Palliative care competencies for PSWs in Long-term Care

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The Quality Palliative Care in Long-Term Care Homes (QPC-LTC) Project is a 5 year project to develop a palliative care philosophy of care in LTC

- Improve the quality of life for residents dying in LTC
- Develop interprofessional palliative care programs
- Create partnerships between LTC homes, community organizations and researchers
- Create a toolkit for developing palliative care in LTC Homes that can be shared nationally
- **Promote the role of the Personal Support Worker in palliative care**

Quality Palliative Care –Long-Term Care Alliance
www.palliativecarealliance.ca

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The focus of this study is the PSW, and the PC competencies for working in LTC

- 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 practice is crucial for interprofessional communication, and inclusion in decision-making.
  - what is the PSW qualified to do?
  - how is the PSW role distinct from other professional roles? What are the areas of possible overlap with the roles of others?

The purpose of having competencies:

- To describe the scope of practice; the major areas of responsibility; the ‘tasks’ that make up the work: What should a PSW be able to do and know in order to work in palliative LTC ?
- To describe the standard of care all palliative residents of LTC can expect to receive
- To provide a framework for ongoing professional development and to guide curriculum development
- To acknowledge and promote palliative care as a specialty for PSWs
- To provide a framework for evaluating practice, write job descriptions, guide hiring

There is a ‘gold standard’ for PSWs providing homecare palliative care

What it addresses:
Help with personal care
Help moving around the home
Comfort measures, including massage and skin care
Managing equipment
Assistance with food prep and homemaking

Also recommended:
Special training in infection prevention and control
Special training in palliative care
“Observation skills”
How to make the pt more comfortable
How to communicate with pt and family
How to ease anxiety the pt and family might experience related to symptoms of dying (stopping eating, respiratory problems)
Impact of culture on eol needs

But we have no ‘gold standard’ or competencies for PSWs in palliative care in LTC, even though LTC is by definition a palliative care setting, and personal care is such an important component of palliative care.

From the PSNO in 2009, came the following recommendations for PSWs providing care in LTC, emphasizing the need for palliative care education:

A standardized approach to in-service training should be implemented. Each Long Term Care Home should have a set of mandatory and a selection of elective training options to provide to frontline staff. Examples of topic areas to be considered:

- Recognition of elder abuse
- Workplace ergonomics
- Workplace violence
- Communication Skills: How to be heard
- Aggressive behaviours
- Depressions/Mental health and addiction issues
- **Palliative Care**
- Dealing with repetitive loss
- Chronic Disease Management

Supervisors and other interdisciplinary team members should be required to complete in-service training which will provide them with an understanding of the scope of practice and value personal support workers bring to care.

What is unique about the competencies required for working in LTC? Why aren't they the same as generic PSW competencies?

- LTC is a unique context of care providing care to very frail older people living with severe, chronic and debilitating illness that ends in death.
  - Currently, 65% or more of residents in Ontario's LTC homes have dementia (Alzheimer Society Ontario, 2010)
  - 67% of dementia-related deaths occur in nursing homes (Mitchell, et al., 2005)
- Some experts project that the number of frail elderly will triple or quadruple in the next 30 years and that the need for LTC beds will increase tenfold (Alzheimer Society, 2010). In Canada 39% of all deaths have been reported to occur in LTC facilities (Fisher et al., 2000)
- There is an urgent need for LTC homes to become palliative care centers of excellence, but the majority of LTC homes in Canada lack formalized palliative care programs. Given that PSWs provide most of the bedside care in LTC, the development of PSW competencies in this unique care setting is crucial to the development of a palliative care philosophy of care

Why do we need a palliative care philosophy in LTC?

- **CHPCA in 2008** formed a special interest group for LTC, recognizing the need for the palliative care philosophy, and the need for improved standards of palliative care in LTC

- Palliative care is a philosophy and a unique set of interventions that aim to prevent and relieve suffering and support the best possible quality of life. At the end of life, when death is inevitable, palliative care aims to provide a “good death” for people, and their family.

- There is a need for the skills, philosophy and compassion of PC teams that address holistically the needs of residents (physical, emotional, social, spiritual and financial domains), so Quality of Life is a goal in itself, and residents fully understand and control their choices regarding quality of life

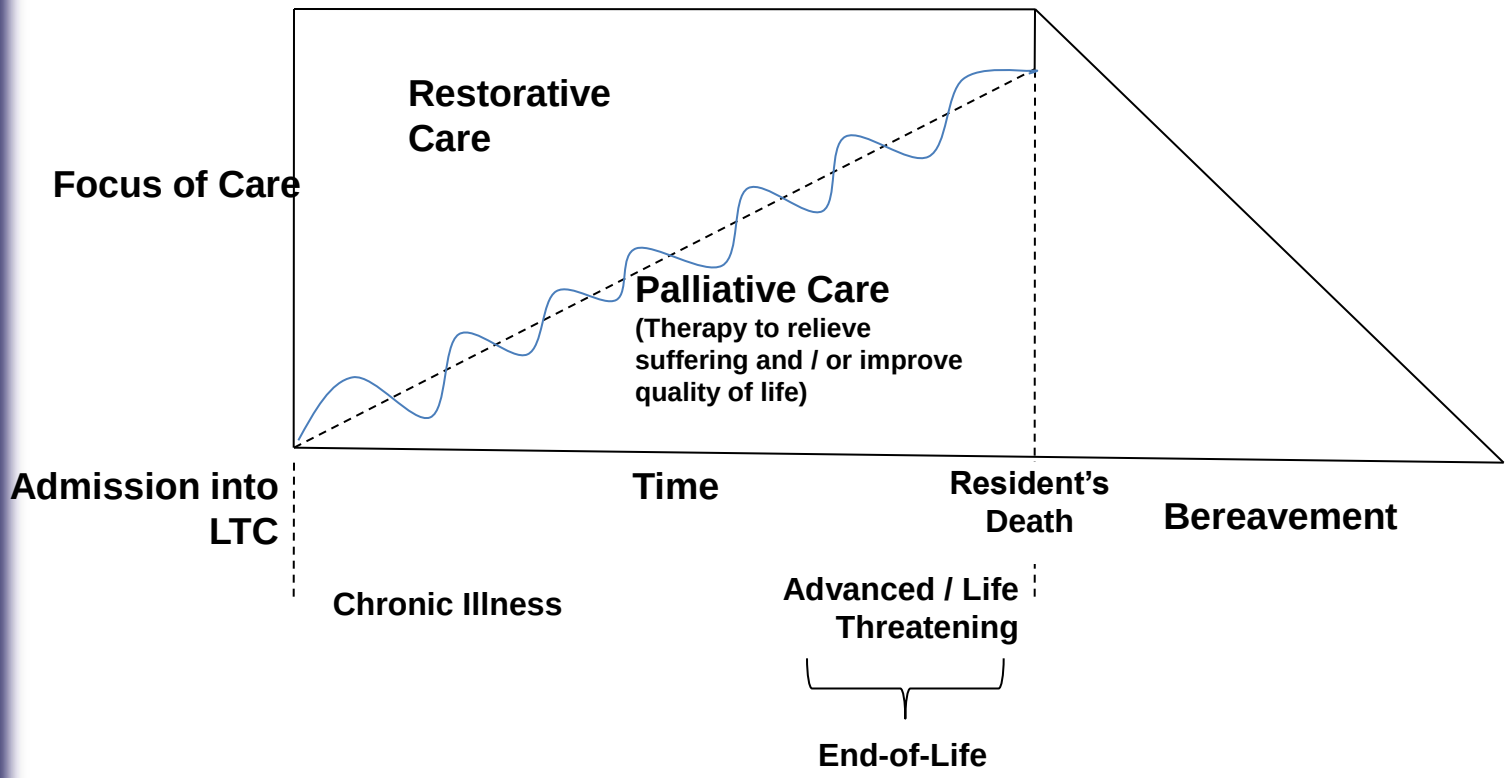
- Most long term care homes do not have a formalized palliative care program that addresses these needs.

What is unique about palliative care in LTC?

- Most of the care “team” consists of PSWs and non-clinical staff, including recreation, dietary aides, housekeeping, and volunteers, all of whom interact with residents on a daily basis in a setting that is more like a “home” than a medical facility, and who have an investment in providing the highest quality care to them.

- Second, residents in LTC are unlike the typical “palliative patient” in other settings. Many suffer from Alzheimer’s and other dementias, or are elderly people whose health is fragile enough to have required their entry into LTC in the first place, and who are “dying”, if not imminently, at least in the near future. It is important to conceptualize “palliative care” in such a context, to distinguish it from “end of life” care, and to develop competencies for both.

When does Palliative Care Begin?



(adopted from CHPCA, 2002)

Creating the Team is crucial, and PSWs are essential to that team

- Registered Nurses
- Registered Practical Nurses
- Life Enrichment
- Housekeeping
- Dietary
- Spiritual Care
- Administration
- Social Work
- **Personal Support Workers**

What is a “competency”?

- “Competencies” refer to the skills, knowledge, abilities, and personal attributes that are necessary for successful work performance....in this case....for being competent in *palliative care in a LTC setting*.

- A typical job description lists tasks and responsibilities. Competencies often begin with a thorough job description, but then go beyond that to try to capture the abilities needed to perform that job. Competencies can then be converted to learning objectives

How did we generate the competencies?

One on one interviews with PSWs who had been identified as “the best of the best” to talk about what they know and do in the course of a day

From these interviews we got a detailed description of the tasks that make up their work. These were then ‘grouped’ together according to similar knowledge and skills, under headings that represent distinct and non-overlapping areas of competence. So, we got:

Role (what they do, what vision they have for their work, what values guide it, what personal qualities are required etc)

What knowledge is required? (above and beyond the basic training)

What are the core competencies? (as they see them)

Then: a ‘working group’ of PSWs began writing up the identified competencies into a more conventional ‘competency framework’

Next steps...

We want to validate the competencies with an expanding group of PSWs

Translate into learning objectives, curriculum development

- college curriculum
- on the job PSW development

A beginning “mission” statement

- To provide individualized person-centered 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.
- To affirm the end of life as natural and innately worthwhile.
- To be a support system to the family through the end of life and through the early bereavement process.

What personal qualities are required?

- willingness to grow and learn
- self-driven, independent AND ability to work closely with others
- love of helping others and bringing joy; compassion; gentleness, patience
- tolerance for fast pace
- flexibility; adaptability
- excellent problem-solving skills
- emotional balance, sensitivity, and maturity
- commitment to self-care; self-awareness
- strength under pressure
- stamina (physical and emotional)
- ability to communicate
- ability to manage difficult emotions
- comfort with aging, dying, and death
- pride in work that is well-done

Values

- the worth and dignity of every resident
- the naturalness of death and the dying process
- the right of every resident to maximum choice, independence and autonomy
- empathy, compassion and love as the foundation for care
- collaboration, cooperation and teamwork
- LTC as a true home

1. Care of the resident

1a. Resident-centered assistance with personal care

- **The PSW provides assistance with all personal care needs:**
  - personal hygiene, toileting, dressing, eating, mobility

- **Understands the special care needs of elderly people with serious, chronic illness (including dementia), increasing frailty and declining capacity**
  - Knows and understands the resident's physical, emotional, and mental abilities and impairments, and continually adapts assistance to the changing needs and declining capacities of residents, to maintain maximum independence, mobility, well-being, and quality of life.
  - Provides assistance in a way that maximizes the resident's dignity and right to privacy, especially in intimate care.
  - Maximizes the resident's participation in their own care, and enables choice to the fullest extent possible. When a resident refuses assistance, the PSW pursues a balance between respect for the resident's right to choice, 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, provides the highest standard of care to maintain the dignity, well-being, and self-image of the resident.

1b. Building relationship

- The PSW knows that a bond of trust is the foundation of high quality personal care
  - gets to know each resident as an individual with unique needs, preferences, cultural and religious customs, and adapts assistance accordingly,
  - builds strong, caring, and empathic relationships with residents,
  - provides assistance reliably and with respect
- Uses ingenuity, patience, compromise, humour and compassion to manage resistant or hostile moods/behaviours of some residents, especially those with dementia, and seeks understanding of what might have led up to the difficult behaviour
- Anticipates difficult behaviours and adapts care (timing, for example) accordingly in order to prevent or de-escalate
- Takes precautions to protect self and others
- Seeks to preserve the dignity of the resident and the bond between resident and PSW by managing difficult behaviours with care and respect
- Respects the right of every resident to choice, even if it means refusing assistance, and problem-solves a compromise

1c. 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** these to nursing staff, and **documents** their observations.

- loss of hair, skin breakdown, lumps, bruises
- changes in mobility, energy
- changes in appetite, loss of weight, swallowing ability, elimination
- pain and discomfort
- changes in emotional or mental state: confusion, restlessness, agitation, fearfulness
- spiritual distress
- changes in pattern of socialization: apathy, giving up
- signs that the person is preparing to die

1d. Specialized Care

- Provides, in accordance with established protocols, under supervision and alongside registered staff, as specified in the care plan:
  - catheter care,colostomy care, skin and wound care, (including baths, creams, ointments)
  - Collection of specimens
  - Recording of input and output
  - Monitoring of oxygen equipment
- Assists nurses with procedures (eg. drawing blood).
- Assists resident to perform restorative care, as directed.

1e. 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:
- Builds personal, genuine relationships with residents by learning about their previous life, their family, career, special interests, religious, spiritual and cultural traditions, music preferences
- Facilitates residents’ participation in personal hobbies and interests that give meaning and enjoyment.
- Facilitates active living, interaction with other residents, and participation in recreational and life-enrichment activities. Gives special attention to residents who need more encouragement to participate or who need greater physical preparation and support.
- Encourages family members to bring in personal items to make a resident’s room more home-like.
- Understands the importance of physical intimacy and sexual expression in some residents’ lives, and respects their right to privacy. Nurtures and supports residents’ desire to pursue intimate relationships in their residence.

2. Care of the family

- Engages with family members, and seeks to understand their desired level of involvement in the care of the resident. Understands and is sensitive to the fact that different families desire different levels or kinds of involvement in care. 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. Monitors the quality of care provided by family members.
- Provides information about process/stages of dying so family members are prepared
- Understands the potential for abusive relationships (physical, emotional, financial) among family members, and is alert to signs of abuse. Reports and documents.
- Understands that family members may find visiting their loved one emotionally challenging; recognizes signs of distress; and provides emotional support at the bedside.
- Particularly near the end of life, anticipates the need for family members to have physical (food and drink, a comfortable place to rest) and emotional support.
- If desired by the family member, stays in touch with family after resident's death; attends funeral when possible and desired by family .

3. Care at the end of life:
3a. Preparing the resident for dying

- The PSW acknowledges and accepts that death of residents in their care is natural and inevitable:
  - Helps the resident prepare for death in a way compatible with the resident's own values, customs, and understandings. Explores and responds respectfully to residents' cultural, religious and spiritual practices.
  - Encourages the resident to find meaning and closure at this stage of life; to express feelings; do or say "last things"; express fears; pursue reconciliation where desired; find peace; say goodbye
  - Talks to the resident and their family about death and dying, to the degree they are able; listens and answers questions; protects resident's and family's need for privacy when having these conversations
  - Explores wishes for end of life: Do they want special music? is there a special person they want present when they die? Do they want their family present? Do they want to be dressed in special clothes after they die?
  - Encourages the resident and family to talk to a spiritual advisor if appropriate
- The PSW prepares self emotionally for losing the resident

3b. Comfort, safety, connection

- The PSW knows the stages of dying, and recognizes the signs of last days
  - Communicates regularly with nurses about the resident's changing needs
  - Makes sure the family is notified; involves the family in care to the extent they wish; demonstrates care when appropriate; provides emotional support and privacy to family; facilitates conversations between resident and family
- Provides an atmosphere of peace and safety and unconditional regard for the dying resident.
- To the extent that it is possible, provides companionship at the very end, so the resident dies accompanied
  - More frequent 'checking in', 'being there'
  - Assembles care team to say goodbye

3c. Total care at the end of life

- The PSW observes changes in the resident's level of pain and distress
  - Is acutely attuned to signs of pain and distress; reports to nurse and documents
  - Provides comfort through touch, presence, sound (music, or silence), more frequent positioning, softened light
- Provides total personal care with tenderness and compassion
  - More frequent care, especially skin, mouth care
  - Talks to resident softly when doing care, with tenderness; supports resident on journey to death

3d. Care for the resident after death

- At the time of death
  - close eyes, mouth; position body; brush hair; cleanse body; put clean clothes on; wash dentures; tidy bed linen; put bed rails down
  - invite staff to say goodbye, pray, have a moment of silence to remember the person
  - help other residents say goodbye
  - provide emotional support to family if present; give them private time. if family not there at the time, arrange to talk to them later
    - help family ‘let go’ and say goodbye; listen to them talk about their loved one; provide food and nourishment
  - rituals that give meaning: opening a window; a special quilt

4. Communication

4a. With other members of the team

- Communicates effectively with registered staff
  - makes effective use of all available reporting and documenting mechanisms so the resident's needs are promptly assessed and addressed
  - communicates promptly about changing health status of residents

4b. Communication with resident and family

- Communicates effectively with resident and family about care needs, preferences, religious beliefs and cultural practices, values.
- Supports resident to talk about last wishes, questions about dying and death
- Communicates effectively with residents and family members, especially during times of crisis and emotional turmoil
  - manages difficult ‘impromptu’ at-the-bedside conversations with residents and family members, and the intense emotions and conflict that come with them:
    - about death, refusal of food, what to do to manage hostile behaviour, or when a family disagrees or complains about care
  - listens, understands and provides support and comfort, even when residents and family members are angry, grieving, confused

5. Time-management skills

- Is able to multi-task, adapt, re-arrange, compromise in order to provide quality care under constant time pressure
- Keeps cool under pressure and time constraints, managing own stress in a healthy manner
- Reliably maintains own workload, and helps others whenever possible
- Manages own stress level by talking, seeking assistance from others

6. Teamwork Skills

- The PSW works effectively as a member of the interprofessional PC team
  - communicates promptly with registered staff about changes in a resident's status
  - collaborates with resident, family, and team to define the goals of care
  - participates in family/team conferences
  - documents activities effectively
- Works effectively with other PSWs

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 for 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

9. 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

10. 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
  - DNR, last wishes, feeding

11. Advocacy

- **At all those times when the resident cannot speak for themselves, the PSW is their voice, acting on their behalf, to ask for those things the resident would ask for themselves if they could.**

Further Information

Visit the website: http://www.palliativealliance.ca/

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