

Care Provider Perspectives on End-of-life Care in Long-Term-Care Homes: Implications for whole-person and palliative care

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Abstract / This study holistically explores the experience of dying and end-of-life care for older persons with dementia in long-term care (LTC) from the perspective of care providers. Using a focused ethnography methodology, seven researchers interviewed LTC staff, residents' families, volunteers, management staff, and spiritual advisers/clergy over a five-day period. Research was guided by two key questions: What is the dying experience of people living in LTC from the perspective of different care providers? and, What are the salient issues in providing palliative care for elderly people dying in LTC? Based on a thematic analysis of verbatim data, three common themes were identified: tension between completing job tasks on time and "being there" for residents; the importance of family-like bonds between front-line staff and residents; and the importance of communication among staff and between staff and residents and their families at the end of life. Findings are discussed in relation to their implications for policies and practices that can support whole-person care and ultimately a good death for residents of LTC facilities.

Résumé / Cette recherche de type holistique portant sur les soins de fin de vie auprès des personnes âgées démentes hébergées dans un établissement de soins de longue durée (ESLD) examine la nature de ces soins de fin de vie dans la perspective des soignants. Au cours d'une période de cinq jours, sept chercheurs utilisant la méthodologie ethnographique ont interviewé le personnel, les familles des malades, les bénévoles, la direction et les cadres, les agents de pastorale, prêtres et pasteurs d'un ESLD. La recherche comportait deux questions fondamentales. Comment meurent les résidents d'un ESLD selon les points de vue des différents

soignants? Quels sont les points saillants à considérer lorsqu'il s'agit de dispenser des soins palliatifs aux malades âgés hébergés dans un ESLD? À partir de l'analyse thématique du verbatim, trois thèmes communs ressortent: la tension ressentie entre le travail devant être accompli dans un temps donné et le désir d'être présent auprès des malades, l'importance de créer des attaches similaires aux liens familiaux entre les soignants de première ligne et les résidents, et la nécessité pour les membres du personnel de communiquer entre eux tout en maintenant la communication avec les résidents et leur famille à l'approche de la fin de vie. Les résultats sont discutés en relation avec les conséquences que de telles données pourraient avoir sur les politiques et applications destinées à encourager les soins centrés sur la personne dans sa globalité et à favoriser une meilleure fin de vie pour les résidents des ESLD.

INTRODUCTION

As the Canadian population ages, more people will die in long-term-care homes (LTCHs), with estimates as high as 39 percent of residents dying in LTCHs by 2020 (1). These people constitute one of society's most frail and marginalized populations. They often struggle to manage multiple chronic conditions and suffer social isolation. Over 75 percent of LTCH residents have some type of cognitive impairment (2), which creates additional challenges to providing them with care, due to related communication, functional, and behavioural problems (3). Thus, people dying in LTCHs form a growing population that consists of some of society's most vulnerable citizens.

Palliative care is a philosophy and a unique set of interventions that aim to enhance quality of life at the end of life in order to provide a "good death" for patients and their families when death is inevitable (4). Quality of life at the end of life is understood to be multi-dimensional and to consist of physical, emotional, social, spiritual, and financial domains. Steinhäuser et al. (5) studied the perspectives of patients and their families on a good death and found that it would include: completion (adequate time to prepare for death); pain and symptom management; clear decision making; affirmation of the whole person; the opportunity to reflect on one's own personal accomplishments and time to be with others. Thus, these elements, which all contribute to whole-person care, can be considered essential to a good death from the perspective of LTCH residents at the end of life and their families.

Palliative care is appropriate for people who are dying of any disease, including those chronic conditions that are the most common cause of death among elderly persons (6). The Canadian Hospice Palliative Care Association (CHPCA) (7) has developed national norms of practice focused on the particular needs of dying people and their families. These needs include assistance with: disease management; physical, psychological, social, spiritual, and practical end-of-life/death management; and loss and grief management. In effect, the CHPCA norms provide a framework for whole-person care, along with the care processes and organizational context to support palliative care. These norms of practice apply to people who are dying in any setting and can guide care planning and delivery of palliative care in LTCHs.

There is an emerging body of knowledge that specifically addresses the processes and structures necessary to provide high-quality palliative care for residents of LTCHs (8, 9). Brazil et al. (8) found that in order to achieve high-quality long-term care (LTC), a number of processes must be undertaken. First, residents need to be provided with physical care; respect and dignity; and cultural, spiritual, and social support. A peaceful, homelike environment must be created, one that allows for privacy. Families must be given emotional support and information about the dying experience. A high-quality care approach must be developed that includes assessment, communication, teamwork, education, and continuous improvement. Death must be recognized as a significant event. And, finally, sufficient institutional resources must be provided, including adequate staffing, equipment, and supplies. Brazil et al. (8) also contend that providing high-quality palliative

care in LTCHs requires an approach that addresses the needs of residents' families and staff.

Many barriers to optimal palliative care in LTCHs have been identified, including lack of knowledge on the part of staff, heavy staff workloads, and a failure to implement a timely end-of-life care plan (10). A large proportion of unregulated care providers with limited training and education and a low ratio of physicians/registered nurses/social workers to residents create additional challenges (11). Support and education initiatives are needed for the staff who care for dying residents in order to facilitate a positive and therapeutic milieu in LTCHs. Personal support workers (PSWs), who deliver the majority of hands-on resident care, are often excluded from continuing education initiatives within the facility or not helped by their employers to attend outside educational initiatives (12). Gaining an understanding of the experience and perceptions of all staff working in LTC would permit us to develop organizational approaches and appropriate training and integrate them into daily practice in LTCHs.

In summary, LTC is a setting in which a growing number of society's frailest and most powerless elderly people die. Many barriers to providing optimal palliative care in LTC have been identified in the literature. One of these barriers is a lack of understanding of LTC staff's experiences and perceptions of dying and palliative care. A better understanding of this could advance our knowledge of the culture of dying and end-of-life care in LTCHs. This would ultimately guide the development of appropriate whole-person clinical and organizational practice and education programs. To extend our understanding of end of life in LTC, the present study explores the subjective experience of dying and end-of-life care from the perspective of PSWs and non-clinical workers (maintenance and house-keeping staff), who are often excluded from research. The research was guided by two key questions: What is the dying experience of people living in LTC from the perspective of different care providers? and What are the salient issues in providing palliative care for elderly people dying in LTC?

METHODS

This research used a focused ethnography method to understand end-of-life care in LTCHs. The research site was a 110-bed accredited LTCH in Ontario that had seen 18 deaths of residents with dementia in the previous year. The methodological approach entailed collecting qualitative data from multiple sources and demographic data in

order to gain an in-depth understanding of the topic from the various perspectives of those working in LTC. A *focused ethnography* involves condensed fieldwork, including short-term field visits and intense data collection (13). Researchers immerse themselves in the field setting to gain an understanding of a specific set of questions or objectives (14). Ethics approval for the study was obtained from the research ethics boards of Lakehead University and the health care organization involved.

Qualitative data were collected using three methods: participant observation and generation of field notes; individual semi-structured interviews; and focus groups. This paper is based on an analysis of the qualitative data. The interviews were conducted over a five-day period in February 2008 in a faith-based, not-for-profit LTCH in Northwestern Ontario. We chose this particular facility because members of our research team have a long-standing and trusting working relationship with it. This relationship was essential; the facility gave us access to participants and provided us with space to conduct our interviews. During the site visit, researchers interviewed front-line staff (nurses and PSWs), residents' family members, volunteers, management staff, spiritual advisers and clergy, and medical staff; 112 interviews were completed. Table 1 summarizes the distribution of the participants. The sample for the present analysis was 48 (n=44 PSWs; n=4 non-clinical workers [maintenance and housekeeping staff]).

To recruit participants, the facility's manager spoke about the research at monthly staff meetings. An information letter was given to meeting attendees and a sign-up sheet was posted for staff to volunteer for specific focus groups. Staff members were also asked by researchers whether they would prefer to discuss their experiences of working with people with dementia and the palliative care process in interviews or in focus groups. Interviews were conducted on the units during times when staff members were available. To recruit more participants, the director of care approached other staff members and asked permission to pass on their contact information to the researchers; the researchers then asked the staff members who had consented to this to participate in an interview. Participation was voluntary, but interested parties were given release time from work to participate. In order to accommodate work rotations and staffing levels, the researchers made themselves available for both day and night shifts. This made it possible for them to interview staff coming on and off shift, ensuring that staffing ratios were maintained.

Interviews of approximately 40 to 90 minutes were conducted either individually or in small focus group formats. Table 2 shows sample interview questions. Interviews were taped and transcribed verbatim by a transcription agency.

ANALYSIS

Over several months, three members of the research team independently analyzed and categorized the data into thematic areas. After each researcher had completed a thematic analysis of the data, we held several meetings during which each team member presented themes and provided examples from the transcripts. Strategies for establishing rigour in this study included conducting research team peer debriefing (via team meetings and smaller focused discussions on the developing themes), writing memos throughout the analysis process, and recording decisions made throughout data collection and analysis (that is, creating an audit trail). In addition, we presented our findings to staff working at the study site and to several conferences attended by LTC staff and family caregivers. Individuals attending these presentations indicated that the themes reflected their experiences of end-of-life care in LTC.

Table 1 / Sample Characteristics

Target Group	Number of Interviews	Number of Participants
Administration personnel	2	2
Physicians	2	2
RNs/RPNs	12	18
PSWs ¹	17	44
Physiotherapists	1	1
Residents	4	4
Family council members ²	1	10
Family members of living resident	9	9
Family members of deceased resident	6	8
Non-clinical staff (maintenance and housekeeping workers)	4	4
Spiritual advisors/clergy	6	6
Volunteers	3	4
Total	67	112

1. In Ontario, Canada, PSW stands for personal support worker; the job is defined differently across Canada, and other titles for it include: direct care worker, residential care aide, and care aide.
2. Family Council is an organized, self-led, self-determining, democratic group composed of family and friends of the residents of Long-Term Care Homes. A Staff Liaison from the Home is usually appointed to support and facilitate the Council. Family Councils provide mutual support, empowerment and advocacy to the family and friends of the residents of Long-Term Care Homes. Although all Family Councils have this goal in common, each Council will be unique in meeting the needs of its members, the residents and the Home.

Table 2 / Sample Interview Questions**For staff**

- What is your understanding of palliative/end-of-life care?
- How do you think palliative/end-of-life care relates to someone with dementia?
- Can you describe a situation in which you were personally involved in caring for someone with dementia who was dying? How were family members involved?
- How do you know when people with dementia are reaching the end of their lives and need palliative care? When you think a resident is in need of palliative care, what, if anything, do you do differently?
- Please describe the things that you think have the greatest effect on the quality of life of people with dementia who are dying in your home (both positive and negative)?
- What are the challenges you experience in providing good/appropriate palliative/end-of-life care? What things facilitate or help you in providing good/appropriate palliative/end-of-life care?

For family

- Has anyone at this facility ever talked to you about palliative/end-of-life care?
- If yes, who [job identification, not personal identification] was it, and what information did that person provide? Was this information helpful? Please explain.
- What is your understanding of palliative/end-of-life care?
- Can you please describe the things that you think have the greatest effect on the quality of life of your [relative identification] in this home (both positive and negative)?
- What role do you think family members play in palliative/end-of-life care?

RESULTS

Based on a thematic analysis of our verbatim transcripts, we identified three key themes that represent the experiences of PSW and non-clinical (maintenance and housekeeping) staff in providing end-of-life care. These themes are: the tension that staff members experience in balancing the necessity of completing their job tasks on time with their desire to be there for residents; the importance of family-like bonds between front-line staff and residents; and the importance of communication among front-line staff members and between staff and residents, their family members, and volunteers as residents reach the end of life. These themes — tension, the importance of family-like bonds, and communication — help to illuminate the culture in LTCHs of caring for dying people, including the facilitators of, and barriers to, whole-person care.

Tension

A key theme, and a significant barrier to providing whole-person care, is the fact that PSWs feel time constraints: they must complete necessary or assigned job tasks on schedule, but they also want to help fulfill what they perceive to be the needs

and care preferences of dying residents. PSWs expressed a desire to “be there” for those who were “close to the end,” especially in the absence of family. This, however, was not always possible, given their workload. As one PSW put it:

“Time, and the staff. We don’t have the staff to do it. There is a lot of residents for not many staff, and everyone needs lots of care. And what I don’t like is that sometimes they unfortunately pass away alone, where it would be nice for one of us to be there if a family member couldn’t, but that can’t always happen.”

Lack of time was particularly evident among PSWs working the night shift:

“Well, mine is more of a physical aspect of it, and we do what we can...in this facility there are only two of us for 56 residents...so it is very limited, especially on the night shift. We do as much as we can physically, but as far as sitting there and taking the time to be with them, especially the ones that have no family [we don’t have time].”

Not having enough staff to meet the complex needs of dying residents contributed to the tension. The PSWs maintained that if more workers were recruited, then they would be able to provide the one-on-one care that they felt the residents deserved, especially at the end of life.

“And you think if you had more staff, you could take the little bit of time and put some makeup on to make them look nice, because sometimes you feel like an assembly line, because you, you know, you’ve got to get them up and you wish you have the extra 10 minutes to spend with them, just even sit and say, ‘Oh, how was your day today?’”

PSWs also noted an increase in the fragility and/or acuity of residents, which resulted in increased demands on PSW’s time. PSWs indicated that staffing levels have not been adequately adjusted to meet the demands of an increasingly frail resident population. Due to lack of time resulting from staffing-level issues, staff members were unable to be with residents as much as they would have liked. One PSW commented:

“Yeah, but you kind of have to be realistic, because the work is so heavy and it just — like life in general, everything is so much faster now, and you might have, like, maybe four or five people dying at the same time.”

Non-clinical staff such as maintenance and housekeeping workers had to balance their assigned job tasks with patient needs and preferences, and in most cases they were not provided with any information about residents’ health

status, and this created tension for them. For example, a maintenance worker described having to go into a resident's room to do a repair without knowing whether it was advisable to wear a mask or gown to protect the resident:

"I think they should let us know more about when we put mask, gown — you know, put the whole garb on — to go in there, because sometimes we have to go in there."

The Importance of Family-Like Bonds

Family-like bonds were identified by care staff as essential to providing high-quality, whole-person care to residents. They indicated that these bonds were especially important for those residents who did not have family or a social network. They also indicated that by developing family-like bonds, they could personalize care for residents. For example, one PSW discussed her personalizing practices, explaining that a certain resident felt like a grandmother to her and that all the workers had their favourites. There was an informal understanding among the workers as to which resident was the favourite of which worker. This understanding was important, as the bonds it supported facilitated better and more personal care. The PSW added:

"You'll get the ones that you give a little extra special care to, and, you know, just sit with them longer and take the extra five minutes to do their hair. Like before [one resident] passed away there, I made sure I washed her hair and we combed it nice. You know...some of us might personally just take a little extra care in doing certain things for them."

Similarly, other PSWs saw building relationships with residents and their family members as essential to performing their job well. Knowing a resident or having a family-like bond with a resident helped a PSW to provide the necessary comfort at the end of life.

"We become family, and so you know what is comforting for the resident, and you really get to know the person. And that's a real fortunate thing, I can say, for example, if they go to the hospital and come back to die with us on palliative care. It is comforting because, as we always say, you know they are within the comforts of their home and with their family because we are extended family, so it's just a personal — even though we may not have known them for years, but some have been here a long time. It's that personal attribute of knowing who that person is or has been or what he's like."

These family-like relationships were seen as particularly significant for those residents who did not have family or friends visiting them.

The desire to interact with residents, even those who seemed very ill, was not limited to care staff. Non-clinical staff also expressed a desire to have friendly relationships with residents. A house-keeping worker said:

"Yeah, and just listen to their stories. You know, when they'll be saying, 'Oh well, when my husband and I were young, and we used to dance a lot,' or whatever they were discussing, just to have an ear for them... you know, acknowledgement of the happier time of his life?"

Communication

This study found that communication among front-line staff members and between staff and residents, their family members, and volunteers is central to the provision of high-quality, whole-person, end-of-life care. PSWs discussed communication in the context of mentoring or teaching one another. One PSW noted:

"And you learn a lot from each other, too. I've been here longer, and I've learned a lot from people and how they, you know, help prepare a person, or even after a person's gone, what you do with them afterwards."

PSWs maintained that both verbal and written communications are important. Speaking about noticing a change in a resident's status, one PSW said:

"I would talk with my co-workers, get their opinions first, and then suggest telling the RN, and then it's up to the RN after that."

Others commented:

"We just bend each other's ear, and it works."

"Oh, I think the system works well. You can walk in the room and look at that sheet of paper and see what's been done, and it gives you an idea of, okay, we need to turn this resident or, you know, just by looking at the chart."

PSWs also discussed at length the importance of communication with other members of the care team, especially the registered nurses. We noted, however, that such communication was typically characterized as one-way. PSWs described situations in which they provided information to nurses, but not vice versa.

"Any extra information that we can think of, we tell the nurse — if there is anything else, and we all keep [up] to date, and there is a report every day, and everybody is told what is going to happen next or what to do."

"If we notice any change with their help, we report it to the nurse, and the nurse then investigates."

Communication was also influenced by the person on receiving end. If the nurse was someone they perceived of as unreceptive to their concerns, then PSWs did not always communicate the information — or they did so with a deep sense of frustration.

"It depends on which nurse is on."

"It is frustrating, and I know I've had an experience of people that are deteriorating really, really quickly, and [the nurses] are still telling you, 'No, get them up, get them in the dining room,' and you're...in tears."

"Yeah, you are just bottom of the barrel. What do you know about that person, you know? Even just day-to-day care, if you go and tell an RN something is different about somebody — 'Oh, they were like that a month ago. That's happened before.'"

Maintenance and housekeeping staff noted a lack of communication and said that better communication between clinical and non-clinical staff could improve both the work and the care environments. They said, however, that it was sometimes difficult to communicate with residents.

"You are working, and then all of a sudden they scream out for whatever reason — they don't realize who you are, they've never seen you before. If they did, they may not remember you from the last time, so I don't know if there could be better communications in that sense, but I think that goes for all of us."

For these non-clinical staff members, it was important to be in the loop with clinical staff and residents.

"That is my job, and I like to know who's who and what they like...[Putting] a name and face together is very important."

DISCUSSION

Findings from the present study illuminate the experiences of PSWs and non-clinical staff members in caring for dying residents in a LTCH. The CHPCA norms of practice call for attention not only to the physical but also to the psychosocial dimensions of care — in effect, to whole-person care. These norms emphasize the fact that organizational supports are required to ensure comprehensive palliative care and a good death. Results of our study highlight the barriers to, and facilitators of, whole-person care from the perspective of non-professional care staff (PSWs) and non-clinical staff (maintenance and housekeeping workers).

Barriers to Whole-Person Care

Based on our findings, we have identified two major barriers to whole-person care: limited resources and lack of time. All participants identified comfort as important at the end of life and expressed their commitment to providing a good death for residents. However, resources and education related to addressing the psychosocial dimension, which are necessary for those committed to providing a good death via a holistic approach, are lacking. Those PSWs participating in our study found that due to time constraints, they had to prioritize disease management and physical care over responding to the psychosocial needs of residents and their families. This caused them moral angst. What is lacking is a broad philosophy of palliative care that encompasses social, psychological, and spiritual concerns and a formalized palliative care program that incorporates the full scope of whole-person care and recognizes the need for adequate staff resources to provide this care.

All participants identified lack of time as a barrier to whole-person care. Previous research has documented the experiences of staff working in LTCHs. Henderson (15) describes the "cult of time and task" in nursing homes, which has created a superficial social interaction between residents and staff. The task-oriented nature of the nurse's aide role is a result of the value the medical world has placed on time conservation, and it has led to care being focused on physical tasks to the detriment of meaningful social interactions with patients. Similarly, our study shows that time constraints, and the poor and/or ineffective communication they give rise to, are barriers to whole-person care. Care staff constantly balance necessary care tasks with the personal needs and preferences of residents. They are torn between wanting to be with residents, particularly those at the end of life, and having to get the job done. There is a push and pull between performing necessary tasks and taking the time to attend to psychosocial needs in order to afford residents comfort, dignity, and personalized care. Time constraints often fracture communication or create a feeling that one's voice or perspective is not valid or valued by others. This is particularly true for maintenance and housekeeping workers, who often do not know how or to whom information should be communicated.

Facilitators of Whole-Person Care

Our findings show that there are three key facilitators of whole-person care: the ability to form meaningful relationships, enhanced and frequent communication, and an expanded definition of

the care team. Meaningful relationships include those between staff members and residents and their family members, and those among staff members. Of course, having sufficient time is essential to building strong relationships, but flexibility and a willingness to communicate and work with others are also important. For example, we saw evidence of strong mentoring relationships between PSWs, particularly when it came to end-of-life care for residents. Strategies for developing such relationships should be part of the training that new staff members receive. Mentoring relationships should also be seen as a means of providing psychosocial support to staff who often work in difficult conditions and grieve when the residents they work with die.

The second key facilitator of whole-person care is enhanced and frequent communication regarding end-of-life care. Our findings suggest that discussions about the end of life should involve everyone who comes in contact with residents and that such discussions should be ongoing. This is partly because workers and residents change, but also because information is absorbed by different people at different times and at different rates. Emotional preparation for death should begin long before a resident enters the final stage of his or her life. Death happens frequently in LTC, and so should discussions about end-of-life care.

Because end-of-life discussions should include all those who interact with residents, we need to expand our notion of who should be considered a member of the care team, and this brings us to the third facilitator of whole-person care. Non-clinical staff members (maintenance, housekeeping, and food service workers) as well as volunteers and residents' family members need to understand the philosophy and trajectory of end-of-life care as fully as possible. As evidenced in our study, those not customarily included in the care team have roles to play: they can offer practical assistance to professional care staff, provide them with emotional support, or simply understand when to ask questions and when to refrain from asking them. In order to expand the care team, we must give information to those who have not traditionally been included. This could be done by establishing or expanding in-service training, by developing resource materials, or by fostering mentoring relationships. By broadening the interdisciplinary clinical care team to include a wider range of contributors, we can improve communication and, ultimately, whole-person care.

Limitations of the Study and Next Steps

There are three main limitations to this study, although the first — its condensed nature — is

both a limitation and a benefit. Because we used a focused ethnography, we could collect our data within a short time frame (which the facility preferred). However, given that this data collection was completed in five days, we may have missed some important observations. Among other things, a longer time frame would have allowed us to observe over time the complexities of the facility's various relationships — between workers and residents, among workers, and so on — and to conduct more than one interview with each participant. The second limitation of our study is that it characterizes the caring relationships between PSWs and residents and between non-clinical staff and residents as being unidirectional. In fact, we observed that staff members benefit greatly from their relationships with residents, but we could not examine this reciprocity to the extent to which we would have liked. The final limitation is that our participants volunteered to participate. Because we only interviewed those who signed up to speak to us, we might have missed others who had a lot to say but chose not to participate. Research with non-professional workers shows that they often feel vulnerable in their employment and are therefore less likely to speak out (16).

Future research would benefit from a longer observational time frame as well as the opportunity to conduct multiple interviews to deepen the themes. Similar studies should also be conducted at other facilities to determine whether the barriers to, and facilitators of, whole-person care are comparable across contexts.

CONCLUSION

This study showed that care providers in the LTC setting saw providing comfort to residents at the end of life as an important goal, and they were committed to achieving it. They expressed this commitment through their descriptions of the bonds that form between staff members and residents. Staff members valued communicating with, and emotionally supporting, residents and their families who were facing the end of life. Among the PSWs, there was evidence of mutual aid and of mentoring relationships; PSWs helped one another make appropriate care decisions and cope with the sadness they felt over residents' deaths. These values and interpersonal processes are excellent resources upon which to build capacity for whole-person care.

At the same time, participants identified barriers to providing whole-person care, such as the current emphasis on physical care and disease management, and communication processes that exclude PSWs and non-clinical staff. These bar-

riers are compounded by organizational issues, such as lack of a formalized palliative care program, lack of staff education to support a palliative culture, and lack of human resources to support increased care. The knowledge generated from our research can be used to guide clinical and organizational changes and to guide the design of education programs that will support the development of a palliative culture in LTCHs.

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