

Developing Quality Palliative Care in Long Term Care Homes Using Participatory Action Research.

Presented by:

Mary Lou Kelley, MSW, PhD
Lakehead University, Thunder Bay, ON

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Co-Investigators

Sharon Kaasalainen, RN, PhD.¹

Kevin Brazil, PhD.¹

Carrie, McAiney, PhD.¹

Paulina Chow ²

Pat Sevean, RN ³

Jo-Ann Vis, MSW, PhD.³

Elaine Wiersma, PhD.³

Joanie Sims-Gould, Post Doctoral Fellow ⁴

Sheldon Wolfson ⁵

Michel Bédard, PhD.³

¹McMaster University, Hamilton, ON; ²St. Joseph's Care Group, Thunder Bay, ON;
³Lakehead University, Thunder Bay, ON; ⁴University of British Columbia,
Vancouver, BC; ⁵Halton Municipal Region, Halton, ON

Research Issue

- ❑ 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



Research Issue

- Personal Support Workers (PSWs) provide 80% of direct care in LTC
- The role of PSWs in providing palliative care is undefined
- PSWs receive minimal training in providing end-of-life care
- Lack of formalized palliative care programs in LTC homes impacts communication, collaboration and inefficient use of existing resources.

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

Research Study Partnerships

Quality Palliative Care in Long-Term Care Alliance (QPC-LTC)

- ❑ Five year project

- ❑ 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

- ❑ Includes 36 organizational partners and 27 researchers nationally and internationally

Methodology

- ❑ **Comparative Case studies** in each of the LTC Homes
- ❑ **Participatory Action Research Methods:** Surveys, Interviews, Focus Groups, Participant Observations, Document Reviews



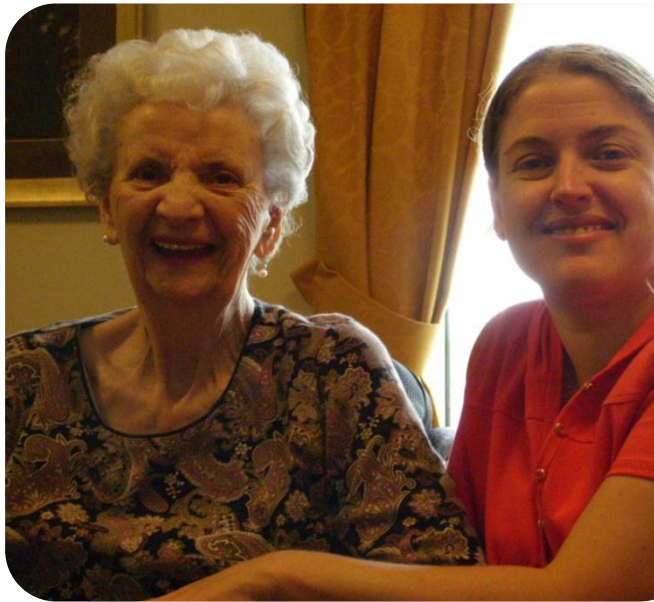
- ❑ **Sample Population:** Residents, Family members, Physicians, PSWs, RNs, RPNs, Support Services (ie Spiritual Care, Dietary, Housekeeping, Maintenance etc.), Administration, and Community Partners

Participatory Action Research in LTC

- Rooted in social action theory
- The goal is to *empower* people to be agents of change
- Researchers and LTC staff work in partnership, recognizing the *expertise and strengths* of the health professionals related to the research topic
- Researchers and LTC staff *co-create* knowledge that results in *structural transformation*



Survey Findings



Frommelt Attitude Toward Care of the Dying

What is the FATCOD Survey?

The *Frommelt Attitude Toward Care of the Dying (FATCOD) Scale* is a 30-item scale designed to measure participants' attitude toward providing care to dying people.



Frommelt Attitude Toward Care of the Dying

Maple overall average = 4.08 out of 5

Birch overall average = 4.07 out of 5

Elm overall average = 4.05 out of 5

Pine overall average = 4.06 out of 5

Quality in Action Scale Survey

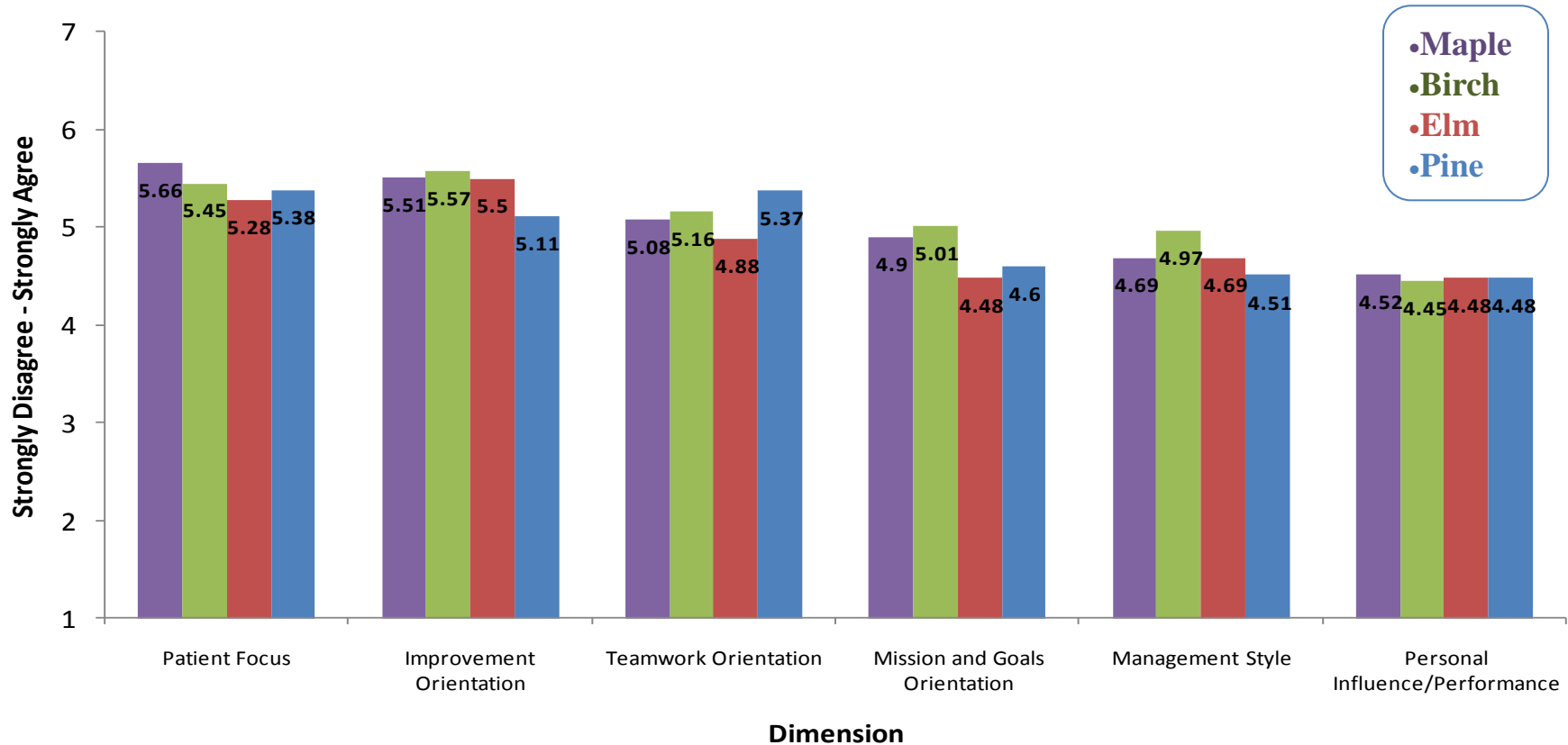
What is the QiAS survey?

The *Quality in Action Scale* (QiAS) survey was developed to measure the culture of healthcare institutions as it relates to quality. Six dimensions are measured (see chart)

<i>Dimension</i>	<i>Example</i>
<i>Patient Focus</i>	'Most people here think it is important to ask patients what they want.'
<i>Management Style</i>	'I can usually believe what I hear from management.'
<i>Teamwork Orientation</i>	'In this organization, people in different departments or programs try to help each other out.'
<i>Improvement Orientation</i>	'Trying to improve the way the work gets done is part of everyone's job.'
<i>Mission and Goals Orientation</i>	'Most people here know how their work contributes to this organization's mission.'
<i>Personal Influence/ Performance</i>	'In my work situation, I have little control over how things are done.'

Quality in Action Scale Survey Results

Average for each Dimension



Support Services included social work, spiritual care, life enrichment, volunteers and employees who designated themselves as "other".

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

What is the PEiW survey?

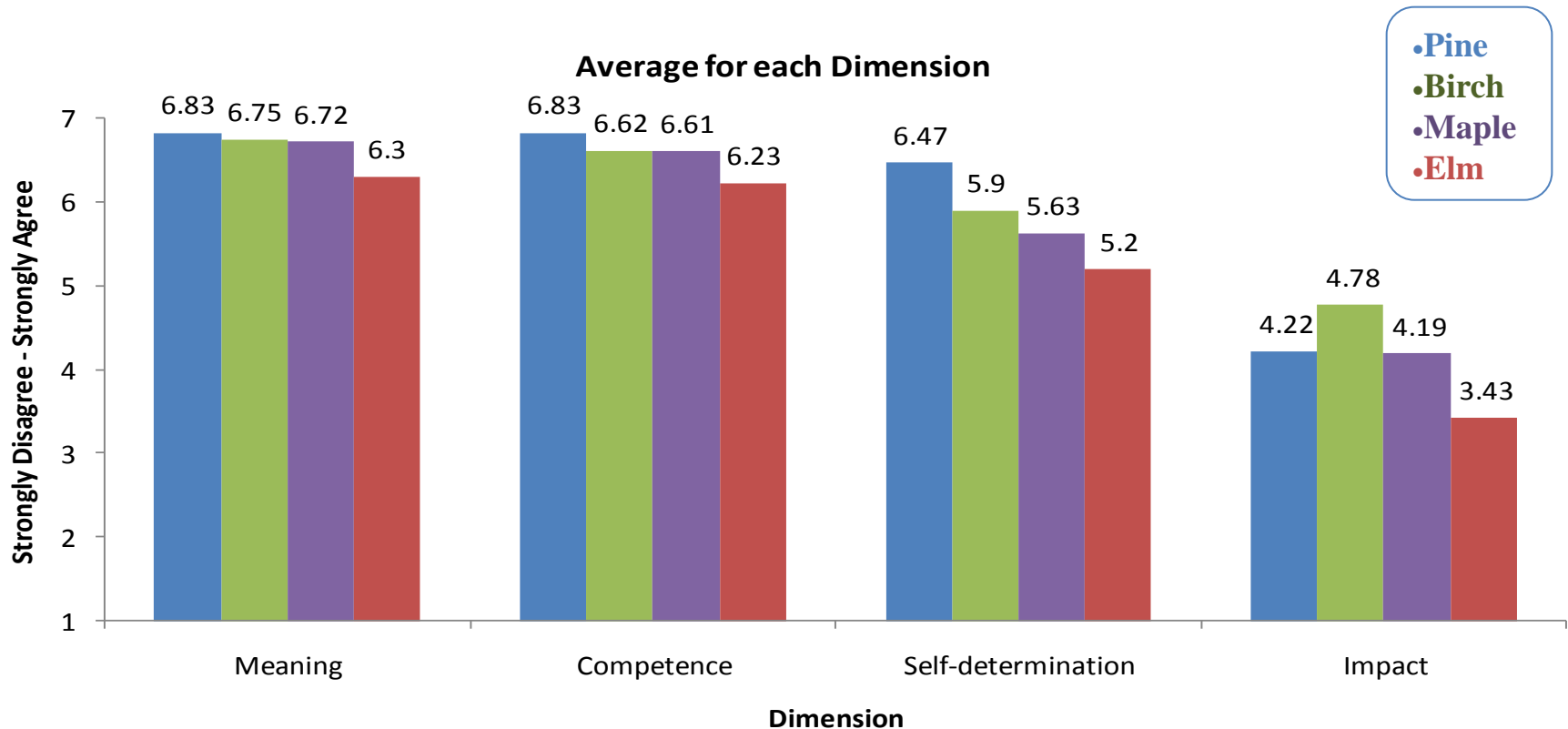
The *Psychological Empowerment in the Workplace* (PEiW) survey was developed to measure four dimensions of work life.

What is empowerment?

Empowerment is the state of feeling you have control of your own destiny. In the workplace, it includes the ability to think, behave, take action and control your work and decision-making in autonomous ways.

<i>Dimension</i>	<i>Example</i>
Meaning	'The work I do is meaningful to me.'
Competence	'I am self-assured about my capabilities to perform my activities.'
Self-determination	'I have considerable opportunity for independence and freedom in how I do my job.'
Impact	'My impact on what happens in my department is large.'

Psychological Empowerment in the Workplace Survey Results



- Pine
- Birch
- Maple
- Elm

Supervisory Support Scale

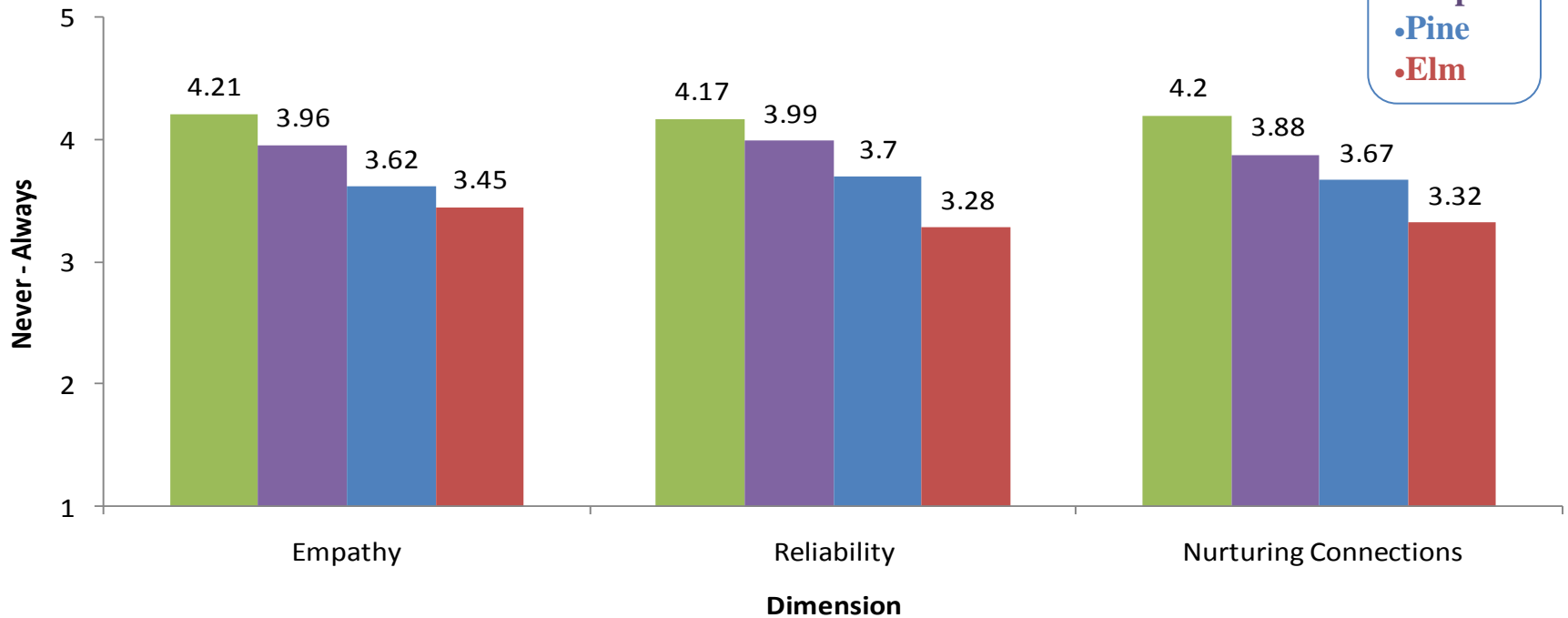
What is the Supervisory Support Survey?

The *Supervisory Support Survey* was developed to measure three dimensions of supervisory support within long-term care settings.

<i>Dimension</i>	<i>Example</i>
<i>Empathy</i>	'My supervisor tries to meet my needs.'
<i>Reliability</i>	'I can rely on my supervisor when things are not going well.'
<i>Nurturing Connections</i>	'My supervisor respects me as a person.'

Supervisory Support Scale Survey Results

Average for each Dimension



PSW Perceived Barriers to P/EOL 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?”

PSWs Provide Relationship-Centred Care

Valuing family-like bonds - “They’re like family, you know. Of course you’re sad. Like I say we’re rich with moms and dads.”

Knowing the resident - “Some times you can just see it, you sense it [they are dying]”

Providing emotional support –
“We’re always there to hold their hands.”



Conclusion

- Palliative care requires a team approach in order to meet the holistic needs of residents and their families.
- PSWs need to be supported by having access to education, having their role clearly defined in providing palliative care and having a voice within the organization
- PSWs are agents of change for improving the quality of life for people dying in LTC



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Thank you to our partners:



Contact Us

Visit our website:

www.palliativealliance.ca

Email us:

palliativealliance@lakeheadu.ca

Call us:

807-766-7228

Thank You 😊