Chart Based Data as a Resource for Tracking and Improving a Person-Centred Palliative Approach in Long Term Care

Tamara Sussman[1], Jack Lawrence[1], Arielle Earn[2], Matt Wilkie[2], Paulette Hunter[3], Sharon Kaasalainen[4]

Version	Post-print/accepted manuscript
Citation (published version)	Sussman, T., Lawrence, J., Earn, A., Wilkie, M., Hunter, P., & Kaasalainen, S. (2022). Chart based data as a resource for tracking and improving a person-centred palliative approach in long-term care. *Journal of Clinical Nursing*, jocn.16558. https://doi.org/10.1111/jocn.16558
Publisher's Statement	This is an Accepted Manuscript of an article published by Wiley in the *Journal of Clinical Nursing* on 10-12-2022, available online: https://doi.org/10.1111/jocn.16558

---

[1] School of Social Work, McGill University
[2] Faculty of Arts & Science, University of Toronto
[3] Psychology, St Thomas More College, University of Saskatchewan
[4] School of Nursing, McMaster University

Abstract

Aims and Objectives: To enhance the practice of a person-centered palliative approach in long-term care.

Background: Implementing a person-centred palliative approach in long-term care entails placing residents at the centre of care planning that attends to the ‘whole’ person, rather than prioritizing biomedical needs.

Design: We conducted a four-stage directed content analysis of long-term care progress notes to meet our study aims and applied the EQUATOR guidelines for qualitative research publication (COREQ).

Methods: We qualitatively analyzed 78 resident charts across three long-term care homes in southern Ontario to capture the extent to which person-centered care was *absent*, *initiated*, or *implemented* in different types of documented care interactions.

Results: Most residents had interactions related to *daily care activities* (65/78, 83%), *social concerns* (65/78, 83%) and *treatment decisions* (53/78, 68%). By contrast, interactions around *pain & discomfort* (34/78, 44%) and *spirituality* (27/78, 35%) were documented for less than half of the residents. Almost all (92%) residents had at least one progress note where staff *initiated* person-centered care by documenting their preference for a certain type of care, but only a third had at least one progress note that suggested their preference was *implemented* (35%).

Conclusions: While person-centred care is often *initiated* by nurses and other allied health professionals, changes to care plans to address resident preferences are *implemented* less often. Nurses and other allied health professionals should be encouraged to elicit care preferences crucial for holistic care planning and equipped with the skills and support to enact collaborative care planning.

Relevance to Clinical Practice: Collaborative care planning appears relatively absent in charted progress notes, constraining the full implementation of a person-centered palliative approach to care.

Patient or Public Contribution: An advisory group consisting of long-term care resident and staff representatives informed the overall study design and dissemination of the results.

What does this paper contribute to the wider global clinical community?

- Person-centered palliative approaches to care are gaining prominence across healthcare sectors, including in long-term care.
- Most studies exploring the implementation of person-centered approaches are based on staff reports, which can vary significantly amongst staff within the same organization.
- This paper uses chart-based data to capture how the principles of a person-centered palliative approach to care are being adopted, if at all, in long-term care.

Introduction

As Canadian and global life expectancy increases, more people are living into old age and dying from chronic progressive conditions such as heart disease, respiratory disease, and dementia (Canadian Institution for Health Information, 2019; Lozano et al., 2012). In response, many scholars and clinicians have called for the adoption of a person-centred palliative approach to care across healthcare settings (Sawatzky et al., 2016), and especially in long-term care (LTC). Evolving populations, public health matters, and social realities are driving the need for staff-led person-centred palliative LTC environments, globally (Hirschfeld, 2009). Nurses and other allied health professionals play a key role in supporting the adoption of person-centred palliative approaches to care in LTC as they are charged with the responsibility of collaboratively developing, overseeing, and implementing current and future care planning in LTC (Bartz, 2010; Keenan et al., 2008).

Background

A palliative approach to care compels staff to attend to quality of life and quality of care throughout the trajectory of life and death. As such, a palliative approach calls on practitioners to attend to the whole person by ensuring that social, emotional, spiritual, and functional domains of care are addressed alongside medical issues (Touzel & Shadd, 2018). A palliative approach encompasses the principles of person-centered care, which aims to elicit "individuals' values and preferences and once expressed, [use these values and preferences to] guide all aspects of their health care" (The American Geriatrics Society Expert Panel on Person-Centered Care, 2016, p. 16). Hence, adopting a person-centred palliative approach to care in LTC calls for practices and systems that support the development and implementation of holistic personalized care plans in collaboration with residents and families from the time of relocation until death (Olsson et al., 2013; The American Geriatrics Society Expert Panel on Person-Centered Care, 2016).

A person-centred approach also provides direction for circumstances wherein personal preferences cannot be incorporated into care planning (Gómez-Vírseda et al., 2019; Larsen et al., 2020). For example, given the social and relational context of LTC, it may be justified to prevent residents' behaviours or deny care requests, especially when compliance would threaten residents' or others' well-being. In such instances, a person-centered approach calls on healthcare professionals to respond to residents in a dignified manner by explaining the parameters of care, validating the resident's desires, and communicating an understanding of their perspective (Crocker & Smith, 2019). In essence, a person-centered palliative approach to care calls for the humanization of healthcare delivery by prioritizing the experiences of people over systems and tasks (Phelan et al., 2020).

There are barriers to implementing a person-centred palliative approach to care in LTC. First, staff are often pressured to prioritize quantifiable biomedical quality indicators (e.g., incidence of bed sores, falls, and hospital transfers) over relational connections and psychosocial quality indicators (e.g., reports of satisfaction with care) (Armstrong & Armstrong, 2020; Rockwell, 2012). This prioritization of biomedical domains of care comes at the expense of attending to social, emotional, and spiritual concerns (Canadian Hospice Palliative Care Association, 2013; Lopez, 2014). Second, the regulatory nature of LTC environments supports the tendency to prioritize the efficiency of routine care over the collaborative nature of person-centred and palliative approaches (Viau-Guay et al., 2013). These organizational pressures can lead to the exclusion of older persons from their own care planning, with rules and routines taking precedence over resident preferences and experiences (Donnelly & MacEntee, 2016; Rockwell, 2012).

A literature is emerging documenting staffs' perceptions of the adoption of person-centred practices in LTC (Dys et al., 2022). Yet, few studies have used documented care interactions between residents and professional staff in LTC to examine how and under what circumstances staff support or undermine a person-centred palliative approach to care (Broderick & Coffey, 2013). Capturing the domains of care in which residents and staff typically interact, and the extent to which such interactions fulfill a holistic person-centred approach could provide a more accurate depiction of an organization's practice of person-centred care relative to staff reporting, which can vary significantly amongst staff within the same organization (Dys et al., 2022). It may also improve the uptake of a person-centred palliative approach to care in LTC.

In light of these challenges and in keeping with the goal of improving the adoption of a palliative approach in LTC, this study sought to illuminate the extent to which charted interactions between nurses/other allied health professionals and LTC residents in three LTC homes in southern Ontario represented (1) holistic care (i.e. interactions related to social, emotional, spiritual, functional and medical concerns) and (2) person-centred care (i.e. recognition of resident preferences and incorporation of those preferences into care planning).

Methods

Design

This study employed qualitative descriptive methodology based on a directed content analysis to explore resident-staff interactions in electronically documented progress notes (Hsieh & Shannon, 2005). This approach allowed us to describe and eventually quantify both the types of care interactions documented and the extent to which those documentations showed evidence of person-centredness (Vaismoradi et al., 2013). Our team consisted of researchers well-versed in the literatures and practices of person-centred and palliative care in LTC contexts. This substantive expertise along with our interdisciplinary representation in the fields of social work, psychology, health policy, and social sciences positioned us well to operationalize and identify person-centred palliative interactions in chart-based data.

In LTC, progress notes are used to concisely document (a) residents' preferences (e.g., notes about residents' histories, attributes, interests, and care preferences) and (b) any current or planned actions based on these elicited or observed preferences (e.g., planned consultations, discussions, and/or care plan changes/maintenances) (Blair & Smith, 2012; Peterson, 2014). A typical LTC progress note that includes all of these elements for a medical concern may read as follows: *Resident was upset to be woken up at night for medication stating, 'he would rather sleep'. Will follow up with physician on the need for nightly medication administration.*

In Ontario, progress notes are entered into an electronic charting system called Point Click Care. While all allied health professionals (e.g., nurses, social workers, physicians, physiotherapists, dieticians, and recreation therapists) are authorized to use this charting system, most progress note charting in LTC is done by nurses who interact with residents on a daily basis and who are charged with collaboratively developing and overseeing care planning (Bartz, 2010; Keenan et al., 2008). Thus, these progress notes might be expected to capture the frequency with which nurses and other allied health professionals document and integrate residents' social, emotional, functional, and medical preferences into current and future care planning. Progress note charting occurs when an allied health professional judges an interaction with a resident or family member to be worthy of communication to other members of the interdisciplinary team. Documentation in progress notes can range from daily to monthly.

The study protocol was reviewed and approved by McGill University Research Ethics Board File #: 16–0617 and McMaster University Research Ethics Board Project Number # 3484. All methods were carried out in accordance with the ethical guidelines and regulations stipulated by these ethical boards, and the EQUATOR guidelines for qualitative research publication (COREQ) were applied (Tong et al., 2007) (Supplementary File 1).

Data Collection

The resident charts which formed the foundation of this analysis were those associated with residents enrolled in a larger study on advance care planning (ACP) in LTC (Kaasalainen et al., 2020). Recruitment for the larger study took place between spring 2018 and spring 2019 in three LTC homes in southern Ontario Canada. These three homes were selected because they represent a mix of LTC organizations found across Canada (Canadian Institution for Health Information, 2019), including for-profit (two) and not-for-profit (one); large (two; 169 and 206 beds) and medium (one; 120 beds); high (one) and low (two) staff turnover; and religiously-based (one) and secular (two) orientations.

Eligibility was limited to residents with health stability, reflected by a charted score of three or less on the Changes in Health and End-Stage Disease and Symptoms and Signs (CHESS) scale (Hirdes et al., 2003). This measure of inclusion was used because the larger study explored the process of initiating ACP and therefore required participants who were not imminently facing end-of-life issues. As such, the charts reviewed were associated with residents who were less likely to pose challenges to person-centred care planning because of compromised communication or judgement (Kitwood, 1997).

Staff in participating homes were asked to review all charts to identify and approach all eligible residents and/or legally authorized decision makers face-to-face, using purposive sampling methods. Based on reported resident profiles in Canadian LTC homes, we estimate 153/495 (31%) residents living in participating LTC homes were eligible (Canadian Institution for Health Information, 2019). Of the estimated 153 eligible residents, 83 expressed an initial interest in participating, and 78 signed written consent forms and were formally enrolled in the study (51% of those estimated eligible).

Analysis

One author (MW) extracted nine months of charted progress notes of all enrolled participants. This extraction took place between July-August 2019 after enrollment in the lager study was complete. During the first few weeks of data extraction, the team noted that many of the extracted progress notes contained information that said nothing about resident preferences or care planning (e.g., a recorded blood pressure measurement). After some discussion and reflection, we decided to limit the extraction to only include progress notes that described residents' verbal or physical response to care (e.g., 'resident was upset being woken up for medication' or 'resident is concerned about blood pressure levels'). Extracted progress notes were imported to a qualitative analysis program called Dedoose (*Dedoose*, 2020).

Following the extraction of all chart-based data, the team engaged in a four-stage directed content analysis (Elo & Kyngäs, 2008; Hsieh & Shannon, 2005). In the first stage, two authors (JL and AE) read all extracted progress notes to gain familiarity with the data. Following their independent review and discussion, a preliminary set of codes was developed to comprehensively capture the range of topics for which care interactions and preferences emerged (e.g., *food & intake*, *walking & transfer*, *social engagement, hospital transfer, grooming*, *financial concerns*, *physical discomfort*, *mental health, spiritual preferences*).

In the second stage, three authors (JL, AE, and TS) reviewed all codes and associated extracts to identify patterns between and within codes, and address redundancies or overlap. Through discussion, reflection, and comparison, the three authors developed a final set of categories and associated codes thought to both broadly capture the nature of charted care interactions (Marshall & Rossman, 2016) and align with the literature on whole person palliative care (Canadian Hospice Palliative Care Association, 2013). For example, at this second stage we noted that excerpts coded as *mental health* most commonly captured expressions of emotional discomfort (e.g., "resident complained to writer that she was having anxiety during the night couple days prior"; *Sharon*, 74). We felt that these aspects of emotional pain aligned with the notion of 'total pain' described in palliative care literature (Brant, 2017), and hence developed the category *pain & discomfort*. This initial coding process allowed us to provide an overview of the types of charted care preferences and interactions typically documented in LTC (informing Research Question 1).

In the third stage, we developed three operational definitions informed by the principles of person-centered care to capture the extent to which person-centred care was implemented (informing Research Question 2) (The American Geriatrics Society Expert Panel on Person-Centered Care, 2016). Person-centered care was (1) *absent* in progress notes that prioritized professional expertise without evidence that a resident's preference was subsequently discussed or considered in care planning (2) *initiated* in progress notes where residents' preferences were documented without evidence that a resident's preference was subsequently discussed or considered in care planning and (3) *implemented* in progress notes where residents' preferences were both identified and addressed in the care plan. To support credibility of our coding structure, two authors (JL and AE) collaboratively engaged in the coding process, consulting a third author (TS) when discrepancies emerged. For example, we coded the excerpt "staff increasingly concerned about resident's lack of cooperation with fall-prevention: several discussions held in past regarding high fall risk and interventions to decrease incidents of falls, yet resident continues to make attempts at self-transfer and self-toileting" *(Doris,* 82) as *absent*, because the resident was framed as overestimating their capacity rather than valuing or desiring independent ambulation. The excerpt "resident would prefer to discontinue weight reduction intervention, instead prefers to self-limit his food choices" (*Robert*, 77) was coded as *initiated* because we agreed that the resident's concerns were acknowledged, but there was no evidence that an action had subsequently occurred to implement the resident's request.

In the fourth and final stage of the analytic process TS, JL, and AE reviewed and discussed a sample of coded extracts to ensure consensus and compliance with the operational definitions for both the types of care documented and the level of person-centredness captured. Following this review, we tabulated the frequencies for all coded data and the circulated the final reporting of the data and their associated extracts to the larger team for review and input. No further changes were made to our coding system at this stage, lending support to the trustworthiness and credibility of our coding process (Cope, 2014).

Findings

Characteristics of Resident Participants

The average age of participating residents was 79.61 (SD: 11.71) with a length of stay in LTC being on average 2.73 (3.93) years. Over half of the residents (51%) identified as female, and most were widowed (45%) and White (79%). The majority of participants had a CHESS score of 1 or lower (88%), indicating low to no health instability (Table 1).

Our sample is relatively younger, and more health stable than general LTC populations in Ontario and Canada (Canadian Institution for Health Information, 2019). Although population-based demographic data pertaining to race and ethnicity is not collected from Ontario and Canadian LTC homes, we suspect our sample is less racially and ethnically diverse than the general population of residents in LTC in these jurisdictions (Flanagan et al., 2021).

Types of Charted Care Interactions

Of the 346 excerpts documenting care interactions, 329 (95%) were written by nurses. Table 2 provides an overview of the types of care interactions developed through our coding process, with frequencies and verbatim excerpts included. The majority of residents (n = 78) had documented interactions related to *daily care activities* (65/78, 83%), *social concerns* (65/78, 83%) and *treatment decisions* (53/78, 68%). By contrast, interactions around *pain & discomfort* (34/78, 44%) and *spirituality* (27/78, 35%) were documented for less than half of the residents and *financial concerns* (6/78, 8%) were rarely documented at all.

Progress notes coded as *daily care activities* most commonly represented residents' concerns around *food & intake* (43/65, 66%) and *walking & transfer* (31/65, 48%) while excerpts coded as *treatment decisions* most commonly represented concerns about general *medical care* (46/53, 87%). Notably, excerpts coded as *pain & discomfort* most often represented concerns about *physical discomfort* (26/34, 76%) with fewer excerpts representing *mental health* (13/34, 38%) concerns.

Association to a Person-Centered Care Framework: From Absent to Implemented

Table 3 provides an overview of the extent to which different types of care interactions aligned with a framework of person-centered care, with frequencies and verbatim excerpts included. Of the 346 excerpts documenting care interactions, person-centered care was coded most frequently as *initiated* in 260/346 (75%), and relatively equally as *absent* in 45/346 (13%) and *implemented* in 41/346 (12%). This pattern was similar when coded extracts were tabulated by resident. More specifically 72/78 (92%) of resident charts had at least one care interaction coded as *initiated*, while 33/78 (42%) and 27/78 (35%) were coded as *absent* or *implemented*, respectively.

Interactions around *daily care activities* were most likely to receive an *absent* (20/65 31%) code, while interactions around *treatment decisions* were most likely to receive an *implemented* (12/53, 23%) code. Table 3 provides an overview of the frequency in which person-centered care were coded as *absent*, *initiated*, and *implemented* across different types of care interactions.

Discussion

A person-centred palliative approach to care considers the experience of the whole person, such that social, emotional, spiritual, and functional domains of care are prioritized alongside medical care (Touzel & Shadd, 2018). It also advocates for personal preferences to be incorporated into care planning (Phelan et al., 2020; The American Geriatrics Society Expert Panel on Person-Centered Care, 2016). Our review of progress notes suggests that while nurses and other allied health professionals document personal preferences in some domains important to EOL care (e.g., social concerns), the personal preferences in other domains are less frequently noted (e.g. pain and discomfort) (Bravo et al., 2016). Further, our analysis of person-centred practices revealed that fully implemented personalized care planning was rare across all domains. Taken together, these findings suggest that more needs to be done to promote a person-centred palliative environment in LTC – or at the very least, a person-centred documentation practice, given that person-centered interventions may have occurred and simply were not documented (Sawatzky et al., 2016; Touzel & Shadd, 2018). Indeed, many electronic documentation systems are designed to track information related to biomedical tasks, rather than relevant psychosocial information like “who that person is, what he or she likes to be called, their favorite activity, or their past occupation” (Johnson et al., 2021, p. 1128). This focus likely influences what professionals elect to document in open progress notes.

Our analysis revealed that residents’ daily care needs, social concerns, and medical issues were frequently documented by nurses and other allied health professionals. However, other domains important to a holistic palliative approach to care (e.g., pain and suffering, spirituality, and financial concerns) were less frequently documented. It is likely that organizational priorities such as conducting personal care and encouraging resident participation in social programming influenced the frequency that such care preferences are observed and documented by nurses and other allied health professionals, suggesting that care practices in LTC may still be largely organizationally driven (Banerjee & Armstrong, 2015; Caspar et al., 2016). Despite being considered pertinent in holistic palliative care models, interactions around end-of-life management and loss/grief rarely emerged in our analysis, perhaps due to the relatively high health stability of our sample (Canadian Hospice Palliative Care Association, 2013). However, establishing a holistic palliative approach to care in LTC requires that a broad array of preferences important to end-of-life planning are frequently elicited and documented.

Nurses and other allied health professionals may benefit from more support and direction to observe and elicit the broad array of preferences considered pertinent for a palliative approach to care. Exposure to programs designed to support holistic palliative care communication such as *Me and My Wishes* (Towsley et al., 2018), *The Conversation Project* (Institute for Health Care Improvement, 2021), and *The Speak Up Campaign* (Canadian Hospice Palliative Care Association, 2021) may help staff elicit resident preferences that extend beyond those commonly observed and documented in the context of usual care.

Although resident preferences were recognized across all domains, 42% of reviewed resident charts contained evidence that person-centred care was absent, most commonly in the domain of daily care interactions. Daily care activities are the most common site of interactions between residents and nurses and other allied health professionals. In these instances, residents' behaviours were often recorded as "impulsive", "over-confident" or "risky". When their behaviour is interpreted as non-compliant and uninformed, residents are socialized to question the value of their expertise, and nurses and other allied health professionals are less inclined to incorporate resident perspectives into care planning (Wiersma & Dupuis, 2010). Such framing stands in stark contrast to the principles of person-centered care, which position residents and families as experts in their own circumstances rather than uninformed recipients expected to comply to expert-driven plans (Phelan et al., 2020; The American Geriatrics Society Expert Panel on Person-Centered Care, 2016).

Instead, nurses and other allied health professionals should be encouraged to inquire about the context of such behaviours in order to promote person-centred discussions and collaborative care planning (Rietjens et al., 2017; Sudore et al., 2017). For example, if a resident at a heightened risk of falling is observed repeatedly attempting to independently ambulate, nurses and other allied health professionals could take the opportunity to ask the resident about the importance of ambulation to their quality of life, or the level of risk they are willing to take to preserve ambulation. Indeed, the act of risk-taking can confer dignity, enhancing an individual's personal growth and quality of life (Woolford et al., 2020). To be consistently implemented by nurses and other allied health professionals, person-centred discussions need to be supported by a culture of care that provides the time and support required for such personalized conversations and collaborative planning (Hunter et al., 2016).

Our analysis illuminated that almost all (92%) residents had at least one progress note where nurses and other allied health professionals initiated person-centered care by documenting a personalized care preference. However, only 1/3 of those observed preferences were implemented into a care plan (35%). This discrepancy is noteworthy, given that residents participating in this study were characterized by higher medical stability relative to the general LTC population, and were thus less likely to require specialized approaches to person-centered care due to impaired communication or judgement (Kitwood, 1997).

The failure to move from preference recognition to collaborative care planning was particularly evident in staff-resident interactions related to daily care activities, social concerns, pain and discomfort, and spirituality. For example, residents' social concerns were recognized by nurses and other allied health professionals 78% of the time but only implemented into care planning 15% of the time. While acknowledging personal histories and social preferences builds relationships between residents and staff, residents can feel as if their preferences are being neglected if efforts are not taken to incorporate this personalized information into care (Broderick & Coffey, 2013; Sussman et al., 2022). Over time, this dynamic can deter residents from opening up about care preferences, impeding the implementation of palliative approaches and practices (Donnelly & MacEntee, 2016). Notably, the capacity of nurses and other allied health professionals to fully implement a care plan change may be limited by lack of resources or the nature of shift work (Mariani et al., 2017). Nonetheless, improving capacities to incorporate all aspects of care into collaborative care planning should be a focus of training. Using scenarios derived from usual practice, such as the chart-based data used in this study, may help nurses and other allied health professionals identify patterns of interaction that threaten person-centred practices in certain domains and offer opportunities to discuss and reflect on more holistic approaches to preference elicitation and collaborative planning (Viau-Guay et al., 2013).

The full implementation of person-centred care was most frequently documented in the domain of medical treatment, where 23% of excerpts contained evidence of preferences being acknowledged and incorporated into care planning. Residents' medical treatment preferences were most frequently incorporated into care planning for decisions related to hospitalization and medication administration, suggesting that LTC homes may be best positioned to enact a person-centred palliative approach to care around medical concerns such as preferences for comfort care or remaining in LTC at EOL.

Study Limitations

Our findings should be considered in light of the following four limitations.

First, while we included a mix of LTC contexts, our study was conducted in three LTC sites in Southern Ontario, limiting the generalizability of our results to other localities. Further, while population-level data on race and ethnicity is not collected from Canadian LTC homes (Flanagan et al., 2021), our sample was predominantly white. Future studies should explore how person-centered palliative approaches to care are documented in the progress notes of racialized residents (Shippee et al., 2022).

Second, it is possible that nurses and allied health professionals omitted the actions they took in response to observed preferences while documenting their progress notes, resulting in an underreporting of person-centred planning (Wickson-Griffiths et al., 2014).

Third, nursing aides provide upwards of 80% of the hands-on care in Ontario LTC homes (Kontos et al., 2009). Since nursing aids are not authorized to document in the Point Click Care system, this study may underreport the frequency with which residents and nursing aides/support staff engage in personalized interactions around daily care. However, the nurses and other allied health professionals whose documentation is represented in the progress notes are typically charged with care planning and hence best positioned to ensure resident inclusion in decision-making as leaders in the LTC home (Bartz, 2010; Keenan et al., 2008).

Fourth, we recognize that not all preferences articulated by residents can nor should be acommodated, due to their unfeasible nature or the scarcity of resources in LTC. However our chart-based data incidcated that more could be done to support a culture of person-centred care in LTC for a group of residents best positioned to articualte their preferences and make informed choices about risk.

Conclusion

Our review of progress notes from three LTC homes in Southern Ontario suggests that LTC homes proficiently recognize residents' daily care, social, and medical preferences, but spirituality, pain and suffering and financial issues are less commonly documented. Further, while person-first language is frequently used in LTC, objectifying charting language (e.g., framing a resident as non-compliant) is still present, particularly in progress notes denoting daily care interactions (e.g., walking and transfer). Finally, collaborative care planning appears relatively absent in charted progress notes, constraining the full implementation of a person-centered palliative approach to care.

The data that informed this paper was collected prior to the onset of the global COVID-19 pandemic. In Canada, LTC accounted for 81 per cent of COVID-19-related deaths (Estabrooks et al., 2020). Furthermore, families were restricted from visitation and staff were forced to focus on implementing rigid rules and regulations to control spread of the virus, leading to LTC residents dying alone, with minimal care, communication, or support (Strang et al., 2020). We hope that our findings serve as a critical reminder that the provision of person-centered palliative care must be viewed as a priority from the time of entry in LTC until death.

Relevance to Clinical Practice

There is a movement to adopt a person-centred palliative approach to care across healthcare sectors, including in LTC. Where other studies have explored the implementation of person-centered palliative approaches to care via the varying self-reports of staff (Dys et al., 2022), this paper is unique for utilizing chart-based data. Our findings suggest that person-first charting language and collaborative decision making could advance the movement towards a person-centered palliative approach to care.

References

Armstrong, P., & Armstrong, H. (2020). Chapter Five: Contracting-Out Care: Nursing Homes in Canada. In F. Collyer & K. Willis (Eds.), *Navigating Private and Public Healthcare* (pp. 87–103). Springer Singapore. https://doi.org/10.1007/978-981-32-9208-6_5

Banerjee, A., & Armstrong, P. (2015). Centring Care: Explaining Regulatory Tensions in Residential Care for Older Persons. *Studies in Political Economy*, *95*(1), 7–28. https://doi.org/10.1080/19187033.2015.11674944

Bartz, C. C. (2010). International Council of Nurses and person-centered care. *International Journal of Integrated Care*, *10*(5). https://doi.org/10.5334/ijic.480

Blair, W., & Smith, B. (2012). Nursing documentation: Frameworks and barriers. *Contemporary Nurse*, *41*(2), 160–168. https://doi.org/10.5172/conu.2012.41.2.160

Brant, J. M. (2017). Holistic Total Pain Management in Palliative Care: Cultural and Global Considerations. *Palliative Medicine and Hospice Care*, *SE*(1), S32–S38. https://doi.org/10.17140/PMHCOJ-SE-1-108

Bravo, G., Trottier, L., Arcand, M., Boire-Lavigne, A.-M., Blanchette, D., Dubois, M.-F., Guay, M., Lane, J., Hottin, P., & Bellemare, S. (2016). Promoting advance care planning among community-based older adults: A randomized controlled trial. *Patient Education and Counseling*, *99*(11), 1785–1795. https://doi.org/10.1016/j.pec.2016.05.009

Broderick, M. C., & Coffey, A. (2013). Person-centred care in nursing documentation. *International Journal of Older People Nursing*, *8*(4), 309–318. https://doi.org/10.1111/opn.12012

Canadian Hospice Palliative Care Association. (2013). *A model to guide hospice palliative care*. Canadian Hospice Palliative Care Association. https://www.chpca.ca/wp-content/uploads/2019/12/norms-of-practice-eng-web.pdf

Canadian Institution for Health Information. (2019). *Profile of residents in residential and hospital-based continuing care, 2018–2019 | CIHI*. Canadian Institution for Health Information. https://www.cihi.ca/en/profile-of-residents-in-residential-and-hospital-based-continuing-care-2018-2019

Caspar, S., Cooke, H. A., Phinney, A., & Ratner, P. A. (2016). Practice Change Interventions in Long-Term Care Facilities: What Works, and Why? *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *35*(3), 372–384. https://doi.org/10.1017/S0714980816000374

Cope, D. G. (2014). Methods and Meanings: Credibility and Trustworthiness of Qualitative Research. *Oncology Nursing Forum*, *41*(1), 89–91. https://doi.org/10.1188/14.ONF.89-91

Crocker, A. F., & Smith, S. N. (2019). Person-first language: Are we practicing what we preach? *Journal of Multidisciplinary Healthcare*, *Volume 12*, 125–129. https://doi.org/10.2147/JMDH.S140067

Dedoose (8.3.35). (2020). SocioCultural Research Consultants, LLC. www.dedoose. com

Donnelly, L., & MacEntee, M. I. (2016). Care Perceptions among Residents of LTC Facilities Purporting to Offer Person-Centred Care. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *35*(2), 149–160. https://doi.org/10.1017/S0714980816000167

Dys, S., Tunalilar, O., Hasworth, S., Winfree, J., & White, D. L. (2022). Person-centered care practices in nursing homes: Staff perceptions and the organizational environment. *Geriatric Nursing*, *43*, 188–196. https://doi.org/10.1016/j.gerinurse.2021.11.018

Elo, S., & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107–115. https://doi.org/10.1111/j.1365-2648.2007.04569.x

Estabrooks, C. A., Straus, S. E., Flood, C. M., Keefe, J., Armstrong, P., Donner, G. J., Boscart, V., Ducharme, F., Silvius, J. L., & Wolfson, M. C. (2020). Restoring trust: COVID-19 and the future of long-term care in Canada. *FACETS*, *5*(1), 651–691. https://doi.org/10.1139/facets-2020-0056

Flanagan, A., Um, S., Sinha, S., Roche, B., Rosenburg, J., Nicin, M., & McKenzie, K. (2021). *Leaving No One Behind in Long-Term Care: Enhancing Socio-Demographic Data Collection in Long-Term Care Settings* (pp. 1–58). National Institute on Ageing & Wellesley Institute. https://www.wellesleyinstitute.com/wp-content/uploads/2021/07/LeavingNoOneBehind-July-20-2021-FINAL.pdf

Gómez-Vírseda, C., de Maeseneer, Y., & Gastmans, C. (2019). Relational autonomy: What does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC Medical Ethics*, *20*(1), 76. https://doi.org/10.1186/s12910-019-0417-3

Hirdes, J. P., Frijters, D. H., & Teare, G. F. (2003). The MDS-CHESS scale: A new measure to predict mortality in institutionalized older people. *Journal of the American Geriatrics Society*, *51*(1), 96–100. https://doi.org/10.1034/j.1601-5215.2002.51017.x

Hirschfeld, M. J. (2009). Accepting Responsibility for Long-Term Care-A Paradox in Times of a Global Nursing Shortage? *Journal of Nursing Scholarship*, *41*(1), 104–111. https://doi.org/10.1111/j.1547-5069.2009.01257.x

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, *15*(9), 1277–1288. https://doi.org/10.1177/1049732305276687

Hunter, P. V., Hadjistavropoulos, T., Thorpe, L., Lix, L. M., & Malloy, D. C. (2016). The influence of individual and organizational factors on person-centred dementia care. *Aging & Mental Health*, *20*(7), 700–708. https://doi.org/10.1080/13607863.2015.1056771

Johnson, K., Razo, S., Smith, J., Cain, A., & Detaranto, B. (2021). A person centered nursing care intervention on a medical surgical unit. *Geriatric Nursing*, *42*(5), 1125–1128. https://doi.org/10.1016/j.gerinurse.2021.06.029

Kaasalainen, S., Sussman, T., Thompson, G., McCleary, L., Hunter, P. V., Venturato, L., Wickson-Griffiths, A., Ploeg, J., Parker, D., Sinclair, S., Dal Bello-Haas, V., Earl, M., You, J. J., & the SPA-LTC team. (2020). A pilot evaluation of the strengthening a palliative approach in long-term care (SPA-LTC) program. *BMC Palliative Care*, *19*(1), 107. https://doi.org/10.1186/s12904-020-00599-w

Keenan, G. M., Yakel, E., Tschannen, D., & Mandeville, M. (2008). Chapter 49. Documentation and the Nurse Care Planning Process. In R. G. Hughes (Ed.), *Patient Safety and Quality: An Evidence-Based Handbook for Nurses* (p. 32). Agency for Healthcare Research and Quality.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Open University Press.

Larsen, L. S., Blix, B. H., & Hamran, T. (2020). Family caregivers’ involvement in decision-making processes regarding admission of persons with dementia to nursing homes. *Dementia*, *19*(6), 2038–2055. https://doi.org/10.1177/1471301218814641

Lopez, S. H. (2014). Culture Change and Shit Work: Empowering and Overpowering the Frail Elderly in Long-Term Care. *American Behavioral Scientist*, *58*(3), 435–452. https://doi.org/10.1177/0002764213503340

Lozano, R., Naghavi, M., Foreman, K., Lim, S., Shibuya, K., Aboyans, V., Abraham, J., Adair, T., Aggarwal, R., Ahn, S. Y., AlMazroa, M. A., Alvarado, M., Anderson, H. R., Anderson, L. M., Andrews, K. G., Atkinson, C., Baddour, L. M., Barker-Collo, S., Bartels, D. H., … Murray, C. J. (2012). Global and regional mortality from 235 causes of death for 20 age groups in 1990 and 2010: A systematic analysis for the Global Burden of Disease Study 2010. *The Lancet*, *380*(9859), 2095–2128. https://doi.org/10.1016/S0140-6736(12)61728-0

Mariani, E., Vernooij-Dassen, M., Koopmans, R., Engels, Y., & Chattat, R. (2017). Shared decision-making in dementia care planning: Barriers and facilitators in two European countries. *Aging & Mental Health*, *21*(1), 31–39. https://doi.org/10.1080/13607863.2016.1255715

Marshall, C., & Rossman, G. B. (2015). *Designing qualitative research* (6th ed.). SAGE Publications.

Olsson, L.-E., Jakobsson Ung, E., Swedberg, K., & Ekman, I. (2013). Efficacy of person-centred care as an intervention in controlled trials—A systematic review. *Journal of Clinical Nursing*, *22*(3–4), 456–465. https://doi.org/10.1111/jocn.12039

Peterson, A. M. (2014). Nursing home medical records: Part 2: Documentation review. *Jounal of Legal Nurse Consulting*, *25*(2), 42–48.

Phelan, A., McCormack, B., Dewing, J., Brown, D., Cardiff, S., Cook, N., Dickson, C., Kmete, S., Lorber, M., Magowan, R., McCance, T., Skovdahl, K., Štiglic, G., & van Lieshout, F. (2020). Review of developments in person-centred healthcare. *International Practice Development Journal*, *10*(Suppl2), 1–29. https://doi.org/10.19043/ipdj.10Suppl2.003

Rietjens, J. A. C., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., van der Heide, A., Heyland, D. K., Houttekier, D., Janssen, D. J. A., Orsi, L., Payne, S., Seymour, J., Jox, R. J., & Korfage, I. J. (2017). Definition and recommendations for advance care planning: An international consensus supported by the European Association for Palliative Care. *The Lancet Oncology*, *18*(9), e543–e551. https://doi.org/10.1016/S1470-2045(17)30582-X

Rockwell, J. (2012). From Person-Centered to Relational Care: Expanding the Focus in Residential Care Facilities. *Journal of Gerontological Social Work*, *55*(3), 233–248. https://doi.org/10.1080/01634372.2011.639438

Sawatzky, R., Porterfield, P., Lee, J., Dixon, D., Lounsbury, K., Pesut, B., Roberts, D., Tayler, C., Voth, J., & Stajduhar, K. (2016). Conceptual foundations of a palliative approach: A knowledge synthesis. *BMC Palliative Care*, *15*(1), 5. https://doi.org/10.1186/s12904-016-0076-9

Shippee, T. P., Fabius, C. D., Fashaw-Walters, S., Bowblis, J. R., Nkimbeng, M., Bucy, T. I., Duan, Y., Ng, W., Akosionu, O., & Travers, J. L. (2022). Evidence for Action: Addressing Systemic

Racism Across Long-Term Services and Supports. *Journal of the American Medical Directors Association*, *23*(2), 214–219. https://doi.org/10.1016/j.jamda.2021.12.018

Strang, P., Bergström, J., Martinsson, L., & Lundström, S. (2020). Dying From COVID-19: Loneliness, End-of-Life Discussions, and Support for Patients and Their Families in Nursing Homes and Hospitals. A National Register Study. *Journal of Pain and Symptom Management*, *60*(4), e2–e13. https://doi.org/10.1016/j.jpainsymman.2020.07.020

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., Matlock, D. D., Rietjens, J. A. C., Korfage, I. J., Ritchie, C. S., Kutner, J. S., Teno, J. M., Thomas, J., McMahan, R. D., & Heyland, D. K. (2017). Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *Journal of Pain and Symptom Management*, *53*(5), 821-832.e1. https://doi.org/10.1016/j.jpainsymman.2016.12.331

Sussman, T., Mintzberg, S., Sinai-Glazer, H., Venturato, L., Strachan, P. H., & Kaasalainen, S. (2022). “Slam Bam, Thank you, Ma’am”: The Challenges of Advance Care Planning Engagement in Long-Term Care. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, 1–8. https://doi.org/10.1017/S0714980821000738

The American Geriatrics Society Expert Panel on Person-Centered Care. (2016). Person-centered care: A definition and essential elements. *Journal of the American Geriatrics Society*, *64*(1), 15–18. https://doi.org/10.1111/jgs.13866

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, *19*(6), 349–357. https://doi.org/10.1093/intqhc/mzm042

Touzel, M., & Shadd, J. (2018). Content Validity of a Conceptual Model of a Palliative Approach. *Journal of Palliative Medicine*, *21*(11), 1627–1635. https://doi.org/10.1089/jpm.2017.0658

Vaismoradi, M., Turunen, H., & Bondas, T. (2013). Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study: Qualitative descriptive study. *Nursing & Health Sciences*, *15*(3), 398–405. https://doi.org/10.1111/nhs.12048

Viau-Guay, A., Bellemare, M., Feillou, I., Trudel, L., Desrosiers, J., & Robitaille, M.-J. (2013). Person-Centered Care Training in Long-Term Care Settings: Usefulness and Facility of Transfer into Practice. *Canadian Journal on Aging / La Revue Canadienne Du Vieillissement*, *32*(1), 57–72. https://doi.org/10.1017/S0714980812000426

Wickson-Griffiths, A., Kaasalainen, S., Ploeg, J., & McAiney, C. (2014). A review of advance care planning programs in long-term care homes: Are they dementia friendly? *Nursing Research and Practice*, *2014*, 875897. https://doi.org/10.1155/2014/875897

Wiersma, E., & Dupuis, S. L. (2010). Becoming institutional bodies: Socialization into a long-term care home. *Journal of Aging Studies*, *24*(4), 278–291. https://doi.org/10.1016/j.jaging.2010.08.003

Woolford, M. H., Lacy-Vawdon, C., Bugeja, L., Weller, C., & Ibrahim, J. E. (2020). Applying dignity of risk principles to improve quality of life for vulnerable persons. *International Journal of Geriatric Psychiatry*, *35*(1), 122–130. https://doi.org/10.1002/gps.5228

Table 1: Participant Profiles

Age	79.6 ± 11.7 years
Gender	
Men	38 (49%)
Women	40 (51%)
Race	
White	61 (78%)
East Asian	5 (6%)
Indigenous	3 (4%)
Black	2 (3%)
Middle Eastern	2 (3%)
Caribbean	2 (3%)
South Asian	1 (1%)
Southeast Asian	1 (1%)
Marital Status	
Never married	11 (14%)
Married/common-law	21 (27%)
Widowed	35 (45%)
Divorced/separated	10 (13%)
Education	
No secondary school	27 (35%)
Secondary school	14 (18%)
Beyond secondary school	37 (47%)
Duration Living in LTC	2.7 ± 3.9 years
CHESS Score	
(0) No health instability	37 (47%)
(1) Minimal health instability	32 (41%)
(2) Low health instability	6 (8%)
(3) Moderate health instability	2 (3%)
(4) High health instability	1 (1%)

Table 2: Types of Charted Interactions

	N (%)	Code	N (%)	Example
Daily Care Activities	65/78 (83%)	Food & Intake	43/65 (66%)	resident would prefer to discontinue weight reduction intervention, instead prefers to self-limit his food choices (*Robert*, 77)
		Walking & Transfer	31/65 (48%)	resident has decreased endurance in walking... is interested in participating in walking program as she does not want to lose the ability to walk (*Sandra*, 76)
		Living Space	21/65 (32%)	wants a picture hung in her room (*Ronnie*, 93)
		Grooming & Routine	17/65 (26%)	does not want showers on cold days, requests bed bath (*Patricia*, 41)
Social Concerns	65/78 (83%)	Internal	60/65 (92%)	resident enjoys independent activities at own comfort in his room such as watching TV, reading or conversing with staff and residents (*Stuart*, 89)
		External	29/65 (45%)	resident's behaviour settles and becomes calm when he sees family members (*Michael*, 84)
		Staff Care	8/65 (12%)	resident states that he does not enjoy one on one monitoring, which he sees as being followed (*Richard*, 77)
Treatment Decisions	53/78 (68%)	Medical Care	46/53 (87%)	resident request to be prescribed prochorperazine instead of Gravol as it does not make her sleepy (*Wilma*, 86; physician progress note)
		Hospital Transfer	19/53 (36%)	resident having an extreme allergic reaction to cephalexin, notified daughter POA, declined to send resident to hospital and asked for comfort measures in [the care home] (*Lionel*, 96)
Pain & Discomfort	34/78 (44%)	Physical Discomfort	26/34 (76%)	resident asks PSW to remove watch as it is hurting his wrist (*William*, 74)
		Mental Health	13/34 (38%)	[the care home will] address client's psychosocial and emotional state by giving client appropriate sleep medication, have

			volunteers come to visit clients, reduce day time napping to increase nighttime sleep (*Thomas*, 88)
Spirituality	27/78 (35%)		resident has individualized weekly visits with Rabbi and community center staff as he chooses (*Maury*, 84)
Financial Concerns	6/78 (8%)		resident upset and not transitioning well to LTC due to finances being transferred to public guardian and trustee, is blaming her life transitions coach for her finances and refuses to talk to this individual (*Nancy*, 70)

All example excerpts were written by nurses, unless otherwise indicated.

Table 3: Frequency of Person-Centered Care Alignments Across Different Types of Care Interactions

	N (%)	PCC	n (%)	Example
Daily Care Activities	65/78 (83%)	Implemented	7/65 (11%)	resident complained to writer that during the night he's a bit worried that his roommate is just too loud and it disturbs him. Assured resident that staff will check on resident and will monitor on roommate's behaviour (*Dennis*, 81)
		Initiated	38/65 (58%)	resident complained about receiving tomato soup for three consecutive days and that he and his wife both hate hamburgers - requests to have different soup and cheese sandwiches for both he and his wife (*Carl*, 78)
		Absent	20/65 (31%)	resident was found walking in the halls unsteadily. Staff redirected resident and she was unhappy stating 'I can walk, I can walk' (*Diane*, 45)
Social Concerns	65/78 (83%)	Implemented	10/65 (15%)	resident states he believes he doesn't have much time to live, and he struggles with his breathing/oxygen, and wants his family to visit him. His daughter explains she's been sick for months and is feeling better now so she will be planning weekly visits with her father, her father is happy with the news (*Charles*, 87)
		Initiated	51/65 (78%)	remains involved socially and often encourages others around her (*Brenda*, 66)
		Absent	4/65 (6%)	resident moved to private room for safety to which resident was upset and crying stating that she did not want to be alone (*Paula*, 80; social worker progress note)
Treatment Decisions	53/78 (68%)	Implemented	12/53 (23%)	reviewed ACP. Wishes Allow Natural Death/No CPR. Does not want to be maintained on life supports if little chance of meaningful recovery; Changed at this meeting (*Maury*, 84)
		Initiated	30/53 (57%)	POA (son) states chemo medication makes the resident feel fatigued, he takes the medication on Friday and usually his days spent in bed are Sunday and Monday (*Edward*, 78)
		Absent	11/53 (21%)	resident requested to discontinue treatment as she finds it stressful to breathe. Resident has been non-compliant with treatment despite encouragement (*Donna*, 82; physiotherapist progress note)

Pain & Discomfort	34/78 (44%)	Implemented	5/34 (15%)	resident has been complaining of hip pain and requested hip x-ray. Results reveal OA, resident already on prn medications and is not interested in taking more med (*Glen*, 62)
		Initiated	25/34 (74%)	resident complained to writer that she was having anxiety during the night couple days prior, feel anxious and would like to discuss with [physician] (*Sharon*, 74)
		Absent	4/34 (12%)	resident has request for bedside pole to help him get from bed was denied due to risk of entrapment and injury - resident upset and unhappy, ‘all I am asking is for help to get up and prevent shoulder pain’ (*Carl*, 78)
Spirituality	27/78 (35%)	Implemented	0/27 (0%)	N/A
		Initiated	27/27 (100%)	resident attends ‘Ask the Rabbi’ as he chooses (*George*, 72)
		Absent	0/27 (0%)	N/A
Financial Concerns	6/78 (8%)	Implemented	3/6 (50%)	resident has asked office manager to control his finances for him (*Roy*, 80)
		Initiated	2/6 (33%)	resident says that last dental consult he had told him that the procedure he requires costs around $2000 – ‘I do not have this money’ (*Jerry*, 65)
		Absent	1/6 (17%)	staff are concerned with resident using electric wheelchair - resident was unable to maneuver while entering the TV room and hit the wall - staff reminded resident that he should be in his room in the wheelchair. POA's concern is over whether it is worth paying for the wheelchair to be repaired when he is not able to use it. (*Brian*, 65)

Person-centered care was (1) *absent* in progress notes that prioritized professional expertise without evidence that a resident’s preference was subsequently discussed or considered in care planning (2) *initiated* in progress notes where residents’ preferences were documented without evidence that a resident’s preference was subsequently discussed or considered in care planning and (3) *implemented* in progress notes where residents’ preferences were both identified and addressed in the care plan.

All example excerpts were written by nurses, unless otherwise indicated.