

It's complicated: Palliative culture and whole system change within LTC

Presented by:
Quality Palliative Care in Long-Term Care Alliance

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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.

Background

- 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)

Palliative Care versus End-of-Life Care

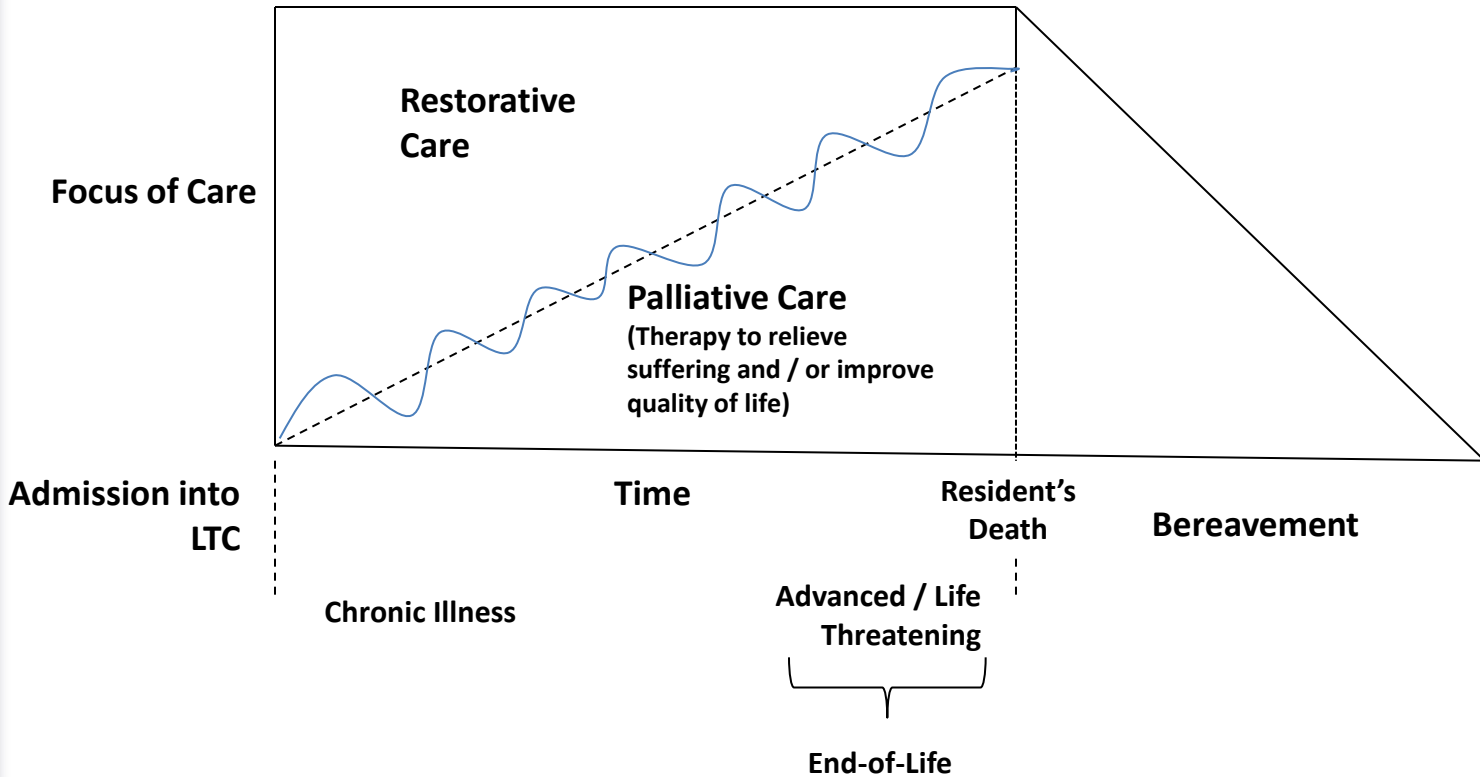
Palliative Care

- 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?



(adopted from CHPCA, 2002)

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
- Participatory Action Research
- 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



Research Timeline

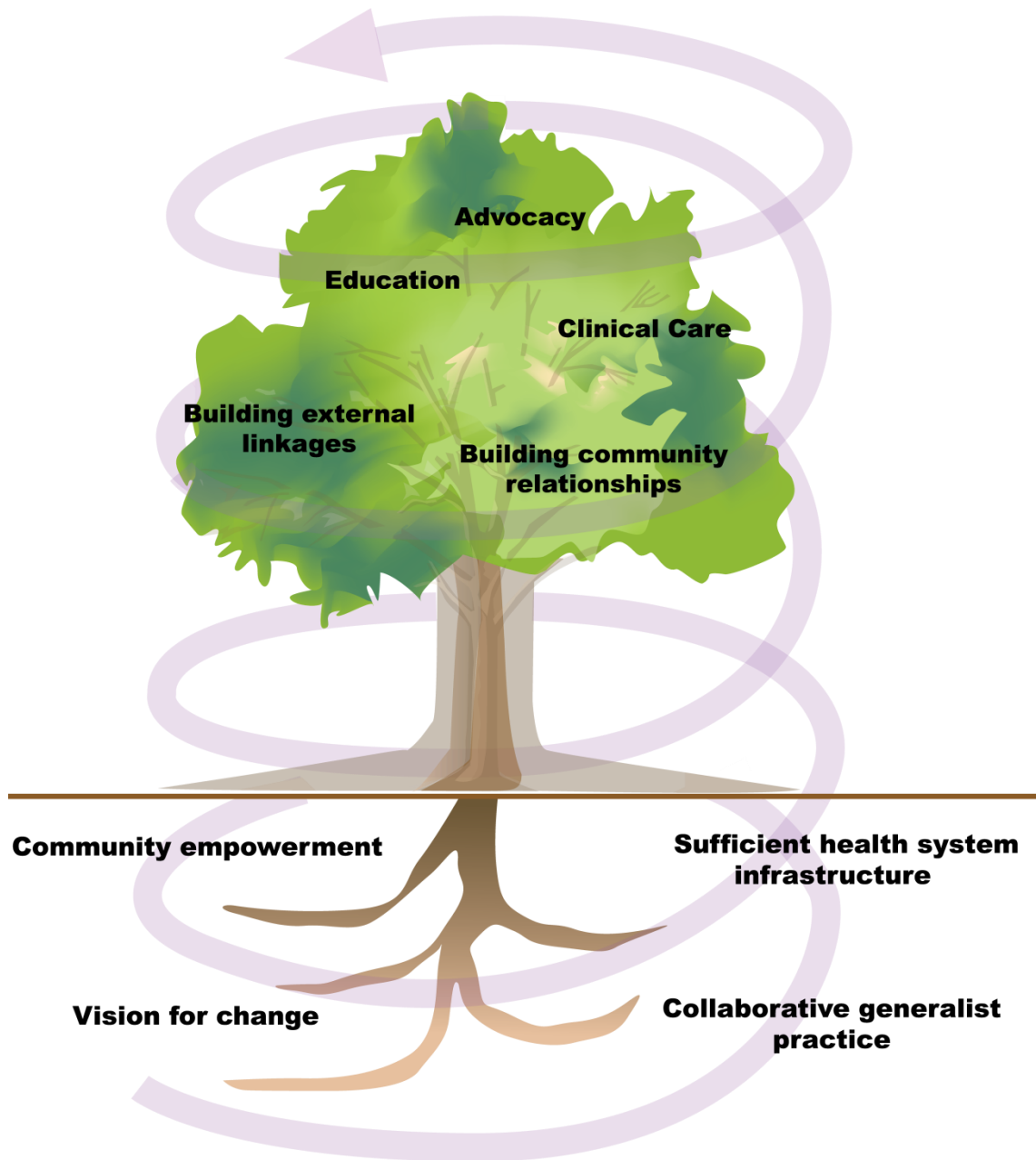
- Year 1 – Environmental Scan in each home to create baseline understanding using CHPCA norms of practice (PC delivery, PC processes, LTC/PC policies, LTC resources).
- Year 2 – Create interprofessional PC teams and identify initial interventions based on evidence
- Year 3 – 4 Develop PC program with 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.

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	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								
COMMON ISSUES Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits - alcohol, smoking Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem 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 Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons Activities of daily living Dependents, pets Telephone access, transportation 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 Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	Disease Management	Patient / Family	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						Governance & Administration	Leadership - board, management Organizational structure, accountability
	Physical								Planning	Strategic planning Business planning Business development
	Psychological								Operations	Standards of practice, policies & procedures, data collection/documentation guidelines Resource acquisition & management Safety, security, emergency systems
	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
	Spiritual								Communications/Marketing	Communication/marketing strategies Materials Media liaison
	Practical									
	End of life/Death Management									
	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				

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



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

Environmental Scan Results

Organizational Readiness

- Lack of policy and dedicated funding related to palliative care in LTC which limits resources.
- Few policies are reflective of a palliative care philosophy
- Strong dedication and commitment of managers and staff to improving palliative care

Environmental Scan Results

Personal Support Worker Empowerment

- Do not feel they can influence change as they often do not have opportunity to be involved in the process
- Limited training related to palliative care
- Role not clearly defined in providing palliative care
- Very resident-focused
- Strong sense of team amongst PSWs

Environmental Scan Results

Vision for Palliative Care

- Families and residents need opportunities to discuss and learn about their end of life options.
- Advance Care Planning needs to be broadened so it does not solely focus on medical interventions, ie DNR orders.
- People who could benefit from palliative care need to be identified in a timely manner
- Requires an interdisciplinary approach




Word Cloud – Diane interventions

Small Group Work





Nadia's Closing comments on her role as the manager



Jackie McDonald – role of the PSW

Conclusion

- LTC culture change requires a multi-pronged approach.
- Change requires commitment and involvement from all levels of staff
- Sustainable change is slow, have to trust the process

Further Information

Visit our website

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Special Thanks to...



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