The Evolution of the Kelley Community Capacity Development Model for Palliative Care

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Faculty/Presenter Disclosure

Presenter Name: Dr. Mary Lou Kelley

Relationships with commercial interests: None to Declare
What is a Model?

- Visual depiction
- Provides a simplified stand-in for a real-world system, and reality
- Important to understand the theory underlying the model
Theory of Change

- Explain or predict
- Guide policy and practice
- Can be adapted to the context and culture
  - Bottom up
  - Inside out
- Empowers and mobilizes people experiencing the need or problem to take action to make change
- Provides a systematic (not structured) process of change
Evolution

- Began in 2002 (15 years)
- Initially developed working in rural and remote communities
- Applied in long term care homes (nursing homes)
- Applied in First Nations communities
- Applied for developing Compassionate Communities
- Can continue to evolve with new contextual applications (eg. internationally)
Plenary Panel Messages

- We were doing it but not aware of it. We were not paying attention. Not language-ing it. (Dr. Denise Marshall)

- What do we notice? (Dr. Alex Jadad)
Model Development

Theoretical perspective: Community capacity development
CD embedded in Complexity & 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, incentives and motivation are the key variables
What is capacity? Capacity development?

- **Capacity** is the inherent capability of individuals, groups, organizations or communities, to perform or produce something of value, related to their desired development or performance. (motivation is a key)

- **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 (even by well intentioned committees).

- 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 (community engagement is inherent)

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
  - Endogenous change & adaptation (growth/change)
  - Capabilities (peoples’ knowledge, values & skills)
  - Endogenous management (internal leadership)
  - Internal features & resources of the system (readiness)
  - External interventions (stimulus, incentives, support)
  - External environment (resources, partnerships, policy)
  - Performance (service/outcome is emergent property)

(Adapted from Baser 2003; European Centre for Development Policy Management 2003)
The Model:
The Growing Tree
The overall research question guiding the early research was:

- What is the process of developing palliative care in rural communities from the perspective of health care providers?

- Aim of research was to improve quality and access to palliative care services in rural and remote communities.
Rural Community Capacity Development Model

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 Model 2010
Major themes:

- Having dedicated providers
- Getting the right people involved
- Strengthening the local PC resource team
- Engaging the whole community
- Sustaining palliative care program
Challenges: Growing the program

- Insufficient resources (funding, equipment, staff)
- Organization and bureaucracy in the current health care system (mandates, jurisdiction, policy etc.)
- Lack of understanding/resistance to palliative care by health care providers and general public
- Small # of deaths at the local community level
- Geography, isolation in some case
Keys to success…

- Clearly identified boundary, primary relationships amongst people, “insiders” (community, organization)

- Local people work together (teamwork)
  - strong relationships, communication, support

- People are very dedicated

- Physician involvement/support
Keys to success…

- Being community-focused (whole community approach) – not just health services
- Educating front line & primary care providers
- Strong leadership (local)
- Feeling pride in accomplishments
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 ..., 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 palliative care CD 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 (sometimes years!)

- **Imposed** external interventions are NOT a major factor
  - External enabling and facilitation is beneficial

- Education is a critical component

- Additional resources and policy are needed—but not until the last phase of Growing the Program
Outcomes

- Documented the dynamics of developing rural palliative care at the community level from the perspective of HCP

- Created a theoretical model that provides a theory of change to guide policy and practice for developing rural palliative care
Long Term Care Homes
LTC is a unique palliative care context

- Frail older people living with progressive life limiting disease
- A “home” where residents will both live and die.
- Heavily regulated and inspected (external standards)
- Primarily staffed by non-regulated health care providers; minimal physician involvement
- Not acknowledged and funded as a major location of death
- Not integrated with other palliative care services
Developing capacity in LTCH

Sequential phases of the capacity development model:

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

Process for Palliative Care Program Development:

- Sufficient infrastructure (services, staff, resources)
- Vision to improve care of dying residents
- Collaborative & interdisciplinary team approach to care
- Sense of empowerment to influence change

- Advocacy
- Clinical Care
- Education
- Building community relationships
- Building external linkages
Model adaptation

Sequential phases of the capacity development model:

1. Antecedent community conditions
2. Community Catalyst
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Process for Palliative Care Program Development:

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

Sufficient infrastructure (services, staff, resources)
Vision to improve care of dying residents
Sense of empowerment to influence change

Community empowerment
Sufficient health system infrastructure
Collaborative generalist practice
Building community relationships
Building external linkages

Advocacy
Clinical Care
Education
Outcomes

- Successfully implemented model in 4 LTC homes
- 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)
Palliative Care in First Nations Communities
<table>
<thead>
<tr>
<th>Zone</th>
<th>Definition</th>
<th>No. of Communities</th>
<th>Population Range</th>
<th>Total Population</th>
</tr>
</thead>
<tbody>
<tr>
<td>Zone 1</td>
<td>The First Nation is located within 50 km of the nearest service centre with year-round access.</td>
<td>32</td>
<td>52-12,757</td>
<td>43,783</td>
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<tr>
<td>Zone 2</td>
<td>The First Nation is located between 50 and 350 km for the nearest service centre with year-round access.</td>
<td>60</td>
<td>31-3259</td>
<td>24,428</td>
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<tr>
<td>Zone 3</td>
<td>The First Nation is located over 350 km from the nearest service centre with year-round access.</td>
<td>1</td>
<td>147</td>
<td>147</td>
</tr>
<tr>
<td>Zone 4</td>
<td>The First Nation has no year-round road access to a service centre, and, as a result, experiences a higher cost of transportation.</td>
<td>32</td>
<td>23-3197</td>
<td>28,348</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>125</td>
<td></td>
<td>96,706</td>
</tr>
</tbody>
</table>
Sequential phases of the capacity development model:

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

Advocating for Individual and Families
Promoting Education
Providing Care
Building External Linkages
Strengthening Community Relationships
Community Infrastructure
Collaboration
Health Services
Empowerment
Vision for change
Local Leadership
Individual, Family, Community and Culture

1) Grounding the Development in Community Values and Principles
2) Having Community Readiness
3) Experiencing a Catalyst
4) Creating the Palliative Care Program
5) Growing the Palliative Care Program

Community empowerment
Vision for change
Collaborative generalist practice
Sufficient health system infrastructure
Building external linkages
Building community relationships
Advocacy
Education
Clinical Care

Process of Palliative Care Development

Lakehead University
PROCESS OF PALLIATIVE CARE PROGRAM DEVELOPMENT

SEQUENTIAL PHASES OF THE CAPACITY DEVELOPMENT MODEL

5) Growing the Palliative Care Program

4) Creating the Palliative Care Program

3) Experiencing a Catalyst

2) Having Community Readiness

1) Grounding the Development in Community Values and Principles

Advocating for Individual and Families
Promoting Education
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Individual, Family, Community and Culture
Developing Palliative Care in First Nations Communities: Implementing 2-Eyed Seeing

CAPACITY DEVELOPMENT
Implementing 2-Eyed Seeing

Create partnerships & relationships between two systems
Engage in knowledge translation & exchange
Implement creative cross jurisdictional funding arrangements
Implement Jordan’s Principle

OUTCOME
Customized palliative care programs that build on local assets & strengths in First Nations Communities

Canadian Health Care System Capacity
- Health care services/organizations
- Specialized palliative home care teams/programs
- Skilled palliative care providers
- Pain & symptom management experts
- Specialized medication & equipment
- Palliative care training & education

First Nations Community Capacity
- Leadership & vision for change
- Local health care workers & services
- Elders & Traditional Knowledge Keepers
- Indigenous understandings of death/dying
- Traditional caregiving practices
- Natural helping networks
- Advocacy

Two-eyed Seeing Concept Created by Mi’kmaq Elder Albert Marshall.
DEVELOPING COMPASSIONATE COMMUNITIES:

A SOCIAL MODEL OF PALLIATIVE CARE
Dying is not fundamentally a medical event, rather it is a social event that happens in the family and community.
Community Capacity Development and Palliative Care

Advocating for Individual and Families
Promoting Education
Providing Care
Building External Linkages
Strengthening Community Relationships
Community Infrastructure
Empowerment
Collaboration
Health Services
Social Services
Individual, Family, Community and Culture
Natural Helping Networks
Vision for Change
Local Leadership
SEQUENTIAL PHASES OF THE COMMUNITY CAPACITY DEVELOPMENT MODEL

5) Embedding Palliative Care in the Community
4) Creating the Palliative Care Program
3) Experiencing a Catalyst
2) Having Community Readiness
1) Grounding the Development in Community Values and Principles
Compassionate Ottawa & Community Capacity Development

Championing the Social Model of Palliative Care

Promoting Education

Enhancing Palliative Care Supports

Building External Linkages

Strengthening Community Relationships

Empowerment

Vision for Change

Local Leadership

Natural Helping Networks

Individual, Family, Community and Culture

Community Infrastructure

Collaboration

Health Services

Social Services

SEQUENTIAL PHASES OF THE COMMUNITY CAPACITY DEVELOPMENT MODEL

5) Embedding Social Model of Palliative Care in the Community

4) Creating Compassionate Community Initiatives (Micro communities)

3) Experiencing a Catalyst for Change

2) Assessing Community Readiness

1) Grounding the Development in Community Values and Principles

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Implications of my Research
Key Principles

- Definition of Need and Solution (relevant to Context and Culture)
- Community Capacity Development – Highly localized not regionally generalized
- Process is sequential but not linear (evolutionary)
- Provides cultural Competence and Safety
- Local Control and Ownership
- Partnerships between communities and governments that fund service(s)/providers
- One size does not fit all (diversity of culture and context)
- Two-eyed Seeing (the best of both local/traditional and HCP Knowledge)
COMMUNITY PALLIATIVE CARE

Palliative Medicine
Health care professionals & institutions

Palliative Home Care
The person who is dying
The primary informal caregivers

Community & Life World
Family, neighbours, friends, workplace
Natural helping networks

Lakehead UNIVERSITY
Question

The new research question guiding the research

- What is the process of developing palliative care in the community from the perspective of community and family caregivers?

- Aim of research to improve degree and quality of community social support and access to appropriate palliative care services for people who are living and dying at home
Is an approach that improves the quality of life of patients, their families and communities facing the problems associated with life-threatening illness through empowering families and communities with skills and resources, strengthening social connectivity, and preventing and relieving suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

Kelley adaptation of WHO definition of palliative care
System Integration is an Outcome
A CHALLENGE TO SOCIAL WORKERS

Social Workers are well positioned to help develop a social model of care that builds upon the resources and networks already surrounding individuals.
Discussion
Contact Information

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