

**RESEARCH ON THE RUN**

End of life care

# The grief experiences of frontline home care workers

Frontline home care workers working in palliative care experience the death of their clients often. How do these workers cope? Are they supported well enough?

## Key Learnings

The grief experiences of frontline healthcare workers in long term care are well understood, and they have opportunities, working in an institution, for social and spiritual support and in-place training.

Home care workers who care for dying clients and their families also experience grief but need different kinds of support because they work in different circumstances: autonomy/isolation in the community, lack of institutional structures to provide face-to-face support, and longer, more personal involvement of direct care workers with dying clients and their families.

Bottom-line: more support is needed for these frontline home care workers.

## Project overview

Studies in acute care hospital and long term care settings show that the effects of grief can have significant negative consequences on staff, the organizations they work for and the clients and families they care for. These consequences include reduced psychological well-being and job performance and lower quality of client care. Many studies have indicated that there is a need to support health care providers with their grief experiences after the death of clients, and experts and researchers have defined possible support strategies for health care providers in acute and long term care settings.

The work of home health care workers is different from work in acute care hospitals and long term care homes. Home health care providers are geographically dispersed and isolated from others in the health care sector. Although home care providers work in teams, these teams are virtual and often their interactions with other team members are limited to notes on charts and occasional employer-organized meetings. Furthermore, the care is often provided longer along the health-illness trajectory resulting in relationships that can extend over many years. The episode of care takes place within the client's and family's home and often home health care workers form close relationships with clients and families, becoming an extension of the family. While the grief experiences of health care workers from the acute care and long term care settings possibly indicate the issues that home care workers face, the contextual differences will likely have some different implications for home health care workers.

We set out to document and analyze the grief experiences of nurses and Personal Support Workers working in palliative home care, determine whether they are appropriately supported, and if not, identify ways for supporting them better.

## What did we do?

Over the course of several months, a researcher interviewed 15 direct care providers and video-recorded the interviews. We included nurses and PSWs working in urban and rural settings, and with a range of experience – from novice to experienced. We compiled a video, and took it to several focus groups composed of supervisors and other frontline workers to validate the findings and identify supports that would address any unmet support needs of frontline providers.

## What did we find?

Isolation and dispersed home care work do make a difference to the grief experiences of home care workers in comparison with workers in institutions. Providing care in a home over an extended period means workers feel a family-member-like loss but they are also often asked concurrently to provide grief support to family members. We found that there were differences in the grief responses of novice and experienced home care workers. Workers expect help to deal with their own grief and want more counseling and time to talk with peers. They also expect time and training to provide support to family members; except in specific cases, they do not feel they get enough of either.

Employers can support their workers in different ways, including providing more time and space for grieving, peer support, and training on supporting grieving families.

### **Innovative approach**

We interviewed frontline staff using digital video, analyzed their experiences and ideas, and compiled them thematically into a 12-minute video. This video formed the basis for validation and investigating better supports.

### **IMPACT: How are we moving Knowledge to Action?**

Changes in supports available within Saint Elizabeth to direct care providers

- EAP process clarification
- Leaders' guide on supporting staff
- Data report on deaths
- Case debrief guidelines
- Revised bereavement visit guide
- Annual celebration of life

In addition, in conjunction with a review of the chaplaincy program at Saint Elizabeth, a series of supportive webinars called Spiritual Care Corner was started. There are plans for continuing this initiative.

### **Who are the researchers?**

- Vicki Lejambe RN, MN, Advanced Practice Consultant , Oncology & Palliative Care, Saint Elizabeth
- Dr. Paul Holyoke, Director, Saint Elizabeth Research Centre

### **How was this project funded?**

Saint Elizabeth funded the research through the Research Centre as an element of its social innovation mission.

### **For more information about this project, please see our webpage:**

[www.saintelizabeth.com/research](http://www.saintelizabeth.com/research)

**Or contact:** [vickilejambe@saintelizabeth.com](mailto:vickilejambe@saintelizabeth.com)

### **About the Saint Elizabeth Research Centre**

Saint Elizabeth has made a strategic commitment to research — \$10 million over 10 years.

At the Saint Elizabeth Research Centre, we study the needs of people, their caregivers, and health care providers to develop innovative solutions to improve health and care experiences across the continuum for more effective approaches to care. The Research Centre has four areas of focus: integrated care and transitions, end of life care, caregivers, and person and family centred care.

Our goal is to improve people's health and care. We work on innovative solutions for tough problems.

*We see possibilities everywhere.*