RESEARCH

Death in Long-Term Care: Focus Groups and Interviews Identify Strategies to Alleviate Staff Burnout

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Context: Interdisciplinary long-term care staff are being challenged with increasing numbers of resident deaths as well as complex resident and family needs. Studies warn that staff responses to the stress generated by residents' deaths can lead to increased ill health, sick time, burnout, and attrition.

Objectives: To alleviate and prevent workplace stress and burnout in staff related to long-term care resident deaths.

Methods: Participatory action research design. Qualitative individual interviews and focus groups were carried out within five long-term care homes, Vancouver, British Columbia, Canada.

Findings: Two key themes emerged: Challenges Staff Experienced and Supporting Action Strategies. Challenges are reported under five sub-themes: 1) *Differing Expectations*, 2) *Communication*, 3) *Acknowledgement*, 4) *Support*, and 5) *Education*. Supporting Action Strategies to minimize the impact of resident death on staff are presented under four sub-themes: 1) *the Individual*: Practice self-care, awareness, mindfulness; 2) *Team*: Enhance end-of-life comfort for residents, strengthen support for families, maximize the use of palliative and spiritual care; 3) *Organization*: Nurture supportive leadership, improve communication, education, resources and 4) *Higher learning*: Build palliative care/emotional preparation into the curriculum and promote long-term care as a specialist area of healthcare.

Limitations: Results may not generalize to other practice contexts; long-term care homes studied are part of a faith-based organization.

Implications: Long-term care policy and system changes are needed to support interdisciplinary care staff and provide them with tools, resources, and supports to prevent burnout and cope with the increasing stress of working in long-term care.

Introduction

Context – Rationale, Significance, and Review of Existing Knowledge

The 2016 Canadian Census highlighted that for the first time since records began, persons aged 65 and over outnumbered those aged 15 and under (Government of Canada SC. Historical Age Pyramid 2017). As the aging population has increased, there has been a growing trend for people to be cared for within their own homes. This has resulted in a change in the long-term care (LTC) population in care homes as such care is being accessed at a later stage when a person's cognitive and physical health are more likely to be precarious. Despite people staying in their homes longer, it has been estimated that by 2035, Canada will need 199,000 additional beds in long-term care facilities to accommodate this aging population (Gibbard R., 2017).

Residents are moving into LTC homes with complex health conditions, require a high level of care, and for many of them, long-term care in this setting is palliative (General Practice Services Committee, British Columbia Ministry of Health, 2019). It was estimated that by 2020, 39% of residents would die in their LTC home each year (Menec et al., 2004; MacLean et al., 2000; Spector et al., 2000). While this trend impacts residents and their families, it also affects the *stress of staff* who are already challenged with caring for what is an unpredictable and complex care group (Cagle et al., 2017; Funk et al., 2017;

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Jahr Svendsen et al., 2017; Woodhead et al., 2016). LTC facilities are striving to meet this increasing need for comprehensive end-of-life care but are not always adequately staffed or resourced for it. The previously forecasted resident death percentages for the year 2020 are now predicted to be much higher than 39% due to the coronavirus disease (COVID-19) pandemic declared by the World Health Organization (WHO) on March 11, 2020, which is increasing the number of deaths in LTC facilities locally, regionally, nationally and internationally (WHO, 2020; CIHI, 2020).

The impact of increasing resident deaths on LTC staff has received growing attention in health care research, with studies warning that team members' responses to the stress generated by residents' deaths can lead to increased burnout, ill health, and sick time (Gao et al., 2014; Gorman et al., 2010). Studies also warn that emotional burnout can be linked to job dissatisfaction, which can, in turn, negatively affect resident care (Aloisio & Estabrook, 2019).

Burnout for nurses and care aides/assistants has been the focus of several studies (Gorman et al., 2010), but less attention has been given to the stress responses of the wider health care team in relation to caring for dying residents as an 'occupational hazard'. Concern about this prompted our research program, in which we asked: "How are the interdisciplinary team members affected by the death of the resident they are looking after?" (Puyat et al., 2019; Leclerc et al., 2017).

Previous studies have identified that older, full-time workers, long-term care workers, and those with a lower hourly wage are particularly at risk of burnout (Gorman et al., 2010).

Phase One of our research (Puyat et al., 2019) confirmed that staff across the included five LTC sites fell into this category (i.e., older, full-time workers), but also found that staff across a wide spectrum of disciplines (and wages) were at risk of stress and burnout. Given this risk of burnout extends to all the members of the LTC team, supports are needed to help with prevention, as burnout can result in health risks for staff and their families, as well as being a significant occupational health problem (Rachel & Francesco, 2018).

Whilst burnout impacts negatively upon staff members, research also suggested that quality of care can be impacted, with levels of patient satisfaction lower in hospitals where nurses experience high levels of burnout (McHugh et al., 2011). It should also be noted that staff burnout in LTC has been linked to elder abuse, stressful working conditions, low wages, staff shortages, and burnout seen as being contributing factors (Hawes, 2003).

In a previous Phase One study, we described and measured interdisciplinary LTC team members' stress related to caring for dying residents. Participants included staff working in five public LTC facilities in Vancouver, British Columbia, Canada. In these locations, approximately 35% of residents were dying each year and 8% of residents within the first three months after admission (Leclerc et al., 2017: Organization's data set in 2013). A survey with a quantitative standardized questionnaire—the Maslach Burnout Inventory (MBI) (Maslach et al., 2016; Maslach &

Jackson, 1981)—examined the additional stress this context may place on interdisciplinary staff (Puyat et al., 2019; Leclerc et al., 2017). Across a range of practitioners, results indicated that almost 50% of staff that responded were experiencing one or more signs of burnout: moderate-to-high emotional exhaustion (Puyat et al., 2019; Leclerc et al., 2017). Burnout symptoms were exacerbated by prolonged and cumulative exposures to deaths and dying (Puyat et al., 2019; Leclerc et al., 2017). Moreover, the findings confirmed that many staff in the LTC facilities were older, full-time workers who had experienced emotional stress and burnout related to high exposure to dying residents. Due to the increasing number of LTC resident deaths annually, Leclerc et al. (2017) considered that these findings might be similar for workers in other LTC facilities province-wide and beyond.

While the trend of increased deaths is echoed nationally and internationally (Cagle et al., 2017; Jahr Svendsen et al., 2017; Marcella & Kelley, 2015; Hasson & Arnetz, 2006), we have been committed to taking action to improve the health and well-being of all LTC staff within our organization in relation to their care of dying residents and those residents' families. Hence, the findings from Phase One led to this study—Phase Two: *Supporting Long Term Care residents throughout the dying process—Understanding and addressing related health care provider stress*. The goal of this second study was to identify practice changes and practical strategies to help reduce and prevent staff burnout in long-term care facilities. As the well-being of staff is linked to the well-being of those whom they serve (individuals, families, and communities) (Rodney et al., 2013a; Rodney et al., 2013b; Rodney et al., 2013c; Rodney & Varcoe, 2012), the hope is that focusing on the well-being of staff will also improve the quality of care provided to (dying) LTC residents and their families.

Aims and Objectives
The purpose of this Phase Two study was to:

1. Explore how LTC facility team members are affected by the increasing number of deaths of the residents they are looking after;
2. Explore strategies team members would find helpful in supporting them to cope with resident deaths;
3. Explore how these strategies can be incorporated into the ongoing work of the five LTC facilities and beyond.

Methods
Research Design
As the aim of our study is to understand the experiences of team members caring for dying LTC residents and their families, a qualitative methodology was employed (Lincoln et al., 2011). Interpretive Description guided this research as a pragmatic approach that can be used to develop knowledge for practice disciplines within LTC, as well as acknowledging the researcher's existing theoretical and practical knowledge of the subject being studied (Thorne, 2016). We aimed to improve practice in the LTC sites by using an inductive qualitative exploration of

long-term care staff members' experiences of resident deaths.

Ultimately, we are employing a participatory action research (PAR) design to generate constructive changes to improve the quality of health care workplaces (MacDonald C., 2012). Participatory action research is an approach that seeks to engage people as active participants and co-researchers to initiate change. In this way, people become "knowing subjects" and come to value and use their knowledge, ideas, and experiences to envisage action aimed at change (Kemmis & McTaggart, 2000; Ladkin, 2004; Reason & Bradbury, 2001).

The qualitative **methods** we used to collect and interpret data consisted of *individual qualitative interviews* and *focus groups*. Focus groups are particularly well suited for qualitative data collection in participatory action research (Ladkin, 2004), as they generate ideas between participants that might not otherwise appear, while individual interviews foster in-depth explorations of individuals' perspectives (Thorne, 2016).

Setting and Sample

Team members in the five LTC sites were to be actively involved in planning strategies to improve their practice context. As the research team identified that the research would have a broad and interdisciplinary focus, a purposeful sampling strategy was used at the LTC sites where eligible study participants included all of the 577 care staff working in them on a full time, part-time or casual basis. Only those providing consent participated in the research. Exclusion criteria included non-clinical staff such as clerical and administrative staff, volunteers; students and their instructors; and residents as well as their family members. This setting and sampling strategy replicated those in Phase One.

Data Collection

Our study (H16-03170) had its detailed procedures reviewed and approved by the University of British Columbia – Providence Health Care Research Ethics Office and all research team members were oriented to the research ethics procedures. As most of the research team were known as colleagues to potential research participants in the various LTC sites, participant recruitment was attended to in a manner that preserved confidentiality and voluntariness, which included a research assistant being hired to oversee the direct recruitment process. Invitation letters were sent to staff attached to their paystubs. Physicians were invited to participate in using the on-site mail distribution system. A copy of the summary of the Phase One findings was provided, which references the organization's LTC team support website for those wishing to access the full report (Leclerc et al., 2017).

The majority of interviews were conducted by the principal investigator, an experienced qualitative researcher. Other interviews were conducted by doctoral students at UBC. All interviews were held in a quiet room at a time, and a location was chosen by each participant. The time allocated for the interviews was 1 hour, with interviews taking 30–45 minutes.

The maximum group size for focus groups was 6 (+–1); this small group number being chosen for reasons of confidentiality, room size, and time. The focus groups lasted 1 hour as this had been agreed with leadership as being a reasonable length of time for staff to be away from their work.

Participants signed a consent form before interviews or focus groups and were given a copy. All participants completed a confidential biographical sheet. Participants were asked how they were affected by the deaths of the residents they are looking after, and about strategies they have found helpful in coping with this. Further recommended strategies were noted and explored. The interview guides for the focus groups and individual interviews were similar. Participants were presented with these open-ended questions:

- How do you find that you are affected by the deaths of the LTC residents you look after?
- What makes the deaths harder for you?
- What helps to make the deaths better for you?
- What strategies do you think would be helpful in supporting you to cope with resident deaths?
- What strategies can you initiate?
- What strategies could be done by others or the organization you work in? Can you think of some examples?
- How might it be possible to implement the suggestions you have provided? Who should be involved?
- How could your suggestions be made sustainable?

Field notes were recorded by research team members at interviews and focus groups to better understand how the organizational context influenced people's experiences (Emerson et al., 1995). Interviews and focus groups were audiotaped and transcribed verbatim by a professional UBC-approved transcriptionist and stored securely.

Participants

Thirteen interviews were conducted. Ten focus groups were held across the five LTC sites, with a total of 57 participants. There was some overlap between individual interview and focus group participants with three people (2 Social Workers and 1 Registered Nurse) participating in both. Overall, there were 67 unique participants. A large majority of direct care staff groups in PHC LTC were represented — resident care aides, dietitians, nurses, physicians, rehabilitation assistants, social workers, spiritual health practitioners, physical therapists, occupational therapists, music therapists, speech and language pathologists, and arts and crafts workers.

Data Analysis and Rigour

Stage One of Data Analysis

After transcripts were anonymized, all team members immersed themselves in the data by reading and re-reading the transcripts and researcher notes. The researchers then selected quotes that they felt were poignant and/or most representative of the data. As the collection and transcription progressed, the team met regularly to

discuss and identify overall inductive themes. Data coding was inductive and proceeded from 'close readings' of what participants said toward these more abstract themes (Thorne, 2016).

Stage Two of Data Analysis
Analytic charts were used to organize the quotes and researcher notes into categories, themes and sub-themes. Credibility of findings was established by analyst triangulation.

Example from analytical chart:

Theme	*Challenges staff experienced*
Sub–theme	*Differing expectations*
Category/Node	*Family expectations*
Transcript quote	"We started to communicate with the family [as to] what is the expectation. But still, you know… they're not necessarily [able] to accept it."

Stage Three of Data Analysis
This commenced with the initiation of the NVivo (QSR International Pty Ltd., 2018) coding program to organize data on the basis of key data 'nodes' developed in *stage two.* Two coders coded data in NVivo: a UBC research assistant with experience using NVivo and a Co-investigator. NVivo was used by the research team to organize/retrieve data and to help confirm and further expand on the thematic analysis findings from the earlier stages of data analysis. Team members carefully and systematically reviewed the analysis and further developed the findings using this clearly coded evidence.

Interim findings were presented to an internal conference attended by staff and management to review and refine findings and recommendations.

Data from the research was used to generate and consolidate planning for action strategies, in keeping with our PAR approach. Recommendations for short- and long-term change to better support staff caring for dying residents in LTC—and ultimately better support the residents and their families—were profiled.

For reliability, all notes, transcripts, and meetings were documented. Also, in terms of reliability, we note that the context of the case sites was stable during the time of the fieldwork; however this has changed markedly since the onset of the COVID-19 pandemic, as we discuss later.

Findings
A. Demographic Data: Table 1
The majority of the participants for both individual interviews and focus groups were over 45 years of age. No data were collected about the ethnicity of the participants.

Most participants have worked at these five LTC sites for more than five years, and most worked at one site. Men accounted for 14% of participants in the focus groups and near 8% in the interviews. More of the interviewees were part-time employees, most likely because this was the more flexible way in terms of timing of participating than

the focus groups. There was a good mix of professional groups in the study.

Table 1: Demographic data.

	Interview		Focus Group	
	Count	**%**	**Count**	**%**
Sex				
Male	1	7.7	8	14.0
Female	12	92.3	43	75.4
Not reported	–	–	6	10.5
Age Group				
Under 36	1	7.7	6	10.5
36 to 45	1	7.7	10	17.5
46 to 55	3	23.1	18	31.6
Over 55	5	38.5	17	29.8
Not reported	3	23.1	6	10.5
Job Category*				
RCA	–	–	18	31.6
RN[#]	3	23.1	7	12.3
Spiritual Health Practitioners	3	23.1	2	3.5
Allied: RD, OT, PT, SW[#], MT, SLP	5	38.5	10	17.5
RA, AW	–	–	13	22.8
Physicians (MD)	2	15.4	–	–
Not reported	–	–	7	12.3
Length of Employment, years				
Less than 1 year	1	7.7	4	7.0
1–5 years	1	7.7	9	15.8
6–10 years	3	23.1	11	19.3
11–15 years	1	7.7	5	8.8
More than 16 years	4	30.8	22	38.6
Not reported	3	23.1	6	10.5
Job Status				
Full-Time	4	30.8	38	66.7
Part-Time	5	38.5	10	17.5
Casual	1	7.7	3	5.3
Not reported	3	23.1	6	10.5

Note: *RCA, resident care aides; RN, registered nurses (includes specialized registered palliative care nurses, registered psychiatric nurses);
RD, registered dietitians; OT, occupational therapists; PT, physical therapists; SW, social workers;
MT, music therapists; SLP, speech and language pathologists;
RA, rehabilitation assistants; AW, arts and craft workers;
MD, medical doctors.
Note: [#]67 unique participants overall, due to the overlap of 2 SWs[#] and 1 RN[#] between interviews and focus groups.

B. Thematic Analysis

Thematic data analysis revealed two key themes:

> **Theme 1: Challenges Staff Experienced** – when caring for dying residents
>> Five sub-theme categories emerged, namely **Differing Expectations, Communication, Acknowledgement, Support,** and **Education**.

> **Theme 2: Supporting Action Strategies** – recommended to help staff cope better with challenges and reduce the risk of burnout
>> Four sub-theme categories emerged, namely **the Individual, Team, Organization,** and **Higher Learning**.

Theme 1: Challenges Staff Experienced

Differing Expectations

Participants spoke of feeling challenged when expectations around care differ between team members or between staff and families. They highlighted that this could be as a result of differing beliefs around death and dying, cultural differences, denial (by a family member), internal family conflict, or lack of understanding regarding the resident's condition and prognosis:

> We're not a homogeneous group. It's a very mixed group, mixed backgrounds, mixed belief systems. People bring their belief systems and what they value to work. And if we don't sit down and talk regularly, openly about it… (Interview Participant 4 [I.P4]).

This can be heightened due to the changing demographic of residents.

> You don't see the frail elderly who have no medical comorbidities …who are just here because they can't walk very well anymore…… I suspect that the pressure on acute care beds has caused people to be discharged from hospital sooner than they would have been in the past, so they can arrive still fairly acutely ill…, or unstable even medically sometimes because of bed pressures in acute care (I.P12).

Participants also highlighted the stress of caring for residents who have multiple and complex needs:

> We're becoming a hospice, but also, now we're getting younger people with mental health or drug addiction problems. It's multi-layered with too little resources (I.P8).

Discussion around goals of care as well as serious illness conversations are ways in which staff seek to prepare families regarding their loved one's deteriorating health. It was highlighted that it's not always easy for family members to accept the reality of the situation and their expectations around care may, therefore, differ from those of the care team:

> Feeling that families are not ready to hear…and so not wanting to traumatize the family or take them to a place where they are not ready to go… especially if what they're hoping for is not matched by what is happening (I.P4).

Participants explained that they try to be mindful of the family's grief process, but find it challenging when the resident, family, and team members have different understandings and expectations, which can mean that moving to a palliative approach to care can be difficult to initiate or sustain.

> We started to communicate with the family [as to] what is the expectation. But still, you know… they're not necessarily [able] to accept it. When we see the physical changes, we start to approach the family and then let them know…. so they get more prepared. But still, it's very challenging (Focus Group 8 Participant 8 [FG8.P8]).

When acute interventions are expected and requested by the family with the aim of prolonging the resident's life, some participants reported experiencing moral distress when they felt a life prolonged by acute intervention resulted in prolonged suffering or poorer quality of life for the resident:

> We have to make sure that they understand that if they want to prolong life…..then how much of the quality of life is being compromised? (FG8.P2)

Staff also described feeling sadness when a transfer to acute care results in a lack of closure and opportunity to care for the resident in their own "home":

> If we keep the resident here when they are dying, the last moments here could be comfortable and beautiful (FG3.P2).

Participants spoke of complicated grief related to the circumstances surrounding a death. Sudden, unexpected death can be very difficult for staff, especially if they may feel it could have been prevented:

> There's a complicated grief that some staff might have around the circumstances of the death [as] there are accidental deaths as well. ……that's a whole different layer of burden as well; about human responsibility (1.P1).

Participants also voiced experiencing stress when they felt there was the expectation that they are able to manage their workload, yet this can be difficult due to the high demands and complexity of resident needs. They described feeling sadness and moral distress if not able to be there when a resident dies:

> They grieve; they want to be with their residents… but the truth is, they don't have the time (I.P8).

Communication

The second sub-theme of Challenges Staff Experienced was *communication*. Participants highlighted the importance of timely and sensitive communication in trying to ensure that all members of the team (including resident and families) are 'on the same page', pointing out that challenges can arise when effective communication does not happen due to, for example, workload and time restraints.

They identified the need for early conversation and more team meetings with family to connect, inform, and build trust:

> So I think it's very good to start with that kind of good communication then if [the resident] is declining, you can explain to [the family], and they would trust you because it's not one-day friendship (FG8.P6).

Staff also described the challenge of 'difficult conversations' such as knowing what to say to comfort families following the death of a loved one:

> What will I say to the family? I feel sorry, but it's so hard....I find that it's stressful sometimes when we think we maybe said the wrong thing (FG10.P7).

Informing co-residents of who may be sick or near end-of-life can also be difficult and might result in an individual not hearing that a fellow resident has passed away. Participants spoke of how communicating the death of a resident to a co-worker needs to be timely and carried out with sensitivity*:*

> It's about how you tell colleagues that someone's died because not everyone's dying on your watch...how do you pass on that information respectfully? (I.P2)

Improved communication between staff members was seen as important, especially with the aim of informing all staff and volunteers when a resident declines or dies:

> Physicians were calling team meetings proactively when resident status is changing (I.P4).

Participants also spoke of how a culture of safety should be nurtured for staff to feel comfortable asking for help or communicating concerns.

Acknowledgment (Dying Resident)

The third sub-theme of challenges was *acknowledgment,* which had two dimensions, namely acknowledgment of the dying resident and acknowledgment from the organization of the difficulties staff face.

Acknowledgment of a person nearing death or having died can be difficult due to heavy workload and time constraints:

> You just don't have time to accept the loss ...you don't have time to process how you feel about it (FG2.P4).

This lack of acknowledgment can result in staff feeling there has been a lack of closure and can lead to suppressed and complex emotions of grief:

> I really struggle with the one I didn't get to say goodbye to", "In my mind, I should go there, but I'm too busy (FG4.P6).

Participants voiced the need for space and time to both acknowledge the resident, say goodbye, and the provision of dedicated space where they can recover:

> If there is a private space that I do get to go and pay my respects, that gives me closure (FG4.P6).

Participants also highlighted the importance of having *acknowledgment from the organization* regarding the unique challenges they face. The ongoing losses that they experience take their toll, and support is requested from the organization to develop and maintain resilience.

> it's like being part of a family and losing somebody. It's important that this is acknowledged, that this is not just treated as part of the job (FG1.P1).

> recognizing the wear and tear it has on the people providing the service. It's not just a one off....it's a continuous, repetitive thing that happens again and again (FG1.P6).

> We've had a run of five people dying on the floor in two weeks. I just don't want to go there right now… but still come to work (FG1.P1).

Support

The fourth sub-theme of challenges was *support*, which had two dimensions, namely the need for *emotional support* and for *clinical support.*

In terms of *emotional support*, participants highlighted the challenge of coping emotionally when caring for dying residents and the need for support in dealing with complex emotions such as guilt, grief, fear, angst, and distress. They warned that failure to address these emotions could lead to burnout. In researchers' field notes for the focus groups, a small number of participants were observed to be visibly emotional (i.e., tears in eyes, weeping, head down body language) when discussing the deaths of their residents and how it had impacted them.

> Grief is such a heavy thing that you don't recognize until it catches up with you at some point in time (FG6.P3).

> It's not just the work grief. It's your own personal grief that you bring to the table too (I.P2).

Participants described how it is emotionally challenging for staff when a resident passes away, and when the bed is filled immediately.

We don't even have time to grieve or even say, 'rest in peace.' We have to go…empty the closets, do all these extra things…put the clothes in the closet—, We don't even have time to grieve. I know we have to fill the beds, but there's no time (FG5.P3).

And suddenly, there's another person there… It's very, very hard because it feels like it pushes aside the memory (I.P4).

The emotional connections staff have with residents and families makes them vulnerable to greater loss when a resident passes away:

When I came back, I learned that he died…I went home that day. I was just doing my dishes; I was crying (FG10.P5).

Participants spoke of how depersonalization can occur as a defense mechanism if they are not provided with adequate support, which can, in turn, adversely affect care.

..And they've experienced enough loss that they don't want to experience it anymore. I've seen a lot of staff who become very burnt out and simply turn off… (I.P4).

Almost like, you know, you feel emotionally numb because it's happening all the time (FG10.P1).

Participants highlighted the need for support in caring for themselves and when caring for their own families.

We're in health care, but who's caring for us? (FG1.P6)

It's hard for people who are giving their whole emotional selves to the job (FG1.P4).

I really think that the human part of us has to be touched because I think that's the best of us that we give in our care (I.P8).

In terms of the second element of support, participants described how insufficient *clinical support* at key times could increase their stress. There can also be moral distress felt by individuals if they are unable to be present for other staff at key times due to their contracted hours:

You're in sort of multiple roles on the phone. You're trying to manage the patient, you're trying to manage the emotions of the [staff], you're trying to teach the [staff], and you're trying to manage your own emotions and solve the case at the same time (I.P13).

It was highlighted that provision of support in terms of 'buy-in' from all the team to initiate palliative care can be challenging at times, and moral distress is reduced when all team members are 'on board': 'Everyone on the same page…really matters' (I.P9).

Specialist palliative care services are viewed as an essential part of the LTC team; however, staff report that they are at times underutilized. Participants also spoke of how underutilizing spiritual care services and support can increase feelings of moral distress and that when the family and resident receive spiritual care at the end of their life, they feel that the resident has been well supported and has had the opportunity to be at peace.

Education
The fifth sub-theme of challenges faced by staff encapsulated the need for *enhanced coaching and education* to increase knowledge, skills, and confidence. When asked about what support they had to prepare them for death in long-term care, participants spoke of the need for the realistic expectation to be set early as part of their orientation to LTC:

When you were orienting to residential, did you receive any information on death and dying? (FG9 Interviewer)

Not really specifically that…. I think that would help, just, you know, someone to just kind of frankly ask… how do you feel about death and dying. Because there's a good chance you're going to encounter it here…"I'm a new grad, and to just really kind of ask yourself, am I ready to be seeing this? Am I ready to experience it, you know? If I can kind of imagine it, how am I going to react? (FG9.P1)

It was suggested that the opportunity to complete core competencies in palliative/end-of-life care be offered to staff, as some mentioned that this had not been a comprehensive part of their training. This training should also include education regarding emotional preparation to equip them for working in long-term care:

in school, there was very little acknowledgment of people that you work with might have emotions, and you might have emotions too… (FG1.P4).

Many participants highlighted the challenge of ensuring that families are provided with comprehensive and timely education:

A lot of people don't know Alzheimer's is a terminal illness… (IP.2).

Also, they identified the need for coaching families on how best to support the resident and other family members:

Sometimes we end up explaining to the family…how to respect the needs/wishes of the resident (I.P2).

Theme 2: Supporting Action Strategies
This theme had four sub-themes, namely *the Individual, Team, Organization, and Higher Learning* of levels of supporting strategies.

The Individual

At the level of the individual member of staff, participants identified the following approaches they have used to support themselves.

<u>Practice self-care, awareness, mindfulness</u> – many highlighted that caring for the self is an essential part of building resilience and gave examples of participating in exercise and leisure activities with friends and family, of creating a healthy balance between home and work**.** Staff also spoke of the importance of self-awareness and activities that promote mindfulness such as meditation and yoga:

> Purposefully taking half an hour or something when I get home to do, like, a little bit of yoga or something to, like, let my mind separate from work… (FG1.P4).

<u>Taking time to say goodbye</u> – participants highlighted the importance of being *proactive* in regard to anticipating the grief that may follow after a resident dies. It was suggested that time should be taken to say goodbye to the resident, as well as attending memorial services:

> It's important to be able to acknowledge and say goodbye to a resident. If you only have five minutes to say goodbye to a resident, just do it (FG1.P5).

<u>Taking time to debrief and reflect</u> – was viewed as being a high priority for all staff when caring for dying residents in LTC, just as it is incorporated into the day for staff who work within hospice care:

> It should be assumed that time needs to be given to grieve and debrief; this is part of the job (I.P1).

Team

At the team level, participants noted the following aspects of support.

<u>Building and nurturing relationships</u>: "*Being on the same page matters*" – participants highlighted the importance of teams communicating regularly to ensure they are 'on the same page' in supporting the resident and family towards acceptance:

> This may include the gentle repeat of information. We have to honor the family's journey. Everyone has their own grief time frame…you can't push that (I.P2).

Teams are also encouraged to ensure all staff is informed about the resident decline or death. Communication within teams should be comprehensive and inclusive of all, including volunteers (when appropriate) and rehabilitation staff.

<u>Supporting Families</u> – participants reported that connecting early and regularly with resident's families can help to build positive relationships and trust. This includes physi-cians having serious illness conversations to help mentally prepare families earlier and calling team meetings proactively when resident status is changing:

> We want to be on the same page for when I call you at 3:00 in the morning, and I'm tired, and you're tired, and Mom is sick. And we don't want to be at that point figuring out what we should do, but we should already be at some agreement about what the plan would be… (I.P11).

Participants highlighted that conversation with the family should ideally begin in acute care if the resident has come from that sector, so there is an opportunity to set realistic expectations before the person moves into long-term care.

> Working with acute care to help them initiate conversations with resident and family about transitioning to a palliative approach to care before moving patients to LTC (FG10.P3).

> so I have more than once actually phoned acute—I should do it more often—and sort of appealed to them to speak with family or a competent resident about what's really going on and what the prognosis is (I.P13).

Early involvement and effective use of the Palliative Care Team (where available, as was the situation in the case sites) was also recommended when residents move into LTC, so that team's relationships and trust are built with the family in the initial stages, even before a resident is deemed palliative:

> Meeting all of the families, letting them know how you would be a support to them whether it's now or down the road (I.P1).

<u>Family comfort</u> – it was suggested that physical comforts such as larger rooms, comfortable chairs, and overnight stays could all provide the family with support when their loved one is dying. The regular presence of staff, even if for just minutes at a time, can provide the family with comfort, reassurance, and feeling of safety:

> The power of the check-in…Can I make you tea or coffee…. snack or sandwich? – so families don't have to leave; a comfort basket (FG10.P6).

<u>Resident Comfort</u> – was of great importance to the participating staff, who voiced experiencing distress if a resident dies in pain or alone. It was stated that staff from all disciplines need time to provide presence, touch, and comfort care:

> Important to moisturize mouth and lips. Putting on soft light at night…I feel so bad if someone dies in the dark (FG7.P1).

It was also suggested that teams utilize trained volunteers from the community or religious organizations to provide client comfort and support:

> More time to give support at the end…just to be there to hold their hand (FG5.P3).

Integrate a Palliative Approach to Care – appropriate use of existing palliative care resources was thought to help ensure that residents and families are provided with privacy and dignity:

> Keeping the palliative care room as a sacred space for dying residents (I.P1).

Participants were also encouraging teams to foster a culture of comfort with speaking the language of the palliative approach, as well as normalizing end-of-life conversations, i.e., not being afraid to use the word death, including the phrase 'a good death'. Through mentoring and education, it was felt that comfort could be developed for staff in talking to families following the death of a loved one.

Spiritual Health Services – participants recommended there be spiritual support referral processes and that staff are aware of their scope and how to use them. It was seen that the role of these services is to support staff and family as well as residents:

> I think spiritual health here is really good. You know, they're very comforting (FG4.P3).

Suggestions also included honoring the deceased resident at the time of death, such as with flowers on the body and bed after the person passes, a quilt over the body when they are moved from the facility, and staff to accompany the body and families when the funeral home service arrives:

> People gathered and stood by the gurney that was taking this [resident's] body out … the flag had been put over [the gurney]… people said it was so respectful and so lovely (I.P4).

'Mini' memorial services on the specific units were seen as being a timely way for staff to be able to acknowledge the resident's death soon after they have died. It was suggested that these could be facilitated by a member of the interdisciplinary team. More formal memorial services led by spiritual health practitioners provide opportunities for staff to connect with families in a service of remembrance.

Organization
At the organization level, participants highlighted the following support strategies.

Education for staff – appropriate ongoing education for staff, especially regarding the palliative approach, personally dealing with grief and loss, and information regarding the dangers of burnout:

> Seeing the Burnout scale was so helpful (I.P6).

Participants also recommended there is coaching for staff on how to inform other residents about a dying/deceased resident. Such coaching is seen as a way of increasing staff knowledge, confidence, and comfort with difficult conversations.

Learning resources for families – a readily understandable brochure can be made that is easily accessible for the family members:

> There's a lovely brochure that we can give to people close to the end of the process – the family might be sitting at the bedside and not know what to do.. just gives them some tips on how to be with someone (I.P2).

Education sessions for the family were also suggested as a means of empowering families with knowledge and understanding regarding the palliative approach to care:

> if we are able to educate families better about what to expect in residential care, about what frailty really means, about dementia as a terminal illness… then the conversation would be different and better for both parties (I.P13).

Supportive leadership – staff valued supportive leadership and highlighted that it is important for leaders to attend memorial services and that they encourage staff to do so. It was also suggested that leaders should debrief regularly with staff:

> To get the group of staff at that moment, and just do a 10-minute debrief to see what they're feeling at that moment (FG2.P3);
> I might not be able to fix that situation, but just having that chance to care and…hearing it out (FG2.P3).

Participants highlighted the importance of leadership, acknowledging staff grief and stress:

> important to staff that they have the acknowledgement from the organization regarding the unique challenges they face… and these challenges should not just be treated as part of the job (FG6.P2).

Sufficient Resources – participants discussed how increasing staffing levels when a resident is dying could help ensure that the level of care given is more in-line with hospice care. They also voiced that allowing greater flexibility of staff schedules when requesting time off would enable staff to be more proactive in managing their work/home life balance and could assist in the reduction of staff burnout. It was also suggested that an increase in physician contracted hours could help to reduce the moral distress of the physicians who feel conflicted when having to provide consults over the phone.

Regular opportunity to debrief, built into the working day, was viewed as being very important. Staff highlighted the importance of allocating physical space for them to grieve and debrief, as well as in-house psychosocial support.

Higher Learning

At the level of higher learning, participants felt that connecting with professional organizations regarding building in palliative care and managing death and dying into the curriculum may help to provide enhanced emotional preparation for healthcare staff working with residents at the end of life. More education highlighting dementia as a terminal illness was seen to be needed to increase knowledge and help to create realistic expectations for staff working within LTC. Participants also emphasized the importance of LTC being promoted as a specialist area of care:

> In long-term care, we're kind of seen like the bottom of the rung (IP.2).

Limitations Of This Study

It is possible that 1) findings may not generalize to other practice contexts, i.e., transferability; we note that the LTC homes we studied are part of a faith-based organization; 2) administrative staff from our organization were consistently supportive of the research process and findings throughout our research; other similar research projects may encounter administrative challenges that our research team did not have to navigate and 3) we may not have heard from potential participants who had lost faith in their ability to influence care delivery or were unable to participate due to heavy workload demands.

Discussion and Implications

Phase One of this study showed loyal, committed interdisciplinary staff who have low levels of depersonalization and a high sense of personal achievement (Puyat et al., 2019). However, the Phase One study highlighted that almost 50% of these interdisciplinary LTC staff were experiencing moderate to high levels of emotional exhaustion, which can be an indicator of burnout (Puyat et al., 2019). Concerns about this prompted this Phase Two study, which focused on qualitative interviews and focus groups to examine the perspectives of LTC staff from a wide range of disciplines regarding the challenges dealing with dying and death in LTC facilities and the supportive strategies that may help reduce the risk of staff burnout.

Participants described the challenges and complexities of care involved in providing direct care to dying residents. These included difficulty negotiating relationships with families, different expectations around care (families, residents, and team), and intense thoughts and emotions associated with grief. Challenges were divided into five sub-themes, namely *differing expectations* (staff, family, resident), *communication* (with teams, families, and residents), *need for support, need for*

acknowledgment, and *lack of education* for staff and families. In light of these challenges, participants were asked what strategies they would recommend as being helpful. Supportive action strategies are suggested for the levels of the individual, team, and organization, and for higher learning.

At the individual level, the value of self-care is emphasized with the recommendation that LTC interdisciplinary staff should work with the expectation that their self-care is *essential* in this line of work. Time and space to say goodbye to residents and to grieve/debrief is also an important element of self-care and should be built into the working day (as it is on palliative care units and within hospice care). It was highlighted that within hospice care, there is a clear patient prognosis, goals of care are clear, and death is expected. In comparison, LTC staff are working with an unpredictable, complex care group, and the expectation from family and staff around the goals of care may differ. The need for system level changes is needed to ensure that residents and family are adequately prepared for discussion regarding goals of care when transitioning to LTC from acute care or the community. After move-in, the early conversation should take place with the family regarding end-of-life care when residents have a chronic life-limiting diagnosis, such as dementia.

On an organizational level, increased resources, consistent workplace programs, and initiatives that attend to the psychological and physical well-being of staff across all care categories and disciplines are recommended, including in-house psychosocial support.

Also recommended are specialized communication skills workshops, the introduction of Core Competencies in Palliative Care for all LTC staff and physicians, team-building workshops, the involvement of Occupational Health and Safety (OH&S) in the provision of educational needs of staff to enhance emotional wellness as well as end-of-life care and emotional preparation built-in to professional curriculum education.

Our study focused on the opinions of a diverse interdisciplinary care team whom the demographics show its members have remained in their positions for a prolonged period (5 years or more), which suggests that they possess a degree of resilience. It should be emphasized that quality, committed, interdisciplinary staff working in LTC are a very valuable resource. Studies have warned that in some areas such as in the United States of America, workers are leaving LTC settings at rates that outpace other industries significantly (Frogner & Spetz, 2015). This indicates that staff in some areas are leaving positions faster than they are entering them, which is very concerning given the increasing need for LTC staff due to an aging population as well as the stress on the LTC system from the current worldwide COVID-19 pandemic.

Although we are five years into the program of work discussed in this paper, the situation in LTC changed abruptly with March 2020's surge of global coronavirus cases. We believe that the recommendations/findings are now even more relevant and support for long-term care staff is more urgent than ever. Any discussion about the

strategic organization and implementation of the recommendation data provided by LTC staff must now take into account the "new world" context the COVID-19 pandemic is leaving in its wake. Since that time in March, LTC facilities across Canada (and worldwide) have experienced infection and mortality rates of LTC residents many times that of the general population. Media attention, public outcry, official public inquiry (and even the need for support from the military) have exposed the systemic lack of preparedness from areas of leadership, both political and professional, as well as weaknesses in the LTC system not just in Canada but globally.

Conclusion

The staff in the LTC sites in this study demonstrated a high degree of resilience and compassion in the face of multiple challenges while caring for dying elders, but also highlighted the suffering and harm they are vulnerable to as a result of these challenges and their hope and determination for change. Their recommendations build on their strengths and resilience while hoping to remove obstacles and obtain much-needed resources to address their burnout and moral distress.

It is, therefore, essential that LTC receives generous investment and provisioning in line with other sectors of health care and that this investment prioritization includes the investment in the LTC staff themselves. For the multi-level strategies (Individual, Team, Organization, and Higher Learning) to be effectively integrated, they need to be embraced by leadership (government and organization), enthusiastically practiced by individuals and teams, enhanced through further research and development, and shared through higher education and professional development.

The excellent care LTC staff offer to frail residents, especially through the dying process, depends so much on their own emotional, physical, and spiritual health.

It's important to acknowledge that it's not easy, and that's actually tied into the quality of care we can give our residents (FG1.P14).

References
Aloisio, L and **Estabrook, CA.** 2019. *Caring for caregivers should be top priority.* Winnipeg, Manitoba: Winnipeg Free Press News Article. Available at: https://www.winnipegfreepress.com/opinion/analysis/caring-for-caregivers-should-be-top-priority-565517532.html (Accessed 12 Jul. 2020).

Cagle, J, Unroe, K, Bunting, M, et al. 2017. Caring for dying patients in the nursing home: Voices from frontline nursing home staff. *Journal of Pain and Symptom Management*, 53(2): 198–207. DOI: https://doi.org/10.1016/j.jpainsymman.2016.08.022

Canadian Institute for Health Information. 2020. *Pandemic Experience in the Long-Term Care Sector: How Does Canada Compare With Other Countries?* Ottawa, ON: CIHI.

Emerson, RM, Fretz, RI and **Shaw, LL.** 1995. *Writing ethnographic field notes.* Chicago: The University of Chicago Press. DOI: https://doi.org/10.7208/chicago/9780226206851.001.0001

Frogner, B and **Spetz, J.** 2015. Entry and Exit of Workers on Long-Term Care. Available at: https://healthworkforce.ucsf.edu/sites/healthworkforce.ucsf.edu/files/Report-Entry_and_Exit_of_Workers_in_Long-Term_Care.pdf (Accessed 24 Oct. 2019).

Funk, L, Peters, S and **Stieber Roger, K.** 2017. The Emotional Labor of Personal Grief in Palliative Care: Balancing Caring and Professional Identities. *Qualitative Health Research*, 27(14): 2211–2221. DOI: https://doi.org/10.1177/1049732317729139

Gao, F, Newcombe, P, Tilse, C, et al. 2014. Models for predicting turnover of residential aged care nurses: A structural equation modelling analysis of secondary data. *International Journal of Nursing Studies*, 51: 1258–1270. DOI: https://doi.org/10.1016/j.ijnurstu.2014.01.011

General Practice Services Committee, British Columbia Ministry of Health. 2019. Enabling and communicating consistent residential care. Available at: http://www.gpscbc.ca/our-impact/residential-care/enabling-and-communicating-consistent-residential-care (Accessed 24 Oct. 2019).

Gibbard, R. 2017. *Sizing Up the Challenge: Meeting the Demand for Long-Term Care in Canada.* Ottawa: The Conference Board of Canada.

Gorman, E, Yu, S and **Alamgir, H.** 2010. When healthcare workers get sick: Exploring sickness absenteeism in British Columbia, Canada. *Work*, 35: 117–123. DOI: https://doi.org/10.3233/WOR-2010-0963

Government of Canada SC. 2017. Historical Age Pyramid. Available at: https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/pyramid/pyramid.cfm?type=1&geo1=01 (Accessed 24 Oct. 2019).

Hasson, H and **Arnetz, JE.** 2006. Nursing staff competence, work strain, stress and satisfaction in elderly care: A comparison of home-based care and nursing homes. *Journal of Clinical Nursing*, 17(4): 468–481.

Hawes, C. 2003. Elder Abuse in Residential Long-Term Care Settings: What Is Known and What Information Is Needed? US: National Academies Press. Available at: https://www.ncbi.nlm.nih.gov/books/NBK98786/ (Accessed 24 Oct. 2019).

Jahr Svendsen, S, Landmark, BT and **Grov, EK.** 2017. Dying patients in nursing homes: nurses provide "more of everything" and are "left to deal with everything on their own". *Norwegian Journal of Clinical Nursing*, 1–13. DOI: https://doi.org/10.4220/Sykepleienf.2017.63396en

Kemmis, S and **McTaggart, R.** 2000. Participatory action research. In: Denzin, K and Lincoln, YS *Handbook of Qualitative Research*, 2nd ed. Thousand Oaks, CA: Sage publications. pp. 567–605.

Ladkin, D. 2004. Action research. In: Seale, C, Gobo, G, Gubrium, JF and Silverman, D *Qualitative research practice*. London: Sage Publications. pp. 536–548.

Leclerc, A, et al. 2017. Caring for Long-Term Care Residents throughout the Dying process: An exploratory Study to understand related interdisciplinary care team stress. *PHC 2015 Research Challenge Report*. Available at: http://professionalpractice.providencehealthcare.org/ltc-team-support

Lincoln, Y, Lynham, SA and **Guba, EG.** 2011. Paradigmatic controversies, contradictions, and emerging confluences, revisited. In Denzin, NK and Lincoln, YS *The Sage handbook of qualitative research*, 4th ed. Los Angeles: Sage. pp. 97–128.

MacDonald, C. 2012. Understanding Participatory Action Research: A Qualitative Research Methodology Option. *Canadian Journal of Action Research*. Dalhousie University, 13(2): 34–50.

MacLean, M, Ross, M and **Fisher, R.** 2000. A guide to end-of-life care for seniors. Ottawa, Ont.: University of Toronto and University of Ottawa.

Marcella, J and **Kelley, M.** 2015. "Death Is Part of the Job" in Long-Term Care Homes: Supporting Direct Care Staff with Their Grief and Bereavement. *SAGE Open*, 5(1): 2158244015573912. DOI: https://doi.org/10.1177/2158244015573912

Maslach, C and **Jackson, S.** 1981. The measurement of experienced burnout. *Journal of Organizational Behavior*, 2(2): 99–113. DOI: https://doi.org/10.1002/job.4030020205

Maslach, C, Jackson, S and **Leiter, P.** 2016. *The Maslach Burnout Inventory – Test Manual*. 4th ed. Menlo Park, California: Mind Garden, Inc. p. 75.

McHugh, M, et al. 2011. Nurses' widespread job dissatisfaction, burnout, and frustration with health benefits signal problems for patient care. *Health Affairs*, 30(2): 202–10. DOI: https://doi.org/10.1377/hlthaff.2010.0100

Menec, V, Lix, L and **Steinbach, C.** 2004. *Patterns of health care use and cost at the end-of-life*. Winnipeg: Manitoba Centre for Health Policy.

Puyat, J, et al. 2019. Exposure to deaths and dying and risks of burnout among long-term care staff: A cross-sectional survey. *Palliat Med*. 33: 717–720. DOI: https://doi.org/10.1177/0269216319833248

QSR International Pty Ltd. NVivo (Version 12, released in 2018).

Rachel, H and **Francesco, S.** 2018. Factors associated with and impact of burnout in nursing and residential home care workers for the elderly. *Acta Biomed*. 89: 60–69.

Reason, P and **Bradbury, H.** 2001. *Handbook of action research: Participatory inquiry and practices*. London: Sage Publications.

Rodney, P, Buckley, B, Street, A, Serrano, E and **Martin, LA.** 2013a. The moral climate of nursing practice: Inquiry and action. In: Storch, J, Rodney, P and Starzomski, R *Toward a moral horizon: Nursing ethics for leadership and practice*, 2nd ed. Toronto, ONT: Pearson-Prentice Hall. pp. 188–214.

Rodney, P, Harrigan, ML, Jiwani, B, Burgess, M, and **Phillips, JC.** 2013b. A further landscape: Ethics in health care organizations and health/health care policy. In: Storch, J, Rodney, P and Starzomski, R *Toward a moral horizon: Nursing ethics for leadership and practice*, 2nd ed. Toronto, ONT: Pearson-Prentice Hall. pp. 358–382.

Rodney, P, Kadyschuk, S, Liaschenko, J, Brown, H, Musto, L and **Synder, N.** 2013c. Moral agency: Relational connections and support. In: Storch, J, Rodney, P and Starzomski, R *Toward a moral horizon: Nursing ethics for leadership and practice*, 2nd ed. Toronto, ONT: Pearson-Prentice Hall. pp. 160–187.

Rodney, P and **Varcoe, C.** 2012. Constrained agency: The social structure of nurses' work. In: Baylis, F, Downie, J, Hoffmaster, B and Sherwin, S *Health care ethics in Canada*, 3rd ed. Toronto, ONT: Nelson. pp. 97–114. (Rev. of Varcoe, C and Rodney, P. 2009. Constrained agency: the social structure of nurses' work. In: Bolaria BS and Dickinson HD *Health, Illness, and Health Care in Canada*, 4th ed. Toronto, ONT: Canada: Nelson Education. pp. 122–151).

Spector, W, Leishman, J and **Pezzin, L.** 2000. *The Characteristics of Long-Term Care Users*. Agency for Healthcare Research and Quality. p. 00–0049.

Thorne, S. 2016. *Interpretive Description: Qualitative research for applied practice*, 2nd ed. Routledge. DOI: https://doi.org/10.4324/9781315545196

Woodhead, E, Northrop, L and **Edelstein, B.** 2016. Stress, Social Support, and Burnout Among Long-Term Care Nursing Staff. *Journal of Applied Gerontology*, 35(1): 84–105. DOI: https://doi.org/10.1177/0733464814542465

World Health Organization (WHO). Available at: https://www.who.int/emergencies/diseases/novel-coronavirus-2019 (Accessed 9 Jul. 2020).