“It’s hard to watch people die for a living”: Improving Palliative Care in Long-Term Care Homes

Presenter:
Mary Lou Kelley, MSW, PhD.
Professor
School of Social Work, Lakehead University
Thunder Bay, Ontario

Alzheimer’s Disease International Conference
Sunday, March 27, 2011
Sharon Kaasalainen, PhD.¹
Kevin Brazil, PhD.¹
Carrie, McAiney, PhD.¹
Paulina Chow ²
Pat Sevean, RN ³
Jo-Ann Vis, MSW, PhD.³
Elaine Wiersma, PhD.³
Joanie Sims-Gould, Post Doctoral Fellow ⁴
Sheldon Wolfson ⁵
Michel Bédard, PhD.³

¹McMaster University, Hamilton, ON; ²St. Joseph’s Care Group, Thunder Bay, ON;
³Lakehead University, Thunder Bay, ON; ⁴University of British Columbia, Vancouver, BC;
⁵Halton Municipal Region, Halton, ON
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.
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?

(CHPCA, 2002)
Long-Term Care Homes and Dementia

- The need for LTC beds will increase tenfold with Canada’s aging population (Alzheimer Society, 2010)

- Currently, 65% or more of people who are 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)
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)
Challenges and Issues

- Lack of policy and dedicated funding related to palliative care in LTC.

- Insufficient training for staff in LTC on palliative care and end stage dementia.

- Families and LTC residents are not given opportunities to discuss and learn about their end-of-life options.

- Advance Care Planning focuses solely of medical interventions, ie DNR orders (not holistic).

- Residents who could benefit from palliative care are not identified in a timely manner, including people with dementia.
Personhood and Dementia

- “each person has absolute value” (Kitwood, 1997)
- Respects the essence of a person’s humanity.
- Valuable in terms of framing interactions with a person diagnosed with dementia.
- Encompasses the domains of physical, psychological, spiritual, and social aspects of self.
- Consistent with holistic values of palliative care that aims to improve the quality of life of people who are dying.
## Square of Care (CHPCA, 2002)

<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>Patient and Family Care</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 Management</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss, Grief</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Quality Palliative Care in Long-Term Care Alliance (QPC-LTC)

- Improve the quality of life for residents in LTC
- Develop formalized 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
- 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
Participatory Action Research

- Rooted in Social Action theory

- Empowers participants to create change in their own situation

- Lakehead University is working in partnership with St. Joseph’s Care Group and the Municipality of Halton to develop formalized palliative care programs for LTC.
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.
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

Community empowerment
Sufficient health system infrastructure
Vision for change
Collaborative generalist practice

Advocacy
Education
Clinical Care
Building external linkages
Building community relationships
Creating a Cultural Change: A Catalyst

A catalyst for change occurs in the LTC home, disrupting their current approach to care of dying people.
Creating a Cultural Change: A Catalyst

- Catalyst for change – New Long-Term Care Act in Ontario, CA (2010) offers support for palliative care as it mandates:
  - Palliative care education and orientation for all new staff
  - Ongoing education in for staff on palliative care
  - Must have defined interprofessional pain management, skin and wound care programs
  - All LTC home programs must be formalized with goals and processes defined.
Creating a Cultural Change: Creating the Team

Interprofessional Care
Providers join together to improve care of the dying and develop “palliative care”.

Creating a Cultural Change: Creating the 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 a Cultural Change: Growing the Program

The team continues to build, but now extends into the community to deliver palliative care.
Creating a Cultural Change: Growing the Program

- Growing a Palliative Care Program
  - Creating palliative care policies and procedures consistent with the LTC Act
  - **Building External Linkages** - Hospice Northwest Volunteers, Divinity students providing spiritual support to residents

- **Education** - Snoezelen therapy education and protocol, Dementia awareness raising book chat - *Still Alice*

- **Clinical Care** – Palliative Care Simulation Lab, Hospice Palliative Care Unit Visit, Comfort Care Rounds

- **Advocacy** – Parliamentary Committee on Palliative and Compassionate Care, National LTC Policy Initiative
Conclusion

- Palliative Care benefits people with dementia and their families
- Long-Term Care homes have an important role to play at the end of life
- LTC homes and staff need support through education and advocacy to provide quality palliative care
- Families and Residents need every opportunity to talk about the end of life holistically
Further Information

Visit our website
www.palliativealliance.ca

Contact us
Email: palliativealliance@lakeheadu.ca
Phone: (807)766-7267

Special Thanks to...