

Quality Palliative Care in Long Term Care

A Community-University Research Alliance

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

Presented By:

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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 through 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

Square of Care and Organization

		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 Transition 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			
		Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation			
PROCESS OF PROVIDING CARE								F U N C T I O N S		
Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies	Disease Management	C O M M O N I S S U E S	Patient / Family						Governance & Administration	Leadership - board, management Organizational structure, accountability
Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits - alcohol, smoking	Physical								Planning	Strategic planning Business planning Business development
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	Psychological								Operations	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	Social								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
Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	Spiritual								Communications/ Marketing	Communication/marketing strategies Materials Media liaison
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									
RESOURCES										
	Financial Assets Liabilities	Human Formal caregivers Consultants Staff Volunteers	Informational Records - health, financial, human resource, assets Resource materials, eg, books, journals, internet, Intranet Resource directory	Physical Environment Equipment Materials/supplies	Community 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.

A Model to Guide Hospice Palliative Care © Canadian Hospice Palliative Care Association, Ottawa, Canada, 2002.

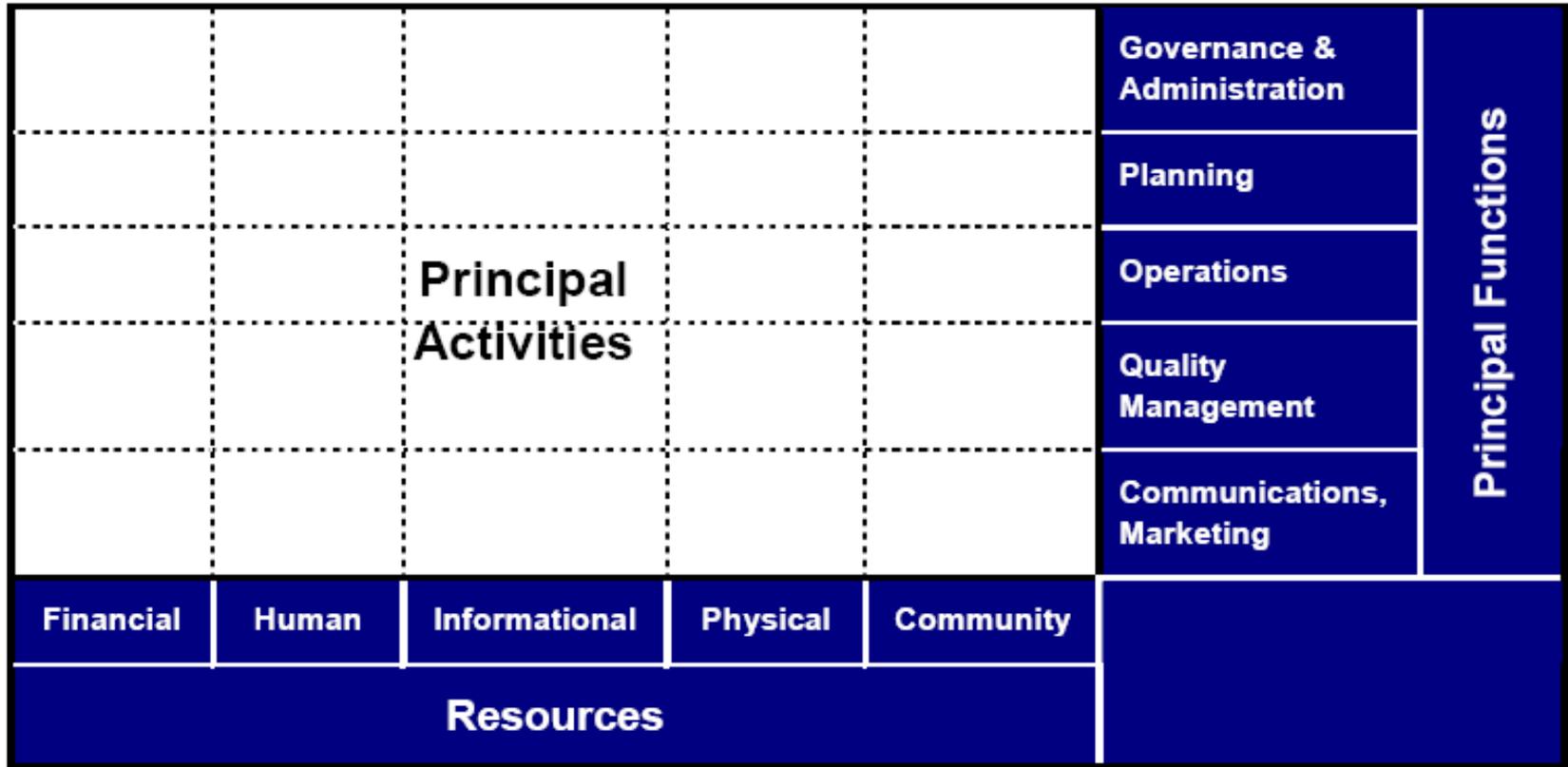
Canadian Hospice Palliative Care Association's Norms of Practice

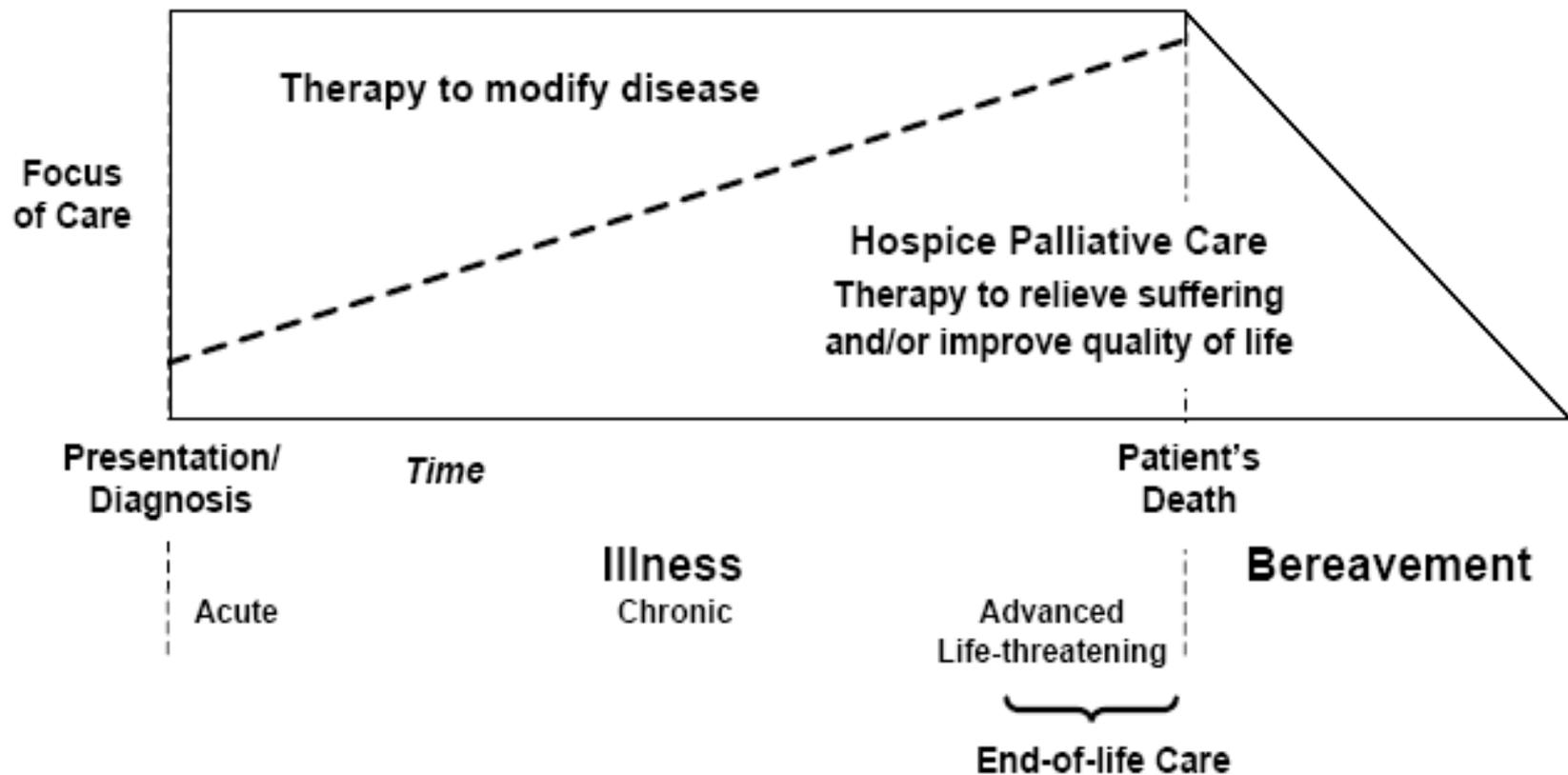
Square of Care

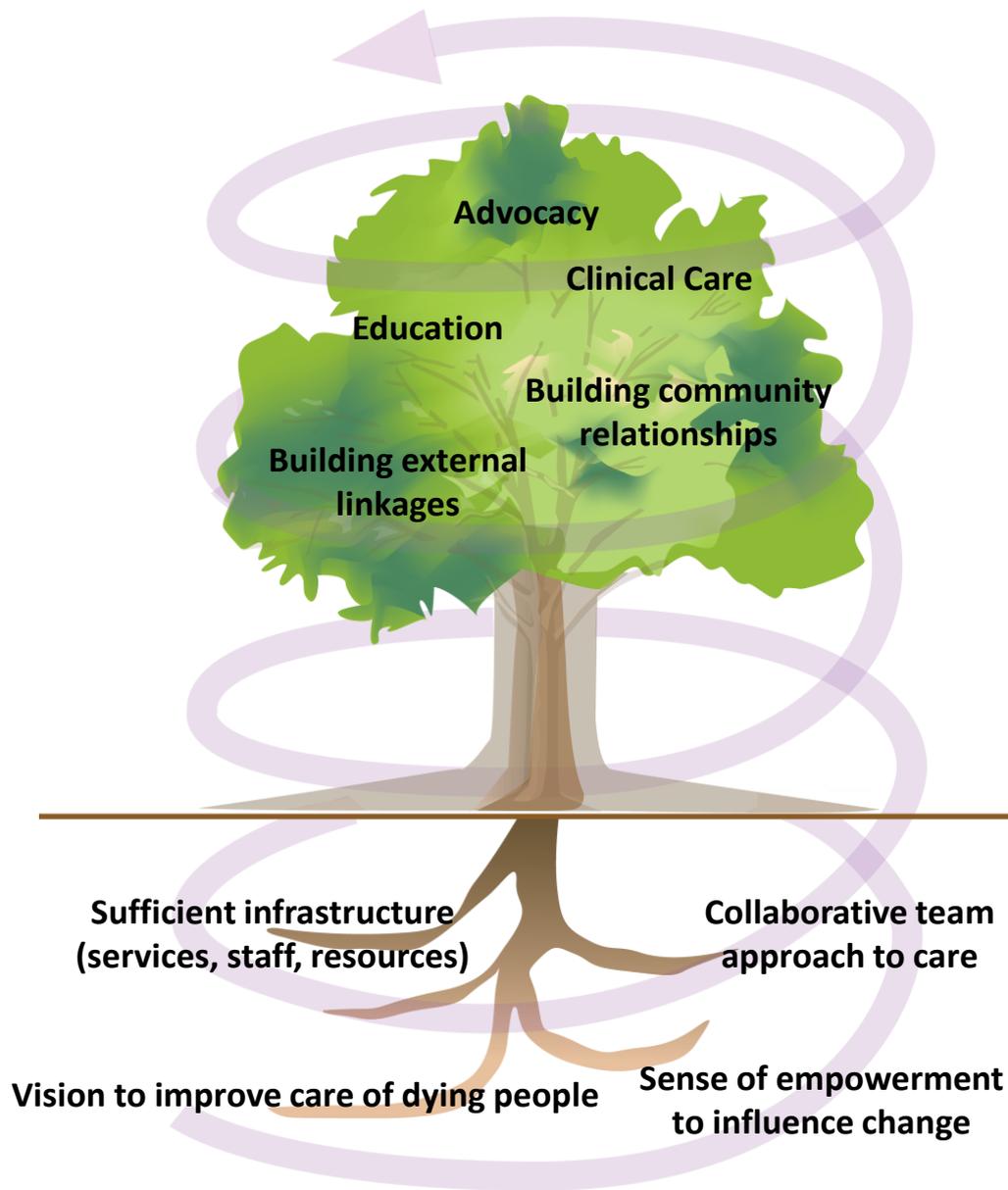
		Process of Providing Care					
		Assessment	Information Sharing	Decision-making	Care Planning	Care Delivery	Confirmation
Common Issues	Disease Management						
	Physical						
	Psychological						
	Social						
	Spiritual						
	Practical						
	End of life/ Death Management						
	Loss, Grief						

Patient and Family Care

Square of Organization







Process for Palliative Care Development

Sequential phases of the capacity development model:

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

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

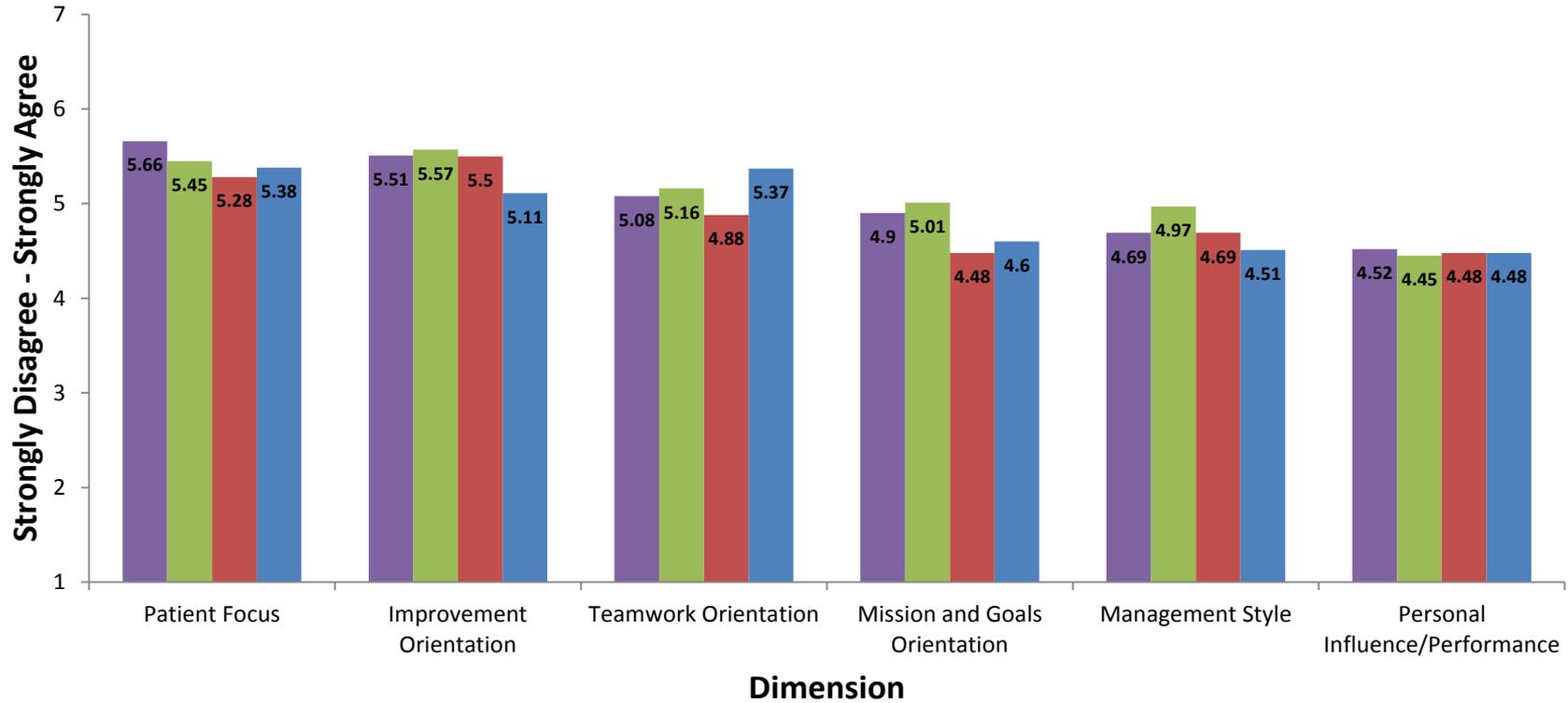
- Surveys
- All LTC home staff completed surveys
 - Sample sizes across 4 homes are approximately:
 - 205 PSWs
 - 69 Licensed Nurses
 - 79 Support Staff
 - 32 Administration
 - 39 Residents
 - 64 Family Members
 - Volunteers

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

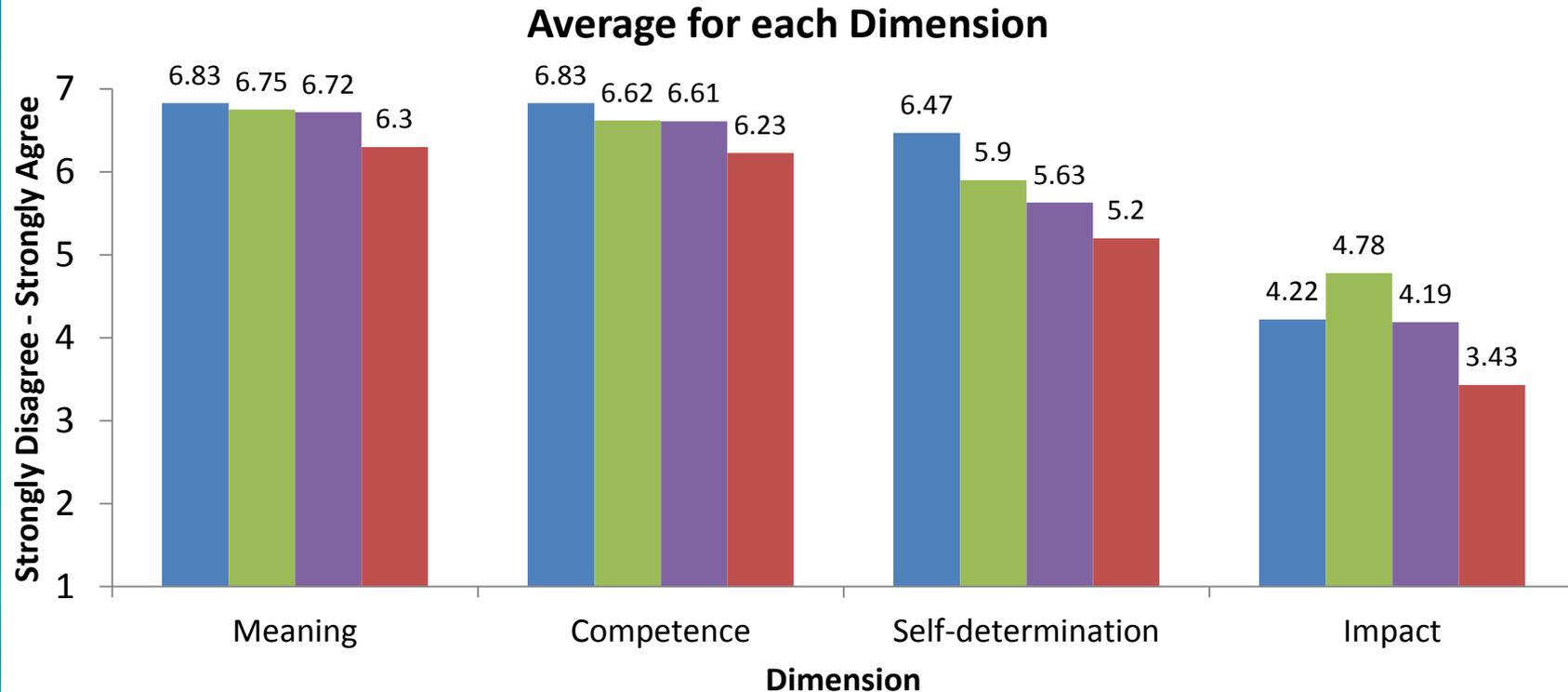


Maple; n= 181 out of a possible 242 respondents
Birch; n= 135 out of a possible 202 respondents
Elm; n= 52 out of a possible 135 respondents
Pine; n = 55 out of a possible 104 respondents

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



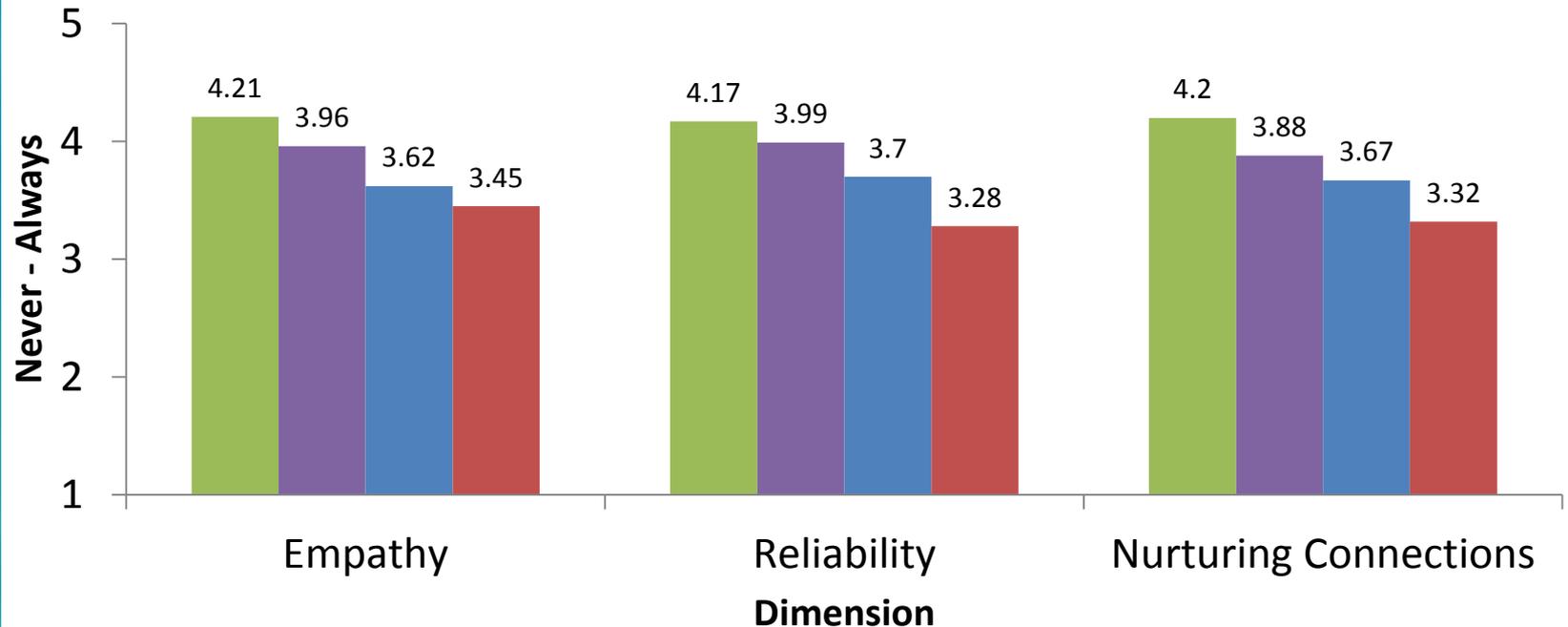
Pine; n= 24 out of a possible 44 respondents
Birch; n= 72 out of a possible 102 respondents
Maple; n= 86 out of a possible 124 respondents
Elm; n= 47 out of a possible 53 respondents

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



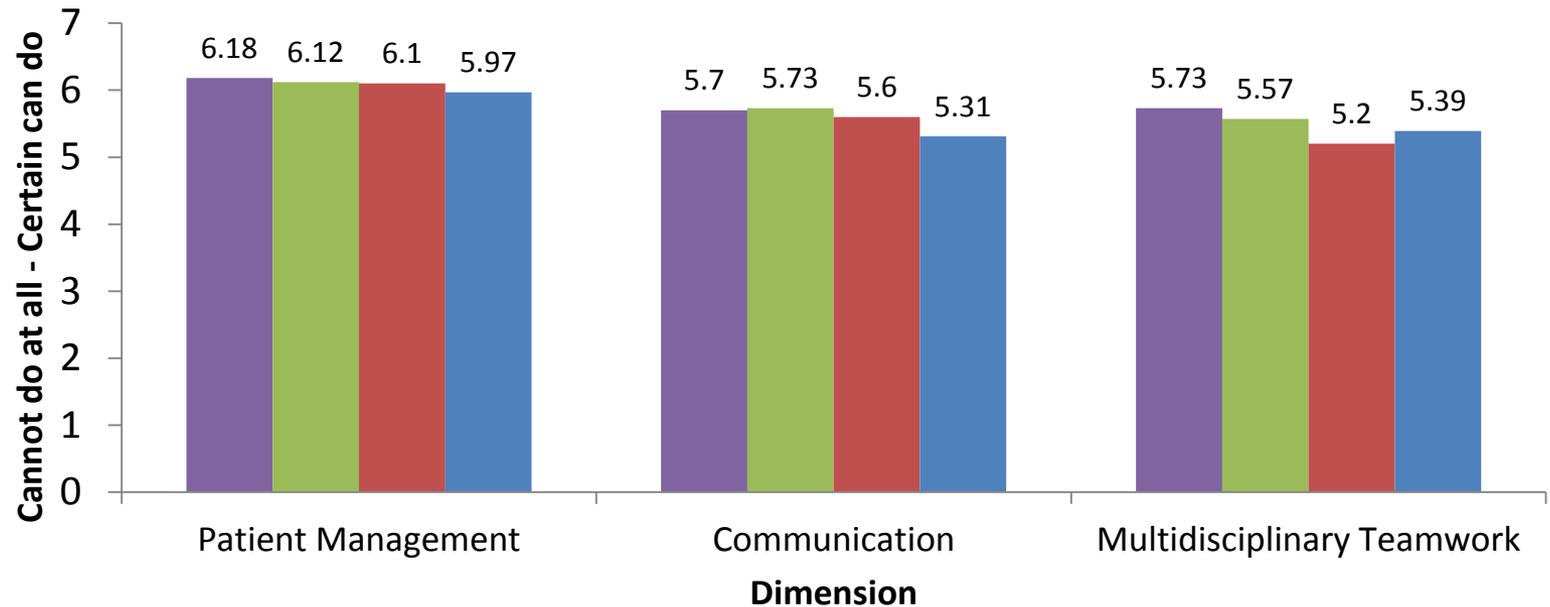
Birch; n= 73 out of a possible 102 respondents
Maple; n= 86 out of a possible 124 respondents
Pine; n= 24 out of a possible 44 respondents
Elm; n= 31 out of a possible 53 respondents

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



Maple; n= 27 out of a possible 43 respondents
Birch; n= 22 out of a possible 42 respondents
Elm; n= 11 out of a possible 16 respondents
Pine; n= 8 out of a possible 18 respondents

Palliative Care Quiz (PCQ)

- Completed by RNs and RPNs
- 20-item scale that measures knowledge of palliative care nursing
- It can be use 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

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The logo of St. Joseph's Care Group, featuring a stylized blue and orange figure with arms raised, set against a white background.
ST. JOSEPH'S CARE GROUP

The logo of Halton Region, featuring a green stylized mountain range above the word "Halton" in green, with "REGION" in smaller green letters below it.
Halton
REGION

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Thank You 😊