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Research Project Report - Brief Summary - Phase 1

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

Team Members: Anne Leclerc, Team Leader, Registered Physical Therapist, MRSc; Kit Chan, Registered Dietitian, BSc, RD; Karen Pott, Registered Occupational Therapist, BScOT (Hons); Chris Bernard, Spiritual Health Leader, MDiv; Annes Song, Registered Nurse, MScN Candidate
Mentor: Dr. Paddy Rodney, RN, PHD Nursing, UBC Associate Professor

This is a brief summary of our research project focused on understanding care team members' experiences while caring for dying residents in Providence Health Care's (PHC) five residential care facilities. This study was funded by the PHC Practice-based Research Challenge 2015. PHC residential care is increasingly providing end-of-life care due to the increased levels of frailty of residents upon admission. This trend is echoed nationally and internationally.

Study Aim:

In Phase 1, we aimed to understand and address:

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

Study Details:

We used a survey to find out how staff feel they are affected by the increasing number of resident deaths and what suggestions they might have to help reduce the levels of stress and/or burnout.
The survey consisted of 3 parts: 1). a Demographic section, 2). a section on open-ended questions and 3). the Maslach Burnout Inventory **(MBI)** - a well validated tool looking into burnout levels in healthcare staff. The results of the MBI consist of 3 separate scores: Emotional Exhaustion (EE), Depersonalization (DP) and Personal Achievement (PA).

(EE) - Measures feelings of being emotionally overextended by one's work
(DP) - Measures an unfeeling or impersonal response towards recipients of one's care
(PA) - Assesses feelings of competence and successful achievement in one's work with people
High values of EE and DP and lower values of PA signify burnout.

During the analysis, to protect the privacy of participants responding from disciplines with smaller numbers (i.e. less than five) of staff, 7 categories were developed by looking at similarities in the staff-to-resident ratio and the workforce role.

List of Categories
Category A: Resident Care Aides
Category B: Registered Nurses, Palliative Nurses, Registered Psychiatric Nurses, Clinical Nurse Leaders
Category C: Spiritual Health Practitioners
Category D: Social Workers, Occupational Therapists, Physiotherapists, Dietitians, Music Therapists
Category E: Rehabilitation Assistants, Unit Coordinators
Category F: Physicians, Psychologists
Category G: Did not say (Job not specified)

Study Results: Key Points

Response Rate and Demographics

1. Response rate: We received **203 of 577 surveys** from the five LTC residential sites: a **35% overall** response rate.
2. Demographics: 67% of respondents reported being over the age of 45, and 56% of respondents reported being employed by PHC for more than 10 years.

MBI Results

1. MBI Results: Of the 203 returned surveys, **175 MBIs** were fully completed and eligible for the data association between demographics and MBI scores.

2. Overall MBI Emotional Exhaustion (EE): **30.3 % of staff reported high EE** and over 50% reported moderate to high EE.
3. Overall MBI Depersonalization (DP): High DP was reported as 6.9% which remains low.
4. Overall Personal Achievement (PA): 53.7% of staff reported high PA, and 80% moderate to high PA.
5. **Males reported higher Emotional Exhaustion (EE) than females** (48% versus 27.5%). Gender and high EE were found to be statistically significant.
6. **Emotional Exhaustion (EE) increased with number of deaths observed** and it was found to be statistically significant. Category D reported the highest number of deaths.

Open-Ended Responses

Thematic analysis of the responses to the open-ended questions in all 203 questionnaires resulted in development of the following ***Seven Themes.*** *Here are a few of the quotes listed under the theme headings:*

1) Feelings of Angst and Distress
- "Caring for a person who is dying is a roller coaster of emotion."
- "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"

2) Feelings of Sadness and Tiredness
- "We have become attached to them like families. You know them like your own, you cry, you feel the loss."
- "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 Experience
- "One day this will be me."
- "Is this the way I will die too? Will my family take care of me?

4) Everyone on the Same Page Matters
- "Some family members can't accept that their loved ones are dying."
- "Importance of helping families through this process", and "Hoping the family understands the options of care."

5) Seeking Privacy and Respect
- "This should be a process driven by the needs and desires of the resident & family."
- "NO TIME to breathe and mourn for the loss"

6) Matching Resources to Needs
- "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"

7) Reaching Towards Acceptance
- "It's my pleasure to walk along side with the resident in the end stage of their life."
- "Spirituality: My spirituality beliefs and practices are central to accepting/coping these losses."

These are the aggregate answers to the open-ended questions about supports.

- ***What supports have helped you in the past?***
  - ✓ Debriefing, talking with colleagues, families and friends, meditation
  - ✓ Team huddles/update on residents' condition
  - ✓ Pastoral care staff, memorials/rituals, and faith/prayers
  - ✓ Education/workshops on death & dying for staff & family
  - ✓ Palliative care team—embedded palliative care nurses on sites
- ***What supports might help you in the future?***
  - ✓ Increased awareness of Palliative Approach, and pain-free/peaceful death for resident
  - ✓ End-of-life (EOL) Education for staff and residents' families and on bedside communication on EOL
  - ✓ Time to reflect/grieve/process
  - ✓ Spirituality & increased presence of pastoral care
  - ✓ Adequate resources for private space for the dying residents, staffing, time
  - ✓ Organizational acknowledgement

In the next phase, we will be exploring these findings further to ensure that LTC teams are well supported to care for the residents through the dying process. Follow-up phase funded by *Worksafe BC "Innovation at Work"* research grant. ***See you in Phase 2!***

Acknowledgements: PHC residential staff; PHC residential physicians, PHC Administration, PHC Practice-based Research Challenge Committee and Ms. Aggie Black, Dr. Joseph Puyat and CHEOS, HSSBC Payroll, UBC School of Nursing, BCNU, HSA and Research Assistants (Jeff Yu, Laura Gall, Nora Abdoh, Shazbeen Ali, and Nassim Adhami).