Innovations in Palliative Care in Long Term Care - QPC LTC Alliance

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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
# Square of Care and Organization

<table>
<thead>
<tr>
<th>Assessment</th>
<th>Information-sharing</th>
<th>Decision-making</th>
<th>Care Planning</th>
<th>Care Delivery</th>
<th>Confirmation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary diagnosis, prognosis, evidence</td>
<td>Disease Management</td>
<td>Pain, other symptoms</td>
<td>Physical</td>
<td>Psychological</td>
<td>Social</td>
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<td>Secondary diagnoses - dementia, substance use, trauma</td>
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<td>Cognition, level of consciousness</td>
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<td>Depression, anxiety</td>
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<td>Co-morbidities - delirium, seizures</td>
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<td>Function, safety, aids</td>
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<td>Emotions, fears</td>
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<td>Adverse events - side effects, toxicity, allergies</td>
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<td>Fluids, nutrition</td>
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<td>Conflict, dignity, independence</td>
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<td>Wounds</td>
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<td>Conflict, guilt, stress, coping responses</td>
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<td>Habits - alcohol, smoking</td>
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<td>Self-image, self-esteem</td>
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<td>Personality, behaviour</td>
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<td>Culture-values, beliefs, practices</td>
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<td>Depression, anxiety</td>
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<td>Relationships, roles</td>
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<td>Emotions, fears</td>
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<td>Isolation, abandonment, reconciliation</td>
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<td>Grief - acute, chronic, anticipatory</td>
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<td>Bereavement planning</td>
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<td>Guardianship, custody issues</td>
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<td>Activities of daily living</td>
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<td>Grief, Loss</td>
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<td>Stakeholders, public</td>
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**FUNCTIONS**

- Governance & Administration: Leadership, board, management, organizational structure, accountability.
- Planning: Strategic planning, business planning, business development.
- Quality Management: Performance improvement, routine review, outcomes, resource utilization, risk management, compliance, satisfaction, needs, financial audit, accreditation, strategic & business plans, standards, policies & procedures, data collection/ documentation guidelines.
- Communications/Marketing: Communication/marketing strategies, materials, media liaison.

**RESOURCES**

- Financial: Assets, liabilities.
- Human: Formal caregivers, consultants, staff, volunteers.
- Physical: Environment, equipment, materials/supplies.
- Community: Hospital Organization, health care system, partner healthcare providers, community organizations, stakeholders, public.

**PROCESS OF PROVIDING CARE**

- Disease Management
- Physical
- Psychological
- Social
- Spiritual
- Practical
- Financial

**FROM:** Ferris PD, Balfour HH, Bowen K, Fairley J, Hardmark M, Lamontagne G, Lundy M, Syme A, West P.

A Model to Guide Hospice Palliative Care © Canadian Hospice Palliative Care Association, Ottawa, Canada, 2002.
Quality Palliative Care in Long-Term Care Alliance (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
Process of Palliative Care Development

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

Sequential phases of the capacity development model:

Community empowerment
Sufficient health system infrastructure
Vision for change
Collaborative generalist practice
Building community relationships
Building external linkages
Clinical Care
Education
Advocacy
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 informed by evidence.
- **Year 3** – Develop PC program with PSWs and community partners. Ongoing initiation and evaluation of PC interventions (quality improvement process).
- **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.
Participants and Data Collection for Environmental Scan

• All LTC home staff completed surveys
  – Sample sizes across 4 homes:
    • 205 PSWs
    • 69 Licensed Nurses
    • 79 Support Staff
    • 32 Administration
    • 39 Residents
    • 64 Family Members
Physicians’ perspective (interviews)

- Role is providing Comfort to Residents, Family and Staff
  - Communication between resident - Physician and Physician – LTC staff is a key element
  - Respecting resident and family wishes a priority
  - LTC staff need to be comfortable with emotionality of death and dying in order to comfort families
- Lack of resources and training for staff
- Families lack information and support
- Feeling the pressures: trends, expectations and government
Family perspective (interviews/focus gp)

- Strong perception that the LTC home is the resident’s home and would like for their family member to stay there until the end of their life
- General lack of awareness of the meaning of palliative care and the benefits
- Know when their loved one is dying and want to talk about it
- Want a staff member to start the conversation
- Feel the LTC home staff are doing the best they can with the resources they have available to them
Personal Support Worker Perspective

- Do not feel that they can influence change as they 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
- Very motivated to provide comfort until the end of life
- Strong sense of team amongst PSWs
Organizational Readiness

- Lack of policy and dedicated funding related to palliative care in LTC
- Focus is on end-of-life care rather than palliative care
- Few policies are reflective of a palliative care philosophy
- Strong dedication and commitment of managers and staff to improving palliative care
- Commitment to keep residents “home” until death
Environmental Scan

LTC Vision for Palliative Care

- Families and residents need opportunities to discuss and learn about their end-of-life options
- Advance Care Planning needs to expand beyond the focus on medical interventions (e.g. DNR orders)
- People who could benefit from palliative care need to be identified earlier and holistic care offered in a timely manner
- Requires an interdisciplinary team approach
Challenges and Issues

- Insufficient training for staff in LTC on PC and end stage dementia.
- Communication barriers at all levels
- Marketing of PC program
- Families and LTC residents need opportunities to discuss and learn about their end-of-life options.
- Advance Care Planning only medical (not holistic).
- Residents are not identified in a timely manner (RAI indicators)
- Lack of policy and dedicated funding
Facilitators to Palliative Care Development

- Organizational mission, vision, and values are in line with a palliative approach (i.e., resident centered care)
- Growing public awareness of need for palliative care and end-of-life care
- Family members desire to start the conversation and keep resident in LTC
- Commitment and attitudes of staff to develop program
- Vision for change by staff, family and resident
- Long term care Act
Creating a Cultural Change

- Management made commitment to QPC-LTC Project
- PSW Champions for Palliative Care internally
- Relationships with research team and students
- Extensive involvement of QPC-LTC Alliance members (community partners)
  - Engaged all local experts and resources such as PSMC
- Physician support and direct involvement
Creating the PC Team

- Interprofessional Teams develop the palliative care program. They include:
  - Registered Nurses
  - Registered Practical Nurses
  - Personal Support Workers
  - Life Enrichment
  - Housekeeping
  - Dietary
  - Spiritual Care
  - Administration
  - Social Work
Creating the PC Program description

- Mission statement and vision statements
- Definitions of PC and EOL care
- List of specific services clearly defined
  - Nursing and personal support services
  - Dietary
  - Medical
  - Spiritual
  - Social (e.g. family education & recreation)
  - Accommodation (housekeeping, laundry etc)
  - Volunteer
- Role of in-house team & community experts
- Screening and training of staff
- Plan of care (EOL protocols)
- Consent or treatment directives (ACP)
Palliative Care Interventions

Direct Care
- Pain and Symptom Chart Audit
- Comfort Care Rounds
- Snoezelen

Community
- Hospice Northwest Volunteers
- Music Utilization
- Alzheimer’s Society Education Seminars

Education
- Simulation Lab Experience for PSWs
- Palliative care for LTC workers – 6 week course
- Hospice Visits
- Spiritual Care In Services
- PC Resources and Books for families

Policy and Procedure
- Palliative Care Program Policy
- RAI for Palliative Care Identifier
- Advance Care Planning Protocol
- Pain Management Toolkit
Conclusion

- Integrating palliative care into LTC processes requires a culture change.

- LTC culture change requires a multi-faceted approach involving direct care, policy, education and community partnerships.

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

- Sustainable change is slow; all have to trust the process.
Hogarth Riverview Manor
Reflection 2009-Present
Reflections on Change

The Process of Change

“I am finding now that all those little baby steps have all come full circle”

“the staff are more empowered, I think some of the barriers have broken down between the nurses, the managers, the PSWs, like they are working better together as a team”
Enhanced staff understanding of palliative and end-of-life care

- Strengthened understanding of palliative and end-of-life care
- Heightened awareness of the difference between PC and EOL care
- Increased acceptance that PC is a process and that it is done everyday
- Increased awareness that PC is a focus area for the LTC home
Increased interest and opportunities for PC education
Strengthened internal and external communication
Enhanced resident centered care during end-of-life

- Increased number of palliative care case conferences
- Increased staff comfort speaking with residents
- Improved understanding of how to meet resident PC needs
Empowered Personal Support Workers
Increased Interprofessional Teamwork
Developed formalized palliative care programs

• PC program description and implementation of interventions and quality improvement process

• Internal organizational structures and leaders
  – Palliative care resource team
  – PSW leads

• Enhanced community partnerships
Quality in Action Survey - All Staff

2009

Patient Focus: 5.38
Improvement Orientation: 5.11
Mission and Goals Orientation: 4.37
Management Style: 4.6
Personal Influence: 4.51

2013

Patient Focus: 5.78
Improvement Orientation: 5.34
Mission and Goals Orientation: 4.61
Management Style: 5.28
Personal Influence: 5.00

8 = Strongly Agree
1 = Strongly Disagree
Quality in Action-PSW

2009

- Patient Focus: 5.33
- Improvement Orientation: 5.24
- Teamwork Orientation: 4.96
- Mission and Goals Orientation: 5.01
- Management Style: 4.55
- Personal Influence: 3.97

2013

- Patient Focus: 5.84
- Improvement Orientation: 5.35
- Teamwork Orientation: 5.63
- Mission and Goals Orientation: 5.48
- Management Style: 5.14
- Personal Influence: 3.24

8 = Strongly Agree
1 = Strongly Disagree
Achieving Sustainability

“we need to carry on with the momentum. We cannot let this fall!”

“I think in the last 4 years there are a lot of work that built into the practice already…. I am positive that the program can be sustained”
Challenges for Sustainability

• Staff Turnover
• Funding for palliative care meetings
• Staff Education
• Competing initiatives
• Maintaining palliative care champion
Commitments from Management

- Monthly meetings
- To fund a PSW team lead for 4 hours a month
- To ensure that there is a facilitator that can support the PSW (if needed) and to help chair the palliative care team meetings
- To actively support recruitment of new staff on the palliative care team by providing them with a brochure during orientation and throughout the year
Commitments from Management

• A commitment to fund RNs/RPNs to attend LEAP, PSWs to attend Palliative Care for front line workers and to send staff for hospice visits each year
• Palliative care is included in orientation of all new staff
• To have family education sessions on palliative care
• Small budget allocated to support the purchase of sympathy cards, butterfly indicators, palliative care pamphlets and comfort bag supplies (if needed)
Further Information

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Special thanks to...