
Patient Centered Long-Term Care

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Drawing upon an individual's needs, values, and expectations to guide decision-making and care giving is integral to long-term care (LTC). Articles in this issue demonstrate that client values and preferences can be elicited and used to guide decisionmaking about LTC. Service delivery and payment features can be shaped to support the patient/consumer, as well as to support and strengthen her or his informal caregivers. Significant constraints to making LTC more client centered are also identified. Key issues relate to the availability of and methods to process information as well as pressures on provider staff that impede their ability to support clients and their families. More broadly, access to appropriate LTC services is being shaped by programmatic shifts and legal forces that may enhance or impede the ability to place patients/clients at the center of LTC.

INTRODUCTION

While a patient's desire to have a voice in determining how and where care is delivered would seem to be self evident, it has only been in recent years that interest in better understanding and incorporating the patient's perspective into actual care delivery has been at all common. But this interest is growing, and a body of work that attends to patients' desires and concerns for medical care is developing (Kravitz, 1996). Principally, this work has focused on the patient's preferences, and expectations in the context of defining and assessing

quality of care (Campen et al., 1995; Cleary and Edgman-Levitan, 1997; Kravitz, 1996). Conceptual models that posit relationships between these expectations and clinical processes and outcomes such as quality of life have been proposed (Kravitz, 1996; Wilson and Cleary, 1995). In addition, a variety of instruments that assess the quality of care from the patient's perspective have been developed (Campen et al., 1995; Cleary et al., 1991), and the use of this information to inform clinical encounters and trials, as well as to inform health policy, has been proposed (Lundberg and Wennberg, 1997; Tsevat et al., 1994).

The phrase "patient centered care" is attributable to a major Picker/Commonwealth initiative that focused on identifying the dimensions of hospital care that patients considered most important. As part of this initiative, a national survey of patients that assessed their recent hospital experiences based on these patient-identified care dimensions was conducted (Cleary et al., 1991) with the result that hospitals can now use this instrument as a way to measure and improve care.

Other studies have focused on patients' experiences in ambulatory care settings (Campen et al., 1995; Cleary et al., 1993; Kravitz, 1996). For example, Cleary and his colleagues developed a set of scales that assess the symptoms and functioning of persons with AIDS receiving primary care, and the study notes the utility of such an assessment in evaluating disease impact and potential treatments.

Although this shift in emphasis is intended to ground care provision and evaluation of that care in patients' needs and expectations, patients have been used sparingly in

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the actual development of instruments to measure care (Campen et al., 1995; Cleary and Edgman-Levitan, 1997; Gill and Feinstein, 1994). Campen et al.'s review of instruments developed to assess the quality of care from the patient's perspective identified only one instrument that offered a method for generating items (that is, single questions) that directly represent patients' views of ambulatory and home care (Campen et al., 1995). Other designers of instruments have implicitly disregarded the differences between physicians' and patients' perspectives for item generation, despite substantial evidence that a patient's perspective on quality of care differs from physicians, other providers, and policymakers.

But in the area of patients' concerns and preferences related to LTC this body of work has been notably silent. LTC, in contrast to acute care, is often intimate and personal in nature (Degenholtz, Kane, and Kivnick, 1997). By definition, LTC is provided over an extended period of time, and for some persons, over a life time, shaping one's daily life and one's opportunities for work and community participation (Kane, Kane, and Ladd, 1998). Decisions about where and from whom to receive services, how much control one might want to have over the service provision, what outcomes of care are desired, derive from values and beliefs that are quite personal. Thus, patient centered care—drawing upon an individual's needs, values, and expectations to guide decisionmaking and caregiving—is particularly integral to LTC.

Extending the concept of patient centered care to LTC service delivery requires attention to several issues. Acute care decisions and care emanate from a medical professional, ideally in consultation with the patient. Conversely, family members frequently fill pivotal roles in LTC, both in making decisions about

services, settings, and outcomes, as well as in the day-to-day provision of LTC. Due in part to the intimate and personal nature of LTC, and the often extended period of time over which it is provided, the process of caregiving—who provides the care and how that caregiver relates to the patient/client, takes on added importance (Kane et al., 1994). LTC is a blend of health and social services. As a result, goals extend beyond those related to physical and mental well being to include social and even spiritual well being (Kane, Kane, and Ladd, 1998). In particular, goals derived from social well being are gaining increasing prominence under the influence of the disability rights and independent living movement and its emphasis on independence and social integration (Harrington, et al., 1998; Kaye and Longmore, 1998; Wiener and Sullivan, 1995). This more socially-oriented model of LTC argues for an active client who makes decisions about, and often directs, the provision of LTC services. Quality of life, measured by attainment of goals such as self-sufficiency, becomes the focal point of LTC service provision. Availability of community-based LTC services is essential to supporting these broader social goals (Batavia, DeJong, and McKnew, 1991; Harrington et al., 1998; Wiener and Sullivan, 1995).

DEFINING LTC AND THOSE IN NEED

The need for LTC arises from serious functional disability associated with limitations in an individual's ability to perform various activities of daily living (ADLs) (eating, walking, bathing) or instrumental activities of daily living (IADLs) (answering the telephone, shopping, managing personal finances). Although discussions of LTC commonly evoke the image of a frail elderly person with deteriorating cognitive

abilities, the need for LTC can arise at any age. Others in need of LTC include those with severe physical disabilities who are cognitively intact, persons with AIDS, children who are chronically ill, those who are technology-dependent or otherwise disabled, children and adults with developmental disabilities, and people experiencing serious mental illness or problems of substance abuse. Nearly 58 percent of people with a disability—defined here as a limitation in activity caused by a chronic condition or impairment—are of working age; about 32 percent are elderly; and approximately 10 percent are children (Trupin and Rice, 1995).

LTC includes the provision of support or social services, and the provision of assistive devices that help a person with functional limitations to maintain independence and to cope with her or his disabling condition. Although long term populations tend to have serious functional disability in common, specific service needs are somewhat heterogeneous. For example, people with developmental disabilities often require income maintenance, habilitation (e.g., training in self care), education and vocational training—services distinct from the elderly person's need for assistance related to functional and cognitive decline. Younger people with physical disabilities typically share the need for assistance in functioning but often require a range of additional services including peer counseling, transportation, vehicle repair/modification, job development, and housing assistance (Wong and Millard, 1992).

LTC DECISIONMAKING

Those involved in decisionmaking about LTC often extend beyond the patient/client to include family members and a case manager or other professional(s). The tenets of patient centered care

argue for the needs, values and preferences of the LTC client to be central to this process, and that, to the greatest extent feasible, the patient/client be afforded the opportunity to control the decisions. Further, client centered LTC requires the availability of key services, such as personal care, that are needed to support client goals (Batavia, DeJong and McKnew, 1991; Harrington et al., 1998; Wiener and Sullivan, 1995).

Eliciting Values and Preferences

It has been demonstrated that clients are willing to describe values and express preferences (Boswell, Dawson, and Heininger, 1998; McCullough et al., 1993) and that these values and preferences vary across clients (Degenholtz, Kane, and Kivnick, 1997). McCullough and his colleagues used a mapping methodology to elicit self-reported values that respondents found to be relevant in the LTC alternatives they considered at a time when they had changed their living situation and/or had started receiving help with personal care because their capacity for self care was reduced. Thirty-six generic values were identified, relating to areas such as the environment (e.g., to be in a familiar setting) and care (e.g., to have reliable care). In a second study, elder consumers were asked to rate the importance of various choices related to the care they might need. Clients attached greater importance to certain choices related to privacy, family involvement, and freedom and safety. Clear differences in preferences were apparent across clients. For example, while the majority of clients would prefer to avoid pain by restricting activity or taking medication, between 15 and 28 percent preferred the pain to diminished activity or medication (Degenholtz, Kane, and Kivnick, 1997).

Boswell and her colleagues (1998) used small focus groups to elicit values related to quality of life from adults with spinal cord injury. All participants identified three domains related to quality of life—attitude toward life, work opportunities, and level of resources. They differed, however, in the relative importance of one domain to the others. Further, life domains were interdependent. For example, the opportunity to work was highly influenced by participants' ability to access adequate levels of resources to maintain quality attendant care.

In most instances, LTC clients can reliably articulate their values and preferences (Boswell, Dawson, and Heininger, 1998; Ju and Thomas 1987; McCullough et al., 1993; Stensman, 1985). This holds even for many with diminished cognitive capacity (Lunsky and Benson, 1997; Lehman, 1988) or severe physical disabilities (Stensman, 1985). On the other hand, for some individuals with severe disabilities, self report measures related to values are contraindicated or even impossible (Baroff, 1986) in which case family or friends may be the more appropriate source for the expression of values and preferences.

Despite an ability to attach an importance rating, LTC clients may have difficulty in prioritizing certain values. For example, a substantial number of elders stated a preference for both freedom and safety and were unable to choose one over the other in one study of preferences (Degenholtz, Kane, and Kivnick, 1997).

LTC decisionmaking typically involves the LTC client, a family member or informal caregiver, and often a professional caregiver, such as a case manager or independent living service provider. The values identified by these participants frequently differ, both in the actual content or domain, and the relative importance attached to specific values (Curtis, 1998; McCullough

et al., 1993). McCullough and colleagues' mapping of personal, familial, and professional values in LTC decisionmaking revealed that while elders' top-listed values concerned the environment (e.g., privacy, mobility), both family members and professionals valued care needs the most (e.g., to have supervision for the elder). In a study of the values attached to social integration outcomes by members of the same "transition community" (including persons with mental retardation, job coaches, and employers), Chadsey-Rusch, Linneman, and Rylance (1997) reported different values attached to outcomes of social participation, workplace acceptance, and personal acceptance by members of the transition community. For example, persons with mental retardation rated the workplace acceptance outcome of higher importance than did their job coach.

In this issue, Kane, Rockwood, Finch, and Philip (1997) report the findings from a comparison between ratings by elder consumers and ratings given by experts of functional status, a key outcome related to LTC. Unlike the previous two studies, these ratings were performed independently, in that the consumers and professionals were not known to each other and were not involved in any shared decisionmaking. This study revealed that elderly clients viewed a dependency in IADLs as a more significant loss than did experts, whereas experts were more concerned with a decline in ADLs.

Negotiating Conflicts

At the heart of individual values and preferences in LTC lies the issue of outcomes of care, particularly as it relates to quality of life. And it is around quality of life issues that conflicts most often emerge in the decisionmaking process. For example, Wong and Millard (1992) examined ethical

dilemmas encountered by independent living service providers. The three most frequently encountered ethical dilemmas encountered by these providers involved conflict between the ethical principles of autonomy and beneficence (e.g., supporting a consumer's own choice of services conflicts with providing services that can increase the consumer's potential). When asked to rate 38 ethical dilemmas in terms of the importance to receive training, 75 percent of independent living service providers rated all 38 dilemmas as somewhat important or higher in terms of receiving training. The four most highly cited ethical dilemmas for which training was desired involved underlying themes of respecting consumer choice conflicting with maximizing consumer potential, safety, or financial security (Wong and Millard, 1992). Similarly, in a study exploring staff's knowledge of factors that reflect central functions of supported community living programs for people with developmental disabilities, Balcazar et al. (1998) found staff to be least knowledgeable about encouraging the people they serve to make choices. He attributed this in part to value conflicts (e.g., safety concerns overriding the dignity of making choices).

The necessity of negotiating conflicts around clients' rights to make informed choices regarding their lifestyles was an ongoing issue in the Community Supported Living Arrangements (CSLA) program discussed by Brown, Lakin, and Burwell in this issue. Efforts to establish a balance between participants' freedom to make choices and the responsibility to protect and monitor consumers' health and well being extended beyond participants with developmental disabilities, their family and direct service providers to those with regulatory oversight. The actual "balances" struck varied substantially from

State to State. Those States who appeared to adjust more readily to the acceptance of risk inherent in supported living were those with demonstrated leadership and commitment to the philosophy of supported living. They then translated this commitment into more flexible and individualized monitoring and provided training related to supported living values.

Hospital discharge is a key decision point for many individuals in need of LTC. Pottoff, Kane, and Franco's review of the state of current discharge planning in this issue notes that the conflicts that frequently arise between patients, their families and discharge planners are often framed as decisions related to alternative types of services (nursing home care versus home care, for example) rather than as a discussion of values underlying those service preferences. They identify a key role of the discharge planner to be assisting patients and family members in identifying, discussing, and resolving or negotiating those underlying values and preferences.

If one argues that clients should be the ultimate decisionmakers, how should one resolve the inevitable conflict between clients, family, and providers? Are there instances when consumer preferences cannot be followed (President's Commission for the Study of Ethical Problems in Medical and Behavioral Research, 1982)? For those incapable of self-report, when is it appropriate to rely on family or friends and what can family or friends meaningfully evaluate (Kane, Kane, and Ladd, 1998)? How can family and provider staff be encouraged to honor conflicting values when it appears reasonable to do so? What response is appropriate from a regulatory agency in face of "poor" outcomes that may occur when client autonomy is honored? These and other issues were faced daily in the CSLA program (Brown, Lakin, and

Burwell, 1997) and will certainly continue to surface as clients gain greater opportunity for choice and control.

Constraints on Decisionmaking

Decisionmaking may be as impacted by insufficient time in which to make a decision as by inadequate information about LTC options. For many of the elderly, changes are precipitated by a crisis, when a serious illness or injury necessitates the search for an immediate solution. Such a crisis-oriented style is not conducive to a thoughtful consideration of preferences for LTC. Malony and her colleagues (1996) found that crisis-oriented decisionmaking for elderly clients in need of LTC tended to lead to nursing home placement. The search for the nursing home itself tended to be cursory and limited, and with little input from the elderly person. Relatives recalled the experience as extremely stressful as they tried to understand options, locate vacancies, understand financing options, negotiate medical and social service systems, and make the right choice. The impact of limited time and inadequate information was the elimination of home- and community-based care from consideration. Constraints imposed by time pressures, stress, and insufficient information are likewise highlighted by Pottoff, Kane, and Franco's review of discharge planning. Further, much of discharge planners' time was consumed by assessing the patient's financial resources and developing service options that were financially feasible.

ENHANCING ACCESS

Respecting clients' values and preferences regarding LTC requires the availability of services to support those values. For example, the value of social integra-

tion, including such essential activities as "living in the community, working in mainstream jobs, receiving education in regular classrooms with non-disabled students, attending cultural and social events, maintaining a network of friends, and engaging in other leisure activities" (Kaye and Longmore, 1998) depends on access to services to support community-based living.

Access to community-based LTC services such as personal assistance services may be quite limited under private insurance (DeJong et al., 1989). Significant disparities exist across States in the availability of publicly funded community-based care and within States, between different disability subgroups (Braddock, 1992; Harrington et al., 1998; Ladd et al., 1995; Miller, Harrington, and Mauser, 1995). For example, Braddock (1992) studied the growth of community mental retardation spending relative to mental health spending in the 1980s, noting that community mental retardation spending grew nearly four times as rapidly as did community mental health spending during that period. While spending on mental retardation services was influenced by State level civil rights activities and consumer advocacy, these factors demonstrated little influence on community mental health spending growth. Ladd et al. (1995) noted that only 10 States have made substantial progress in developing home- and community-based services for elderly individuals.

Several of the articles in this issue describe programs intended to enhance access to publicly funded, community-based LTC services and increase the flexibility with which LTC services are provided. The congressionally mandated Medicare Alzheimer's Disease Demonstration had at its heart the provision of case management services to both persons with dementia and their caregivers and an expanded array of Medicare-funded community-

based LTC services (Yordi, DuNah, Bostrom et al., 1997). Under the CSLA program, States could provide an array of LTC services not currently available in their State, such as personal assistance services and transportation. Participants had access to more flexible funding mechanisms, such as vouchers and individually controlled budgets, to obtain those services (Brown, Lakin, and Burwell, 1997).

The Cash and Counseling Demonstration expands this flexibility by providing consumers the option of cash to purchase personal care and other LTC services. A question of ongoing interest is how many consumers, when presented with a cash option, will elect to use it to purchase services? Are there key differences, such as age, that will predict who will elect cash? The study of consumer preferences described by Simon-Rusinowitz, Mahoney, Desmond, Shoop, Squillace, and Fay in this issue highlights demographic and attitudinal differences. For example, a consumer's desire to be more involved in determining the amount and type of services received was a strong predictor of preferring cash, as was a consumer's willingness to perform employer tasks needed to self direct care.

PROCESS OF CAREGIVING

The caregiving process takes on added meaning in patient centered LTC. Given the personal nature of the care and its ongoing provision, who the caregiver is, his or her caregiving skills, and the relationship between the caregiver and client have repeatedly been voiced as important in evaluating the quality of LTC (Kane et al., 1994). For example, in a series of focus groups conducted with home care consumers, consumer representatives, home care providers, paraprofessional personnel, payers and regulators, consumers

clearly stated a preference for "enabling" process measures over structural and outcome measures when evaluating the quality of home care. Enabling criteria included such care aspects as worker tardiness, no shows or early departures, and the home care user having insufficient control over selection, training, job definition, supervision, and firing of home attendant (Kane et al., 1994).

One impact of the disability rights and independent living movement on LTC has been to focus attention on the caregiving process through the movement's advocacy of a consumer directed model of care. Under this model, the person with a disability is an active participant who recruits, selects, manages, and directs his or her provider of services, known as a personal assistant. The person with a disability is an active consumer to whom the personal assistant is accountable. Often the personal assistance provider is not trained and not supervised by a nurse or other trained professional.

Some recent work suggests that increased consumer choice and control of LTC services is related to increased consumer satisfaction (Doty, Kasper, and Litvak, 1996; Benjamin et al., 1998), empowerment, quality of life (Benjamin et al., 1998) and productivity (DeJong, 1998). A central feature of the Cash and Counseling Demonstration described in this issue is to enhance consumer choice and control through the use of cash to purchase services, and to then examine effects of this option on client satisfaction and quality of care, costs, and its impact on formal and informal care giving (Simon-Rusinowitz et al., 1997).

Although this discussion has focused on formal (paid) LTC services, most LTC is provided on an informal basis by family and friends. Most people who need LTC are living in the community; only 18 percent

receive institutional care (U.S. Bureau of the Census, 1990). Among people with functional disabilities who live in the community, roughly 90 percent receive some informal help, whereas 67 percent depend solely on help from family and friends, which is often provided at significant emotional and financial cost (Smith, 1997). As previously noted, the Medicare Alzheimer's Disease Demonstration provided case management and expanded community-based services to both Medicare beneficiaries with dementia and their caregivers, in part to assist caregiver efforts to maintain community residence for the participant with dementia. In their article, Yordi, DuNah, Bostrom, Fox, Wilkinson, and Newcomer describe the impact of these expanded community services, including a variety of caregiver support services, on caregiver burden. They note significant reductions in caregiver need over a 3-year period, relative to caregivers in the control group, while caregiver informal assistance with ADL/IADL tasks declined significantly less over time for demonstration participants, relative to the control group.

SUMMARY

Patient centered care—drawing upon an individual's needs, values, and expectations to guide decisionmaking and caregiving—is integral to LTC. Articles in this issue demonstrate that client values and preferences can be elicited and that these can be used to guide decisionmaking about LTC. Service delivery and payment features can be shaped to support the patient/consumer and to support and strengthen her or his informal caregivers. Yet significant constraints to this process are apparent. For clients with the capacity to make decisions, the needed information about options and methods to process this infor-

mation in a systematic, thoughtful way, may not be available. Not all clients can directly provide information regarding their values. Thus, learning how to appropriately involve family members and other surrogates is required. Pressures on provider staff that impede their ability to support clients and their families are substantial, and are increasing, in light of market changes. A long standing concern is the availability of services to support clients' LTC preferences; the structure of this service market, and access to LTC in it, is being shaped by programmatic shifts and legal forces at the local, State and Federal level. Arguably, placing patients/clients at the center of LTC requires a sustained, focused effort to attend to these issues.

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