




Slam Bam, Thank you, Ma'am: The Challenges of Advance Care Planning Engagement in Long-Term Care

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Article

Cite this article: Sussman T, Mintzberg S, Sinai-Glazer H, Venturato L, Strachan PH, & 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* 41(3), 443–450. <https://doi.org/10.1017/S0714980821000738>

Received: 01 March 2021
Accepted: 02 October 2021

Mots-clés :

vieillesse; communication en fin de vie; soins palliatifs; centres de soins; planification préalable des soins; directives anticipées; foyers de soins résidentiels

Keywords:

aging; end-of-life communication; palliative care; nursing homes; advance care planning; advance directives; residential care homes

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Résumé

Cette étude qualitative interprétative a exploré les perspectives des résidents et des familles sur la planification préalable des soins (PPS) dans les centres de soins de longue durée (CSLD). Le moment, la manière et les personnes avec lesquelles les discussions sur la PPS devraient être engagées, ainsi que les obstacles et les solutions à l'amélioration de la participation ont été abordés dans ces perspectives. Sept groupes de discussion ont rassemblé cinquante-et-un résidents et des membres de leurs familles. Les résultats révèlent que les résidents et leur famille ont accordé une priorité aux liens affectifs plutôt qu'au rang professionnel lorsqu'ils envisageaient la contribution du personnel à la PPS. Les résultats indiquent également que l'environnement bienveillant et compatissant, considéré comme une condition préalable essentielle à l'engagement dans la PPS, était plus souvent instauré en fin de vie, alors que la PPS ne représentait plus une option. Nos résultats suggèrent que les pratiques professionnelles et les structures organisationnelles au sein des CSLD jouent un rôle déterminant dans l'inhibition de la participation à un processus de PPS.

Abstract

This interpretative, qualitative study explored residents' and families' perspectives on advance care planning (ACP) in long-term care (LTC). Perspectives on when, how, and with whom ACP discussions should be introduced and barriers and solutions to improving ACP engagement were examined. Fifty-one residents and families participated in seven focus groups. The findings revealed that residents and families prioritized caring connections over professional rank when reflecting on staff involvement in ACP. The findings further revealed that the caring and compassionate environment considered to be a critical pre-condition for ACP engagement was more typically enacted at end of life when ACP was no longer an option. Our findings suggest that work practices and organizational structures within LTC play an important role in inhibiting ACP engagement.

Introduction

Advance care planning (ACP) is a process designed to help people with life limiting conditions reflect on, communicate, and, at times, document their wishes for future care, including end-of-life (EOL) care, before the need for such care arises (Rietjens et al., 2017). ACP is a core element of a palliative approach to care because it aims to normalize death by supporting early and ongoing communication about views on quality of living and quality of dying (Touzel & Shadd, 2018). ACP is also a person-centred approach, as it presumes that the delivery of quality EOL care is grounded in an appreciation for the personal preferences, values, and needs of those who are receiving care (Jeong, Higgins, & McMillan, 2010). With the rising incidence of death in skilled nursing facilities, residential care homes, or nursing homes (referred to herein as *long-term care (LTC)*) (Canadian Institute for Health Information, 2020) and the philosophical drive aimed at humanizing and centralizing personhood in LTC (Phelan et al., 2020; Rockwell, 2012), ACP offers promise for supporting residents living and dying in LTC environments.

Evidence is growing that ACP can enrich residents' and families' experiences with EOL care in LTC. Positive outcomes of ACP interventions implemented in LTC include improved congruence between care preferences and care provided, decreased rates of unwanted hospitalizations at EOL, and increased care satisfaction for residents and family members (Martin, Hayes, Gregorevic, & Lim, 2016; Robinson et al., 2012).

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While the literature also suggests that residents and their families believe it is important to discuss preferences and concerns about future EOL care with staff in LTC, implementation of ACP practices in LTC is still relatively low (Cable-Williams & Wilson, 2017). Barriers to ACP engagement in LTC homes include staff discomfort introducing the topic of death or deteriorating health, uncertainties about what should be discussed, and concern by staff that residents and families do not want to engage in conversations about death and dying (Ampe, Sevenants, Smets, Declercq, & Van Audenhove, 2017; Frechman, Dietrich, Walden, & Maxwell, 2020; Harasym *et al.*, 2020; McGlade *et al.*, 2017; Mignani, Ingravallo, Mariani, & Chattat, 2017; Sussman *et al.*, 2017a). Barriers also include a context of care that prioritizes efficiencies over relational connections, and physical tasks over emotional bonds, limiting the time and resources allocated to support staff's engagement in these emotionally laden discussions (Armstrong & Armstrong, 2020).

A myriad of ACP tools and processes have been developed to support ACP reflections, communication, and documentation (Butler, Ratner, McCree, Shippee, & Kane, 2016; Sussman *et al.*, 2017b; Sussman *et al.*, 2019; Van der Steen *et al.*, 2012). While these materials and interventions have shown some promise in providing staff, residents, and families with structured mechanisms for reflecting on issues of importance, communicating preferences, and/or documenting decisions (Capps, Gillen, Hayley, & Mason, 2018; Davis, Morgans, & Dunne, 2019; Fahner *et al.*, 2019; Kaasalainen *et al.*, 2021; Oczkowski, Chung, Hanvey, Mbuagbaw, & You, 2016; Sussman *et al.*, 2021), the roles that non-regulated staff may play in the distribution and discussion of ACP materials, and the optimal conditions for engaging in such discussions within the context of LTC, remain unexplored (Dixon & Knapp, 2018; Sussman *et al.*, 2019). For example, in the context of LTC where 70–90 per cent of hands-on care is provided by non-regulated staff such as personal support workers/care aides, recreational workers, and dietary assistants, it may not be feasible or desirable to rely on ACP protocols designed to be implemented by nurses and physicians (Kontos, Miller, & Mitchell, 2009). Yet few studies have explored residents' and families' receptivity to divergent staff involvement in ACP discussions (Shaw, Hewson, Hogan, Raffin Bouchal, & Simon, 2018). Further, the long-standing stigma associated with living in LTC makes discussions about death, dying, and deterioration complex (Kinley, Froggatt, & Bennett, 2013; Ramsbottom & Kelley, 2014). However, we are limited in our understandings of how to have supportive conversations with residents and families about deterioration and death without threatening their hopes for good quality of life and quality of care (Ramsbottom & Kelley, 2014). Finally, contextual issues in LTC such as inadequate staff-resident ratios, an increasingly complex resident profile, and limited resources from which to attend to emotional needs have been noted by staff to challenge the implementation of person-centred approaches to care (Armstrong & Armstrong, 2020; Banerjee, Armstrong, Daly, Armstrong, & Braedley, 2015; Ludlow, Churruca, Ellis, Mumford, & Braithwaite, 2021). However, the extent to which these contextual features impact residents' and families' capacities to engage in ACP has remained largely unexplored.

Redressing these gaps in the literature, this article reports findings from a series of focus groups with residents and families intended to (1) explore when, how, and with whom ACP discussions should be introduced and (2) identify conditions thought to challenge and support ACP communication between residents and/or their families/friends and staff within an LTC environment.

Methods

We used an interpretative, descriptive approach informed by the principles of reflexive thematic analysis to explore participants' experiences (Clarke, Braun, Terry, & Hayfield, 2019; Thorne, 2016). Interpretative description presumes the existence of multiple realities that are constructed through social interactions and influenced by context (Thorne, 2016). Researchers are hence expected to bring their expertise to the research process to support the development of rich interpretations that can be used to guide practice (Thorne, 2016). The approach provided us with avenues for applying our collective expertise in nursing, social work, LTC, and EOL communication to the research process.

We selected focus groups as a method of data collection because they allow participants to help one another open up and elaborate on difficult subjects such as death, through dialogue, laughter, and empathic connection (Allen, 2006; Krueger & Casey, 2000). Furthermore, focus groups can create a space in which participants feel validated through shared experiences, which can support rich exchanges, especially from participants whose voices are often overlooked in research and practice such as older persons living in LTC (Allen, 2006; Sussman *et al.*, 2017a).

Site Selection and Recruitment

We recruited participants from four LTC homes in southern Ontario, Canada, in the spring of 2018. The homes represented the mix of LTC contexts found across Canada (Berta, Laporte, Zarnett, Valdmanis, & Anderson, 2006). The homes included for-profit (three) and not-for-profit (one) facilities; ranged in size from large (two; 169 and 206 beds), medium (one; 120 beds), and small (one; 60 beds); included sites with high (two) and low (two) staff turnover; and comprised religious-based (one) and secular (three) facilities. All sites asked residents and families about their resuscitation preferences during their provincially mandated care conferences (offered within six weeks of relocation and every six months thereafter) (Ministry of Health and Long-Term Care, 2007). All study sites had undergone ACP training in the past three years. Two of the homes were piloting an ACP intervention aimed at preparing residents to think about future concerns prior to attending their care conference. This initiative was part of a quality improvement effort led by the senior leadership team overseeing these homes.

Partnering LTC homes assisted us with the recruitment of participants for two distinct focus groups: (1) residents with the cognitive ability to participate in a group discussion and (2) family members of current residents. Recruitment, which occurred over a three-week period in the spring of 2018, included e-mails to families and staff; flyers within the care homes; announcements at staff and programming meetings; and sign-up boards in visible parts of the homes where individuals could register for a group. For resident groups, staff also encouraged residents with known capacity to participate.

One participating site, whose resident population comprised many individuals with limited to no family support, had difficulty recruiting family members. After consistent attempts at outreach, the decision was made to conduct a resident focus group only.

A total of 51 individuals in seven focus groups across four study sites participated in this study: 35 residents in four focus groups (ranging from 8–9 participants per group) and 16 family members in three focus groups (ranging from 3–6 participants per group). Resident participants were an average of 74 years of age (range

57–92), with a slightly higher representation for women (20/35 [57%]) than men (15/35 [43%]). Most residents had lived in LTC for at least one year (23/35 [74%]), had known at least one other resident who had died within the past year (26/35 [74%]), and had not talked to any staff about preferences for future EOL care (30/35 [85.7%]).

Family participants were an average of 66 years of age (range 25–83), were evenly split between adult children (4/16 [25%]), spouses (4/16 [25%]), siblings (4/16 [25%]) and other relatives (4/16 [25%]), were predominantly female (14/16 [88.5%]), and had supported a relative in LTC for an average of 3 years (ranging from 4 months to 12 years). Slightly more than half (9/16 [64%]) had discussed some element of EOL care with staff.

Data Collection

We conducted a total of seven focus groups across four study sites: three with family members and four with residents. Each focus group discussion lasted 75–90 minutes and was co-facilitated by two members of the research team.

We developed a semi-structured interview guide to encourage participants to address their views on ACP (what it means to them, what it should entail), to discuss their perceptions and experiences of ACP within LTC (which staff should introduce the topic, when it should be introduced), and to identify conditions that they feel support or hinder ACP engagement in LTC (what, if anything, makes having ACP discussions difficult in LTC; how, if at all, are ACP discussions supported or encouraged?).

At the start of every focus group, we asked participants to complete a short questionnaire about gender identity, years in LTC, and prior engagement in ACP. Families were asked about their relationship to the resident they were supporting in LTC. The facilitators also provided participants with a working definition of ACP (Rietjens et al., 2017), which included examples of possible topics for reflection and discussion (e.g., preferred location of death, spiritual needs at EOL).

We obtained written consent from all participants prior to conducting focus groups. Facilitators in all groups took time to discuss the purpose of the focus group, the voluntary nature of participation, and the areas that would be explored during discussions. For residents, willingness and physical/cognitive capacity to participate were also monitored by facilitators on an ongoing basis, by ensuring that all residents were actively following and contributing to the discussions (Brown Wilson, 2011). All facilitators were trained health professionals in nursing or social work and were positioned to assess participation capacity.

We conducted the research in accordance with the standards of the Tri-Council Policy Statement for Ethical Conduct for Research Involving Humans 1998 (with 2000, 2002, and 2005 amendments). Procedures were approved by the Office of Research Ethics Board at McGill and McMaster Universities (Kaasalainen et al., 2021).

Data Analysis

We audio-recorded, transcribed, and thematically analysed the focus group deliberations in six stages (Clarke et al., 2019). In the first stage, the second author read the focus group transcripts thoroughly, noting observations and meanings. We then discussed these observations and identified initial codes we thought would broadly capture participants' thoughts, experiences, and reactions to ACP (Marshall & Rossman, 2006). We developed descriptive codes such as participants' concerns about future care, the

challenges of addressing ACP, and beliefs and experiences with ACP at this stage.

In the second stage, the second author matched initial codes with extracts from transcripts. We used large parts of extracts (typically two paragraphs) to ensure the context was preserved. Following this process, we discussed possible meanings and patterns within, between, and across codes, and codes were placed under tentative categories (Marshall & Rossman, 2006). We developed five preliminary categories at this stage that we thought captured the relational and personalized aspects of ACP described by participants.

In the third stage, the first three authors engaged in continuous discussions and reflections about the codes and categories that were generated thus far. Through this process, we developed two themes we thought comprehensively captured how relational care and concerns about staff roles and responsibilities supported or impeded ACP engagement in LTC: (1) "The significance of meaningful discussions" and (2) "Care and compassion."

In the fourth stage, the third author went back to the original transcripts to develop a more detailed analysis of each theme while exploring accuracy, redundancy, and comprehensiveness (Marshall & Rossman, 2006). Through this re-examination, we noted differences in compassionate care enacted for the living and dying representing a key barrier to engaging with ACP. Hence we added a third theme: (3) "Juxtaposing practices for the living and dying."

In the fifth stage, we reviewed the three themes extensively and continued to refine and rename them so that the scope and focus of each theme was clear. In this stage, for example, we renamed the theme "Juxtaposing practices for the living and dying" to "A compassionate environment for the living and the dying is an important pre-condition for ACP engagement." We thought this revised name more clearly connected our observations of differential practices to ACP engagement and also centred the concept of compassion emerging as a critical condition for engaging in ACP discussions. We made similar refinements to the other themes.

In the sixth stage, the first author wrote and distributed the written formulation of the findings to the larger research team for review, input, and final refinement. At this last stage, we assigned all participants pseudonyms to maintain confidentiality while allowing their personal thoughts and experiences to be followed.

Results

Overview of Findings

Findings from focus group discussions revealed that most residents and families had engaged in limited and basic forms of ACP, such as signing non-resuscitation orders or finalizing estate and funeral planning. However, expansive and holistic conversations that included reflections on personal values and care concerns were rare. While many agreed that these holistic conversations were a critical component of care provision in LTC because they can *give you options that you never even thought of* (Alice, family focus group [FFG] 2) and ensure that *there are no misunderstandings* (Steven, resident focus group [RFG] 1), most also felt that staff needed to initiate such exchanges because without guidance and direction they *don't really know exactly what you would say to the staff* (Shannon, FFG 2). Participants across focus groups suggested that relational connections rather than staff rank, time for meaningful exchanges, and a caring and compassionate living environment were necessary pre-conditions to ACP engagement and

discussion. Unfortunately, as depicted by the sentiments expressed below, the work practices that govern life in LTC played an important role in inhibiting ACP engagement with staff.

Relational connections with staff are more important than staff rank for ACP engagement

When residents and family members were asked if specific staff within LTC should be charged with encouraging ACP reflection, similar sentiments were expressed within and across all focus groups. Each group felt that care and compassion were more important than professional designation or rank. The following exchange between residents demonstrates that feeling cared about by staff was a necessary pre-condition to engage in ACP discussions.

I: *What staff would you have that discussion [about ACP] with?*

Ben: *Those who care.*

Eliot: *Those who care and want to try to help.*

Lillian: *Not the ones who are here because it's a job.* (RFG 4)

Family members emphasized how powerful a caring relationship can be for encouraging ACP conversations: *As far as the staff goes, I would think anybody that you're comfortable with* (Debra, FFG 1).

Participants further suggested that all staff in LTC, regardless of role, should be available, open, and willing to engage in ACP discussions, and that these discussions should not be restricted to doctors and nurses with whom one may have reduced access and limited connection. The information exchanged in such discussions could subsequently be shared with other staff members, as needed. One family member suggested: *I'd say talk to everybody you can, it doesn't matter [what their role is]. And speak to them and get the questions answered and ask questions. It shouldn't be one person* (Rachel, FFG 4).

According to participants, limiting ACP conversations to particular professional staff can lead to residents' and families' discomfort, particularly if conversations occur with someone with whom they may have little rapport. Rhonda expresses the relationship she has with her doctor in LTC as follows: *He's just somebody who isn't good with people with relationships.... There's no connection* (RFG 1).

Families, too, highlighted the importance of relational connections in ACP engagement. They noted that if a clinical staff must initiate the conversation, then a second member of the staff, with whom the resident has a good connection, should be present as well. Lucy, a granddaughter emphasizes this sentiment as follows: *It should be someone that connects with your family member. So, for example, my Grandma has a few PSWs [personal support workers] that she loves, but the ones that show the affection you know she feels comfortable with. Even being there, I think, would be really important for the resident to feel like they're being heard and they have someone that cares about them* (FFG 1).

Overall, both residents and family members considered caring relationships with staff as an important and critical aspect of ACP in LTC. They suggested that the nature of their relationship with staff, rather than that person's professional affiliation, was fundamental for determining with whom they would choose to discuss ACP.

Time and opportunities for meaningful exchanges with all staff in LTC are limited

While residents and families were open to engaging in ACP discussions with staff regardless of rank, many wondered whether the

priorities for care in LTC would allow for such exchanges. This sentiment is depicted in the exchange below between residents.

Lillian: *Most of them [staff members] are trying to do everything they can, but... they only have so much strength and they only have so much time. And it is impossible for them to cover everybody.*

Yasser: *They don't have any time they're too busy. I mean they might like to but they just don't have time.*

Ben: *They're just busy.*

Lillian: *They [the caregivers] come in and they wash me, they get me ready for the day but they don't have time to chitchat about how I want to die. They just need to get the job done.* (RFG 4)

In extreme cases, the staff's focus on tasks rather than connections left residents feeling completely overlooked or ignored, inhibiting their desire to open up about preferences and concerns for future EOL care. This was the case for Charlotte who described her experiences as follows: *A lot of times when you talk to the staff here, they just totally ignore you and I think that I want to make sure that my last requests are taken seriously* (RFG 3).

As a consequence, residents reported limited dialogue and discussion with staff about EOL care preferences. When asked by facilitators whether any had had discussions with staff about their wishes for EOL care, a typical response was, *No, not yet* (Florence, FFG 2).

Families more commonly described having engaged in EOL discussions about residents' care preferences with staff. However, these exchanges were often brief, occurred in public spaces, and tended to be activated when relatives were perceived to be near EOL. This is reflected by a daughter, who was given information about her mother's health status in a hallway:

I had a very brief five-minute meeting in the hall at the nursing station, where they told me that 'well you know she's palliative and we're going to keep her comfortable and pain free.' That was it. [But] I would like to sit down with staff and talk about different options available ... just so they could tell me their thoughts and I could either you know agree or disagree (Shannon, FFG 2).

Families, like residents, longed for meaningful exchanges with attentive and caring staff who could take the time to explain and sort through the information about EOL planning, connecting it to their relative's circumstances. With many interactions described as rushed and task-oriented, significant barriers for profound reflection and discussion about EOL wishes were expressed.

A compassionate environment for the living and the dying is an important pre-condition for ACP engagement

The compassionate environment residents felt was needed to allow for ACP discussions seemed to occur more frequently during the final days of life when ACP was no longer an option. Maria, a resident, describes the compassionate care she has observed at EOL as follows:

Maria: *I have been a witness to a lady who is a resident here and just before she passed away, I have seen or witnessed the care, the staff provided for her daughter. I think it was a very nice gesture not only for the resident but also for the daughter.*

I: *Okay, great. What were some of the things that they did?*

Maria: *You know they always bringing a tea or coffee or bring a trolley. You know things like a book to read or a cookie, tea, coffee.* (RFG 2)

Families, likewise, spoke of discrepancies between the style of daily care and attention their relatives received with what they

observed when residents were dying. Rafael explained that moving into LTC was a real slam, bam, thank you, ma'am (FFG 1). Daily care always felt rushed and impersonal. Some families suggested that their relative's deterioration was due to care that focused on efficiency rather than on personalization:

I've had conversations with the nurses and with the PSWs around allowing my mom to be doing as much as she can for herself. Letting her do things, don't do things for her. ... And it doesn't happen and I've seen her decline and forget how to use a utensil for example. Because it's easier just to spoon things in her mouth instead of allowing her to do it. So she can't do those things anymore and I know with her dementia, I mean I know she's kind of on a downward slope there but I think that things have progressed quicker than perhaps they should have ... (Shawn, FFG 4).

In contrast, families observed staff that would go the extra mile in the final stages of life as depicted by the following comments:

Well, the good things were when the time was to come, you know they [the staff] did make them comfortable. They did put them in the bed, you know like if they were really close to that time and made sure that they had the cloth on them and they were changed. I have to say the staff is very good that way ... so yeah they still looked after the residents that way when it came time (Jim, FFG 2).

I have had experience here [at the LTC home] with my mother-in-law that we brought back from the hospital to allow her to [die] here. And they were really good. They were good with her, they were good with us. There was probably a forty-eight hour period and the nurses talked us through each stage and would come and say this is what is happening now. Don't be upset by it ... But it was really very good and even the PSWs, because they're part of it too ... (Rachel, FFG 4).

These exchanges highlight striking differences between daily life in LTC and EOL care practices. It is noteworthy that the type of meaningful and attentive care that residents and families considered important for discussion about ACP with staff was typically offered when death was imminent and ACP was no longer viable.

Discussion

ACP is a process of thinking about and communicating values, wishes, and preferences for future care, including EOL care. ACP is gaining acceptance as an essential aspect of quality health care in Canada because it improves the delivery of personalized EOL care, reduces health costs, enhances care satisfaction, and normalizes dying (Canadian Hospice Palliative Care Association, 2008). Our study findings illuminate some of the conditions within LTC that inhibit ACP engagement from the perspective of residents and families.

According to participants in our study, relational connections rather than roles and professional designations should be used when determining which staff to involve in ACP programming. More specifically, from the perspective of participants, all staff who are familiar with residents' beliefs, preferences, and personal histories have a valuable role to play in the implementation of ACP in LTC. Unfortunately, many of our participants questioned whether the staff whom they felt most connected to had the time to partake in such conversations. As a result, most residents and families who discussed future care considered their exchanges short and focused rather than meaningful and iterative.

The literature on staff perceptions of ACP affirms and expands the sentiments expressed by our study participants. This research suggests that non-regulated staff such as nursing and recreational aides are well positioned to contribute to ACP engagement because of their frequent and intimate interactions with residents (Sussman et al., 2017b; Sussman et al., 2019). Unfortunately, these staff members report being overlooked and disempowered when attempting to share their observations and perspectives about residents with regulated staff (Fryer, Bellamy, Morgan, & Gott, 2016; Kontos et al., 2009). This dynamic is reinforced by the hierarchical structure of LTC, wherein staff who are the most implicated in the daily care have the least power (e.g., limited involvement in care planning and decision making) and resources (e.g., infrequent access to training). As a result, when meaningful exchanges regarding ACP do occur with non-regulated staff, a formalized structure to ensure the interactions are integrated into ACP may be lacking (Armstrong, Daly, & Choiniere, 2016; Caspar, Ratner, Phinney, & MacKinnon, 2016). Taken together, it appears that non-regulated staff, who tend to be viewed by residents and families as ideally positioned to participate in ACP engagement, lack both the time and authority to do so.

Some scholars have suggested that role clarity of professional (regulated) staff such as nurses, social workers, and other allied health professions could help to move ACP engagement forward in LTC (Badger et al., 2012; Beck, McIlfatrick, Hasson, & Leavey, 2016; Shaw et al., 2018). Our findings go further, suggesting that clarifying and creating a role for all staff in ACP engagement may improve its implementation in LTC. This inclusive approach aligns with the compassionate-communities movement and the recent emergence of concepts such as "grief literacy," which position discussions about death and dying as everyone's responsibility, suggesting that medicalization of death and grief has resulted in the silencing of meaningful exchanges and connections (Breen et al., 2020). It also aligns with a relational approach to care, which purports that supporting relational connections between and amongst staff can strengthen connections with residents and families by fostering a collective, reflexive, and inclusive approach to care (Banerjee et al., 2015; Rockwell, 2012).

Indeed, our findings highlight the extent to which work practices and priorities in LTC serve as critical barriers to ACP engagement from the perspective of residents and families. More specifically, participants expressed how the prioritization of task performance over relational connection interferes with all staffs' capacities to offer the time and space required for intimate conversations and exchanges about preferences for EOL care (Sutherland, 2020; Tolson, Dewar, & Jackson, 2014). While relational connection is a critical pre-condition for ACP engagement from the perspective of residents and families, opportunities to connect with staff in a meaningful and intimate way are viewed as rare in LTC (Baines & Armstrong, 2018; Beck, Törnquist, & Edberg, 2012).

Our findings also suggest that compassionate care, which evolves from the alleviation of pain and suffering through relational bonds, was rarely experienced by residents and families in the context of daily care in LTC (Sinclair et al., 2016; Singh et al., 2018). Rather, this type of care was typically witnessed when fellow residents were receiving EOL care. While these final acts of compassion were appreciated by residents and families in our study, they did little to mitigate the daily reminders that in LTC, physical and medical issues take precedence over relational and emotional experiences. These practices also reinforced the dichotomy of living and dying in LTC – the very dynamic ACP is meant to challenge.

According to family participants, the automated non-personalized nature of care in LTC begins with the process of relocation itself, when residents are treated like bodies being moved into beds rather than persons relocating to spaces (Sussman & Orav-Lakaski, 2020). These circumstances led many residents and families in this study to question staffs' availabilities to address daily needs and future concerns. These conditions also caused some families to question whether their relative's deterioration might be related to the care they were receiving rather than their illness trajectory.

It is noteworthy that resident and family "readiness" to engage in ACP has been a topic of exploration in earlier research (Shaw et al., 2018). Most typically, "readiness" is framed as an individual issue, and strategies to address it include raising awareness about the importance and value of ACP (Fried, Bullock, Iannone, & O'Leary, 2009). Our findings highlight that "readiness," or lack thereof, can be systemically driven. While most of our study participants acknowledged the value of engaging in discussions about future EOL care, many expressed uncertainty about staffs' availability to support such exchanges in a meaningful way. This is particularly noteworthy given that all sites in our study had provided ACP training, and education to staff and ACP initiatives had been implemented in two of the study sites.

There exist a number of programs and initiatives that have shown promise in supporting ACP engagement in LTC. For example, "Me and My Wishes" (Towsley, Wong, Mokhtari, Hull, & Miller, 2020), "The Conversation Project" (Institute for Health Care Improvement, 2020), and "The Speak up Campaign" (Canadian Hospice Palliative Care Association, 2008) are programs found to be acceptable and feasible to implement in LTC from the perspective of staff (Sussman et al., 2020).

Regularly scheduled team huddles or reflective debriefings may offer promising complements to ACP programs, as they can help staff to collectively identify which residents to approach about ACP, and allow them to reflect on what role each staff may play in supporting the process (Banerjee & Rewegan, 2016). However, our findings suggest that if these ACP initiatives are not accompanied by a systemic shift in LTC, they will simply serve to replicate an environment wherein tasks take precedence over people – the precise situation that hinders ACP engagement in the first place (Armstrong & Armstrong, 2020). Further, if staffing levels are not adequate to support the participation of all staff in ACP, the involvement of non-regulated staff will remain at the margins, as those providing direct care will not have time to attend initiatives such as team huddles (Banerjee et al., 2015; Caspar et al., 2016).

Our study aimed to uncover the conditions thought to support and inhibit ACP engagement in LTC from the perspective of residents and families. Our findings revealed that workplace practices and organizational structures within LTC may play an important role in inhibiting ACP engagement. Until all staff are encouraged and supported to participate in meaningful exchanges with residents and families, and care and compassion are consistently provided to the living and the dying in LTC, residents' and families' apprehensions about addressing ACP will continue and meaningful conversations about future care will be limited.

Study Limitations

This study should be viewed in light of three important limitations. Firstly, it relied on a small sample of self-selected participants in one Canadian province. These circumstances limit the transferability of findings to other older persons and families residing in

different jurisdictions. Secondly, our small sample size precluded us from exploring differences such as gender identity and cultural/racial affiliation that may impact perceptions and experiences of ACP. Future research should examine the extent to which such markers of identity influence perceptions regarding the importance of ACP and the conditions that may support/hinder it. Thirdly, while residents and families offered important insights about how ACP could be successfully implemented in LTC, future work should explore the models of care that best support the relational conditions that participants identified as critical.

Conclusion

During the final stages of writing this paper, a global pandemic began to surge. While the sheer volume of deaths in LTC should be cause for much concern – in Canada, LTC accounted for 81 per cent of COVID-19-related deaths (Estabrooks et al., 2020) – equally concerning has been the medicalized and task-based nature of our responses. With families restricted from visitation and staff forced to focus on implementing rigid rules and regulations to control spread of the virus, residents who have died in LTC have done so alone, with minimal care, communication, or support (Strang, Bergström, Martinsson, & Lundström, 2020). Furthermore, families were unable to receive the compassionate care they were awaiting at EOL. We hope that our findings serve as a critical reminder that the provision of compassionate care must be viewed as a priority in LTC from the time of entry until death. Not only has its absence inhibited engagement with ACP but it has compromised the quality of life and care in LTC for residents, families, and staff alike.

Funding. This work was supported by the Canadian Frailty Network Transformative [Research Grant # TG2015-03].

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