

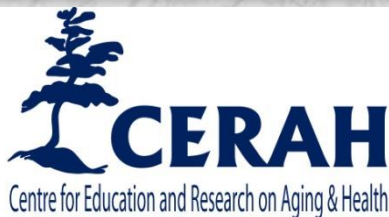
Developing Quality Palliative Care in Long Term Care Homes Using Participatory Action Research.

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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*

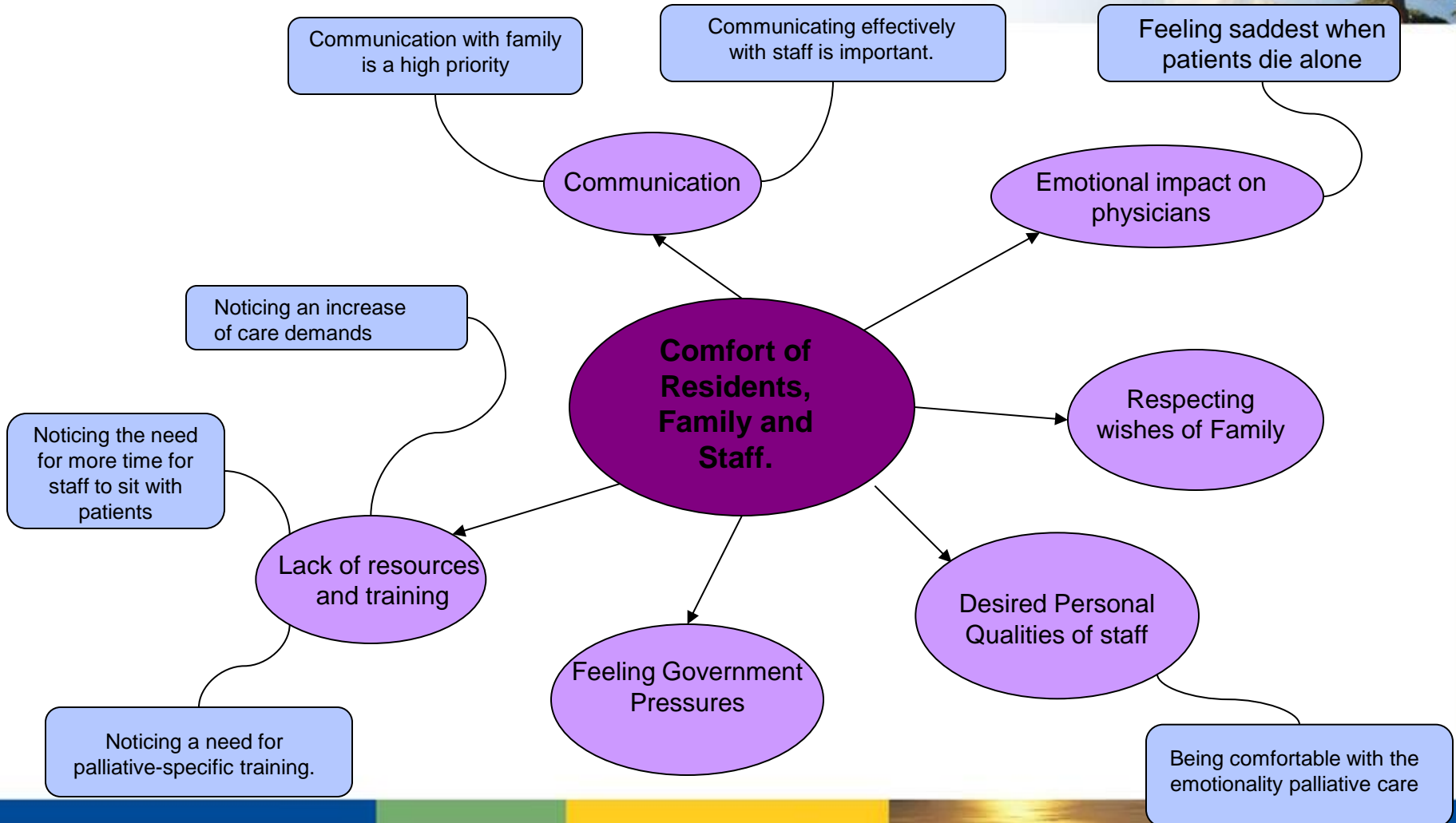




Physicians' Data

Physicians' Data

Physicians Fig. 1



Physician's Results

- Providing Comfort to Residents, Families and Staff
 - Comfort often referred to their role in addressing the physical symptoms of dying, however they acknowledged the importance of social and emotional supports for family and residents.
- Sub-Themes that Impact Resident, Family and Staff Comfort
 - Desired Personal Qualities of Staff, Respecting Family Wishes, Emotional Impact on Physicians, Communication, Lack of Resources and training.

Communication

- Communication between physician and family, and between physician and LTC home staff was a necessary element.
- It helped to foster good working relationships with staff and ensures families get the information they need.

“I make myself available so I would interview the family, relatives or whatever else and inform them as to where they are right now with their loved ones, and what I anticipate in terms of length of time that they will survive...so that they can inform family and bring people home.”

Respecting Family Wishes

- Family have a lot of power when it comes to decision making.
- Physicians listen to these wishes even at times when it might go against their own judgement.

“I’ve talked to the relatives and some of them want the patients sent to the hospital and they insist upon it and I don’t interrupt those choices and some of them ask ‘is there any point?’ and I explain what I feel.”

Desired Personal Qualities in Staff

- The quality of care given to residents and their families is very much dependent upon the personal qualities of staff.
- Staff need to be comfortable with the emotionality of death and dying in order to comfort families.

“It depends on who’s on that particular shift, if they are not comfortable, they won’t offer it... they won’t sit with the family or spend any quality time to discuss issues with the family and make sure that the family is in fact comfortable with you know the way that relatives are passing on.”

Lack of Resources and Training

- LTC homes are under resourced when it comes to adequate staffing levels, equipment and training opportunities.

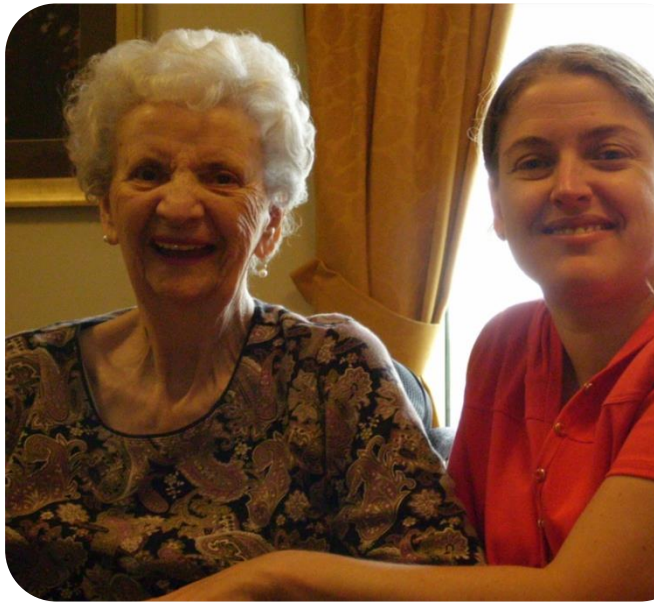
“Over the years, I’ve seen the work has become more demanding and heavy for the nurses and I’m told there is always a number of them who have back injuries and some of the people are quite heavy and they do, they work very hard, nurses and more staff would probably be best from what I see on the rounds.”

Feeling the Governmental Pressures

- Government has placed increasing demands on physician care. Paper work often gets in the way of what matters
- Some current policies conflict with good patient care, such as what medications are covered by drug plans.

The oxygen...is just to maintain a little bit of comfort so the patients are not gasping for that air hunger. To get that, you almost, you have to fill out all kinds of stupid, ridiculous forms. They're inconvenient...for the patient.

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.

Completed by staff in all departments and profession.



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?

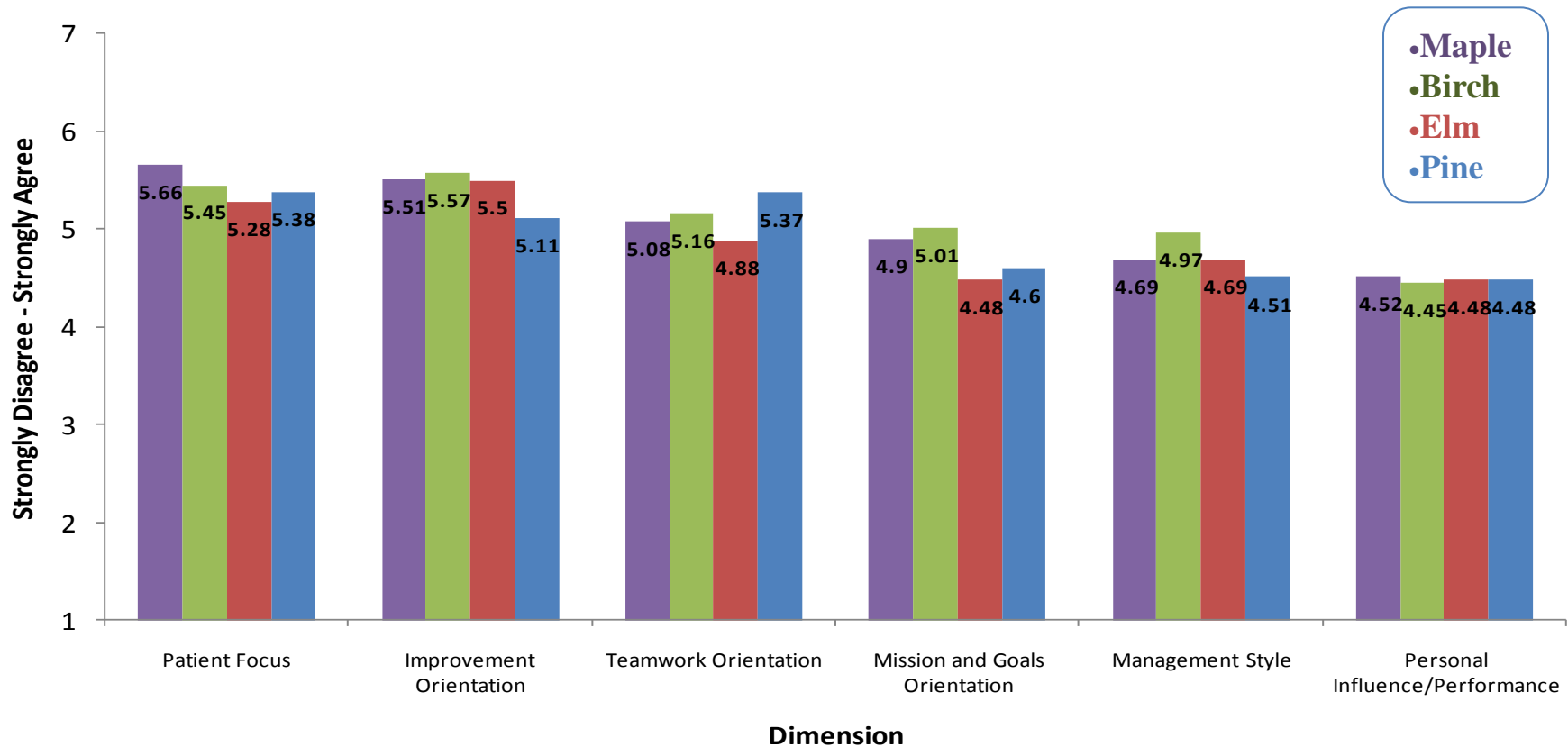
The *Quality in Action Scale* (QiAS) survey was developed to measure the culture of healthcare institutions as it relates to quality. Six dimensions are measured

Completed by staff in all departments and professions

<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



Personal Support Worker Data

Personal Support Worker Data

Psychological Empowerment in the Workplace

What is the PEiW survey?

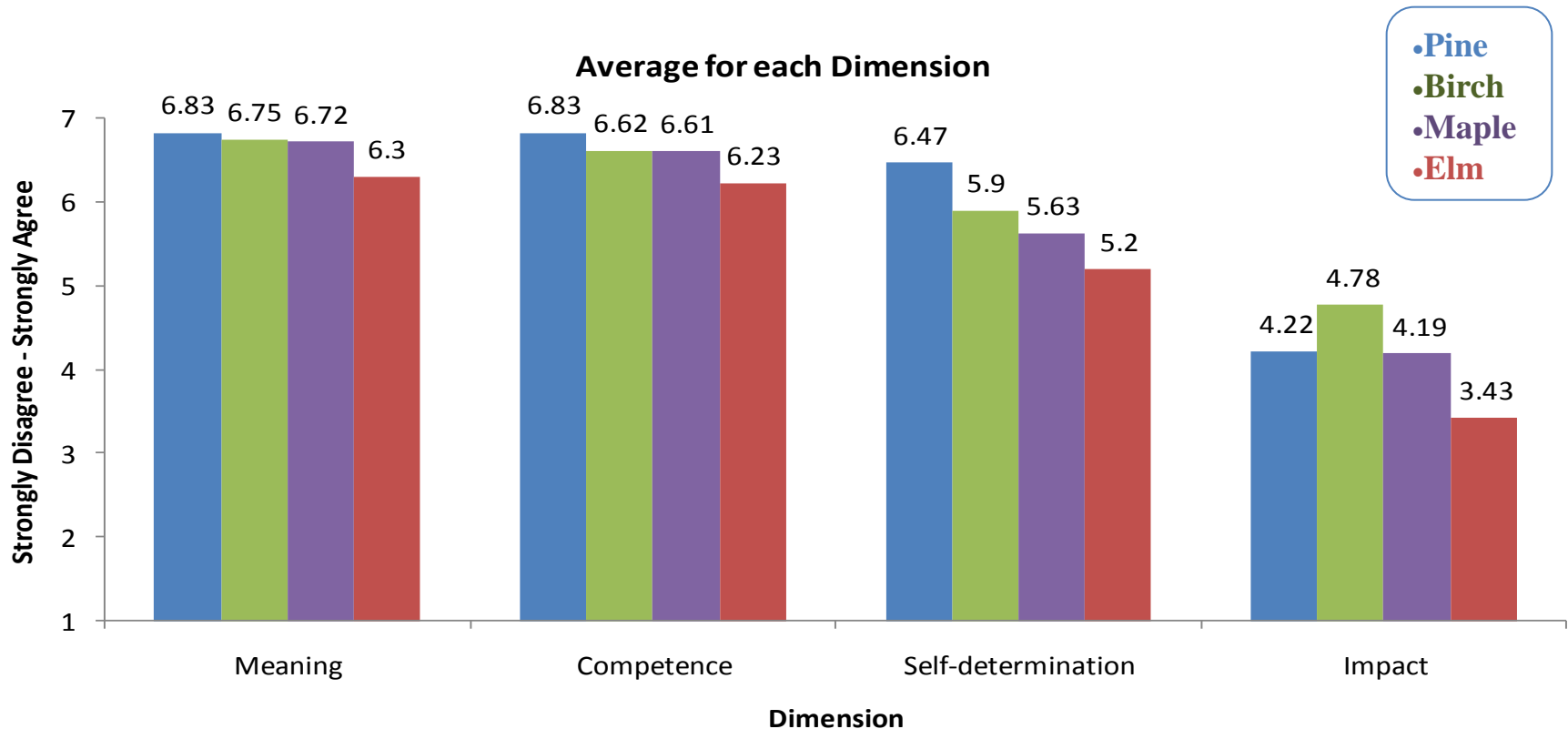
The *Psychological Empowerment in the Workplace* (PEiW) survey was developed to measure four dimensions of work life.

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



Supervisory Support Scale

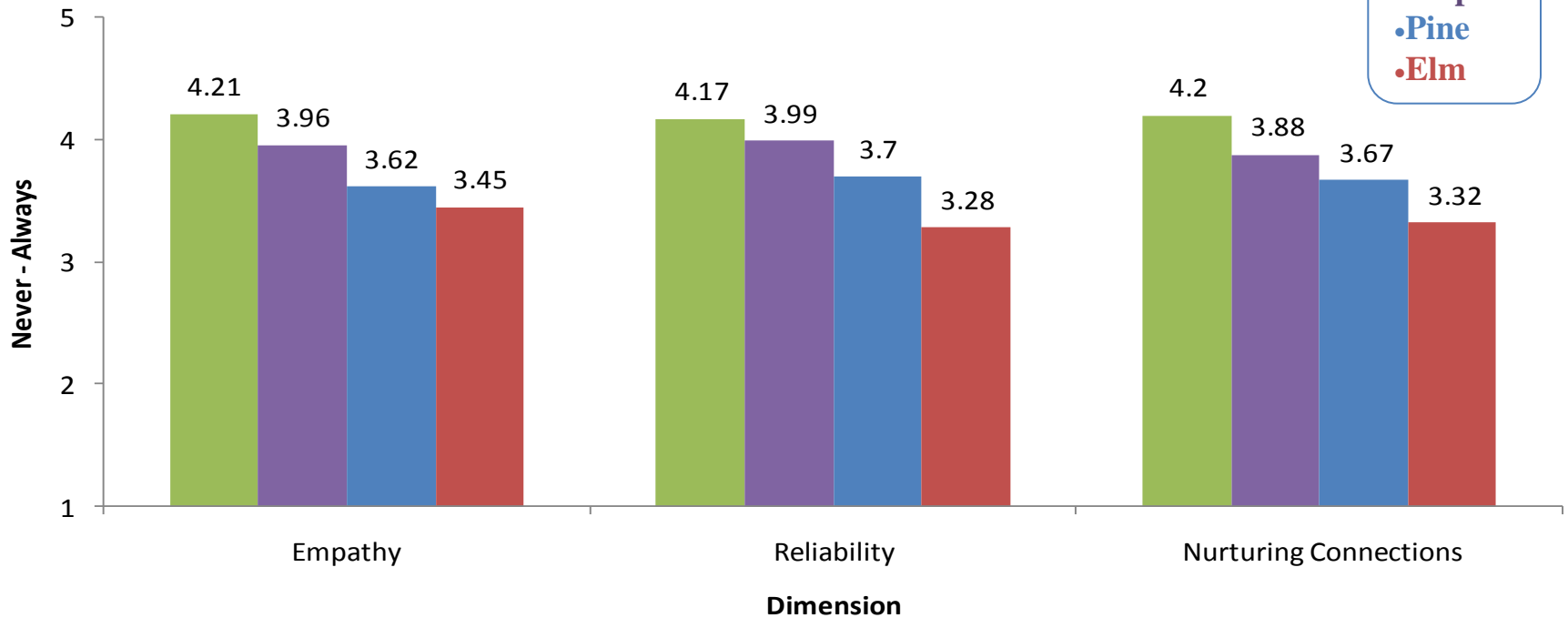
What is the Supervisory Support Survey?

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 is 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.

Communication can be improved and supported by an interprofessional approach that includes the physician.

Interprofessional care helps avoid duplication of work and is an efficient use of already stretched resources in LTC

Conclusion

PSWs have an intimate relationship with residents and families that can create a strong foundation for improved palliative care

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:



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Thank You 😊