

New Knowledge and Research Needs for End-of-Life Care among Elderly Persons in Long-Term Care Settings

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ABSTRACT

Given the aging of the population, an increase in the number of persons in need of long-term care and end-of-life care can be expected in the coming years. The scientific literature underlines the lack of end-of-life care for elderly people in long-term care centres. The aim of this study is to explore needs in terms of new knowledge and research on end-of-life care for elderly persons in long-term care settings, from the perspective not only of the scientific and international community, but also of Quebec professionals concerned by the issue. An online survey using the LimeSurvey® tool was conducted in 2015 among health professionals involved in end-of-life care for elderly persons in long-term care settings in Quebec. 208 professionals rated the priority of new knowledge and research needs related to 1) health professionals; 2) delivery and quality of care; 3) residents and their loved ones; and 4) organization and management of care. The results show that the statements collected in scientific literature resonate with health professionals. The most important need is to identify the symptoms of distress in residents in the final stages of their lives, as well as their causes and treatments. This study also shows professionals' concerns about attitudes, beliefs, and values of practitioners and the related impacts on end-of-life care in long-term care settings. This study shows that there is a significant need for new knowledge and research. It revealed that there are few studies on end-of-life care for elderly persons in long-term care settings and that there is much more to be discovered in this field.

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Introduction

In Quebec, as in other contemporary Western societies, death generally strikes at a late age, past 65 years of age, as is attested by the fact that four out of five deaths occur in this segment of the population. Moreover, the older a person is, the higher is the "probability" of dying³. This late mortality, often the result of a gradual decline, normally occurs in a care institution⁴, including long-term residential care centres (CHSLD – centres d'hébergement de soins de longue durée), where more than a third of residents die each year⁵⁻⁷. Given the aging of the population, a dramatic increase in the number of deaths can be expected in the coming years⁸. This trend will also signify an increase in the number of persons affected by chronic and degenerative diseases, who will need long-term care and end-of-life care.

However, despite increasing political and social interest in Quebec concerning issues such as 'dying with dignity', regulating end-of-life care, and oversight of care practices, which led notably to the 'Act respecting end-of-life care' coming into force on 15 December 2015, the province of Quebec is significantly behind in ensuring that services are adequate to the needs of its aging population. Not only are the number of beds for home, hospital, and specialized care limited, there is an even greater deficiency with respect to long-term care facilities⁸. In fact, according to a report by Shang⁹ on palliative care in long-term care settings, end-of-life care forms part of residents' regular care pathway. In other words, it is not a distinct practice unto itself. Among all the settings investigated in 2013, none had a team dedicated to end-of-life care. Although the act respecting end-of-life care represents a turning point for care establishments, including CHSLDs, requiring them to adopt policies and programs for end-of-life care, individual institutions are free to organize their care environments as they wish.

The grey and scientific literature¹⁰⁻¹⁶ underlines the lack of end-of-life care for elderly people in long-term care centres. It points to lack of experience, education, and knowledge concerning end-of-life care, communication, and symptom relief as reasons for deficiencies in end-of-life care for elderly persons in institutional settings. According to studies by Nielsen and Glasdam¹¹ and Hopkinson, Hallett¹⁷, these explanations tend to sidestep the issue of organizational and structural problems within care establishments, especially long-term centres, whether in terms of care objectives, time pressures on operationalization of work, or lack of staff¹⁸. The culture of silence and of avoidance of the topic of death, which is encouraged in certain establishments¹⁰, might also contribute to deficiencies in end-of-life care.

The aim of the present study is to explore needs in terms of new knowledge and research on end-of-life care for elderly persons in long-term care settings, from the perspective not only of the scientific and international community, but also of Quebec professionals concerned by the issue.

Methods

An online survey using the LimeSurvey® tool was conducted from October 1st to December 31st, 2015, among health professionals, patient care attendants, nursing assistants, nurses, physicians, pharmacists, other healthcare practitioners, managers, and researchers involved in end-of-life care for elderly persons in long-term care settings in Quebec. To reach as many professionals as possible across Quebec, we circulated the survey in English and French to various groups, associations, professional orders and federations, as well as centres for research on aging, palliative care, and social gerontology. The survey was also advertised in several magazines, websites, and watch newsletters for healthcare professionals. It was aimed at all professionals concerned by end-of-life care

for elderly persons in residential long-term care centres (CHSLD) or in assisted living residences.

Questionnaire

The questionnaire used for the survey was constructed based on a review of the literature conducted to examine new knowledge and research needs identified by the international scientific community. The document search was conducted using the PubMed database to list articles published between 2003 and 2015, in English or in French, on the topic of end-of-life care in long-term care settings. The following keywords were used: "long-term care" or "nursing home" AND "palliative care" or "end-of-life care" or "terminal care." The articles selected had to be from industrialized countries, such as Canada, the United States, Germany, Australia, Austria, Denmark, the United Kingdom, Ireland, France, Japan, Norway, New Zealand, the Netherlands, and Sweden. Based on a review of titles and abstracts, 175 articles covering end-of-life care for elderly persons in long-term care settings were selected.

Qualitative and thematic analysis of the discussion section of the selected articles was conducted to shed light on the needs identified by study authors in terms of new knowledge and research. These needs were divided into four broad categories: 1) needs related to health professionals; 2) needs related to delivery and quality of care; 3) needs related to residents and their loved ones; and finally 4) needs related to organization and management of care. After being identified and grouped into themes, the needs were expressed in the form of statements that could be used to construct the survey questionnaire.

The questionnaire consists of three sections. The first collects respondents' demographic data, such as health region, professional category, and main work establishment. The second covers the four themes,

divided into sets of at most 13 statements, for each of which respondents must indicate a level of priority (1 = low priority to 5 = high priority). The last section provides additional space to submit comments or to identify needs not included in the questionnaire.

Data Analysis

The data were collected on the LimeSurvey® platform and analyzed statistically using the SPSS v. 19.0 (SPSS Inc., Chicago, ILS) data analysis software. Descriptive statistics were used to summarize the data. Each statement was tabulated under two categories representing level of priority, namely 1) the sum of percentages for levels of priority 4 and 5, and 2) the percentage for the highest level of priority, 5. The qualitative data from the questionnaire's third section were summarized by the authors and grouped under corresponding theme.

Several participants who responded to the first section of the questionnaire on demographic data did not respond to the questions concerning new knowledge and research needs. They were not counted in the results.

Results

Survey participants

In all, 208 professionals completed the full survey. Although each health region of Quebec was represented by at least one respondent, the majority of respondents were in the Montreal (49%), Montérégie (10.6%), and National Capital (9.1%) regions. Two thirds (66%) of them worked at public long-term residential care centres. Close to half of the respondents were assistant nurses (43.3%). The other professional categories were represented as follows: patient care attendants (1%), nurses (14.4%), physicians (1.9%), pharmacists (1.4%), other health professionals (21.2%), managers (14.4%), researchers (1%), and 'other' (less than 1.5%).

General Results

Table 1 presents the sum of percentages for high level of priority (combination of levels 4 and 5), along with the percentage corresponding to just the highest priority (level 5), for each statement under the four categories of new knowledge and research needs. The statements are presented in decreasing order according to the highest level of priority (level 5). Statements Q1 to Q13 concern new knowledge and research needs related to health professionals, statements Q14 to Q24 concern needs related to care delivery and quality, statements Q25 to Q36 concern needs related to residents and their loved ones, and finally statements Q37 to Q41 concern needs related to organization and management of care.

The percentages for 'high' level of priority, defined as the combination of levels 4 and 5, show that all of the statements were considered priorities by at least half of the respondents. However, looking at the highest level of priority (level 5) alone, only five statements were flagged by one out of two respondents. The table also shows that elements in all four categories of new knowledge and research needs are considered a priority by a majority of respondents. However, when focusing on percentages over 50% for high priority level 5, we see that statements related to residents and their families were considered to be the most important.

Qualitative Results

Survey respondents both acknowledged their own needs for new knowledge and for research on end-of-life care for elderly persons in long-term care settings or identified needs not included in the questionnaire.

Needs related to Healthcare Professionals

Many healthcare professionals emphasized the importance of identifying the training needs of all professionals involved in care, including casual workers.

Respondents identified training needs in areas such as taking into account cultural differences, different palliative approaches, components of the law concerning end-of-life care, how to interact with the families of those who are dying, managing medication prescribed at end of life, and recognizing signs of pain. Some suggested that studying these needs should be part of basic training for all healthcare professionals.

Others mentioned the importance of investigating the different understandings and meanings of 'dying with dignity', as well as perceptions regarding medication prescribed at the end of life – perceptions that can hinder pain relief.

Some respondents stated that there is a need with respect to identifying and understanding the roles of different actors involved in end-of-life care: namely, the need to clarify the attitudes and beliefs of professionals with respect to end of life and death. This can also be linked to the need to assess professional's understanding of the different levels of care, including end-of-life care.

Needs related to Delivery and Quality of Care

Respondents mentioned the needs for new knowledge on the transition of elderly persons from curative care, and the need for it, to comfort and end-of-life care. Furthermore, there is a need to look at the understanding and meaning of futile medical treatment, and to evaluate the use of certain procedures and medications among elderly persons at end of life.

A wish was expressed for research to help develop clinical assessment tools for different purposes, such as documenting the level of comfort of persons at end of life or establishing clinical signs for identifying when someone is at end of life.

There was a definite interest in new knowledge needs related to end-of-life legislation. In this regard,

TABLE 1. Level of priority new knowledge and research needs according to respondents

Statements	High level of priority (Levels 4 and 5) %	Highest level of priority (Level 5) %
Q30 Identify the symptoms of distress in residents in the final stages of their lives in a long-term care residence, as well as their causes and treatments	89.8	66.8
Q20 Identify training needs for end-of-life care in long-term care residences	85.4	57.6
Q25 Evaluate the needs of patients and their families with regard to end-of-life care in a long-term care residence	84.3	57.4
Q14 Identify and describe what quality end-of-life care in a long-term care residence should consist of	83.2	54.5
Q40 Evaluate and compare diverse palliative pharmacotherapies used in end-of-life care in long-term care residences	85.1	53.8
Q15 Evaluate the offer and quality of end-of-life care in the context of long-term care residences in particular, the care generally provided to residents and the care provided specifically to residents suffering from dementia and Parkinson's disease	80.6	49.3
Q41 Evaluate the human, material, and financial resources required for the organization of end-of-life care in long-term care residences	75.5	48.5
Q11 Understand how practitioners deal with the pain and suffering of residents who are in the final stages of their lives	77.4	47.6
Q13 Investigate the daily ethical dilemmas of individuals who work with residents nearing the end of life in long-term care residences	77.9	47.1
Q31 Investigate the decision-making process among loved ones of residents near the end of their lives in a long-term care residence	77.5	46.4
Q23 Evaluate the benefits for residents of being monitored by a specialized end-of-life care team in a long-term care residence	75.3	46
Q27 Study the attitudes, beliefs, and values of residents and their loved ones with regard to end-of-life care in a long-term care residence	81.1	45.9
Q36 Evaluate the impact of staff changes on end-of-life care provided to residents and on their satisfaction level	72.8	45.6
Q29 Understand the role of ethnic, cultural, and religious differences in decision-making and access to end-of-life care in a long-term care residence	75.4	43.6
Q26 Study the role of family caregivers in delivering end-of-life care in a long-term care residence	75	43.4
Q33 Explore residents' preferences with regard to end-of-life care and their beliefs about what constitutes a "good death"	79.6	42.9
Q34 Identify an understand the signs and expressions of loved ones of residents with regard to the idea of "dying in peace"	81.6	42.6
Q16 Develop tools to measure and control the quality of end-of-life care and services in long-term care residences	71.7	42.3
Q17 Assess different mechanisms for ensuring continuity of end-of-life care when practitioners leave and new practitioners take over	76.3	40.4
Q2 Identify, understand, and evaluate the practices, knowledge, and competencies of front-line professionals in end-of-life care in long-term care residences	75.8	40.1

Statements	High level of priority (Levels 4 and 5) %	Highest level of priority (Level 5) %
Q35 Evaluate the benefits linked to end-of-life support for residents and their loved ones	72.5	39.8
Q5 Evaluate the interdisciplinary practices involved in end-of-life care in long-term care residences	72.3	39.3
Q18 Investigate the transition from curative or chronic care to end-of-life care in the context of long-term care residences	73.4	39.2
Q7 Explore the attitudes, beliefs, and values of practitioners and the related impacts on end-of-life care in long-term care residences	70.6	38.9
Q19 Identify barriers as well as conditions that facilitate the delivery of end-of-life care in long-term care residences	73.1	38.6
Q9 Study interactions among long-term care practitioners and loved ones of residents who are in the final stages of their lives in long-term care residences	72.2	38.5
Q4 Investigate the role of practitioners in the transition from curative or chronic care to end-of-life care in the context of long-term care residences	76.2	38.3
Q10 Examine the balance between what practitioners are actually able to perform in terms of quality end-of-life care and what they want to be able to do for the sick person	76.9	37.5
Q21 Evaluate the impact of clinical practice training sessions on end-of-life care in long-term care residences	72.2	37.4
Q6 Evaluate practitioners' job satisfaction in the context of end-of-life care in long-term care residences	66	36.4
Q3 Investigate the contribution of general practitioners to decision-making in the context of end-of-life care in long-term care settings	69.6	35.3
Q1 Know and distinguish the roles of hospital staff and the different professionals (including physicians) in the offer of end-of-life care in long-term care residences	70.2	35.1
Q22 Study psychosocial and spiritual approaches to end-of-life care in long-term care residences	73.5	34.2
Q24 Evaluate the effect of the prognosis on the care of residents nearing the end of their lives	70.2	33.8
Q28 Investigate the experience of patients receiving end-of-life care in a long-term care residence	64.9	31.4
Q8 Investigate different approaches to support for end-of-life practitioners when a resident dies, and during the grieving period	66.4	31.3
Q12 Evaluate the relationship between the burden of grief and the risk of burnout among long-term care practitioners	63.5	29.8
Q38 Evaluate the deployment and impact of legislative and regulatory measures regarding end-of-life care in long-term care residences	57.9	28.7
Q32 Study the effects of a resident's death on other residents in long-term care units	64.1	26.2
Q39 Understand the influence of organizational culture on the deployment of end-of-life care practices in long-term care residences	52	21.9
Q37 Evaluate the cost/effectiveness ratio of investments in end-of-life care in long-term care residences	49.7	20

some mentioned the need to clarify the distinctions between medically assisted dying and end-of-life care, to explore the underlying issues, and to evaluate implementation.

Other respondents were concerned by the need to evaluate the effects of patient care attendant and nursing assistant workloads (or staff/resident ratio) and of weekly team meetings on the quality of care management for elderly persons at end of life.

Needs Related to Residents and their Loved Ones

New knowledge and research needs related to residents and their loved ones also bore on professionals and the organization of work. There were concerns regarding the effects of the physical environment, care teams, staff turnover, and organization of care on the end-of-life experience of residents and their loved ones.

In their comments, respondents repeatedly brought up the need for new knowledge and research concerning cultural differences, values, and beliefs of residents and their loved ones. According to respondents, better knowledge in this area would help them improve their interventions with family members.

Also identified was the need to assess family members' counselling needs following the death of their loved one and to assess the effect of a resident's death on other residents.

Needs related to Organization and Management of Care

In this last category, respondents provided fewer comments. One voiced concern regarding the different uses of the pharmacopeia by different physicians and pharmacists, while others suggested evaluating the benefits of standardizing end-of-life care practices within establishments, or even across the province.

One person mentioned the need to explore the potential influence of the living environment approach on end-of-life care in a CHSLD. The need to explore the general population's perceptions of end-of-life care in CHSLDs was also raised.

Discussion

The results show, on a general level, that the statements gathered from the scientific literature resonate among health professionals in Quebec. The majority of statements describing new knowledge and research needs were considered as a high priority (4-5) by at least half of respondents.

The most pressing need is to identify distress symptoms, along with their causes and treatments, among end-of-life residents in long-term care settings. Close to 90% of respondents assessed this statement as being a high priority (4-5). Moreover, some respondents mentioned the need for new knowledge and research to develop clinical tools for evaluating clinical signs not only of comfort or pain, but also of end of life. These needs support observations made in Quebec regarding the increasing number of "very active" examinations and treatments carried out up until patient death. In fact, according to the grey literature^{8, 19, 20}, recourse to acute care increases during the last weeks of life of dying persons, whether they are at home or already in an institution. The results of various studies^{12, 21} show that professionals across all categories are late in recognizing clinical signs of approaching death. Although some professionals claim they know "in their hearts"¹² that an elderly patient is nearing death, many seem to attempt to treat aggressively. The transfer of residents from a long-term care facility to an intensive care unit helps shore up the belief that medical expertise can be found in a different location^{12, 16}. According to Froggatt²² and Ternstedt and Franklin²³, palliative care in long-term care settings should be adapted to elderly persons, since the approach's philosophy is not particularly suitable in

such a context. Elderly persons who are likely to benefit from it are generally those with diseases other than cancer and whose prognosis involves a much less certain end-of-life trajectory^{14, 24-27}.

This last point echoes the need for new knowledge and research related to evaluating training needs. More than 85% of respondents considered this, as a priority need. Other statements, related to lack of knowledge and education, support these needs. In fact, several respondents referred to this in their comments. Lack of experience, education, and knowledge regarding end-of-life care and symptom relief were generally pointed to as reasons for deficiencies encountered in end-of-life care provision for elderly people in institutions. According to some authors^{11, 28-30}, these care settings for elderly persons have difficulty in attracting and retaining care staff with significant university education^{11, 31, 32}. As a result, a large number of caregivers working on a daily basis with elderly persons have a lower level of education, which affects the care delivered to elderly persons at end of life. However, according to studies by Nielsen and Glasdam¹¹ and by Hopkinson, Hallett¹⁷, these explanations tend to sidestep the issue of organizational and structural problems in long-term care facilities, whether in terms of care objectives, time pressures on operationalization of work, or lack of staff¹⁸.

This study also shows respondents' concerns with regard to new knowledge and research surrounding the attitudes and beliefs of the different actors involved in end of life (residents, family, professionals) in long-term care settings. Similar concerns applied to ethnic and cultural differences in understanding end of life. Indeed, there were numerous comments by respondents on this topic. End of life and death are extremely sensitive subjects that represent the end of human existence. In Western society, the omnipresent subject of death, far from being taboo, is paradoxically notable when it is

absent. In 2016, although the majority of individuals died in care institutions^{4, 33}, end of life is often passed over in silence, something that Fortin and Blain³⁴ explain as a reflection of a larger "society that is uncomfortable with death" (p. 13).

Although it had not been among the needs identified in the scientific literature, a great number of survey respondents mentioned the need to explore understandings and meanings of end-of-life elements such as 'dying in dignity', 'medically assisted dying', 'end-of-life care' itself, and of representations concerning the use of certain pain relief drugs. This last element was also raised in a recent study by Lessard and Leclerc³⁵. The authors reported that the family members of dying people had social representations regarding the use of medication, notably morphine, to relieve pain, which they largely perceived as the "goodbye injection." It goes without saying that the current political and social context surrounding dying in dignity has an impact.

The adoption and coming into force of the act respecting end-of-life care and the debates generated by the act in the media and in healthcare settings have greatly influenced the Quebec healthcare landscape. In the process, various issues related to 'dying in dignity' and to the act respecting end-of-life care, such as medically assisted dying and palliative sedation, have been widely reported on. Other elements, such as euthanasia and assisted suicide, have been brought into the discussion as well. The definitions, understandings, interpretations, and especially the meanings of these concepts vary significantly depending on the individual facing them and on the circumstances in which they arise. It is not surprising that so many survey respondents highlighted the need to clarify these themes.

Conclusion

In short, this study shows that there is a significant need for new knowledge and research. It revealed that there are few studies on end-of-life care for elderly persons in long-term care settings and that there is much more to be discovered in this field. This observation can also be related to the predominantly poor attitude that prevails in current society toward the elderly, and especially toward those in institutions, an attitude born from the association between old age and terminal illness^{29, 33, 36, 37}. The concept of the social loss of dying persons developed by Glaser and Strauss³⁸ might partly explain the generally uncaring attitude toward elderly persons in institutions. The social loss of a dying person relates to the social value assigned to the individual, a value that shapes how caregivers invest in that person and therefore affects the care provided. The most commonly observed attribute in this respect is probably age. According to the authors, the social loss of an elderly individual is considered less important than that of a younger individual. Given this lower level of social investment, we can consider that new knowledge and research needs are even more critical.

Finally, this study has some limitations. As enlightening as the results may be, the authors cannot claim that the sample is representative. As with other studies, the results could be coloured by self-selection bias. The survey respondents might represent persons who are more aware and more concerned by end-of-life care than others.

The priority percentages are fairly clustered, which makes it difficult to establish a clear order of priorities. It does suggest that respondents found it a challenge to select their own priorities. All in all, the concerns, needs, and beliefs of professionals with respect to end-of-life care in long-term care settings appear to be meaningful.

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