



Creating a Palliative Care Culture

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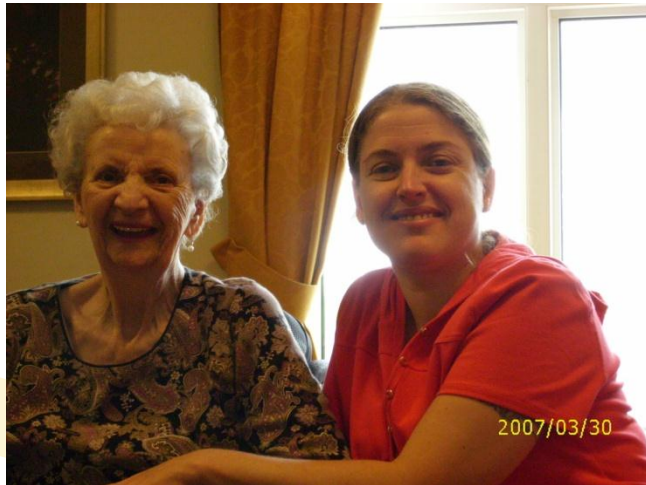
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Workshop Objectives

- 1. Understand Participatory Action Research's role in creating cultural change in LTC**
- 2. Understand the role and impact Personal Support Workers have in developing palliative care**
- 3. Understand a conceptual model for developing organizational capacity in palliative care**

Background

- By the year 2020, it is estimated that as many as 39% of LTC residents will die each year in a LTC home.
- These people represent one of society's most frail and marginalized populations who often struggle with managing multiple chronic conditions and social isolation.



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.

Fundamental Questions



- What is an appropriate criteria for offering palliative care in a LTC home?
- At what point should palliative care become the main focus of care?
- How can we identify those residents who would benefit from palliative care?
- What is the difference between palliative and end-of -life care?
- How can palliative care be enhanced within existing resources?

QPC-LTC Alliance

The Project

- 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 36 organizational partners and 27 researchers nationally and internationally.
- Involves 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

QPC-LTC Alliance

The Project Aims to...

- 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

Methodology

- Comparative Case studies in each of the LTC Homes
- Quantitative and qualitative research methods: Surveys, Interviews, Focus Groups, Participant Observations, Document Reviews



- Sample Population: Residents, Family members, Physicians, PSWs, RNs, RPNs, Support Services (ie Spiritual Care, Dietary, Housekeeping, Maintenance etc.), Administration, and Community Partners

QPC-LTC Alliance

Participatory Action Research

- Rooted in Social Action theory
- Empowers participants to be a part of the change

• Lakehead University, McMaster University, St. Joseph's Care Group, Thunder Bay and the Municipality of Halton are working in partnership to develop a formalized palliative care program for LTC.



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 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
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	COMMON ISSUES
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 Perideath care of family, handling of body Funerals, memorial services, celebrations	
Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	

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

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
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From: Ferris FD, Salfour 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.

Square of Care and Organization

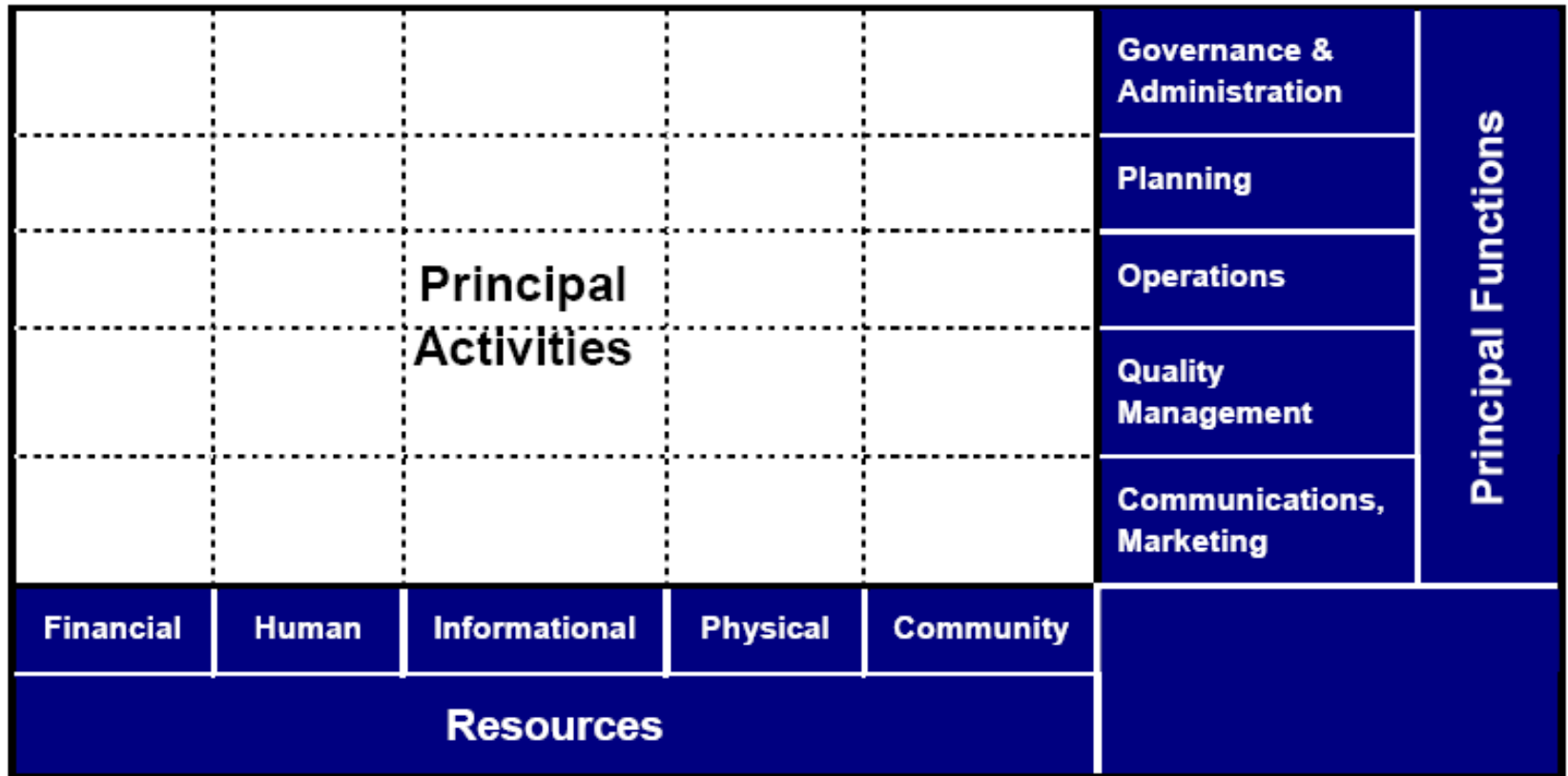
(CHPCA, 2002)

		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						

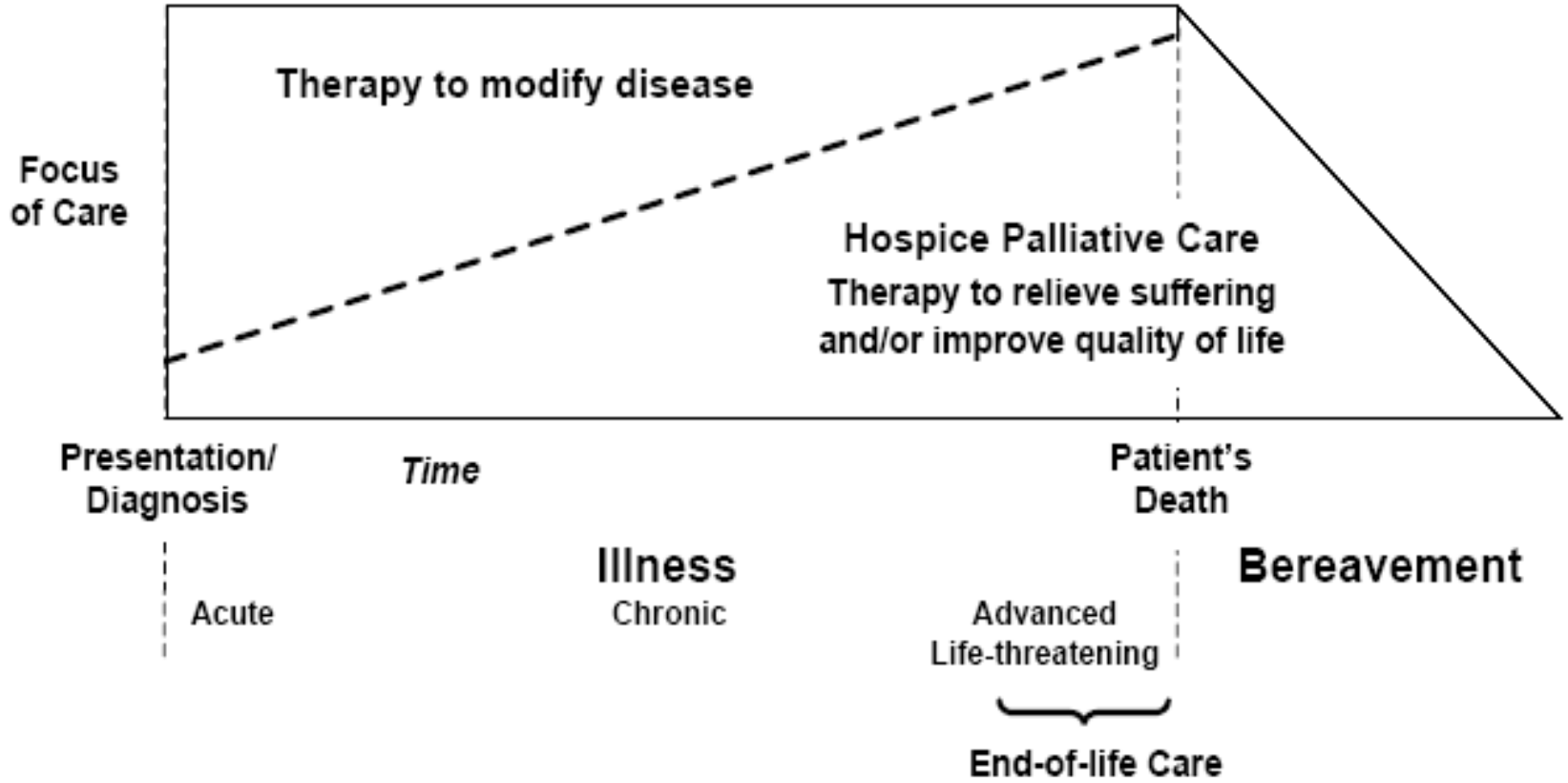
**Patient and
Family Care**

Square of Care and Organization

(CHPCA, 2002)



When does Palliative Care Begin?



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

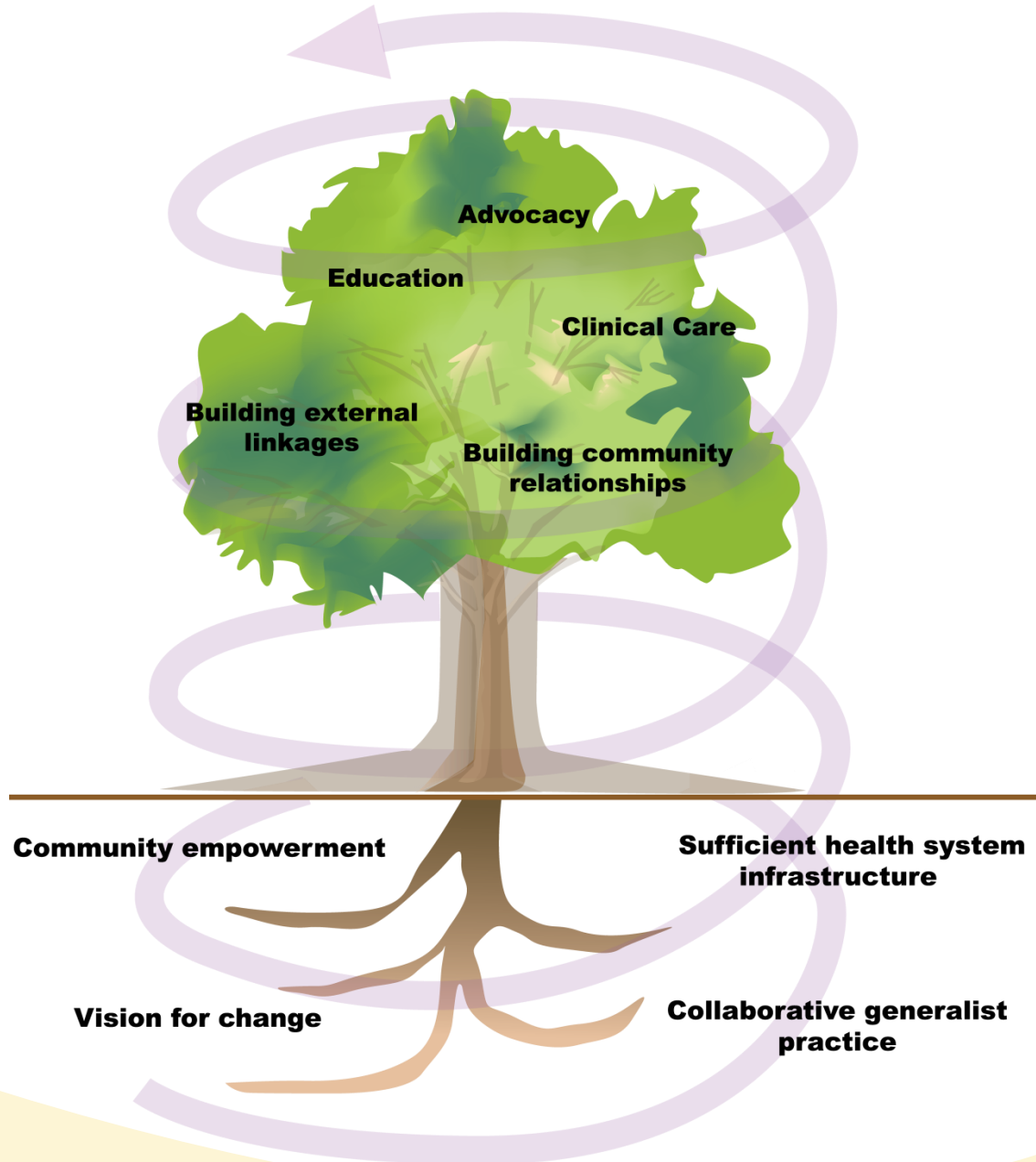
EOL Care (includes palliative care and...)

- Death is inevitable
- Trajectory is short (6 months)
- Focus is on supporting patient and family choices
- Addresses anticipatory grief

Process of Palliative Care Development

Sequential phases of the capacity development model:

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



(Kelley, 2007)

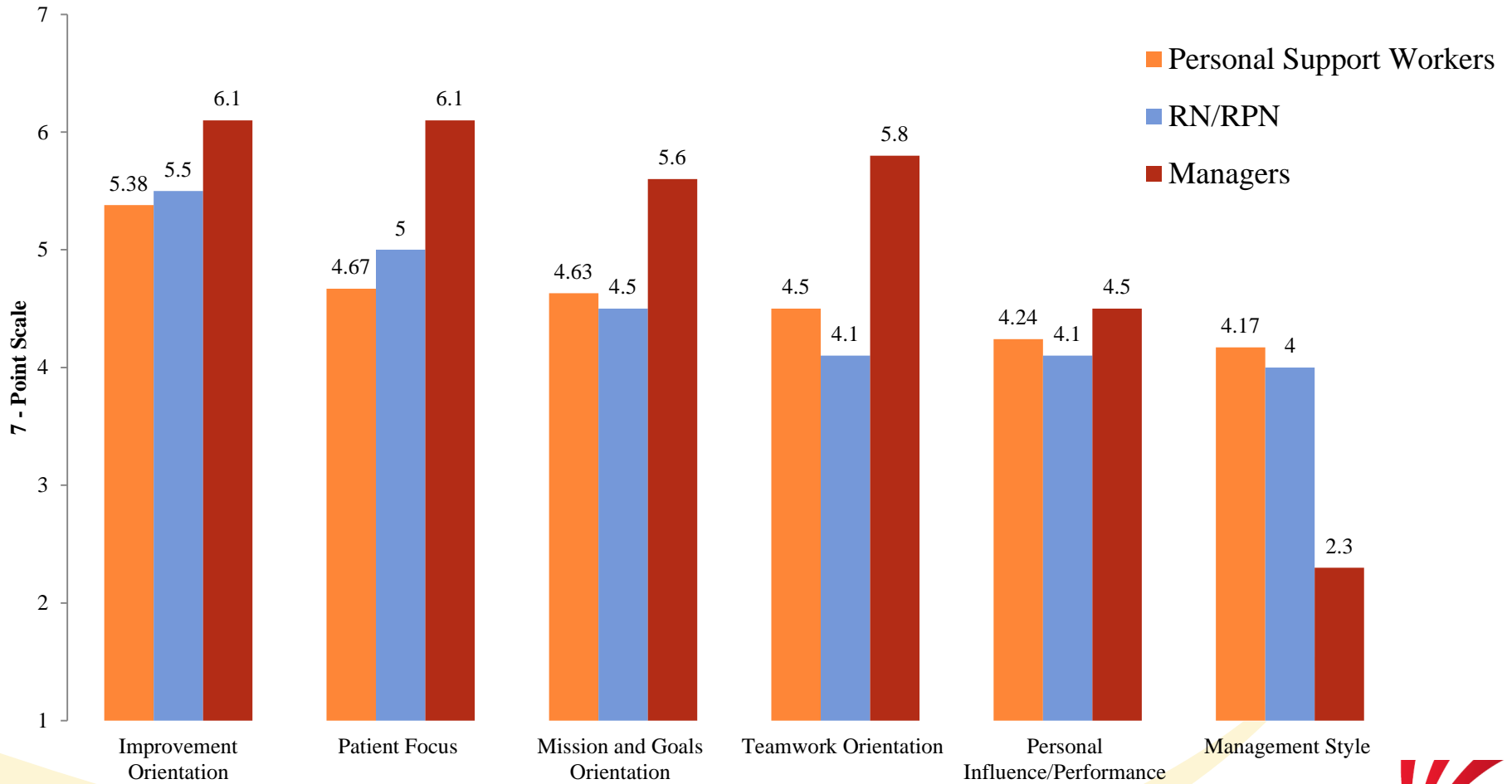
Progress of the Project



**Preliminary Results of Year 1
in One Long Term Care Home**

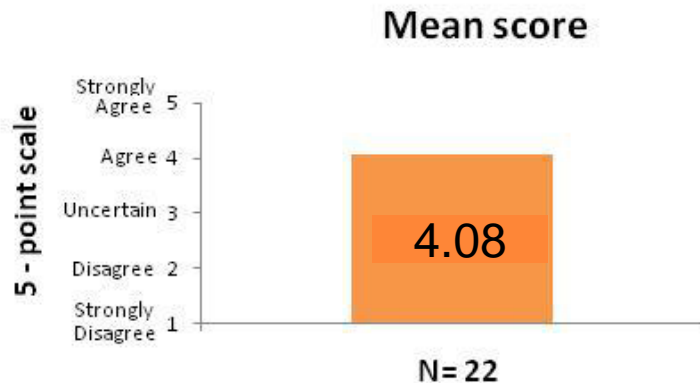
Quality in Action Survey Results

(Baker et al., 1995)

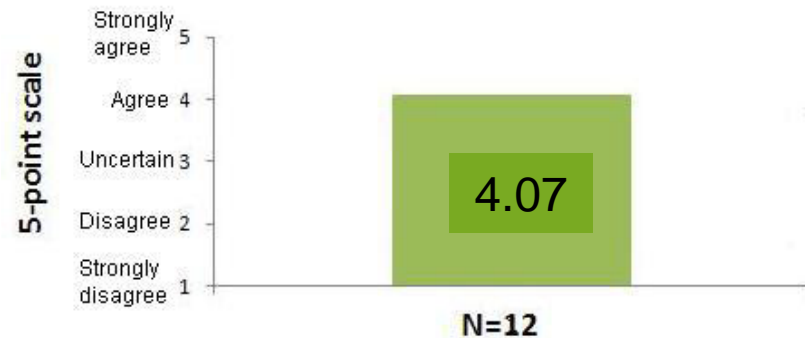


Frommelt Attitudes Toward the Care of Dying (FATCOD) (Murray Frommelt, 2003)

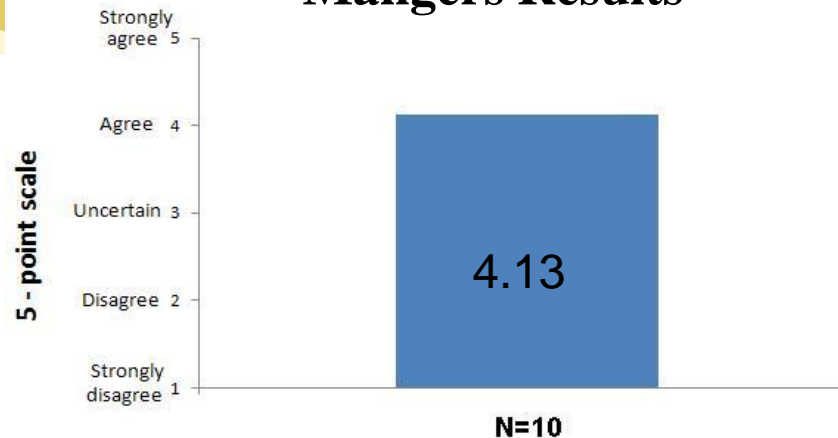
PSW Results



RN/RPN Results



Mangers Results



Attitudes Toward the Care of the Dying

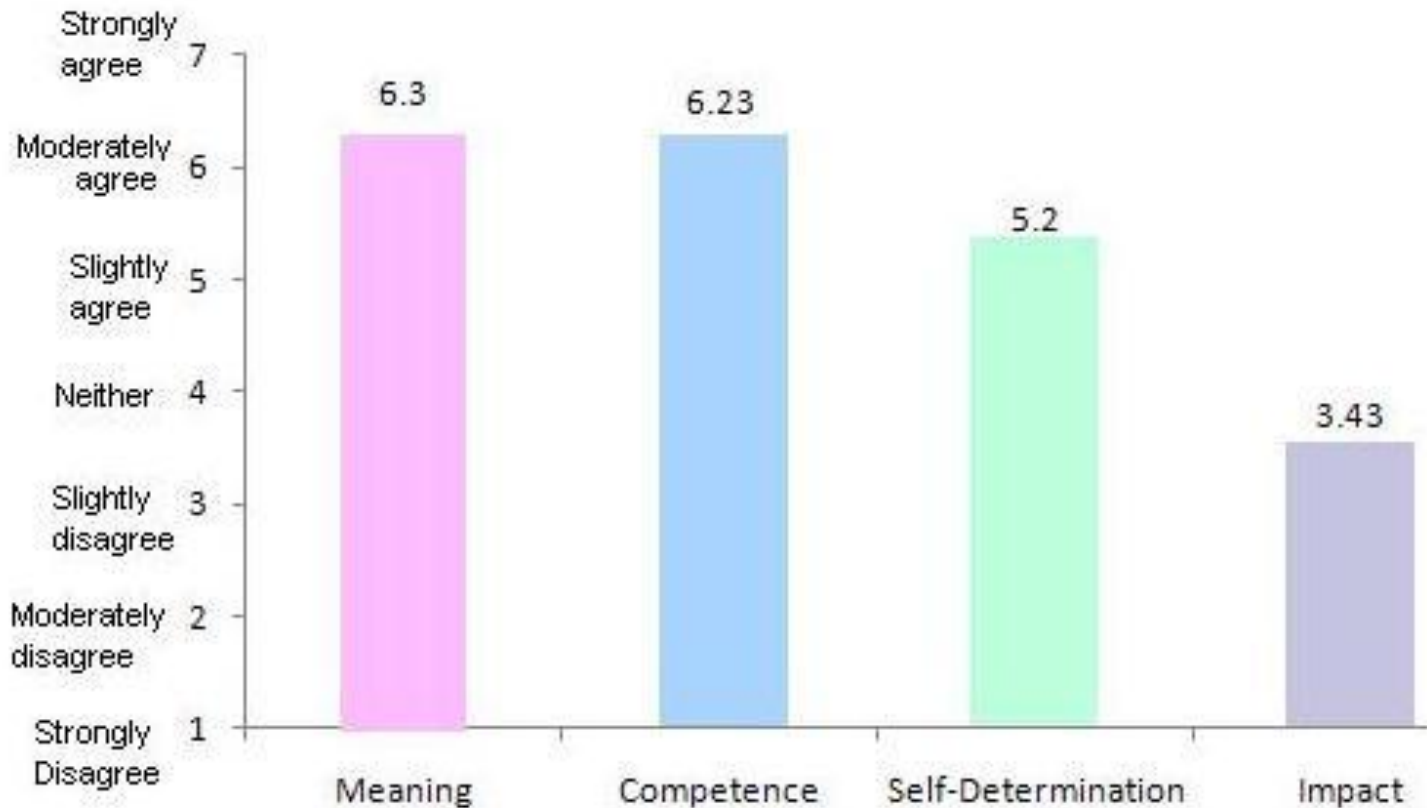
- Caregivers should permit dying persons to have flexible visiting schedules
- Giving care to the dying person is a worthwhile experience
- Families need emotional support to accept the behaviour changes of the dying person
- The dying person should not be allowed to make decisions about his/her physical care
- I am afraid to become friends with the dying person
- I would feel like running away when the person actually died
- As a patient nears death, the nonfamily caregiver should withdraw from his/her involvement with the patient

Findings to Discuss

- What is the family’s involvement in the physical care of the dying person?
 - Is it encouraged? Do family “interfere?”
- What is the role of the staff in talking about death with the dying person?
- What is the role of the staff in educating families about death and dying?
- What can we do about the staff feeling a lack of comfort in talking about impending death with the dying person and responding to their emotions (crying etc)?

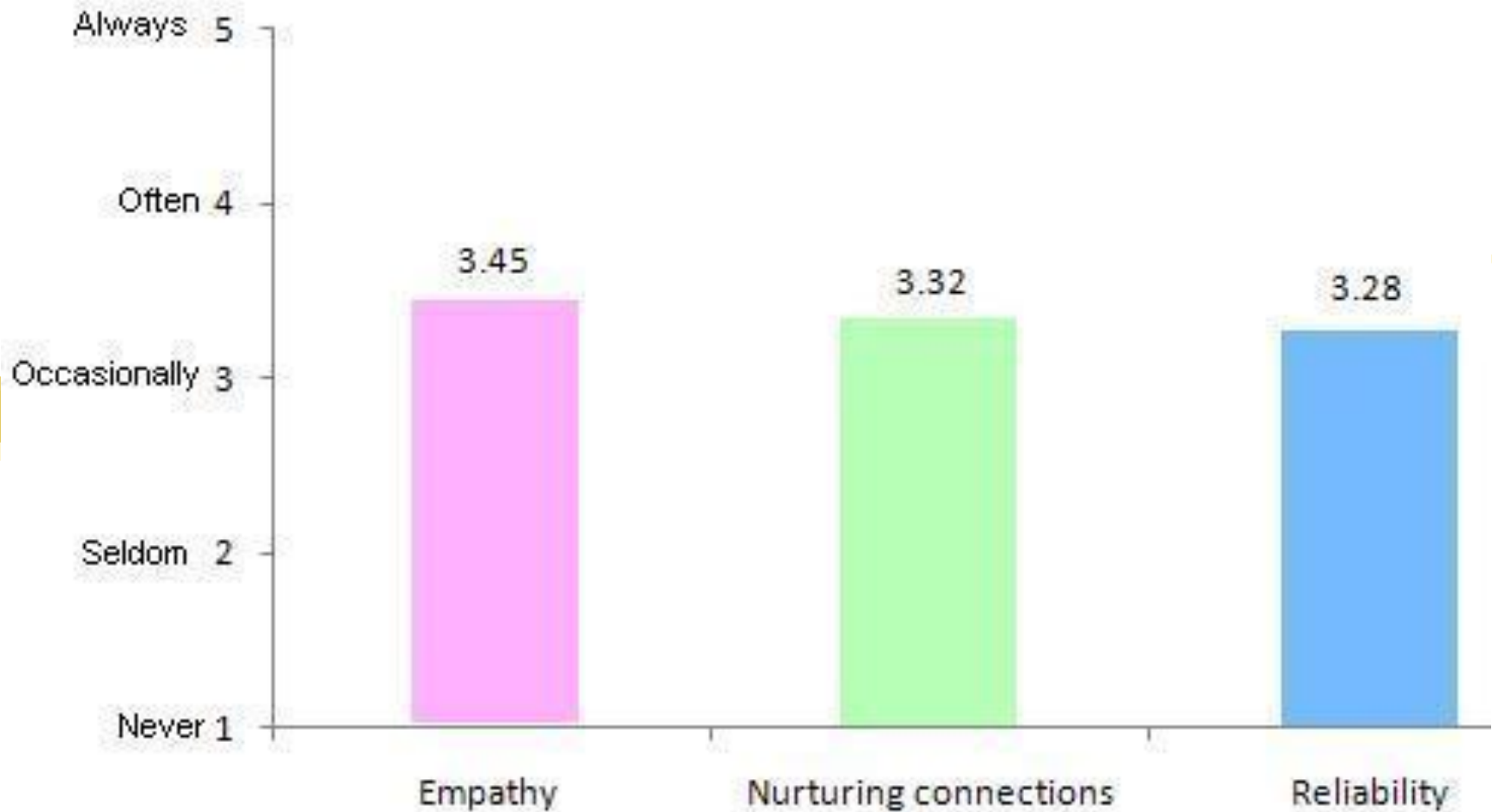
Psychological Empowerment in the Workplace (Spreitzer, 1995)

Personal Support Worker Results



Supervisory Support Scale (McGilton, 2003)

Personal Support Worker Results



PSW Thoughts on Palliative Care

Having an Internal Conflict

“...there is nothing worse than seeing somebody by themselves, and they are scared, and we just don't have the time.”

Providing Comfort in Central Goal

“And just making sure they are comfortable. If they are in pain you know, more than ordinary, just to make sure their pain medications taken care of.”

Needing Education

“...how can I offer any spiritual comfort when I don't even really know the catholic background?”



Next Steps

- Continue to share the results back to the participants
- Collect feedback from participants on how to move forward and create change
- Create an interprofessional palliative care team and program with the help of the community partners
- Develop and evaluate “interventions” based on participant input and priorities – Long term goal is an evidence based Toolkit.
- Disseminate findings of our work nationally and internationally

References

- Baker, G., Murray, M., Tasa, K. (1995). The quality in action instrument: An instrument to measure healthcare quality culture. University of Toronto
- Ferris, F, Balfour, H., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A. and West, P. (2002). A model to guide hospice palliative care: Based on national principles and norms. Canadian Hospice Palliative Care Association. Ottawa.
- Kelley, ML. (2007). Developing rural communities' capacity for palliative care: A conceptual model. *Journal of Palliative Care*, 23 (3), 143-153.
- McGilton, K. (2003). Development and psychometric evaluation of supportive leadership scales. *Canadian Journal of Nursing Research*, 35 (4), 72-86.
- Murray Frommelt, K.H. (2003). Attitudes toward care of the terminally ill: An educational intervention. *American Journal of Hospice & Palliative Care*, 20(1), 13-22.
- Spreitzer, G. (1995). Psychological empowerment in the workplace: Dimension, measurement, and validation. *Academy of Management Journal*, 38(5), 1442-1465.

Discussion Questions



Developing formalized palliative care programs in LTC home:

1. What do the survey and focus group results tell us about the challenges in organizational culture in LTC?
2. How do we better empower and engage PSWs in organizational change?
3. What might be some of the best approaches to developing palliative care in LTC?

Further Information

Check out our Website!

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