

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

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



# Long-Term Care Homes and Dementia

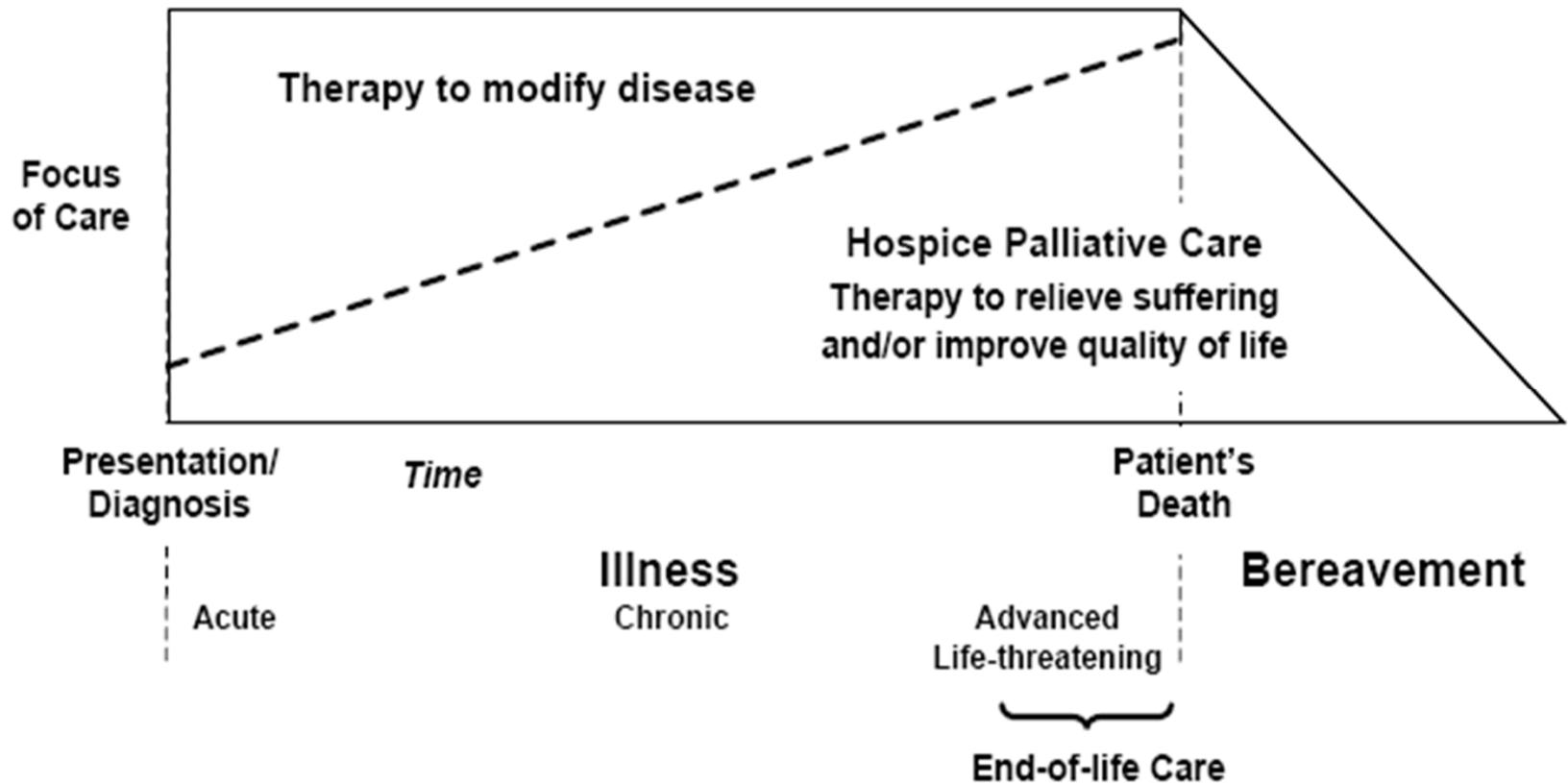
- The need for LTC beds will increase tenfold with Canada's aging population (Alzheimer Society, 2010)
- Currently, 65% or more of residents in Ontario's LTC homes have dementia (Alzheimer Society Ontario, 2010)
- 67% of dementia-related deaths occur in nursing homes (Mitchell, et al., 2005)



# 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)

# When does Palliative Care Begin?



(CHPCA, 2002)



# Challenges and Issues

- Lack of policy and dedicated funding related to palliative care in LTC.
- Insufficient training in LTC on palliative care and end stage dementia.
- Families and 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.
- People who could benefit from palliative care are not identified in a timely manner

Square of Care and Organization		History of issues, opportunities, associated expectations, needs, hopes, fears	Confidentiality limits Desire and readiness for information Process for sharing information	Capacity Goals of care Requests for withholding/withdrawing therapy with no potential for benefit, hastened death Issue prioritization	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	Care team composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Understanding Satisfaction Complexity Stress Concerns, issues, questions			
		Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation			
PROCESS OF PROVIDING CARE										
Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies	<b>Disease Management</b>	<b>Patient / Family</b>						<b>Governance &amp; Administration</b>		Leadership - board, management Organizational structure, accountability
Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits - alcohol, smoking	<b>Physical</b>							<b>Planning</b>		Strategic planning Business planning Business development
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	<b>Psychological</b>							<b>Operations</b>		Standards of practice, policies & procedures, data collection/documentation guidelines Resource acquisition & management Safety, security, emergency systems
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	<b>Social</b>							<b>Quality Management</b>		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
Meaning, value Existential, transcendentals Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	<b>Spiritual</b>							<b>Communications/Marketing</b>		Communication/marketing strategies Materials Media liaison
Activities of daily living Dependents, pets Telephone access, transportation	<b>Practical</b>									
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death pronouncement, certification Peri-death care of family, handling of body Funerals, memorial services, celebrations	<b>End of life/Death Management</b>									
Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	<b>Loss, Grief</b>									
RESOURCES										
		<b>Financial</b> Assets Liabilities	<b>Human</b> Formal caregivers Consultants Staff Volunteers	<b>Informational</b> Records - health, financial, human resource, assets Resource materials, eg, books, journals, internet, intranet Resource directory	<b>Physical</b> Environment Equipment Materials/supplies	<b>Community</b> Host Organization Healthcare System Partner healthcare providers Community organizations Stakeholders, public				

# 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
- 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





# QPC-LTC Alliance Methods

## 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 on developing 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.



# 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



# FATCOD Survey(Frommelt Attitudes Toward the Care of Dying)

- 30-item scale designed to measure participants' attitude toward providing care to dying people
- Has no subscales
- Each item is scored on a scale of 1 (strongly disagree) to 5 (strongly agree)
- 15 items are scored positively and 15 negatively (lower scores consistent with PC philosophy)

# Findings of the FATCOD Survey

➤ Average scores across: 4.075

- All four homes: 4.075
- PSWs: 3.82
- Licensed nurses: 4.21
- Support Services: 3.89
- Management: 4.16



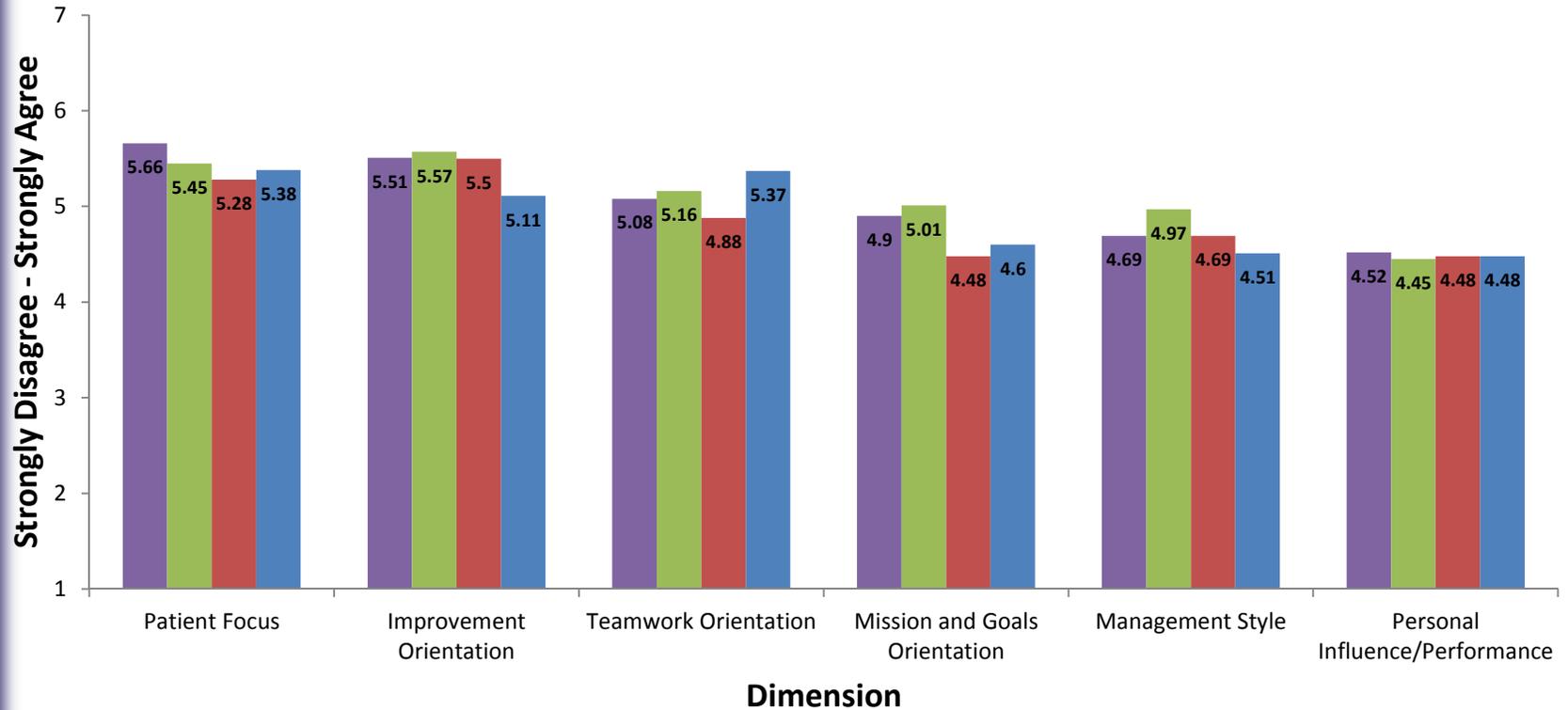
➤ On average, staff demonstrated a positive attitude about providing care for dying residents

# 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



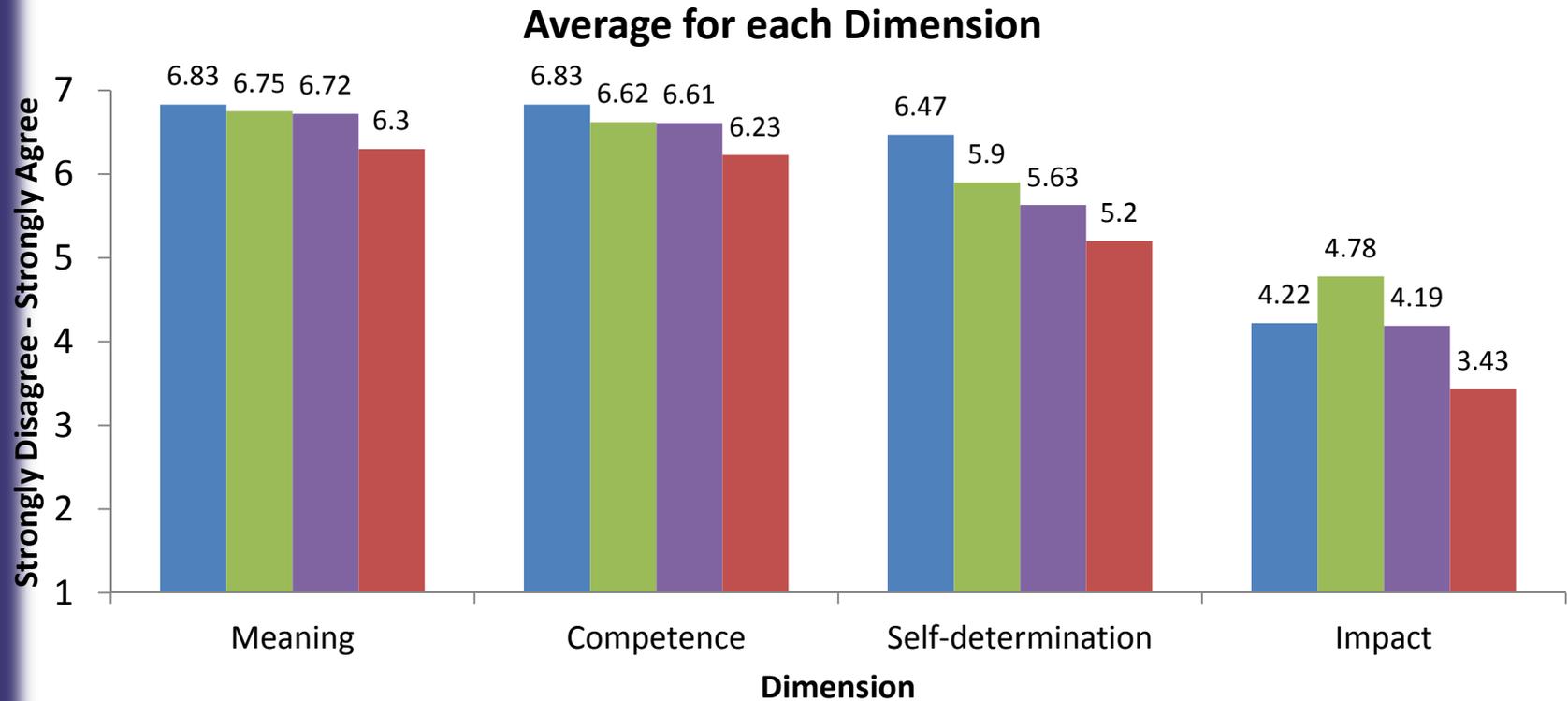
**Maple; n= 181 out of a possible 242 respondents**  
**Birch; n= 135 out of a possible 202 respondents**  
**Elm; n= 52 out of a possible 135 respondents**  
**Pine; n = 55 out of a possible 104 respondents**



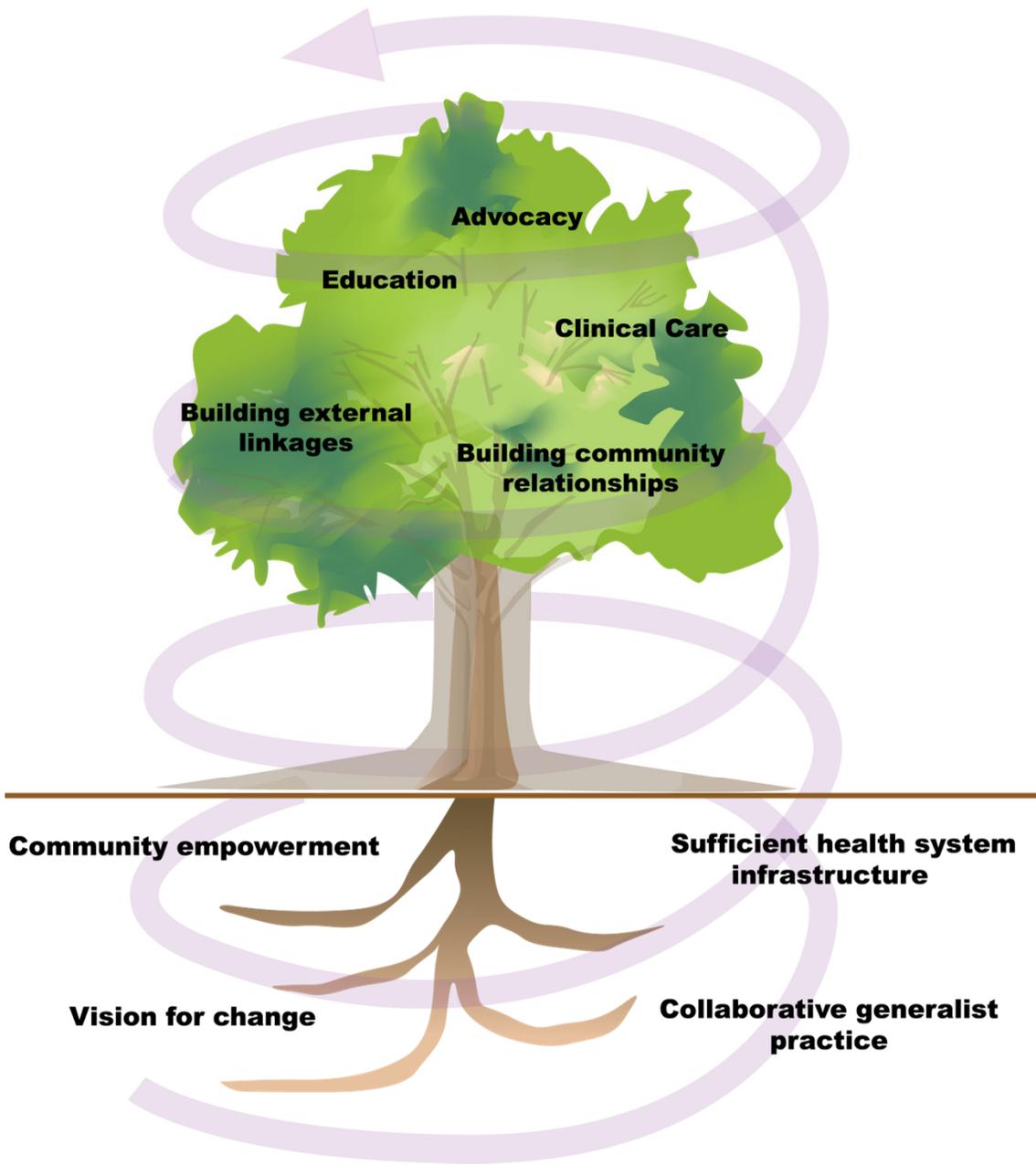
# Psychological Empowerment in the Workplace (PEiW) Survey

- 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



**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**

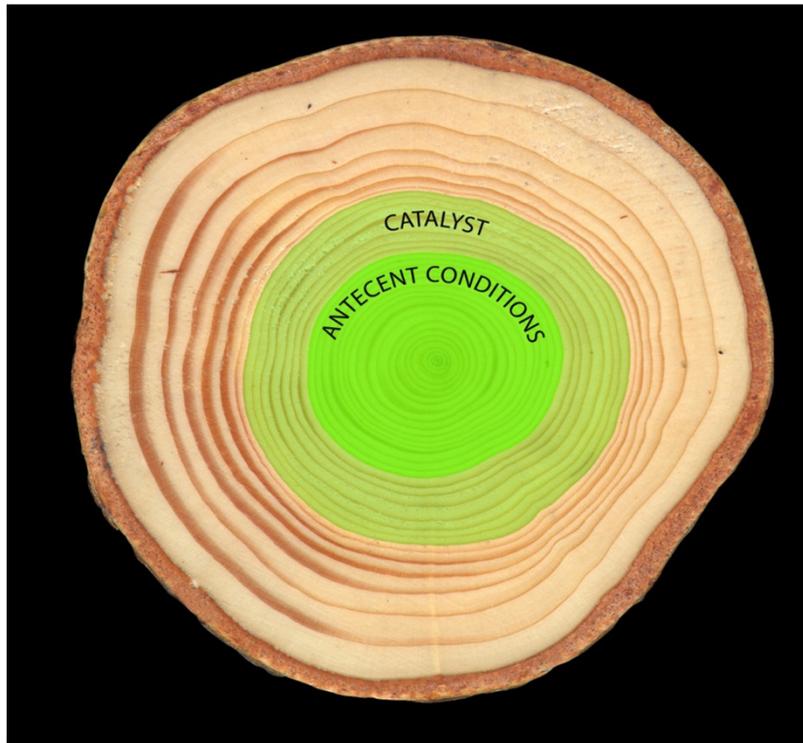


**Process of Palliative Care Development**

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



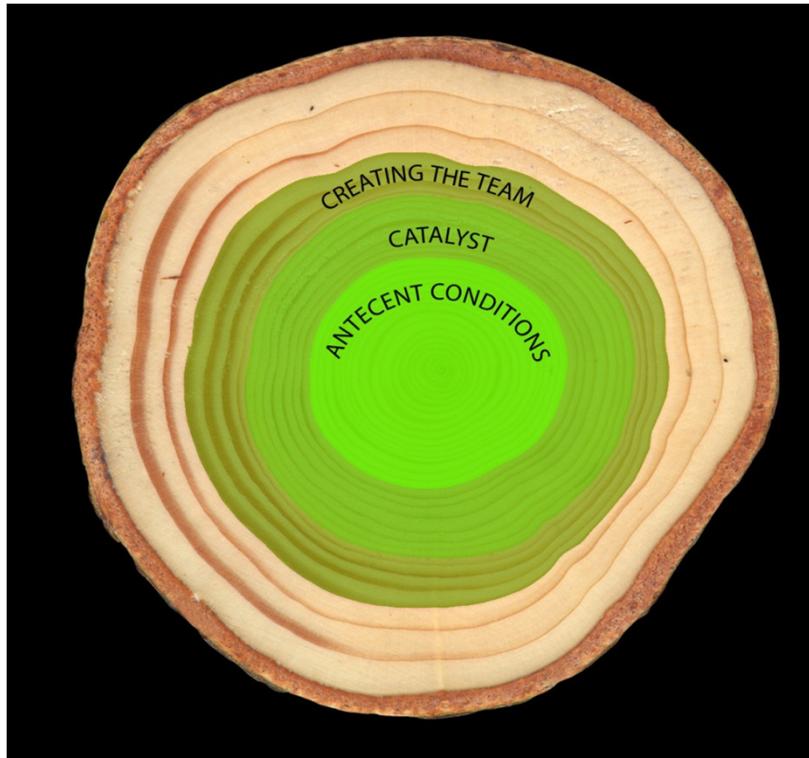
A catalyst for change  
occurs in the LTC home,  
disrupting their  
current approach to  
care of dying people



# Creating a Cultural Change : A Catalyst

- Catalyst for change – New Long-Term Care Act (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
- QPC-LTC Research Project
- PSW Champions for Palliative Care

# Creating a Cultural Change: Creating the Team



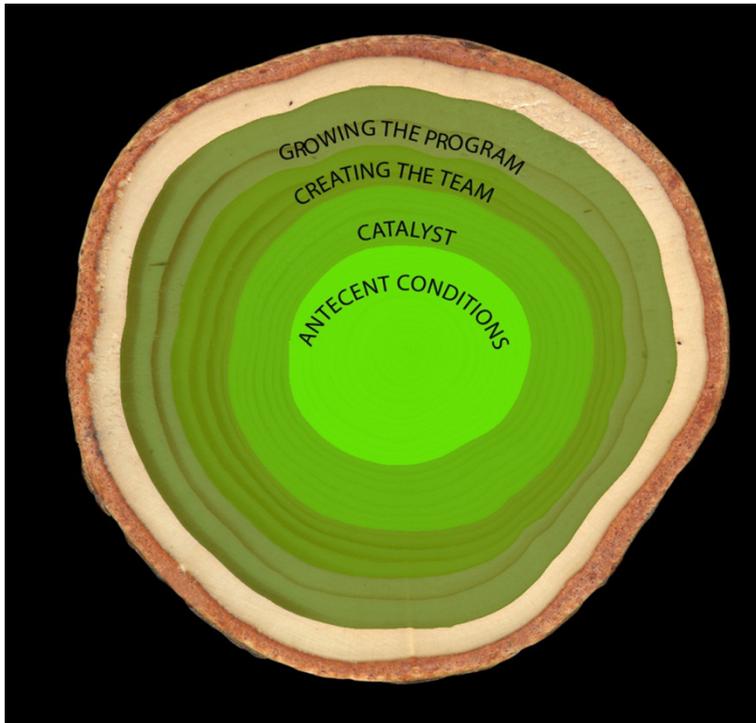
Interprofessional Care  
Provides join together  
to improve care of the  
dying and develop  
“palliative care”.



# 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, Pain and Symptom Consultants
  - 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



# Tools for Development

- Information on Advance Care Planning in LTC for families
- Guide for staff to have conversations regarding Advance Care Planning
- Brochure on what it means to receive palliative care in LTC
- Personal Support Worker Competency development
- Understanding culture and diversity at the End of Life



## 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](http://www.palliativealliance.ca)

Contact us

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