

Caring for Long Term Care Residents throughout the Dying Process: An Exploratory Study to Understand Related Interdisciplinary Care Team Stress

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Introduction

As the Canadian population ages, more people will die in Long Term Care (LTC), with estimates as high as 39% of residents dying in their LTC home (each year) by 2020 (Marcella & Kelley, 2015). While this trend puts increasing stress on residents and families, it also affects the stress of interdisciplinary care team members in LTC, who are dealing with increasingly complex resident and family needs throughout the dying process. Care team members’ responses to stress can contribute to their burnout and attrition. PHC residential care or LTC facilities are increasingly providing end-of-life (EOL) care with approximately 35% of residents dying each year and 8% of residents within the first 3 months after ‘moving-in’ or admission (n=629, 2013 data; see Table 1). This PHC mortality trend has increased since 2009, when approximately 20% of residents died each year and 4% within the first 3 months after ‘moving-in’ (2009 data, see Table 1). Minimum Data Set (MDS) data supports that residents are ‘moving-in’ in a frailer state, with increasing acuity, and having a larger number of life threatening illnesses (PHC Decision Support data, 2015). This trend is echoed nationally and internationally (Hasson & Arnetz, 2006; Marcella & Kelley, 2015). PHC residential or LTC facilities are increasingly acting like ‘hospices’ providing palliative care, however they are not resourced for such services. The current residential care workload is heavy and makes it challenging for a care team member to provide equitable and just care service to each resident.

PHC Decision Support Data - Resident deaths by year (Source: MDS, 2015)

Year	# Resident Deaths (5 res. sites combined)	% of total population of residents dying annually	# Residents Deaths within 3 months of ‘move in’ or admission	% of total population dying within 3 months of ‘move in’ or admission
2009	140	140/686 = 20%	29	29/686 = 4%
2013	221	221/629 = 35%	53	53/629 = 8%

Table 1

Purpose of the Study

The purpose of this study was to describe and measure care team members’ stress related to caring for dying residents. The results from this study could be used to provide evidence-based knowledge on how to improve on the current processes and supports that exist for interdisciplinary care team members in Long Term Care.

The Research Questions were:

1. How are interdisciplinary care team members in PHC residential care facilities affected by the death of the residents they are looking after?
2. What do interdisciplinary care team members in PHC residential care facilities find helpful in supporting them to cope with resident deaths?

Methods

Design

A non-experimental descriptive research design was used to summarize the status of the phenomenon the team was interested in, the stress of the interdisciplinary clinical team members who are caring for LTC residents throughout the dying process. A non-probability convenience sampling was used to reach all interdisciplinary clinical staff working in all five PHC LTC sites.

Data Collection

A pen-and-paper survey was created consisting of three sections. Part 1 consisted of a section to briefly capture the Demographics of the respondents; Part 2 consisted of a two-page section with several Open-ended Descriptive questions designed to capture the respondents’ perceptions of how resident deaths were affecting them; and Part 3 consisted of the

22-item version of the Maslach Burnout Inventory-Human Services Survey (MBI-HSS), the leading and validated measure of burnout, for which the team had purchased the copyright for 600 reproductions. The survey was pilot-tested with a small sample (n=3) of equivalent interdisciplinary clinical care staff from another health authority. Feedback from pilot testing indicated a need for minor changes to Part 1 and 2 of the survey to ensure ease of comprehension. Hard copies of the finalized survey were attached to staff pay stubs and distributed to all interdisciplinary clinical staff in all five PHC LTC sites (n = 577). Locked and secured drop boxes were provided at each site for participants to submit their completed surveys anonymously. All completed surveys were collected weekly from the locked boxes at all 5 sites by a research assistant. All hard copy data were transported to and secured at the UBC locked filing cabinets in the Principle Investigator’s office.

Data Analysis

The identities of people completing the survey were not collected or shared. Details of the written comments were edited as necessary by the UBC-based research assistants, under the supervision of the Principal Investigator to further protect confidentiality before the surveys data were shared with rest of the research team. All numerical and narrative data were entered in the computer by the research assistants. The team analyzed the frequency distributions for each group of interdisciplinary clinical staff from the ordinal questions from the MBI with assistance from a research methodologist at the Centre for Health Evaluation and Outcome Sciences (CHEOS). The open-ended descriptive questions were organized into general groups and patterns and analyzed via thematic summaries to further explore the stress of interdisciplinary clinical team members who are caring for LTC residents throughout the dying process.

Results

Results of the survey are presented in the following sections: **Demographics, Maslach Burnout Inventory (MBI) Scores and Descriptive Responses.** 203 of the 577 distributed questionnaires were returned from the five residential care facilities, representing a 35% response rate (n=203).

Demographics

67% of respondents reported being over the age of 45, with 34% being over the age of 55. 56% of respondents reported being employed by PHC for more than 10 years, with 44% of respondents being employed for more than 15 years.

Category/Discipline/Respondent Breakdown: To protect the privacy of participants responding from disciplines with smaller numbers of staff, categories were developed by looking at similarities in the staff-to-resident ratio and the workforce role. Care aides are generally assigned 6 to 7 residents per work shift. RNs have a caseload of approximately 37 residents per shift. Physiotherapists and occupational therapists, in their supervisory (consultant) roles, have a caseload of about 140 residents, and so on. Disciplines with less than five respondents were added to similar categories. Even though the Spiritual Health Practitioner respondents were small in number, they were identified as a unique group within PHC residential care. 17 respondents did not identify their job (see Table 2).

Category/Discipline/Respondent			
Category	Disciplines	Responded/Total Possible	Percentage
A	Resident Care Aides	94/355	26.5%
B	Registered Nurses, Palliative, RPN, CNLS	47/114	41.2%
C	Spiritual Health Practitioners	5/8	62.5%
D	Social Workers (SW), Occupational Therapists (OT), Physiotherapists (PT), Dietitians (RD), Music Therapists	15/30	50%
E	Rehabilitation Assistants, Unit Coordinators	17/31	54.8%
F	Physicians, Psychologist	8/30	26.7%
G	Did not say (Job not specified)	17/unknown	Unknown

Table 2

Maslach Burnout Inventory (MBI) Scores

The results of the inventory consist of three separate scores; Emotional Exhaustion (EE), Depersonalization (DP) and Personal Accomplishment (PA). Higher values of DP and EE and lower values of PA signify burnout (Maslach & Jackson, 1981). Of the 203 returned questionnaires, 175 MBI’s were fully completed and eligible for data analysis comparing Demographics to MBI scores.

Proportion of Staff with Low/Mod/High MBI Scores by Demographic Characteristics

There were 149 females, 25 males, and one respondent with gender reported as other. Of the female sample, 27.5% reported having high levels of Emotional Exhaustion; **more males (48%) had high levels of Emotional Exhaustion than females. The association between gender and Emotional Exhaustion (EE) was found to be statistically significant (p = .04234).** More males

(72%) reported high levels of Personal Achievement than females (50.3%) (see Table 3). The highest Emotional Exhaustion by Age was in the 46-to-55 year olds at 34.5% followed by the 26-to-35 year olds at 33.3%. Age was not significantly associated with EE ($p = 0.9686$). The highest EE by Length of employment was 45.5% at 11-15 years (not statistically significant, $p = 0.2573$). The highest EE by job status was full-time status at 34.6% ($p = 0.08481$). The highest EE by 'multiple versus one site' was one site at 31.3% (not statistically significant, $p = 0.8989$). The highest Depersonalization was reported in the Length of employment of 11-15 years at 18% ($n=22$). The lowest Personal Achievement was in the age 26-35 at 26.7% ($n=15$).

Proportion of Staff with Low/Mod/High MBI Scores by Demographic Characteristics

Characteristic	Emotional Exhaustion			Depersonalization			Personal Achievement			n
	Low	Moderate	High	Low	Moderate	High	Low	Moderate	High	
<i>Gender</i>										
Female	48.3	24.2	27.5	76.5	17.4	6	20.1	29.5	50.3	149
Male	44	8	48	60	28	12	12	16	72	25

Table 3

MBI Scores Overall

Figure 1 in the Appendix demonstrates the overall MBI scores for the 175 respondents by MBI category and by percent reported. More than 50% of the respondents reported having moderate to high levels of EE. 30.3 % of respondents were in the high EE category. High DP was low at 6.9, and about 80% of respondents had moderate to high PA, with 53.7% in the high category (see Figure 1).

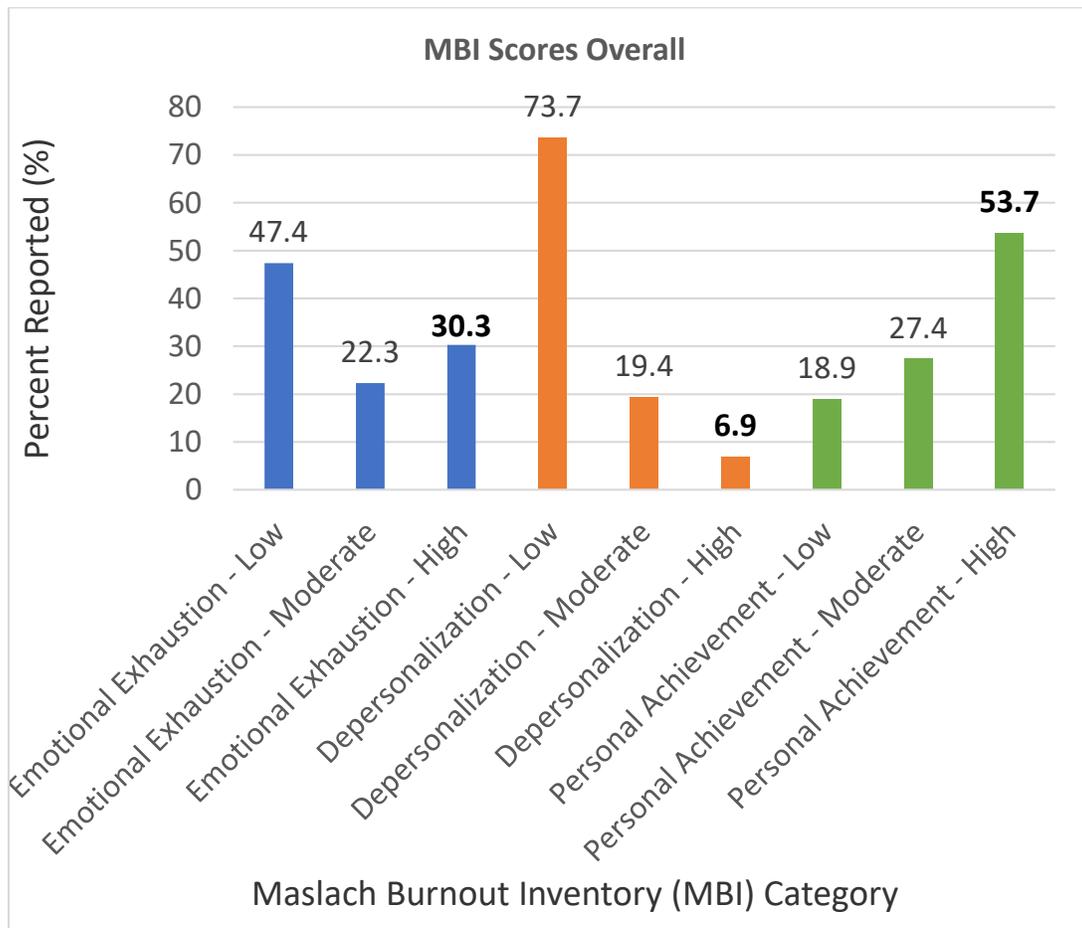


Figure 1

Proportion of Staff with Low/Mod/High MBI Scores by Category A to G

Category F had the highest proportion of staff with high EE (50%), though the sample size was small (n=8: see Table 2). This is followed by category G at 46.2%. Looking at Moderate to high EE combined, 80% of category C was in this range (small sample n=5), 75% of category F and 69.3% of category D. The lowest EE was noted in category B at 56.1%. The largest group, category A, had 27.4% of its members with high EE scores, which would translate into 23 staff members. The observed differences between categories was not statistically significant at $p < 0.05$. However as statistical significance is almost always about sample size, given adequately large sample sizes in any future studies, it is possible that some of the observed group differences would become statistically significant. The category with the lowest DP was category C (Spiritual Health Practitioners) with 100%. The category with the highest DP was category G at 15.4% (Job not specified category). The category with the highest PA score was category C at 100% whereas category E had the lowest PA at 36.4% (see Table 4).

Category	Emotional Exhaustion			Depersonalization			Personal Achievement			n
	Low	Moderate	High	Low	Moderate	High	Low	Moderate	High	
A	51.2	21.4	27.4	70.2	20.2	9.5	17.9	34.5	47.6	84
B	56.1	19.5	24.4	87.8	7.3	4.9	14.6	24.4	61	41
C	20	40	40	100	0	0	0	0	100	5
D	30.8	38.5	30.8	53.8	46.2	0	23.1	23.1	53.8	13
E	45.5	18.2	36.4	72.7	27.3	0	36.4	27.3	36.4	11
F	25	25	50	62.5	37.5	0	12.5	12.5	75	8
G	38.5	15.4	46.2	69.2	15.4	15.4	30.8	15.4	53.8	13

Table 4

Proportion of Staff with Low/Mod/High MBI Scores by Exposure to Deaths in the Past 6 Months

The participants were asked the following question: "In the past 6 months, can you estimate how many of the residents you regularly cared for have died?" Check box options were: 0; 1-5; 6-10; 11-15; 16-20; and 21 or more. **The Spearman's rho suggested that EE increased with the number of deaths observed. It is a positive association ($r = 0.18$) and it is statistically significant ($p = 0.02$)** (see Table 5).

Number of Deaths Seen in 6 mos	Emotional Exhaustion			Depersonalization			Personal Achievement			n
	Low	Moderate	High	Low	Moderate	High	Low	Moderate	High	
0	71.4	0	28.6	71.4	14.3	14.3	21.4	28.6	50	14
1 to 5	53.5	20.9	25.6	74.4	18.6	7	22.1	25.6	52.3	86
6 to 10	42.5	30	27.5	82.5	15	2.5	12.5	25	62.5	40
11 to 15	28.6	21.4	50	57.1	28.6	14.3	28.6	50	21.4	14
16 to 20	66.7	16.7	16.7	83.3	16.7	0	16.7	50	33.3	6
21+	13.3	33.3	53.3	60	33.3	6.7	6.7	13.3	80	15

Table 5

Proportion of Staff in Each Category by Number of Deaths Reported Within the Past 6 Months

The extent to which each category reported having residents they cared for die within the past 6 months is presented in Table 6. Most of those in categories A, B, E and G reported 1 to 5 deaths, whereas most of those in category F reported 6 to 10 deaths. Most respondents in category D reported 21 or more deaths. Very low numbers in some of the categories and the presence of too many zeroes in some of the cell sizes may affect any statistical significance of these results (see Table 6).

Category	Number of Deaths Seen in 6 Months						n
	0	1 to 5	6 to 10	11 to 15	16 to 20	21+	
A	14.3	60.7	17.9	4.8	0	2.4	84
B	0	51.2	24.4	7.3	4.9	12.2	41
C	0	20	20	20	20	20	5
D	0	7.7	23.1	23.1	7.7	38.5	13
E	9.1	36.4	27.3	9.1	18.2	0	11
F	0	25	62.5	0	0	12.5	8
G	7.7	46.2	23.1	15.4	0	7.7	13

Table 6

Proportion of staff with Low/Mod/High Scores by Religious Beliefs

Staff who expressed religious beliefs had lower scores on DP than those who did not express religious beliefs. None of the observed differences are statistically significant (see Table 7).

Expressed Religious Beliefs	Emotional Exhaustion			Depersonalization			Personal Achievement			n
	Low	Moderate	High	Low	Moderate	High	Low	Moderate	High	
No	50.5	19	30.5	68.6	22.9	8.6	16.2	25.7	58.1	105
Yes	42.9	27.1	30	81.4	14.3	4.3	22.9	30	47.1	70

Table 7

Descriptive Responses

Thematic analysis on the unstructured textual data responses to the open-ended questions, in all 203 returned questionnaires, resulted in the development of the following seven themes: 1) Feelings of Angst and Distress; 2) Feelings of Sadness and Tiredness; 3) Personal Reflections Shape Experience; 4) Everyone *on the Same Page* Matters; 5) Seeking Privacy and Respect; 6) Matching Resources to Needs and 7) Reaching Towards Acceptance (see below).

Quotes from the respondents that portray the deep thoughts and feelings that staff experience when their residents are dying or have just died:

1). Feelings of Angst and Distress (Some staff reported how very emotionally-draining and stressful it was)

- "Caring for a person who is dying is a roller coaster of emotion"
- "Some die peacefully, others suffer and they die slower. That is what is painful for the care workers and their families"
- "You are mourning for the loss and we are expected to still do our own job well, with a full smile as if nothing ever happened"
- "What could I have done better?"
- "I feel exhausted, no appetite, light-headed, headache..."

2). Feelings of Sadness and Tiredness (Most staff reported feeling sad, tired and a great sense of loss)

- "Sense of loss of knowing the love and care you have for this person is gone and you will not see them again; even though they are not your family they become a part of you"
- "Hard to let them go, I miss them. It's like losing someone dear"
- "We have become attached to them like families. You know them like your own, you cry, you feel the loss."
- If you were not on shift at the time of the death you may not have had chance to say goodbye which is sad"
- "I feel sad and tired but try to remain strong so I can continue to provide comfort and support to the resident and their family"
- "Keeping up with the turnover at the site (welcoming new residents and saying goodbye to others), the continuous demand of doing this can be mentally exhausting"

3). Personal Reflections Shape Experiences (Many staff reflected on their own mortality and family issues)

- "One day this will be me"
- "Is this the way I will die too? Will my family take care of me?"
- "Sadness as I reflect on my own aging + mortality + the aging of my parents, soberness of the fragility of life"
- "The fear of what my death would look like...opens me to deeper questioning about the meaning of life"
- "With each death, our own losses become fresh like a film in front of our eyes"

4). Everyone *on the Same Page* Matters (Many staff pointed out conflict between parties increased distress)

- "Importance of helping families through this process"
- "Hoping the family understands the options of care"
- "Some family members can't accept that their loved ones are dying"
- "Whenever I talk to family and try to educate them about the dying process, the easier it is for the staff, family and myself to help the resident go through the process of dying comfortably and with integrity"
- "The Interdisciplinary team if all working together, will truly make a difference"

5). Seeking Privacy and Respect (Many staff reported gaps in the provision of adequate private spaces)

- *Resident and Family*
- "This should be a process driven by the needs and desires of the resident and family who have been well supported and informed with dignity and privacy preserved"
- "Respectful language regarding preparing the body of the resident rather than using words such as bagging"
- "Private rooms, room for families to visit and sleep when necessary"
- *Staff*
- "I need rest and go to a private place to process but usually don't get the opportunity..."
- "NO TIME to breathe and mourn the loss"
- "Recognizing us as we go through this not just as us (doing) a job, but also as people who feel and are human beings"

6). Matching Resources to Needs (Staff very concerned and distressed when resident dies alone)

- "No one should die alone"
- "I feel drained and helpless when I can't even provide comfort to the family and to be at the bedside with my dying resident because I have to do other work."
- "They need your touch and your care; you are needed just to be there to hold their hands, especially when there are no family members around. I can feel their hands holding me tight so I stay with them for a while"
- "Time - trying to juggle my work...to give adequate support to families and residents at end of life"

7). Reaching Towards Acceptance (Some staff more accepting of death - appear to cope better than others)

- Spirituality: "My spiritually beliefs and practices are central to accepting/coping with these losses"
- Accepting the reality of the Life-cycle
- Resilience can be developed
- Peaceful death easier to accept
- Accomplished- feeling
- "It's my pleasure to walk along side with the resident in the end stage of their life"

The Responses to the Research Question "What do interdisciplinary care team members in PHC residential care facilities find helpful in supporting them to cope with resident deaths?" are presented in Tables 8 and 9.

Aggregate Descriptive Data Responses to the Survey Question: 2.e) What supports have helped you in the past?

Aggregate Category A-G Responses

1.	Debriefing, talking with colleagues, families and friends
2.	Team huddles/update on resident's condition
3.	Team work - support from ID team, MDs & management
4.	Palliative care team – embedded palliative care nurses
5.	Pastoral care staff
6.	Education/workshops on death & dying for staff & family
7.	Resource provided to meet need
8.	Memorials/rituals
9.	Faith/Prayers
10.	Music, meditation, breathing, walking, gardening, exercise, outdoors, fishing

Table 8

Aggregate Descriptive Data Responses to the Survey Question: 2.f) What supports might help you in the future?

Aggregate Category A-G Responses

1.	Increased awareness of Palliative Approach
2.	Pain-free & peaceful death for resident
3.	EOL Education: for staff & family
4.	Better communication: informed team & family
5.	Time to reflect/grieve/process
6.	Spirituality & the presence of pastoral care
7.	Adequate Resources: time, staffing, space
8.	Organizational Acknowledgement

Table 9

Discussion

The foregoing results give increased clarity around certain variables and correlations, but uncover more questions and discussion about those that are statistically insignificant or at first glance puzzling.

The MBI survey responses indicated that 52.6% of staff identified themselves as having either moderate or high levels of emotional exhaustion, which is a high proportion of staff. Our aim was to evaluate how this stress may be related to caring for dying residents and to make recommendations on how supports can be put in place to reduce the stress and associated burnout that staff may be experiencing.

One limitation of our study was the survey response rate; we sent out surveys to 577 staff and 203 staff responded. Smaller sized groups (e.g. PT, OT, RD, SW) were clustered together for the purpose of data analysis and to ensure confidentiality was maintained. In future, it would be helpful to increase the response rate from the groups with lower response rates.

Another limitation of our study was regarding the statistical significance of some of the correlations or differences we observed in the data. An example of this was regarding the association between staffs' religious belief/practice and their ability to cope (resiliency) signaled by low DP (Table 7). Although we found that those who explicitly expressed religious beliefs had lower DP

compared to those who did not express such beliefs, this was not statistically significant. One might think that this association would be stronger in a faith-based organization. Future investigation could therefore consider this more systematically.

The statistically significant demographic association between gender and EE is important and we are, careful with our interpretation that we do not fall into gender stereotyping (Puranova & Muros, 2010). If almost twice as many males as females report having high levels of EE, twice as many males as females report having high DP and, if almost 30% more males than females report having high levels of PA, then we may have to look more closely at the different ways men and women process death and dying and how each gender sees themselves in their care team roles in regards to coping mechanisms. Further research into these findings could help determine how we allocate supports organizationally for the diverse needs of each gender.

Regarding the correlation of EE with the “Proportion of participants’ MBI scores by exposure to deaths in the past 6 months” (Table 5). This finding points to the accumulative effect of multiple, successive and accelerated numbers of deaths upon staff. This type of accumulative grief is something we might explore more in a future study addressing caregiver stress. This correlation is important as it appears to identify thresholds that trigger high EE in staff (e.g., 11-15 and 21 or more deaths in the last 6 months) where demands on care outpace resources of the caregivers (time, attention, human presence, processing).

One of the strengths of our study was having a wide spectrum of disciplines participating in the study and the numbers of participants in the allied health disciplines were well represented (over 50% in categories C, D and E), which are not seen in many studies. Many studies focused on one specific group of professionals such as nursing aides, nurses, general care providers (licensed or unlicensed), residents, or residents’ families.

The wealth of responses that the staff generously contributed to the descriptive questions gave an insight into the Residential care team’s personal experiences as they care for dying residents. In these responses, we saw a rich tapestry of mixed emotions.

Low Depersonalization and high Personal Achievement along with high Emotional Exhaustion demonstrates the ability of our staff to be truly caring and relational amid suffering and death; this ability is precious and to be highly valued in our organization. However, our study has shown that compassionate care comes with a price and can increase risk of stress and burnout in residential care team staff if they are not provided with adequate support.

The question therefore remains: Can we support staff by reducing this risk as we promote the benefits of compassionate caring? The staff responses demonstrated that there is already the presence of coping skills, strengths and signs of resiliency in the midst of their stress which is encouraging.

These insights have been summarized, to provide the following recommendations to PHC leadership:

➤ ***The need for debriefing:***

Many staff highlighted the importance of debriefing both when caring for a resident who is dying as well as after their death. This may involve talking with colleagues who can provide empathy and insight as to what they are going through. Families and friends are also seen as being a great source of support.

It is also recommended that staff be made aware of other support services such as the Employee and Family Assistance Program (EFAP) and the Centre for Practitioner Renewal (CPR) if they are struggling to cope in any way.

➤ ***The need for good team work and communication:***

Good team work involves making sure that there is available support from all team members, including management. The respondents also highlighted the need for strong communication as this provides staff members with clear plans for care and clear expectations. Regular team huddles which include an update on resident’s condition are recommended to ensure that everyone “is on the same page” and that resources are being utilized to the maximum benefit of the resident, families and team.

➤ ***Increased awareness/provision of Palliative Approach:***

The Palliative care team was seen as being a hugely valuable resource, providing expert support for residents, their families and for staff. Palliative care nurses that are embedded within the different facilities provide the maximum opportunity for provision of this type of support.

It was also clear that having all staff on the same page with the palliative approach was needed to ensure consistency of care and to make sure that intervention is timely and appropriate. This is in line with the very strongly voiced staff desire for a pain-free & peaceful death for the resident.

➤ ***Families need to be well informed:***

Families need to be regularly and clearly informed regarding their loved one’s condition. Education was seen as being needed to support the families who at times may not fully understand the resident’s condition or in some instances may be in denial. This could be provided by regular communication with relevant staff as well as the provision of reading material, workshops and lectures. The aims being to empower them with knowledge, which in turn can help provide them with clear and realistic expectations and tools to help them through this difficult process.

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➤ **Staff education is important:**

Staff expressed a need for ongoing education to support them in knowing how to deal with the complexities of caring for a resident through the dying process. This included, for example, advice on how to "know what to say to grieving families," as well as increase knowledge of the dying process, the resources available and increase knowledge of the palliative approach.

➤ **Increase access to Pastoral Care:**

It was clear that staff place considerable value on maximizing access to Pastoral care staff (Spiritual Health Practitioners), who they see as being a key member of the team that provides support to the dying resident, their families and to staff. Seeing residents and families supported spiritually appears to help to reduce the moral distress of the care staff as well as being an invaluable support for the staff themselves. Spiritual Health Practitioners coordinate memorials and rituals that help staff by providing time and space to grieve or reflect. This can be seen as a way of giving "closure" which could otherwise be missed when staff are so busy with other resident's new admissions etc.

➤ **Spirituality**

Faith/Prayers were used by many as a way of coping with the emotional stress caused by caring for dying residents. Staff report that spirituality helps by giving some sense of meaning to this process and can "help to provide an acceptance of the life cycle". It is recommended that staff are encouraged to have time and space to express their spirituality.

➤ **Resources are provided to meet needs:**

One of the greatest personal needs that staff expressed was for time and space to care for their dying residents and to grieve their deaths. It is recommended that management explore how this can be provided as well as ensuring that this essential staff need is considered when the new residential care facilities are designed.

➤ **Self-help:**

It is recommended that staff use relaxation methods as a way of de-stressing in their own time. The aim being to reduce their baseline stress levels. Staff reported that the use of music, meditation, breathing techniques, walking, gardening, exercise, time outdoors and fishing can be beneficial.

Knowledge Translation

- Present at PHC Residential Practice Council; Elder Care Council; Nursing Practice Council; Residential Dietitians Group; Residential Occupational Therapists/Physiotherapists Council; Nursing Resource Group, Palliative Outreach Team meeting and Music Therapy meetings. The team will be presenting a poster at the Quality Forum and will apply to present at other relevant conferences. Write journal articles.

Complete Further Research

- The data gathered from the surveys presented as many questions as answers to this very complex question. The research team felt very strongly that further research is needed to explore this question further and to ensure that residential care team staff are well supported to care for residents through the dying process, thus minimizing levels of stress and burnout.

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