, 1994).

This unequal distribution of privilege and power highlights that the cure/care divide is not simply a matter of disembodied values and beliefs. It is unquestionably grounded in structural conditions and the sociohistorical path of medicine as an occupation in the United States. Health care policy addressing these inequities is as important as returning to a Hippocratic Oath by which practitioners seek to “do no harm” rather than do “great deeds.” Practitioners might revisit their calling to the public good by considering that what is good for them must also be good for those they serve, and for society at large beyond the patient room. After all, we continue to confer great respect on highly trained medical and health professionals, and we hold them as paradigmatic of achievement and success.

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