

What Older People Want From Long-Term Care, And How They Can Get It

Determining older persons' long-term care preferences is a necessary prelude to devising a system that honors their wishes.

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ABSTRACT: Seniors' long-term care preferences resemble those of younger persons with disabilities, but the two groups are treated differently. Younger persons with disabilities pursue the goal of social integration, whereas safety and efficiency receive undue emphasis and ageist differences prevail in the way older persons are served. Among the changes needed to help older consumers get what they want are empowering older persons and their agents to make better decisions, including providing them with more structure and better consumer information; revising attitudes toward safety and protection; and developing more vigorous advocacy by and for seniors.

114**SENIORS'
PREFERENCES**

ONE SHOULD NOT EXPECT GREATER CONSENSUS about preferences for long-term care (LTC) than for any other area of consumer choice. Nonetheless, searching for a central tendency in older people's LTC preferences is a worthwhile prelude to serious consideration of how to reshape policies and practices in LTC for the elderly. Older people generally hold varying, multiple, and potentially conflicting preferences for their LTC, and current policies and practices often fail to meet their wishes.

Ageism, that is, basing attitudes and treatment of a person on age, has long been recognized as a problem in the care of old people.¹ This ageism is reflected in the differences between how older and younger persons are treated in LTC policies and programs.² In the last decades of the twentieth century, strong efforts were made to ensure that younger adults needing these services receive them in the most normal social settings possible, where they can control the

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details of their help—even to hiring, training, supervising, scheduling, firing, and sometimes directly paying their publicly subsidized caregivers. Despite some advocacy and organized efforts at change, the options for older persons have been more restricted and have reflected paternalism—that is, doing something to or for a person against his or her will for his or her own good.³

For both young and old, the preferences of others besides the direct consumer can be relevant, but they sometimes are given undue weight. Furthermore, preferences change over time; sometimes people are unaware of their own preferences; and sometimes consumers need to grapple with their own competing goals and the inevitable trade-offs posed.

The ultimate way to maximize choice is to ensure that people have the cash to purchase the services they prefer. This approach is actively espoused by many spokespersons for young adults with disabilities. It has gathered momentum from the recent *Olmstead* decision, which ruled that persons with disabilities are entitled to care in the most integrated setting.⁴ Various coaches, counselors, or surrogates are effectively used to promote community living and self-determination for cognitively impaired persons.⁵

In decelerating order, cash, vouchers, and individually employed workers rather than packages from agencies are used to enhance control and flexibility for younger consumers. All of these strategies are sometimes available to older persons but are much more commonly available to younger persons with disabilities.⁶

In this paper we present our rationale for changing the way the elderly receive LTC so as to better reflect their preferences. We base our discussion on our review of the pertinent literature, and also on our years of research, experience, and observation in the area of long-term care for the elderly. The differences in care preferences among older and younger consumers, in particular, are difficult to quantify based on existing research, but we believe that the current LTC market reflects the reality that older and younger consumers are treated differently.

Research On Long-Term Care Preferences

The research literature on the LTC preferences of older persons is sparse and confusing. Surveys of community residents show a strong aversion to nursing home; in one study with a large sample of seriously ill persons over age seventy, 29 percent indicated that they would rather die than enter a nursing home.⁷ Despite this, studies of nursing home residents reveal a generally high level of satisfaction, perhaps reflecting an accommodation to the inevitable.⁸ A profile of what older LTC consumers want can be pieced together from

twenty years of sporadic research using interviews, questionnaires, and focus groups to elicit preferences.

Aspects of care that are particularly important to nursing home residents include kindness, caring, compatibility, and responsiveness.⁹ Nursing home residents also value control and choice on aspects of their daily lives, particularly with reference to leaving the facility from time to time and telephone and other communication with those outside the facility.¹⁰

Older persons who need to relocate for LTC value having private accommodations. Private rooms and baths are rare in nursing homes and still far from ubiquitous, although more common, in assisted living.¹¹ Most residents and prospective residents would prefer a smaller private space than a larger shared one and would trade off activity programs for privacy. Competent care, in contrast, is considered a nonnegotiable necessity.¹²

Older home care consumers value interpersonal qualities (the caregiver liking and caring about them, being compatible with the caregiver), reliability (caregiver showing up on time, staying the expected time, and being trustworthy), task competence (the caregiver doing housekeeping and care tasks the way the older person likes), and adequacy in the amount of care and help received.¹³

Under a broader definition of home care, which encompasses home health care, consumers valued physical, social, and psychological outcomes and certain quality processes, but they also valued other attributes such as reliability, honesty, and kindness.¹⁴

In another, larger study, seniors receiving in-home services under a Medicaid waiver varied in whether they preferred flexible or fixed routines (those preferring the latter being more vehement about the preference) and whether and how they wanted family members involved in their direct care. The majority placed a high value on privacy, but that concept held various meanings, including bodily privacy, privacy in personal and financial affairs, and being literally alone at times.¹⁵

The goals for LTC present obvious conflicts. Most apparent is the tension between safety versus choice, control, individuality, and continuity of a meaningful personal life. Families often opt for nursing homes because they fear leaving their relatives at home where some untoward event may occur. But nursing home admission usually means relinquishing one's own routines for the schedule of an institution modeled after a hospital, which places efficient deployment of staff and routine processes for job performance and accountability ahead of individual preferences. Families justify such trade-offs on a belief that nursing homes provide safe and watchful environments for ongoing care of illness, an assumption refuted by

problems unearthed in various investigations and exposés of poor technical quality.¹⁶

Older persons receiving care and services at home may have difficulty articulating their preferences, especially those regarding abstract matters phrased as safety versus freedom. When that query was put to home care clients, about one-third preferred to come and go as they pleased and be less safe; about one-third preferred to be safe and protected even with restricted freedom; and one-third were ambivalent, undecided, or wanted both safety and autonomy.¹⁷

Older Versus Younger Long-Term Care Consumers

Older and younger persons approach LTC somewhat differently. Younger persons, or their spokespersons, seek control and flexibility, emphasizing living as productively, meaningfully, and normally as possible. Discussions of LTC for older persons emphasize safety and protection; regulators, professionals, families, and even older persons themselves have long seemed to endure an extraordinary diminishment of privacy, independence, and normal life to receive care. The nursing home itself, an institution that bears no resemblance to ordinary life and infringes on autonomy in many ways, is the extreme example.¹⁸ Similarly, older persons have accepted home care on schedules, which means that bathtime and bedtime are far from normal or in their control. Many older persons need LTC because of cognitive impairment, but the differences in the societal approaches to seniors with dementia and younger persons with cognitive impairment due to developmental disability suggests that ageism, not dementia, is at the root of the distinction.¹⁹ Younger persons with cognitive disabilities have steadily achieved gains in the amount of freedom permitted along with and related to their care, whereas the latter group is relentlessly protected.²⁰

Younger persons with disabilities reject the concept of standard home health care, which is considered a major step toward autonomy for older consumers, compared with entering a nursing home.²¹ Instead, the younger group prefers personal care attendants who accompany them they leave their homes and enable them to participate in a full range of activities.²² Many perceive medication management, help with catheters and ostomies, and the like as extensions of routine tasks of daily living, which can be done without the close supervision of a nurse. Being homebound as an eligibility criterion is excessively restrictive.

Advocates for younger persons emphasize individual housing. Group homes and even apartment-style assisted living with individual kitchenettes and full bathrooms but congregate dining are often regarded as just another institution. However, judging from the

market response to the availability of these settings, many older persons are attracted to congregate settings where services and care are easily found. For example, they are choosing assisted living that provides for a private apartment but also provides congregate meals, housekeeping, personal care, and access to health care.²³

Little formal research has been done to compare LTC preferences by age group controlling for other characteristics, let alone studying how the preferences of persons with LTC needs change as they get older. Relationships, activities, comfort, functioning, and dignity are important to both groups, but the context differs because of life-stage tasks. Younger persons see their lives largely ahead of them and seek care that permits them to develop a life that reflects their aspirations and abilities. In contrast, many older persons see their lives as coming toward a conclusion and seek to make meaning out of their life histories, while conserving resources for end-of-life care and legacies for family.

Perhaps because disability is a common and gradual concomitant of aging or because of the emphasis of advocates, seniors tend to perceive themselves not as disabled but rather as old or sick. The downside of this self-perception means that seniors are cut off from the insights and experiences of younger persons with disabilities, and they do not seek or know how to use the protections of the Americans with Disabilities Act (ADA). For example, ADA case law and deinstitutionalization programs are disproportionately focused on younger persons, even though most nursing home residents are over age sixty-five.²⁴ Ending nursing home care is an overt goal of the disability movement. Older persons, in contrast, seem reconciled to nursing homes as an inevitable consequence of dependency, perhaps because they remain unaware of other possibilities.

Helping The Elderly To Make Care Decisions

Most older consumers are naïve shoppers in the LTC marketplace, having had few relevant experiences in their lifetime. Moreover, these decisions are often made with a crisis mentality and a sense of great time urgency. An acute event, especially one involving life-threatening illness, usually entails a hospital stay and gathering of relatives; the hospital discharge triggers the need to take quick action. Immediate concerns about finding an available service may trump more long-range considerations. Unfortunately, the initial decision may set the course for subsequent care.

Furthermore, people's wants may change with their status. At times of stress certain demands take primacy, such as survival and freedom from pain, but most persons do not operate on that level most of the time. Finally, family members, who are important play-

ers in their own right (especially if the plan depends on their labor), may emphasize wishes that differ from those of their older relatives. Older persons recovering from acute episodes are in a poor position to be consulted about their wishes or to actively shop among alternatives. Although case managers and discharge planners could act as decision facilitators, they often fail to inquire about clients' values and preferences and are unable to incorporate such preferences effectively into individual care plans.²⁵

Deciding about LTC options inevitably means addressing conflicts. Some of these conflicts are internal, related to ambivalence and mixed goals. Others may require addressing long-standing conflicts within families, when family members disagree on desirable actions. Family decisions involve consideration of what is best for both care recipients and caregivers. Yet families can persevere to the point of collapse and then press for an extreme solution to justify addressing that collapse.

Good hospital discharge decisions require separating several steps that are too often confounded. Deciding which type of care is likely to produce the best result involves knowing the benefits, risks, and costs of alternatives. It requires clarifying which outcomes are most highly prized by each patient. Once a decision about the mode of care is reached, the next issue addresses which particular provider is most suitable. Here considerations about convenience for family visitors, lifestyle, religious or other social environment, general ambience, and, perhaps most important, availability, must be considered.²⁶ Making such decisions carefully and thoughtfully requires time, structure, and information. The pressure of contemporary hospital discharges provides little opportunity for contemplative deliberation.

Dealing With Dementia

Many older persons receive LTC services because of dementia. The presence of cognitive impairment is sometimes seen as rendering an older person vulnerable and incapable of making decisions. Yet many persons with mild cognitive impairment retain the capacity to express preferences.²⁷ Thus, a major issue is when a person with dementia is so impaired as to justify a surrogate decisionmaker.

Legal surrogate arrangements tend to lead to restrictive choices for persons with dementia.²⁸ There is no way of knowing whether family surrogates, formal or informal, accurately represent the wishes of the older person with dementia. Family members' and older residents' ratings of the services of both nursing homes and assisted living facilities reveal little congruence.²⁹

Earlier we noted that the policies regarding younger persons with

cognitive impairments increasingly give them more control of their lives, whereas the policies directed at elderly persons are only slowly moving in that direction. With both young and old, counselors, consultants, or coaches have been used to help cognitively impaired clientele use cash, vouchers, or nonagency flexible service; however, such coaches for the young seem bent on determining how to realize the consumer's preferences, whereas counselors for the old are watchful lest the older person make a bad decision.³⁰ A process known variously as managed risk contracting or negotiated risk agreements has been introduced to permit informed risk taking among LTC consumers, but these vehicles are new, providers need training in their use, and their legal status is somewhat ambiguous.³¹

Assessing The Quality Of Long-Term Care For The Elderly

There are two markets for LTC services in the United States. A privately paid market has long been available for home care and has arisen in the form of assisted living to respond to changing demand. At least some assisted living offers attractive living settings, with private apartments, physical environments designed to accommodate disabilities, and an assurance that care can be provided or arranged to meet varying levels of need. The popular press has raised questions about the safety and quality of care provided in these settings.³² These reports inflame the anxiety of consumers and regulators, although studies suggest that the quality outcomes are at least comparable to those in nursing homes and that satisfaction is high.³³ The initial market enthusiasm for assisted living has attracted a wide assortment of players and the grandfathering in of extant residential care settings without the privacy and function-enhancing amenities; as a result, the term *assisted living* carries no clear definition.

Quality oversight of assisted-living facilities has thus far been a matter for individual states, some of which do little when there is no state subsidy and some of which have developed elaborate policies requiring staffing levels or prohibiting serving persons with various characteristics in assisted living. The usual state regulatory response tends to drive assisted living closer to nursing homes and away from the kinds of settings that seniors had opted for.

The publicly paid sector, the second market for LTC, has been slower than the private sector has been to embrace new forms of care. A few states have made substantial moves to use assisted living or consumer-directed home care for seniors, but it is still unclear whether these approaches can provide care at Medicaid prices. Medicaid is still viewed as a medical program. The combined cover-

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age of services and housing allotted to nursing homes (as a vestige of hospital care) is difficult to replicate in any other venue; it will only approach cost-neutrality when less professional and less agency-based forms of service are used. Under a medical model, innovation is impeded by concerns about quality, with quality defined to emphasize structural standards for staff inputs, zero tolerance for bad health outcomes (such as weight loss, bedsores, or falls), and low priority for bad quality-of-life outcomes (such as general misery). Given already serious concerns about the quality of nursing home care, some regulators and senior advocates have little enthusiasm for these newer assisted-living forms that provide even less professional staffing, rely on universal workers and nurse delegation, and seek a range of outcomes besides those related to health and safety.

Judgments about LTC quality reflect expectations. Most consumers seeking LTC want both an opportunity to live as normal and unconstrained a life as possible and a situation that will keep them functioning as well as they can. To the extent that LTC is seen as solely a compensatory mechanism that provides services to replace lost capabilities, the expectations for health and functioning will be low; quality of care is measured by the absence of untoward events. Concerns about quality of life and comfort ought to predominate. A complementary view is that good LTC can at least slow the rate of decline in physical, emotional, and social functioning. Viewed in this way, the goals related to quality of life and quality of care are compatible rather than competitive.

Most consumers assume that any licensed agency or professional must provide adequate quality or else their license will be revoked. When LTC consumers think about quality, they are more likely to assume that key elements (such as safety) exist and to stress quality of life, however vaguely it is made operational. In contrast, when providers think of quality, they often give quality of life secondary status; they seek the best quality of life that is consistent with health and safety. Perhaps the formula should be stood on its head, and the best health and safety outcomes consistent with good quality of life be sought.

Investing In Long-Term Care Improvement

Shifting the Medicaid program's emphasis toward supporting care that is more akin to assisted living, which better addresses quality of

life, would be expensive. The United States has a huge capital stock of nursing homes built on blueprints that resemble hospitals in the early Hill-Burton era. Replacing these buildings and their care systems requires a major infusion of capital. It is not clear where the money would come from or who would be willing to pay the costs of amortization of such an investment.

The power of mythology is strong. Social institutions that are believed to provide health benefits justify large infusions of technology and money, even when their actual health yield fails to match their publicity. Hence, we continue to invest heavily in futile care in the hope that at least for some it will work. In contrast, the lower expectations attached to nursing home care become self-fulfilling. Even its accomplishments are dismissed. It is not held accountable for positive accomplishments in either quality of life or quality of care, although its potential in both spheres is real.

■ **Role of government.** The perceived impotence of LTC has undermined its political power. Viewed as a necessary but unproductive social service, LTC is unlikely to be a rallying point for politicians. Unconvinced that an investment in improving it will generate social support, few have made it a political issue. Instead, entrenched forces representing established service providers lobby to hold onto and expand what has become a major industry; pressures for fundamental reform have trouble finding an audience.

The government has several possible roles in improving LTC. As a major payer for privately provided services, it has assumed a strong regulatory stance, particularly with regard to nursing homes. Were the emphasis to shift to simply providing clients with money to purchase care, the regulatory effort might be expected to diminish, falling back to only such activities as licensing and providing better market information.

Government efforts to regulate nursing homes have been in effect since shortly after they were covered under Medicare and Medicaid in the mid-1960s. Regulatory efforts became more sophisticated with the introduction of the Minimum Data Set in 1990. Although the current standards speak to several quality-of-life issues (such as dignity and respect), the emphasis has been primarily on quality of care, which has improved over the past two decades.³⁴

■ **Changing the goal of governmental nursing home spending.** At present the government spends a great deal on nursing home regulation. For fiscal year 2001 the total federal Medicare survey and certification budget was \$242,147,000. Of that amount, \$26,274,827 is for state survey agencies to survey skilled nursing facilities (SNFs) and \$125,206,139 to survey SNF/nursing homes.³⁵ The resources devoted to regulation could instead be allocated to a more market-

based approach that emphasizes information. Such an approach would require collecting enough standardized data to provide consumers with better information on which to base better-informed LTC decisions. Data on various types of care could be arrayed to show measures of quality (of care and of life), the nature of the services provided, staffing stability, and consumer satisfaction. The information could be disseminated through Web sites, but it could also be packaged to make it readily accessible to case managers.

The concept of mandatory data collection can be expanded to require better information for hospital discharge planning. Medicare's paying directly for this service would encourage discharge planners to provide more structured explorations of preferences and options. Covering additional time in a hospital or a postacute care unit would allow the opportunity for adequate consideration of these options and their implications.

What Needs To Be Done

The task of aligning LTC with consumers' preferences is complex. Nonetheless, some first steps are possible. Empowering older persons (or their agents) to play a more active role in decision making requires (1) giving them better information on what types of care are associated with which LTC outcomes, and (2) creating an environment to support good decision making.

■ **Improved information for discharge planning.** A structured approach to decision making should be employed that encourages clients to explore their most desired goals for such care, and information should be provided to assess the risks and benefits of alternative forms of care for clients with given characteristics. Decisions about the best type of LTC should be made separately from those about the best provider of a given type of care. Decision facilitators, such as discharge planners and case managers, need training in how to elicit consumers' preferences and facilitate real choices.

The Medicare program could play a crucial role in improving discharge planning by mandating standardized information, such as the unsuccessful Uniform Needs Assessment Instrument proposed a decade ago. A better-designed approach would assure that pertinent information is collected but also that structured decision making is employed. Such a process requires training discharge planners and case managers, and allowing sufficient time—that is, paying for longer inpatient stays—to grapple with the subtle and complex issues involved. Carried too far, the penchant for shortening hospital lengths-of-stay may prove to be penny-wise and pound-foolish. Hospitals will likely resist any demands for required information and structured discharge planning. Paying them would ease the

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burden. Early evidence will be needed to show that such an approach can actually produce better outcomes.

The current regulatory approach to quality improvement in LTC should shift its emphasis to utilize a market-driven approach, which would provide valid information to consumers about both the value of various types of LTC and the relative effectiveness of different vendors of a given mode of LTC. The Medicare Payment Advisory Commission (MedPAC) has already noted, for example, that any comparisons among different forms of postacute care will require a common database for both outcomes and risk adjusters.³⁶ The same principle applies to LTC. An infrastructure is slowly developing to collect such data. These data should be analyzed in more creative ways, which contrast actual and expected outcomes, and disseminated in user-friendly versions.

Better outcomes data can help to demonstrate that good LTC does make a difference and should help to improve LTC's image. Such an outcomes-focused approach could be applied equally to all types of LTC. Other relevant information would address how programs vary on characteristics that are not required by regulation (sometimes dismissed as being amenities) but that are important to consumers. Privately researched and published consumer guides exist to provide “authoritative” information on hotels and resorts, but it is impossible to get comparable information on the nature of accommodations or many other attributes of life in nursing homes and assisted-living settings. The information must be more trustworthy than provider-generated Web sites and more comprehensive and less medically focused than reports of government regulatory agencies.

It will be difficult for any private system to emerge with sufficient credibility to undertake this information task. The federal government must play a central role, but this role might be better tolerated if it were combined with eliminating (or reducing) the current regulatory burden. Perhaps public-private partnerships could be tested to develop an information base that uses public data for health outcomes information, combined with imaginative private rating systems for the hotel and living functions of the programs.

■ **Bundled payment.** Another strategy for improving hospital discharge planning would be to combine (bundle) payments for both hospital and posthospital care for those conditions that are

likely to require the latter. Hospitals would not be more motivated to involve patients more in discharge planning, but they would have incentives to choose the most effective venues. Such proposals have met with active opposition from both hospitals and postacute care providers. The former are not anxious to assume more responsibility, and the latter fear the hospitals will cherry-pick. Part of the solution may lie in finding the right price to make the option attractive and in developing means to assure that competition will be fair.

■ **Removing age-based differences.** Frail older persons should be afforded the same opportunities as are younger persons with disabilities. The approach to safety should be revised in favor of a concept of managed or negotiated risk, an idea that is gaining some currency in assisted living and other settings and is increasingly recognized in state law.

To make more informed choices about the risks involved, older consumers need better information about the magnitude of the risks they are considering. Risks can no longer be presented as dichotomous. Older persons should be able to negotiate risk contracts whereby the risks of various alternatives are made explicit and the older consumer acknowledges these risks and holds the provider harmless for them. This contract is not, however, a blanket waiver of liability for inadequate care.

Ironically, the biggest impediment to moving in this direction may be the advocates of the frail elders, who have labored hard and long to create the regulatory climate that they believe is necessary to protect their charges. A new breed of elderly advocates is needed, perhaps abetted by increased support from the community of younger adults with disabilities, which has successfully fought for more mainstream treatment.

LONG-TERM-CARE HAS NOT BEEN a strong political issue. No one seems willing to assume much risk to lobby hard for its improvement. A new belief system is needed, one that emphasizes the benefits that good LTC can bring. Some of that can come from better research, but much of it depends on better advocacy.

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