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COMMENTARY

Changing the image of long-term care

Long-term care affects the life of almost every adult directly or indirectly but no one wants to talk about it. Why? Most adults will have to deal with the long-term care system at some time in their lives, either as direct users or on behalf of a family member. Nonetheless, few are willing to confront the need for reforming the institutions that provide such care or even to show concern about how they will deal with such problems when they arise in their own lives. Denial of unpleasant realities is not unusual. Most of us are thanaphobic. Nonetheless, many more people buy life insurance than buy long-term care insurance. Something else is going on here.

Long-term care has come to use increasingly large amounts of public money. Although dissatisfaction with the care purchased increases, few politicians have addressed long-term care reform. Indeed, such discussion about needed reforms has never made the major political agenda in the United States, despite serious efforts to introduce it.

This reluctance to confront the realities of long-term care goes beyond simple denial. Long-term care is not viewed as a topic worthy of discussion. If progress is to be made, this attitude must change. Part of long-term care's unattractive aura can be traced to its central symbol. The nursing home, for most people the embodiment of long-term care, is the bastard child of the alms house and the hospital, expressing some of the worst characteristics of each parent. Patients and professionals alike avoid going there. It is seen as a place of last resort, much like the hospital of the 19th century. The stereotype is a place that is physically unattractive, often smelly, and populated with people who are frail and often demented. Some institutions conjure up images of Pinel's mental institutions.

The failure to make long-term care a priority reflects a prevalent belief that such care is of little avail; the best that can be done is to make the patients comfortable. In general, long-term care induces responses of helplessness. The situations that lead to needing such care are seen as end-stage and therefore hopeless. The lessons of reversibility that were taught by geriatric pioneers like Marjorie Warren have gone unheeded or been forgotten. The underlying paradox of geriatric care—that these frail patients, whom traditional medicine has forsaken, may be the ones with the greatest potential for benefit from even modest systematic efforts—has been ignored.

Improving well-being and function

Even geriatricians can be heard describing nursing-home care as end-of-life care. Although many people in nursing homes have limited life expectancies and may be poor subjects for major technological interventions, a great deal can be done to improve the quality of their living circumstances and even their functioning. Much of it involves reversing iatrogenic situations.

A key to changing the political and professional fortunes of long-term care lies in changing the perceptions about the responsiveness of long-term care recipients to improvements in care. We must demonstrate and disseminate that good care makes a difference. Ironically, the literature of long-term care is strewn with studies that demonstrate the effectiveness of pathetically modest interventions, such as allowing nursing-home residents to care for a plant [1] or keep a pet [2]. There are also studies showing how better primary care can improve residents' outcomes [3, 4]. However, there is little systematic work to show how more comprehensive approaches to changing the fundamental approaches to such care can produce results.

Medical and social care need to be better integrated. Geriatrics in both the US and the UK has struggled to separate its image from that of the nursing home, despite a need for better primary care for most people [5]. Models of care that use professional dyads of physicians (sometimes geriatricians and sometimes not) working with nurse practitioners have emerged as a productive answer to the primary-care gap in American nursing homes [6–8]. Integrated payment, wherein medical care is provided under a subcontract to the nursing home, may help to integrate such care. In the US, investments in better primary care have been stimulated by capitating the medical care for nursing-home residents paid under Medicare [6].

Some authors have embraced better information systems, like the Resident Assessment Inventory [9–15], which may be more successful in countries where it is not mandated [16, 17]. Certainly, systematic approaches to collecting and using information to identify and track residents' problems, both medical and psycho-social, are a critical first step. Such information can form the basis for focusing on the outcomes of care, where the outcomes are expressed as the difference between observed and expected rates of both good and bad events. Demanding accountability on this level both reinforces the concept of case-mix-adjusted performance and allows more latitude in developing innovative approaches [18].

Providing information on the difference that good care can make provides a strong incentive to line workers, who see for the first time the effects of their efforts. Because the dominant pattern in chronic care is

decline over time, it is critical to present data in terms of slowing the rate of that decline. Showing people the effects that their care creates (especially when that effect is imperceptible without appropriate controls) can make a world of difference in job satisfaction.

Other shibboleths need to be addressed as well. The basic hospital model, which ties care to housing, needs to be revisited. The distinction between home care and institutional care can be eliminated if services are separated from room and board. In effect, long-term care services can be provided in a variety of settings. In some cases, clustering may ensure more efficient use of staff, but such clustering does not mean that people have to forsake living in an environment that supports their quality of life. Indeed, people with equivalent levels of disability may be able to afford very different levels of accommodation, and should be able to enjoy them. But even the least of these should match our society's beliefs about what represents a minimal standard of living.

We will continue to be reluctant to invest in long-term care until we believe that it is worth investing in. This does not mean we will ignore it. Like many other socially necessary services, we will begrudgingly maintain it, but we will not rally around it. No one gets excited by a new land-fill. We know we need to provide for solid waste disposal, but it is not the stuff that ends up on campaign platforms. Likewise no one will get excited about building more nursing homes, even if someone makes a convincing case that they are needed.

We are much more willing to invest in medical procedures that often carry a low expectation of benefit than we are in geriatric care that can promise far higher yields, largely because the former come with an optimistic scenario. The challenge for those who would move forward the long-term care agenda is to create both the myth and the reality of benefit from better long-term care.

Regulation of long-term care

Long-term care in the US has a long history of being reactive rather than proactive. Its fate has been shaped largely by external forces, especially payment and regulation. In response to scandals in the 1970s, strong pressures for strict regulation arose [19–21]. This tradition has continued and expanded ever since. The industry has responded by finding ways to both appease and challenge the regulators. The most effective means of achieving the latter has been through litigation. However, while this strategy may have thwarted regulatory effectiveness, it has done nothing to improve long-term care or its image.

Regulations thwart creativity, especially those based largely on professional beliefs unsupported by empirical evidence. At the very time when long-term care desperately needs to create a climate of innovation and experimentation, regulations dampen any spirit of creativity. At the very least, they discourage sticking out one's neck when the safest course is to remain invisible. To exacerbate matters, the regulatory response to litigation is to seek ever more measurable targets, which deflects attention away from what is most important to both quality of care and quality of life.

What is needed is some form of accountable innovation, a means by which creativity can be encouraged within a climate of responsibility and accountability. The logical solution is to rely more heavily on regulation on the basis of outcomes, especially case-mix-adjusted outcomes. There is some basis for optimism that such an approach could work [22], but only in a less catastrophobic environment. Outcomes rely on probabilities and can never guarantee complete elimination of risk. (In truth, the current regulatory system is far short of being risk-free, but people see even more stringent regulation as the answer to each newly uncovered deficiency.)

The problem posed is the proverbial chicken-and-egg. Until long-term care has a better image, few will advocate giving it more leeway to develop a more workable regulatory strategy. Few will grant the opportunities to experiment with badly needed new forms; but without such experimentation, the image is unlikely to change.

Long-term care is a long way from claiming an empirical basis for practice. We have yet to clarify the underlying values premises. We need strong evidence that good care can make a difference, and we need more efficient ways to provide such care.

At the same time, we must create a policy environment that encourages the adoption of effective innovations. Risk aversion and punitive payment systems deter such action. Paying for services rather than for results reinforces adherence to the orthodoxies that drive coverage decisions.

Robert L. Kane
University of Minnesota School of Public Health,
Mayo Mail Code 197,
University of Minnesota School of Public Health,
Minneapolis, MN 55455, USA
Fax: (+1) 612 624 8448.
Email: kanex001@tc.umn.edu

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