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 decision making 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
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 lifetime, 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 heterogenous. 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 elder 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 Potoff, 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 integration, 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 pro-
gram, 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 con-
sumers the option of cash to purchase per-
sonal care and other LTC services. A ques-
tion of ongoing interest is how many con-
sumers, when presented with a cash
option, will elect to use it to purchase ser-
vices? 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 atti-
dudinal differences. For example, a con-
sumer’s desire to be more involved in
determining the amount and type of ser-
vices received was a strong predictor of
preferring cash, as was a consumer’s will-
ingness 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 rela-
tionship 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 con-
sumers, consumer representatives, home
care providers, paraprofessional person-
nel, payers and regulators, consumers
clearly stated a preference for “enabling”
process measures over structural and out-
come measures when evaluating the qual-
ity 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, supervi-
sion, 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 dis-
ability 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 per-
sonal assistance provider is not trained and not
supervised by a nurse or other trained pro-
fessional.

Some recent work suggests that
increased consumer choice and control of
LTC services is related to increased con-
sumer 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 Coun-
seling Demonstration described in
this issue is to enhance consumer choice
and control through the use of cash to pur-
chase 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 com-
munity, 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 pro-
vided 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 ser-
vice, including a variety of caregiver sup-
port services, on caregiver burden. They
note significant reductions in caregiver
need over a 3-year period, relative to care-
givers in the control group, while caregiver
informal assistance with ADL/IADL tasks
decayed significantly less over time for
demonstration participants, relative to the
control group.

SUMMARY

Patient centered care—drawing upon an
individual's needs, values, and expecta-
tions 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/con-
sumer 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 deci-
sions, 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 appro-
priately involve family members and other
surrogates is required. Pressures on
provider staff that impede their ability to
support clients and their families are sub-
stantial, and are increasing, in light of mar-
ket 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.

REFERENCES

Balcazar, F., MacKay-Murphy, M., Keys, C., et al.: Assessing Perceived Agency Adherence to the
Values of Community Inclusion: Implications for
Staff Satisfaction. American Journal on Mental
Retardation 102(5): 451-463, 1997.
Baroff, G.S.: Maximal Adaptive Competency.
Mental Retardation 24:367-368, 1986.
Batavia, A.I., DeJong, G., and McKnew, L.B.: Toward a National Personal Assistance Program: The Independent Living Model of Long-Term Care
for Persons with Disabilities. Journal of Health
Politics, Policy and Law 16(3):523-552, 1991.
Benjamin, A.E., Matthias, R.E., Franke, T., et al.: Who's in Charge? Who Gets Paid? A Study of Models
for Organizing Supportive Services at Home. Final
Report to the Assistant Secretary for Planning and
Evaluation. Los Angeles, CA. School of Public
Policy and Social Research, University of California
Los Angeles, 1998.
Boswell, B.B., Dawson, M., and Heininger, E.: Quality of Life as Defined by Adults with Spinal
Cord Injuries. Journal of Rehabilitation 19(1):27-32,
1998.
Braddock, D.: Community Mental Health and
Mental Retardation Services in the United States: A
Comparative Study of Resource Allocation.
American Journal of Psychiatry 149(2):175-183,
1992.
Brown, S.L., Lakin, K.C. and Burwell, B.O.: Beneficiary-Centered Care in Services to Persons With Developmental Disabilities. *Health Care Financing Review* 19(2):23-46 1997.

Campen, C.V., Sixma, H., Friele, R.D., et al.: Quality of Care and Patient Satisfaction: A Review of Measuring Instruments. *Medical Care Research and Review* 52(1):109-133, 1996.

Chadsey-Rusch, J., Linneman, D., and Rylance, B.J.: Beliefs About Social Integration From the Perspectives of Persons With Mental Retardation, Job Coaches, and Employers. *American Journal on Retardation* 102(1):1-12, 1997.

Cleary, P.D. and Edgman-Levitan, S.: Health Care Quality. Incorporating Consumer Perspectives. *JAMA* 278(19):1608-1612, 1997.

Cleary, P.D., Edgman-Levitan, S., Roberts, et al.: Patients Evaluate Their Hospital Care: A National Survey. *Health Affairs* 19(4):254-267, 1991.

Cleary, P.D., Fowler, F.J., Weissman, J., et al.: Health-Related Quality of Life in Persons with Acquired Immunodeficiency Syndrome. *Medical Care* 31(7):569-580, 1993.

Curtis, R.S.: Values and Valuing in Rehabilitation. *Journal of Rehabilitation* 19(1):42-47, 1998.

Degenholtz, H., Kane, R.A., and Kivnick, H.Q.: Care-Related Preferences and Values of Elderly LTC Consumers: Can Case Managers Learn What’s Important to Clients? *The Gerontologist* 37(6):767-776, 1997.

Defong, G., Batavia, A.I. and Griss, R.: America’s Neglected Health Minority: Working-Age Persons with Disabilities. *Milbank Quarterly* 67(Supplement 2, Part 2):311-351, 1989.

Doty, P., Kasper, J., and Litvak, S.: Consumer-Directed Models of Personal Care: Lessons from Medicaid. *Milbank Memorial Fund* 74(3):377-409, 1996.

Fabian, E.S.: Using Quality-of-Life Indicators in Rehabilitation Program Evaluation. *Rehabilitation Counseling Bulletin* 34(4):344-356, 1991.

Gill, T.M. and Feinstein, A.R.: A Critical Appraisal of the Quality-of-Life Measurements. *JAMA* 272(8):619-626, 1994.

Harrington, C., LaPlante, M., Newcomer, R.J., et al.: A Review of Federal Statutes and Regulations for Personal Care and Home and Community Based Services. A Final Report. Final Report to the Health Care Financing Administration. San Francisco, CA. Department of Social & Behavioral Sciences, University of San Francisco, California, 1998.

Ju, J.J. and Thomas, K.R.: The Accuracy of Counselor Perceptions of Client Work Values and Client Satisfaction. *Rehabilitation Counseling Bulletin* March:157-166, 1987.

Kane, R.A., Kane, R.L., Illston, L.H. and Eustis, N.N.: Perspectives on Home Care Quality. *Health Care Financing Review* 16(1):69-89, 1994.

Kane, R.L., Kane, R.A. and Ladd, R. The Heart of Long-Term Care. Oxford University Press, 1998.

Kane, R.L., Rockwell, T., Finch, M. And Philip, A.: Consumer and Professional Ratings of the Importance of Functional Status Components. *Health Care Financing Review* 19(2):11-22 1997.

Kaye, H.S. and Longmore, P.K. Disability Watch: The Status of People with Disabilities in the United States. Report. San Francisco, CA. Disabilities Rights, Inc. Cited in Harrington, et al., 1998.

Kravitz, R.L.: Patients’ Expectations for Medical Care: An Expanded Formulation Based on Review of the Literature. *Medical Care Research and Review* 53(1):3-27, 1996.

Ladd, R.C., Kane, R.L., Kane, R.A. and Nielson, W.: *State LTC Profiles Report*. Minneapolis, MN. School of Public Health, University of Minnesota, 1995.

Lehman, A.F.: A Quality of Life Interview for the Chronically Mentally Ill. *Evaluation and Program Planning* 11:51-62, 1988.

Lundberg, G.D. and Wennberg, J.E.: A JAMA Theme Issue on Quality of Care. A New Proposal and a Call to Action. *JAMA* 278(19):1615-1616, 1997.

Lusky, Y. and Benson, B.A.: Reliability of Ratings of Consumers with Mental Retardation and Their Staff on Multiple Measures of Social Support. *American Journal on Mental Retardation* 102(3):280-284, 1997.

Maloney, S.K., Finn, J., Bloom, D.L. and Andresen, J.: Personal Decisionmaking Styles and Long-Term Care Choices. *Health Care Financing Review* 18(1):141-155, 1996.

McCullough, L.B., Wilson, N.L., Teasdale, T.A., et al.: Mapping Personal, Familial, and Professional Values in Long-Term Care Decisions. *The Gerontologist* 33(3):324-332, 1993.

Miller, N.A., Harrington, C., and Mauser, E.: Explaining Variation in Medicaid Community Based Long Term Care Expenditures: 1987-1993. Paper presented at the American Public Health Association Annual Meeting, San Diego, CA, 1995.

Potthoff, S., Kane, R.L and Franco, S.J.: Improving Hospital Discharge Planning for Elderly Patients. *Health Care Financing Review* 19(2):47-72 1997.
President's Commission for the Study of Ethical Problems in Medical and Behavioral Research, 1982. The Values Underlying Informed Consent. In McKenzie, N.E. (Ed.) The Crisis in Health Care. Ethical Issues. New York, NY, Penguin Group, 1990.

Simon-Rusinowitz, L., Mahoney, K.J., Desmond, S.M., et al.: Determining Consumer Preferences for a Cash Option: Arkansas Survey Results. Health Care Financing Administration 19(2):73-96 1997.

Stensman, R.: Severely Mobility Disabled People Assess the Quality of their Lives. Scandinavian Journal of Rehabilitation Medicine 17:87-99, 1985.

Trupin, L and Rice, D.P. Health Status, Medical Care Use, and the Number of Disabling Conditions in the United States. Disability Statistics Abstract (9). National Institute on Disability and Rehabilitation Research, 1995.

Tsevat, J., Weeks, J.C., Guadagnoli, E., et al.: Using Health-related Quality-of-life Information. Clinical Encounters, Clinical Trials, and Health Policy. Journal of General Internal Medicine 9:576-582, 1994.

U.S. Bureau of the Census: Survey of Income Program Participation. Washington, DC, U.S. Government Printing Office, 1990.

Wiener, J.M. and Sullivan, C.M.: Long Term Care for the Younger Population: A Policy Synthesis. In Wiener, J.M., Clauser, S.B. and Kennell, D.L. (Eds.) Persons with Disabilities. Issues in Health Care Financing and Service Delivery. Washington, DC. The Brookings Institution, 1995.

Wilson, I.B. and Cleary, P.D.: Linking Clinical Variables with Health-Related Quality of Life. JAMA 273(1):59-65, 1995.

Wong, H.D. and Millard, R.P.: Ethical Dilemmas Encountered by Independent Living Service Providers. Journal of Rehabilitation 13(4):10-15, 1992.

Yordi, C., DuNah, R., Bostrom, A., et al.: Caregiver Supports: Outcomes From the Medicare Alzheimer's Disease Demonstration. Health Care Financing Review 19(2):97-117 1997.

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