Keeping the Light Shining

Supporting Long Term Care Residents throughout the Dying Process: Understanding and Addressing Related Health Care Provider Stress – a Phase 2 study

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Outline of Presentation

- Introduction to Project: Phase 1 & 2
- Background
- Summary of Phase 1
- Study Design of Phase 2
  This research was funded by the Research Services at WorkSafeBC
- Data Collection
- Data Analysis – 5 Themes
- Recommendations
- Next Steps
Introduction to the Project Phases

- Phase 1 funded through the Spring 2015 PHC Interdisciplinary Research Challenge
  Aug 2015 – Completed Jan 31, 2017

- Phase 2 of Project funded through the Fall 2015 WorkSafeBC Innovation at Work Research Grant Competition
  Awarded $32,000.00 in 2016 - Completion date of Oct 31, 2018
Introduction to the Team

Team picture at PHC Research Challenge event in July 2015

Joseph joins the team in 2017 for WorkSafeBC Project
Background/Rationale for Studies

Observed increase in stress and distancing behaviours in staff:
- Dealing with increasing numbers of resident deaths

*Number of Resident Deaths across PHC 5 sites:*
- 2009: 140 (20%)
- 2013: 221 (35%)

- Increasing complexity of care and resident frailty
- Insufficient knowledge of how to support families of dying residents
- Feeling of insufficient time and resources to deliver safe, compassionate and ethical care
Summary of Phase 1
Maslach Burnout Inventory (MBI)

Is designed to assess the 3 aspects of burnout syndrome:

- **Emotional exhaustion (EE)**
  Measures feelings of being emotionally overextended by ones work

- **Depersonalization (DP)**
  Measures an unfeeling or impersonal response towards recipients of ones care

- **Lack of personal accomplishment (PA)**
  Assesses feelings of competence and successful achievement in ones work with people
**MBI Scores Overall**

<table>
<thead>
<tr>
<th>MBI Category</th>
<th>Percent Reported (%)</th>
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<tbody>
<tr>
<td>Emotional Exhuasion - Low</td>
<td>47.4</td>
</tr>
<tr>
<td>Emotional Exhuasion - High</td>
<td>22.3</td>
</tr>
<tr>
<td>Depersonalization - Low</td>
<td>30.3</td>
</tr>
<tr>
<td>Depersonalization - Moderate</td>
<td>73.7</td>
</tr>
<tr>
<td>Depersonalization - High</td>
<td>19.4</td>
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<tr>
<td>Personal Achievement - Low</td>
<td>6.9</td>
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<tr>
<td>Personal Achievement - Low</td>
<td>18.9</td>
</tr>
<tr>
<td>Personal Achievement - High</td>
<td>53.7</td>
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</table>
# MBI Scores by Exposure of Deaths in the Last 6 Months

<table>
<thead>
<tr>
<th>Number of Deaths Seen in 6 months</th>
<th>Emotional Exhaustion</th>
<th>Depersonalization</th>
<th>Personal Achievement</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>Low</td>
<td>Moderate</td>
<td>High</td>
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<tr>
<td>0</td>
<td>71.4</td>
<td>0</td>
<td>28.6</td>
</tr>
<tr>
<td>1 to 5</td>
<td>53.5</td>
<td>20.9</td>
<td>25.6</td>
</tr>
<tr>
<td>6 to 10</td>
<td>42.5</td>
<td>30</td>
<td>27.5</td>
</tr>
<tr>
<td>11 to 15</td>
<td>28.6</td>
<td>21.4</td>
<td>50</td>
</tr>
<tr>
<td>16 to 20</td>
<td>66.7</td>
<td>16.7</td>
<td>16.7</td>
</tr>
<tr>
<td>21+</td>
<td>13.3</td>
<td>33.3</td>
<td>53.3</td>
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Summary of Phase 1

Seven Main Themes Emerged:

1) Feelings of Angst and Distress
2) Feelings of Sadness and Tiredness
3) Personal Reflections Shape Experiences
4) Everyone on the Same Page Matters
5) Seeking Privacy and Respect
6) Matching Resources to Needs
7) Reaching Towards Acceptance

For Full Report - Phase 1

http://professionalpractice.providencehealthcare.org/ltc-team-support
Study Purpose

Objectives for Phase 2

- To explore how residential care facility team members are affected by the increasing number of deaths of the residents they are looking after.

- To explore strategies team members would find helpful in supporting them to cope with resident deaths.

- To explore how these strategies can be incorporated into the ongoing work of the PHC’s five residential care facilities and beyond.
Study Design
Qualitative Research - Interpretive Descriptive

Participatory Action Research (PAR)

- Individual Interviews
- Focus Groups
  - Audiotaped (2 recorders) then Transcribed + Researcher Field Notes
  - Data Coding – Inductive
  - NVivo Analysis
Sites and Participants

Five Residential Sites
Project Timeline

Initiation and Planning Phase
- Proposal funded Spring 2016
- Ethics application September 2016 - Jan 2017
- Communications plan launched March 2017

Data Collection Execution Phase
- Start date June 2017
- Interviews available June 2017 - April 2018
- Focus Groups available Oct 2017 – Dec 2017

Data Analysis
- Data Transcription Dec 2017 – Spring 2018
- Data Analysis March 2018 – Fall 2018
Ethical Processes

- Completed ETHICS application submitted end of Jan 2017
- PHCRI Behavioural Research Ethics Board (BREB) Approval Certificate March 14, 2017
- Ensure Data Security at all times
- Ensure Protection of Confidentiality at all times
Promoting Project

KT events for Phase 1; Promotion of Phase 2

Poster presentation at 15th Annual Geriatric Services Conference
Data Collection Phase

Participant Recruitment

- Volunteers
  - Recruited through advertisements provided in verbal and written form

Inclusion:

- All interdisciplinary clinical care team members working in all 5 Providence Health Care Residential Sites

Exclusion:

- Non-clinical staff: contracted, administrative
- Volunteers, students, their instructors, residents, family

- Incentives - draw slip at sites
- Numerous reminders
Questions asked

During the **interviews** and **focus groups**: 

1. What do you think about the results and the recommendations in the report from the 1st phase of our PHC LTC stress research?

2. How do you think it might be possible to move forwards on the recommendations within and across PHC LTC sites over time?
Data Analysis Phase

- 13 Individual Interviews
- 57 Participants attended 1 of 10 Focus Groups

Total: 70 Participants
Demographics
Length of employment – **Focus groups**

- **More than 16 years**: 43%
- **6-10 years**: 21%
- **11-15 years**: 10%
- **1-5 years**: 18%
- **Less than 1 year**: 8%
Demographics
Individual interviews - Disciplines

- MD: 15%
- RN: 23%
- SHP: 23%
- SW: 23%
- Music Therapist: 8%
- OT: 8%
Demographics
Focus group - Disciplines

- Arts and Crafts worker: 2%
- RA: 21%
- SLP: 2%
- Dietitian: 2%
- Unknown: 2%
- RN: 8%
- CNL: 6%
- OT: 6%
- SW: 4%
- SHP: 4%
- PT: 6%
- RCA: 35%
Demographics

Summary

• **More than 70%** of the participants for both individual interviews and focus groups were in over **45 years of age**

• Majority of disciplines working in PHC LTC sites were represented

• **Over 74%** of the participants have worked at PHC LTC sites for **more than 5 years**

• Most of the participants worked at **one site**
Our Strengths

- A loyal committed workforce
- High standards of care
- Low Depersonalisation
- High Personal Achievement

Staff expect a lot from themselves and want to be able to give the best care to residents...
Data Analysis: Key Challenges

- Expectation
- Communication
- Support
- Acknowledgment
Unclear Expectations

In Hospice care
- Clear prognosis and goals of care
- Death is expected by individual, family and staff
- More homogenous group

In Residential care
- Prognosis and goals of care can be unclear
- Unpredictable complex care group
- Residents at different stages of life’s journey
- More complicated in terms of expectation
  - family
  - staff
Differing Goals of Care

- Resident, family and team members may all have different understandings
  
  “which means that a palliative approach to care can be difficult to initiate and sustain”

- Default can sometimes be acute intervention
  
  “If we keep the resident here when they are dying the last moments here could be comfortable and beautiful”

(Challenges)
“Sometimes the family have expectations around care that differ from those of the residential care team”

“We have to honour the families journey. Everyone has their own grief timeframe. You can’t push that”
“The expectation that we are able to manage”

- Moral distress if not able to be there when a resident passes away
  
  “Need time to allow for proper care”

- “Time to give support at end, with emphasis on the little things – they matter”

- “They grieve, they want to be with their residents... but the truth is, they don’t have the time”

(Challenges)
Balancing Workload

- “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”

- “Workload is a challenge when someone is dying...”

- “Huge time constraints from assessment and charting for several disciplines (RN, OT, PT, SW, RD, etc.) due to all the deaths and move-ins leaving little time to debrief, grieve and remember”
Communicating with Family

- Not knowing what to say to comfort families
  "I don’t know what to say (when the resident dies). What will I say to the family? I feel sorry, but it’s so hard.”

- Need more team meetings with family to connect and build trust
  "it is hard to be present enough to consistently support residents, families and LTC team"

- “There can be a language barrier”
Communicating with Residents

Residents are not always aware of who is sick or near end of life. May not hear that a fellow resident has passed away

- "a lot of people are left in the dark on the residents‘ side”
- “actually it’s really hard to inform the other residents especially when they passed on already and they don’t have any idea”
Communicating with Colleagues

▪ “Its about how you tell colleagues that someone's died because not everyone's dying on your watch”

▪ “It’s like someone just suddenly disappears...sometimes you can hear a week later or if you start looking for the resident”

▪ I am always scared before going on vacation....hoping and praying that when I come back, they're still there“

(Challenges)
Acknowledging the Resident

- “I really struggle with the one I didn’t get to say goodbye to”

- “I’d like to have the ability to say goodbye, get closure and have a sense of peace”

- “In my mind, I should go there, but I’m too busy...”

(Challenges)
Staff seeking Acknowledgement

- “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.”

- “If you’re feeling exhausted, you won’t be able to help the residents and the families as well”

- “The recognition of the stress...the anxieties”
Staff seeking Acknowledgement

- “its 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”

- “in residential care, I find that we are kind of seen like the bottom of the rung…”

- “We need to feel listened to and valued”

- “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.”

(Challenges)
The Need for Emotional Support

▪ “Grief is such a heavy thing that you don’t recognize until it catches up with you at some point in time”

▪ “Staff feeling guilt because they can’t spend as much time as they would like with the dying resident and their family”
Support Needed to Debrief and Acknowledge Grief

▪ “In hospice care, we have these lovely debriefing and I thought we should do that here”

▪ “because everyone’s feeling a bit scattered but nobody is talking about the elephant in the room”

▪ “You have to put your feelings out there and then you can move on with it”

▪ “we're all left to our own devices...go talk to a colleague. There is no formal venue for it.”

(Challenges)
Caring for Self and Own Families

- "We're in health care, but who's caring for us?"

- “It's hard for people who are giving their whole emotional selves to the job”

- “Without an in-house PHC psychosocial support, we rely on EFAP which leaves gaps”
Accessing appropriate services

Lack of being able to access appropriate services at key times can increase staff and physician stress

- Physician availability due to limited contracted hours
- Having ‘buy-in’ from all the team to initiate palliative care
  “everyone on the same page...really matters”
- Under utilization of palliative care services

(Challenges)
The Need for Coaching and Education

- "in school, there was very little acknowledgement of people that you work with might have emotions, and you might have emotions too."

- "(good to have) staff awareness of what kind of energy staff are bringing into the room (and) info on heightening the sense of presence they bring into the room"
Self

Care and awareness

▪ Take time to nurture self

▪ Walking, time in the nature, yoga, fishing and camping, time with friends and family....

▪ Mindfulness

▪ Maintaining boundaries between work and home

(Recommendations)
Self
Take time to say goodbye

- "If there is private space that I do get to go and pay my respects, that gives me closure"

- "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"

- "Memorial services are really good because if you don’t have a chance to say goodbye to someone, it gives you a little bit of an opportunity for closure"

(Recommendations)
Self

Take time to debrief and reflect

- “It should **assumed** that time needs to be given to grieve and debrief; this is part of the job”

- “Giving us the benefit of the doubt if we need a moment to talk about the emotional impact on us”
Team

Connecting with families

- Cultural sensitivity
  “Staff should be aware of the cultural and belief differences and adapt the communication strategy appropriately”
  
- Clear gentle language

- Use of translators

(Recommendations)
Relationship-building
Team

Supporting resident and family towards acceptance

- Regular meetings to prepare residents and families:
  
  “Physicians having serious illness conversations to help mentally prepare families earlier”

- Call team meetings proactively when resident status is changing.

(Recommendations)
Team

Supporting resident and family towards acceptance

- Gentle repeat of information to support towards acceptance
  - “Work 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.“

- “We have to honour the families journey. Everyone has their own grief timeframe. You can’t push that”
Team

Comfort for families

- To provide families with some physical comforts
  "larger rooms, comfy chairs, overnight stays"

- Regular check-in
  "can I make you tea? coffee? Offer you a snack or sandwich? - so families don’t have to leave; a comfort basket"

(Recommendations)
Team
Comfort for residents

- “Putting on a soft light at night - I feel so bad if someone dies in the dark”

- “Just to be there to hold their hand”

- “important to moisturize mouth/ lips”

- “it makes me feel good to help them – more time to give support at the end”

- Utilize trained volunteers to also spend time with residents e.g. religious organizations
Team
Enhanced palliative care resources

- Improved integration of Palliative Care Outreach Team
  “Integrate PCOT nurses everywhere in the facilities, on all the teams and at all the tables”

- Early Involvement of PCOT when resident moves in
  “so relationship and trust is built with family “

- Effective use of existing palliative care resources
  "Keep palliative care room as a sacred space for dying residents"
Team

Increase comfort with end of life conversation

- Speak the language of the palliative approach
  
  “Palliative care helps patients to achieve the best possible quality of life right up until the end of life.”

- Normalise end of life conversation
  
  “Don’t be afraid to use the word death including a good death”

- Develop comfort with talking to families following death of loved one
  
  “There may be things staff can do to lighten up the spirit in the room with the family members if you know them well”
Team

Increased use of Spiritual Health Services

- Raise awareness of referral process e.g. SCM referral, pager, on-call process (24/7)
- Increase awareness of the scope of spiritual health service
  - supporting staff
  - supporting family
  - grief after loss workshops
- Mini memorial in the neighborhood
Team
Incorporate additional rituals/practices

Honouring the deceased resident at the time of death

- Flowers on the body and bed after resident died
- Quilt over the body when they are moved from the facility
- Staff to accompany the body and families when funeral home service arrives
- Memory boxes with residents pictures when they passed
Organization

Supportive leadership

- Encourage staff to attend memorial services

“Important for leaders to be there (at memorial services) and maybe staff would follow “

“I think it gives permission... people feel like they are encouraged to have the space if the leader sets the example.”
Organization

Supportive leadership

- “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.”

- “I might not be able to fix that situation, but just having that chance to care and...hearing it out”
Organization

Communication

- Improve communication system at each site, with the aim of informing all staff (including volunteers and Rehab staff) about resident decline or death

  “It’s the difference of knowing ahead of time”

- Continue to promote a culture of safety where staff feel empowered in communicating their concerns
Organization

Learning resources for families

- Make a readily understandable brochure 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"

- Education sessions for family provided by the health care organization/ facility
Organization

Education for staff

- Palliative Approach
- Best practices in EOL care, especially the “little things” that can make a big difference for comfort and QOL of dying residents
- around staff personally dealing with their grief and loss and dangers of burnout:
  "seeing the Burnout scale was so helpful..."
- Coaching for staff on how to inform other residents about a dying/deceased resident
Organization

Provision of resources

- Re-assess staffing levels when resident is dying
- Re-evaluate staffing level for palliative care team coverage
- Allowing greater flexibility of staff schedules when requesting time off
- Consideration to increase physician hours
- Allocate physical space for staff to grieve and debrief
- Regular opportunity to debrief built into working day
  
  “in hospice care the debrief wasn’t an extra, it was part of your duties”

- In-house PHC psychosocial support for staff
Palliative care as part of residential care job interview questions, job description and job advertisement process

Make death/dying significant part of residential orientation

“knowing palliative care is part of residential care...that’s huge”

Enhance awareness of residential care staff needs and facilitate their voice in the structure and provision of health care
Higher learning

- Connect with professional organizations regarding building in palliative care/death/dying into curriculum
- Provide enhanced emotional preparation for healthcare workers working with residents at end of life
- More education highlighting dementia as a terminal illness
- Promote residential care as a specialist area of healthcare
Recommendations for Self

- Awareness and mindfulness
- Take time to say goodbye
- Take time to debrief and reflect
Recommendations for Team

- Supporting resident and family towards acceptance
- Connecting with families
- Provide comfort for families
- Time to give comfort to residents
- Enhanced palliative care resources
- Increased use of Spiritual Health Services
- Increase comfort with end of life conversation
Recommendations for Organization

- Effective communication
- Provision of resources
- Supportive leadership
- In-house PHC psychosocial support for staff
- Coaching and training for staff and volunteers on death and dying conversations
- Providing learning resources for families
- Recognition of residential care staff needs in caring for dying residents
Recommendations for Higher Learning

- Build up palliative care/death/dying into curriculum
- Prepare healthcare workers for emotional stressors working with residents at end of life
- More education highlighting dementia as a terminal illness
- Promote residential care as a specialist area of healthcare
Next Steps

- Knowledge Translation at the 5 sites and with leadership
- Action planning to help reduce health care provider stress and burnout
- Strategy implementation
- Knowledge Translation at the Provincial, National and International levels
Acknowledgements

- PHC Residential Staff & Physicians
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