Quality Palliative Care in Long Term Care Alliance (QPC-LTC)

Personal Support Worker Competencies

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Personal Support Worker research participants
Development of Personal Support Worker Competencies in long-term care is a sub-project of a five year Community-University Research Alliance funded by the Social Sciences and Humanities Research Council (SSHRC) entitled *Improving the Quality of Life for People Dying in Long Term Care Homes*. The goal of the project is to develop, through Participatory Action methods, a palliative care philosophy in long-term care (LTC).

LTC is a unique palliative care context: It is the home of very frail older people living with multiple, serious, chronic illness, and it is the place where they will die.

There is an urgent need for LTC homes to become palliative care centres of excellence where older people live the highest possible quality of life, and die with dignity, and free of suffering. However, the majority of LTC homes in Canada lack formalized palliative care programs.

Given that PSWs provide most of the bedside care in LTC, the empowerment and education of PSWs is key to the development of a palliative care philosophy of care. The development of palliative care competencies for PSWs is a key step in the development of the palliative care team in LTC.

**Focus on the PSW**

- PSWs provide the majority of the bedside care to residents at the end-of-life in LTC, but their role on the interprofessional team has not been clearly defined.

- Understanding the role and scope of the practice is crucial for interprofessional communication, and inclusion in decision-making.

- It is necessary to first understand what the PSW is qualified to do, how the PSW role is distinct from other professional roles, and the areas of possible overlap with the roles of others.

**Why have competencies?**

The goals of competencies are to describe the scope of practice: What should a PSW know and be able to do to work in a palliative care LTC setting? The minimum competencies are:

- To facilitate interprofessional communication and mutual understanding of roles on the palliative care team.

- To describe the standard of care all palliative residents of LTC can expect to receive.

- To promote palliative care as a specialization for PSWs.

- To provide a framework for evaluating practice, understanding education needs of PSWs, develop curriculum, write job descriptions, and guide hiring practices.

**The Process**

**INTERVIEWS**

Seven PSWs identified by their peers as the “best of the best” were recruited to participate in in-depth interviews to talk about their practice. Interviews were recorded, transcribed, and analyzed by the researcher using standard qualitative methods, to produce a detailed description of the tasks they perform.

**PSW COMPETENCY WORKING GROUP**

A volunteer working group of PSWs then met regularly to transform the ‘tasks’ into a standard competency framework by grouping the tasks according to similar knowledge and skills under headings representing distinct and non-overlapping areas of competence.

The current competency document is the product of a collaborative and participant-driven process between the researcher and the PSWs. It is an evolving document that reflects the working group’s understanding of their own practice and is intended to be a foundation for consultation and discussion with other PSWs.

**VALIDATION**

A process of validation is underway to see if the competencies accurately reflect the palliative care experience of a wider group of PSWs.
**Palliative Care Competencies**

1. Care of the resident
   a. Resident-centered assistance with personal care
      The PSW provides assistance with all personal care needs and understands the special care needs of elderly people with serious, chronic illness (including dementia), increasing frailty and declining capacity. PSWs know and understand the resident’s physical, emotional, and mental abilities and impairments, and continually adapt assistance to the changing needs to maintain maximum independence, mobility, well-being, and quality of life. The PSW maximizes the resident’s participation in their own care, and enables choice to the fullest extent possible, while providing assistance in a way that maximizes the resident’s dignity and right to privacy, especially in intimate care. When a resident refuses assistance, the PSW pursues a balance between respect for the resident’s right to choose, and the need to provide a minimum standard of care. When a resident is no longer able to communicate or contribute to their own care, the PSW provides the highest standard of care to maintain the dignity, well-being, and self-image of the resident.

   b. Building a relationship
      The PSW forms a bond of trust with the resident to create a foundation for high quality personal care. PSWs tailor assistance by getting to know each resident as an individual with unique needs, preferences, cultural and religious customs. Strong, caring, empathetic relationships that are built on reliability and respect are formed. PSWs use ingenuity, patience, compromise, humour, and compassion to manage resistant or hostile behaviours, while preserving the dignity of the resident and resident-PSW bond, carefully and respectfully. Difficult behaviours are anticipated and precautions are taken to protect themself and others. The PSWs respects the right of every resident and problem-solves to achieve a compromise, even if it means refusing assistance.

   c. Ongoing observation
      While giving care at the bedside, the PSW continuously observes the resident’s daily physical, emotional, and psychological functioning, promptly recognizes changes in functioning, reports changes to nursing staff, and documents observations.

   d. Specialized care
      Under supervision and alongside registered staff, PSWs provide specialized care as specified in the care plan and in accordance with established protocols.

   e. Creation of a home-care setting
      The PSW understands the loss/disorientation that comes with moving into LTC and does everything possible to create a “home” for the resident where there is genuine quality of life by:

      ⇒ Building personal, sincere relationships.
      ⇒ Facilitating participation in personal hobbies and interests.
      ⇒ Facilitating active living, interaction with other residents, and participation in recreational and life-enrichment activities.
      ⇒ Encouraging family members to bring in personal items to make a resident’s room more home-like.
      ⇒ Understanding the importance of physical intimacy and sexual expression in some residents’ lives, and respecting their right to privacy. Nurturing and supporting residents’ desire to pursue intimate relationships in their residence.
2. Care of the family

The PSW engages with family members, and seeks to understand their desired level of involvement in the care of the resident, understanding and being sensitive to the fact that different families desire different levels or kinds of involvement in care. The PSW empowers family members to assume the level and kind of care they are comfortable with, assesses the need to guide, demonstrate, and emotionally support the family member, while monitoring the quality of care provided by the family members. The PSW understands the potential for abusive relationships (physical, emotional, financial) among family members, and is alert to signs of abuse. Abusive relationships are reported and documented by the PSW on a case-by-case basis. The PSW understands that family members may find visiting their loved one emotionally challenging, by recognizing signs of distress, and providing emotional support at the bedside. In addition, the PSW provides information about process/stages of dying so family members are prepared. Particularly near the end of life, the PSW anticipates the need for family members to have physical and emotional support. If desired by the family member, the PSW stays in touch with family after resident’s death and attends the funeral when possible.

3. Care at the end of life

a. Preparing the resident for dying

The PSW acknowledges and accepts that death of residents in their care is natural and inevitable. The PSW respectfully helps prepare the resident for death in a way compatible with the resident’s own values, customs and understandings, encouraging the resident to find meaning at the end stages of life. The PSW talks to the resident and their family about death and dying and explores their wishes for end of life by listening, answering questions, and protecting their privacy. If appropriate, the PSW will encourage the resident and family to talk with a spiritual advisor. The PSW also emotionally prepares themself for losing a resident.

b. Comfort, safety, connection

The PSW knows the stages of dying, recognizes the signs of last days and communicates regularly with nurses about the resident’s changing needs. The PSW ensures the family is notified and involved to the extent they wish while providing emotional support, facilitating conversations with the resident, and protecting privacy. The PSW provides an atmosphere of peace and safety and unconditional regard for the dying resident, providing companionship at the very end so the resident dies accompanied.

c. Total care at the end of life

The PSW observes changes in the resident’s level of pain and distress, reports to nurse, documents, and provides comfort through touch, presence, sound/silence, positioning and softened light.

d. Care for the resident after death

At the time of death, the PSW may:

⇒ Close eyes/mouth, position body, brush hair, cleanse body, put clean clothes on, wash dentures, tidy bed linen, etc.
⇒ Invite staff to say goodbye, pray and/or have a moment of silence, and remember the resident.
⇒ Help other residents say goodbye.
⇒ Provide emotional support for the family.
⇒ Employ rituals that give meaning (e.g. opening a window).
Palliative Care Competencies

4. Communication
a. Other team members
The PSW communicates effectively with registered staff and other PSWs so the resident’s needs are promptly addressed.

b. Resident and family
The PSW communicates effectively with the resident and family about care needs, preferences, religious beliefs, cultural practices and values, supporting the resident to talk about last wishes and answers questions about death and dying. The PSW listens, understands and provides support and comfort to the resident and family in times of crisis.

5. Time management skills
The PSW is able to multi-task, adapt, rearrange, and compromise in order to provide efficient quality care, keeping cool under pressure and time constraints. The PSW manages their own stress in a healthy manner by talking and seeking assistance from others. The PSW reliably maintains their workload and helps others when possible.

6. Teamwork skills
The PSW works effectively as a member of the interprofessional palliative care team.

⇒ Communicates promptly with registered staff about changes in a resident’s status.
⇒ Collaborates with resident, family member and team to define goals of care.
⇒ Works effectively and collaboratively with other PSWs.
⇒ Participates in family and team conferences.
⇒ Documents activities effectively.

7. Self-care
⇒ Recognizes the importance of personal-awareness and self-care, and commits to a plan of regular self-care in order to stay physically, mentally, and emotionally healthy.
⇒ Acknowledges the personal, emotional impact of a resident’s death and seeks ways to debrief and grieve.
⇒ Advocates for institutional acknowledgment of the significance of loss on PSWs, and institutional support for time off to debrief and to attend funeral.
⇒ Advocates for chaplaincy support of PSWs.
⇒ Understands own personal limits, and commits to seeking help if “impaired” by cumulative loss.
⇒ Understands the signs of compassion fatigue and takes steps to support self and others.

8. Professional development/mentorship
⇒ Recognizes the value of research findings and follows the developments affecting practice.
⇒ Recognizes the value of life-long learning and seeks out educational opportunities.
⇒ Participates in in-house training and supervision opportunities.
⇒ Mentors students, volunteers, and family members.
⇒ Attends local and provincial conferences.
⇒ Stays up-to-date on developments in the profession.

9. Ethical and legal issues
⇒ Understands the special ethical issues near the end of life.
⇒ Recognizes the need for confidentiality.
⇒ Supports the resident and family in the choices they make.

10. Advocacy
At times when the resident cannot speak for themselves, the PSW is their voice, acting on their behalf, to ask for things the resident would ask for themselves if they were able.
The Mission of PSW Working in LTC

To provide individualized assistance tailored to the needs of each resident: assistance that affirms the value and worth of the resident; that maximizes choice, independence, and autonomy; that preserves dignity; that is culturally sensitive; that allows each resident to feel like a person who is worthy of care and assistance; that helps each resident live as actively and with as much meaning as possible until death.

To create a secure and respectful home-like care environment where residents and their loved ones have a sense of personal control, belonging and safety; where daily living has meaning and purpose; where every resident is seen as a person rather than a diagnosis.

To provide the highest quality of holistic personal care throughout the dying process so residents can die with the highest possible dignity and comfort, with their questions answered and their personal choices followed, free from fear, pain, and suffering, surrounded by the people they choose.

Next Steps

⇒ Consult with a wider group of PSWs to validate and refine the competencies.
⇒ Translate the competencies into learning objectives.
⇒ Consult with provincial colleges to determine which components of the current competency framework translate well into entry-level curricula, and which are better suited for continuing education.
⇒ Develop on-the-job training tools for PSWs currently working in LTC.