

# Staff Perspectives of Barriers to Access and Delivery of Palliative Care for Persons With Dementia in Long-Term Care

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## Abstract

Dementia is a syndrome that is progressive, degenerative, and terminal. The palliative care philosophy aims to maximize quality of life for the dying individual and is both beneficial for and underused with persons dying with dementia. **Objectives:** The purpose of this study was to investigate the experiences of long-term care staff delivering palliative care to individuals with dementia to determine how care was delivered, to learn which guidelines were used, and whether policies affected the delivery of palliative care. **Methods:** Twenty-two staff participants were interviewed. Their experiences were interpreted using phenomenological methodology. **Results:** Findings yielded 3 key themes: confusion, resource shortages, and communication difficulties. **Conclusion:** Implications for practice include clarification of terminology surrounding palliative care, education of families about dementia and palliative care, better resource management, and the need to address when palliative care best fits within the dementia process.

## Keywords

dementia, palliative care, barriers to access, long-term care, end of life

## Introduction

Dementia is a progressive syndrome resulting in impairments in brain function, memory and cognition, communication, speech, swallowing, balance, essential bodily functions, and activities of daily living.<sup>1</sup> Approximately 564,000 Canadians currently live with dementia.<sup>2</sup> This number is expected to reach 1.4 million by 2031 partly due to Canada's aging population. According to the World Health Organization (WHO),<sup>3</sup> the median age of survival for an individual with Alzheimer's disease is 7.1 years, but survival rates with a diagnosis of dementia vary. Persons with dementia often die from complications associated with the causative diseases, such as pneumonia stemming from swallowing problems.<sup>3</sup> The combination of cognitive, communicative, physical, and behavioral difficulties in dementia means complex care is required at later stages and is often provided in long-term care homes or hospitals.<sup>4</sup> Thus, it is important to examine what kind of care is available to persons with dementia as they progress to the end of their lives.

Palliative care is a noncurative care approach that improves the quality of life of persons with life-threatening illness and their families through the prevention and relief of suffering and treatment of pain.<sup>3</sup> Palliative care can be implemented at all stages of an incurable or chronic illness, not solely at the end of life.<sup>5</sup> It is delivered in varied settings, including hospitals, hospices, and long-term care homes and private homes.

Palliative care is recognized as being appropriate for those with dementia.<sup>6,7</sup> It aligns with person-centered dementia care.<sup>3</sup> Persons with dementia often experience painful and futile end-of-life treatments, especially compared to persons with other diagnoses, such as cancer.<sup>8</sup> If persons with end-stage dementia receive palliative care, it is often suboptimal compared to persons with other diagnoses.<sup>9</sup> Persons with dementia have substantial unmet palliative care needs including elevated pain and emotional or behavioral problems,<sup>10</sup> all of which provide challenges to dying with dignity.

The definitions of and distinctions between "hospice palliative care," "palliative care," and "end-of-life care" are unclear in the literature and in practice. Definitions used in this study are consistent with WHO and Canadian Hospice Palliative Care Association<sup>11</sup> interpretations. Specifically, end-of-life care describes care, primarily focused on symptoms

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management, that occurs in the last days or weeks of life. Palliative care is a broader philosophy of care, beginning earlier in the disease trajectory with a focus on maximizing quality of life and is synonymous with hospice palliative care, which is a term used in Canada to recognize hospice and palliative care converging into one movement.<sup>11</sup>

Palliative care remains underutilized among persons with dementia.<sup>12,13</sup> Barriers to the widespread use of palliative care include the unpredictable disease trajectory and uncertainty around timing of palliative care,<sup>14,15</sup> perceptions that dementia is not terminal, families being unreceptive to the idea of palliative care due to its associated stigma,<sup>16,17</sup> lack of professional knowledge about palliative care,<sup>18</sup> and policies or funding availability.<sup>19,20</sup>

Although the need for and barriers to accessing palliative care among persons with dementia are well documented, there is a dearth of research from a Canadian perspective. The demand exceeds current resources available in Canada, putting Canadians at a disadvantage.<sup>21</sup> Moreover, little is known about Canadian policies that may act as barriers. What remains unknown are the barriers to access palliative care and the efforts, if any, to address the barriers in Canada. Specifically, there is a lack of consensus regarding prognostic measures,<sup>22</sup> the timely transition to palliative care for persons with dementia, and the ideal setting for delivering palliative care. This lack of consensus is present in both Canadian and international literature. Large-scale studies investigating best practices for increasing participation in palliative care for persons with dementia are in the early stages.<sup>23,24</sup>

Accordingly, the present study focused on the experiences of staff delivering palliative care to individuals with dementia. Primary research questions investigated how palliative care was delivered to persons with dementia in long-term care homes located in the south-west region of the province of Ontario, with a focus on processes that guided the initiation of palliative care. A secondary research question examined what policies or funding incentives in Ontario enable or prohibit individuals with dementia from accessing palliative care.

## Method

This study used a transcendental phenomenological approach<sup>25</sup> to understand the experiences of staff providing palliative care. Moustakas' approach is postpositivist, which seeks to obtain an objective interpretation of the experiences of the staff. Moustakas' approach includes constant comparative method throughout the data collection and analysis process. Categories and themes are deduced from the information collected. The purpose of the constant comparison method in transcendental phenomenology is to learn about an experience or phenomenon from someone who has experienced it without actually experiencing it oneself.<sup>26</sup> The research team used this method throughout the data collection and analysis processes.

**Table 1.** Description of Facilities.

Facility	Approximate Number of Beds	Type of Funding	Number of Participants
I01	250	Public	4
I02	400	Public	1
I03	250	Public	2
I04	125	Public	1
I05	150	Public	10
I06	75	Public	1
I07	200	Public	1
I08	50	Private	2

## Participants and Procedure

Interviews were conducted with 22 multidisciplinary professional staff working in 1 of 8 private or semiprivate long-term care homes varying in size (Table 1). Participants ranged in age from 23 to 67 years. Most had been working in their positions for 16 years or more. Most (86%) participants were women. The sample varied by discipline and included participants from medicine, nursing, pharmacy, social work, pastoral/spiritual care, recreation therapy, and volunteer services (Table 2). Semistructured interviews lasted an average of 30 minutes. All interviews were digitally audio-recorded and transcribed verbatim. Ethics approval for this study was obtained from Western University's research ethics board.

## Analysis

Analyst triangulation, triangulation of sources,<sup>27</sup> and bracketing were used to ensure credibility and confirmability and reduce systematic bias in interpreting the experiences of the participants.<sup>28</sup> Analyst triangulation involves having multiple analysts to review the findings to assess whether similar conclusions were drawn. Each member of the team coded a different transcript to establish an initial code list. The team read the transcripts broadly to see what emerged and created basic codes from this process. Next, using that list, the team coded the same transcript to ensure that there was a shared understanding of the definitions of each code. This list yielded similar results when used by different researchers. It took 3 rounds of coding to establish a list of codes that was agreed upon. This final list was used for the remainder of the analysis process. Transcripts and codes were organized using NVivo 10 software. Next, the first author engaged in inductive analysis, grouping similar codes into subthemes and themes. Coauthors assisted with interpretation of emerging themes. The first author continued to collect data until saturation was achieved, with no new information being uncovered. The themes that were identified were featured across all different groups of providers. Common themes were clustered because there were no significant differences among the different groups of providers.

Triangulation of sources involves examining the findings to ensure they are consistent with a variety of data sources. In this

**Table 2.** Participant Information.

Category	Total (%)
<b>Role</b>	
Registered nurse	9 (41.0)
Personal support worker	3 (14.0)
Registered practical nurse	2 (9.0)
Social worker	2 (9.0)
Pharmacist	1 (4.5)
Volunteer	1 (4.5)
Volunteer coordinator	1 (4.5)
Physician	1 (4.5)
Recreation therapist	1 (4.5)
Chaplain	1 (4.5)
<b>Palliative care education</b>	
No education	2 (9.0)
Education	20 (91.0)
<b>Gender</b>	
Men	3 (14.0)
Women	19 (86.0)
<b>Length at facility</b>	
0-5 years	4 (18.0)
6-10 years	2 (9.0)
11-15 years	3 (14.0)
16+ years	6 (27.0)
No response	7 (32.0)
<b>Number of residents responsible for</b>	
Less than 100	15 (68.0)
100-199	5 (23.0)
200+	2 (9.0)

study, an effort was made to include a broad range of professions, experience levels, and different long-term care homes. Finally, the research team used bracketing, which involves being mindful of our own biases and assumptions and making sure that the analysis was not guided by our individual experiences and perspectives with the topic.

## Results

Analyses of the interviews revealed three key themes that appeared most prominently across the interviews in 400 coded excerpts: confusion with the distinction between end-of-life care and palliative care, resource shortages, and communication difficulties.

### Theme 1: Confusion

The theme of confusion comprised 29% of all the coded excerpts and had 3 subthemes: confusion in terminology, confusion in initiation, and lack of guidelines.

**Confusion in terminology.** Most participants used the terms palliative and end-of-life care interchangeably. Although many participants agreed that “everyone who is in this facility is palliative according to the definition of palliative” (registered nurse [RN]), no one received the designation of “palliative”

until they were no longer able to eat, drink, and get out of bed. Residents usually died within days of this designation. Participants reported this confusion was problematic because residents were not able to access resources, such as specialized pain medication, until they had the palliative designation.

The confusion about terminology permeated participants' beliefs about pain relief. Occasionally, nurses were afraid of giving the prescribed dose of pain medication because they were concerned about side effects and that they might be blamed for accelerating the dying process. Consequently, staff delayed palliative measures until they were certain of their necessity, usually when the resident stopped eating and drinking and had decreased consciousness and mobility. Given that additional pain medications were made available only after the palliative designation, one participant reported that residents who did not get an early palliative designation had untreated pain until they were at end of life. Staff observed indications of pain in persons with dementia who were unable to communicate their own pain levels by noting changes in behavior, mood, or appetite.

**Confusion in initiation of palliative care.** Participants felt uncertain in initiating palliative care because of the uncertainty in the palliative versus end-of-life distinction. Nurses mostly shared this confusion because they often made decisions about continuing treatments and beginning palliative care. Guidelines about when to stop nutrition and hydration were unclear because some residents would stop eating for periods of time and then resume eating.

Most frequently, it [palliative care] is way too late. That's what I find in long-term care, it's way too late . . . It's so difficult to prognosticate at end of life. (RN)

Indeed, the philosophy of care shifted to be more person-centered after the resident received the palliative designation. Prior to this distinction, the focus was on curative care, with less emphasis on pain management. Several participants explained their philosophy around pain management at end of life, stating that being pain-free was the most important goal. This dramatic shift in philosophy also appeared in visits from volunteers and family members. One participant noted that most individuals with dementia were marginalized before they reached end of life, and that once they were at the end of life, it “evened the playing field” (RN). The palliative designation appeared to change the way residents were viewed and treated.

People with dementia sometimes are marginalized even before they become palliative, and that's a challenge because residents who are physically frail but cognitively intact don't understand why people with dementia are the way they are. I know one dementia care unit I worked on . . . people [staff, family members, volunteers, other residents] were afraid of coming to the dementia care unit . . . but then I find once they [residents] do become palliative, people start showing up. (RN)

Participants expressed that staff and other residents did not understand that behaviors such as exit-seeking, confusion, and agitation were typical of dementia and not reflective of the individual. Consequently, persons with dementia had little meaningful contact with other residents who were afraid of interacting with them. One staff member felt frustrated that residents received no extra support at a time when they had greater awareness and ability to appreciate that someone was spending time with them. In contrast, when they were deemed palliative and usually unresponsive with diminished consciousness, residents with dementia had access to volunteers who would sit with them, and family members were contacted and encouraged to spend more time with the resident as they died.

*Lack of guidelines for dementia-specific palliative care initiation and delivery.* An important study objective was to determine whether there were assessment tools or guidelines to aid in the delivery of palliative care for individuals with dementia, specifically to guide when initiation should occur. Participants from 3 long-term care homes reported using the Palliative Performance Scale (PPS),<sup>29</sup> which outlines typical changes in mobility, evidence and level of disease, ability to care for self, intake of food and fluid, and level of consciousness that people undergo as they move from 100% (disease-free) to 0% (deceased). None of the homes using the PPS relied on a threshold that indicated when palliative care should be initiated. Instead, they used it as an educational tool to teach families about the dying process.

Participants responsible for initiating palliative care used their experience and professional judgment to determine when palliative care was best initiated. Most said the assessments were based on common sense. One participant explained “When they’re done, they’re done. We just know (Registered Practical Nurse)”. Usually, when a resident with dementia stopped eating and drinking, the RN made the decision to contact the physician and request that the resident be designated palliative. They also made assessments based on abnormal vital signs and uncharacteristic and distressing resident behaviors.

Knowledge was not often shared among staff across and within long-term care homes. Consequently, each facility operated independently by creating their own palliative care approaches in the absence of formal guidelines. The need for dementia-specific guidelines was related to the unique complications that individuals dying with dementia presented. Individuals with dementia did not always follow a predictable dying trajectory, making it difficult for staff to allocate resources like the palliative care room. Additionally, staff had to combat the misconception that dementia was not a terminal disease.

Palliative care in long-term care was typically initiated late in the dying process. At this stage, participants reported that the needs of residents with dementia were not different from the needs of residents with other chronic conditions. Where the difference lies is in the care that residents with dementia received before the “end-of-life” stage. One participant elaborated on the unique approach to palliative care:

I think if we talked about palliative care as being a philosophy of care, not a type of care, I think there’s a misunderstanding that palliative care is only for people who are dying. It’s a problem we don’t acknowledge, that chronic disease is not curable. And it will end in death. And really, what we’re doing with chronic disease is treating the symptoms, which is palliative care. But people don’t see it that way; it’s not explained to them that way. (RN)

## Theme 2: Resource Shortages

The second theme involved resource shortages, including staff time, staff shortages, and physical resources. It comprised 30% of all the coded excerpts. Nearly every participant expressed a need for more staff time. Good quality palliative care is inherently more time-intensive because communication difficulties make needs assessments difficult and because extra time is needed to reassure the resident and provide a calming environment. This is discrepant with the current task-oriented nature of care in most long-term care homes. Direct care staff were particularly personally affected by this. Many participants expressed this sentiment:

The challenge is having the time and staff available to figure out what those individual needs are for the person, and then meeting them. So typically if it means you’re dealing with agitation, you could give them a medication, or you could give them one-on-one. But one-on-one isn’t an option, even though that would be ideal. So I would say it’s not so much that there’s a strategy that’s being missed, but we’re under resourced to have the time to be able to figure out what unique strategies work for each person and meet them. (RN)

Participants felt that not having enough staff contributed to a poor experience for the individual receiving palliative care. Some participants, particularly ones doing more hands-on care, were personally affected by this shortage.

You have some staff take it really hard, really we have staff members that will cry, literally, if they have to leave the room to go attend to a call bell or something, you know, these people are family. We come here, we spend 8, 9 hours a day with them, so they become a part of us, right? (Personal Support Worker)

Long-term care homes lacked funds to hire staff to address psychosocial care needs, particularly social workers, chaplains, and recreation therapists. Many of these professionals had reduced hours and were responsible for half or the entire resident population of the facility. These positions were the first to be cut with funding limitations. Furthermore, most staff were not trained in palliative care during their formal education and relied on work experience and training which employers did not have the resources to fund.

Participants expressed a desire to implement more alternative therapies, such as music or massage therapy, even on a limited basis. Many also expressed a desire to create rooms designated specifically for palliative care, or to improve existing ones, although most stated this was unlikely to happen.

Participants shared insights on factors that facilitated better palliative care in more progressive homes. Firstly, staff were trained formally in palliative care. Most had taken the Center to Advance Palliative Care course, offered by an American organization dedicated to increasing the availability of palliative care services.<sup>30</sup> Most felt confident in their skills and were willing to evaluate their own performances and learn from their mistakes. Secondly, dying residents had access to palliative care volunteers. Some homes had private rooms or specific palliative rooms, which included beds for family members. Most homes used a palliative care cart which included soothing lotions, extra soft sheets and nightclothes, music, and resources for the family, including information about what to expect at the time of death and information on funeral arrangements. Most homes had a sign (eg, butterfly on room's door) to let others know the resident's status. Finally, supportive administrators committed to the goals of palliative care were more willing to allocate funds for resources, extra staff time with residents, and palliative care training.

### Theme 3: Communication Difficulties

The third theme identified communication barriers throughout the palliative care process in the areas of staff–resident communication, staff–coworker communication, and staff–family communication. It comprised 42% of all the coded excerpts.

*Staff–resident communication.* Participants felt uncertain whether they were meeting the needs of residents with dementia because of the lack of meaningful communication with them. As reflected in the quotation below, participants indicated that residents with dementia, who were unable to express themselves verbally or who had increased pain, might communicate by being aggressive toward staff, family, and other residents.

They're not able to verbalize that they're in pain. If they're more restless, we'd spend more time trying to be the detective and their care, knowing that we have to be the one telling if they're in pain, and then lots of them are not able to verbalize that information. (PSW)

*Staff–coworker communication.* Communication among transdisciplinary staff was challenging. Nurses indicated that they did not have enough communication with physicians who were prescribing drugs and designating residents as palliative. Physicians were responsible for different long-term care homes and cared for many residents. Others such as social workers, chaplains, and recreation therapists also felt excluded at times. Additionally, staff at homes with no formal palliative care committee expressed frustration in making end-of-life decisions with no protocol to guide them and no one willing to lead in decision-making.

Inconsistent staffing was also noted as an issue. Participants reported that residents' relationships with ever-increasing part-time staff were not as strong as with full-time staff. Part-time

staff switched between floors, units, and facilities, did not get to know residents or coworkers well, and were generally not as consistent as full-time staff. Part-time staff were also less likely to be trained in palliative care techniques.

*Staff–family communication.* Participants reported that communication between staff and family was challenging. Families, especially those ill-informed about the dying process, could become emotional, aggressive, irrational, and distressed as their family member approached the end of life. This made it difficult to make care decisions collaboratively. Participants noted that sometimes families wanted all potential lifesaving measures provided and as many treatment options as possible, or as one participant stated: “wanted the book thrown at them” (RN). Staff had difficulty accommodating these requests, knowing the futility of the interventions and anecdotal evidence families provided. This led to conflict over decision-making. Staff reported that some families would not follow their relative's advance directives and felt they had to comply with family requests, especially if the family was insistent or aggressive.

Mummy and Daddy make their wishes known, but Tommy and Johnny, they don't want to see Daddy die, so even though they know those are their wishes, and even though the staff know those are their wishes, they fear repercussions if they don't do what they're told, or what they're asked to. There are big issues with that. It [the advance directive] is supposed to be [binding] you see, but . . . when you get families who are aggressive, I mean legally aggressive, staff give in. (RN)

Although participants reported these situations were relatively rare, they were nonetheless salient and distressing. One participant felt that the solution to this was more education for families.

I would have more conversations with families at end of life, more realistic conversations. That means when you're talking with the family, that you actually talk about death and dying, and that you don't sugar coat it, because I think that's what happens, we're afraid to tell people the truth, which is: they're going to die. (RN)

Educating families and the public was a facilitator for palliative care identified by participants, especially about the dying process, the nature of dementia, and what services were provided, and when, in the long-term care home at end of life. Most participants felt there was a general lack of knowledge about the dying process. They reported that families were more likely to request that residents be moved to the hospital if they were not aware of what care could be provided within the long-term care home. Participants stated that a better relationship could be fostered with the family if there was a discussion about the dying process with the family during the admission interview. Specifically, participants expressed that it was imperative that long-term care home staff explain in detail what

care could be given and discuss the wishes of the resident, including advance directives.

Participants reported that palliative care was more successful when staff utilized a team approach, with open communication, shared goals for each resident, and grief support for families. This approach extended beyond medical staff to include housekeeping and dietary managers so that extra meals, beds, or chairs could be provided for families of dying individuals. A team approach also reduced emotional stress on staff enabling them to deal collectively with their grief.

## Discussion

The first theme, “confusion,” was the most prevalent. Participants were confused about the distinction between “palliative” and “end-of-life” care and how and when palliative care should be initiated. This resulted in untimely and inconsistent care. This confusion affected the two other themes. If staff were confused, resources could not be used effectively, and communication with staff, residents, and family was more difficult.

Similar findings were found in the literature. For example, participants in a UK study reported that palliative care for persons with dementia was disorganized.<sup>31</sup> Some staff indicated that guidelines were too strict, while others indicated too few guidelines resulted in chaotic care. In our study, staff felt that there were too few guidelines; none expressed any frustration with guidelines being too strict.

Contrary to previous studies,<sup>19,20</sup> most study participants did not report any policies explicitly preventing or facilitating palliative care delivery in long-term care homes. Provincial legislation states that direct care staff should be trained in pain management but does not state that they must be trained to provide end-of-life or palliative care.<sup>32</sup> The legislation provides minimal guidance for what palliative or end-of-life care should entail, who should deliver it, and when it should begin.

Funding limitations had implications on the care individuals with dementia received. Staff were not always trained in how to deliver palliative care and represented a barrier to accessing palliative care, also reflected in existing literature.<sup>6,18,31</sup> Additionally, most facilities did not have enough staff to meet the extra time demands required for palliative care.

Participants in the current study, consistent with previous findings,<sup>14,15</sup> stated that dementia’s unpredictable dying trajectory made it difficult to allocate resources, plan for the initiation of palliative care, and determine when palliative care should be initiated. Previous findings indicate that individuals with dementia often decline very slowly, with brief periods of increased health.<sup>19</sup>

Consistent with previous research,<sup>17,19,33</sup> participants in this study indicated that dementia-related communication difficulties made it more difficult to provide palliative care, especially in pain and needs assessment, resulting in residents dying with unmet pain needs. The fact that current study participants were unaware of existing guidelines and assessment tools to aid in this process exacerbates the problem.<sup>34</sup> These findings support the need for a dementia-specific model of palliative care,<sup>7</sup> as

current practice does not account for the unique challenges in caring for a resident with dementia earlier in the disease process.

In the literature, uninformed family members represented a significant barrier to the initiation of palliative care.<sup>16,17</sup> In the current study, family members created barriers when they did not consent to their relative receiving palliative care. It is possible that family members were guided by the stigma surrounding palliative care and its associated misconceptions, especially the notion that palliative care is not limited to end-of-life care.<sup>35</sup> Education by staff to families about the terminal nature of dementia and benefits of palliative care, however, helped facilitate access.

## Implications for Practice

While hospice palliative care is aimed at relief of suffering and improving the quality of life for persons who are dying from advanced illness, the combination of these terms makes it challenging to implement palliative care earlier in the disease, alongside treatment for persons living with serious illness. Yet, getting palliative care early for persons facing serious illnesses, such as dementia, is very important.

There is much that can be done for the comfort of persons with dementia and their family members over the progression of the disease. The need for more training for staff, families, and the general public was identified in the interview data. Specifically, staff training should aim to increase awareness about dementia and the dying process to ensure that individuals with dementia have timely opportunities to access high-quality palliative care and to provide staff with the knowledge and tools to make decisions regarding initiation of palliative care. Additionally, families and the public would benefit from education about effective care for persons with dementia (eg, understanding cognitive and communicative changes) and increased awareness of the benefits of palliative care so that they are more likely to seek it out and consent to it. Additionally, having clear medical directions/preferences discussed and set up early when the person with dementia has capacity is critically important, so the family can learn and implement their relative’s wishes for care when the advanced disease stage prevents self-report.

Secondly, terminology regarding palliative care should be clarified. Before individuals with dementia are deemed to be at end of life, the philosophy of their care is less person-centered, with less emphasis on maximizing their quality of life. A precise definition of what palliative care entails and guidelines about when it should be initiated would help clarify this confusion and provide consistency in care. Moreover, health professionals need to be trained to address the stigma associated with initiating palliative care earlier in the disease process.

Thirdly, palliative care resources should be spread over a longer period rather than concentrated at end of life. New solutions are needed to address resource and staff shortages to ensure volunteers, massage therapy, and chaplaincy visits are

available while the resident with dementia is still able to interact.

Lastly, as endorsed by prior research,<sup>7</sup> a dementia-specific approach to palliative care is needed, particularly in the long-term care setting. The current study's findings indicate that the care required for someone dying with dementia was not substantively different from the care required for someone with another diagnosis. However, persons with dementia experience agitation, fear, confusion, and pain that they are unable to communicate.<sup>36</sup> The uniqueness of dementia must be incorporated in palliative care delivery, particularly earlier in the disease process where the differences between residents with dementia and residents without dementia are more pronounced. The "Comfort Matters" model developed in the United States in the Beatitudes nursing home in Arizona offers a concrete example of a model of care for advanced dementia that addresses unique behaviors such as sun downing and agitation.<sup>37</sup>

### Limitations and Future Directions

This study was limited by recruiting participants from 1 city using snowball sampling. Many participants were recruited from a community of practice with shared knowledge about palliative care delivery. Therefore, the sample may not be representative of the larger population of long-term care staff who work in homes that do not provide palliative care. Secondly, some professions were represented by 1 participant. However, including participants from a range of disciplines and both private and publicly funded long-term care homes provided a more complete picture of how palliative care is currently delivered. Future studies with larger sample sizes that cover larger geographic regions are needed in order to make recommendations for best practices.

Participants expressed difficulty in initiating palliative care, uncertainty around pain assessments for individuals with dementia, and expressed a desire for more assessments and guidelines to aid in care delivery. Future studies are needed to test the efficacy of existing assessment tools, develop strategies to maximize the efficiency of resource use at end of life, examine how information is shared with practitioners working within this field, and gain the perspectives of persons with dementia and their family caregivers. As the numbers of older adults with dementia continue to grow, there will be a greater need for increased resources. An industry-standard dementia-specific model of palliative care for individuals in long-term care is critically required.

### Authors' Note

Marie Y. Savundranayagam designed the study, contributed to data collection, and analyzed the data. Emily Hill contributed to data collection and data analysis. Emily Hill and Marie Y. Savundranayagam contributed equally to the manuscript. All authors contributed to data analysis interpretations and writing of the manuscript.

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