Editorial

Humanity in long-term care

Ethical, clinical, and social challenges

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There are many challenges in providing good-quality health and social service care to the aging Canadian population, especially to frail and cognitively impaired elderly people. Despite the best efforts of families and professionals to assist elderly people in the community, the need for facility-based long-term care (LTC) is a big challenge. Remaining in the community "at all costs" is a laudable goal, but for many elderly people, admission to an LTC facility is appropriate.

Long-term care: for whom and by whom?

The Canadian LTC system has evolved to care for older people who can no longer remain at home. How do we ensure that the system and its professional staff meet the needs of those it serves? Important concerns in any LTC evaluation include issues related to clients, their families, health care professionals, and the health care system in general. Important value-related questions to be considered include how to achieve high-quality clinical care; how to fulfil our social roles and goals as a caring society; how to meet societal needs in an economical way; and how to provide ethically sound care.

Ethics-based principles, as outlined by Beauchamp and Childress, can be used to help examine the ethical challenges in LTC.[1,2] These principles are beneficence, autonomy, nonmaleficence, and justice. The context of consideration includes psychosocial issues, system resource and provision issues, and professional quality-of-care issues.

Why reside in an LTC facility?

Does anyone ever say, "Please put me in a nursing home"? What motivates elderly people or their families to consider such a move? Long-term care is usually required when community living is not possible because of increased medical needs, safety issues, or a general decline in health. People are usually placed in LTC because their families cannot cope with daily care, despite their best efforts, or when family members do not live close enough to provide the required care.[3,4] Many families experience enormous guilt when making such a decision, even when the need is clear. A range of alternatives needs to be available to provide facility-based LTC that recognizes clinical, psychosocial, and personal needs and preferences.[5]

Ethical issues are connected to the LTC admission process. Autonomy issues include who decides when someone requires LTC, how do they decide, how are conflicts in the decision-making process resolved, and what is the role of mental capacity?[6] From the ethical perspective of beneficence, what is the "good" that we want for the elderly person? From the perspective of nonmaleficence, what are the potential harms, and how do we mitigate them? Finally, from the perspective of justice, how do we organize the LTC system so that resources are shared in an equitable and sustainable way? For example, what is the ethical perspective of a situation where a surrogate arranges for alternative living options, based on the preferences of her aging relative, when LTC is recommended? We need to balance autonomy, nonmaleficence, and justice; essentially, unless the risk to the elderly person or others is great, the decision of the elderly person,

as personally voiced or through his or her surrogate, should be respected.

Supporting the decision

Helping a person and family accept the need for LTC is complex and involves the prospective resident, family, and facility staff. Try to avoid urgent and sudden decisions; the most problem-filled transfers are from general hospitals to LTC facilities. Staff and family should attempt to engage the prospective resident. Discussions among family members are important when LTC is not an immediate need and when promises, such as, "Mom, we will never put you in a nursing home," are impossible to fulfil.

It is useful to get help from experts in the field, such as community workers, social workers, social agencies, community care access centres, and external consultants. Primary care physicians and geriatricians can be important resources, building on the trust of doctor-patient relationships. Once a person is admitted, family members should provide support through frequent visits and by choosing an emissary to help with transition and care decisions.[7] In general, LTC staff appreciate caring families and learn who can assist in defining a resident's personal profile and preferences.

Why choose LTC as a professional career?

A great challenge in LTC is finding qualified and committed professional staff. In health care, acute care is at the top and LTC near the bottom of the popularity hierarchy. Professionals appear to choose LTC either because they "love it" or they have no choice due to abilities, training, job opportunities, or geography. Those who love it are very important; those who "learn to like it" are key to successful programs, and those who have no choice end up resenting LTC and causing problems. The challenge for the LTC field is to nurture those who love it and turn them into role models and leaders and to find those who learn to like it and build on their discovery.[8] For those who resent the work, the only option is to help them find alternative work because they could undermine the quality of care and the commitment of others.

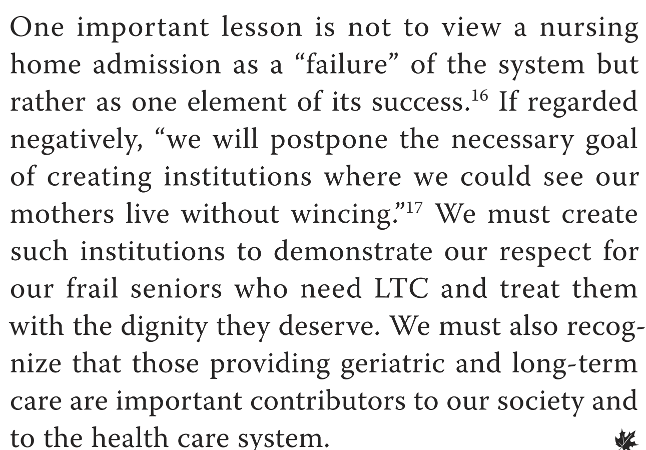
The challenge is to nurture young medical trainees into LTC. Conventional medical training is often counter-productive in achieving this goal. For the most part, training occurs in general hospitals (more recently in ambulatory care and LTC); training and mentoring in approaches to aging, frailty, and chronic disease is inadequate.[9] The classic book The House of God highlights the negative experience of emergency-room LTC patients; they are often anonymous, are unable to communicate, have a poor long-term prognosis, and usually have no committed advocates. Many physicians have difficulty valuing LTC patients, and acute care physicians often lack an appreciation of the "big picture" or a sense of a patient's personhood and place in his or her family or community.

Special challenges in LTC

The challenges in LTC include the enormous and complex demands for individualized care, and general understaffing, including physicians who are only periodically available, few full-time nurses, and limited rehabilitation and recreational staff.[10] There are multifaceted medical problems, complex pharmacotherapy with a tendency to therapeutic nihilism, and severe behavioural issues that result in psychotropic medication therapy with its associated benefits and problems.[11-13] There are psychosocial and ethical implications of the high prevalence of dementia and the need for surrogate decision makers where "expressed wishes" and "best interests" standards are uncertain.[14] Many end-of-life decisions entail areas of potential conflict, such as nutrition and hydration, cardiopulmonary resuscitation, "quality of life," and equitable resource allocation.[15] Clinical staff are often disturbed by concepts such as "aging in place"; by the idea of sanctity of life for those with strong religious convictions; by conflict between surrogates, resident, and staff over decisions; and by patients' behaviour, including expressions of sexuality.

What kind of LTC system?

In Canada, we have a mix of private, public, and not-for-profit facilities. We must examine the LTC system and determine whom it should serve and its philosophy of care within the health care system. Currently, despite payments that often provide standard per-diem payments for resident care, it is difficult to determine appropriate "standards of care." Part of the problem might result from chronic underfunding and the difficulty in attracting adequate and well trained staff. The challenge is to better define standards and to maintain realistic expectations. We must determine the correct mix and relationships of staff and find ways to recruit and retain those who are qualified and dedicated.



Not a failure

One important lesson is not to view a nursing home admission as a "failure" of the system but rather as one element of its success.[16] If regarded negatively, "we will postpone the necessary goal of creating institutions where we could see our mothers live without wincing."[17] We must create such institutions to demonstrate our respect for our frail seniors who need LTC and treat them with the dignity they deserve. We must also recognize that those providing geriatric and long-term care are important contributors to our society and to the health care system.

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