"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

Halton Region | McMaster University | St. Joseph's Care Group | Lakehead University

Quality Palliative Care –Long-Term Care Alliance
www.palliativecarealliance.ca

Co-Investigators

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]

[1]McMaster University, Hamilton, ON; [2]St. Joseph's Care Group, Thunder Bay, ON;
[3]Lakehead University, Thunder Bay, ON; [4]University of British Columbia, Vancourver, BC;
[5]Halton 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

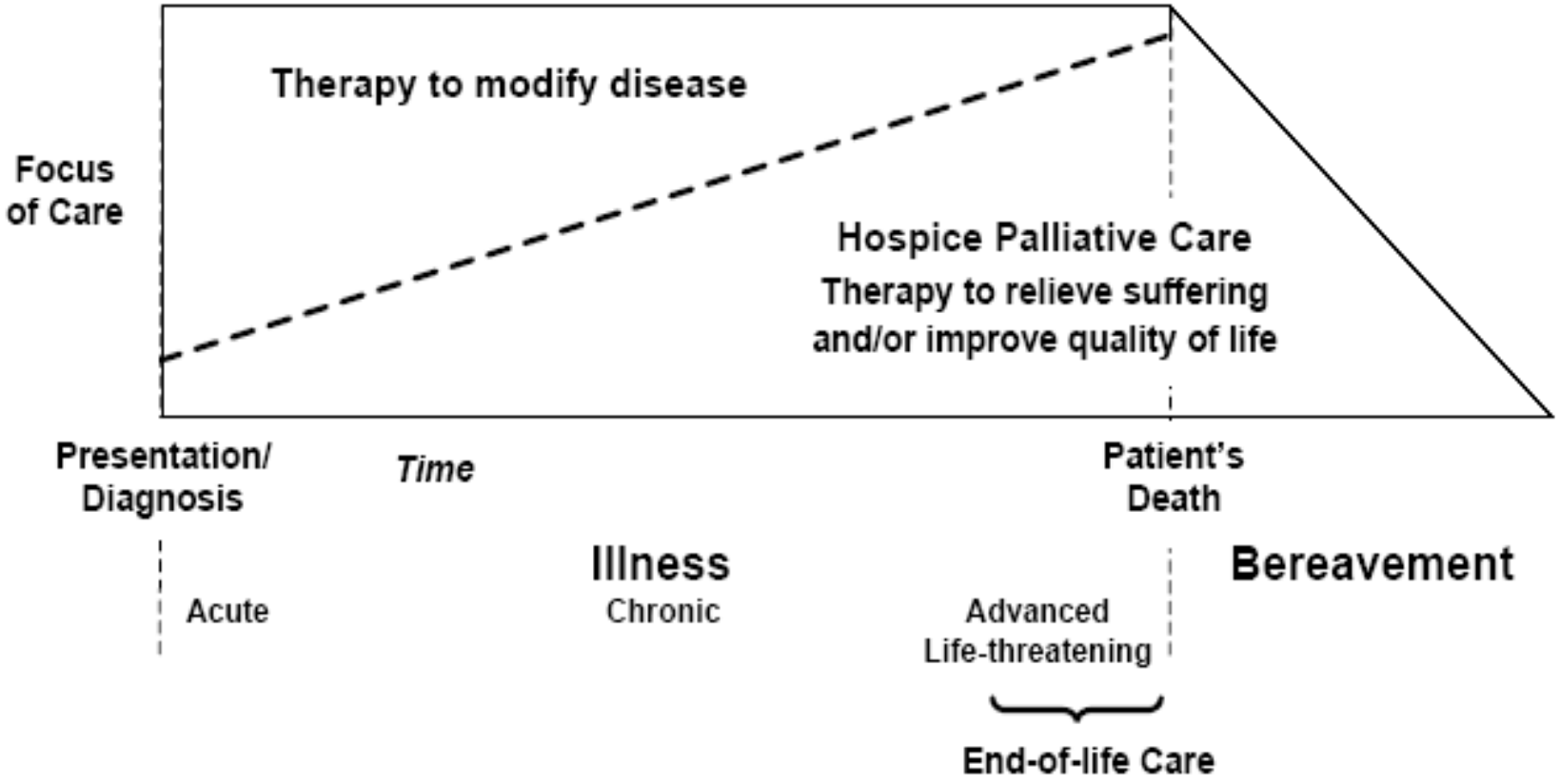
Palliative Care

- 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)

Long-Term Care Homes and Palliative Care

- 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 and Organization

	Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation
	History of issues, opportunities, associated expectations, needs, hopes, fears Examination - assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity Goals of care Requests for withholding/ withdrawing, therapy with no potential for benefit, hastened death Issue prioritization Therapeutic priorities, options Treatment choices, consent Surrogate decision-making Advance directives Conflict resolution	Setting of care Process to negotiate/ develop plan of care - address issues/ opportunities, delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning, emergencies	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Understanding Satisfaction Complexity Stress Concerns, issues, questions

PROCESS OF PROVIDING CARE

COMMON ISSUES

Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies	**Disease Management**
Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits - alcohol, smoking	**Physical**
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	**Psychological**
Cultural values, beliefs, practices Relationships, roles Isolation, abandonment, reconciliation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guardianship, custody issues	**Social**
Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	**Spiritual**
Activities of daily living Dependents, pets Telephone access, transportation	**Practical**
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death pronouncement, certification Perideath care of family, handling of body Funerals, memorial services, celebrations	**End of life/ Death Management**
Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	**Loss, Grief**

Patient / Family

FUNCTIONS

Governance & Administration	Leadership - board, management Organizational structure, accountability
Planning	Strategic planning Business planning Business development
Operations	Standards of practice, policies & procedures, data collection/documentation guidelines Resource acquisition & management Safety, security, emergency systems
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	Human	Informational	Physical	Community
Assets Liabilities	Formal caregivers Consultants Staff Volunteers	Records - health, financial, human resource, assets Resource materials, eg, books, journals, internet, intranet Resource directory	Environment Equipment Materials/supplies	Host Organization Healthcare System Partner healthcare providers Community organizations Stakeholders, public

From: Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West P.

Square of Care (CHPCA, 2002)

		Process of Providing Care					
		Assessment	Information Sharing	Decision-making	Care Planning	Care Delivery	Confirmation
Common Issues	Disease Management						
	Physical						
	Psychological						
	Social						
	Spiritual						
	Practical						
	End of life/ Death Management						
	Loss, Grief						

Patient and Family Care

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

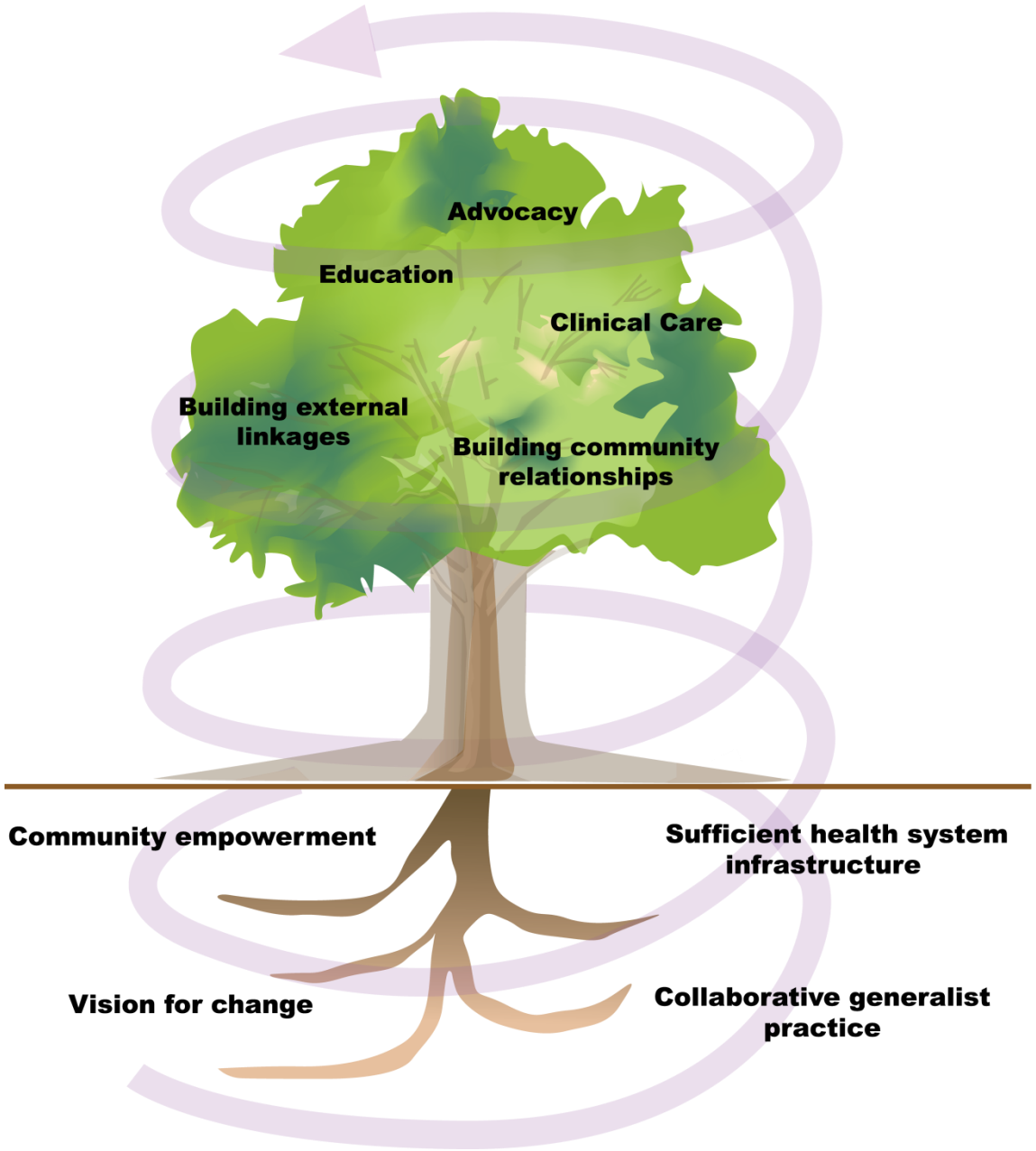
- Comparative Case study design with four LTC Homes as study sites
- Quantitative and qualitative research methods: Surveys, Interviews, Focus Groups, Participant Observations, Document Reviews
- Participants: Residents, Family members, Physicians, PSWs, RNs, RPNs, Spiritual Care, Social Work, Recreation, 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.



Process of Palliative Care Development

Sequential phases of the capacity development model:

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

Creating a Cultural Change : A Catalyst

A catalyst for change

occurs in the LTC home,

disrupting their

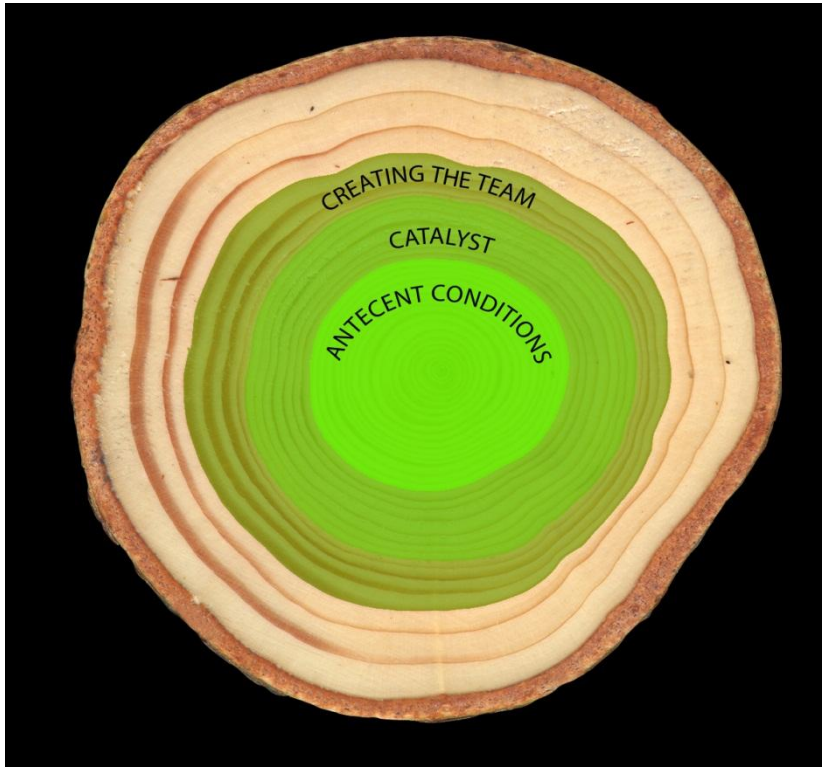
current approach to

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

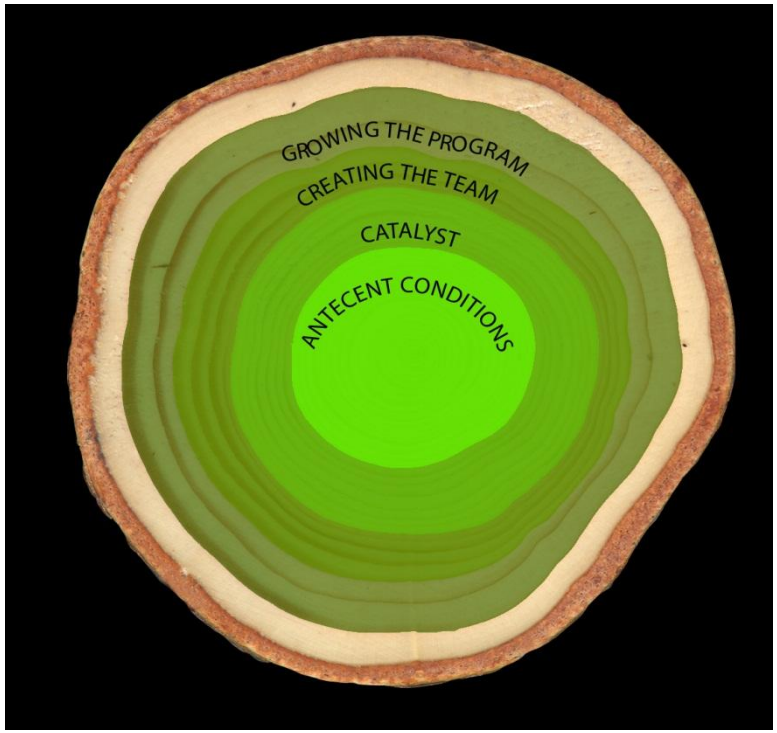
dying and develop

“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…

Social Sciences and Humanities Research Council of Canada

Conseil de recherches en sciences humaines du Canada

Halton Region

McMaster University

St. Joseph's Care Group

Lakehead University