

**Quality Palliative Care in Long Term Care**  
A Community-University Research Alliance

## Long-Term Care Homes: Hospices of the Future



Submission to the Long-Term Care Innovation Expert Panel

October 24<sup>th</sup>, 2011



## Section 1: Introduction and Project Background

### Introduction

Palliative care is a philosophy and a specialized set of care processes that encompasses the physical, emotional, social, psychological, spiritual and financial needs of residents of long term care facilities and their families. Therefore, Palliative Care aims to enhance quality of life at the end-of-life in order to provide a “good death” when death is inevitable.

While LTC homes have become a major location of death in Canada, most do not have formalized Palliative Care programs. Last year 50% of the residents who lived in one of the Ontario LTC homes participating in our research died. This was approximately four deaths per month for a home with 110 residents. This demonstrates that without a doubt LTC homes are in the “business of dying.” The majority of residents who die in LTC have Alzheimer’s disease or related dementias in conjunctions with several other chronic and terminal illnesses. The new LTC Act in Ontario has recognized this new reality by mandating the provision of palliative care education for all staff providing direct care to residents in LTC homes.

### Project Background

In 2009, the Social Sciences and Humanities Research Council funded the Quality Palliative Care in Long Term Care Alliance (QPC-LTC) for five years to address the need to develop formal palliative care programs in LTC homes. The Quality Palliative Care in Long-Term Care Alliance is comprised of 31 researchers and 43 organizational partners who actively contribute their expertise to the research project entitled, *Improving Quality of Life for People Dying in Long-Term Care Homes* (see Appendix A for list of Alliance members). The Alliance’s primary goal is to develop sustainable, person-focused palliative care programs consistent with the Canadian Hospice Palliative Care Association’s Square of Care using a capacity development process. For further information please see the project website [www.palliativealliance.ca](http://www.palliativealliance.ca)

The Principal Investigator is Dr. Mary Lou Kelley from Lakehead University Thunder Bay Ontario. The research is conducted with four key partners; Lakehead University, McMaster University, the Municipality of Halton and St. Joseph’s Care Group in Thunder Bay. The QPC-LTC Alliance partners are municipal, provincial and national organizations that represent individuals, families, caregivers, health care providers, educators and other stakeholders. There are four long-term care (LTC) homes in Ontario that are study sites for the project: Bethammi Nursing Home and Hogarth Riverview Manor in Thunder Bay, and Allendale Village in Milton and Creek Way Village in Burlington.

The primary goal of the research is to improve the quality of life of people dying in LTC homes by developing palliative care programs which integrate the Canadian Hospice Palliative Care Model of Care (see Appendix B). The specific project objectives are:

1. to empower PSWs to maximize their role in caring for people who are dying and their families and support them to be catalysts for organizational changes in developing palliative care
2. to implement and evaluate a 4-phase process model of community capacity development in four LTC sites, and create an evidence-based tool kit of strategies and interventions to support this development.
3. to create sustainable organizational changes that will improve capacity to deliver palliative care programs through empowering PSWs, developing palliative care teams and programs within LTC homes and strengthening linkages with the community partners.
4. to develop knowledge and skills in palliative care and participatory action research

The QPC-LTC methodology is **participatory action research** (PAR), which has two unique features.

- *Participatory* means that those people and organizations that will benefit from the research also fully participate and guide the research
- *Action* means that the goal of the research is to create social change.

Over the past two and half years, the study has explored issues that serve as barriers to implementing palliative care in LTC homes, and is now assisting facilities in creating environments and specialized services for their residents. Together, researchers, organizational partners and LTC home staff have assessed the needs, implemented interventions and evaluated the results. This is an ongoing process for the next two years. The outcome is development of an evidence based "toolkit" of interventions which can be used by other LTC homes to develop their own palliative care programs. Consequently, this project has benefit to residents, families and LTC homes nationally and internationally. The research also contributes to existing theory on organizational capacity development in a LTC home by implementing by implementing and evaluating a community capacity model to guide the organizational change process. This model outlines a four phase non-linear process for developing palliative care in LTC from the ground up (see Appendix C).

The report *Elements of an Effective Innovation Strategy for Long Term Care in Ontario* (Conference Board of Canada, 2011) recognized LTC homes potential to become centres for excellence in providing P/EOL care. The report states:

*"LTC providers could also take a great leadership role in providing palliative, pain management, and end-of-life care to residents and others who wish to receive the services of LTC homes. Based on LTC experience and expertise in aging and dying, the homes are well-positioned to become centres of excellence in palliative and end-of-life care."*

The findings of our research indicate that, although LTC homes do have expertise in aging and dying, there are large gaps and barriers in resources that hinder their ability to take on the role of becoming centres of excellence in palliative and end-of-life care. In order for these homes to provide optimum palliative care there is a need for *internal innovation, innovation in the sector, and innovation for systemic integration and transformation*. The following section of this report provides recommendations for consideration by the expert panel based on our research finding and experience of the QPC-LTC project over the last few years.



## Section #2: Overview of Recommendations for Creating Palliative Care Programs in LTC Homes & Related Sector and System Transformation

This section of the report provides an overview of our recommendations organized using the framework provided within the document *Elements of an Effective Innovation Strategy for Long-Term Care in Ontario*. Our recommendations are organized by system level, namely, internal, sector wide, or system. Within each system level we address the challenges described below:

- **Human resources:** The ratio of persons aged 20-64 (i.e. the working population) to the number of people aged 85 or older (i.e. those most likely to need LTC) is diminishing- in 2009 the ratio was 19 to 1; in 2035 the ratio will be 10 to 1. This will make it difficult to identify and recruit future LTC staff.
- **Technology:** Regulatory and financial barriers limit the rate at which the sector adopts technologies that can help provide high quality, efficiently-delivered, and cost-effective care.
- **Funding:** LTC providers lack sufficient resources in light of current and future demand, acuity levels, and resident preferences
- **Regulations:** The LTC sector is highly regulated making it difficult for LTC providers to innovate to deliver high-quality, cost-effective care.

The following table summarizes our recommendations by system level and issue.

	Internal Innovation	Sector-Wide Innovation	Innovation for Integration and Health System Transformation
<b>Human Resources</b>	<ul style="list-style-type: none"> <li>→Recognize and respect PSWs as valuable members of the interprofessional team</li> <li>→Enhance Palliative Care education using innovative methods such as simulation lab training, hospice visits, mentoring and specialized Palliative Care for Front Line Workers curriculum</li> <li>→ Build external linkages with key community groups such palliative pain and symptom consultants, Alzheimer's society, hospice volunteers in order to supplement human resources</li> </ul>	<ul style="list-style-type: none"> <li>→Increase education regarding palliative and end of life care in regulated college/ university programs that prepare people to work in LTC</li> <li>→Make grief support programs for staff of LTC home mandatory components of workplace wellness programs</li> <li>→Provide financial support or paid time for LTC home staff to participate in continuing education in P/EOL Care</li> <li>→Reward LTC staff who develop expertise in P/EOL Care</li> <li>→ Target health care providers who are motivated to provide palliative care to work in LTC homes</li> </ul>	<ul style="list-style-type: none"> <li>→ Link Hospice Units with LTC homes to enhance P/EOL Care and provide consultation and education for staff</li> <li>→ Reduce professional hierarchies in LTC homes and promote interprofessional collaboration and team work between PSW, registered staff, and medical directors</li> <li>→Promote the use of nurse led outreach teams to support EOL Care and facilitate smooth transitions if hospitalization is required</li> <li>→Provide dedicated pain and symptom management consultants for LTC homes</li> </ul>
<b>Technology</b>	<ul style="list-style-type: none"> <li>→Provide LTC homes with access to high fidelity simulation labs for training in P/EOLC</li> </ul>	<ul style="list-style-type: none"> <li>→Use the computer based assessment tool MDS-RAI to assist in identifying residents who could benefit by Palliative or EOL care</li> <li>→Provide/promote use of Ontario Telemedicine Network (OTN) within LTC Homes</li> </ul>	
<b>Funding</b>		<ul style="list-style-type: none"> <li>→Enhance funding to provide psychosocial / spiritual care in LTC</li> <li>→ Increase funding for resident care when resident is expected to die within 6 months (J5 in RAI-MDS)</li> <li>→Fund LTC homes to build capacity in P/EOL care with 5 year development grants</li> </ul>	<ul style="list-style-type: none"> <li>→ Fund a provincial marketing strategy that promotes LTC as place where quality P/EOL Care can be provided</li> <li>→ Fund an additional LTC Centre for Learning, Research, and Innovation dedicated to palliative and EOL care</li> </ul>
<b>Regulation</b>	<ul style="list-style-type: none"> <li>→Require all LTC homes to have formalized Palliative care programs with policies/procedures/protocols</li> <li>→ Require advance care planning beyond medical directives that includes social, spiritual and cultural preferences for EOL care</li> </ul>	<ul style="list-style-type: none"> <li>→ Encourage a more holistic model of care by adopting the CHPCA models of palliative care</li> <li>→Increase recognition of the importance of Palliative and EOL care within the LTC Act</li> </ul>	<ul style="list-style-type: none"> <li>→Include P/EOL care in Accreditation process to provide incentives for LTC homes to develop, formalize and market their programs</li> <li>→ End-of-Life Care Networks should create LTC working groups where best practices, policies, and resources can be shared</li> </ul>

An elaboration of each of these recommendations can be found in the sections below.

## Section #3: Human Resources Recommendations

Our data indicate that LTC home staff lacks knowledge skills, and confidence in providing P/EOL care. While PSWs are highly motivated to provide care at the EOL they identified the need for more education, and assistance from volunteers and consultants, better communication and team work. PSWs expressed the feeling that their important contribution to P/EOL care was not recognized. In response to these issues we have work: to promote empowerment of PSWs and their role in the interprofessional care team, to promote education for all staff on palliative and end-of-life care, to build external linkages to enhance the human resources that are existing, and to provide grief support for staff.

### Recognition of PSWs as Valuable Members of the Team

One of the main priorities of the Alliance has been to empower PSWs as they provide the majority of the direct care for residents and their families. This makes them a very important member of the palliative care team. The data collected within this project indicated that PSWs did not feel that they had a strong voice to influence change within the organization. The professional hierarchy within LTC creates difficulties with communication and teamwork between PSWs, registered staff and physicians. The project has been working with PSWs to establish a voice within the organizational culture by including them in management meetings; involving palliative care and helping them create their own palliative care competencies.

### Simulation Lab

PSWs identified the need to improve their skill and comfort communicating with residents and families about EOL issues. To address this need, an educational intervention was developed using a high fidelity simulation lab. A simulation lab uses high fidelity manikins (with laptops, software, and compressors) to provide a realistic experience of being at a resident's bedside. The resident (manikin) can communicate and has fully functioning blood pressure, pulse point, respiratory and cardiac sounds, as well as a chest that rises and falls with breathing. A case study was designed for use in the simulation lab so PSWs could further develop their skills talking to residents and families about palliative care / end-of-life care in a controlled and safe environment. The simulation experience and the debriefing session at the end of the simulation gave PSWs the opportunity to learn from each other. This intervention proved effective based on a pre and post survey as well as a post interviews. See Appendix G for more detail



*Simulation Manikin*

### Hospice/Palliative Care Unit Visits

Most staff in LTC had never visited a hospice unit and did not understand how the culture of hospice palliative care differed from LTC. To create this understanding, nursing staff from LTC homes visited specialized hospice units for a two day "placement." During the two day period the LTC staff worked alongside the hospice staff. The objectives of the hospice visits were for LTC staff to:

- develop an understanding of the philosophy of palliative and end-of-life care from a hospice perspective
- Identify how palliative care looks different in a LTC setting compared to a hospice setting
- Determine what tools / techniques and/or ideas that might be applicable to LTC.

During the LTC staff's visit they worked in pairs with a hospice staff member. This was an important exercise for LTC staff to experience the hospice culture and to see how working as a team is integral to achieving the goals of care of their residents.



*Carpenter Hospice, Burlington Ontario*

### **Palliative Care for Front Line Workers Curriculum**

LTC staff lacked basic education on P/EOL. Existing curriculum was designed for registered staff and did not meet the needs of PSWs. Palliative Care for Front Line Workers was created by the Centre for Education and Research on Aging & Health (CERAH) at Lakehead University specifically to educate non-registered LTC staff about palliative care. The curriculum contains 10 modules that can be delivered in 6 sessions that are two and a half hours in length or over one weekend. The modules include the following topics:

- Module #1: Dying in Canada
- Module #2: Envisioning a Good Death
- Module #3: Physiology of Dying
- Module #4: Pain
- Module #5: Working with Families
- Module #6: Advance Care Planning
- Module #7: Culture
- Module #8: Grief and Bereavement
- Module #9: Helping Relationships and Self Care
- Module #10: Team Building

This curriculum was offered to PSWs, recreation staff, dietary, and volunteers and was delivered onsite in the LTC homes by PC specialists. Pre and post evaluation demonstrated improvement in participant's knowledge.



*PSWs from Bethammi Nursing Home*

### **Staff Mentoring**

The data showed that experienced PSWs mentor inexperienced PSWs who are beginning to work with dying residents. Mentorship and teamwork within the PSW group is an extremely valuable resource that can be reinforced and supported. New staff reported the benefit of working with others knowledgeable about the EOL process in order to build their own comfort.

### **Building External Linkages**

All staff reported a lack of human resources and a shortage of time to provide enhanced care at the EOL. Building linkages with community organizations is one way to supplement LTC staff as well as a method of bringing time and specialized knowledge or skills into the homes. Many community organizations have a mandate to provide services in LTC, but the homes do not always engage these services. In our project, some key organizations that proved beneficial for LTC homes include:

- Pain and Symptom Management Consultants
- Alzheimer Societies
- Multicultural and Multifaith groups
- Hospices / Hospice Volunteer Groups

### **Increase Palliative and EOL care education within college programs for PSWs**

Many PSWs indicated to the Alliance that they felt unprepared to provide P/EOL care after basic education. They stated they had little to no P/EOL content within the curriculum and limited opportunities for continuing education once in the workforce. The staff commonly said they learned to provide PC through on-the-job experience caring for the dying. The Alliance is working towards identifying educational competencies for PSWs providing PC. We are also advocating for these competencies to be included in PSW curriculum in the Ontario colleges.

### **Grief Support for Staff**

One PSW participating in the project stated: “it’s hard to watch people die for a living.” This is a common feeling among the staff. Staff members become very attached to the residents and consequently carry a heavy burden of grief when residents die. Currently, providing grief support to staff as a routine part of staff health and wellness programs does not commonly occur. This lack of recognition of the emotional impact of grief and bereavement for staff can contribute in staff burnout and increased sick time. Social Work graduate students conducted eight individual staff interviews and prepared a report highlighting workplace wellness strategies to address grief and loss in LTC. The goal is to develop organization policies that normalize the staff’s experience with grief and formalized programs available to all LTC staff.

### **Provide Support and Rewards for Continuing Education**

Staff expressed a desire for LTC homes to support them financially to participate in continuing education in PC. Once the education is received it is important that it be recognized in the home and used as a resource.

### **Target Health Care Providers who are Motivated to Provide Palliative Care to Work in LTC homes**

LTC homes have historically not been an attractive place for health care professionals to practice for various reasons. Into the future, it will be important for LTC homes to market themselves as an attractive place to work for health care professionals. Students in the health professions are increasingly interested in providing PC and EOL care. These students could be encouraged to consider employment in LTC.

### **Link Hospice Units with LTC homes**

Local Hospice Units can provide significant assistance for LTC homes when providing P/EOL Care. Some hospices have 24-hour consultations for people living in the community and LTC home staff may access. Hospices may also help LTC staff find written resources (e.g. books, brochures, directories) or community experts to assist families and residents struggling during EOL. Hospice unit staff could also provide education to LTC staff.

### **Reduce Professional Hierarchies in LTC homes**

A culture within LTC homes that is based on professional hierarchies is detrimental to developing P/EOL programs requiring teamwork. Professional hierarchies impede communication if PSWs who know residents and families the best are unable to participate in care planning or communicate directly with physicians and nurse practitioners. The development of a PC team where each professions role and scope of practice is respected and complimentary facilitates communication and provides a structure for collaborative care planning. The team should have member representation from all departments.

### **Promote the Use of Nurse Led Outreach Teams**

Nurse Led Outreach Teams can be a significant resource to LTC homes. They provide assistance to staff when residents are transitioning towards P/EOL goals of care and support staff to provide EOL care. They help prevent unnecessary transfers to hospital at EOL. If the resident is transferred to hospital, the Nursed Led Outreach team can ensure smooth transitions during this period by sharing information with both the hospital and the LTC home.

### **Provide Dedicated Pain and Symptom Management Consultants**

Pain management is an important component of P/EOL care and was outlined in the new LTC Act as one of the four mandatory programs that LTC homes must provide. Currently LTC homes have access to Pain and Symptom Management Consultants however these consultants are responsible for large geographical areas and several organizations. Providing LTC homes with dedicated Pain and Symptom Management Consultants would enhance LTC staff education and better manage resident pain.



## Section #4: Technology

### High Fidelity Simulation

High Fidelity Simulation is an educational technology that has demonstrated its effectiveness for PC education in LTC. Simulation Labs are not available in LTC homes and accessing them in universities, colleges, and hospitals is difficult. The Alliance recommends that LTC homes have increased access to High Fidelity Simulation Labs.

### Use MDS-RAI 2.0 to Identify Residents Needing PC or EOL Care

The MDS-RAI is now mandated for use in all LTC homes in Ontario. The MDS-RAI is a unique tool that could be used for earlier identification of residents who would benefit from a P/EOL care plan. Research shows that earlier identification of residents improves satisfaction and quality of life for residents and families. There has been work done in Canada, Europe and the USA to identify indicators within the RAI tool that should trigger a Palliative Care or EOL care plan. Using RAI data provides homes a systematic way of determining residents eligibility for their programs. The Alliance has seen anecdotally throughout this project that this box is rarely checked off because there is confusion around whether a doctor's order is required or if a team decision is sufficient. Also there is a fear of repercussion by staff if the resident does not die within the 6 months.

### Ontario Telemedicine Network

All LTC homes should have access to OTN. This technology helps build capacity amongst the LTC homes as they are better able to share innovations across geographic boundaries and have more access to education.



## Section #5: Funding

### Enhance Psychosocial and Spiritual Funding

Palliative Care and EOL Care should be holistic as required by the CHPCAs models (Appendix B). Currently the funds that are allocated to LTC are dedicated. The majority of funds (around 90%) are allocated to personal nursing care and the rest of the funds are divided into pockets to funding including program and support services, raw food, other accommodations. This leaves very little funding for the psychosocial and spiritual domains of PC. Thus, LTC homes generally have to choose whether they will provide a Spiritual Care Associate or a Social Worker as most cannot afford both.

### Increase Funding for Providing EOL Care

Currently, the MDS-RAI 2.0 includes an indicator for EOL care. J5 asks staff to indicate whether the resident is “end-stage disease; 6 months or less to live.” This indicator is not currently attached to funding. Providing quality EOL care in LTC requires enhanced human resources and we recommend that it be attached to enhanced funding.

### Fund LTC Homes to Build Internal Capacity

The QPC-LTC research has identified the need for enhanced resources to support LTC homes in developing PC programs. Funding is required to provide LTC home staff with time for education, to have regular palliative care meetings, and to undertake quality improvement initiatives relating to implementing P/EOL team/care. Through the QPC-LTC research the LTC homes have received additional funding which has proven essential to the success of our work. We recommend that five year capacity building grants be provided to LTC homes that are committed to developing their PC programs.

### Fund a Provincial LTC Marketing Campaign

Data indicated that residents and families do not understand that PC can provided in LTC homes. When this is clearly communicated, most families express a preference to have the resident remain in their LTC home until the EOL. In order for the LTC sector to transition itself to be a place that is known to provide residents with quality P/EOL care LTC homes need to market themselves in this way. If LTC homes could market P/EOL care as an essential part of quality resident centred care there would be many benefits to staff, families, residents, and the health care system. These benefits could include more people choosing to die in LTC homes, more communication about P/EOL care, and more opportunity for advance care planning.

### Fund a Centre for Learning, Research, and Innovation dedicated to palliative and EOL care

The Ontario Ministry of Health recently three Centres for Learning, Research, and Innovation. It is recommended that a fourth centre be funded with a focus on P/EOL care.

## Section #6: Regulations

### Formalize Palliative Care Programs

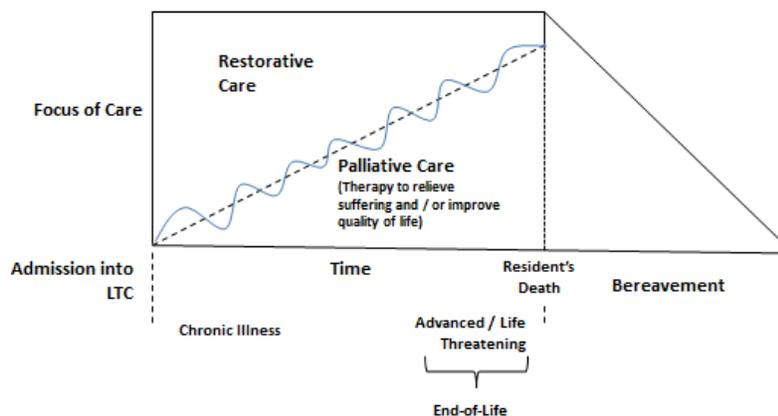
There is no formal palliative care program description or policies and procedures directly related to palliative care in the LTC homes within this project. In order to undertake this task, a Palliative Care Team was created. The Palliative care team members came together for a one day retreat to discuss the mission, values, and responsibilities of the team. The retreat was organized using a knowledge café style. Small groups worked through different stations to give input into what would eventually become their palliative care program description. The new LTC Act was also considered during the creation of this program description. The new Palliative Care program description is currently being launched in the LTC homes.

### Require Advance Care Planning for all Domains of Care

Currently Advance Care Planning is limited in most LTC homes to the medical directives. It is important that LTC homes move beyond solely discussing medical directives and begin to incorporate discussion around social, spiritual, and psychological care needs of the resident and family. This will help residents and families to better understand the scope of care that LTC homes may provide at EOL life and it will also allow staff to learn more about EOL care goals of the resident and family in a more systematic way.

### Adopting CHPCA models of PC

Our research indicates that the current culture within LTC is dominated by the medical model with a focus on restorative care. The Canadian Hospice Palliative Care Association (CHPCA) provides models that any organization can use to guide them in providing palliative care concurrently with restorative care. The CHPCA model was slightly adapted by the Alliance to better reflect the fluctuating care needs of residents in LTC.



This model demonstrates that providing care to residents within LTC homes is both restorative and palliative in nature. A common misconception is that when someone is benefiting from palliative care they no longer benefit from restorative care. However, a more appropriate model for providing care within LTC homes is to have both restorative and palliative goals of care and have the focus of care change depending on the illness trajectory.

CHPCA also has another model called the Square of Care and Organization. This model outlines the common issues faced by residents and families, the process to providing palliative care, and the different organizational functions and

resources that are require to provide a formalized palliative care program. Please see Appendix B to view the CHPCA square of care and organization model. Both of these CHPCA models can be used by LTC homes to guide the development of their palliative care programs.

### **Increased Acknowledgment of Palliative Care and EOL Care in the LTC ACT**

The LTC Act 2007, stipulates for the first time that LTC homes must provide EOL care and provide palliative care training for staff providing direct care. In the future the Alliance hopes to see palliative care become a mandatory program for LTC homes that is reflective of the CHPCA holistic philosophy.

### **Palliative Care Accreditation for LTC**

Currently, LTC accreditation standards do not include P/EOL care. Having an accreditation with special recognition for palliative care programs would provide an incentive for LTC homes to formalize their programs. It would also assist with marketing LTC homes as locations where excellent palliative care can be received.

## Section #7: Conclusion

The role of LTC in the health care system has changed drastically in the last 20 years. LTC homes are now a major location of death in Ontario and trends suggest that their role in providing EOL care will increase into the future. The LTC homes participating in our research embrace their new EOL care role, viewing it as part of the continuum of resident centred care they provide. Our project has demonstrated many successful innovations some of which can be found in the project research posters in the Appendices. At the same time, our project has identified challenges and barriers for LTC homes to implement formalized palliative care programs. Formalized PC programs have been shown to increase resident satisfaction and quality of life in other settings where people die. In an effort to advance the provision of P/EOL care in LTC, we have provided a series of recommendations. We have also compiled some supplemental resources including relevant research and projects from around the world. We would welcome the opportunity to discuss these recommendations or any other issues relevant to implementing formalized palliative care programs in LTC homes.



## Appendix A: Alliance Members

### Co-Investigators

	Title	Title/Organization
1.	Kelley, Mary Lou	Professor, School of Social Work, Centre for Education and Research on Aging and Health, Lakehead University, Thunder Bay, ON
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11.	Wiersma, Elaine	Lakehead University Thunder Bay, ON

### Collaborators

	Representative	Organization
1.	Allard, Pierre	Institute of Palliative Care, University of Ottawa, Ottawa, ON
2.	Brajtman, Susan	School of Nursing, University of Ottawa, Ottawa, ON
3.	Stephanie Flynn – PSW coordinator	Conestoga College of Applied Arts and Technology, School of Health, Life Sciences, and Community Services, Enhanced Seniors Care
4.	Kortes-Miller, Kathy	Centre for Education and Research on Aging and Health, Lakehead University
5.	MacDonald, Colla	Faculty of Education, University of Ottawa, Ottawa, ON
6.	Thompson, Genevieve	CancerCare Manitoba Manitoba Palliative Care Research Unit
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8.	Hockley, Josephine	St. Christopher's Hospice, Hospice
9.	Kozak, Jean-Francois	Faculty of Medicine, University of British Columbia, Vancouver, BC
10.	Dr. Peter Brink	Lecturer & Graduate Coordinator Master of Public Health Program Lakehead University
11.	Dr. Robin Cohen	Research Director and Associate Professor, Division of Palliative Care, Departments of Oncology and Medicine, McGill University
12.	Dr. Geoff Davis	Director of Palliative Care of St. Joseph's Care Group & Thunder Bay Regional Health Sciences Centre
13.	Dr. Douglas McGregor	Medical Director, Palliative Care Vancouver Coastal Health

	<b>Representative</b>	<b>Organization</b>
14.	Dr. Samantha Pang	Professor and Head, School of Nursing, The Hong Kong Polytechnic University
15.	Dr. Deborah Parker	Associate Professor, Director, University of Queensland/Blue Care Research and Practice Development Centre
16.	Dr. José Pereira	Full Professor and Head, Division of Palliative Care, University of Ottawa Medical Chief, Palliative Medicine, Bruyère Continuing Care/The Ottawa Hospital
17.	Marg McKee	Associate Professor, School of Social Work, Lakehead University
18.	Susan Scott	Assistant Professor, School of Social Work, Lakehead University
19.	Dean Jobin-Bevans	Associate Professor, Dept. of Music, Lakehead University
20.	Kristen Jones	Lecturer, School of Nursing, Lakehead University

### Community Partners

	<b>Organization</b>	<b>Representative</b>
1.	Allendale Long-Term Care Home	Janice Sheehy
2.	Creek Way Village	Janice Sheehy
3.	Bethammi Nursing Home	Paulina Chow
		Buckler Tracy
4.	Hogarth Riverview Manor	Paulina Chow
		Buckler Tracy
5.	Alzheimer Society of Hamilton/Halton	Marg Eisner
6.	Alzheimer Society of Ontario	Cathy Conway
7.	Alzheimer Society of Thunder Bay	Alison Denton
8.	Anishnawbi Mushkiki	Bernice Dubec
9.	Canadian Coalition for Seniors Mental Health	Kimberley Wilson
10.	Conestoga College Institute of Technology and Advanced Learning	Stephanie Flynn – PSW coordinator
11.	Confederation College	Kathleen Lynch
12.	Family Councils Program	Lorraine Purdon
13.	Mississauga Halton Palliative Care Network	Carol Sloan, Interim Contact, Palliative Pain and Symptom Management Consultants Network (Organization is currently without an ED)
14.	Hospice Northwest	Joan Williams
15.	Hospice PC Network, Hamilton Niagara Haldimand Brant	
16.	Indian Youth Friendship Society	Anne LeSage
17.	L'Accueil Francophone de TB	Angele Brunelle
18.	Lakehead University - School of Nursing	Karen Poole

	Organization	Representative
19.	Lakehead University - Gerontology Program	
20.	Lakehead University - School of Social Work	David Tranter
21.	Lutheran Community Care Centre	Michael Maunula
22.	Mohawk College of Applied Arts and Technology	Donna Rawlin
23.	National Initiative for the Care of the Elderly	Lynn McDonald
24.	Northwestern Ontario End-of-Life Care Network	Katherine Campbell
25.	North West Community Care Access Centre (CCAC)	Tuija Puiras
		Sandi Homeniuk
26.	ON Assoc. of Non-Profit Homes & Services for Seniors	Donna Rubin
27.	ON Interdisciplinary Council for Aging and Health	Larry Chambers
28.	Vice President, Research and Program Development	Catherine Brookman
	Saint Elizabeth Health Care Ontario Community Support Association	
29.	Ontario Multifaith Council on Spiritual & Religious Care	John Kaminsky
30.	Ontario Multifaith Council on Spiritual & Religious Care	Paul Carr
31.	Ontario Network for the Prevention of Elder Abuse	Lee Stones
32.	Ontario Palliative Care Association Palliative Pain & Symptom Management Program	Margaret Poling
33.	Schlegel-UW Research Institute for Aging,	
34.	Seniors Health Research Transfer Network (SHRTN)	Deirdre Luesby Elizabeth Lusk
35.	Palliative Care Program Pain Management Program St. Joseph's Hospital	Tracy Buckler
		Marianne Larson Manager
36.	Thunder Bay Multicultural Association	Cathy Woodbeck

	Organization	Representative
37.	College of Dental Hygienists of Ontario	Fran Richardson, President
		Lynda McKeown, Dental Hygienist Thunder Bay Representative
38.	Canadian Hospice Palliative Care Association (CHCPA)	Sharon Baxter, Executive Director
39.	Thunder Bay Regional Health Sciences Centre, Regional Cancer & Diagnostic Services;	Michael G. Power, Vice President
		Dr. Scott Sellick Director

# Appendix B: CHPCA Model

Square of Care and Organization		History of issues, opportunities, needs, hopes, fears, expectations, assessment needs, physical, radiology, procedures	Confidentiality needs, Desire and readiness for information	Capacity: Goals of care, Requests for withdrawal/advance directives, Treatment choices, consent, Surrogate decision-making, Advance directives, Conflict resolution	Setting of care: Process to negotiate, develop plan of care - address issues, opportunities, delivery options, coverage, respite, bereavement care, discharge planning, emergency	Continuum composition, leadership, education, support, Essential services, Patient, family support, Therapy delivery, Errors	Understanding, Satisfaction, Complexity, Stress, Complex, Issues, questions	
		Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation	
<b>PROCESS OF PROVIDING CARE</b>								
COMMON ISSUES	<b>Disease Management</b>	Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity <i>Diagnosis</i>	<b>Patient / Family</b>				<b>Governance &amp; Administration</b>	Leadership - board, management Organizational structure, accountability
	<b>Physical</b>	Pain, other symptoms Cognition, level of consciousness Function, safety, skills Fluids, nutrition Wounds Holds, restraints, splines					<b>Planning</b>	Strategic planning Business planning Business development
	<b>Psychological</b>	Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self-esteem					<b>Operations</b>	Selection of practice, policies & procedures, data collection/documentation guidelines Resource acquisition & management Daily, security, emergency systems
	<b>Social</b>	Cultural values, beliefs, practices Religious, spiritual, values Isolation, abandonment, restriction Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocations Financial, legal Family caregiver protection Guardianship, custody issues Meaning, value					<b>Quality Management</b>	Performance improvement Risk/reduce Capacity, resource utilization, case management, complex selection needs, financial audit, accreditation, audit Analysis - outcome gaps, assessment, process & procedure, data collection/documentation guidelines
	<b>Spiritual</b>	Dilemmas, transcendental Values, beliefs, practices, affirmations Spiritual advisors, rites, rituals Spirits, songs Activities of daily living Telephone access, transportation					<b>Communications/Marketing</b>	Community/outreach Marketing Media Website
<b>Practical</b>	Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death announcement, certification Personal care of family, handling of body Funerals, memorial services, celebrations Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	<b>Loss, Grief</b>						
<b>RESOURCES</b>								
		Financial Assets Liabilities	Human Formal caregivers Consultants Belt Volunteers	Informational Records, health records, literature, resource, website Resource materials, eg. books, papers, internet, internet Reference library	Physical Equipment Medications/supplies	Community Institution/Organization Healthcare System Private healthcare providers Community organizations Benevolent, clubs		

From: Ferris FD, Barlow HM, Rosen K, Faller J, Harshbark M, Lamontagne C, Lundy M, Syne A, Wind P. A Model for Durable Hospice Palliative Care. © Canadian Hospice Palliative Care Association, Ottawa, Canada, 2002.

Square of Care		History of issues, opportunities, needs, hopes, fears, expectations, assessment needs, physical, radiology, procedures	Confidentiality needs, Desire and readiness for information	Capacity: Goals of care, Requests for withdrawal/advance directives, Treatment choices, consent, Surrogate decision-making, Advance directives, Conflict resolution	Setting of care: Process to negotiate, develop plan of care - address issues, opportunities, delivery options, coverage, respite, bereavement care, discharge planning, emergency	Continuum composition, leadership, education, support, Essential services, Patient, family support, Therapy delivery, Errors	Understanding, Satisfaction, Complexity, Stress, Complex, Issues, questions	
		Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation	
<b>PROCESS OF PROVIDING CARE</b>								
COMMON ISSUES	<b>Disease Management</b>	Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity <i>Diagnosis</i>	<b>Patient / Family</b>				<b>Governance &amp; Administration</b>	Leadership - board, management Organizational structure, accountability
	<b>Physical</b>	Pain, other symptoms Cognition, level of consciousness Function, safety, skills Fluids, nutrition Wounds Holds, restraints, splines					<b>Planning</b>	Strategic planning Business planning Business development
	<b>Psychological</b>	Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self-esteem					<b>Operations</b>	Selection of practice, policies & procedures, data collection/documentation guidelines Resource acquisition & management Daily, security, emergency systems
	<b>Social</b>	Cultural values, beliefs, practices Religious, spiritual, values Isolation, abandonment, restriction Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocations Financial, legal Family caregiver protection Guardianship, custody issues Meaning, value					<b>Quality Management</b>	Performance improvement Risk/reduce Capacity, resource utilization, case management, complex selection needs, financial audit, accreditation, audit Analysis - outcome gaps, assessment, process & procedure, data collection/documentation guidelines
	<b>Spiritual</b>	Dilemmas, transcendental Values, beliefs, practices, affirmations Spiritual advisors, rites, rituals Spirits, songs Activities of daily living Telephone access, transportation					<b>Communications/Marketing</b>	Community/outreach Marketing Media Website
<b>Practical</b>	Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death announcement, certification Personal care of family, handling of body Funerals, memorial services, celebrations Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	<b>Loss, Grief</b>						

From: Ferris FD, Barlow HM, Rosen K, Faller J, Harshbark M, Lamontagne C, Lundy M, Syne A, Wind P. A Model for Durable Hospice Palliative Care. © Canadian Hospice Palliative Care Association, Ottawa, Canada, 2002.

## Square of Organization

<h1>Principal Activities</h1>					<b>F U N C T I O N S</b>	<b>Governance &amp; Administration</b> Leadership - board, management Organizational structure, accountability
						<b>Planning</b> Strategic planning Business planning Business development
						<b>Operations</b> Standards of practice, policies & procedures, data/documentation guidelines Resource management Safety, security, emergency systems
						<b>Quality Management</b> Performance improvement Routine review outcomes, resource utilization risk management compliance satisfaction, needs financial audit accreditation strategic & business plans standards, policies & procedures, data/documentation guidelines
						<b>Communications/Marketing</b> Communication/marketing strategies Materials Media liaison
<b>RESOURCES</b>						
<b>Financial</b> Assets Liabilities	<b>Human</b> Formal caregivers Consultants Staff Volunteers	<b>Informational</b> Records - health, financial, human resource, assets Resource materials, eg, books, Journals, Internet, Intranet Resource directory	<b>Physical</b> Environment Equipment Materials/supplies	<b>Community</b> Host Organization Healthcare System Partner healthcare providers Community organizations Stakeholders, public		

From: Ferris FD, Balfour 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.

# Appendix C: Community Capacity Development Model

## ASSESSING ANTECEDENT CONDITIONS FOR DEVELOPING PALLIATIVE CARE PROGRAMS IN LONG TERM CARE HOMES

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<sup>1</sup>Lakehead University, Thunder Bay, ON, Canada  
<sup>2</sup>McMaster University, Hamilton, ON, Canada

### BACKGROUND

In Canada, approximately 39% of residents die in long-term care (LTC) homes each year. However, most LTC homes lack formalized palliative care (PC) programs that provide holistic palliative care for residents & their family members. LTC funding, legislation & compliance regulations have not acknowledged and supported the role of LTC in caring for dying people. Participatory Action Research is currently underway by a Quality Palliative Care in Long Term Care Alliance to create PC programs in LTC homes & develop a tool kit of interventions to support a cultural change for LTC homes.

### OBJECTIVE

A community capacity development model is being used as a theory of change to develop PC programs. The 4 phase model, depicted in the figure below as a growing tree, illustrates a bottom-up & sequential change process. Phase 1, Having Antecedent Conditions, identifies four conditions underpinning organizational change that must be assessed & strengthened to achieve sustainable progress through the subsequent phases of PC program development.

### METHOD

The research began by conducting a comprehensive assessment of the antecedent conditions in 4 LTC homes in Ontario, Canada. Data were collected through document reviews of policy & procedures as well as surveys (8), interviews & focus groups with residents, families, community stakeholders & LTC staff of all disciplines. The identified barriers, gaps & enablers provided the basis for developing & evaluating a series of evidence informed interventions to strengthen the antecedent conditions & build organizational capacity. Over the next three years multiple interventions will be implemented & evaluated.

## THE 4 PHASE PROCESS OF PALLIATIVE CARE DEVELOPMENT IN LONG-TERM CARE HOMES

### PHASE 1 HAVING ANTECEDENT CONDITIONS WITHIN THE LTC HOME

In the model at the roots of the tree, 4 antecedent conditions form the basis for future palliative care development. An assessment of these conditions thus began the change process & included assessing the state of: 1) health care infrastructure in the LTC home; 2) collaborative team approaches to care; 3) vision to improve care of dying people; 4) sense of empowerment amongst staff to influence organizational change.

**PROJECT OUTCOMES:** The environmental assessment identified the following barriers in the LTC homes: staff lacked knowledge of PC & access to PC education; there was no comprehensive resident PC assessment and no systematic process to identify residents approaching end-of-life; the LTC home lacked policies and procedures relating to PC; communication problems existed amongst staff, residents, and families regarding PC issues.

### PHASE 2 EXPERIENCING A CATALYST FOR CHANGE WITHIN THE LTC HOME

In phase 2 of the model, a catalyst for change occurs within the LTC home that disrupts their current approach to caring for dying people. This catalyst can be a person or an event.

**PROJECT OUTCOMES:** The QPC-LTC Alliance was the catalyst to create change within the 4 participating LTC homes. The change process was supported by a new LTC home act that required PC programs & by personal support workers who were champions within each home.

### PHASE 3 CREATING THE PALLIATIVE CARE TEAM WITHIN THE LTC HOME

In creating the team, providers join together in order to collectively improve care of the dying & develop PC programs. The team requires dedicated people of all disciplines & getting the “key” LTC staff & managers involved.

**PROJECT OUTCOMES:** An interdisciplinary Palliative Care Resource Team was developed using a full day planning retreat & a series of meetings to engage the staff. The focus was on engaging direct care workers.

### PHASE 4 GROWING THE PROGRAM WITHIN THE LTC HOME

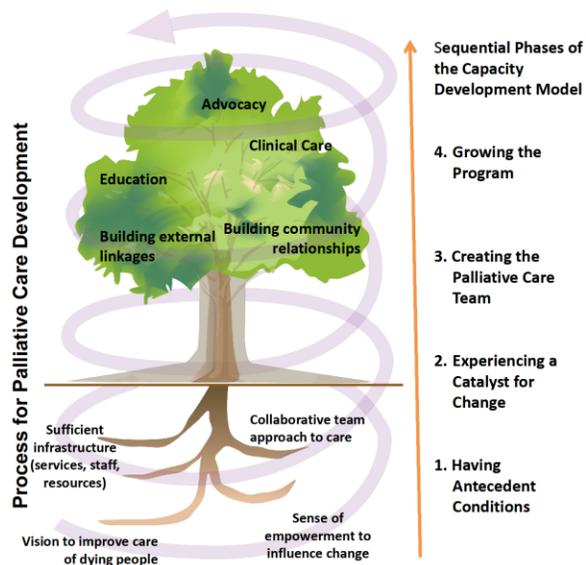
In this phase, the PC team continues to build, but now is ready to deliver palliative care. Ongoing tasks include: strengthening the team; engaging LTC staff of all disciplines; engaging community PC experts & resources; sustaining new palliative care practices.

**PROJECT OUTCOMES:** The 4 LTC homes are now creating their own palliative care programs, policies & procedures while engaging staff, residents and families. Some examples of interventions supporting PC development are: **Enhancing Clinical Care** – Created opportunities for staff to improve clinical skills through working in a Simulation Lab, through visiting to a speciality Hospice Palliative Care Unit & by participating in “Comfort Care Rounds” where residents’ care plans were reviewed with a PC consultant.

**Enhancing Education** - A 6-module (12 hr.) PC education course was offered for direct care workers; a Snoezelen therapy toolkit was created & staff, family and volunteers were engaged to use the resource; “book chats” focusing on understanding dementia were initiated with front line staff.

**Advocating for PC** –Based on the research, a brief was presented to the Canadian Federal Parliamentary Committee on Palliative & Compassionate Care to advocate for resources & policy to enable providing PC in LTC.

**Building External Linkages** – Hospice volunteers & divinity students were engaged to work in the TC homes to support staff with providing social & spiritual care.



### CONCLUSION

LTC homes should assess their antecedent conditions for change to identify their enablers, gaps, & barriers before developing & implementing their own PC programs. The model provides a theory of change to guide the assessment. A wide range of data collection methods are needed to assess antecedent conditions. Taking a whole system approach to change within LTC requires engaging families & residents, managers, staff of all disciplines & especially direct care staff. Creating evidence informed interventions will strengthen the antecedent conditions & support growing the PC program. The success and sustainability of new PC programs in LTC requires internal cultural transformation. For more information on the research instruments used and detailed results please visit our website:

[www.palliativealliance.ca](http://www.palliativealliance.ca)



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## Quality End-of-Life Care in Long-Term Care: Communication is the Key

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Centre for Education and Research on Aging and Health & Gerontology Graduate Students <sup>(1,2,3,4)</sup>, Lakehead University

### Purpose

To explore the experience of dying and end-of-life care (EoLC) in long-term care (LTC) homes for persons with dementia, and to understand the supports and constraints of providing EoLC in LTC from multiple perspectives.



### Methods

Using a focused ethnographic case study methodology, data were collected from 112 participants through individual interviews and focus groups, conducted on site over 4 days in a 100 bed LTC home. This project was conducted in partnership with St. Joseph's Care Group.

### Participants included (N=112):

- nurses & personal support workers (PSWs)
- family members
- volunteers
- life enrichment staff
- housekeeping & maintenance staff
- managers
- spiritual advisors
- physicians



### Results

All participants agreed that that **comfort was the ultimate goal** when working with residents and families facing EoL issues. **Communication** that was effective and inclusive of all staff, families and residents emerged as the essential element to providing comfort at the end-of-life.

**Communicating with families is extremely important and has a high priority for staff.** Discussing the goals of care and educating families on end-of-life issues aids in residents' comfort and provides support for families.

*"I make myself available [to] interview the family, relatives or whoever else and inform them as to where [residents] are right now...and what I anticipate in terms of length of time that they will survive...because a lot of these people need to know. They want to know if they should call siblings back home or not and that type of thing."*

-Physician

*"Some of them [family members] have more anxiety than others. They want everything done or they want nothing done. You find that conflict. That's when the communication comes in. That's when you've got to sit down beside them at their level and tell them about the different things..."*

-Registered Nurse

**Personal Support Workers use communication to guide and support one another.**

PSW's communicate within their group to relay important care information, to emotionally support one other and to help one another make care decisions. Experienced PSW's mentor new staff.

*"Well personally I would talk with my co-workers [about a resident's change in status], get their opinions first and then suggest telling the RN and then it's up to the RN after that"*

-Personal Support Worker

**Clinical staff recognize that communication is essential between direct care providers for EoLC; non-clinical staff also interact with residents and want to be more included in communication.**

*"Usually you hear word of mouth [about a resident's death]...basically they put their name up there [on the memorial board]. I didn't know about that for a while...because we had to fix it...that's when I realized, oh that's the in-memoriam."*

-Maintenance Worker

**Barriers to Communication**  
Communication challenges that interfered with the quality of EoLC include staff's time constraints and the hierarchy of power between the professions and between professional and non-professional staff.

*"I found sometimes if I tell this staff member about a situation, whatever it is, other staff members don't find out about it so there is some sort of break up in communication on the staff level...it comes down to (whispers), they just don't have bloody enough time!"*

-Family Member

### Conclusion

Communication has a direct effect on the residents' EoL care, and it is the key to comfort in LTC homes. Each discipline and group valued communication and perceived room to improve this process in their facility. More formalized palliative care teams were mentioned as one strategy to address barriers and improve communication across and between disciplines and improve teamwork.

**COMMUNICATION**  
Improves  
Quality End-of-Life  
Care

Emotional Support  
Decision-Making  
Comfort  
Education  
Teamwork



Centre for Education and Research on Aging and Health  
Lakehead University

Funding for this project was provided by CHRR through the New Emerging Team grant, End-of-Life Care for Seniors

# Appendix E: Assessing Organizational Resources and Functions

## An Assessment of Organizational Infrastructure Gaps, Barriers and Enablers to Developing Formal Palliative Care Programs: A Comparative Case Study of Two Long-Term Care Homes in Northern Ontario (Thesis in Progress)

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### Introduction

This research is a sub-study of a five year SSHRC funded Community-University Research Alliance project, "Improving Quality of Life for People Dying in Long-Term Care Homes", which is in progress. This sub-study used the Canadian Hospice Palliative Care Association's (CHPCA) model of practice as a framework to understand how the organizational infrastructure of long-term care homes affects their capacity to develop and deliver formal palliative care programs. Data used for this analysis were gathered in two northern Ontario homes over 2009-10. Both homes are operated by a non-profit and faith based organization.

### Research Questions

1. What organizational resources and functions enable the development and delivery of formal palliative care programs?
2. What are the gaps or barriers in organizational resources and functions for the development/delivery of a formal palliative care program?

### Method

This thesis uses a comparative case study methodology. Both primary and secondary types of data were used for data collection. The two tables below depict the data collected.

Primary Analysis	Type Documents reviewed	Number of Documents
Documents Review	<ul style="list-style-type: none"> <li>• Policies</li> <li>• Annual Reports</li> <li>• Community Reports</li> <li>• New Hire Orientation Checklists</li> <li>• New Admission Handbooks</li> </ul>	46 policies 2 annual reports 1 community report 3 Checklists: PSW, RN, RPN 2 handbooks (1 / home)

Secondary Analysis Of Staff Surveys and Focus Group Data	Domains Measured	Participation Rates
Frommelt Attitude Towards the Care of the Dying (FATCOD)	Attitudes regarding working with the dying	Total: 104/171 Home A: 57/91 Home B: 47/80
Quality in Action Scale (QIAS)	Patient Focus, Management Style, Teamwork Orientation, Improvement Orientation, Mission and Goals Orientation, and Personal Influence / Performance	Total: 108/171 Home A: 61/91 Home B: 47/80
Personal Empowerment in the workplace (PEIW)	Meaning, Competence, Self-Determination, and Impact	Total: 74/97 Home A: 47/53 Home B: 27/44
Supervisory Support	Empathy, Reliability, and Nurturing Connection	Total: 52 /97 Home A: 31/53 Home B: 21/44
Self Efficacy in End-of-Life Care Survey (S-E EOLC)	Patient Management, Communication, and Multidisciplinary Teamwork	Total: 19/34 Home A: 11/16 Home B: 8/18
Palliative Care Quiz	Palliative Care Nursing Knowledge	Total: 20/34 Home A: 12/16 Home B: 8/18
Focus Groups	Understand of palliative care, supports and barriers to practice, role of family members (etc.)	Total: 90/205 Home A: 58/119 Home B: 32/ 86
Interview	Understand of palliative care, supports and barriers to practice, role of family members (etc.)	Total: 20/32 Home A: 11/16 Home B: 9/16

### Findings

Both qualitative and quantitative data findings are displayed in the table below. The qualitative data was analyzed using a process of analytic induction and the relevant survey findings extracted for this analysis.

CHPCA Domain	Findings
Government and Administration	<ul style="list-style-type: none"> <li>•Scopes of practice and professional hierarchy in long-term care homes affect communication with residents and families and the ability for staff to work as a team</li> <li>•Limited supervision hinders PSWs and nurses' ability to work with complex palliative clients</li> </ul>
Planning	•Staff of both long-term care homes moderately agreed that they understand the mission and goals of their organization and how it relates to their work (mission and values are consistent with a palliative approach) (QIAS)
Operations	<ul style="list-style-type: none"> <li>•Staff in both long-term care homes have attitudes that are consistent with a palliative care approach (FATCOD)</li> <li>•Although staff in both homes scored high on the PEIW survey for perceived competence with work, there was a significant variability in their feelings of autonomy and ability to have impact within the workplace.</li> </ul>
Quality Management	•Both homes had a high scores on staff attitudes regarding looking for and working towards making improvements in their workplace (QIAS)
Communication and Marketing	•During admission, staff have difficulty communicating with residents and their families about advanced care directives and that death can be supported within the homes.
Financial Resources	•Funding given to the long-term care homes from the Ontario Ministry of Health and in Long-Term Care comes with strict guidelines and accountabilities, requiring the homes to spend most of the money on physical care as opposed to psychological, spiritual, social and other types of care.
Human Resources	•Employees at both homes feel that recent changes to their work schedules are benefiting residents because there is now more consistency for staff and residents.
Informational Resources	•Staff discussed the benefits of having change of shift updates which allow them to gauge change in residents' health. Staff indicated they would like more education regarding palliative care, including, talking to residents and families about death, and working with families who are not accepting of a "palliative diagnosis".
Physical Resources	•Staff would like to see more dedicated space within their homes for palliative care, and more informational resources and medical supplies readily available within palliative care rooms.
Community Resources	•During focus groups and interviews ,staff expressed that having active and involved families and volunteer support from the community helps them provide better palliative care to residents

**Conclusion:** Enablers, barriers, and gaps exist in both homes. Some results varied between the two homes, however, their were many common findings across homes that influence the development and delivery of palliative care. Some of these influences are internal to the home, while some are external forces in the community, the health care system, or related to government regulations that prescribe how long-term care homes function.



### Reference:

Ferris, F. D., Balfour, H. M., Bowen, K., Farley, J., Hardwick, M., Lamontagne, C., Lundy, M., Syme, A., & West, P. (2002). A model to guide hospice palliative care. Ottawa, ON: Canadian Hospice Palliative Care Association.

### Acknowledgements:



# Appendix F: Heart Failure in LTC

## Managing Heart Failure in Long-Term Care Residents: A Nursing Perspective

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<sup>1</sup> Lakehead University, Thunder Bay, ON, <sup>2</sup> University of Ottawa, Ottawa, ON, <sup>3</sup> University of Waterloo, Waterloo, ON



**Heart failure (HF) is a chronic, progressive and debilitating illness affecting up to 45% of residents in long-term care (LTC) homes.**

Though potentially preventable, unplanned transfers of residents with HF to acute care are common, contributing to a growing burden on hospitals and often poor functional outcomes for the residents.

**Purpose**  
 This study aims to prevent unnecessary hospitalizations by adapting the Canadian Cardiovascular Society (CCS) Heart Failure Guidelines for LTC settings. Understanding the perspective of the Registered Nurses (RN) and Registered Practical Nurses (RPN) will contribute to the development and implementation of these guidelines.

**Methods**  
 Phase 1 – A Delphi survey identified recommendations for adapting the CCS Heart Failure guidelines for LTC  
 Phase 2 – Five focus groups with RNs and RPNs were held in three LTC homes in Ontario. Participants were asked to discuss the current practices as recommendation resulting from the Delphi survey.

**Results**  
 RNs and RPNs identified four main themes that impact HF management in LTC: Understanding Scope of Practice, Communicating about Resident Care, Accessing Resources and Respecting Resident Autonomy.

*"We are not using the skills that we were trained to use by sitting at our computers typing a bunch of paperwork."*

*"Well I'd like to know to how to identify congestive heart failure signs and symptoms, how to manage it. And it would not only benefit RPN's but the Health Care Aides as well"*

Theme	Facilitators	Barriers
<b>Understanding Scope of Practice</b>	Teamwork amongst the nurses as well as across the care team enhanced HF care for residents.	The blurring of roles between RN and RPN places more expectations on medication management and administrative task versus time spent on clinical assessments.
<b>Communicating about Resident Care</b>	Informal communication networks between families, personal support workers and nurses helped with the recognition of subtle changes in resident health status.	Interprofessional and interorganizational communication was seen as the ideal. However, a hierarchy exists both within the homes and across the health care setting that impacts what type of information and with who it is shared.
<b>Accessing Resources</b>	Having the support and access to an interprofessional team that included Social Work, Dietician, Occupational Therapy, Pharmacy, Life Enrichment and family.	Limited knowledge of HF physiology impacted their clinical and assessment skills. Lack of time and human resources limited access to continuing education on HF management.
<b>Respecting Resident Autonomy</b>	Advance care directives and Power of Attorney's provide guidance on HF management based on resident wishes.	Best practice guidelines don't reflect resident autonomy.








**Conclusion**

The clinical profile of residents living in LTC homes is changing due to people living longer and increased resources to home care. Resident acuity has increased therefore LTC homes are faced with the challenge of managing complex care for diseases such as heart failure.

Team work, informal communication and access to interprofessional resources help facilitate HF management. However, findings indicated that nursing staff are limited by a general knowledge of HF management. Organizational factors such as values, hierarchical decision-making process and limited human resources can impede resident care. LTC homes will develop protocols to enhance the management HF in order to optimize internal resources and clinical consultation from external specialists such as physicians, pharmacists and nurse practitioners.





## Appendix G: Simulation Lab Intervention

# Improving Communication around Death and Dying for Personal Support Workers in Long-Term Care using High-Fidelity Simulation

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Lakehead University, Thunder Bay, ON, Canada.

### Introduction

- In Canada, long-term care (LTC) could be thought of as the hospices of the future, caring for older people with chronic conditions, with a long trajectory to death, the most common being dementia.
- Personal Support Workers (PSWs) provide 80% of direct care to LTC home residents, yet currently receive little formal training in palliative care (PC);<sup>2</sup> communication about death and dying has been identified as a key challenge for PSWs in LTC.
- High-fidelity simulation (HFS) is an innovative tool that has shown potential for its use in both palliative care education and communication skills training.

### Objectives

- The overall objective of this pilot-study as part of a larger five-year project entitled, *Improving the Quality of Life for People Dying in Long-Term Care Homes*, was to **develop, implement, and evaluate a HFS experience** as an intervention that can be used to **improve PC in LTC**.

### RESEARCH QUESTION:

Is HFS an effective teaching strategy for improving confidence and communication around death and dying for PSWs in LTC?

### Method

#### STUDY DESIGN & SAMPLE:

- **“Caring in the Moment”: Companioning Carolyn at the End-of-Life**, was developed through a collaborative process and in conjunction with a **Participatory Action Research (PAR)** project within 2 LTC homes in Thunder Bay, ON.
- The following data were collected utilizing a mixed-methods approach: **surveys, focus group debriefings, participant observations, and follow-up interviews** with participants 2 ½ months after the intervention.
- **(n = 17) PSWs and (n = 1) Life Enrichment Aid**



The above photo on the left shows the HFS control room; the photo on the right is the resident 'Carolyn', created for this intervention.

### Results

#### SURVEYS:

- The participants had overall **improvement on self-efficacy scores related to the provision of end-of-life care to a statistically significant level** (when  $p < 0.05$ ).



The line graph above depicts participant changes in ratings of self-efficacy. The blue line shows pretest scores; the red line shows posttest scores.

#### FOCUS GROUP DEBRIEFINGS:

- Participants reported a **positive and affirming experience**, believing that HFS should be **more widely used in PSW training**. Participants appreciated the opportunity for **mentorship** and the **fidelity** or realism of the intervention.

**“When I was sitting there holding her hand, I felt comfortable with my conversation with her and that’s, that’s reassuring to know that I’m confident with that”.** [Participant]

#### PARTICIPANT OBSERVATIONS:

- The participants demonstrated many of their **strengths and learning needs** related to palliative care during the HFS experience. A vast amount of **new knowledge** was shared and **numerous skills** were **learned** during the intervention.

#### FOLLOW-UP INTERVIEWS:

- Participants reported **improved confidence, communication skills, awareness and understandings of palliative care**, and an **increased comfort level discussing issues around death and dying** with both residents and their family members.

### Conclusion

- **This study provides important beginnings for a currently non-existent body of literature supportive of the use of HFS for PC education with PSWs in LTC.**

### Bibliography

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