It’s complicated: Palliative culture and whole system change within LTC

Presented by:
Quality Palliative Care in Long-Term Care Alliance

Canadian Hospice Palliative Care Association
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Background

- Palliative care is a philosophy and a unique set of interventions that aim to enhance quality of life at the end of life in order to provide a “good death” for people, and their family, when death is inevitable.

- Quality of life at the end of life is understood to be multidimensional and to consist of physical, emotional, social, spiritual and financial domains.
Background

- In Canada 39% of all deaths have been reported to occur in LTC facilities (Fisher et al., 2000)

- The majority of LTC homes in Canada lack formalized palliative care programs.

- LTC could be thought of as the hospices of the future, caring for older people with chronic conditions with a long trajectory to death, the most common being dementia. (Abbey et al., 2006)
Palliative Care versus End-of-Life Care

**Palliative Care**
- Begins when a disease has no cure
- Focus is on quality of life, symptom control
- Interdisciplinary in approach
- Client centered and holistic

**EOL Care (includes palliative care and...)**
- Death is inevitable
- Trajectory is short (6 months)
- Focus is on supporting patient and family choices
- Addresses anticipatory grief
When does Palliative Care Begin?

(adopted from CHPCA, 2002)

Focus of Care

Restorative Care

Admission into LTC

Chronic Illness

Palliative Care
(Therapy to relieve suffering and/or improve quality of life)

Advanced/Life Threatening

End-of-Life

Time

Resident’s Death

Bereavement

(adopted from CHPCA, 2002)
Quality Palliative Care in Long-Term Care Homes (QPC-LTC)

➢ Improve the quality of life for residents 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
QPC-LTC Alliance Methods

- Comparative Case study design with four LTC Homes as study sites
- Participatory Action Research
- Quantitative and qualitative research methods: Surveys, Interviews, Focus Groups, Participant Observations, Document Reviews
- Participants: Residents, Family members, Physicians, PSWs, RNs, RPNs, Spiritual Care, Social Work, Recreation, Dietary, Housekeeping, Maintenance, Administration, Volunteers and Community Partners
Research Timeline

- Year 1 – Environmental Scan in each home to create baseline understanding using CHPCA norms of practice (PC delivery, PC processes, LTC/PC policies, LTC resources).
- Year 2 – Create interprofessional PC teams and identify initial interventions based on evidence.
- Year 3 – 4 Develop PC program with PSW and community partners. Ongoing initiation and evaluation of PC interventions (PDSA cycle).
- Year 5 – Evaluate change and sustainability of changes (repeat environmental scan). Create evidence based toolkit of successful interventions.
- Year 5 onwards – Promote change in policy, practice and education.
## Square of Care and Organization

<table>
<thead>
<tr>
<th>Process of Providing Care</th>
<th>Disease Management</th>
<th>Physical Care</th>
<th>Psychological Care</th>
<th>Social Care</th>
<th>Community Care</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assessment</strong></td>
<td>History of issues, opportunities, associated expectations, needs, hopes, fears</td>
<td>Examination - assessment scales, physical exam, laboratory, radiology procedures</td>
<td>Personal, behavioural, family, spirituality</td>
<td>Relationship, roles, culture, values, beliefs, practices, finances, legal</td>
<td>Education, community resources</td>
</tr>
<tr>
<td><strong>Information-sharing</strong></td>
<td>Confidentiality limits</td>
<td>Process for sharing information</td>
<td>Depression, anxiety, emotions, fears, control, dignity, independence</td>
<td>Social support, care planning, advocacy,Launching</td>
<td>Community engagement, partnerships, public education</td>
</tr>
<tr>
<td><strong>Decision-making</strong></td>
<td>Capacity for treatment</td>
<td>Issue prioritization, therapeutic priorities, options</td>
<td>Pain, other symptoms, cognition, level of consciousness, function, safety, aids</td>
<td>Physical care, psychological care, social care</td>
<td>Community support, advocacy</td>
</tr>
<tr>
<td><strong>Care Planning</strong></td>
<td>Goals of care</td>
<td>Treatment choices, consent</td>
<td>Fluids, nutrition, habits, alcohol, smoking</td>
<td>Physical care, psychological care, social care</td>
<td>Community resources, support</td>
</tr>
<tr>
<td><strong>Care Delivery</strong></td>
<td>Process to negotiate</td>
<td>Management Decision-making</td>
<td>Wounds, allergies</td>
<td>Physical care, psychological care, social care</td>
<td>Community partnerships, education</td>
</tr>
<tr>
<td><strong>Confirmation</strong></td>
<td>Understanding</td>
<td>Advance directives, conflict resolution</td>
<td>Self-image, self-esteem</td>
<td>Social support, care planning, advocacy, Launching</td>
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### Patient / Family

#### Physical
- Pain, other symptoms
- Cognition, level of consciousness
- Function, safety, aids
- Fluids, nutrition
- Wounds
- Habits - alcohol, smoking

#### Psychological
- Personality, behaviour
- Depression, anxiety
- Emotions, fears
- Control, dignity, independence

#### Social
- Culture - values, beliefs, practices
- Relationships, roles
- Isolation, abandonment, reacclimation
- Privacy, intimacy
- Routines, rituals, recreation, vacation
- Financial, legal

#### Spiritual
- Meaning, value
- Existential, transcendent
- Values, beliefs, practices, affiliations
- Spiritual advisors, rites, rituals

#### Practical
- Activities of daily living, dependents
- Telephone access, transportation

#### Financial
- Life closure, grief giving, legacy creation
- Preparation for unexpected death
- Management of physiological changes in last hours of life
- Rites, rituals
- Death pronouncement, certification
- Perinatal care of family, handling of body
- Funerals, memorial services, celebrations

#### Loss, Grief
- Grief - acute, chronic, anticipatory
- Bereavement planning, mourning

### Resources

<table>
<thead>
<tr>
<th>Financial</th>
<th>Human</th>
<th>Informational</th>
<th>Physical</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Assets</td>
<td>- Caregivers</td>
<td>- Records, health, finance, human resource, assets</td>
<td>- Environment</td>
<td>- Partner healthcare providers</td>
</tr>
<tr>
<td>- Liabilities</td>
<td>- Consultants</td>
<td>- Resource materials, eg, books, journals, internet, internet</td>
<td>- Equipment</td>
<td>- Community organizations</td>
</tr>
<tr>
<td>- Formal caregivers</td>
<td>- Staff Volunteers</td>
<td>- Resource directory</td>
<td>- Materials/supplies</td>
<td>- Stakeholders, public</td>
</tr>
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# Square of Care (CHPCA, 2002)

<table>
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<td>Practical</td>
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<tr>
<td>End of life/Death Management</td>
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<td>Loss, Grief</td>
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[Table continues with dashed lines indicating missing data]
Sequential phases of the capacity development model:

1. Antecedent community conditions
2. Community Catalyst
3. Creating the PC team
4. Growing the PC program

Process of Palliative Care Development
Environmental Scan Results

Organizational Readiness

- Lack of policy and dedicated funding related to palliative care in LTC which limits resources.
- Few policies are reflective of a palliative care philosophy
- Strong dedication and commitment of managers and staff to improving palliative care
Environmental Scan Results

Personal Support Worker Empowerment

- Do not feel they can influence change as they often do not have opportunity to be involved in the process
- Limited training related to palliative care
- Role not clearly defined in providing palliative care
- Very resident-focused
- Strong sense of team amongst PSWs
Environmental Scan Results

Vision for Palliative Care

- Families and residents need opportunities to discuss and learn about their end of life options.

- Advance Care Planning needs to be broadened so it does not solely focus on medical interventions, i.e., DNR orders.

- People who could benefit from palliative care need to be identified in a timely manner.

- Requires an interdisciplinary approach.
Word Cloud – Diane interventions
Nadia’s Closing comments on her role as the manager
Jackie McDonald – role of the PSW
Conclusion

- LTC culture change requires a multi-pronged approach.

- Change requires commitment and involvement from all levels of staff.

- Sustainable change is slow, have to trust the process.
Further Information

Visit our website

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