

Personal support workers and ethical issues in front-line care

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The growing cost of caring

LTC homes are the fastest growing housing sector for older adults

- between 75,000 and 80,000 people in approximately 600 LTC homes in Canada today
- 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

The changing demographic in LTC

- older adults receive care in their homes longer now
- people enter the LTC system only when their **care needs are very complex**
- Most residents will die within 2 years of admission to LTC

Demographics of LTC:

- Most residents suffer from Alzheimer's and other dementias, or are elderly people with severe, chronic and debilitating illness that will end in death.
- This makes LTC a major site of dying for old people: **It is a hospice for old people**

The “setting”

- is intended to be more like a “home” than a medical facility.
- This has special implications for the PSWs who provide the majority of bedside care: If this is a “HOME”, then **the relationships** that develop within that ‘home’ are important – both to the residents and to the staff providing their care

There is unrelenting and largely unrecognized and unspoken grief and loss

- Extended length of stay in LTC; close, intimate bonds with both residents and their family members; intimate personal care over a period of many months – all make this setting so unique for PSWs
- When a resident dies it is often like losing a family member
 - Multiply this many times over in a year, and you get a sense of the magnitude of the grief

The care team in LTC

- Is different from the 'care team' in other PC settings: Most of the care "team" consists of non-clinical staff, including recreation, dietary aides, housekeeping, and volunteers, all of whom interact with residents on a daily basis
- Most of the bedside care is provided by PSWs who are ***unregulated care providers***, and often have no specific training in palliative care

The role and scope of practice of PSWs

- In the LTC setting the PSW role goes well beyond the simple role of “providing personal care”, simply because the residents of LTC have such complex care needs

The reality is...

- What they actually DO in LTC has evolved to include activities that require a level of knowledge, skill and compassion beyond what their college programs prepare them for
- And they are doing this without extra training and support
- And funding and staffing models have not kept up, placing PSWs at risk for burnout
- And finally, adequate supports are not in place to provide the level of bereavement support that would be considered necessary in any other palliative care/hospice setting

The ten broad competencies

1. Care of the resident
2. Care of the family
3. Care at the end of life
4. Communication
5. Time Management
6. Team work
7. Self-care
8. Professional Development
9. Ethical and Legal Issues
10. Advocacy

**Now.....Just a “glimpse” at the
complexity of the work.....**

If we look at the first competency (care of the resident)

- We see how clearly it reflects the signature *physical personal care* that is so much the hallmark of being a PSW

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

But the next 'item' under providing personal care....

is a detailed description of relationship-building as a core competency for PSWs

- as important as the physical care

- 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

The PSW:

- 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

And then, while providing this personal care, the PSW must also do the following:

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

And the PSW....

- 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.

And all of this personal care must be provided in a setting that is as home-like as possible

- 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.

The next required competency is CARE OF THE FAMILY

- Again, I want to draw attention to how important the building of relationships is to PSWs.
- Notice too how complex some of these communication skills are

- 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

Next we turn to the third area of competency: Care at the end of life

Again, how complex these skills are!

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

At the time of death, the PSW:

- closes eyes, mouth; positions body; brushes hair; cleanses body; puts clean clothes on; washes dentures; tidies bed linen; puts bed rails down
- invites staff to say goodbye, pray, have a moment of silence to remember the person
- helps other residents say goodbye
- provides emotional support to family if present; give them private time. if family not there at the time, arranges to talk to them later
- helps family 'let go' and say goodbye; listens to them talk about their loved one; provides food and nourishment
- Provides rituals that give meaning: opening a window; a special quilt

The fourth major competency:

Communication!

With other members of the team, the PSW:

- 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

With the resident and their family, the PSW:

- 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

And the final 6 competencies...

1. Time Management
2. Team work
3. Self-care
4. Professional Development
5. Ethical and Legal Issues
6. Advocacy

The cost of caring

Providing care or delivering a service?

Burnout and demoralization

**The solution is not to stop caring,
but to create and fund
the institutional structures and policies
that make caring work possible
and sustainable**