



Palliative Care for all Canadians: A Capacity Development Approach to Improving Quality and Access for Marginalized Populations

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Agenda for today

- Brief overview of Canadian context of palliative care provision
- Describe my program of research related to developing, applying and evaluating a model community capacity development in rural communities (2005-10), long term care homes (2009-13) and First Nation communities (2010-15).

10 year Program of research

- Focus on service delivery and in particular improving access to palliative and end of life care for marginalized populations
- Using systems thinking and creating capacity development models to guide development of services at the primary care level in rural and First Nations communities and LTC homes.
- Uses participatory action research approaches

Map of Canada



Current Access to PC in Canada

- Only 16-30% of Canadians who need it receive specialty palliative care (CHPCA)
- Goal is to increase access to palliative care for all Canadians regardless of age, diagnosis, where they live or receive their care
- How can this goal be achieved?

Canadian health system context

- Shift from hospital to community care
- Aging population and increased in life expectancy
- Predominance of chronic illness as cause of death and new dying trajectories
- Increased expectations of consumers for access to specialized and life saving health services
- Limited understanding of benefits of palliative care in general population to preserve quality of life
- Attempts to reduce health care spending, especially in hospitals

Evolution of Palliative Care in Canada:

- Introduction of palliative medicine and palliative care as “specialty care” people who are imminently dying (1975)—hospital based; physician oriented care
- Promoting a palliative approach to chronic disease management for the last year(s) of living (2000)
- Promoting of a vision for a palliative approach in primary health care that is accessible to all (2011)
- PC service delivery models have not evolved to achieve this.

A palliative approach to primary care..

The essential idea is that interprofessional primary care teams, regardless of setting of care, should have the skills, resources and processes necessary to recognize, assess and manage basic palliative care needs in a timely fashion in a community setting.



Palliative Care and End-of-Life Care

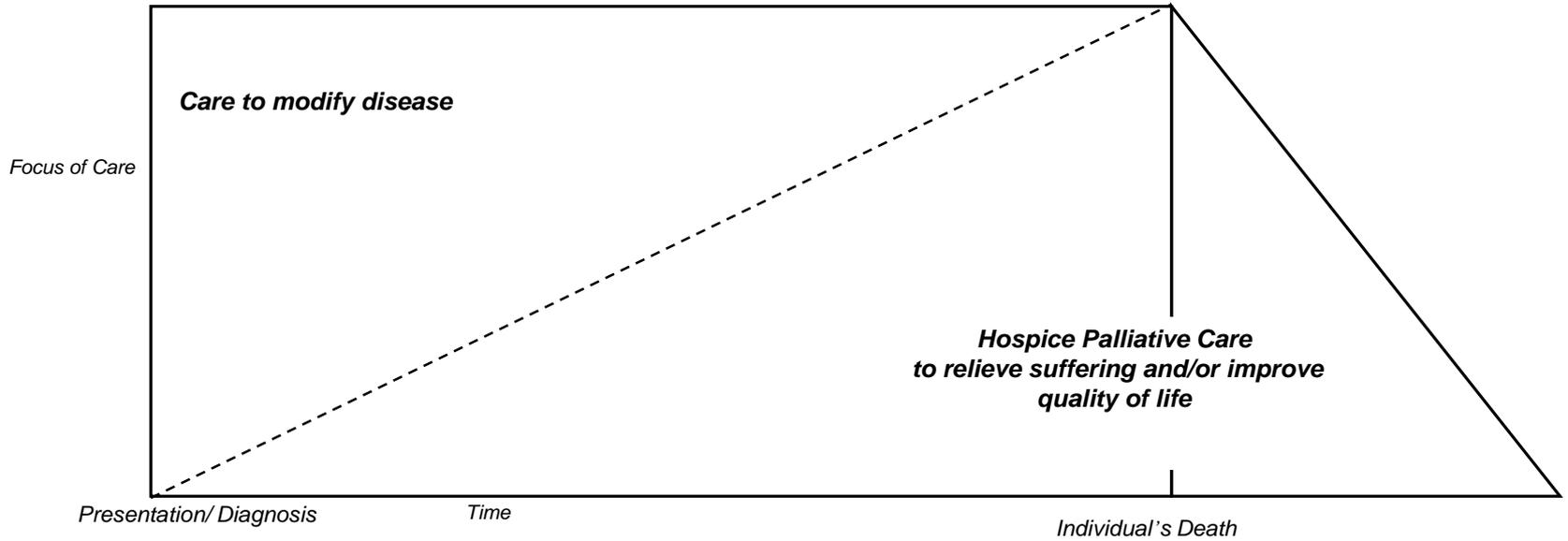
(Adapted from CHPCA, 2002)

Palliative Approach to Care

- Focus is on quality of life, symptom control
- Interdisciplinary in approach
- Client centered and holistic
- Begins when death would not be “unexpected” in the next year; sick enough to die
- Integrated into chronic and terminal care
- All settings of care

EOL Care

- Death is inevitable
- Trajectory is short (6 months or less)
- Focus is on supporting patient and family choices
- Addresses anticipatory grief
- Supports people with a “good death”



Acute

Illness
Chronic

Advanced
threatening

Bereavement
Life-

End-of-Life Care

The palliative approach is...

- Concurrent with curative care when desired by patients
- Holistic with an interprofessional team
- Involves person and family
- Provided by people who know you best
- Engages specialists only if needed
- Aims to provide care where you are living, i.e. rural, community, First Nation community, LTC home

Ref: Shadd:

Goal of research program

- To improve access and quality of palliative care services to marginalize populations in Canada:
 - Rural communities (20-30%)
 - Frail elderly people living in long term care homes
 - Indigenous people living in FN communities (2%)
- To generate theories of change to guide development of PC policy and practice using PAR and capacity development approaches.

What is PAR?

- Collaboration, education, and action are the three key elements of participatory action research
- The purposes are education, taking action or effecting social change
- It is the process of producing new knowledge by systematic inquiry, with the collaboration of those affected by the issue being studied

- Role of the researcher in PAR is observer, facilitator, consultant
 - Facilitates and supports the development process, and documents the process while doing this
- Requires involvement and commitment of local health care providers and organizations
- Multi years of community engagement for research
- Process is to use model as a framework for community assessment, goal setting, development intervention plans (ongoing process) to systematically move the development process along.

Program of research

- Development of CD model (rural)
- Validation of CD model (rural)
- Application of CD model in intervention studies
 - Rural
 - Long Term Care Homes
 - First Nations communities (in progress)
- Application of CD model internationally?



Model Development

Theoretical perspective:
Community capacity development

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CD embedded in Systems- thinking

- Places less faith in planned, engineered solutions-- systems are seen as having a dynamic of their own that is only marginally open to management and direction.
- Change is not linear. More emphasis on evolution, on discovery and emergence. Human behaviour.
- Takes a post-modern way of seeing the world-- nothing is objective and independent of its context.
- Knowledge can only be constructed by taking different perspectives

What is capacity? Capacity development?

- **Capacity** is the capability of individuals, groups, organizations or communities, to perform or produce something of value, related to their desired development or performance.
- **Capacity development** is the evolutionary process of change and adaptation that occurs from inside as individuals, groups, organizations or communities act to accomplish their goals.

(Chaskin 2001; European Centre for Development Policy Management 2003; Kaplan 1999)

Principles of Capacity Development

- Development is essentially about building on existing capacities within people, and their relationships
- Development is an embedded process; it cannot be imposed or predicted
- The focus is on change, and not performance
- Development has no end

- 
- Change is incremental in phases, however development is dynamic & non-linear
 - The change process takes time
 - Development process engages other people & social systems
 - Different levels and forms of capacity are interconnected in a systematic way (individuals, teams, organizations and communities)

(Kaplan 1999; Lavergne & Saxby, 2001)

Adopted ECDPM framework for CD

- Consists of 7 interdependent, interacting concepts
 - Capabilities (focus of change)
 - Performance (emergent property)
 - Endogenous change & adaptation (core concept)
 - Endogenous management (leadership)
 - Internal features & resources
 - External intervention
 - External environment

(Adapted from Baser 2003; European Centre for Development Policy Management 2003)

Developing Rural Palliative Care



Model Development (2002)

- Data were from eight focus groups of rural health care providers and community members who have involvement in palliative care (66 participants)
- Data were collected in Yukon, BC, Alberta, Manitoba, Ontario, Nova Scotia and Prince Edward Island
- Analysis using process of analytic induction with Nvivo examining data in relation to concepts and principles of capacity development



The Model: The Growing Tree

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Developing
palliative care
in

Communities:
A four phase model



Process of PC Development

Antecedent community conditions



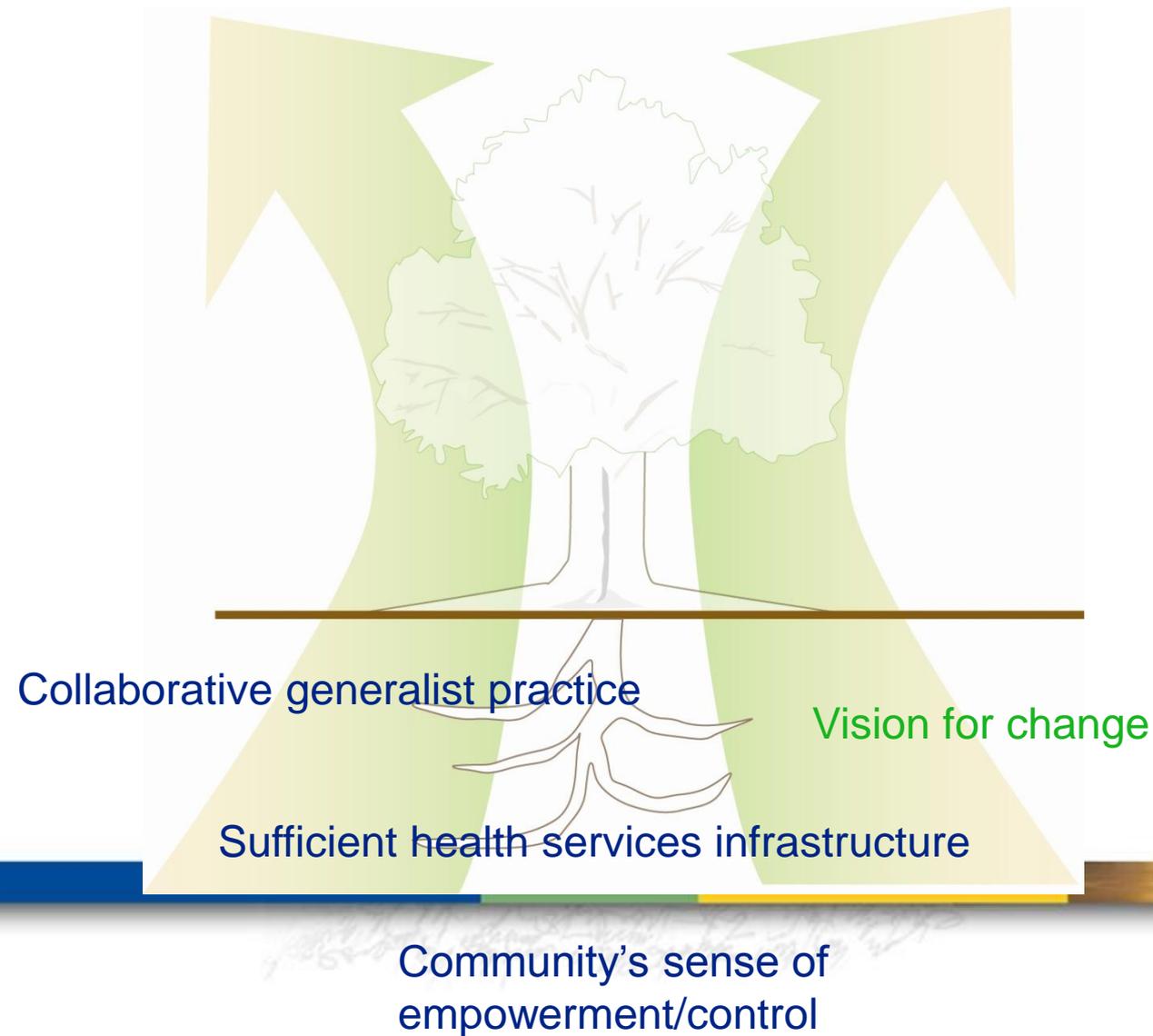
Phase 1:

Antecedent

Community

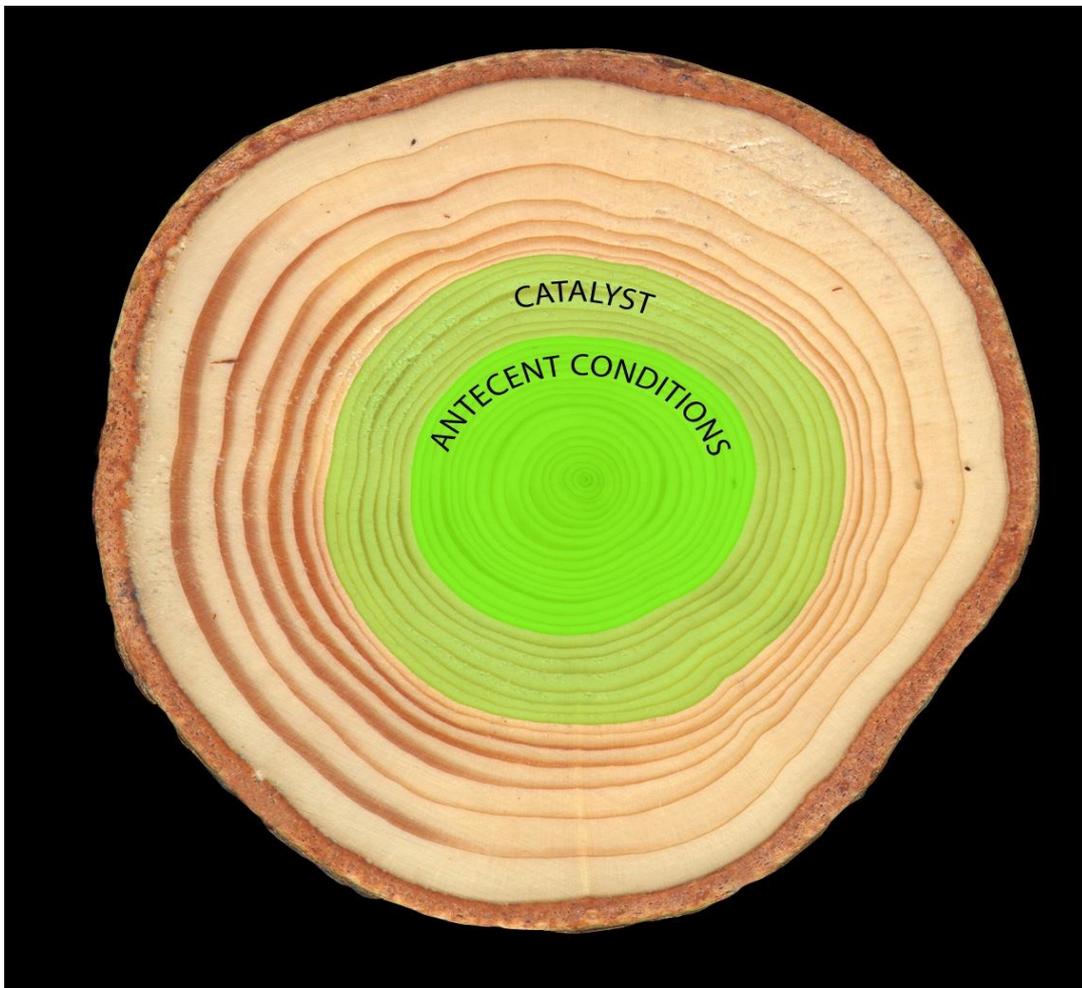
Conditions

(nutrients in soil
& seed)



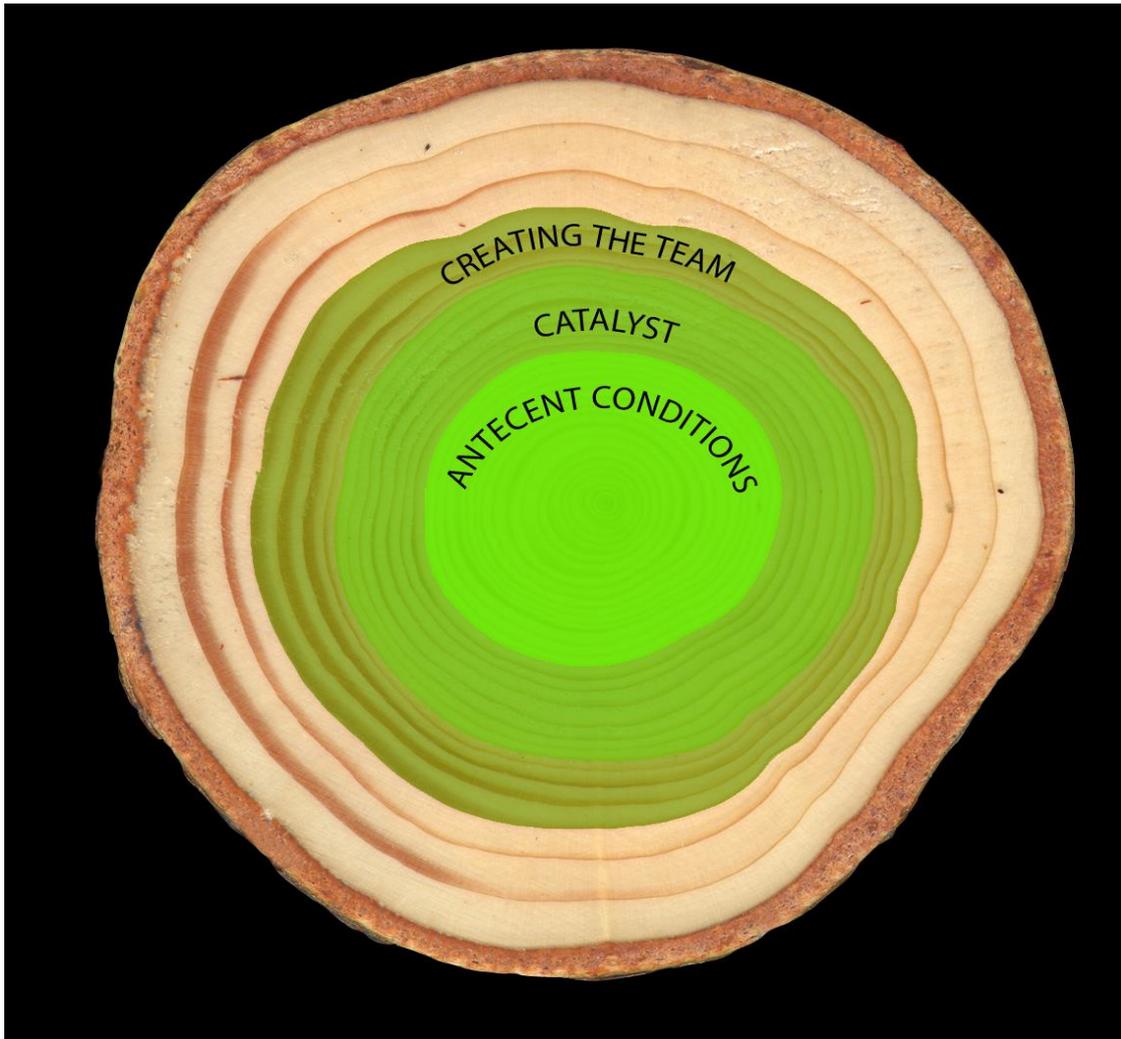
Keys to success...

- Working in a **small** community
- Working **together**
- Being community-focused (focus on the whole)



A catalyst for change
occurs
in the community,
disrupting their
current approach to
care of dying people
-triggers change

Phase 2: Catalyst



Generalist providers
join together
to improve community
care of the dying and
develop “palliative care”.

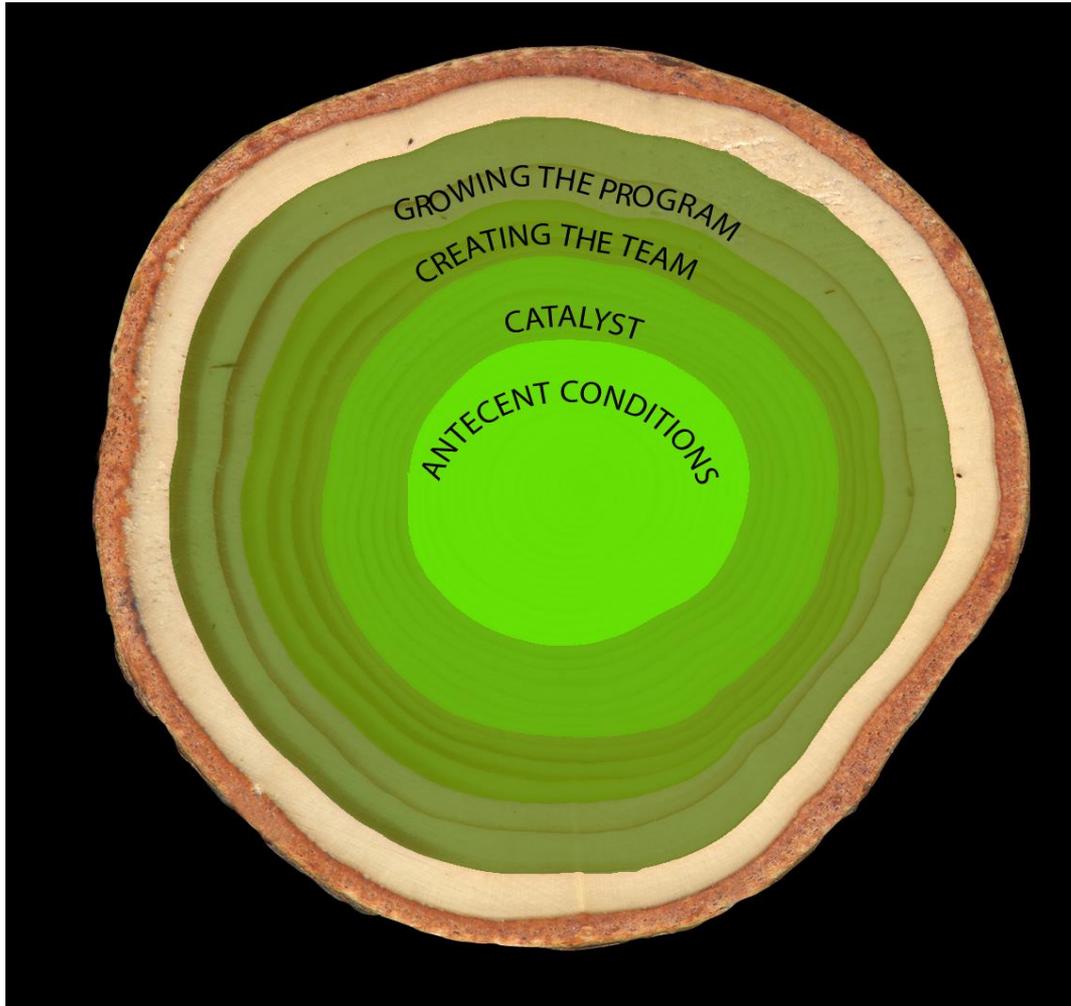
Phase 3: Creating the Team

Major themes:

- Having dedicated providers
- Getting the right people involved

Keys to success...

- Working together
 - strong relationships, communication, support
- People have been very dedicated
- Physician involvement



The team continues to build, but now extends into the community to deliver palliative care.

Phase 4: Growing the Program

Major themes...

- Strengthening the team
- Engaging the community
- Sustaining palliative care

Strengthening the team

- Developing members' expertise
 - Sharing knowledge and skills
 - Creating linkages outside the community
 - Learning-by-doing (taking risks)
- Developing members' self-confidence

Engaging the community

- Changing clinical practices
 - Developing/implementing tools for care (e.g. in home chart, ESAS, PPS)
 - Care planning
 - Family education & support
- Educating and supporting community providers
- Building community relationships to improve service delivery

Sustaining palliative care

- Volunteering time
- Getting palliative care staff and resources
- Developing policy and procedures

Doing it with what we had

- *We try to do the best we can with our clients, with what we have. And I think that a great asset to us is because we have such good communication and a great team of people work with in the community, who are very interested in caring.*

I never feel I am alone out there...

- *I never feel that I am out there alone. I can pick up the phone; I can talk to our pharmacist who is really tremendous support for us all. If I've got medical problems, I can pick up the phone and talk to [others]. So, that back-up, the support that other people can give; so I don't feel like I've got to know it all or do it all. I couldn't.*

We tried to be innovative & flexible...

- *...We tried to be innovative and flexible. We sort of get our knuckles rapped for some of those innovative things. But I guess I strongly believe that unless you do those things, we're never going to progress. So maybe we need to do things, get our knuckles rapped but then, you know, help other people to see the light*

Challenges: Growing the program

- Insufficient resources
- Organization and bureaucracy in the health care system
- Lack of understanding/resistance to palliative care
- Nature of the rural environment

Keys to success...

- Being community-focused
- Educating providers
- Working together/teamwork
- Leadership (local)
- Feeling pride in accomplishments

Being community-focused...

- *I mean you have to really be thinking rural perspective. You can't just take a program from an urban area and plunk it into rural communities. It just won't work if you do that.*
- *People live in rural areas by choice and those people don't do well in formalized programs, I don't think of any sort. And so I think the key to anybody wanting to start a program in a rural area, keep it as simple as possible without all the rules and regulations and registration forms and so on.*

- *I think this is one of the advantages of rural death, is that you don't have access to all the high tech resources and specialists, on the other hand, I think there is more flexibility [yes] in the system [Mm hmm]. And we'll just move them flexibly through through the system and they're in the hospital, they're on home care....and lets not have too many policies that are gonna be barriers [Mm hm] to doing the work on the front line*

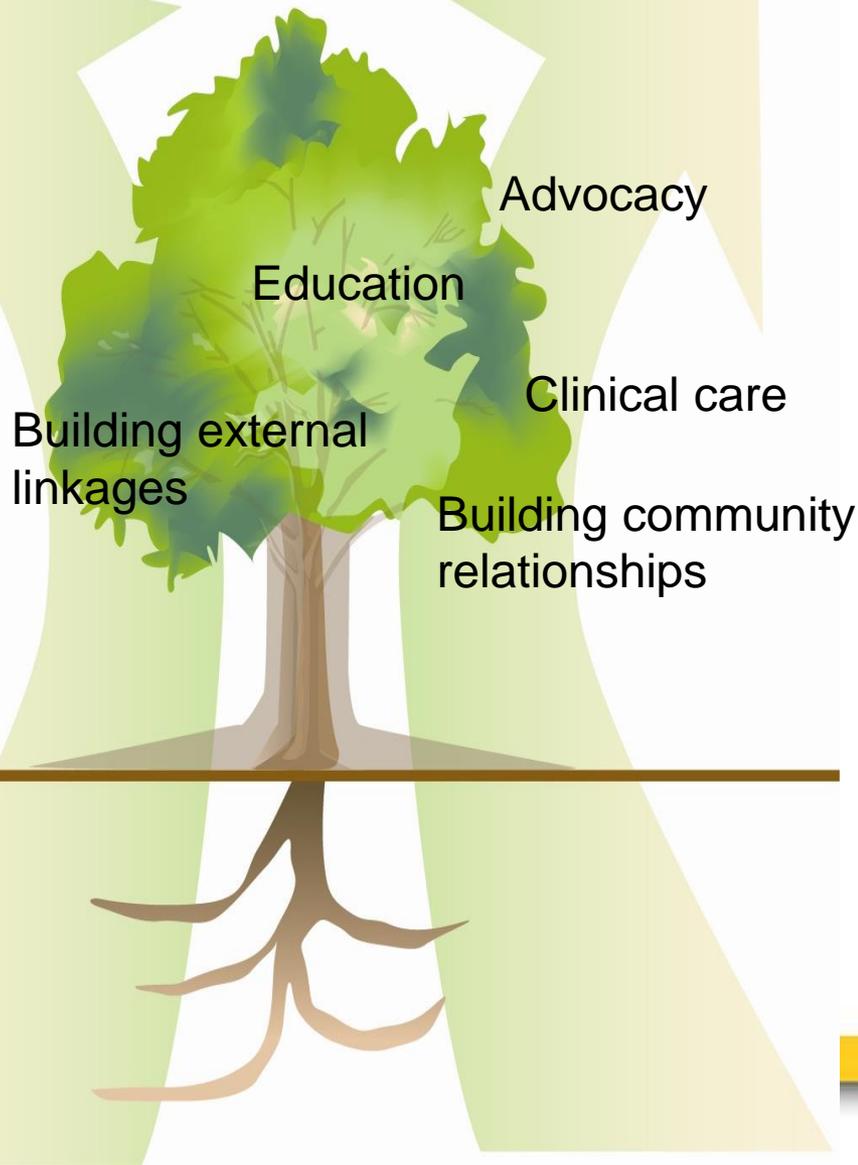
Development is formalizing the informal...

- *I think palliative care has always occurred in rural areas; it's just formalizing [the process] a little bit, and getting the **educational component** from the hospice in Victoria, that example of what works. And not being afraid of **jumping in and doing it**. And **getting the other team members on board** as others have said, to manage the symptoms. But not being afraid, and just recognizing that its always occurred.*

Essence of the developing rural palliative care model...

- Rural palliative care needs a “whole community” approach: community-focused is overarching
- Building rural palliative care is an “inside job”
- The process is incremental, sequential (4 phases)
- Antecedent conditions are the foundation
- Nothing happens without a catalyst

- Building the local team is essential
- Growing the program takes time (years!)
- Imposed external interventions are NOT a major factor
- Education is a critical component
- Additional resources and policy are needed—but not until the last phase of Growing the Program



Capacity Development Process

4. Growing the Program

Performance
Leadership
Team capabilities

3. Creating the Team

Internal features and resources
of the team

2. Catalyst

1. Antecedent Community Conditions

Individual capabilities
External environment

Model Validation Method

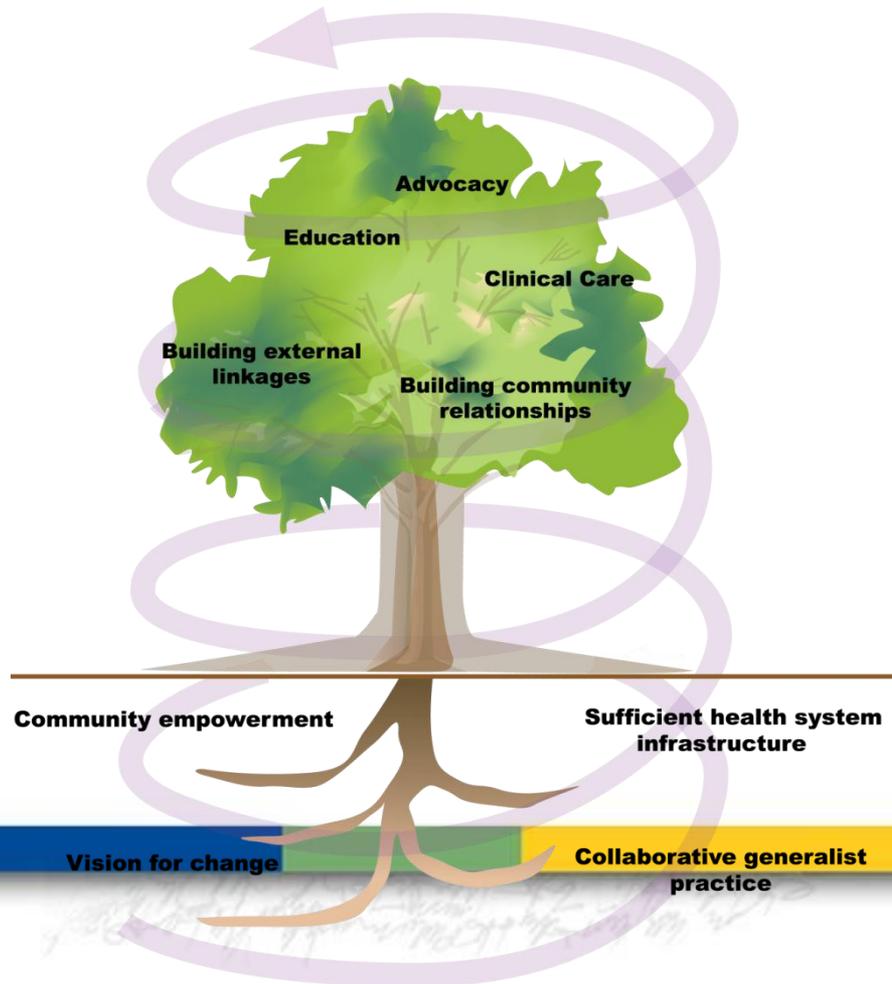
- Goal was to determine if the model accurately represented the experience of a palliative care providers in rural communities, revise as needed
- Return to one community where data had originally been collected for member checking (Dryden, ON)
- Visit six rural communities that were not part of the initial model development to determine if it fit with their experience
- Focus groups, presented model and solicited comments

Results

- Data validated the model-empirically based
- Added one antecedent condition
 - Previous: sufficient infrastructure, collaborative generalist practice and vision for change
 - Added: providers have sense of empowerment, personal control over their work (stability vs externally imposed change)
- Elaborated on environmental influences to process
 - Incentives to develop PC were demographics, resources and isolation
 - Minimum population size and resources required

- Illustrated principles, i.e. development process is not linear (seasons like winter, spring, fall); not all branches grow at the same rate (i.e. clinical, education, advocacy etc.)
- Elaborated the issues around “getting started”
 - In Chinook palliative care was a local initiative, then regionalized --six years ago program standardized/imposed by health authority
 - Role of the “consultant” (internal/external) and local leadership
 - Local vision for change, commitment

Community Capacity Development Model



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

Revised model

PAR Intervention study

- To document the process of how rural community's can use the model prospectively to develop palliative care in a rural community
- To evaluate its utility
- Researcher visited community two-three times a year
- Liaised with a local collaborator by telephone between visits
- Used the principles of CD and the identified “keys to success” to guide the process of implementing the model

Outcomes

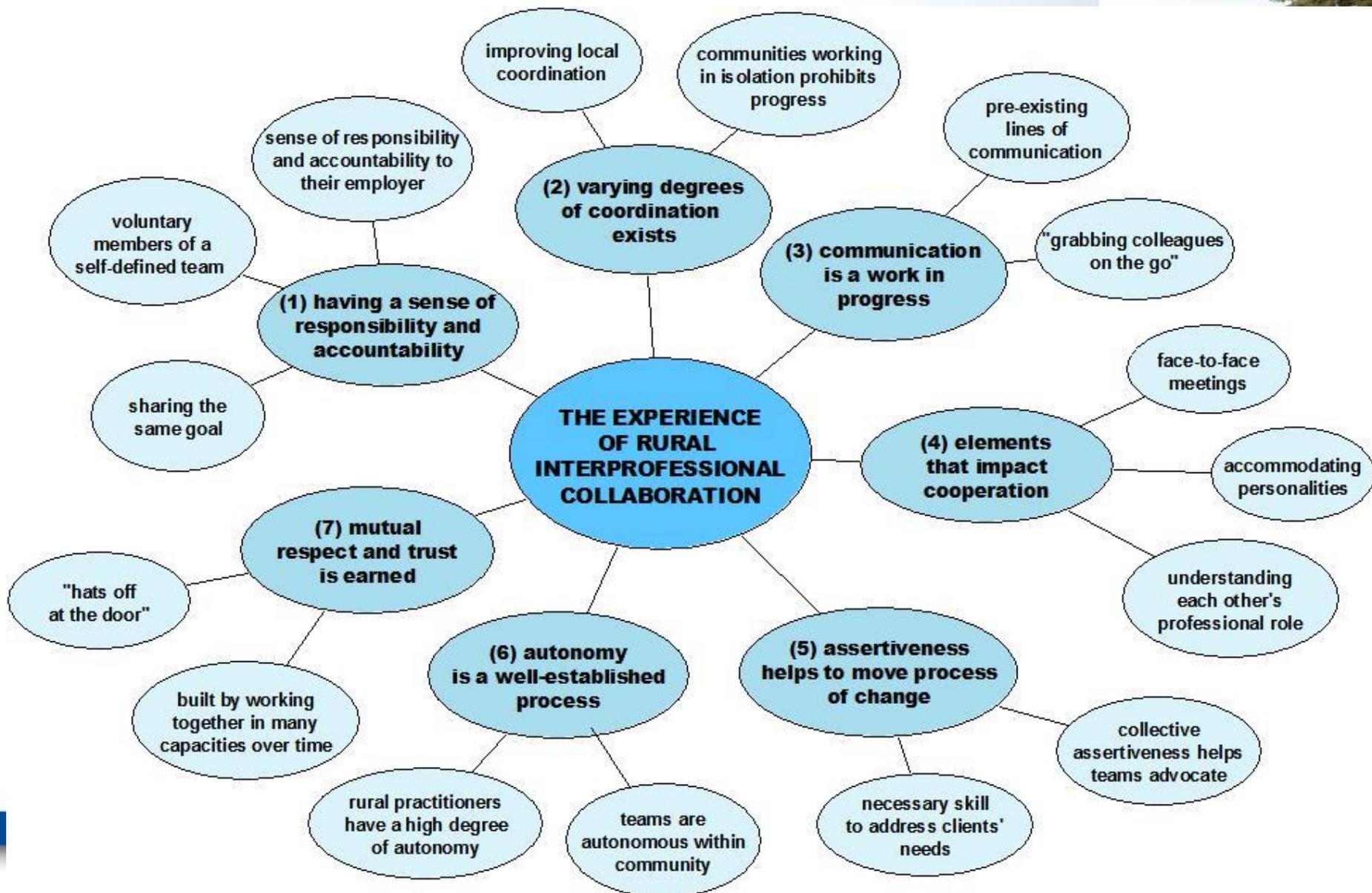
- Practical toolkit for developing rural palliative care and analysis of how it was utilized for local capacity development
- Documenting the dynamics of developing rural palliative care at the community level
- Theoretical enhancement of the CD model and teamwork phase
- Contributed to theorizing of rural interprofessional collaborative practice

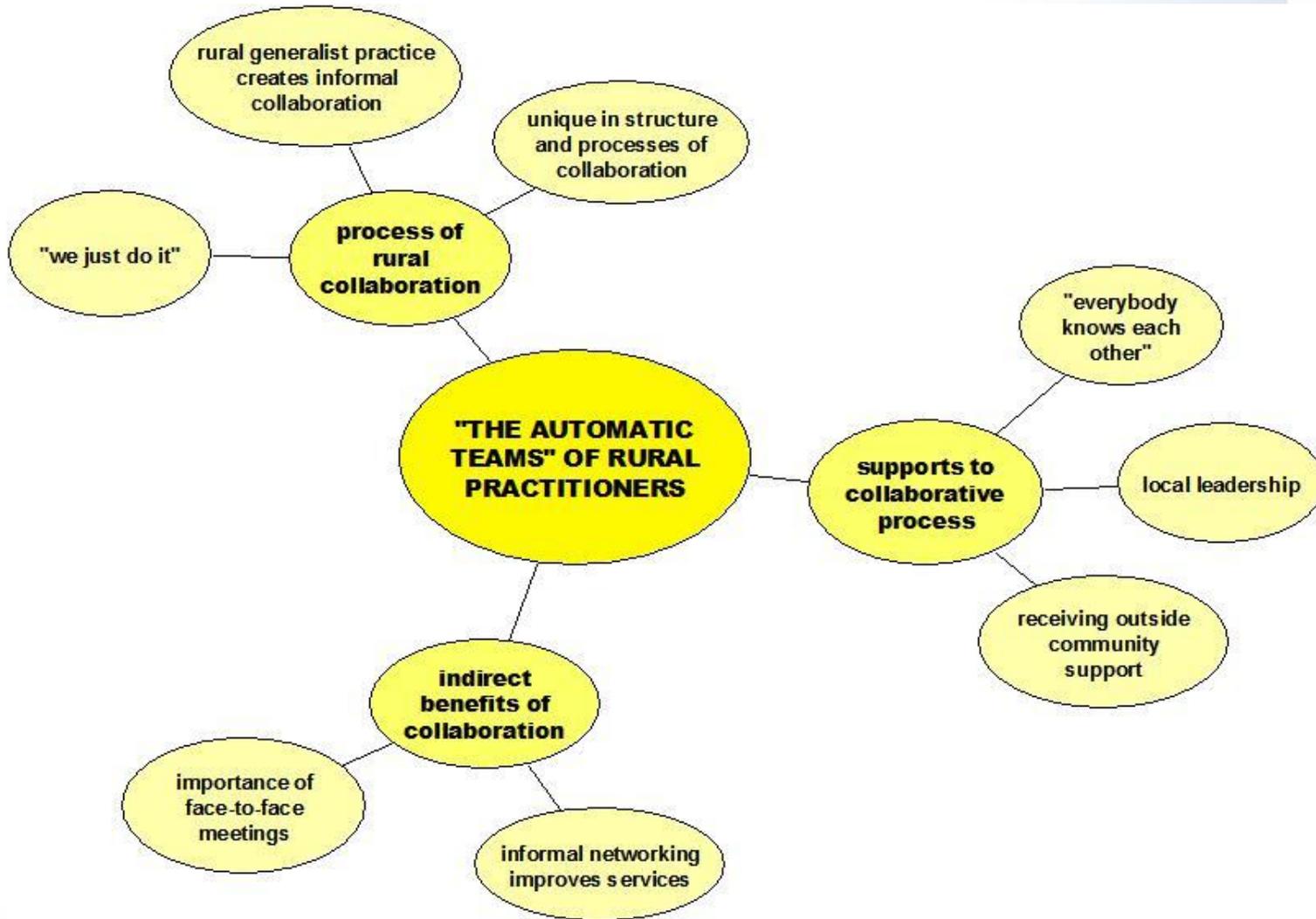
Rural Palliative Care Toolkit

Phases of the Model	Resources in the Toolkit
Phase 1: Assessing the Antecedent Community Conditions	<ul style="list-style-type: none">• Template for developing a contact list of local community care providers.
Phase 2: Experiencing a Catalyst for Change	<ul style="list-style-type: none">• Materials for organizing an initial meeting with community care providers interested in palliative care
Phase 3: Creating a Community Palliative Care Team	<ul style="list-style-type: none">• Terms of Reference for both a Community Team and a Clinical Team• Pamphlet for local program•
Phase 4: Growing the Palliative Care Program	<ul style="list-style-type: none">• Path of Care & Alternate Path of Care• Patient Flow Sheet• Common Assessment & Referral Form• Case Conferencing templates & guidelines• Expected Death in the Home Checklist

Process of Utilization of Toolkit

Concept	Meaning
Use/ predevelopment	<ul style="list-style-type: none">- Information has been received and read- Does not necessarily imply that information has been understood- Does not imply that an action has been taken- Communities without antecedent conditions did not use tools
Utility/ Creating the team	<ul style="list-style-type: none">- Represents some user's judgment that information could be relevant for some purpose which has not been identified as yet- Does not imply that an action has been taken- Newly formed rural PC teams reviewed the tools
Influence/ Growing the program	<ul style="list-style-type: none">- Information has contributed to a decision, and action, or a way of thinking about a problem- The user believes that by using information, he/she was aided in a decision or action- Rural PC team discussed toolkit and adopts tools as a prototype
Impact/ Growing the program	<ul style="list-style-type: none">- Information has been received, understood, and it has led to some concrete action, even if that action is to reject the information- One community decided NOT to use the toolkit after reviewing it as they had another process in place already.

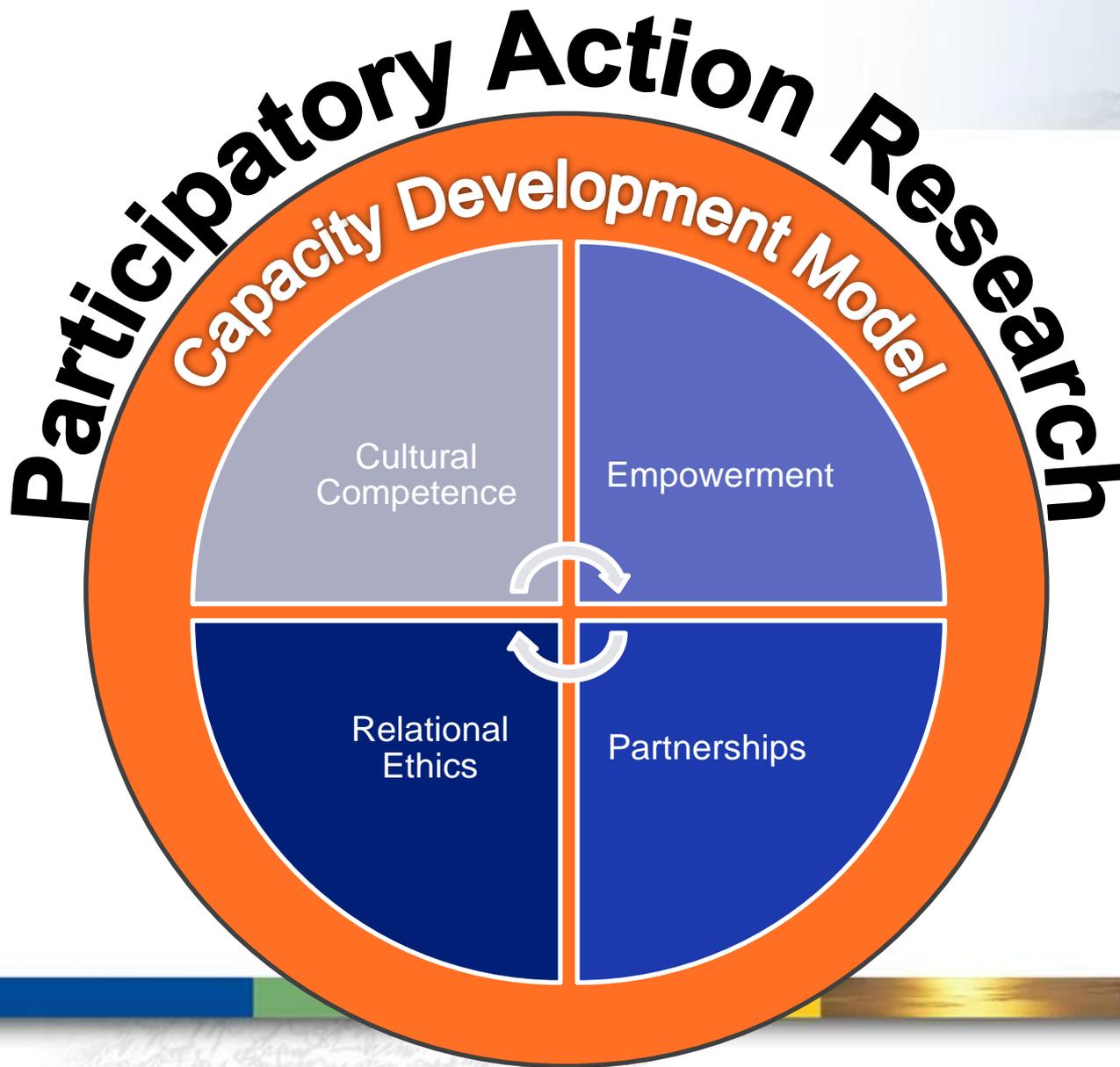




Long Term Care Homes

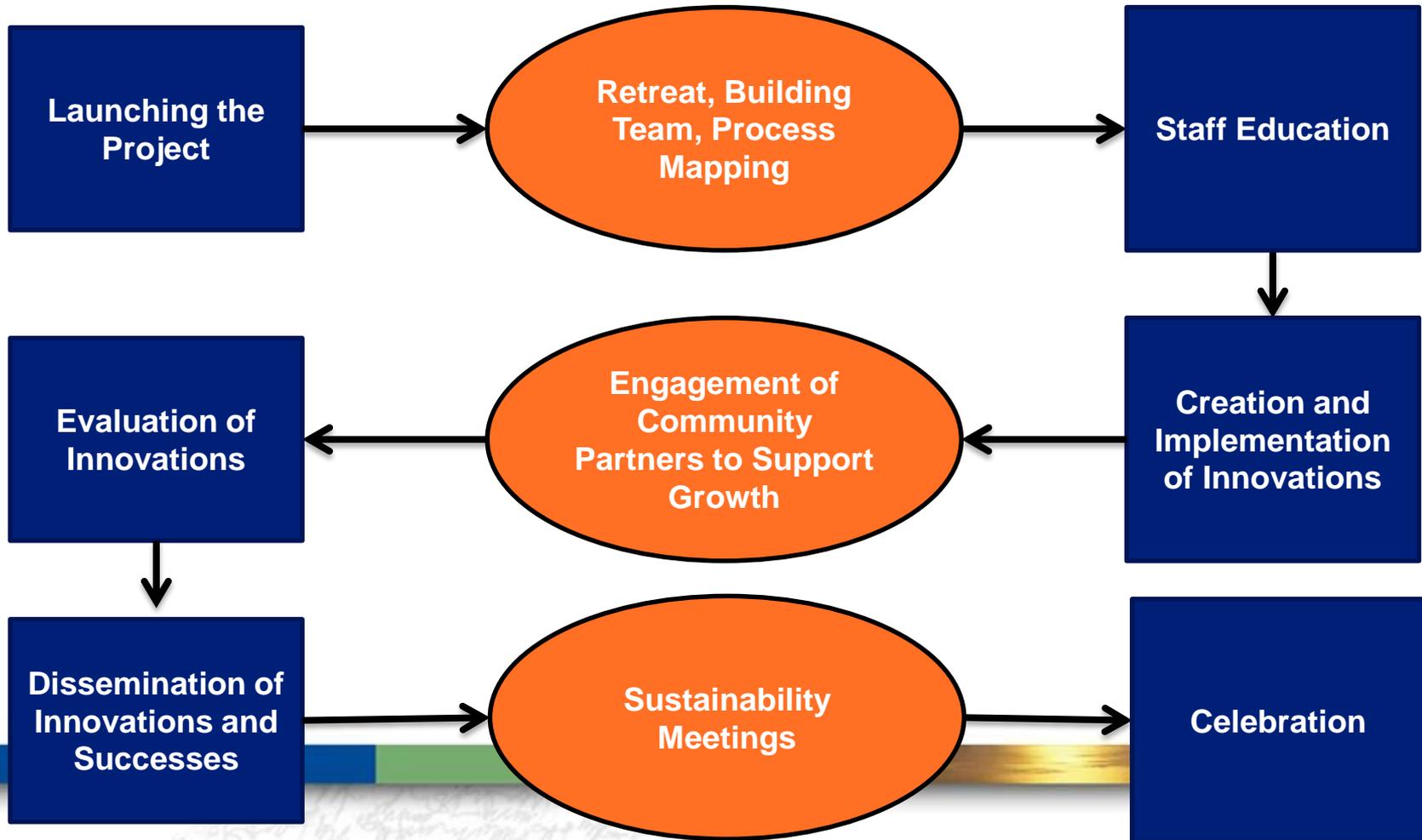


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PAR method to develop PC in LTC

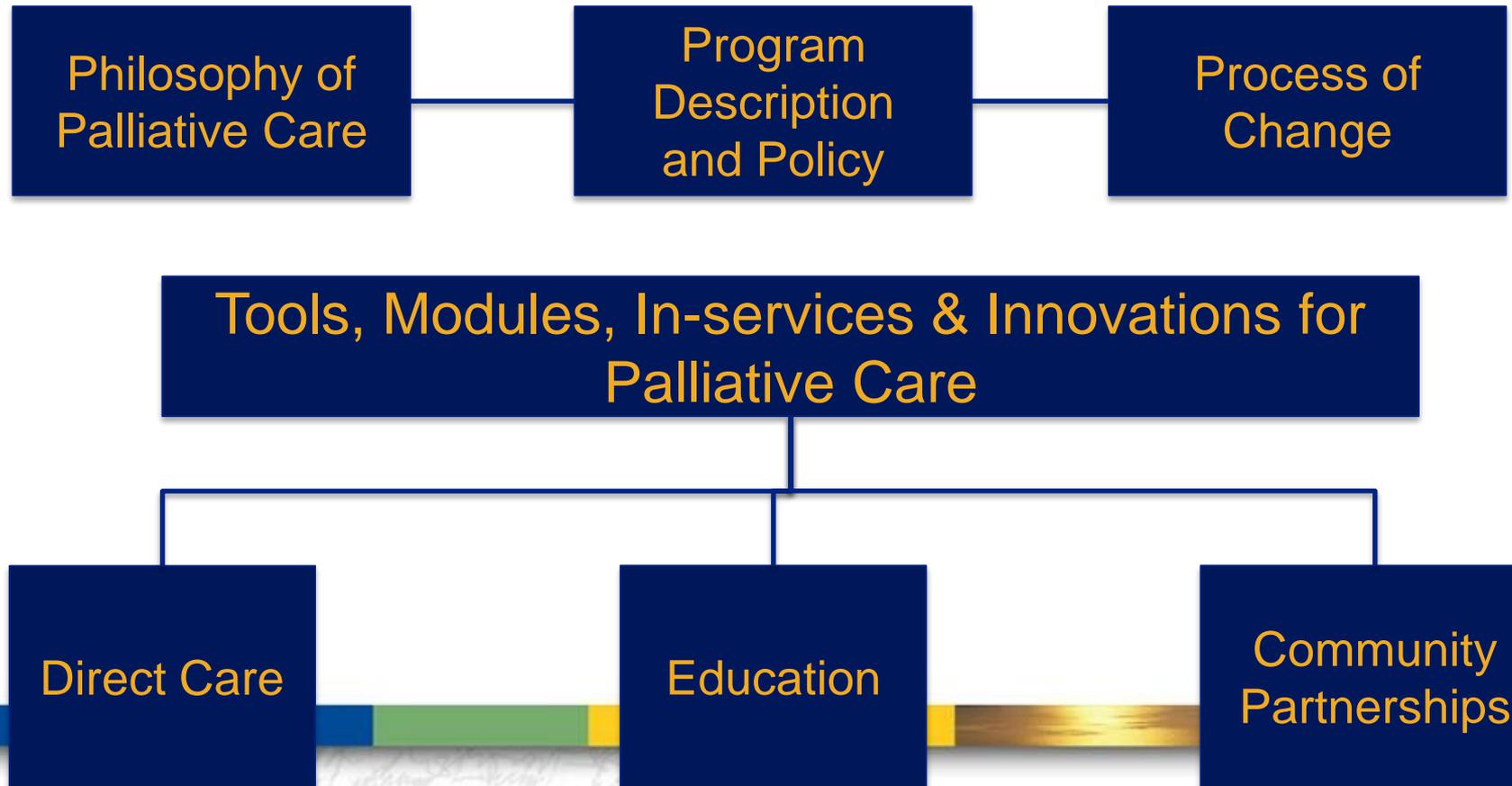
Change Process



Outcomes

- Developed framework for PC in LTC and 40+ tools and resources
 - Focused on empowerment and articulated the role of unregulated health care providers
 - Focused on process or organizational change (capacity development)
- Catalyzed policy changes in Ontario
- Catalyzed changes to accreditation of LTC homes in Canada
- Contributed to knowledge of conducting PAR in LTC homes

Framework of Palliative Care in Long Term Care

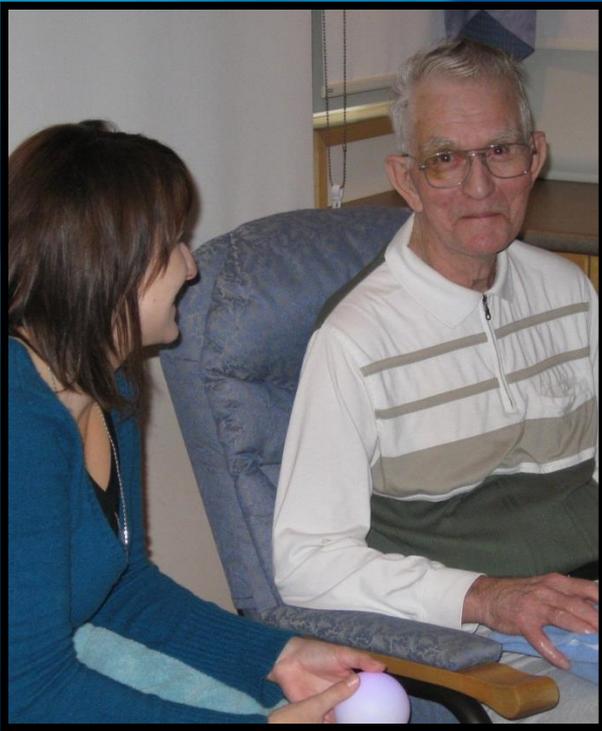




PALLIATIVE CARE WEEK

May 6th – 12th, 2012

Palliative Care...

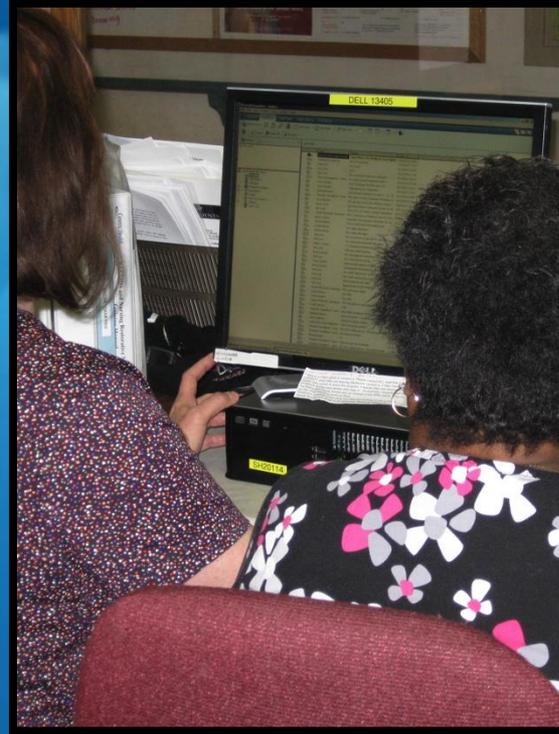


- **is resident-centered**
- **supports family members**
- **benefits residents living with and dying from progressive, chronic and life-limiting conditions**
- **is available at Bethammi Nursing Home and Hogarth Riverview Manor**





Palliative Care includes....



Doing Assessments
Information-sharing
Decision-making

Care Delivery
Care Planning
Confirmation

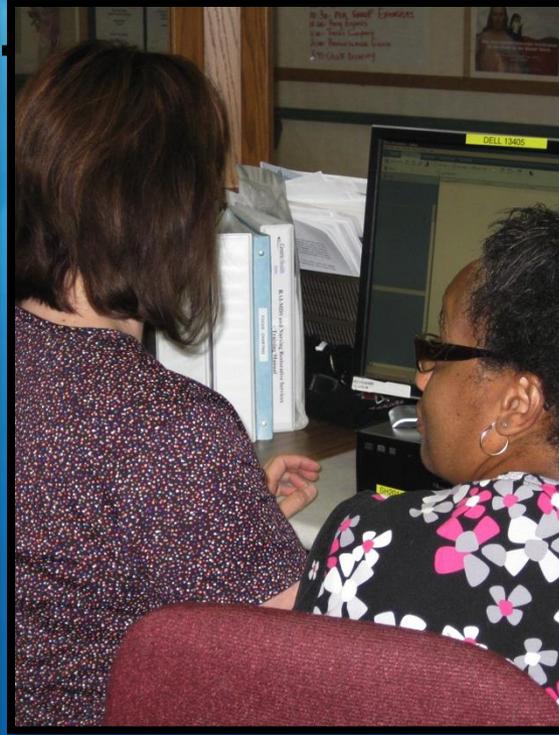


Some things that we are doing to support our residents, families, volunteers and staff include...



Palliative care education using simulation labs which allows staff to practice their skills outside the home

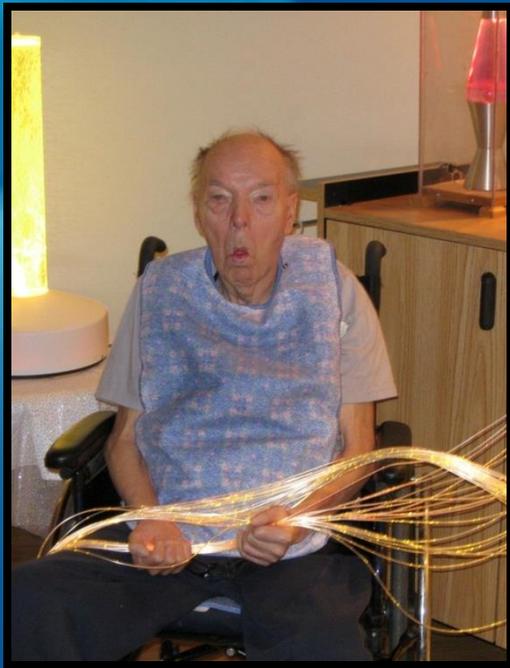
Updating our policies and



- To reflect that we offer palliative care
- To help guide our teams in the end-of-life care process



We offer social and therapeutic activities that benefit all of our residents, including those receiving palliative care, such



The Snoezelen Room



Music Programming



For more information about our palliative care programs



talk to the Palliative Care
Resource Team



Centre for Education
& Research on
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Lakehead
UNIVERSITY

First Nation Communities





<http://youtu.be/5S3-CmBaedk>

Summary

- Thinking about palliative care has changed from being specialty care that very few people needed and few health care professionals could provide.
- Now, palliative care is understood to be an important part of primary care and part of the role of all health care providers whether they work at the primary care or specialty care level.
- Developing localized capacity for palliative care can improve access, in particular in for marginalized populations like rural, First Nations and long term care home residents.

- Continued efforts are needed to build capacity in the primary care sector and in local communities/LTC homes.
- My research has demonstrated that primary care providers can very successfully delivery palliative care
- Collaborations, education and action are needed to support them in their efforts.
- Change process requires capacity development/PAR, systems thinking, whole system approach that begins at the organization or group level and expands to include individuals, group/teams and partners with regional networks, provincial and national groups for sustainability.

Citations

1. CANADIAN PALLIATIVE CARE
2. <http://www.ehospice.com/canadaenglish/Default/tabid/1997/ArticleId/708#.UhdxrX-N5ac>
3. Williams, A. M., Crooks, V. A., Whitfield, K., Kelley, M. L., Richards, J. L., DeMiglio, L., & Dykeman, S. (2010). Tracking the evolution of hospice palliative care in Canada: a comparative case study analysis of seven provinces. *BMC health services research*, 10(1), 147.
4. Shadd, J. (2012, June). What Shapes Family Physicians' Patterns of Care for Community Patients at End of Life? A Grounded Theory Study. In *JOURNAL OF PALLIATIVE CARE* (Vol. 28, No. 3, pp. 186-187).
5. Kelley, M. L. (2007). Developing rural communities' capacity for palliative care: a conceptual model. *Journal of palliative care*, 23(3), 143.
6. Way D, Jones L, Busing N. *Implementation strategies: "Collaboration in primary care – family doctors & nurse practitioners delivering shared care"*. Discussion paper. Toronto, ON): Ontario College of Family Physicians; (Online) 2000. Available: <http://www.eicp.ca/en/toolkit/hhr/ocfp-paper-handout.pdf> (Accessed 23 January 2012).

Rural Publications

- Kelley M.L., Williams A., DeMiglio L., & Mettam H. (2011). Developing rural palliative care: Validating a conceptual model. *Rural and Remote Health*, 11 (online), 2011: 1717.
- McIntosh, M. J., Mettam, H., Kelley, M. L., & Williams, A. (2012). Evaluating the knowledge utilization of a toolkit to enhance the capacity of rural communities to deliver palliative care. *The Journal of Rural and Community Development*, 7(4), 92-108.
- Kelley, M., DeMiglio, L., Williams, A., Eby, J., & McIntosh, M. (2012). Community capacity development in palliative care: An illustrative case study in rural Northwestern Ontario. *The Journal of Rural and Community Development*, 7(4), 76-91.
- Habjan, S., Pisco, L., & Kelley, M.L. (2011). Using education to develop capacity in rural health services. In Kulig, J.C. & Williams, A. (Eds.), *Rural Health: A Canadian Perspective*, University of British Columbia Press.
- Kelley, M.L., Williams, A., Sletmoen, W., & Puiras, T. (2011). Integrating research, practice, and policy in rural health: A case study of developing palliative care programs. In Kulig, J.C. & Williams, A. (Eds.), *Rural Health: A Canadian Perspective*, University of British Columbia Press.

Rural Pubs cont'd

- McKee, M., Kelley, M.L., Guirguis-Younger, M., MacLean, M., & Nadin, S. (2010). It takes a whole community: The contribution of rural hospice volunteers to whole person palliative care. *Journal of Palliative Care*, 26(2), 103-111.
- Williams, A.M., Crooks, V.A., Whitfield, K., Kelley, M.L., Richards, J.L., DeMiglio, L., & Dykeman, S. (2010). Tracking the evolution of hospice palliative care in Canada: A comparison of seven provinces. *BMC Health Services Research*, 10:147.
- Kelley, M.L. (2007). Developing rural communities' capacity for palliative care: A conceptual model. *Journal of Palliative Care*, 23(3), 143-153.
- McKee, M., Kelley, M.L., & Guirguis-Younger, M. (2007). So no one dies alone: A study of hospice volunteering with rural seniors. *Journal of Palliative Care*, 23(3), 163-172.
- MacLean, M. J., & Kelley, M. L. (2001). Palliative care in rural Canada. *Rural Social Work*, 6(3), 63-73.
- Gaudet, A. Kelley ML. Williams A. (2014 in press) "Understanding the distinct experience of rural interprofessional collaboration in developing palliative care programs. (2014 in press) *Journal of Rural and Remote Health*.

Long term Care Publications

- Kelley, M.L., McKee, M. (2013). Community capacity development in participatory action research. In Hockley, J., Froggatt, K., & Heimerl, K.(Eds.). *Participatory Research in Palliative Care: Actions and Reflections*, Oxford University Press.
- Kaasalainen S., Brazil K., & Kelley M.L. (2012). Building Capacity in Palliative Care for Personal Support Workers in Long Term Care through Experiential Learning. *International Journal of Older Persons Nursing*. Published online October 2012.
- Brazil, K., Brink, P., Kaasalainen S., & **Kelley, M.L.**, McAiney, C. (2012). Knowledge and perceived competence among nursing staff responsible for the care of the dying in long-term care homes. *International Journal of Palliative Nursing*. 2012 Feb;18 (2):77-83.
- Sims- Gould, J., Wiersma, E., **Kelley, M.L.**, MacLean, M., Habjan, S., Arseneau, L., & Kozak, J.F. (2010). Perspectives on end-of-life care in long-term care homes: Implications for whole person and palliative care. *Journal of Palliative Care*, 26(2), 122-129.
- Kortess-Miller, K., Habjan, S., **Kelley, M.L.**, & Fortier, M. (2007). Development of a palliative care education program in rural long-term care facilities. *Journal of Palliative Care*, 23(3), 154-162.

First Nations Publications

- Kelley, M.L. (2010). An Indigenous Issue: Why now? (guest editorial). *Journal of Palliative Care*, 26(1), 5.
-
- Prince, H., & Kelley, M.L. (2010). An integrative framework for conducting palliative care research with First Nations communities. *Journal of Palliative Care*, 26(1), 47-53.
- Habjan, S., Prince, H., & Kelley M.L. (2012). Caregiving for Elders in First Nations Communities: Social System Perspective on Barriers and Challenges. *Canadian Journal of Aging*, 31(2): 209-222.