The Quality Palliative Care in Long Term Care Alliance: Integrating PAR, Partnerships and Palliative Care

Presented By:
Mary Lou Kelley, MSW, PhD.
School of Social Work, Lakehead University, Thunder Bay, ON
QPC-LTC Background

• By the year 2020, it is estimated that as many as 39% of LTC residents will die each year.

• These people represent one of society’s most frail and marginalized populations who often struggle with managing multiple chronic conditions and social isolation.
QPC-LTC 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.

Most long term care homes do not have a formalized palliative care program that address these needs.
QPC-LTC Project Summary

• Funded by Social Sciences and Humanities Research Council (SSHRC) for a five year Community-University Research Alliance called: *Quality Palliative Care in Long Term Care Alliance (QPC-LTC)*.

• Includes 40 organizational partners and more than 30 researchers nationally and internationally.

• Study Sites include 4 LTC homes in Ontario;
  • Hogarth Riverview Manor & Bethammi Nursing Home, St. Joseph’s Care Group, Thunder Bay;
  • Allendale Long Term Care Home, Milton; and
  • Creek Way Village, Burlington
Goals of QPC-LTC

1. To empower PSWs to maximize their role in caring for people who are dying and their families and support them to be catalysts for organizational changes in developing palliative care.

2. To implement and evaluate a 4-phase process model of community capacity development in four LTC pilot sites, and create an research-based tool kit of strategies and interventions to support this development.
3. To create sustainable organizational changes that will improve capacity to deliver palliative care programs though empowering PSWs, developing palliative care teams and programs within LTC homes and strengthening linkages with the community partners.

4. To develop knowledge and skills in PC and participatory action research methodology for students in PSW, Gerontology, Social Work and Nursing programs.
QPC-LTC Activities

• Improve the quality of life for residents in LTC

• Develop interprofessional PC programs

• Create partnerships between LTC homes, community organizations and researchers

• Create a toolkit for developing PC in LTC Homes that can be shared nationally

• Promote the role of the PSWs in PC
Research Design

• Comparative Case Study (comparing four unique sites in Ontario)
  – 2 LTC homes in Thunder Bay Ontario, Faith Based, Non-Profit
  – 2 LTC homes in Halton region, Municipally Owned and Operated

• LTC homes vary in location, size, age, physical structure, organizational sponsorship, staffing structure, existing PC practices and history.

• Two conceptual frameworks guide the comparison and research activities
  – CHPCA norms of practice for PC (Sharon Baxter to discuss)
  – Model for Community Capacity Development
Canadian Hospice Palliative Care Association’s Norms of Practice
# Square of Care

<table>
<thead>
<tr>
<th>Common Issues</th>
<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>Disease Management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spiritual</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Practical</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>End of life/Death</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Patient and</td>
</tr>
<tr>
<td>Management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Family Care</td>
</tr>
<tr>
<td>Loss, Grief</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Patient and Family Care
## Square of Organization

<table>
<thead>
<tr>
<th>Principal Activities</th>
<th>Financial</th>
<th>Human</th>
<th>Informational</th>
<th>Physical</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Governance &amp; Administration</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Operations</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quality Management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communications, Marketing</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Resources**
1. Antecedent conditions

Sufficient infrastructure (services, staff, resources)
Collaborative team approach to care
Vision to improve care of dying people
Sense of empowerment to influence change

Sequential phases of the capacity development model:

4. Growing the PC Program
3. Creating the PC Team
2. Experiencing a Catalyst
1. Antecedent conditions

Process for Palliative Care Development

Advocacy
Clinical Care
Education
Building community relationships
Building external linkages
Methods

Participatory Action Research (PAR)

• The goal of PAR is to create social change in relation to a desired goal through the empowerment of people.

• The empowerment process, the change process and its outcomes are systematically documented through a variety of data collection methods before, after and throughout the research process.

• PAR recognizes the existing expertise of LTC staff and promotes integration of palliative care into existing practices
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.
Overview of Environmental Scan Findings
Environmental Scan – Year 1

• 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
Participants and Data Collection

- Surveys
  - All LTC home staff completed surveys
    - Sample sizes across 4 homes are approximately:
      - 205 PSWs
      - 69 Licensed Nurses
      - 79 Support Staff
      - 32 Administration
      - 39 Residents
      - 64 Family Members
      - Volunteers
QiAS (Quality in Action Scale)

• 43-item scale designed to measure aspects of work culture related to quality:

• Six subscales:
  • improvement orientation
  • patient focus
  • personal influence/performance
  • management style
  • mission and goals orientation
  • team work orientation
  • participants’ attitude toward providing care to dying people

• Each item is scored on a scale of 1 (strongly disagree) to 7 (strongly agree)
Findings of the QiAS

Average for each Dimension

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Focus</td>
<td>5.66</td>
<td>5.45</td>
</tr>
<tr>
<td>Improvement Orientation</td>
<td>5.51</td>
<td>5.57</td>
</tr>
<tr>
<td>Teamwork Orientation</td>
<td>5.08</td>
<td>5.16</td>
</tr>
<tr>
<td>Mission and Goals Orientation</td>
<td>4.90</td>
<td>5.01</td>
</tr>
<tr>
<td>Management Style</td>
<td>4.69</td>
<td>4.97</td>
</tr>
<tr>
<td>Personal Influence/Performance</td>
<td>4.52</td>
<td>4.45</td>
</tr>
<tr>
<td></td>
<td>4.48</td>
<td>4.48</td>
</tr>
<tr>
<td></td>
<td>4.48</td>
<td>4.48</td>
</tr>
<tr>
<td></td>
<td>4.48</td>
<td>4.48</td>
</tr>
</tbody>
</table>

Maple; n= 181 out of a possible 242 respondents
Birch; n= 135 out of a possible 202 respondents
Elm; n= 52 out of a possible 135 respondents
Pine; n = 55 out of a possible 104 respondents
Psychological Empowerment in the Workplace (PEiW) Survey

• Completed by Personal Support Workers

• PEiW is a 12-item scale that measures direct care workers’ sense of personal empowerment within their workplace

• Each item is scored on a scale of 1 (strongly disagree) to 7 (strongly agree)

• Four dimensions are measured:
  • meaning
  • competency
  • self-determination
  • Impact
Findings of the PEiW Survey

Average for each Dimension

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Pine (n=24)</th>
<th>Birch (n=72)</th>
<th>Maple (n=86)</th>
<th>Elm (n=47)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>6.83</td>
<td>6.83</td>
<td>6.47</td>
<td>4.22</td>
</tr>
<tr>
<td>Competence</td>
<td>6.75</td>
<td>6.62</td>
<td>6.61</td>
<td>4.78</td>
</tr>
<tr>
<td>Self-determination</td>
<td>6.72</td>
<td>6.23</td>
<td>5.90</td>
<td>5.10</td>
</tr>
<tr>
<td>Impact</td>
<td>6.30</td>
<td>5.60</td>
<td>5.63</td>
<td>3.43</td>
</tr>
</tbody>
</table>

Pine; n= 24 out of a possible 44 respondents
Birch; n= 72 out of a possible 102 respondents
Maple; n= 86 out of a possible 124 respondents
Elm; n= 47 out of a possible 53 respondents
Supervisory Support Survey

- Competed by Personal Support workers
- 15-item scale that assesses aspects of supervisory support
- Each item is scored on a scale of 1 (never) to 5 (always)
- Three dimensions are measured:
  - empathy
  - reliability
  - nurturing connections
Findings of Supervisory Support Survey

Average for each Dimension

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Birch</th>
<th>Maple</th>
<th>Pine</th>
<th>Elm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empathy</td>
<td>4.21</td>
<td>3.96</td>
<td>3.62</td>
<td>3.45</td>
</tr>
<tr>
<td>Reliability Dimension</td>
<td>4.17</td>
<td>3.99</td>
<td>3.7</td>
<td>3.28</td>
</tr>
<tr>
<td>Nurturing Connections</td>
<td>4.2</td>
<td>3.88</td>
<td>3.67</td>
<td>3.32</td>
</tr>
</tbody>
</table>

Birch; n= 73 out of a possible 102 respondents
Maple; n= 86 out of a possible 124 respondents
Pine; n= 24 out of a possible 44 respondents
Elm; n= 31 out of a possible 53 respondents
Self-Efficacy in End-of-Life Care (S-E EOLC)

- Completed by RNs and RPNs

- This 25-item survey measures confidence in the ability to provide palliative care

- Each item is scored on a scale of 0 (Cannot do at all) to 7 (Certain can do)

- Includes 3 subscales:
  - patient management
  - communication
  - multidisciplinary teamwork
Findings of Self-Efficacy in End-of-Life Care Survey

Average for each Dimension

<table>
<thead>
<tr>
<th>Dimension</th>
<th>Maple (n=27)</th>
<th>Birch (n=22)</th>
<th>Elm (n=11)</th>
<th>Pine (n=8)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Management</td>
<td>6.18</td>
<td>6.12</td>
<td>6.1</td>
<td>5.97</td>
</tr>
<tr>
<td>Communication</td>
<td>5.7</td>
<td>5.73</td>
<td>5.6</td>
<td>5.31</td>
</tr>
<tr>
<td>Multidisciplinary Teamwork</td>
<td>5.73</td>
<td>5.57</td>
<td>5.2</td>
<td>5.39</td>
</tr>
</tbody>
</table>
Palliative Care Quiz (PCQ)

- Completed by RNs and RPNs

- 20-item scale that measures knowledge of palliative care nursing

- It can be used to stimulate discussion of palliative care nursing and to identify misconceptions about the delivery of palliative care.
Findings of the Palliative Care Quiz

- Overall, nurses scored an average of 60.22% on the PCQ. Scores for the individual homes are listed below:

  Birch average score = 63.4%
  Maple average score = 62.98%
  Elm average score = 62%
  Pine average score = 52.5%

- Higher scores were achieved on questions related to use of pain medications

  Birch; n= 22 out of a possible 42 respondents
  Maple; n= 27 out of a possible 43 respondents
  Elm; n= 12 out of a possible 16 respondents
  Pine; n= 8 out of a possible 18 respondents
Process for Developing Palliative Care

- Process for change is slow
- Change needs to be sustainable
- Program needs to maximize on existing resources and fit into the culture of the LTC home
- LTC homes determine priorities and own the process of developing interventions which will create the palliative care program
- Researchers facilitate and provide resources such as clinical tools and expertise, build relationships with community partners and evaluate interventions
Process for Developing Palliative Care

- Palliative Care program will consist of:
  - Clinical tools and initiatives,
  - educational strategies and
  - policy development
- New LTC Legislation has offered some direction to support the provision of palliative care
- Currently creating interprofessional palliative care teams
Clinical Tools and Initiatives

• Multi-Sensory Stimulation Therapy
  – Developing Best Practices guidelines
  – Training volunteers and family members
  – Improving referral procedures and documentation

• RAI End of Life Care Plan

• Consultation with Palliative Pain and Symptom Consultant

• Developing protocols for the use of music in palliative care
Educational Strategies

• **Palliative Care for Personal Support Workers** – 6 modules that introduces the palliative care philosophy

• Pre and Post Survey completed in conjunction with course

• Survey showed an improvement in three areas:
  - Physiology of Dying
  - Advance Care Planning
  - Cultural Competency

• No change in their understanding of the role of bereavement in palliative care

• Development of PSW competencies for the provision of Palliative Care in LTC
Policy/Procedure Development

• Formalized program description for palliative care
• Grief and Bereavement support for Staff
• Protocol for the involvement of Hospice Volunteers in LTC
Community Partnerships

• Ontario Multi-Faith Council – helping address spirituality in LTC
• Hospice Northwest – Hospice volunteers in LTC to address social aspect of dying
• Vancouver Coastal Health – RAI Care Plan for End of Life Care
Conclusion

• Creating a palliative care culture in LTC home is a very complex and multifaceted process

• No one intervention or strategy will create change – change is incremental over time

• Requires clinical, educational and policy changes for staff, residents and families

• The outcome of the process is expected to be a unique LTC approach to palliative care
Acknowledgement

Funding Provided By:
Social Sciences and Humanities Council of Canada

Thank you to our partners:
Contact Us

Visit our website:
www.palliativealliance.ca

Email us:
palliativealliance@lakeheadu.ca

Call us:
807-766-7228

Thank You 😊