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Original Study

Attitudes Toward Death, Dying, End-of-Life Palliative Care, and Interdisciplinary Practice in Long Term Care Workers

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A B S T R A C T

Background: Besides personal and professional experiences, long term care providers' own attitudes toward death may affect the care given to dying residents.
Objectives: To assess beliefs, values, and attitudes toward death, dying, palliative, and interdisciplinary care in long term care workers and identify any differences between different job categories and places of work.
Design: Descriptive cross-sectional survey study.
Setting: Five public long term care facilities.
Participants: One thousand one hundred seventy volunteers, clinical managers, and all categories of residential long term care workers.
Measurements and Methods: An anonymous paper or electronic self-administered survey questionnaire consisting of 24 items, answered on a 4-point bipolar Likert scale. Between-group differences were compared with the analysis of variance test after adjustment for the multiple post-hoc comparisons.
Results: Healthcare workers had a relatively positive attitude toward more than one-half of the selected aspects of interdisciplinary practice and end-of-life palliative care for long-term residents. However, attitudes were more mixed about 10 other aspects and a higher percentage of respondents indicated negative attitudes toward them. Overall, there are significant differences between upper-level professionals and managers (registered nurses, physicians, rehabilitation staff, and clinical managers) vs the hands-on caregivers (nursing assistants, patient assistants, and volunteers) with regard to some aspects of the care of the dying.
Conclusions: The results suggest that healthcare workers' attitudes need to be taken into account in long term care facilities. Patient assistants, volunteers, and nursing assistants seem most likely to above all benefit from training and support programs.

In Quebec, as elsewhere in the world, demographic aging and societal changes that lead to decreased co-residence of elderly with their families will increase demand on long term care (LTC) facilities.[1] Nursing homes and LTC facilities often represent the last place people will live before they die.[2,3] About one-third of residents die each year in these settings.[4,5]

Many guidelines and policies from developed countries recommend the implementation of end-of-life palliative care to provide quality of life for patients and families, achieved through an interdisciplinary approach.[6–9] Work-related continuing education and training opportunities are also recommended to everyone involved in

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health and social care.[10,11] Palliative care is not restricted to special places. Ideally, this care should be available to people where appropriate, which may range from the person's home to specialized hospices.[8,12] Nursing homes and LTC residents have multiple, chronic conditions, such as dementia or Alzheimer's. These individuals should also benefit from palliative care.[3,13–15]

Unfortunately, the approaches to end-of-life palliative care are generally absent or poorly developed in these settings,[2,4] the services being given by the usual care teams having received no special training. Endeavours to design, test, and implement such a palliative care or training program to the particular needs of LTC residents and their families are still in their early stages. Since 2008, the University Institute of Geriatrics of Montreal has established an interprofessional training program on end-of-life palliative care in LTC facilities, to train those who will in turn teach others in their own institution.[16]

Effective end-of-life palliative care requires long term care staff to readjust their focus and acquire skills and knowledge beyond those attainable through books or school instruction alone.[17] Palliative care practice and education is not just a matter of knowledge but also attitudes. It is acknowledged that attitudes of healthcare workers toward death and dying patients may influence the quality of care they provide them and the relationships they establish with their families.[18–25] As the literature suggests, implementing an educational program tailored to workers' needs may be useful in helping to foster more positive attitudes toward end-of-life care.[23]

Of the previous studies exploring attitudes toward death, dying, and end-of-life palliative care, most have focused on nurses and primarily examined homecare, hospice, medical-surgical, pediatric, and cancer settings. There is a gap in research regarding other workers, specifically in LTC settings. We need this information to support training and skills development programs to bring about a change in the workplace culture and people's attitudes. We, thus, conducted a baseline assessment and comparison of attitudes among LTC providers from different job categories and places of work.

Long Term Care Facilities in Quebec

Residential and facility-based LTC in Canada are governed by the provinces, which vary across the country in terms of terminology, range of services offered and cost coverage. On a continuum of graduate services, the residential and long term care centers, as they are called in Quebec, correspond to the resources offered to people with the highest degree of loss of autonomy. The LTC centers divide themselves into three types: public, subsidized (non-profit private institution under agreement) and private. Public and subsidized differ only in their ownership; all other aspects of funding, admission criteria, and cost to the individuals are regulated by the Quebec Ministry of Health and Social Services. Private facilities are residential properties independent from government ownership and funding; they have their own admission criteria.

The public LTC centers are specialized institutions that provide more than 3 hours of care per day to adults (mainly seniors) who, by reason of major loss of functional or psychosocial autonomy, can no longer live in their own home despite the support of their families and friends. Overall, they provide living accommodation for people who require on-site delivery of 24 hour, 7 days a week supervised care, including professional health services, personal care and services such as meals, laundry and housekeeping. A recent report about the residents and public LTC centers[26] indicates that 41% of the clientele was 85 years old and older and 80% had cognitive losses. People admitted (and selected) during the last years showed a severe loss of autonomy and had important needs for nursing, medical services and professional services. The average length of stay is three and a half years, so that more residents are often at the end of life. The vast majority of the staff of the public LTC centers is dedicated to the care of residents. Almost two thirds (63%) of staff members act as patient assistants and 35% have responsibilities of nursing. A financial contribution is required on the part of the adult residents who are accommodated in Québec LTC facilities to cover costs of the bed and board. The average contribution amounts to a little more than Canadian $1200 per month, or approximately $14,600 per year. A place in the center costs on average Canadian $93,256 per year to the Quebec government health system.[26]

In the vast majority of cases, LTC centers in Quebec have no palliative care program, no specialized palliative care teams and don't set aside palliative care beds.[8] There's no special code that allows identifying a permanent facility resident at the end of his/her life. Terminal residents receive care in their usual unit and by the usual untrained institutions' healthcare workers.[8]

Methods

Studied Setting

We only approached five LTC facilities of a given multi-ethnic district of Montreal and all five institutions agreed to participate. The studied facilities are public, secular, non-profit institutions. They are parts of a same local territorial community-governed health organization that includes two local community health centers that provide primary health care, health promotion and community development services, which as a whole forms a single university affiliated organization. In total, the five facilities have a capacity of 987 beds, distributed as follows: 398, 140, 147, 282, and 20 beds, respectively. The smallest center hosts people with Alzheimer's type dementia. The largest center includes a specialized 10-bed palliative unit whose workers were specifically excluded from the survey.

A total of 629 of the 1170 participants completed and returned the questionnaires (54%), from which 580 of the 1050 (55%) paper questionnaires were returned and 49 of the 120 (41%) respondents contacted electronically completed the online questionnaire. A simple random sample size of ours ($n = 629$) would give estimates with a maximal margin of error of 4% with a 95% confidence interval.

General Procedure of Administration

We conducted a cross-sectional descriptive survey among all healthcare workers and volunteers who have direct contact with the disabled and chronically ill adult residents from the LTC facilities. Nursing assistants, registered nurses, dieticians, occupational therapists, physiotherapists, psychologists, social workers, spiritual advisers, patient assistants, volunteers, and managers (including clinical officers and heads of unit) were invited by the director of each LTC facility to complete a voluntary and anonymous self-administered questionnaire during working time. These workers were also encouraged to participate via an initial invitation and a subsequent reminder on closed-circuit television and local weekly electronic newsletter as well as via email sent by the president of the local council of nurses, the multidisciplinary council, and the group of volunteers to their respective members. Physicians were contacted via the administrative secretary of the Department of Family Medicine and General Practice.

In LTC facilities in Quebec, we find 2 types of hands-on caregiver job with a secondary-level training that provide basic care in healthcare facilities: patient assistant and nursing assistant. A nursing assistant is a person who provides residents with bedside care and performs the duties and tasks planned by the nursing and medical staff (eg, prepare and administer medications, take patients' blood