Community Long-Term Care Services: What Works and What Doesn't?

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To establish a context, long-term care (LTC) can be provided either through institutions or in the community; can include both formal (i.e., generally paid and often specialized) and informal (i.e., generally unpaid and often unspecialized) care; and that formal care can have either public or private funding. Within this context, a fundamental conceptual structure for addressing the topic of what works and what does not in formal community long-term care (CLTC) might be reduced to four components:

- Who gets something?
- What do they get?
- Who pays?
- What impact does it have?

Concerning who receives formal CLTC, we often have two subgroups. The first subgroup of formal CLTC users comprises those who are certified by their state officials as functionally eligible for institutional LTC. These users are often assumed to represent a type of substitution of home- and community-based services for traditional nursing home care. This assumption of substitution persists, although for at least 25 years it has been documented that there are two or three older people with the same configuration of needs and disablements living in the community for every one person residing in a nursing home (Branch, 1976, 1977, 1980), and gerontological researchers have yet to understand clearly why the one person enters the nursing home and the other two or three do not. Those CLTC users who meet nursing home admission requirements may not represent substitution at all.

The second subgroup of CLTC users comprises those whose frailty is substantial but not severe enough to qualify for state-funded nursing home care. The second subgroup is actually expanding the continuum of LTC clients.

The clients of CLTC have not always behaved predictably, however. There have been more than a few examples where the potential clients of an innovative CLTC demonstration simply declined to enroll. In some of these instances, the potential CLTC client had been approved by the intake worker as appropriate for the innovative program based on their frailty, there was no out-of-pocket payment required of the client, and yet the client declined to enroll. Why? Why are clients declining to participate in some of our alternative CLTC programs? Solving this riddle should help gerontological researchers to understand better who the clients of CLTC are and whom they should be.

Concerning the second issue, what do CLTC clients receive as services, the short answer is that across all the communities they receive a full continuum of care, but within specific communities there are often gaps in the continuum of care. A continuum of care generally includes acute medical services (e.g., inpatient care, outpatient care, emergency care, primary care, specialty care, rehabilitative care, and skilled therapies at home), long-term care services (e.g., institutional nursing home care, community adult day treatment centers, respite care, community nutrition sites, community recreational and educational senior centers, home-delivered meals, home health aids, homemaker care, personal care attendants for assistance with activities of daily living [ADLs] and instrumental activities of daily living [IADLs], and various opportunities for socialization), housing services (assisted living options, board-and-care options, senior independent living options, and subsidized housing). Evashwick (2000) has written an excellent and expanded perspective on the continuum of care.

An issue related to understanding these components in the continuum of CLTC is understanding who provides such care—formal sources or informal sources. In general, about three out of four frail community-dwelling elders rely solely on informal sources (e.g., family and friends) for support, while most of the others rely on a combination of family care and paid assistance (Liu, Manton, & Liu, 1985). In trying to meet unmet needs for CLTC, most would agree that the policy goal should be to encourage formal sources to complement informal sources, not substitute for them. Agreement on the implementation of this policy goal has been elusive, however.

What are the weak links in the continuum of care? A lack of structure to facilitate a seamless continuum of care, a lack of information readily available to potential...

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users of CLTC and their informal support network to construct their own continuum, and a lack of professional support to construct and/or manage a continuum of services as appropriate. If a person is frail enough to need a variety of these CLTC services, then he or she is probably too frail to overcome a structure that is not user friendly, too frail to find difficult-to-obtain information, and too frail to manage and coordinate the components of their care effectively.

Concerning the third issue, who pays for CLTC services, the old stalwarts of Medicare and Medicaid are the primary sources of public moneys for CLTC. A recent summary of expenditures for formal LTC during 2000 indicated that Medicaid paid about 40% of all bills, Medicare about 20% (with half going to nursing homes and half going to home care), and out-of-pocket payments accounting for most of the remaining 40%, with some augmentation by state general funds in some cases (e.g., Maine, Massachusetts, and New York). The problem, of course, is that Medicare was established to pay for hospital and hospital-related care for its beneficiaries, and while over time there have been some inclusions of institutional and community LTC as covered services, it only pays for about 20% of such services. Medicaid, on the other hand, was established with the broader mandate to pay for all health care of its beneficiaries, but its beneficiaries are limited to those in poverty as defined by their state of residence. Certainly many older people are also poor by the Medicaid criteria of their state, but the tragedy is that they often had to spend down their income and assets by paying out of pocket for health care in order to become eligible for Medicaid. The implication of both the limited Medicare coverage and the requirement for impoverishment to receive Medicaid services is that much of the CLTC is paid out of pocket by the user and/or provided by the informal (and generally unpaid) support system.

Concerning the fourth issue, what impact does it have, it is worth remembering that the desired outcomes of CLTC vary widely. In the more traditional fields of clinical epidemiology, health services outcomes research, and cost-effectiveness research, the traditional outcomes of mortality, morbidity, and costs predominate. For CLTC, I suggest that there are at least eight appropriate outcomes to monitor and use as the basis for quality assurance. Borrowing on previous work by Lohr (1988), these are:

- **Death**—First make sure that no unnecessary serious harm is occurring.
- **Disease**—Primary, secondary, and tertiary prevention of diseases is essential; secondary prevention would include optimal control of chronic conditions such as diabetes or hypertension.
- **Dollars**—Everything else equal, the treatment or services should not cost more than traditional alternatives (but I would contend that an alternative of not providing any services or treatment is not acceptable).
- **Disability**—The physical function of the CLTC client is extremely important; sometimes just slowing an expected downward trajectory is a favorable outcome.
- **Depression**—The emotional function of the CLTC client is also extremely important, and emotional dysfunction may have atypical presentation in older CLTC clients.
- **Disorientation**—The client’s cognitive function can be the primary concern of some CLTC programs, and its importance should be recognized.
- **Discomfort**—The pain that a CLTC client endures can be both an important outcome and an indicator of quality care.
- **Dissatisfaction**—The client is the ultimate consumer, and consumer satisfaction is a legitimate outcome in CLTC (albeit extremely difficult to measure reliably and validly); a surrogate indicator of dissatisfaction may be disenrollment, which represents an extreme expression of dissatisfaction; the satisfaction of the CLTC client’s family can also be as important as the satisfaction of the client.

Each of these domains represents an important outcome in CLTC, and therefore can serve as the basis for monitoring the quality of CLTC services. But who should do the monitoring — the person paying the bills for the services or the person receiving the service? In the simpler model of most consumer transactions in a market economy, the payer and the receiver of services are the same person, and that person monitors quality with backup assistance from consumer protection agencies on rare occasions. In the CLTC model (and with most of health care in general), the payer and the receiver of services are two different entities, and so the question of who should do the monitoring is not always obvious. For outcomes like satisfaction and pain, it is obvious that the recipient of services has to be involved in if not in charge of these components of quality assurance. Other outcomes may not be as clear, but ignoring quality assurance is not an appropriate option.

In summary, knowing what works and what does not in community long-term care can be facilitated by having a structure to guide the innovations and the evaluations.

**References**


