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

By

Jessica McAnulty

B.A. Lakehead University, 2008

H.B.S.W. Lakehead University, 2009

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SUPERVISORY COMMITTEE

An Assessment of Organizational Gaps and Enablers to Developing Formal Palliative Care and End of Life Care Programs in LTC Homes

Supervisory Committee

Supervisor:	Dr. Mary Lou Kelley (School of Social Work)
Departmental Member:	Dr. Elaine Wiersma (Public Health and Gerontology Program)
Outside Member:	Dr. David Richards (School of Business)

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Abstract

This research paper is a sub-study of a five year Social Sciences and Humanities Research Council of Canada (SSHRC) funded Community-University Research Alliance project: *Improving Quality of Life for People Dying in Long-Term Care Homes,* in progress from 2009 to 2013. This sub-study uses a comparative case study design and the Canadian Hospice Palliative Care Association's (CHPCA) model of practice as a framework to understand how the organizational infrastructure of two long-term care (LTC) homes affects their capacity to develop and deliver formal palliative care programs. The three main goals of this sub-study were: 1) to identify resources and functions within the two LTC homes that serve as enablers to support palliative care development and delivery; 2) to identify current gaps and barriers that influence the development and delivery of formal palliative care programs within these two care homes; and 3) to determine a list of priorities for change at the organizational level in efforts to make the LTC homes more successful during the development and delivery their own formalized palliative care programs.

Data used for this analysis were gathered in two northern Ontario homes during 2009-2010. Several types of data were analyzed to assess the current resources and functions to determine whether they were enablers, barriers, or gaps to the development and delivery of formal palliative care programs. The data analyzed included interview and focus group data that was collected from LTC home staff of different disciplines and roles, six types of survey data that were collected from LTC staff, as well as a document review of all the in-home policies specific to the LTC homes.

The result of this research has identified priority areas for change for the LTC homes to facilitate their development of formalized palliative care program and ensure that the programs that they create can be sustained and successful. Consistent with the methodological approach of Participatory Action Research, the methodology of the five year project, these findings will be offered to the managers of the LTC homes for their review and consideration to guide organizational change.

Introduction

What is Palliative Care?

Palliative care is defined as "the specialized care of people who are dying – care aimed at alleviating suffering (physical, emotional, psychosocial, or spiritual), rather than curing. The term palliative care is generally used in association with people who have an active, progressive and advanced disease, with little or no prospect of cure" (Canadian Hospice Palliative Care Association, 2002, pg. 3). Palliative care begins at the time of diagnosis of a life-limiting, chronic or terminal condition and extends into bereavement. "Palliative care is appropriate for any patient and/or family living with, or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care" (Canadian Hospice Palliative Care Association, 2002, pg. 17).

Palliative care strives for a "good death". "A good death may include elements such as: being pain-free, operating at the highest possible level of functioning, resolving long-standing conflicts, satisfying final wishes, and/ or relinquishing control over care to significant others" (Fisher, Ross, & McLean, 2000, pg. 14). Although the process is very individual, long-term care LTC residents' experience the dying process as an integral aspect linked to the delivery of care.

For example, if proper pain control is not being achieved it will affect residents' quality of life and thus affect the ability for a "good death". Furthermore, looking at residents' care through a palliative care model, "places patients and their families into a circle of care which is a truly holistic approach, just as hospice does for terminal patients. The circle of care addresses the physical, psychosocial, behavioral, and spiritual dimensions of suffering and illness by establishing a multidisciplinary team approach" (Levine, 2000, p. 222). Thus, it is important to see palliative care programs as functioning at both an individual (micro) and a systemic (macro) level of the organization.

When someone has a terminal illness or health condition that would benefit from palliative care within a LTC home, the care must be flexible enough to change or shift. "The regular services available in residential care facilities need to be supplemented, as necessary, to make it possible for quality end-of-life services to be provided to residents" (Canadian Hospice Palliative Care Association, 2002, pg. 9). It is important to note that even though a person is seen as requiring palliative care, the standard residential care that is restorative[1] or disease modifying is supplemented and not replaced. Although palliative care is focused on care that is non-curative and prioritizes comfort towards the end of life, this does not mean that it cannot be used in combination with a more restorative or traditional medical model. When looking at Figure 1, one can see that both types of care can be provided to an individual; however the focus of care shifts as time passes and death becomes more imminent.

[1] Restorative care is a planned, systematic program that focuses on helping each client obtain and maintain the highest level of function. It focuses on: helping clients do things for themselves rather than "doing for" the client; short, achievable goals; on the client's functional potential, not a diagnosis or limitations; on preventing deterioration whenever possible; improving the client's self-image and self-esteem. Examples of goals of restorative care: promote activity, mobility and independence in ADL's; increase muscle strength and balance; promote continence ; prevent contractures and pressure ulcers

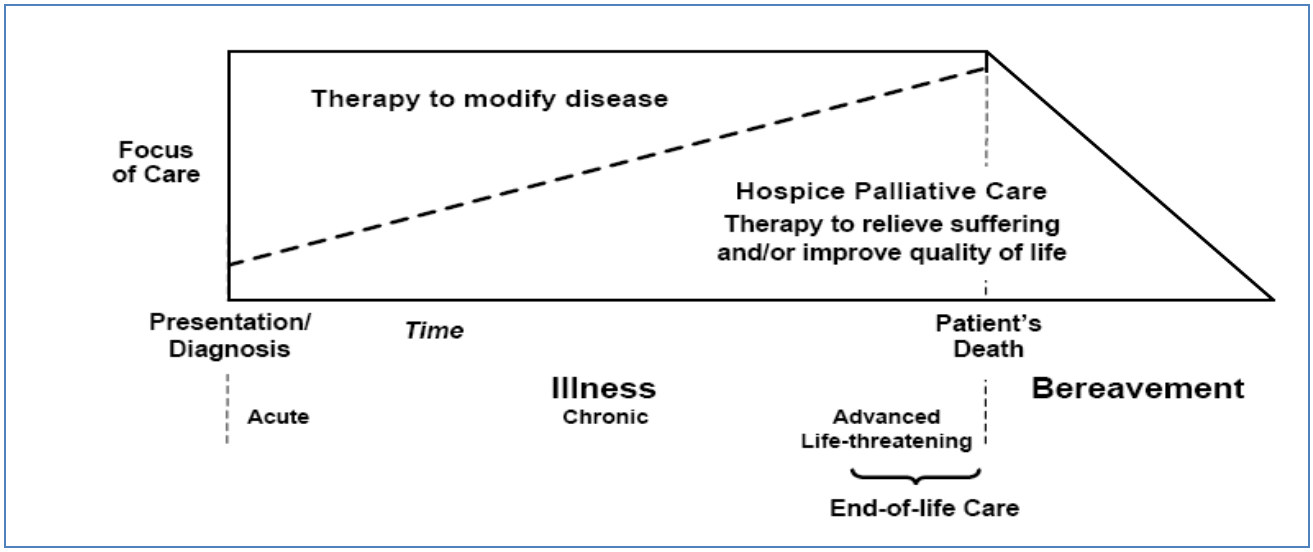


Figure 1: CHPCA's model- The Role of Hospice Palliative Care during Illness

Why Study Palliative Care in LTC Homes?

In recent years there has been research indicating that the Canadian population is aging and discussion around how this changing demographic will increase demand for our health care and palliative care programs. "Currently, there are approximately 3.7 million Canadians aged 65 and over; by 2021, 6.9 million Canadians will be 65 and older" (Fisher, Ross, & McLean, 2000, pg. 5).

Despite social trends, there has been little research attention given to understanding the palliative care needs of older people who are living and dying in LTC settings. This is surprising given that "there are approximately 600 LTC homes in Ontario that provide care to more than 75,000 residents" (Sharkey, 2008, p. 12). It is also important to consider that as the Canadian population continues to age there will be an increase in residents dying in LTC each year. It is predicted that by 2020 as many as 39% of residents living in LTC will die each year (Fisher, 2000). Research into how to create palliative care programs and the creation of palliative care teams in a LTC setting is also needed because "success and failure are based on the ability of the

team to meet the needs and expectations of the patient and family, rather than just successfully treating the individual disease" (Levine, 2000, p. 222). Also there are several current barriers to providing palliative care in LTC indicated within the literature. Research conducted by Brazil et al (2006) assessed the current barriers to providing palliative care in LTC. Some barriers that were found include: inadequate staffing levels, lack of pain assessment and management skills, lack of a consensus about what constitutes palliative care, staff's lack of knowledge and skills for providing palliative care for dying residents, and lack of support for interdisciplinary health care teams in facility (Brazil et al 2006)

Thus, it is important to study the delivery of palliative care in LTC as there is a growing population of service users that will increase within the years to come, and there are currently barriers to providing palliative care that have been identified by researchers and people working in this field.

Current Palliative Care Delivery in LTC homes

Palliative care is an extremely important component of LTC because "an elder requires a disproportionately large amount of palliative care for a disproportionately long period of time" (Steel, et al., 2003, pg. 212). As explored above, the need for palliative care will continue to grow because of the increasing frailty of LTC residents. People are now living longer and moving into LTC at a much later age. While the majority of older adults do not live in LTC, there are still a high percentage of the Canadian population that die in LTC homes. "With increased incidence of chronic disease, and continuing increase in incidence and prevalence of cancers as the population ages, it is predicted that LTC facilities will become the major location of the provision of palliative care" (Kortes-Miller, Habjan, Kelley, & Fortier, 2007, p.154).

Models and Frameworks for providing Palliative Care in LTC homes

There are very few frameworks to help LTC homes with developing palliative care programs within their facilities. In Australia the National Health and Hospitals Reform Commission has made progress in exploring this area. They set out to create a broad set of directions that support system-wide improvement in the delivery of care at the end of life (National Health and Hospitals Reform Commission, 2010).The main idea of their project was to create standards for providing quality palliative care for all Australians and create a language that crosses sectoral boundaries and creates requirements that can be shared by all (National Health and Hospitals Reform Commission, 2010). The standards created are now being applied in LTC homes in Australia and models of care for LTC are under development (Parker, 2010).

How can LTC homes develop capacity to deliver palliative care?

There are many organizational change models in the literature , however, research indicates low success rates within LTC facilities related to implementing and sustaining organizational change using an organizational change model. Related to implementing palliative care, Abbey et al (2006) point out that "issues of transferability and sustainability have had a major impact on shaping care for older people towards end of life in LTC settings" (Abbey, Froggatt, Parker, & Abbey, 2006, p. 57). These researchers offer some insight on why this occurs, stating "that an integrated, comprehensive approach to change must be applied or supported at four levels: the environment in which the organization operates, the organization itself, the team and the level of the individual" (Abbey, Froggatt, Parker,& Abbey 2006, p. 59).

The overall research methodology of the project conducted by the Quality Palliative Care in Long Term Care (QPC-LTC) Alliance to develop palliative care in LTC homes is a participatory action methodology that encompasses all four levels identified by Abbey et al.

(2006). The study described in this thesis examines one of these levels - the organizational level as part of the change context. Further, the QPC-LTC participatory action research uses a bottom-up philosophy as compared to a top-down philosophy which is generally used in organizational change models. Also, "promoting change in any care setting requires careful attention to the established practices within the existing context, especially the obstacles to change and the available means for pursuing it; and the form in which the new objectives need to be presented" (Abbey, Froggatt, Parker, Abbey, 2006, p. 59). Thus from an organizational level, it is important to look at the gaps, barriers, enablers in order to provide insight to the QPC-LTC Alliance and the LTC homes will be needed to provide a formal palliative care program.

A four phase Community Capacity Development Model created and validated by Dr. Mary Lou Kelley offers insights on how rural communities can develop their own palliative programs (Appendix A). If one understands LTC as a community, the model can also offer many insights about developing palliative care programs in LTC homes using a bottom up capacity development process. This capacity development model is the guiding conceptual framework for the participatory action research Quality Palliative Care in Long Term Care project which aims to develop formalized palliative care programs in LTC homes over the next four years.

The four phases of Kelley's capacity development model include: phase 1- having required antecedent community conditions, phase 2- experiencing a catalyst for change, phase 3- creating the local team, and phase 4- growing the program. The first step in the model describes the importance of having specified antecedent community conditions when looking at creating a palliative care program within the community. The antecedent conditions in the capacity development model are: collaborative generalist practice, a vision for change, a sense of local community empowerment, and sufficient infrastructure. (Kelley, 2010) The model also indicates

the ‘keys to success’ for developing capacity in palliative care are: working in a small community, working together, and having a strong community focus. Please see appendix A for more information regarding this model.

Applying Kelley’s model in a LTC home requires conducting an organizational assessment of the antecedent conditions before beginning a change process. More specifically there is a need to assess organizational infrastructure which includes the organization’s functions and resources as outlined in the CHPCA model for palliative care. Having the required resources and management processes as resources is an antecedent condition for building capacity in clinical practice within the homes. Having this organizational assessment will allow LTC homes to identify where they need to strengthen their organizational resources and processes to delivery clinical palliative and end of life care, and show them how they can ultimately move forward.

Canadian Hospice Palliative Care Association Square of Care and Organization

The Canadian Hospice Palliative Care Association (CHPCA) has developed a national model of care that can be applied to any setting, including LTC. The model of care is represented as the Square of Care and Organization (See Figure 2). The CHPCA Model suggests that developing and delivering palliative requires involves attention to all four sides of the square of care. If even one side of the square is incomplete, the organization will not be able to develop and deliver a comprehensive palliative care program to their clients. This model could be applied to LTC to give guidance on what to incorporate in palliative care programs. To our knowledge this framework has not been applied to develop palliative care programs in LTC homes in Canada.

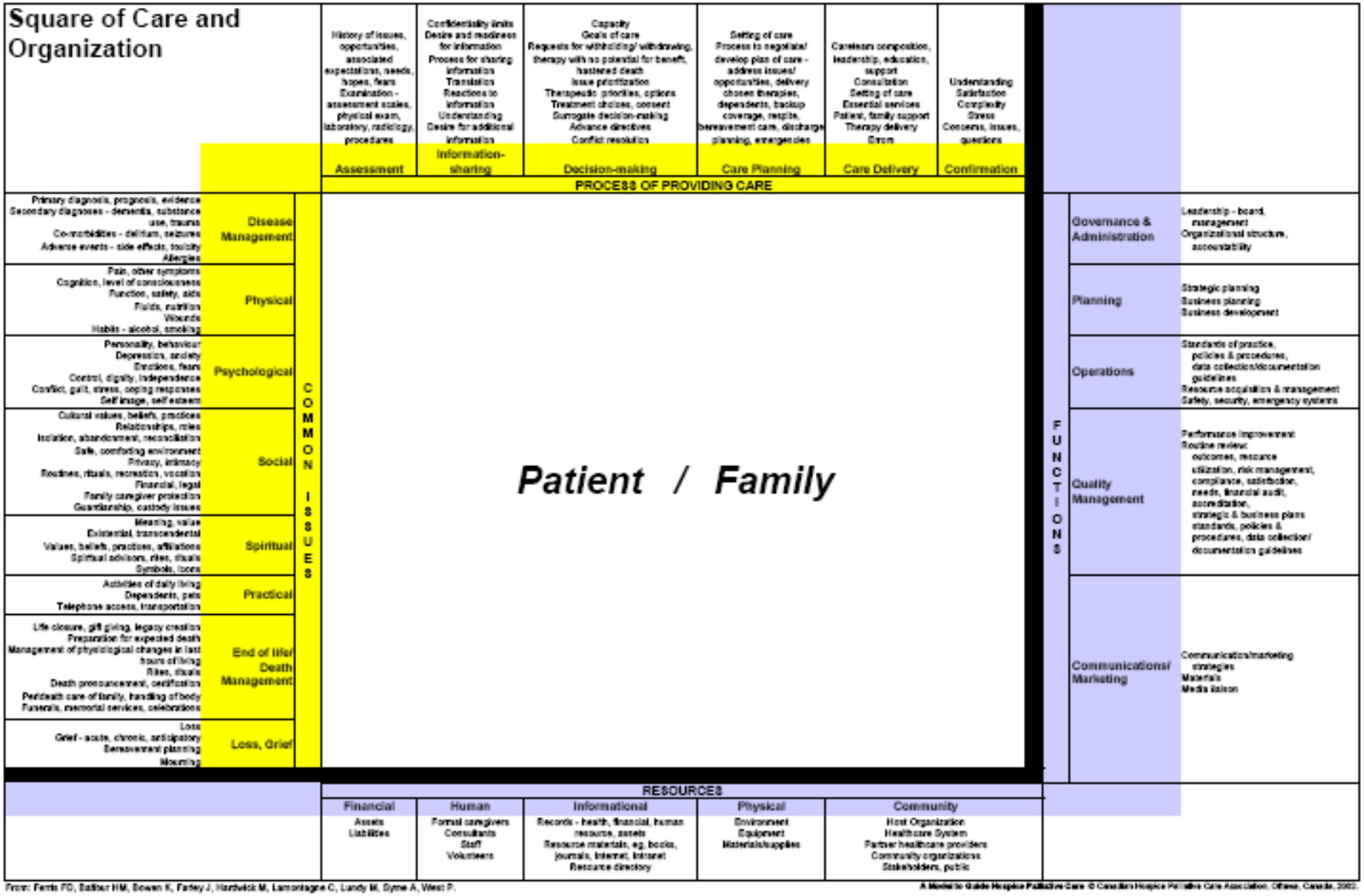


Figure 2: CHPCA square of care and organization

In the CHPCA model, the left hand side of the square indicates the common issues that patients and or families face during the palliative process. “To change their experience of an illness, patients and families seek assistance from healthcare providers who they believe will be knowledgeable and skilled at addressing their issues, expectations, needs hopes and fears” (CHPCA, 2002, p.25). The common concerns an organization needs to address, as indicated by the CHPCA, for providing palliative care services are disease management, physical, psychological, social, spiritual, practical, end of life death management, and loss or grief. More detail about the scope of each of the common issues is included in Figure 2.

The top of the square of care indicates the different components of the process of providing palliative care. “During each therapeutic encounter, the process for providing care involves six essential and several basic steps that guide the interaction between caregivers, and the patient and family. While these steps do not need to occur in any specific order, each one must be completed during each encounter” (CHPCA, 2002, p. 26). These care processes include: assessment, information sharing, decision making, care planning, care delivery and confirmation.

Across the bottom of the square, the CHPCA model indicates the importance of having sufficient resources to implement a palliative care program. Necessary types of resources include financial, human, information, physical, and community resources are all needed in order to provide palliative care (See Figure 3). For example, LTC homes need specialized equipment, medications and multi-disciplinary staff to provide palliative care consistent with the model.

Financial Resources	Human Resources	Information Resources	Physical Resources	Community Resources
Assets • Cash • Capital • Investments • Receivables Liabilities • Payables • Depreciation • Taxes Insurance	Formal caregivers • Bereavement counselors • Chaplains • Dietitians • Integrative therapists • Nurses • Occupational therapists • Pharmacists • Psychologists • Physicians • Physiotherapists • Psychologists • Social workers • Speech pathologists • Support workers • Volunteers (caregivers) • Consultants (e.g., ethics, clinical, legal, administrative) Staff • Administration • Support Volunteers (non-caregivers)	Records • Health • Financial • Human resource • Assets Resources • Resource, reference materials, (e.g., books, journals) • Internet, Intranet Resource directory	Environment • Space • Lighting • Heating, cooling • Utilities • Parking Equipment • Medical • Diagnostic and investigative • Office • Communication systems, (e.g., telephones, pagers, e-mail) • Information technology systems, (e.g., computers, printers, networks, internet access) • Security systems Materials, Supplies • Medical • Office • Other	Host organization Healthcare system Partner healthcare providers Community organizations Faith/religious communities Stakeholders Public

Figure 3: CHPCA's Square of Care and Organization – Resources

Lastly, the right side of the square represents the organizational functions that must support the development and delivery of a formal palliative care program. Principal and basic functions include: governance and administration, planning, operations, quality management (evaluation), communication and marketing (See Figure 4).

Governance and Administration	Planning	Operations	Quality Management (Evaluation)	Communications/ Marketing
Leadership • Board • Management Organizational structure/ accountability	Strategic plan • Needs assessment • Mission, vision • Values, purpose, principal activities • Goals, objectives, strategies, tactics • Timelines, strategic decision points Business plan • Organizational/ accountability structure • Resource acquisition and management • Implementation • Quality management • Communications, marketing Business development	Standards of practice, policies and procedures, standards for data collection/documentation Resource acquisition and management: • Fund development – stewardship, annual program, foundation and research grants, planned giving • Financial resources - billing, accounting, banking, dispersement • Human resources - recruitment/retention, credentialing, orientation, education, evaluation, staffing, support, recognition, incentives, occupational risk/stress, critical incident debriefing and support, self-actualization and spiritual growth, termination, outplacement • Informational resources - data collection, purchasing, storage, maintenance, reporting, destruction • Physical resources - purchasing, stock control, maintenance, disposal • Community resources - relationship building, contracting, relationship management, contract/ relationship termination Safety, security, emergency systems	Performance improvement • Outcomes • Resource utilization • Adverse events, including errors, complaints • Satisfaction Routine review • Utilization review, clinical outcomes and resource utilization • Risk management • Compliance • Caregiver and employee satisfaction • Community needs • Financial audit • External accreditation • Strategic and business plans • Standards of practice, policies and procedures, standards for data collection/documentation	Communication and marketing strategies Materials Support for fundraising Media liaison Adverse situations

Figure 4: CHPCA's Square of Care and Organization – Functions

Preliminary research conducted by the Quality Palliative Care in Long Term Care Alliance (QPC-LTC) research team indicated that current practice in LTC is not consistent with this CHPCA model of care. Very few of the issues in palliative care, beyond physical care and disease management, are being consistently addressed in LTC homes, and the existing care processes are not inclusive of all the steps outlined in the care process. Data suggested that these gaps in care relate, in part, to lack of resources and other factors in the organizational context of the LTC homes. The influence of resources and functions developed by the CHPCA on the delivery of palliative care in LTC has not been previously investigated and requires attention from researchers. Further, use of the Square of Care to implement organizational change related to resources and functions in LTC has not been reported in the literature. This thesis research aims to address these gaps in knowledge.

For this thesis research, the CHPCA's square organization model will provide a framework for an organizational assessment of the resources and functions of two Ontario LTC homes that are part of the QPC-LTC Alliance project. This research will help determine how these organizational functions and resources support or enable the creation and delivery of a palliative care program as well as how they may result in gaps and barriers that interfere with the development and growth of palliative care and end of life programs within each of the LTC homes. This organizational assessment will allow each LTC home to identify what next steps to include in their action plan for creating and delivering a more formal palliative and end of life program within each of their facilities. These data will be assessed using the CHPCA's Square of Care and Organization framework.

It is important to note that LTC like most organizations is very complex in nature. "With respect to environments, complexity is equated with the number of different items or elements

that must be dealt with simultaneously by the organization" (Anderson, 1999, p. 217).For the purpose of this research the resources and functions as identified in the CHPCA Square of Organization will represent the items or elements required to develop palliative care as a new formalized program. Within organizations such as LTC the elements can also be seen to change in a non-linear fashion. "In nonlinear systems, intervening to change the behavior of the whole system, and the whole system can be very different from the sum of the parts." (Anderson, 1999, p. 217) Thus, when one resource or function changes within the organization it can create change among the other resources and functions and the LTC organization as a whole. The two conceptual frameworks for this research, the CHPCA Square of Organization and the Kelley Capacity Development Model are consistent with and support the view of LTC homes as a complex system requiring incremental and cumulative changes in multiple elements.

Situating the Research in the Researcher's Life Context

My personal experience, educational experiences, and research experiences have all contributed to my ability and my choice to complete this thesis. The topic evolved from the importance that palliative care and long-term care have had in my personal life. My academic training in Social Work and Gerontology have shaped the theoretical approach I have taken.

From a very young age, I was exposed to deaths of family members. At a very young age I was exposed to the deaths of both my grandfathers, only years apart. One of my grandfathers lived with my family and I while receiving therapy at the hospital for stomach cancer. I remember pureeing his food, waiting in the waiting room at the cancer clinic during his treatment session, and also helping my mother and grandmother (as much as I could as a child) with his care.

Even though I did not fully understand dying or the dying process, it gave me a sense how important family and care are when someone's health is declining. The deaths of both of my grandfathers were not sudden but predicted, which allowed time for family, advanced care planning, and caregiving.

A couple years ago, my grandmother became ill. Unlike my grandfathers, my grandmother chose to move into a LTC home as she was having a slow but steady decline in health. My grandmother was very aware of the benefits and disadvantages of LTC as she was a primary caregiver to her aunt in LTC earlier in life. As a loved one visiting my grandmother in her new home I realized quickly some of the benefits and shortcomings of this changing situation. This sparked my interest in gerontology.

Learning about gerontology in general and more specifically palliative care continued to fuel my need to understand more about the LTC and how to better navigate the health system in order to have the best care possible for my grandmother and other aging seniors. Social Work training has given me the ability to critically look at the policies and system approach to palliative care.

Five years later, my grandmother is still living in LTC. I had the opportunity to be a student trainee on a project that focused on what interested me in learning about gerontology from the beginning. I worked with a research team that looked into at the perspective of palliative care delivery in LTC included staff, resident, and their families.

This project has also given me the opportunity to complete the follow thesis and better understand the present state of palliative care delivery in context by looking at the organization of LTC homes.

Chapter Two: Relevant Literature

The following section will explore literature relating to palliative care and long-term care. It will begin with a brief overview of LTC homes specifically within Ontario, and then will proceed into exploring some of the organizational culture that has been reported within the literature, and then will explore literature from each resource and function domain listed within the CHPCA square of care and organization that is relevant to providing palliative care in LTC homes.

Overview of Long-Term Care

Canada has a great diversity in health care delivery changing from province to province. LTC homes are governed by provincial legislation. In Ontario, the Ministry of Health and LTC sets provincial standards and policies regarding the provision of services to residents as well as the operation and management of LTC homes. Table 1 outlines the characteristics of LTC homes in Canada.

Table 1: Characteristics of Long-Term Care in Canada, (Armstrong et al, 2009)

Facilities	2, 089
Approved Beds	206, 170
Residents	196, 242
Beds per Facility	95.5
Full-Time Employees	82, 645
Part-Time Employees	76, 090
Paid Hours	335, 127, 707
Salaries and Wages ($)	$ 6, 992, 966, 143
Total Expenses ($)	$ 10, 852,242, 676
Total Revenues ($)	$ 10, 993, 732, 092
Profit Margin ($)	$ 141, 489, 416

Each province has a mixture of the following types of LTC homes which include: for profit homes, not-for profit homes, and homes run by a municipality. Not all provinces have the same

number of each type which makes direct comparisons difficult. For instance; "in Ontario 52% of publicly funded nursing homes are for profit, as compared with 15% in Manitoba" (McGregor et al. 2005, pg. 645). Table 2 outlines characteristics of LTC homes more specific to Ontario as both LTC being explored within the thesis are located within Ontario.

Table 2: Ontario Long-Term Care in Numbers (Armstrong et al, 2009)

Total beds in 2004	70, 100
Total LTC homes	577
For-Profit	343
Non-Profit	68
Municipal Homes	102
Charitable Homes	64
Per Diem (per resident) in 2008	$51.88-69.88
Accommodation Cost in 2008 per month	$1578 to $2125
Average Age	83
Sex	76.6% Female
Care (RN, RPN, aide)	2.04 hours

For the purposes of this study, I will focus upon the care provided in Ontario. The history of LTC in Ontario provides an explanation to why the province has the most for-profit homes (Ontario Health Coalition, 2002) compared to other provinces within Canada. Due to a shortage of LTC beds to meet the demands "contracts for the construction of 20,000 desperately needed new LTC beds in Ontario, more than two-thirds have been handed over to the private sector." (Ontario Health Coalition, 2002) The result of this shift in private ownership from what was once a service offered by the municipalities, "Ontario's facility-based long-term sector is more than ever a two-tiered system – 60% of beds are now reserved for those who can afford to pay an additional daily fee for 'preferred' accommodation." (Ontario Health Coalition, 2002). It is also important to note that "provincial waiting lists for admission to a LTC facility are at their highest levels ever." (Ontario Health Coalition, 2002)

The residents who access LTC services have also changed throughout the years. Currently, "the average age of a LTC home resident is 83 years." (Sharkey, 2008) There also has been a noticeable increase in the care needs that residents require. "More than 85% of residents are classified as requiring high levels of care including constant supervision and assistance in performing one or more activities of daily living (ADL) including dressing, eating or toileting." (Sharkey, 2008) And, staff are also needing to consider the increased cognitive impairments that residents have and the number of residents that have cognitive impairments "approximately 73% of residents have some form of cognitive impairment, including Alzheimer's disease and related dementia." (Sharkey, 2008)

Culture of Long-Term Care

The culture within LTC homes has a large influence in the care that is provided. Several studies have emerged indicating the unique cultural components of LTC homes. These cultural components have impacts and are important to consider when developing and delivering formal palliative care programs. One aspect to consider with regards to the culture in LTC homes is its hierarchical structure. This refers to the hierarchy of professional authority and status that is linked to qualifications and role or scope of practice. For example, physicians in LTC are the most qualified and have the most status and decision-making authority followed by registered nurses. It was indicated through the work of Foner (1995) that personal support workers, who were found to be at the bottom of the hierarchical structure, had extensive responsibilities but little status and autonomy in practice. When looking at the relationship between personal support workers and nursing staff, Jervis (2002) explained that personal support workers feel a lack of independence and felt controlled by the nursing staff. And finally Dupuis and Wiersma

(2007) noted that nursing staff indicated that they felt that personal support workers did majority of the work and how front line staff felt a lack of support from supervisors.

Also relevant to the current culture in LTC homes is the lack of knowledge of palliative care by staff. Watson, Hockley, and Dewar (2009) reported a lack of education regarding palliative care given to staff within LTC homes in England. When asking medical directors in Ontario about their palliative care education, "most respondents (90%) agreed that their undergraduate medical education did not give them adequate training in palliative care" (Brazil, Bedard, Kruegar, Taniguchi, Kelley, McAiney, & Justice, 2006, p.472). Other authors also reported that health care aids wanted a variety of types of education. "In terms of knowledge and skills, participants would like to receive education on geriatric conditions, training in dealing with death and dying, brief but focused counseling skills especially for handling residents with greater frailty" (Lo, Kwan, Lau, Kwan, Woo, 2009, p. 268).

Financial Resources

LTC homes receive two types of funding. The first type of funding is given to the homes by the Ministry of Health and Long-Term Care. Residents living within a LTC facility also have to pay a co-payment to help supplement the ministry funding in order to pay for the costs of the LTC facility.

The Ministry of Health and Long-Term care determines the funding by looking at the amount of care each resident needs within the home. "The system is based on seven categories ranging from 'A' (light care) to 'G' (heaviest care)" (Ontario Health Coalition, 2002). The care needs of each resident are evaluated annually using the Alberta Classification System and includes eight indicators that identify the level of care which the resident requires. The eight

indicators to determine a resident's level of care includes: eating, toileting, transferring, dressing, potential for injury to self or others, ineffective coping, urinary continence and bowel continence.

The two homes (or cases) within this study were pilot homes for the new form of funding determination and thus did not use the Alberta Classification during the time of the data collection during data collection. The legislation regarding funding recently changed on July 1, 2010 and since that data all long-term care homes are now required to use the funding system that was piloted within the two homes as well as some others in the province. The new standard that the Ministry of Health and Long-Term Care uses to determine resident care needs and thus the level of funding it called the Resident Assessment Instrument Minimum Data Set or RAI-MDS 2.0. The two cases began this new system in 2007. This review is conducted by the Ministry of Health and Long-Term Care. "The Ministry of Health hires registered nurses as 'classifiers' to undertake assessments of the facilities. Their task is to review residents' records from the previous three months and categorize them based on their 'care requirement' " (Ontario Health Coalition, 2002)."It classifies patients into one of seven groups based on four activities of daily living (eating, toileting, transferring, and dressing), two behaviours of daily living (potential for injury to self or others and ineffective coping) and two for continence (urinary and bowel continence). The data is then grouped together to determine the Case Mix Measure (CMM), or total care requirements, of all residents in each facility." (Ontario Health Coalition, 2002) The average score is 100 in Ontario and thus those above this score receive a larger amount of money in proportion with their score.

Ontario's LTC home accommodation fees are the largest within Canada. In 2001 the following rates were found:

Table 3: *Comparative Basic Accommodation rates of province, as at November 21 (Ontario Health Coalition, 2002)*

Province	**Minimum Daily Accommodation Rates**	**Minimum Monthly Accommodation Rates**
British Columbia	$27.20	$816.00
Alberta	$28.22	$858.21
Saskatchewan	$27.23	$817.00
Manitoba	$25.80	$774.00
Ontario	**$44.21**	**$1326.30**
Quebec	$27.76	$836.80

When funding is received by the LTC home from the Ministry of Health and Long-Term Care it is said to be delivered in envelopes. "LTC funding in Ontario is allocated through the following four funding envelopes: 1) nursing care and personal care, 2) program and support services, 3) raw food and 4) accommodation costs (facility costs, administration, housekeeping, building and operational maintenance, and dietary and laundry services.)" (Armstrong et Al, 2009)

Human Resources

Within LTC homes the adequacy of the human resources plays an integral role in integrating a palliative care program. Not only is it important to have sufficient staff, but it is also important to have mixed skill level, job satisfaction, appropriate number of full time, part time, and casual staff, and to take in consideration the resident needs when determining a staffing ratio, which will be explored below.

Within the literature the theme of challenges in maintaining staff levels is prevalent; recruitment and retention of qualified staff seems to be a struggle within most LTC homes. "Demographically, the balance is shifting between the number of people who need care services and the number willing and able to provide them" (Abbey, Froggatt, Parker, &Abbey, 2006, p. 57). However, there appear to be differences between the for-profit and the not-for-profit sector that is represented by the two private non-for-profit, faith-based LTC homes that are

participating in this thesis study. “The American literature has also shown that, compared with for-profit nursing homes, not-for-profit facilities have higher direct-care staffing levels and lower staff turnover rates.” (McGregor et al., 2005)

There are also issues related to the mix of staffing in LTC homes. This relates to the number of professional registered staff (e.g. nurses) versus the non-registered staff (e.g. personal support workers or health care aides). “Higher numbers of registered-nurse hours per-day have been associated with fewer violations of care standards and improved functional ability of residents.” (McGregor, Cohen, McGrail, Broemeling, Adler, Schulzer, Ronald, Cvitkovich, & Beck, 2005) Staff ratios and turnover are important when looking at developing palliative care program.

Information Resources

The literature speaks a lot about technology and how that can help facilitate palliative care delivery. If sufficient information is present and information technology is applied properly it can be a great benefit for the development and more effective formal palliative care program. The opportunity for staff at all levels to have access to information technology for gaining clinical knowledge, communicating with members of the health care team, overcoming professional isolation, improving record keeping and providing quality assurance opportunities should not be underestimated (Abbey, Froggatt, Parker, &Abbey, 2006) “Technology should be seen as only a tool, not a master of what we do, despite its insidious capacity for inserting itself the provider and recipient of service in ways that limit, apparently objectively, what is possible within the relationship” (Abbey, Froggatt, Parker, & Abbey, 2006, p.?)

Physical Resources

Physical resources within LTC homes have a great impact on how palliative care can be developed and delivered. When considering a palliative care program it is important to look at the structure of the LTC home. “However, organizational constraints may work against staff developing relationships that lead to a person-centered approach, such as increasing workloads that does not allow staff sufficient time to be devoted to begin with older people in their care” (Brown Wilson, 2009, p.178). The issue was also raised regarding having the proper medications available in order to provide adequate pain management. If a resident was not prescribed pain management medication in the past it is hard to access medication when needed and LTC homes are not suited with ‘emergency pain kits.’ “Nursing homes are not permitted to hold stock drugs unless they are for a named resident; it was often felt that prescribing pain medication was potentially a waste of money as drugs were destroyed if not used.” (Watson, Hockley, & Dewar, 2006, p.236)

Governance and Administration

As seen in Figure 4: *CHPCA*’s Square of Care and Organization – Functions, this section has two main categories: Leadership and Organization. Leadership includes a governing board, and management and organization includes the structure and accountability system.

A major theme within the governance and administration aspect of providing palliative care is that the managers must be on board with the change and be active within the change process for that change to be successful. Leaders of corporate and not-for profit organizations who manage groups of institutions, and leaders of individual care providers need to be confident and

supported about the relevance, importance, and provision of palliative care at the end-of-life (Abbey, 2006, p.60)

Operations

The Canadian Hospice Palliative Care Association also outlines the operations within an organization to be important when looking at the functions and how they guide palliative care. As seen in Figure 4: *CHPCA*'s Square of Care and Organization – Functions. This section goes beyond having the item but how it is used. The Operations domain is divided in three different sections which include: standards of practice, policies and procedures, resource acquisition and management, and safety, security, and emergency systems. The resource management and acquisition section is broken down into sub-categories which include: fund development, financial resources, human resources, informational resources, physical resources, and community resources.

The human resources portion of the operations piece was very strongly identified within the literature as important when developing and delivering palliative care. To begin the literature talks strongly regarding the education and experience level of staff. It was stated that it is important for staff to understand clearly how palliative care is defined and what can be offered to residents who are in need of those services "Some individuals, because of life events, do face up to their own mortality, but for the vast majority this is not addressed ahead of time. It is important that people have knowledge about the different kinds of palliative care available and the need for advance directives to guide this care when the person is no longer able to do so." (Abbey, 2006, p.60) There was also literature acknowledging that most staff not equipped with the knowledge to provide informed pain management. An article written by Watson, Hockley, and Dewar in 2006 called *Barriers to Implementing an Integrated Care Pathway for the Last*

Days of Life in Nursing Homes noted that before receiving interventions many of the staff members were lacking knowledge surrounding pain control and medications used in palliative care (p 236).

Another important consideration that was documented within the literature is the use of multidisciplinary teams. It recognizes that there are many different disciplines that need to be involved when providing palliative care and these specialists also need to work together in order to have seamless provision of care." Using a care pathway for the last days of life assumes that nurses, carers, families, GPs normally come together in order to make a decision that someone is dying – a diagnosis of dying. Such teamwork was lacking in a number of nursing homes and caused difficulties around end-of-life decision making" (Watson, Hockley, Dewar. 2006, p. 237).

There is an acknowledgement in the literature that staff members need to possess positive care giving traits in order to provide palliative care and that their attitudes effect the care that they will provide. "Personal philosophies often influence how individual staff members approached their care, and staff often referred to a 'good team' that comprised others with a similar approach." (Brown Wilson, 2009, p. 182)

Finally, there was an understanding that grief and loss supports are very important for those providing palliative care. An important aspect of the literature review also speaks about the importance for nursing staff to grieve. With a study conducted by Kaasalainen et al. noted that "nurses repeatedly spoke of their need to take time to grieve themselves, but often they were deprived of this opportunity" (Kaasalainen, Brazil, Ploeg, Schindel Martin, 2007, p. 178).

Quality Management

Quality Management is another organizational factor that must be considered when delivering palliative care within any setting. As seen in Figure 4: *CHPCA*'s Square of Care and

Organization – Functions. When assessing quality management the figure shows that one must look at performance improvement and routine review of the organization. The figure outlines that for performance review one looks at outcomes, resource utilization, adverse events and satisfaction where as for routine review one looks at utilization review, risk management, compliance, caregiver and employee satisfaction, community needs, financial audit, external accreditation, strategic and business plan, and standards of practice, polices and procedures. LTC homes in Ontario are heavily mandated with their regulations and quality measures being enforced by the provincial government and, in some case, the individual home as well. The following are only two of the quality enforcement managers that assess LTC homes in Ontario: the Ministry of Health and Long-Term Care public online reporting and the Ontario Health Quality Council public reporting system.

One of the quality assessors is the public reporting process of inspections made by the Ministry of Health and Long-Term Care. To improve quality of life for those living in LTC homes and to provide information to the public, the Ministry began publishing online reports regarding their inspections. The reports are home specific and the public may gain access to the specific reports by looking up the homes through map, postal code, city, or home name directories. The reports provide the public with general information regarding the coordinating Local Health Integration Network and Community Care Access Centre, the administrator and organization, number of beds, information regarding resident and family councils, LTC home accreditation, and a summary of last inspection that would include any infractions. More specific information regarding inspection findings and verified complaints can be accessed. This information is provided along with provincial averages so that one may compare the infractions by the LTC home to the provincial average. The information provided to the public does not

include specific information regarding palliative care as it is not currently being assessed within long-term care homes.

In September 2005, the Ontario Health Quality Council began their first initiative to examine the measuring and reporting to the public on the quality of LTC, resident satisfaction, and home care alternatives. However since that time, their mandate has expanded greatly to include: monitoring and reporting to the people of Ontario, supporting continuous quality improvement, and promoting health care that is supported by the best available scientific evidence.

The LTC home online reports provide the public with scores for a number of different medical themes at a provincial and home level. Provincial scores are reported on the following themes: bladder function, mobility and daily tasks, pain control, mood, language / memory / thinking, weight and nutrition, and potential preventable emergency department visits. When looking at individual home results they report solely on four categories which include: falls, new pressure ulcers, worsening pressure ulcers, and bladder functioning. They do not include palliative care or end-of-life care measurements.

Chapter Three: Research Purpose and Questions

Research Purpose

This research paper is a sub-study of the SSHRC funded Community University Research Alliance Project (CURA) called "Improving Quality of Life for People Dying in Long Term Care Homes". The overall goal of the CURA research is to form a Quality Palliative Care in Long Term Care Alliance that will develop strategies and best practices for creating formalized palliative care programs in LTC homes. The Alliance has adopted two conceptual frameworks to guide the research. The Kelley model of Community Capacity Development (2010) guides the process of organizational change and the CHPCA model for palliative care (Figure 2) has been adopted as the conceptual framework for palliative care program development. As a sub-study of the larger study, this thesis research thus uses these two frameworks to assess organizational infrastructure of LTC homes.

The purpose of this thesis research is to assess the infrastructure of two LTC homes in Ontario as a step towards developing their capacity to implement formalized palliative care programs. Having sufficient infrastructure is one of the four antecedent conditions in the Kelley Capacity Development model (2010). For this assessment, the research will apply the CHPCA square of organization (functions and resources) as an organizing and analytic framework.

Introducing the Two Long-Term Care Homes

The two LTC homes that are involved in this research are non-profit and operated by a faith-based organization. They both have residents' councils, family councils and are currently accredited. Both LTC homes state that they provide a variety of services including: nursing and personal care, physician coverage, medical supplies, personal care supplies, nutritional meals,

bedding and linens, bedroom furnishings, housekeeping, laundry, spiritual care, recreational activities and prescription medication.

Services provided with additional fees include: telephone, cable, subscriptions to magazines and newspapers, hairdressing, gift shop, assisted devices, transportation, foot care, alternative incontinent products, fees for some activities and outings, and additional physiotherapy.

The following services are available on referral: occupational therapy, physiotherapy, speech therapy, professional chiropody, geriatric assessment, social work, psychogeriatric assessment, and other medical specialists.

Home A

Home A is an older LTC home. It was built in 1979 and is an older LTC home. This LTC facility currently houses 110 residents. There are three classifications of accommodations offered at this home which include basic, semi-private, and private. Within a basic room there are three beds, a washroom and a shared sunroom between two of the basic accommodation rooms. The semi-private rooms there are two beds within the room, one bathroom, and a sunroom shared by two semi-private rooms. A private room has one resident, a private bathroom and a sunroom. In this LTC home there are 60 basic rooms, 42 semi-private rooms, and 8 private rooms. The building also houses a variety store, a hairdressing shop, a supportive housing facility, as well as some offices for local community organizations including a hospice volunteers, physiotherapy, and a swimming pool.

Home B

Home B is a new home that opened in 2005. It houses 96 residents and like Home A offers three accommodation types. Although the room classifications have the same names they

are very different. A basic room is a one bed room that has a shared bathroom with another room. A semi-private room is a one bed room with a shared bathroom but has 12 square feet more of living space. A private room is a one bed room with a private bathroom and special furnishings. Within this home there are 40 basic rooms, 28 semi-private rooms, and 28 private rooms.

Comparison of Staffing and Client Care Needs

The table below (Table #4) compares the number of staff that each home had during the 2008 reporting period:

Table #4: Hired Nursing Staff (FT- full time, PT – part time, C –Casual)

Staff Type	Home A (110 beds)	Home B (96 beds)
Registered Nurse	FT- 2 PT-6 C-8	FT-3 PT-3 C-8
Registered Practical Nurse	FT-5 PT-4 C-11	FT-5 PT-5 C-8
Personal Support Worker	FT-22 PT- 36 C- 8	FT-18 PT-23 C-25

Both homes also have a director of care, assistant director / nursing manager, nursing secretary, staffing coordinator, activity director and staff, dietitian, volunteer coordinator, and spiritual care associate. As mentioned in the financial resources section of the literature review, each home is assigned a Case Mix Measure or CMM determined by residents level of care need and used to establish funding. For the month of June 2010 Home A had a CMM of 112.66 and Home B had a CMM of 97.51. This means that the level of care of residents in Home A was greater than Home B. Home A also has more staff as indicated in Table 4.

Research Questions

1. What organizational resources and functions exist in the study homes to enable the development and delivery of formal palliative care programs?
2. What are the gaps or barriers in organizational resources and functions within these two homes for the development/delivery of a formal palliative care program?
3. What are the priority areas for change in organizational infrastructure (resources and functions) in order to increase capacity to develop and deliver palliative care in these LTC homes?

Defining Key Terms

- Resources: the assets and means available within the LTC organization including financial, human, information, physical, and community.
- Functions: the organization's governance and administration, planning, operations, quality management (evaluation), and communication / marketing.
- Formal palliative care programs: a clearly defined organizational policy and procedure for providing specialized and holistic care to residents who are dying that aims to alleviate suffering (physical, emotional, psychosocial or spiritual) consistent with the CHPCA Square of Care and Organization rather than a traditional medical model of care that aims to find cures for ailments.
- Gaps: A resource or function that does not exist and is required to develop a formalized palliative care program.
- Organizational barriers: A resources or function that exists but does not allow for the development of a formal palliative care program.

Importance of this Research

In general, this research will apply the CHPCA Square of Care and Organization to two LTC homes. The model was created with the premise that all health care organizations could guide themselves in delivering palliative care services. The CURA research team has not found any attempts to apply this model to LTC homes. This research could provide an example and some that other LTC homes could use to compare and assess how the organizational piece will impact their own palliative care development and delivery.

This research will benefit the overall SSHRC grant *Improving Quality of Life for People Dying in Long-Term Care Homes* as it will complete their analysis of their environmental scan data looking at how the resources and functions effect the common issues and processes of care as outlined by the Square of Care and Organization. The results will also be presented to management and the palliative care teams at the research homes so that they may understand how the organizational infrastructure affects their venture to develop and deliver their own formalized palliative care programs.

Chapter Four: Research Design

Design of the Community University Research Alliance Project

This thesis is a sub-study of a larger project called *Improving Quality of Life for People Dying in Long-Term Care Homes* which is a five-year Community University Research Alliance (CURA) research study funded by Social Sciences and Humanities Research Council of Canada (SSHRC.) The Alliance members include: staff, residents, and families of four LTC homes; community partners; and researchers. The project is based out of the Centre for Education and Research on Aging and Health (CERAH), Lakehead University.

A participatory methodology is being used to conduct overall research that has the ultimate goal of creating a toolkit of formal palliative care programs in LTC homes nationally. The thesis study maintained the main Participatory Action philosophy as the QPC-LTC Alliance will be presenting these thesis findings back to each home and allowing them to act on the findings as they wish.

There are four homes that are participating in this project which include two homes in Northern Ontario and two homes in Southern Ontario. This thesis study focused only on the two LTC homes in Ontario.

Thesis Methodology

The methodology used for this thesis was a comparative case study design. "A case study is an exploration of a "bounded system" or a case (or multiple cases) over time through detailed, in-depth data collection involving multiple sources of information rich in context." (Creswell, 1998, p. 61) There were two bounded systems explored which are defined as bounded by location. These systems were the LTC homes. The reason for choosing a case study approach for this research was because "the strength of the case study method is its ability to examine, in-

depth, a "case" within it's 'real-life' context" (Yin, 2009, p. 111). The case study approach was helpful to get a closer understanding of what the enablers, barriers, and gaps were in the organizational infrastructure of the study homes. Each home was analyzed using the CHPCA Square of Care and Organization's basic functions and resources. A comparison was done to determine how the two homes are similar and how they differ in aspects involving their resources and functions. The analysis was completed by using the following types of research data: transcripts of focus groups and interviews of all levels and types of staff within each home; survey summaries that incorporate the view point of all staff members; and a documentation review of the homes' information packages, policies, and procedures.

Methods

Both primary and secondary data analysis was conducted in this comparative case study. Primary analysis of data included: a document review of several information packages, policies, and procedures of each home.

Secondary analysis was also completed using data collected by the QPC-LTC Alliance project during 2009-2010 as part of the environmental scan of these two homes. These data included: transcripts of focus groups and interviews and survey results. The following is a breakdown of the data that was analyzed for this thesis study.

Documentation Review

Documents outlining policies and procedures were accessed using the home's intranet. The majority of the documents retrieved were specific to each LTC home rather than the larger organizations to which the homes belonged. Other key documents not available on the intranet were also used in the review including: financial documents from the finance manager, the July 1, 2009 to June 30, 2010 inspection report from the Ministry of Health and Long-Term

Care (MOHLTC) as well from Residents First, new employee orientation checklists, resident admission package, and 2009- 2010 organization annual report.

Once documents were collected they were separated into two categories: Category 1- relevant to palliative care, Category 2- not relevant to palliative care. Those documents in Category 1 (relevant to palliative care) were then analyzed using the documentation review tool created for this research to assess whether the documents reported on functions or resources that operated as enablers or a barriers to creating a formal palliative care program (see Appendix B). The document review tool was created to incorporate all the information on the CHPCA's Square of Care and Organization in a friendly format for documenting information. The document review tool provided a consistent and systematic framework for a content analysis of these documents and the review tool could be compared with each document to identify relevant content or gaps in content. It was as important in the analysis to note what was absent from the documents as what content was present.

All documents were kept in a binder for easy reference and stored in a secure area for confidentiality. All intranet policies relating to the organization's LTC homes were reviewed for this thesis. Of these, forty-nine (49) documents were identified to have relevance to palliative care. The remainder of the documents did not have relevant content. Relevance was determined using the domains of the square of care framework. The following is a list of documents that were analyzed. The 49 bolded documents, which were considered to have relevant content, will be reported on in the findings section.

1. **Community Report 2009-2010**
2. **Annual Report 2009-2010**
3. **Accreditation**
4. Electronic Communication
5. **Internal Communication**
6. Library Services
7. Quality of Care Reviews
8. Guidelines for Quality Care Reviews
9. Global Policy and Procedure Development Part
10. Consent to Treatment Part
11. Resuscitation Orders
12. Advance Directives
13. Disagreement with Treatment Plan
14. Bill of Rights
15. Complementary Therapies
16. Healing Touch
17. Pronouncing Death
18. Documentation
19. Client Care Standards
20. Client Nutritional Intake
21. Client Hygiene
22. Client Sleep/ Rest Patterns
23. Client Activity Patterns
24. Recruitment of Staff
25. Attendance Management
26. Attendance Monitoring
27. Resident Assessments
28. Resident Care Plan
29. Oxygen Therapy
30. Restorative Care
31. Spiritual and Religious Programs
32. Medical Assessment
33. Resident Satisfaction Survey
34. Transfer of Resident
35. Resident Care- Post Hospitalization
36. Resident Death
37. Unplanned Resident Weight Change
38. Skin Care and Wound Management
39. **New Employee Resident Checklist for Registered Nurses**
40. **New Employee Resident Checklist for Registered Practical Nurses**
41. **New Employee Resident Checklist for Personal Support Workers**
42. **New Resident Admission Handbook for Home A**
43. **New Resident Admission Handbook for Home B**
44. **LTC Home Payment Calculation Notice for Home A**
45. **LTC Home Payment Calculation Notice for Home B**
46. **Ministry of Health and Long-Term Care LTC Home Reporting (April 2009-March 2010) Home A**
47. **Ministry of Health and Long-Term Care LTC Home Reporting (April 2009-March 2010) Home B**
48. **Resident's First Report Home A**
49. **Resident's First Report Home B**

Focus Groups and Interviews Analysis

The QPC-LTC Alliance collected interview and focus group data from all staff that were present within the homes on the dates of data collection and that were willing to participate. Overall participation rates were high as indicated in the footnote below[2] however some staff were on vacation or not working at the time of the data collection. The following table (Table 4) summarizes the total number of participants from each department and the number of focus groups or interviews conducted in total.

Table #4: Interview and Focus Group Participation

Dataset	**Department**	**Home A**		**Home B**	
		Total # of Participating Staff	**# of Focus Groups or Interviews**	**Total # of Participating Staff**	**# of Focus Groups or Interviews**
Staff Focus Groups	PSW Administration Housekeeping Dietary Maintenance Recreation	32 8 10 3 2 3	8 1 1 1 2 1	17 8 6 3 1 2	6 1 1 1 1 1
Staff Interviews	RN and RPN	11	11	9	9
Total		**69**	**25**	**46**	**20**

Registered nurses and registered practical nurses were interviewed instead of speaking within focus groups as there were only one or two available during a shift to complete the interview. One will also notice that some focus groups do not have the traditional number of participants (6 to 8 participants). It was required to do focus groups with as few as 2 participants

[2] The participation rate for each of the groups of employees was as follows: PSW Home A (60.4%), and Home B (38.6%), Administration Home A and Home B (61.5%), Housekeeping Home A (58.8%), and Home B (54.4%), Dietary Home A (10%), and Home B (21.4%), Maintenance Home A (66.7%), and Home B (50%), Recreation Home A and B (100%), RN / RPN Home A (68.8%), and Home B (56.3%)
.

as the home could not manage with daily tasks if many staff were pulled off the floor at one time to complete the focus group.

The interview guide (Appendix C) outlines the 16 questions that were asked during each focus group and interview. Although the data from the entire transcript was thoroughly read and examined for organizational implications to providing palliative care, an emphasis was placed on questions 10, 11, 12, and 14 as they were most relevant to the research questions. These four questions were:

10. What challenges do you experience in addressing the physical, social, psychological and spiritual needs of dying residents and their families?

11. What things facilitate or help you in providing good palliative care?

12. How well do you think the current policies and procedures in this home meet the needs of people who are dying and their families?

14. What would be your vision for change with regards to providing care in this Home? What could be done in [name of LTC home] to help realize this vision?

The CHPCA Square of Care and Organization (Figure 2) was used to guide the creation of categories after the relevant document content was identified and inductively coded using the document analysis tool previously discussed.

Using the data described, a systematic process of analysis was used guided by the research questions that focused on understanding the resources and functions, gaps, barriers, enablers and priorities for organizational change related to the development of palliative care programs. For the focus group and interview data, all of the transcripts were first read thoroughly. Then the content analysis of the transcripts began. The transcripts were read a second time and each of the ideas contained in them were compared with the document analysis guide to identify the data relevant for this research. All ideas relevant to the document analysis

guide were next highlighted using a coloured marker, a different colour of marker used to identify different types of content (gaps, barriers, enablers etc). These ideas were sorted and put into thematic categories. The categories were drawn from the CHPCA Square of Organization's domains related to the functions and resources required for palliative care delivery. This process used the conceptual framework in the analysis. Using these steps in the analysis allowed all relevant ideas to emerge from the documents but linked them to the conceptual framework to understand how the categories of functions and resources affected the development and delivery of formal palliative care programs within the two LTC homes.

Surveys

An analysis of the results of six surveys was also completed for this thesis. The survey findings had been analyzed previously in SSPS by the QPC-LTC. For each survey, the results were reported in a two-page summary and shared with staff from the LTC homes. The six survey summaries were used as documents and analyzed for this thesis since the findings describe and illustrate aspects of the functions and resources of the organization[3].

Quality in Action Survey- QiAS

The Quality in Action Survey measures six different domains that include: patient focus, management style, teamwork orientation, improvement orientation, mission and goals orientation, and personal influence and performance. All staff were eligible to complete the survey. They were asked several questions that were related to the domains and were able to score their perceptions on a scale from 1 representing a score of 'strongly disagree' and 7 representing a score of 'strongly agree.' The forty four question survey can be found in Appendix D and the results of the survey in Appendix K.

[33] These survey results documents were thus used as documents and analyzed descriptively. There was no statistical analysis performed on these survey data for the thesis.

Frommelt Attitude Toward Care of the Dying Scale- FATCOD

This survey measures attitude towards caring for those who are dying. All staff were eligible to complete the survey. They were asked several questions that were related to providing care to those who are dying and were able to score their perceptions on a scale from 1 representing a score of 'strongly disagree' and 5 representing a score of 'strongly agree.' The thirty two question survey can be found in Appendix E and the results of the survey in Appendix L.

Self-Efficacy in End-of-Life Care - S-E in EOLC

Self-Efficacy in End-of-Life Care Survey measures three different domains that include: patient management, communication, and multidisciplinary teamworking. Nursing staff (Registered Nurse, Registered Practical Nurse) were eligible to complete the survey. They were asked several questions that were related to providing care to those who are dying and were able to score their perceptions on a scale from 1 representing a score of 'cannot do at all' and 5 representing a score of 'certain can do.' Survey can be found in Appendix F and Results in Appendix M.

Palliative Care Quiz

Palliative Care Quiz is a tool to assess basic palliative care medical knowledge of nurses. The twenty question survey can identify areas in which the nursing staff have satisfactory knowledge and areas where more education is needed. Nursing staff (Registered Nurse, Registered Practical Nurse) were eligible to complete the survey. The survey can be found in Appendix G and the results in Appendix O.

Personal Empowerment in the Workplace- PEiW

The Personal Empowerment in the Workplace survey measures four different domains that include: meaning, competence, self-determination, and impact. Personal

Support Workers were eligible to complete the survey. They were asked several questions that were related to the three domains and were able to score their perceptions on a scale from 1 representing a score of 'strongly disagree' and 7 representing a score of 'strongly agree.' The twelve question survey can be found in Appendix H and the results of the survey in Appendix N.

Supervisory Support Survey

The Supervisory Support survey measures three different domains that include: empathy, reliability, and nurturing connection. Personal Support Workers were eligible to complete the survey. They were asked several questions that were related to the domains and were able to score their perceptions on a scale from 1 representing a score of 'never' and 5 representing a score of 'always.' The survey can be found in Appendix I and the results of the survey in Appendix P.

The results summaries of the surveys were examined in relation to the research questions and survey findings were used to show discrepancies or reinforce ideas that were presented in the documents or focus group and interview data. Of interest was the similarity and differences between data sets as they addressed the research questions. Table #5 outlines the participation rate for each survey.

Table #5: Participation Numbers for the Surveys

Instrument	**Total # Participants**	**Home A # Participants**	**Home B # Participants**
FATCOD	104	57	47
QiAS	108	61	47
PEiW	74	47	27
Supervisory Support	52	31	21
S-E EOLC	19	11	8
Palliative Care Quiz	20	12	8

The table above depicts what survey data were used to enhance document, focus group, and interview data for the analysis. Overall participation rates were high as indicated in the footnote below[4]; however, some staff were on vacation or not working at the time of the data collection.

Rigour

Yin proposes that the tests of research rigour include trustworthiness, credibility, conformability, and data dependability (Yin, 2009, p. 40). These criteria as well as the procedures used to determine if research is rigourous should be specific to the research purpose. This research is trying to understand how the organizational infrastructure of two LTC homes is affecting the development and delivery of a palliative care program. Thus, because this research is using a case study methodology and being done to 'understand' a phenomena in context, the criteria of trustworthiness will be the concept for rigour. There are many ways in which trustworthiness can be shown which include: triangulation, member checking, thick description, prolonged engagement, persistent observation, appropriate and adequate sampling, seeking negative cases, collecting and analyzing concurrently, reflectivity, peer review, audit trial, external audit, and code-recode strategy. The Table 6 depicts how rigour was maintained within this thesis.

[4] The participation rate for each of the groups of employees was as follows: FATCOD Home A (62.6%), and Home B (58.6%), QiAS Home A (67%), and Home B (58.8%), PEiW Home A (88.7%), and Home B (61.4%), Supervisory Support Home A (58.5%) and, Home B (47.7%), S-E EOLC Home A (68.8%) and Home B (44.4%), Palliative Care Quiz Home A (75%) and B (44.4%)
.

Table #6: Procedures to Ensure Rigour in the Thesis

Procedure for Rigour	Definition of Procedure	How was Procedure Completed
Triangulation	"Researchers make use of multiple and different sources, methods, investigators, and theories to provide corroborating evidence" (Creswell,1998, p.202).	Analysis used survey analysis descriptive results, document review and interviews and focus groups to determine if all three sources of data gave a similar image.
Collecting and analyzing concurrently	Data is collected and analyzed simultaneously	Data was collected and analyzed during the same period of time.
Reflexivity	"Reflexivity in qualitative research specifically invites us to look 'inward' and 'outwards', exploring the intersecting relationships between existing knowledge, out experiences, research roles and the world around us" (King & Harrocks, 2009, p. 125).	The findings are similar to research and other studies completed in the past looking at palliative care and LTC. The findings also resonated with the lived experience of the researcher.
Peer Review	"Peer review or debriefing provides an external check of the research process, much in the same spirit as interrater reliability in quantitative research" (Creswell,1998, p.202).	During analysis of the data , debriefing took place with other research team members on the QPC-LTC team as well as the thesis supervisor and thesis committee members.
Audit Trial	"An audit trail in qualitative research consists of a thorough collection of documentation regarding all aspects of the research." (Given, 2008, p.43)	Analysis decisions were documented throughout the process.
Code, recode strategy	Data is coded but is returned to and re-code to ensure meaning is maintained	Interviews and focus groups were coded and then recoded when new themes emerged to ensure consistency.

Ethical Considerations

This sub-study was conducted under the Research Ethic Board (REB) requirements of the larger study which has been approved by the REBs of Lakehead University and St. Joseph's Care Group. Anonymity was maintained for both the homes and the participants within this thesis study. As some department only have a few staff members, data from small departments have been merged into large groupings or categories to ensure that when the report is handed back to the homes none of the participants will be able to be identified. These categories include: personal support workers, nursing staff, support services staff, and administration.

Limitations of the Research

The two main limitations regarding the thesis research are that the results of this research cannot be generalized to all LTC homes and the results only include the perspectives of staff and information gained from a document analysis. Not discussed are the other two sides of the Square of Care and how they interact with the resources and functions as this was beyond the scope of this thesis.

To begin, although there are similarities between the two homes that were displayed within the data, one cannot generalize these similarities to all LTC homes within the province or the country. Results are only applicable to other LTC homes with similar characteristics and contexts. Both LTC homes studied are operated by the same health care organization, are both faith based and not-for-profit, both house a relatively similar number of residents, and they are both situated within the same geographical location or Local Health Integration Network (LHIN). In addition to the reasons above, the results cannot be generalized to other LTC homes within the country because of the differences between provinces in LTC home services, legislation, and quality or accreditation measures. It is not the purpose of case study research to

generalize findings widely but rather to understanding the dynamics of organizational context in LTC in the cases studied.

Also, because this research is looking at a culture change within specific communities it would be important to capture the thoughts and knowledge of everyone involved within the community. Even though there was a conscious effort to include staff from all levels and departments, it must be noted that the thoughts and information from residents and family were not included within this research. It would be important to consider them and their thoughts when developing and delivering a formal palliative care program as they are a large and important part of the LTC community.

Chapter Five: Findings

In a comparative case study design, an important aspect of analysis is the similarities and differences across cases. It was important to use this methodology because "multiple or collective case study will allows the researcher to analyze within each setting and across settings" (Baxter & Jack, 2008, p.550). This section will now report only on the noteworthy findings that emerged through this research answering the three research questions which were:

1. What organizational resources and functions exist in the two study LTC homes to enable the development and delivery of formal palliative care programs?
2. What are the gaps or barriers in organizational resources and functions within these two homes for the development/delivery of a formal palliative care program?
3. What are the priority areas for change in organizational infrastructure (resources and functions) in order to increase capacity to develop and deliver palliative care in these LTC homes?

Similarities and Difference between the Long-Term Care Homes

This findings section will begin by looking at the similarities and differences between the homes with regards to the various domains: governance and administration, planning, operations, quality measures (evaluation), communications / marketing, financial resources, informational resources, physical resources, and community resources. As an overview, the following table displays the similarities and difference between homes.

Table #7: Long-Term Care Homes Similarities and Differences

Domain	Comparison	Description
Governance and Administration	Same	Both Home A and Home B are part of the same health care organization and thus have the same corporate structure.
Planning	Same	The two homes belong to a larger organization and thus they have the same strategic plan and business plan. This plan is not unique to LTC as the organization offers many different types of health care services other than LTC
Operations	Same	Policies and Procedures are created within the corporation and applied across the corporation. These apply to both homes. There are a few policies and procedures that are specific to LTC but many are global to the entire organization.
Quality Management Mission and Values	Same	Unlike the other functions, this is mainly external to the organization. Both LTC homes must comply with provincially enforced quality control such as the Long-Term Care Home Act & compliance process, accreditation standards and OHQC (quality improvement and public reporting)
Communication Strategy	Same (Internal)	The communication to the public is fairly standardized to the organization but tailored to each home to some degree.
Financial Resources	Different	Both homes receive two sets of dollars. The first set is from the Ministry of Health and Long-Term Care and is dependent on the home's

		CMM which unique. Secondly the homes receive co-payments that differ as they have different numbers of residents, and types of accommodations.
Human Resources	Similar and different Different care processes	They both have access to the same number and type of staff however Home A would like more access to spiritual care and there are slight differences based on individual personalities/interpersonal styles, leadership styles, etc.
Informational Resources	Same but perceived access to clinical information is different with the homes	The layout of each of the homes effect how they access information. Each home has different layouts. Both wanted palliative care protocols and care pathways that could guide client care without waiting for the doctor's orders.
Physical Resources	Same and Different	Home B is newer so that the physical environment is more comfortable and functional. Neither has satisfactory dedicated space for palliative clients and their families. Both seem satisfied with their equipment. Both want an emergency medical kit for palliative clients.
Community Resources	Same	They both have access to similar community resources the difference is how each home decides to use them.

After reviewing Table 7, one can see that the two homes have the same functions however they identify that they have or perceive to have different resources.

Enablers, Barriers, and Gaps to Palliative Care Development and Delivery

The second part of this findings section will look at the break down of each of the domains of the Square of Organization (conceptual framework) and present the results of the analysis of how they impacted palliative care using the information gathered for this thesis. Table 8 outlines the whether the domain and theme were identified as being an enabler, a barrier, or a gap in formal palliative care development and delivery. The table will then be followed by a description of how the analysis leads to the interpretation of identifying each element an enabler, barrier or gap. As previously stated, the survey findings were used for descriptive purposes and to reinforce the document review and focus group and interview data and not to measure statistical significance of differences.

Since the smaller departments of workers were grouped into larger categories to ensure anonymity of the participants, there are only be four categories of staff in the findings: nursing (registered practical nurses and registered nurses), personal support workers, administration, and support services workers (dietary, housekeeping, maintained, and recreation).

Table 8: Findings: Enablers, Barriers, and Gaps

Part 1:Enablers	Part 2: Barriers	Part 3: Gaps
1. *Planning:* Organization Mission and Values	1. *Resources:* Financial Resources	1. *Informational Resources:* Lack of Proper Policies / Procedures
2. *Operations (Human Resources):* Employee Possessing Positive Care Traits	2. *Operations:* Communication Strategies among Staff	2. *Human Resources:* Lack of having access to allied health professionals
	3. *Physical Resources:* Lack of Appropriate Physical Space	3. *Communications and Marketing:* Marketing Palliative Care to Residents and Families
	4. *Governance and Administration:* Working within a Hierarchical Structure	*4.Operations (Human Resources):* Palliative Care Education for all staff
	5. Community Resources: Underutilization of Community Resources	5. *Operations (Human Resources):* Grief and Loss Support for Staff
	6. *Human Resources:* Lack of Human Resources and Time	6. *Quality Management (Evaluation):* Lack of Palliative Care Criteria within Accreditation and Evaluation Measures

Part 1: Palliative Care Development and Delivery Enablers

An enabler for the purposes of this paper was defined as a resource or function that was interpreted to be present in the organization based on the data analysis. This existing resource or function will help the LTC homes move forward when developing and delivering a formal palliative care program. The key enablers that were found within the data included: the mission and vision of the organization are consistent with a palliative approach within the planning domain, and employees possess caring traits within the operations (human resources domain) of the CHPCA model.

1. Planning- Organization Mission and Values

One enabler that can be seen when examining the homes is that their mission and values are compatible with a palliative care approach. This is an enabler for both homes since they are within the same organization and thus have the same mission and value set.

Document Review

The mission and values of the organization are displayed on many of their materials including but not limited to: annuals reports, community reports, new resident admission guide, and website. The mission and values of the organization include words such as: compassionate and holistic care and services, dignity, respect, inclusiveness, faith-based care, truthfulness and trust. Although the mission and values do not include palliative care explicitly, it is implicit within the information present that the concepts are compatible with a palliative approach.

Survey Findings

In addition to having mission and values that are compatible with a palliative care approach it is also important that the staff knows and understands these concepts. When looking at Figure #5, one can see and compare the scores between Home A and Home B with regard to the staff mission and goals orientation. All staff represents administration, nursing staff, personal support workers, and all support staff. The mission and goals orientation of staff was calculated using the Quality in Action survey. The author defined this domain as "the staff's perceptions of the extent that they and others understand the mission and goals of the organization and how their work relates to them." These results show that both homes received a similar score which was around a mid 4 points out of a 7 point scale.

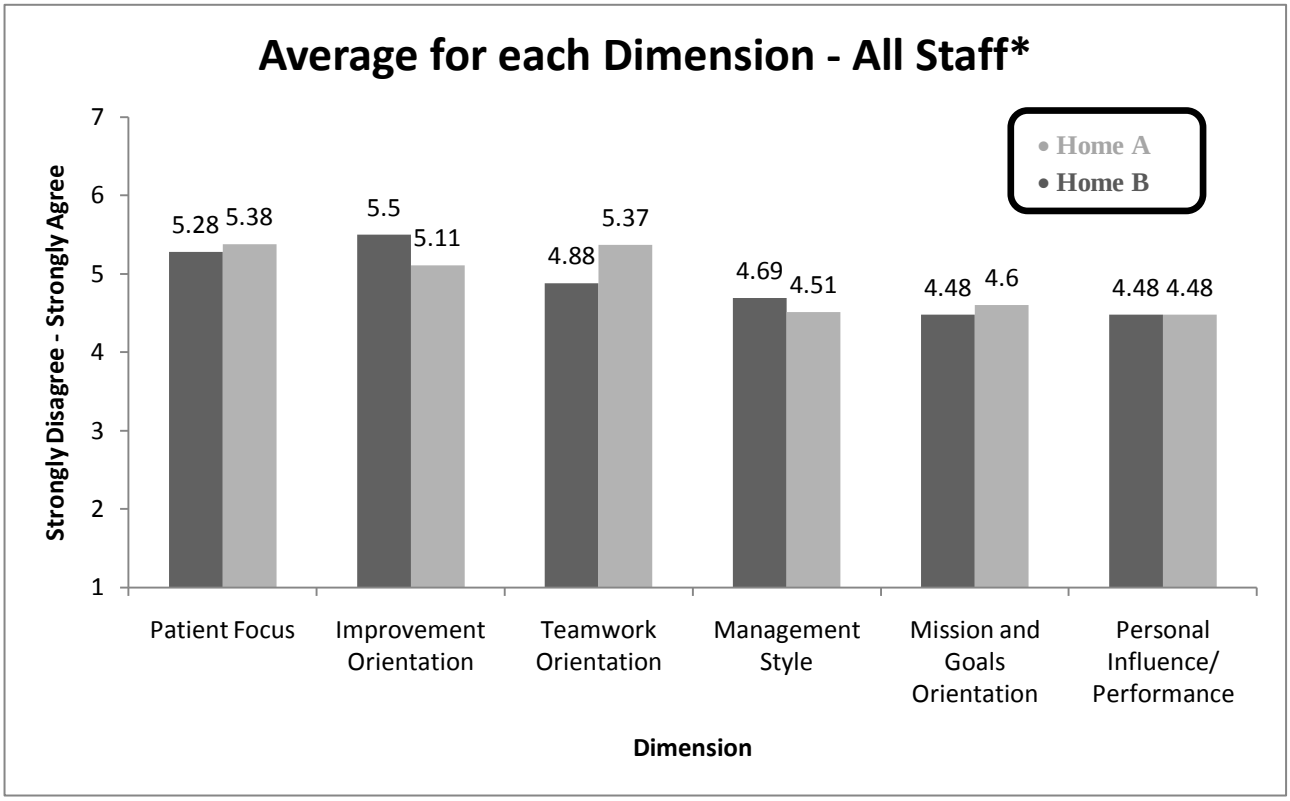


Figure #5: Quality in Action Scores- All Staff Results Totals for Each Home

Focus Group and Interview Data

The importance of the philosophy of the organization and how this translates to the care of the residents who are in need of palliative care was also identified by staff through interview and focus groups.

> *"But I think the home's philosophy is very strong and I think that everybody in the home definitely rises to the occasion of providing palliative care."* (Supervisory Support Staff, Home B)

Having an organizational mission and values was stated to be very important within the Canadian Association of Hospice Palliative Care within the planning section of the right side of the model. Having a mission and vision that is compatible with a palliative approach and having staff that understands the mission and values of the organization and how this influences their work will help move both LTC homes forward when developing and delivery palliative care programs.

2. Operations (Human Resources) - Employee Possessing Positive Care Traits

Another enabler that was highlighted within the data is that the LTC homes employee personal traits positively affect the palliative care that can be given within the LTC homes.

Document Review

No data from documents were relevant and thus documents are not included in this section of the analysis.

Survey Findings

The FATCOD survey results are shown within Appendix L. Not only did the scores show that the homes are very similar but these results show that both LTC homes have staff who have very strong traits that are in line with a palliative care philosophy and approach. When comparing each home by discipline breakdown, one can see that both homes have the same ranking pattern. Both homes had the same order in trait strength from highest to lowest which were: nursing staff, managers', personal support workers, followed by support services.

Focus Group and interview Data

This finding was echoed in focus group and interview data. The staff within both homes indicated that they have co-workers or employees with positive caregiving traits. These traits were seen to be a great asset to the organizations and would be expected to enable developing and delivering formal palliative care programs.

> "*…Just being a nice human being….what you would want done to your family*" (Home A, Personal Support Worker)

Staff also expressed a desire to try to do their best in meeting all the needs of the resident and family even if that is not what they individually think is best or should be done. They describe this as keeping an open mind to care and respecting the resident's wishes.

> "*We're supposed to keep an open mind, an open mind not to form an opinion*." (Home B, Personal Support Worker)

Thus these data show the existance of positive caregiving traits and this is beneficial when working with those receiving palliative care. Further, these caregiving traits are important when developing and delivering a formal palliative care programs within the homes. Each LTC home had staff identify within interviews and focus groups that having caring staff was important and that this was evident within the LTC homes. Also, the FATCOD scores displaying the attitude scores within each home are consistent with these findings.

Part 2: Palliative Care Development and Delivery Barriers

A barrier within this section can be described as a resource or function that currently exists within the organization and that will weaken or present obstacles to the development and delivery of a formal palliative care program within the LTC home. Some key ideas that were presented as barriers within the data include: government funding requirements under financial resources, communication among staff under the operations (informational resources) domain, and the lack of appropriate design to accommodate a palliative care environment under the physical resources domain.

1. Resources- Financial Resources

Document Review

LTC homes receive two types of funding the first is from the Ministry of Health and Long-Term Care and the second is a co-payment which is paid by the resident who is living in long-term care. Both funding amounts are determined by the government and thus the LTC homes in Ontario do not have the ability to manipulate these amounts.

The amount of funding that is given to the LTC homes from the Ministry is dependent on a ‘Adjusted Case Mix Measure’ also known as the CMM. The CMM is determined by a Resident Assessment Instrument and is determined by the current level of care of residents living within the LTC facility as described in the financial resources section in Chapter 2. The most recent

financial documents show that Home A receives $156.15 per person per day, and Home B receives $145.00 per person per day as a part of their government funding.

One of the large issues with the government funding is that it is allocated with very specific instructions regarding how the money must be spent. When looking at the breakdown of the funding for LTC expenditures, one can see that the funding allocation comes with weighted limits for certain aspects of care and some forms of care get little consideration. The following table (Table #9) provides the cost breakdowns that are outlined by the Ministry for the different aspects of care.

Table #9: Allocation of Ministry Funding (per resident per day)

Home	**Nursing and Personal Care**	**Program and Support Services**	**Raw Food**	**Other Accommodation (excluding food)**
Home A	$89.68	$7.57	$7.31	$49.14
Home B	$77.62	$7.57	$7.31	$49.14

This is a definite barrier for LTC homes in providing palliative care as the physical care is the only aspect of providing holistic care. When referring to the breakdown above in Table 9, this funding model does not take into consideration the psychological, social spiritual, practical, end-of-life / death management or loss and grief access of caring for people whom are palliative within their homes.

The second type of funding is the resident co-payments and this funding is used to supplement the funding that the Ministry of Health and Long Term Care gives to the LTC facilities. The co-payment fees are determined by the Ministry of Health and Long Term Care and range in amount depending on the type of accommodation in which the resident is residing. The following chart indicates the number of dollars each LTC home receives for each type of accommodation (see Table #10).

Table #10: *Long-term care home copayment rates from the Ministry of Health and Long-Term Care*

Type of Accommodation	Daily	Monthly
Basic Accommodation	$53.23	$1619.08
Semi-Private Accommodation	$61.23	$1862.41
Private Accommodation	$71.23	$2166.58

Each LTC home also has a different number of LTC beds that are dedicated to each type of accommodation. The following table indicates the number of beds in each of the two homes that fall under each classification of accommodation.

Table 11: Breakdown of Accommodation Type

Accommodation Type	Home A	Home B
Private	8	28
Semi Private	42	28
Basic	60	40
Total	110	96

Thus, because Home B is a newer home and was built to accommodate more private and semi-private rooms they are able to receive a greater number of dollars in co-payments compared to Home A.

Survey Findings and Interview and Focus Group Data

No relevant data found within document review.

2. Operations: Communication Strategies among Staff

Communication between disciplines and part-time and full-time staff members is depicted in the data as a barrier against the development and delivery of a formalized palliative care program by the staff even though it is encouraged by organizational policy. This is illustrated below.

Document Review

The governing policies regarding internal communication for both homes encourage communication. Some themes that emerged from their policy was that they strive for ‘excellent

communication', they encourage communication that 'promotes efficiency and generates a better understanding of strategic priorities', 'provides appropriate resources' for internal communication, 'recognizes importance of face-to-face communication', etc. Thus, the organization is promotes open and ongoing internal communication among disciplines and staff.

Survey Findings

No survey findings depict internal communication.

Focus Group and Interview Data

Staff reported internal communication to be very different then what the LTC homes' policies aim to achieve. Internal communication was identified by staff as being a barrier. Some part time staff expressed their concerns regarding not being included in information sharing between their shifts.

> *"We do communicate pretty well but it's just like I say nobody's communicating with me for eleven days through no fault of anybody's but so, we do have a pretty good network but it's not perfect and like I can even be able to communicate all those things…"* (Personal Support Worker, Home A)

Issues with communication also became present when the staff spoke about communication between the different departments in LTC homes. The staff expressed there is segregation between departments.

> *"…I think all the departments are a little segregated…you know, they are, they do their thing, they don't interfere with us, like over doing our work."* (Support Services Staff, Home A)

It was evident in the data that the communication is more informal especially regarding palliative care and death. The quote below provides an example.

> *"Yea, you hear [about death], through the grapevine."(*Support Services Staff, Home A)

And, there is also little conversation or debriefing that happens after a death. This example shows that the communication and debriefing is done by staff at home with family.

> *"I know you're not supposed to let your feeling, like, you know, or have any kind of empathy. But I'll go home and my husband's out of town and I'll phone him and say – you know what? We had two or three people die. You know how that feels like? Because I used to talk to them, sit with them…"* (Support Services Staff, Home A)

Thus, even though the policies found in the document review support positive and meaningful internal communication, the front line staff in LTC did not report that the communication was experienced to be consistent to the standards set out by the policies.

3. Physical Resources: Lack of Appropriate Physical Space

A last barrier identified in the data is the physical space including physical structure, and lack of space designated for dedicated palliative care services.

Document Review

No relevant data found within document review.

Survey Findings

No relevant data found within survey findings.

Focus Group and Interview Data

The staff mentioned, especially in Home A (where there are more traditional ward rooms), that it is very important that residents in need of palliative care services get the dignity they deserve. This dignity would include lower noise levels and space for family. Staff indicated that there were many reasons why they believed that there should be more space dedicated to palliative care within the homes. One important example was improving privacy. The physical structure of older homes are more ward-like in structure with several people per room and therefore staff reported that they cannot provide the privacy needed for proper palliative care.

> *"I like having the palliative room …, especially when you've got 3 people in a room and it gives the family [a place] when they do come"* (Personal Support Worker, Home A)

> *"It would be nice if they [palliative residents] did not need to move to a different room or anything but [we could] bring them somewhere more like not so much noise, not people up and down the halls…"* (Personal Support Worker, Home B)

Noise levels were also raised as a concern by staff. Staff felt that providing residents and families with space dedicated to palliative care would provide them with a less noisy atmosphere which would be supportive with fewer distractions.

> *"I think when they put them in the palliative care room and they have their own privacy and, and all that kind of stuff it makes a huge difference…"* (Support Services Worker, Home A)

The two homes differ in the sense that their physical layouts are very different. Home A is an older home that has two floors whereas Home is newer and has a one-floor layout with small resident home centers called groves. Home B, the newer home, has fewer ward room style rooms and more semi-private and private style rooms consistent which changed social expectations for privacy. Because of ward room style of Home B there is a dedicated palliative room that allows for increased privacy and promotes greater family visitation. Unfortunately, this facility, does not have a room for each of the two floors making it difficult for residents who live on the other floor as they would have different 'neighbors' and different staff caring for them. Thus, according to staff they generally do not utilize this room for residents who do not live on the floor where it is located.

The second major difference that emerged from the data was in the ability to build relationships and bonds between the staff and residents because of the differing physical layouts. Due to the smaller 'home areas' in Home B and staff consistency it is easier for staff and residents to build bonds. Also, it is easier for support services staff and nursing staff to maintain

bonds because they are always assigned to the same home area. In Home A, staff and residents still build and maintain bonds but the layout is not as conducive as it is not as intimate.

Another important factor to consider is the ability for staff to access information. In a physical structure like Home A, it takes longer for Staff members to get from one side of the unit to the opposite side of the unit. In a smaller 'home area' the staff can access information with more ease, which also saves the staff time.

4. Governance and Administration: Working within a Hierarchical Structure

The relationships and authority structures within LTC organizations are hierarchal which makes it more difficult to provide palliative care which is best done using an interdisciplinary team approach. Decision-making is organized in such a way that the staff with the highest professional qualifications make decisions on care and then provide direction to those with lower power, normally without consulting them. In a long term care setting, the professional hierarchy is: physician, registered nurse, registered practical nurse and personal support worker. Below is the evidence to support that the hierarchical nature is hindering the staff's ability to provide palliative care.

Document Review

No relevant data found within document review.

Survey Findings

When examining the personal support worker results of the PEiW survey in Appendix N one can see that the impact domain which is 'the degree to which an individual can influence strategic, administrative or operating outcomes at work' was the lowest scored domain for personal support workers in both homes. This result is only amplified when looking at the QiAS scores in Appendix J, one can see that personal influence which is 'The extent to which people feel that they have some control over their work, have an impact on work, and can do their best

work' is the lowest score out of all domains within the 'all staff' graph. When looking at the breakdown of how different disciplines score, all but managers, scored below 5 out of 7 in both homes.

Focus Group and Interview Data

It was identified that all level of staff feel the pressure of working in the hierarchy of decision making and authority. The nursing staff feels the constraints of talking meaningfully to the family who demand to speak with the doctor as he or she is seen to be 'higher in command.' The quote below is an example of staff's response indicating that families look for information higher up within the command instead of accepting the credibility of the staff member present.

> *"It's just like, a ladder you climb for some reason. And family, like I think I'd probably even do it, I think that way maybe you know, I am going to go to the hospital say and I think you know, I'm going to listen to the doctor before I listen to the nurse."(*Nursing Staff, Home A)

The personal support workers feel like they are not consulted when the nurses are dealing with residents and families. They also feel that they are not informed by nursing staff about outcomes or decisions. Better communication would allow them to do their job properly or use their expertise more effectively. The PSWs' frustration about being excluded from communication with the family is illustrated in the quote below:

> *" ...nurses will go in and they'll sit for like an hour talk to the family about our resident and what the nurses really don't know squat about that person from before or anything."(*Personal Support Worker, Home A)

Another issue created by the organizational hierarchy is that when staff see things as being outside of their responsibilities, they do not take action. Thus, when a responsibility is not allocated to a specific discipline to deal with, it is not done or not done consistently. This applies to the need to talk to the resident and family regarding palliative care options. While PSWs have

the most interaction with the residents and families, they also feel that they do not have the expertise in the area and that another discipline or team member should or will take on that role.

5. Community Resources: Underutilization of Community Resources

The Square of Care and Organization states the importance of community resources when delivering palliative care. The information below shows how the utilization of community resources is currently a barrier within the two long-term care homes.

Document Review

Within the new admission handbooks, there is very limited information regarding community services available for their residents. All services are provided by the home other than some information regarding a hairdresser, volunteer service, and outside church groups coming in to support spiritual care.

Survey Findings

No relevant data found within document review.

Interview and Focus Group Data

When speaking regarding community involvement, the staff responding within Home A expressed that they do not utilize community resources like they did in the past. They now feel like there are few volunteers that come to help support them.

> *"I remember years ago when the nuns were here, they used to sit with the residents quite a bit and that was kind of comforting for them [residents] because they were alone"* (Personal Support Worker, Home A)

Other respondents in both homes indicated that more work needs to be done to involve volunteers from the community as resources within care.

> *"I don't even know what department takes care of volunteers but if they could look into the residents that don't have family nearby and have a volunteer."* (Personal Support Worker, Home B)

Very rarely did staff mention that there were resources from the community coming in to support them with the care of their residents even though some of these resources are advertised within the new resident admission handbook as possible services.

6. Human Resources: Lack of Nursing Human Resources and Time

Another important piece within the Square of Care and Organization is the human resources which includes not only the amount of human resources within the homes but also the qualifications and background of the staff members. The following is evidence indicating why the lack of nursing human resources and limitation of time is a barrier and hindering the LTC homes ability to provide formal palliative care.

Document Review

No findings to report.

Survey Findings

No findings to report.

Interview and Focus Group Data

Nursing staff including personal support workers, registered practical nurses and registered nurses identify that there is a lack of human resources and time to provide required care to the residents. It was identified that in the past this was not as great an issue as residents were less ill and were more capable. Now, the care needs of residents are greater and much more nursing and personal care and help is needed for individuals to maintain their quality of life and well being.

> *"There used to be times where you would comb their hair and cream their backs… with cut backs half the time you don't have cream or I don't know if that's a big deal to some people, it is to me…When I first started… we would change the nightly every 2 hours, combing their hair and turning them, and… it's just different now, there's no time for anything it seems."* (Personal Support Worker, Home A)

The nursing staff also express that time is harder to find if they are short of staff on a particular shift. A staff shortage may be due to a staff illness or an unforeseen event and was indicated that there is frequently difficulties in replacing staff.

> *"There's been a shortage of staff so sometimes you don't even have a float, so you're doing both floors yourself."* (Nursing Staff, Home A)

Nursing staff also expressed their concerns regarding palliative residents. They expressed their inability to provide them with more care then they would routinely receive as staff's limited time is hindering their abilities to meet the resident's enhanced palliative care needs. Nursing staff experience a dilemma between providing needed routine care to all residents and special care to those who are dying.

> *"…we don't have more time to give extra attention…or even sit with personally with them."* (Personal Support Worker, Home A)

> *"...the time involved with the family certainly increases; and unfortunately, the floors don't change. You still have to do your same workload. Sometimes it can be quite overwhelming trying to get it all done because people are still failing and people are still getting sick; and the need to be in multiple places certainly draws on you."* (Nursing Staff, Home A)

It was identified that the lack of nursing human resources is a critical barrier that needs to be overcome in order to provide palliative care to the residents in LTC. It was stated that due to the increase care needs of their residents the staff are not able to provide clients with the level of care and attention that residents received in past years. There are staffing shortages and the staff members are not being replaced producing even more difficulties. The nurses are uneasy about residents being designated palliative because they know there is an increased requirement for palliative care and they feel unable to provide the additional care.

Part 3: Palliative Care Development and Delivery Gaps

In the final section of the findings, the gaps within the organization will be identified. A gap, as outlined in the key terms, is resource or function that does not exist and would be required in order to develop a formalized palliative care program. Gaps that will be discussed within this section include: lack of policies and procedures pertaining to palliative care, lack of access to allied health professionals, lack of marketing or education about palliative care to residents and families, lack of palliative care education for all staff, lack of grief and loss support for staff, and lack of palliative care criteria within accreditation and evaluation measures.

1. Informational Resources: Lack of Proper Policies and Procedures

Both Home A and B have the same policies and procedures as they are within the same organization. They both must follow organizational policies but also policies specific to the LTC homes. They have a paperless system thus, all of their policies can be found on their intranet.

Document Review

After reviewing the organizational policies and procedures for the LTC homes, no specific palliative care polices or procedures were found. Policies relating to the following areas were found: resuscitation orders, advanced directives, resident bill of rights, pronouncing death, and client-centered care. However, there is nothing in existing policy describing palliative care specifically or how this care should be delivered.

Survey Findings

No relevant data found within document review.

Interview and Focus Group Data

The lack of policies and procedures regarding palliative care caused confusion among staff about expectations for the provision of palliative care; this confusion was evident during the

focus groups and interviews. Many staff mistakenly believed that there must be palliative care policies and procedures within their home.

> *"No, there's policies, there's I know the one, there is the one policy. I have never read them but I know there is policy..."* (Nursing Staff, Home B)

> *"I'm sure we have a binder on the floor, in each [home area] with information to read up on."(*Personal Support Worker, Home B)

But many also stated that they were unsure regarding policies and procedures related to the palliative care existed or specific details regarding them within the homes.

The impact of not having policies and procedures for palliative care also was demonstrated within the qualitative data when staff discussed how they are often unable to recognize if someone is palliative. Focus group data also indicted that new staff do not know how to provide palliative care and thus they must take direction from staff with more experience.

2. Human Resources: Lack of Having access to Allied Health Professionals

Another important piece within the Square of Care and Organization is the human resources which is not limited to the amount of human resources within the homes but also the qualifications and background of the staff members. The following is evidence indicating why a lack of variety of allied health professionals is a gap and hindering the LTC homes ability to provide formal palliative care.

Document Review

The new admission handbook indicates that there are several services to which the LTC homes can refer their residents, though they are not specific to the LTC home. These services include: occupational therapy, physiotherapy, speech therapy, professional chiropody, geriatric assessment, social work, psychogeriatric assessment, a referral to other medical specialists.

Survey Findings

When looking over the results of the Self-Efficacy in End-of-Life Care (SE-EOLC) survey completed by nursing staff, within the domain 'multidisciplinary teamwork'. there are items related to working with other professionals to provide palliative care and referring clients to other types of health care providers (see figure 6).

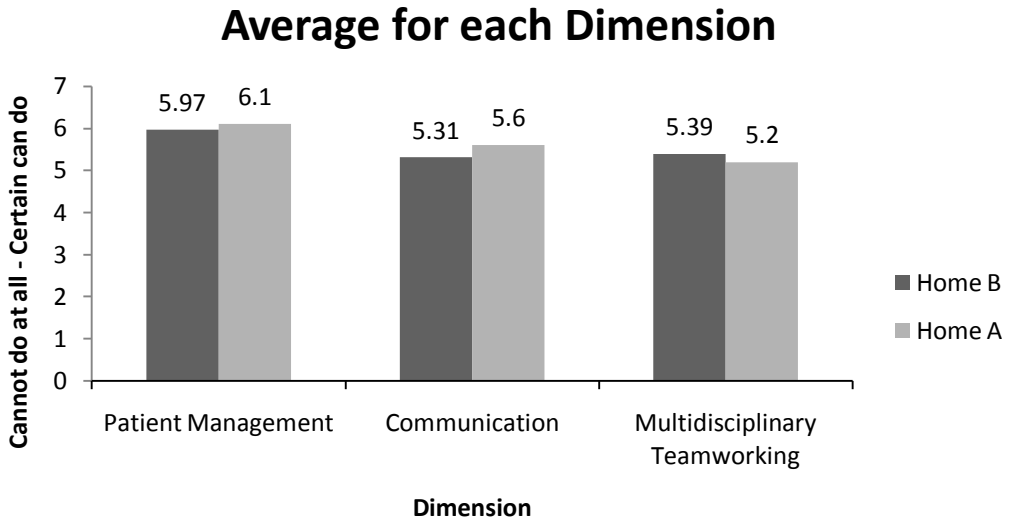


Figure #6: SE-EOLC Results

When looking at this figure displaying the results of the SE-EOLC, one can see that although the score for multidisciplinary teamworking is not extremely low, there is some room for improvement. This has relevance to providing palliative care since best practices indicate the need for a team approach.

Interview and Focus Group Data

Residents at both LTC homes have access to the same staffing allocations and number of qualified staff. There were indications from staff during the interviews and focus groups, especially the nursing staff that they perceive that they are having difficulty meeting the social and spiritual needs of residents. Neither home has access to a social worker but both homes share

access to a full-time spiritual care provider who is intended to spend half-time at each home. Both homes stated that having a social worker would be a great asset to their team. Home A stated that they required more spiritual care assistance and Home B stated that access to spiritual care at their home was satisfactory. This suggests that the spiritual care may not be equally available in both homes.

3. Communications and Marketing: Marketing Palliative Care to Residents/ Families

When entering or touring the LTC homes, residents and families are given information about the services provided by the home. Communication about the availability of palliative care for residents in the home appears to be a gap.

Document Review

Documents indicate that the homes do not strongly market that they to provide palliative care services for residents and family members. On admission each resident receives a guide to the services that are available within the home. The information packages for Home A and Home B are very similar. As the principal guide book for new residents and families, the guide describes the services of the LTC homes but also the services of other health care services within the organization. Within this document palliative care is mentioned as follows:

> "in a situation when death is expected, residents often want to remain at their home facility rather than be sent to hospital. Nursing and Spiritual Care staff are trained and very skilled and experienced in providing excellent palliative care."

This entry in the guide does not describe palliative care or give insight to the family or resident about what specific palliative care programs and services are offered and how they may access them.

The LTC homes' websites are another resource that provides information for residents and families about the facilities and programs. The review of the website of Home A, does not

state that they offer palliative care services. Home B's website does advertise such a service under the spiritual care section. The program is described in the following way: the 'nursing and spiritual care staff trained to provide comfort and support'. As described by the CHPCA model there are many common issues that need to be addressed when someone is palliative. Thus, the program description is limiting itself as a person in need of palliative care may require the assistance of team members from a professional background other than nursing or spiritual care.

Survey Findings

Not only did the difficulties with regards to communicating with family and resident about palliative care appear in staff's documentation, these communication difficulties were reinforced from the findings of one of the surveys that was completed by the nurses. The Self-Efficacy in End-of-Life Care Survey measures "the belief in one's ability to perform a specific behaviour or skill." The following figure shows a comparison between both homes. (see figure #7)

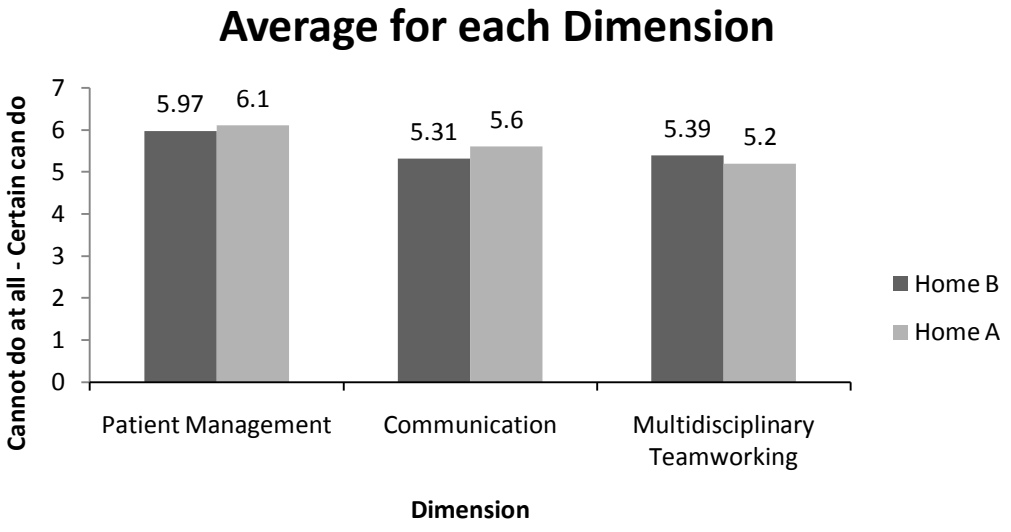


Figure 7: Self Efficacy in End-of-Life Care Survey- All Staff Results

The communication section of this graph, "includes items related to discussing the course of illness with the client and family, discussing issues related to death and dying, talking about specific client concerns, and responding to questions such as 'how long have I got to live?' and 'will there be much suffering or pain?' When looking at the figure depicting the survey findings one can see that the score for communication, while fairly high, there remains room for improvement within this domain.

Interview and Focus Group Data

The staff described in the interviews and focus groups that the families are sometimes unprepared to make decisions due to a lack of knowledge regarding what to expect.

> "*I really think a lot of families…when they do come into a home, I don't even think they really know you know[what to expect], they just know that they're going to bring their loved ones to the nursing home."* (Personal Support Worker, Home B)

The staff also describe that they feel that the families do not understand long-term care or the process of providing care in this type of environment which can cause conflict between families and staff members.

> *"There are some that, when they want something, they want it right now; and it doesn't work that way. Like with the government, you have to go through the red tape."* (Personal Support Worker, Home B)

Finally, staff describe that conflicts also arise because the family has a lack of understanding or acceptance for the change in the resident's status.

> *"..Sometimes think that their family member is going to improve, get better, and eat again. They don't accept exactly what's happening, not that anybody has to accept what's happening."* (Nursing Staff, Home A)

It was noted by some staff, however, that if they had conversation with families and residents before the resident became palliative or were at the end-of-life, that there may be a better outcome and less conflict when the status of a resident changes.

Thus, there is no specific marketing of a formal palliative care program currently within these homes which is shown through the minimal information provided in the new admission guide and the organization website. This lack of information was noted by staff to cause conflict when palliative care or end-of-life issues arise as illustrated in the data of the focus groups and interviews.

4. Operations (Human Resources): Palliative Care Education for all Staff

The evidence below shows that education for staff is a gap when trying to deliver palliative care within the homes. In order to provide quality palliative care, staff need to be educated before entering the LTC home environment and have continuing education regarding palliative care issues. The following sections will show why this is a current gap.

Document Review

When looking at new employee handbooks for personal support workers, registered practical nurses, and registered nurses and the type of training each employee receives during orientation. Only registered nurses were provided with palliative care as a requirement for their orientation package. Palliative care education is not included in personal support worker or registered practical nurse training.

Survey Findings

Evidence of the staff's lack of education regarding palliative care is also evident when looking at Table #12 Staff Training in Palliative Care, very few support service workers reported that they were trained in palliative care. Most reported they received some or no training in this area. One question in the FATCOD survey (Appendix L) asked respondents to indicate whether they had received palliative care training. The following table (table #12) displays the number of staff who responded that they had or had not received formal training in their programs.

Table #12: Staff Training in Palliative Care

	HOME A			HOME B		
	Received Training	Some Training	No Training	Received Training	Some Training	No Training
PSW	11	10	1	1	6	1
RPN/RN	7	5	0	14	9	1
Support Staff	0	4	6	4	0	9
Manager	7	2	1	7	2	1

The lack of formal education and continuing education was also seen in another survey that was given to registered practical nurses and registered nurses. The Palliative Care Quiz Survey measures the knowledge that nursing staff have regarding palliative care (see Appendix O for the results). The findings indicate that staff in both Home A and Home B had relatively low scores regarding their specialized palliative care knowledge. Home A had 62% (12.4/20) of questions answered correctly and Home B had 52.5% (10.4/20) answered correctly.

Interview and Focus Group Data

Palliative care education is also seen to be a great need that is not being met in the interviews and focus group data. Palliative care education was mentioned through the qualitative data in three different contexts: lack of palliative care education received by new staff prior to employment, lack of on-going palliative care education for staff members, and lack of palliative care education for support services staff.

To begin, there is a strong acknowledgement by staff that there is a lack of education regarding palliative care, death, and dying during schooling before entering the workforce. This lack of education is hindering new employees as they are unsure of themselves when faced with a palliative care scenario. New staff indicated the lack of formal training regarding palliative care before working within LTC.

> *"I think I had in my 2nd year, I think there was a small portion …[of education] but half was supposed to be job related and the other half was dealing with, psychological disorders and some was carried in there but not..."* (Nursing Staff, Home B)

Some staff reported that their comfort level working with the dying has improved with their experience level.

> *"…the first time for everyone I guess is kind of a little bit nerve wrecking, kind of what to say, what to do you know, you don't want to say the wrong thing or..."(* Nursing Staff, Home B)

And, the employees that have been working in LTC for a longer period of time, referred to the lack of palliative care experience and education among newer staff.

> *"And there are a lot of brand new staff, so they too are not familiar with and comfortable with death and dying."* (Nursing Staff, Home A)

> *"Brand new staff that they're not familiar with death. That might be the first death, and that's happened before."* (Nursing Staff, Home A)

Thus, data indicate that lack of education for new and existing staff is a barrier for both LTC homes as the staff verbalized their concerns regarding the lack of formal education for new staff entering the workforce, continuing education, and education for support of services staff. The lack of education could also be identified through the orientation checklists as registered nurses were the only staff being trained in palliative care even though palliative care requires team involvement. The need for education was echoed again when looking at the FATCOD results which were completed by all staff. One of the questions on this survey asked staff to self-report the amount of training they received. The results are displayed in Table 12.

5. Operations (Human Resources): Grief and Loss Support for Staff

Under "operations", the CHPCA square of care also mentions the importance of grief support for staff members. The description below indicates why this was also interpreted as a gap within the data.

Document Review

No findings to report.

Survey Findings

No findings to report.

Interview and Focus Group Data

A gap that was strongly identified through the qualitative data was that there are not sufficient opportunities or time for staff to grieve. There were different types of grief that were identified through the data. The first type of grief that was mentioned was that staff members become close with the residents and thus they felt that grief support should be offered to them and their colleagues.

> *"…we feel their pain too. It might not be our relative but we feel their pain…"* (Personal Support Worker, Home A)

> *"I'd like just to be offered, I'd like it to you know, would you like to talk to someone I know you were really close to, to you know, there is many full-time staff that know these residents like the back of their hand and not all the time but I am sure there are times that they may want to speak to someone and they don't want to speak to me."* (Nursing Staff, Home B)

> *"I mean I don't want to say it's, it's management or administration because we all have jobs to do and we all have things that need to get done but again it's just the recognition. I think it was just the recognition of knowing that you know we recognize that you are upset that he has been here awhile, even if it's a we have grove meetings, even if it was a matter of having a grove meeting and sitting down with the critical care coordinator and saying you know, how does everyone feel about this, especially when you have residents that have been here since the place opened."* (Nursing Staff, Home B)

It was also mentioned within the focus groups and interviews that often after a resident dies there is a sense of guilt with the staff feeling that they had not performed their jobs well and that this is what caused the death of the resident.

> *Where you feel like, you feel like you didn't do a good job like you know, sudden, there's some suddenly death like you know they died instantly."* (Personal Support Worker, Home A)

Finally it was mentioned that staff were never given an opportunity to say goodbye to the residents that they cared for.

> *"…we never really have time to say goodbye to them."* (Personal Support Worker, Home A)

Overall there were many different types of unresolved grief and emotions that the staff spoke of related to resident's deaths. Staff feel like they are not offered support to grieve, that the deaths are because of their job performance, and that they do not have a chance to say goodbye to their residents.

6. Quality Management: Lack of Palliative Care Criteria within Evaluation Measures

Document Review

There are various evaluation methods that are mandatory for LTC homes in Ontario to conform to the Ministry Health and Long-Term care requirements as well as the Resident's First Initiative. Although both LTC Home A and Home B meet the requirements for these assessments the assessments do not include measures on palliative care.

The Ministry of Health and Long-Term Care provides web-based reports regarding Ontario LTC homes to provide information to the general public. These reports can be accessed at http://www.health.gov.on.ca/english/public/program/ltc/26_reporting.html. These reports provide the public with basic information regarding the home and information regarding the home's last inspection; however, it does not outline which LTC homes offer palliative care among their services.

Some information that should be considered in evaluating Home A and Home B is an information source about complaints and unmet standards. The average amount of citations / 100 beds within the province is 0.19. Home A and B did not receive any citations between July 01, 2009 to June 30, 2010. Where the homes differ is within the unmet standards section of the

report. During the same reporting period, Home A received 0 unmet standards citations whereas Home B received 4 unmet/ 100 beds. The provincial average was 2.70/ 100 beds. Home B's unmet standards included:

- 1 count of B3 which is that "each resident shall receive care and services consistent with his/ her plan of care and with residents' rights outlined in the bill of rights"
- 1 count of B5 which is that "all significant information about each resident shall be documented in his / her record"
- 1 count of A 1.11 which is that "Residents' rights which shall be fully respected and promoted include, but are not limited to the following rights contained in the Long-Term Care Statute Law Amendment Act"
- 1 count of M 2 which is that "there shall be a comprehensive, coordinated home-wide program for monitoring, evaluating and improving the quality of accommodation, care, services, programs, and goods provided by the home."

Although, these unmet standards do not mention palliative care within the home, these counts do have implications for developing a palliative care program as some of the descriptions include fundamental ideas that would apply to palliative care. Such ideas include: 'care and services consistent with resident plan', 'charting of significant information', ' resident's rights being respected', 'monitoring, evaluating, and improving quality of accommodation, care, services, programs, etc.'

In addition to the Ministry of Health and Long-Term Care, the Ontario Health Quality Council (OHQC) also monitors quality care in LTC homes. Findings from these assessments are presented in a report called the *LTC Public Reporting Home-level Risk Adjusted Indicators.* This document only reports on four categories: bladder function, falls, worsening of pressure ulcers, and new pressure ulcers. Again, this measure does not report on palliative care; however, these indicators may be examples of symptoms to consider when questioning whether palliative care planning needs to begin. Home A had scores lower on all four categories when comparing them to the provincial averages which are positive. Home B however, had scores above the provincial average in all 4 domains.

Thus, there are provincially mandated quality measures but they do not give direct insight the LTC homes on how to develop, implement, or evaluate formal palliative care programs within their homes.

Survey Findings

When looking at the results of the Psychological Empowerment in the Workplace Survey PEiW (Appendix N) filled in by the personal support workers, one can see that the impact score was low. The impact score indicates " the degree to which an individual can influence strategic, administrative or operating outcomes at work." Also, the QiAS, which all staff were able to contribute their perceptions, indicated under management style a similar perception. Management style being "perceptions of the believability of management, their commitment to quality improvement, and their involvement of others in decision making."

Interview and Focus Group Data

To findings to report.

In conclusion, it is difficult to assess the quality management of palliative care within the homes as many of the quality indicators that are mandated from the government and do not specifically include palliative care.

Chapter Six: Discussion and Conclusion

Implications of a new Ontario Long-Term Care Act

The section will begin by a brief summary of the findings found within this study. The section will then continue by outlining some possible areas for change followed by some examples on how the homes can proceed to develop and deliver their own palliative care programs.

Summary of Findings

The following table (see Table 13) summarizes how each domain is assessed as an enabler, barrier or gap in developing palliative care. The "X" in the table below represents that there were no enablers, barriers, or gaps within that particular domain found within the data.

Table #13: Breakdown of Resource and Function Domains into Enablers, Barriers, and Gaps(as found within this thesis)

Domain	Enablers	Barriers	Gaps
Financial Resources	X	Ministry Funding and Division of Funds	X
Human Resources	X	X	Lack of Having Allied Health Professionals
Informational Resources	X	X	Lack of Policies and Procedures relating to Palliative Care
Physical Resources	X	Lack of Appropriate Physical Space to Provide Palliative Care	X
Community Resources	X	Underutilization of Community Resources	X
Governance and Administration	X	Working within a Hierarchical Structure	X
Planning	Organizational Mission and Values	X	X
Operations	Human Resources: Employees Having Positive Caregiving Traits	Communication among staff members	Palliative Care Education and Grief and Loss Support for Staff

Quality Management	X	X	Measures do not include Palliative Care
Communication and Marketing	X	X	Marketing Palliative Care to Residents and Families

Possible Areas for Change

This section will explore the complexity of change using the CHPCA's Square of Care and Organization, examining change through the community capacity model, and listing some of the priorities for change.

CHPCA Square of Care and Organization

As pointed out within the Canadian Hospice Palliative Care Association's guide surrounding the Square of Care and Organization Model, the four sides of the square are directly linked to each other. "They are also interdependent. Clinicians cannot provide care without the resources and principal functions of an organization, and the organization cannot fulfill its mission or vision without a well-established process of providing care that addresses the issues commonly faced by patients and families." (CHPCA, 2002, p. 54) Thus, even though for this thesis only the function and resource components of the model were assessed, the functions and resources of the organization have a direct impact on the common issues and the processes of providing care. This also means that the organization's change in infrastructure guided by the Square of Organization needs to be directed by the goal of addressing the common issues and processes of providing care within the homes.

Change using Community Capacity Development Model

As one can see in the table above there were two enablers, five barriers, and five gaps reported within this thesis project. As stated earlier when exploring the community capacity development model, LTC is a very complex organization and thus, change is non-linear and all domains are interconnected. A change in one domain or element of the organization can change other elements. To illustrate this complexity, Figure #6 demonstrates a negative change within the relations and function and Figure #7 demonstrates a positive change. Both of the change processes also show the interconnectedness of the domains or elements within the organization.

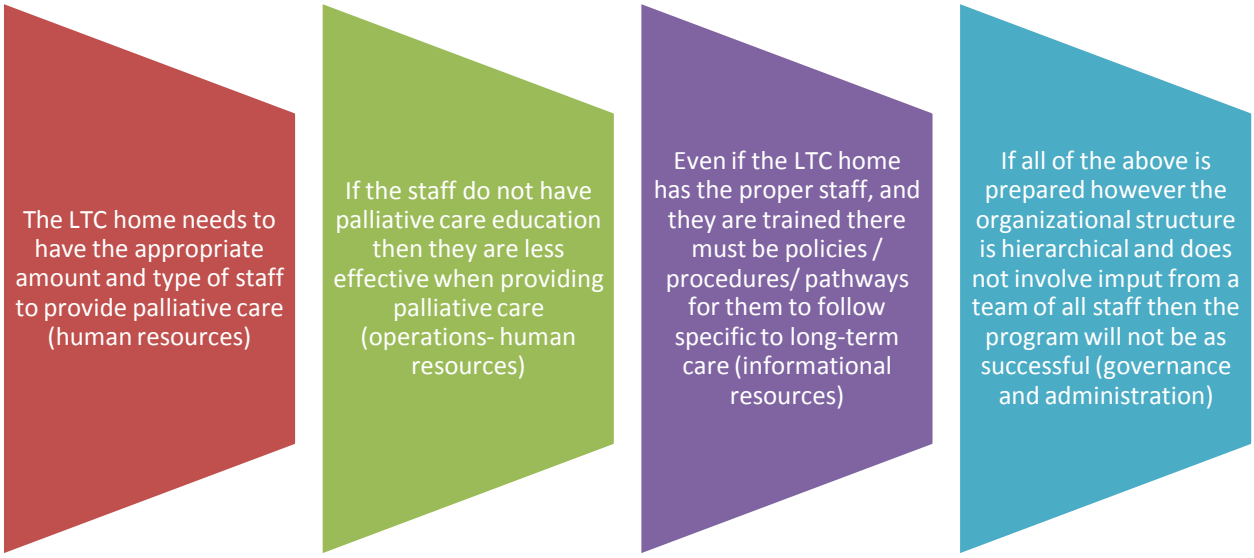


Figure 6: Negative Change within the Resources and Functions

Figure 7: Positive Change within the Resources and Functions

During the change period it will be important for the LTC homes to commit to re-enforcing the enablers, removing the barriers, and filling the gaps. Kelley's Community Capacity Development model (Appendix A) reinforces that the change must be embraced within the community; if the change is forced externally the change will not be sustainable. Thus, the change will be positively influenced by the new act but must be internally driven for the change to be sustainable. Therefore, the QPC-LTC project and the new long-term care act are both catalysts for change and have synergies. The priorities for change listed below will need to start with the current home's capacities and develop incrementally in order to change the gaps and the barriers which will 'develop the program' and create more foliage. These barriers and gaps are now clearly understood as reported in this thesis.

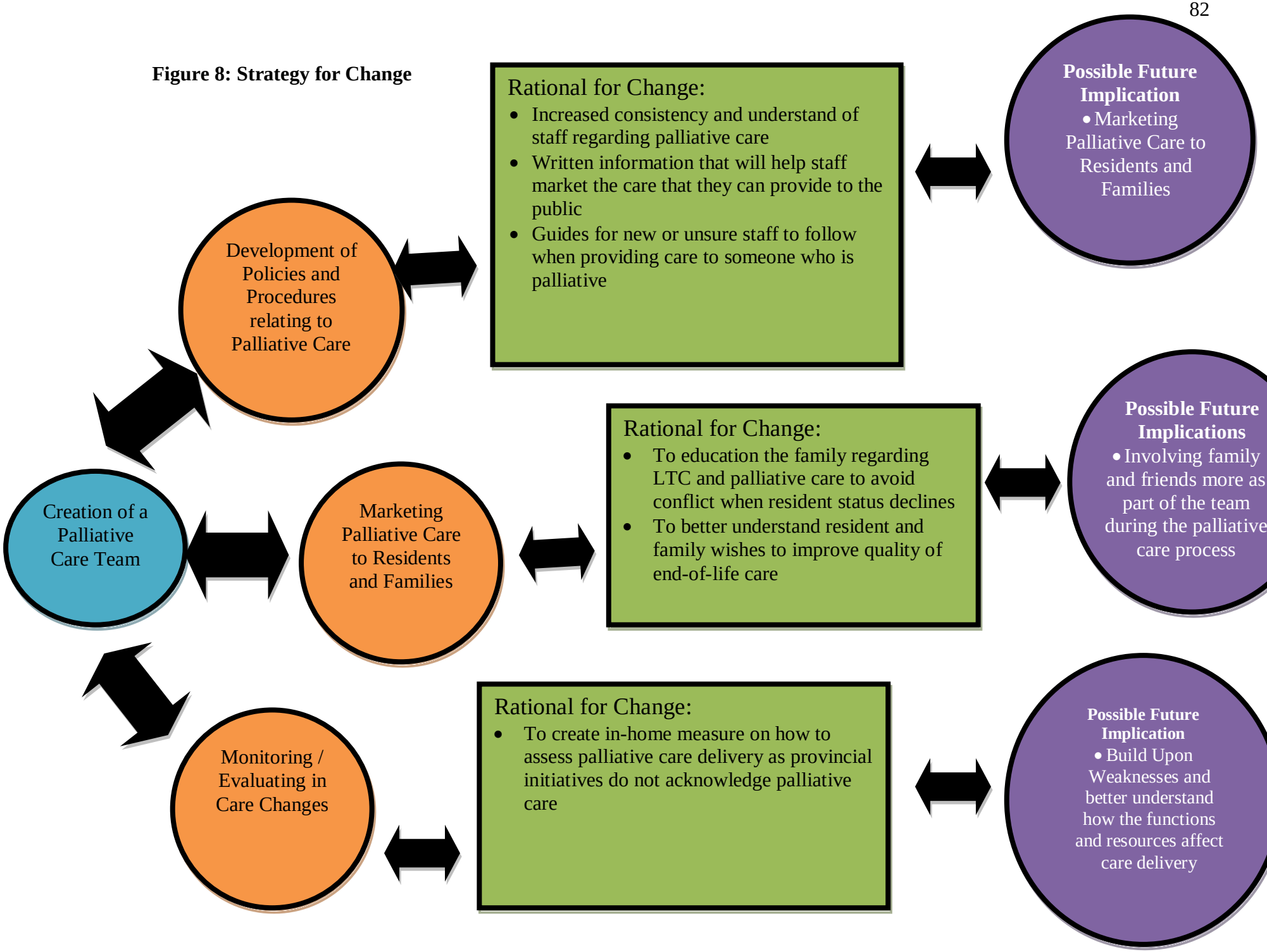
Strategy for Change

The following are the suggested priorities of change for the two LTC homes to consider when developing and delivering their new formal palliative care programs. The main priority areas are: developing a palliative care team, developing more concrete policies and procedures,/ developing pathways and program description for staff to call upon when providing

palliative care, marketing palliative care more strategically to residents and family members, and continuing to monitor change during the development and delivery of the program.

As stated above any change within the homes' resources or functions affects the other elements within the Square of Care and Organization and the current status reported in this thesis can be used as a baseline to continue change within the other domains of the Square of Care and Organization . The following priorities were chosen because not only are some of these aspects now mandated by the legislation but they also would provide the homes with a solid foundation in the change process. The following figure (Figure #8) depicts the possible changes.

Figure 8: Strategy for Change



Change Influenced by the New LTC Act

During the data collection by the Quality Palliative Care in Long-Term Care Alliance, the Ontario government changed legislation for LTC homes. On July 1, 2010, the new act Long-Term Care Homes Act, 2007 replaced the three previous pieces of legislation that governed LTC homes. These included: the Charitable Homes Act, the Homes for the Aged and Rest Homes Act and the Nursing Homes Act. Now, not only were the homes governed by one piece of legislation but also there was a significant change in legislation.

Changes within the Legislation in Relation to Palliative Care

Changes to the legislation are intended to and will impact palliative care service delivery within LTC homes. Jane Meadus of the Advocacy Centre for the Elderly provides an expert legal analysis of these legislative changes (Meadus, 2010). The Meadus document was used to analyze the impact of these changes on the development of palliative care programs in LTC homes.

To begin, although the old legislation included a bill of rights for residents; Meadus (2010) identified some new or amended elements to that bill of rights. Some of the new residents' rights that would impact palliative care include: 'when very ill or dying to have friends or family present 24 hours a day; to meet privately with their spouse or another person; to have any friend, family member, or other person of importance to the resident attend any meeting with the licensee or the staff of the home." (Meadus, 2010, p.2) These changes could help the development and delivery of palliative care programming as rights now include involvement by the family and friends. When followed, this may encourage more communication and education for not just the resident but also the family and friends who are important and should be a part of the team when planning or delivering palliative care.

The new Long-Term Care Home Act (hereafter referred to as the Act) further outlines that there are additional services that all LTC homes must provide. Some of the services are: "recreational and social activities, including for those residents with cognitive impairments or who are unable to leave their rooms, organized programs to ensure a reasonable opportunity for residents to pursue their religious and spiritual practices, and volunteer programs" (Meadus, 2010, p.3). These new services will offer direct benefits for residents who are receiving palliative care as there are now more opportunities for residents to have meaningful interactions and more social and spiritual interventions. Gaps in these areas were shown in the data analysis to be major concerns of staff members.

Also, Meadus reports that each program in LTC homes must now comply with the following requirements: include a written description of the program, including goals, objectives, and relevant policies, procedures, and protocols providing methods to reduce risk and monitor outcomes, including protocols regarding referrals of residents to specialized resources where required (Medus, 2010). This new requirement to formalize all programs will help with the communication of services to family, friends, and residents. New or existing palliative care programs will now need to follow these specified criteria. Lack of written palliative care policies is a current gap, and creating policy will provide more written information for staff to understand and implement the palliative care program and services they provide. Thus, the new requirements of the Act will help address the lack of policies and procedure the study homes have regarding palliative care.

Additional new requirements of the Act (Medus 2010) are that each home must have teams for skin and wound care and pain and wound management (p. 4). These issues are important aspects in the provision of palliative care and can either be provided by the palliative

care team or will support the palliative care team. Thus, there is encouragement within the Act for LTC homes to provide palliative care teams in order to meet the legislative demands.

Another significant change in the legislation impacting palliative care is that there is a new staff training component with which the homes must comply. For example, staff that provide hands-on care must be trained and re-trained in palliative care, skin and wound care, and pain management. The data analysed for this thesis indicate that staff feel that they did not have enough education in this area when hired as there is not a significant amount of palliative care training within their college or university programs. Furthermore, staff feel that once hired they need on-going education to be able to provide proper palliative care to their residents. This legislation will help to ensure that the staff within these homes have the palliative care educational opportunities they feel they need.

The change in legislation states "within 14 days of being admitted to the home, assessments must be completed in order to prepare the initial care plan, which must be developed within 21 days of admission. Each resident must have a written plan of care setting out his/her planned care, proposed goals and clear directions to staff and others who will be providing the care to the resident" (Meadous, 2010, p.6). Thus, the legislation will require residents, families, and staff to come together to determine a care plan for the resident. Developing and reviewing the care plan will provide an opportunity for a discussion regarding palliative care and how the plan would change or remain the same over time.

Meadus 2010, also explains that resident and family councils are now required (p. 6). Although both LTC homes already had both forms of councils, this legislation creates expectations and opportunities for the homes that do not. These councils can be used for quality

control regarding implementing palliative care programs as well as disseminating information to residents and families from staff.

To conclude, the new LTC legislation will influence the LTC homes to develop and deliver palliative care programming as they require homes to have many new components that directly affect palliative care. These components were not required in the past legislation which demonstrates that palliative care in LTC is becoming acknowledged as more central to the role of LTC in the health care system.

Summary of Possible Implications Regarding Enablers, Barriers, and Gaps

One of the most substantial changes within the new act that will have a large impact on the LTC homes is the new requirement to have a program description and policies and procedure in place regarding all program which would include palliative care programs. By requiring more formalized documentation this will hopefully lead to a better overall understanding and unified direction of staff with regards to what palliative care is and how it should be delivered. The written documents will also provide staff with direction when providing care and the ability to know what services the program will deliver so that they may communicate that with the residents and families. Secondly, the new act requires teams to provide skin and wound care as well as pain management which are essential services within a palliative care program. By formalizing these services by creating teams it will create more strength for the palliative care team as these two areas will need to be further explored and developed. Finally, a lack of education was seen to be a large gap that staff in LTC homes need to overcome to provide palliative care. The new act requires staff to be trained and re-trained in palliative care which will allow staff to gain more knowledge and expertise regarding palliative care on a more on-going basis. The drawback of this change is that the education is only needed for staff that

provide ‘hands on’ care. This would not extend to all staff and thus it may not facilitate a team approach.

Using Job Satisfaction Model to Reinforce Organizational Change

As stated above, two of the main enablers that the LTC homes have is a mission and values statement that is compatible with palliative care and the reported positive care traits among the staff. It is therefore important to continue to promote these strengths as enablers within the homes. This approach is supported by Hackman and Oldham (1975) who outline a theoretical model that includes job dimensions, critical psychological states, and on-the-job outcomes can be used to continue to promote the human resources. Figure #9 outlines the model.

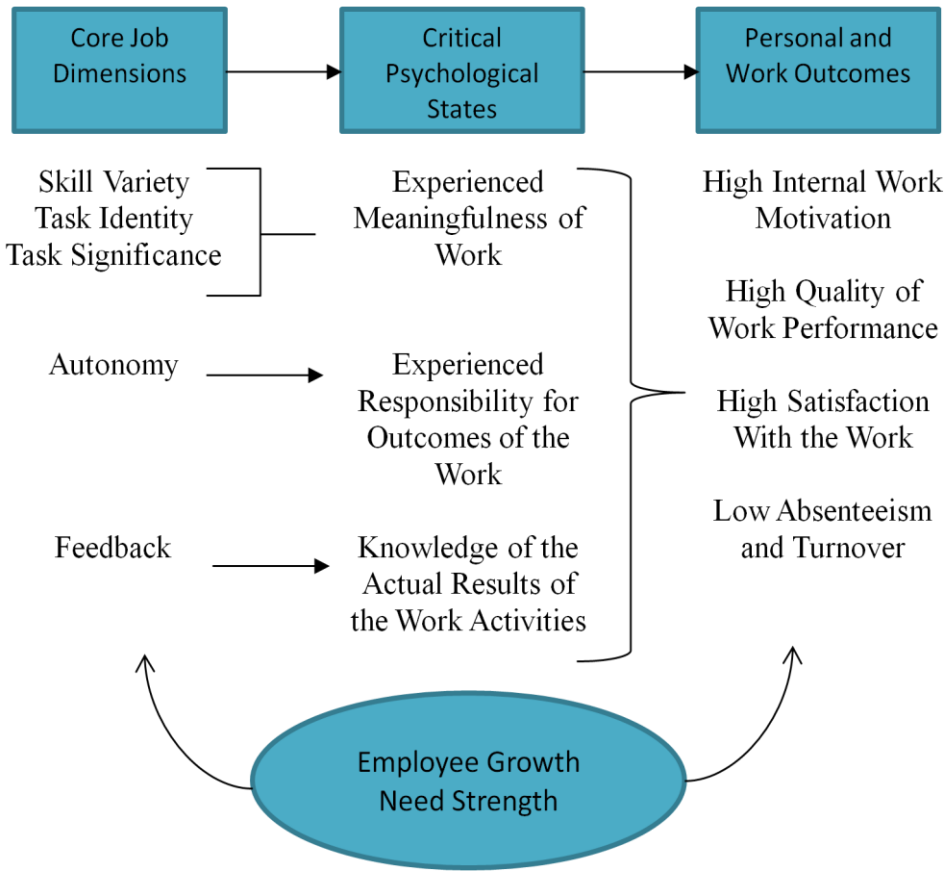


Figure #9: Job Diagnostic Survey, Hackman and Oldham, 1975

A model such as this could help the LTC homes to continue to build upon the human resources traits and dedication to their work. The model would suggest that the front line employees need to have skill variety (different activities), task identity (variety of different task to complete the job), task significance (importance to the worker), autonomy (freedom within work), and feedback (from managers and from clients), in order to increase the psychological state of the employees (p. 161-162). When linking this information with the findings, autonomy and feedback from supervisors could be improved. This model should be considered when implementing the palliative care team as these elements could be fostered within this team.

In 2011, the Ontario Long-Term Care Home Association (OLTCA) released a document called *Elements of an Effective Innovation Strategy for Long Term Care in Ontario.* The document states that "long-term care providers could also take a greater leadership role in providing palliative care, 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" (OLTCA, 2011. p.47). The report identified three levels LTC homes could foster innovation which include: internal innovation, sector-wide innovation, and innovation for integration and health systems transformation. The first level internal innovation is "innovation focused on improving performance inside the firm or institution" (OLTCA, 2011. p.5). This is a direct alignment with this thesis is proposing change must occur within the LTC homes before a sector-wide or health system transformation can occur.

The OLTCA report also supports that change in LTC is needed to be able to cope with today's demand and the growing need for care into the future. "Although the facilities have a total of 76,904 beds, the system is unable to keep with demand. With almost 99 per cent of beds in use, there are still over 24,000 people waiting for a bed" (OLTCA, 2001, p.4). The OLTCA

predicts that there is about 98,000 people within Ontario that need LTC homes today and that the number will increase to 238,000 in 2035 (p.6). The report also informs the reader of the Alternative Level of Care (ALC) Strategy and the Aging at Home Strategy and how they may influence the future demand. They suggest that these strategies could increase the acuity of residents entering LTC, especially those from hospital. "ALC patients diverted to LTC homes may have greater average health care needs than facilities are accustomed to dealing with. At the same time, even if more individuals are encouraged to stay at home longer- and therefore will not access LTC until much later- when many of those individuals do request LTC services, their healthcare needs are also likely to be higher than what has been experienced in the past by the LTC sector." (OLTCA,2011)

Conclusion

In conclusion, there are many influences that impact the development and delivery of a formal palliative care program within the two Ontario LTC homes. The framework used within this thesis to guide organizational infrastructure was the Canadian Hospice Palliative Care Association's Square of Organization. The model outlines the resources and functions that are required within an organization in order to support the provision of a formal palliative care program. The resources include: financial, human, information, physical, and community. And the functions include: governance and administration, planning, operations, quality management, and communication and marketing. These domains of resources and barriers were used to identify barriers, gaps, and enablers that would affect the development and delivery of a formal palliative care program.

The enablers seen within the data collected and analyzed for two LTC homes include an organizational mission and value set that is consistent with a palliative care orientation, and

having staff with positive caregiving traits. However, there are also both barriers and gaps that will challenge the palliative care development and delivery. The barriers include: financial resources, communication strategies among staff members, lack of appropriate physical space to dedicate to palliative care, working within a hierarchical structure, underutilization of community resources, and lack of human resources and time. The gaps include: lack of policies and procedures relevant to palliative care, lack of having access to allied health professionals, marketing palliative care to residents and families, palliative care education for all staff, grief and loss support for staff, and lack of palliative care criteria within accreditation and evaluation measures.

Using the capacity development model and a complexity theory perspective that it implies, priorities were set that the LTC homes should consider during their changes processes. The priorities include: development of a palliative care team followed by: developing policies / procedures, and clinical pathways for palliative care delivery, marketing palliative care to residents and family members, and monitoring the change process especially to see the change in care processes. These priorities were chosen as the first change process encompasses the main two enablers that are foundation to the change process. This foundational change is then followed by three changes that were chosen as they are all internal to the homes and within the homes current means to control and implement. Once these changes are made, the homes will have a better sense of how they can change to enhance their resources but also better identify where the remaining gaps and barriers lie. Finally, the barriers that have more externally controlled such as financial resources, physical space, lack of access to allied professionals as well as human resources, and criteria for monitoring palliative care in LTC can be advocated for within different avenues. Each of the priorities will then create a change in a number of other

resources and functions and thus, the third stage is hard to predict as there are so many unknowns.

Finally, Kelley's model for Community Capacity Development predicts the success of creating the team following the aforementioned enhancements within the LTC homes. The creation of the team would represent the third stage in the development of a palliative care program. The further changes would be within the fourth step which is the growth of the program represented by the activities depicted with foliage of the tree. While it will take time to know if this prediction is accurate in the two LTC homes included in this thesis research, the applicability of the capacity development model to explain the current state would suggest it will continue to be useful. The usefulness of the CHPCA's model of practice has been demonstrated to guide the comprehensive analysis in the thesis. Ultimately, the value of this thesis will be determined by how useful it is to the management of the LTC homes involved in the research and how these findings are used to create social change. These are the ultimate goals of participatory action research.

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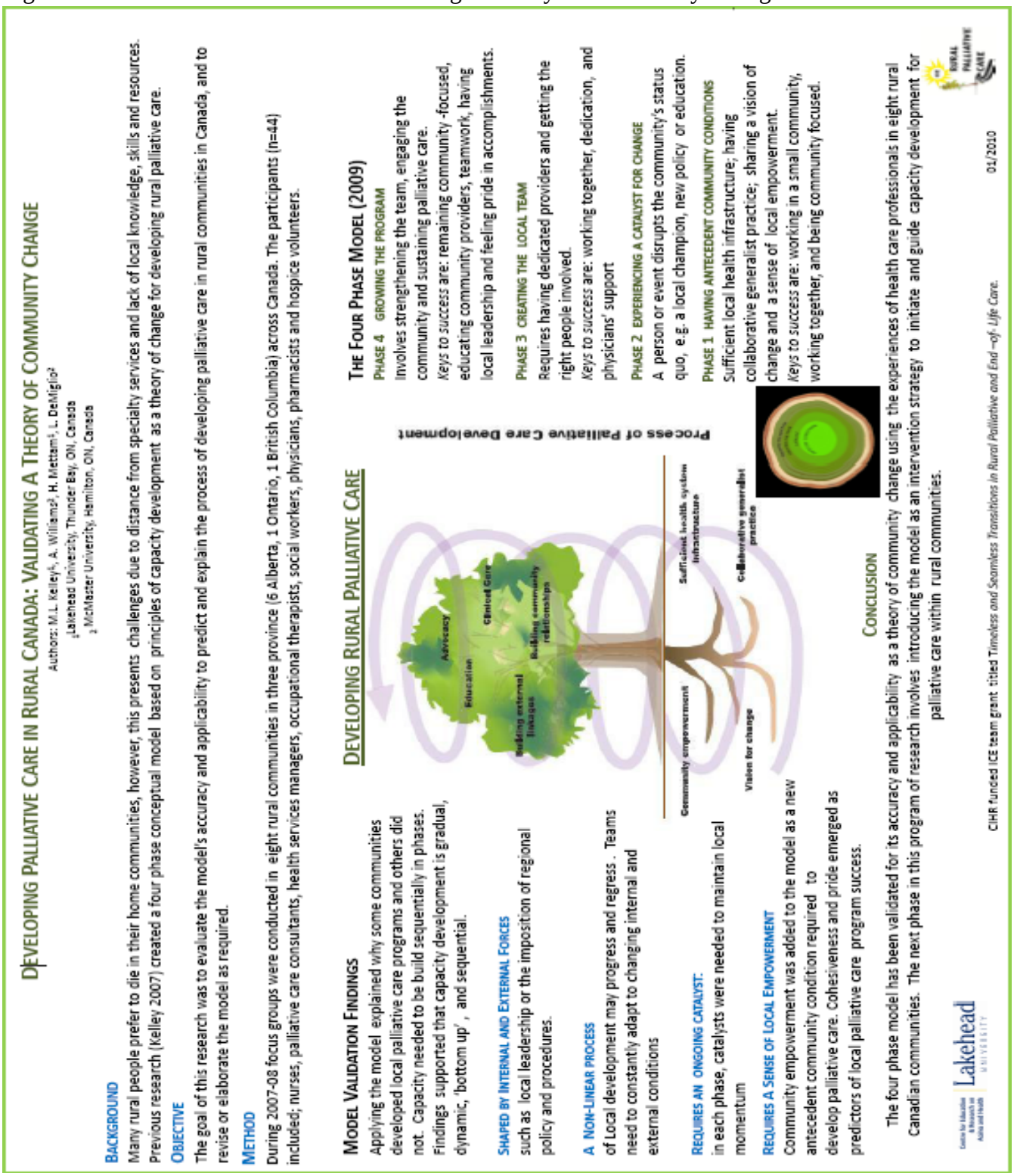
Appendix A

Developing Palliative Care in Rural Canada: Validating a Theory of Community Change



DEVELOPING PALLIATIVE CARE IN RURAL CANADA: VALIDATING A THEORY OF COMMUNITY CHANGE

Authors: M.L. Kelley[1], A. Williams[2], H. Mettam[1], L. DeMiglio[2]
[1] Lakehead University, Thunder Bay, ON, Canada
[2] McMaster University, Hamilton, ON, Canada

BACKGROUND

Many rural people prefer to die in their home communities, however, this presents challenges due to distance from specialty services and lack of local knowledge, skills and resources. Previous research (Kelley 2007) created a four phase conceptual model based on principles of capacity development as a theory of change for developing rural palliative care.

OBJECTIVE

The goal of this research was to evaluate the model's accuracy and applicability to predict and explain the process of developing palliative care in rural communities in Canada, and to revise or elaborate the model as required.

METHOD

During 2007-08 focus groups were conducted in eight rural communities in three province (6 Alberta, 1 Ontario, 1 British Columbia) across Canada. The participants (n=44) included; nurses, palliative care consultants, health services managers, occupational therapists, social workers, physicians, pharmacists and hospice volunteers.

MODEL VALIDATION FINDINGS

Applying the model explained why some communities developed local palliative care programs and others did not. Capacity needed to be build sequentially in phases. Findings supported that capacity development is gradual, dynamic, 'bottom up' , and sequential.

SHAPED BY INTERNAL AND EXTERNAL FORCES

such as local leadership or the imposition of regional policy and procedures.

A NON-LINEAR PROCESS

of Local development may progress and regress . Teams need to constantly adapt to changing internal and external conditions

REQUIRES AN ONGOING CATALYST:

in each phase, catalysts were needed to maintain local momentum

REQUIRES A SENSE OF LOCAL EMPOWERMENT

Community empowerment was added to the model as a new antecedent community condition required to develop palliative care. Cohesiveness and pride emerged as predictors of local palliative care program success.

DEVELOPING RURAL PALLIATIVE CARE

Process of Palliative Care Development

THE FOUR PHASE MODEL (2009)

PHASE 4 GROWING THE PROGRAM

Involves strengthening the team, engaging the community and sustaining palliative care.
Keys to success are: remaining community -focused, educating community providers, teamwork, having local leadership and feeling pride in accomplishments.

PHASE 3 CREATING THE LOCAL TEAM

Requires having dedicated providers and getting the right people involved.
Keys to success are: working together, dedication, and physicians' support

PHASE 2 EXPERIENCING A CATALYST FOR CHANGE

A person or event disrupts the community's status quo, e.g. a local champion, new policy or education.

PHASE 1 HAVING ANTECEDENT COMMUNITY CONDITIONS

Sufficient local health infrastructure; having collaborative generalist practice; sharing a vision of change and a sense of local empowerment.
Keys to success are: working in a small community, working together, and being community focused.

CONCLUSION

The four phase model has been validated for its accuracy and applicability as a theory of community change using the experiences of health care professionals in eight rural Canadian communities. The next phase in this program of research involves introducing the model as an intervention strategy to initiate and guide capacity development for palliative care within rural communities.

CIHR funded ICE team grant titled *Timeless and Seamless Transitions in Rural Palliative and End –of- Life Care.*

01/2010

Appendix B

Documentation Review

Document Name:
Document author (if known): eg. Government, Board of Directors, Management etc.

Last updated:

Reviewer:
Date:

PART A

1. Is the document available for everyone to access? Yes No
   a. If not, who is the audience of this document?

2. Is the document easily accessible? Yes No
   Where can it be accessed (library, web, home's library etc.)

3. What is the purpose of this document? How is it relevant to Palliative Care in LTC?

4. Is this document mandated or optional (eg. a guideline)

5. Is this a provincial document or developed specific to this LTC home? Mandated Unique

PART B

1. Does the document mention palliative care or end of life care? Yes No
   a. If not, does the document have wording/intent/content that supports a palliative care philosophy or approach to care? Yes No

(an example would be resident centred care policy—does not state PC per se, but clearly is compatible supportive of the philosophy.)

**If indicated yes for question 1 or 1b please fill in PART C if not please complete part D*

PART C- (if indicated yes to one of the questions in Part B)

1. Please highlight the phrase or section of the document that illustrates a palliative care philosophy and attach to this document review sheet
   a. Document Attached Yes No
   b. If no, reason?

**If no document can be attached please create an additional document highlighting your findings*

PARTD- (if answered no to both of the questions in Part B)

1. Please highlight the phrase or section of the document that illustrates a philosophy/intent/content that is a barrier to palliative care delivery and attach to this document review sheet (this could also include what is NOT said/included in the document)
   a. Document Attached Yes No
   b. If no, reason?

**If no document can be attached please create an additional document highlighting your findings*

PART E- (all other content relevant to the purpose of this study)

Please indicate any other information regarding this document that would be important for this study.

Appendix C

Staff Interview Guide

We are interested in residents who are dying in long-term care homes, so all of these questions will relate specifically to that group:

1. What are your involvements with people who have are dying in [name of LTC home] and their families?

2. Please describe the things that you think have the greatest effect on the quality of life of people who are dying in [name of LTC home] (both positive and negative)?

3. What is your understanding of palliative care? End-of life care?

4. What role do you think family members play in palliative care?

5. How do you think palliative care can benefit someone dying in a LTC home?

6. How do you think palliative care can benefit the family members of someone who is dying?

7. Do you provide palliative care to residents? (If no, go to question 14)

8. If yes, how do you know when a resident needs palliative care?

9. What if anything, do you do differently when you are told a resident requires palliative care?

10. 10.What challenges do you experience in addressing the physical, social, psychological and spiritual need of dying residents and their families?

11. What things facilitate or help you in providing good palliative care?

12. How well do you think current policies and procedures in this home meet the needs of people who are dying and their families?

13. What can you tell me about the policy and procedure pertaining specifically to Treatment Directives (also known as Advance Directives or DNAR)?

14. What would be your vision for change with regards to providing care in this Home? What could be done in [name of LTC home] to help realize this vision?

15. Is there anything else you would like to add?

16. Do you have any questions for us?

Appendix D

QiAS Survey
(Staff)

Instructions:
This survey asks for some information about your organization and some of its activities. Most of the questions use a rating-scale format. There are no right or wrong answers. Please read each question carefully and give your honest opinion.

Each of the statements below is something a person might say about the place where he or she works, and some of the activities that go on there. Please circle the number from 1-7 that best reflects what you think about each statement.

1 Strongly disagree	2 Moderately disagree	3 Slightly disagree	4 Neither agree or disagree	5 Slightly agree	6 Moderately Agree	7 Strongly agree

1. In this organization, people in different programs or departments try to help each other out.	1	2	3	4	5	6	7
2. Most people here know how their work contributes to this organization's mission	1	2	3	4	5	6	7
3. People in this organization do not pay enough attention to how the clients feel.	1	2	3	4	5	6	7
4. I can usually believe what I hear from management.	1	2	3	4	5	6	7
5. I talk up this organization to my friends as a great organization to work for.	1	2	3	4	5	6	7
6. People who have a lot of experience doing something don't need to spend time collecting a lot of information to figure out how to do it better.	1	2	3	4	5	6	7
7. This organization's mission is understood by everyone who works here.	1	2	3	4	5	6	7
8. The people I work with are comfortable suggesting changes and improvements to each other.	1	2	3	4	5	6	7
9. I am willing to put in a great deal of effort beyond that normally expected in order to help this organization be successful.	1	2	3	4	5	6	7

1 Strongly disagree	2 Moderately disagree	3 Slightly disagree	4 Neither agree or disagree	5 Slightly agree	6 Moderately Agree	7 Strongly agree

10. My performance is judged more by how much work I do than by how well I do it.	1	2	3	4	5	6	7
11. When staff hear from a client about the problem, they always do something about it right away.	1	2	3	4	5	6	7
12. People in this organization do not feel that the organization's goals have much to do with their work.	1	2	3	4	5	6	7
13. Trying to improve the way the work gets done is part of everyone's job.	1	2	3	4	5	6	7
14. I am proud to tell others that I am part of this organization.	1	2	3	4	5	6	7
15. People in this organization are satisfied as long as our work just meets the minimum standards.	1	2	3	4	5	6	7
16. When people in this organization make changes in the way things are done, they always talk first with people who will be affected.	1	2	3	4	5	6	7
17. There is a lot of cooperation between work groups in this organization.	1	2	3	4	5	6	7
18. The people who work here do not exactly know how their work contributes to the goals of the organization.	1	2	3	4	5	6	7
19. I would accept almost any type of job assignment in order to keep working for this organization.	1	2	3	4	5	6	7
20. In my work situation, I have little control over how things are done.	1	2	3	4	5	6	7
21. If I have an idea for improving the way we do our work, people in the organization will usually listen.	1	2	3	4	5	6	7
22. An important part of everyone's job is to study the way we work.	1	2	3	4	5	6	7
23. This organization devotes a lot of energy to trying to learn what clients need and want.	1	2	3	4	5	6	7
24. I find that my values and the organization's values are very similar.	1	2	3	4	5	6	7
25. People in this organization put more energy into catching mistakes than into figuring out how to do things right the first time.	1	2	3	4	5	6	7

1 Strongly disagree	2 Moderately disagree	3 Slightly disagree	4 Neither agree or disagree	5 Slightly agree	6 Moderately Agree	7 Strongly agree

26. In most work groups in this organization, people do not work together to solve problems.	1	2	3	4	5	6	7
27. The people who run this organization are willing to spend money to improve the quality of our services.	1	2	3	4	5	6	7
28. In this organization, people never forget that taking care of clients is always the first and highest priority.	1	2	3	4	5	6	7
29. Regular meetings to analyze the way work gets done make an important contribution to improving client care.	1	2	3	4	5	6	7
30. This organization really inspires the very best in me in the way of job performance.	1	2	3	4	5	6	7
31. Everyone who works here understands exactly what this organization's specific goals are.	1	2	3	4	5	6	7
32. People in this organization get all the facts before they make decisions.	1	2	3	4	5	6	7
33. I don't have much influence on how things are done in my work group.	1	2	3	4	5	6	7
34. I am extremely glad that I chose this organization to work for over others I was considering at the time I joined.	1	2	3	4	5	6	7
35. In this organization it is easy for patients to express their concerns.	1	2	3	4	5	6	7
36. Work groups in this organization hardly ever communicate with each other.	1	2	3	4	5	6	7
37. The idea of continually studying the way we work so that we can improve it does not really apply to everyone's job.	1	2	3	4	5	6	7
38. I really care about the fate of this organization.	1	2	3	4	5	6	7
39. Senior managers in this organization are completely committed to the idea that we study the way we do our work; we can make things better around here.	1	2	3	4	5	6	7
40. Most people here think it is very important to ask patients what they want.	1	2	3	4	5	6	7

	1 Strongly disagree	2 Moderately disagree	3 Slightly disagree	4 Neither agree or disagree	5 Slightly agree	6 Moderately Agree	7 Strongly agree
41. If something seems to be working well, trying to improve on it may be asking for trouble.	1	2	3	4	5	6	7
42. The way things are organized around here makes it hard for people to do their best work.	1	2	3	4	5	6	7
43. For me this is the best of all possible organizations for which to work.	1	2	3	4	5	6	7

44. Discipline - please check (Y) one:
(Completion of this question is optional.)

_____ Administration

_____ Dietary

_____ Nursing (RN, RPN)

_____ OT/PT

_____ Medicine

_____ Personal Support Worker

_____ Support Services (social work, spiritual care, life enrichment)

_____ Volunteer (palliative care volunteer, recreational volunteer)

_____ Other: _____

Thank you for completing this survey!

Appendix E

FATCOD Survey
(Staff)

Please create an anonymous identification number using *your month and day of birth.*
For example, if you were born on January 5, then your identifier code would be 0105.

_____ _____ _____ _____

Instructions:

Please circle the number that corresponds to your own personal feelings about the attitude or situation presented. Please respond to all 30 statements on the scale.

	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
1. Giving care to the dying person is a worthwhile experience.	1	2	3	4	5
2. Death is not the worst thing that can happen to a person.	1	2	3	4	5
3. I would be uncomfortable talking about impending death with the dying person.	1	2	3	4	5
4. Caring for the patient's family should continue throughout the period of grief and bereavement.	1	2	3	4	5
5. I would not want to care for a dying person.	1	2	3	4	5
6. The nonfamily caregivers should not be the one to talk about death with the dying person.	1	2	3	4	5
7. The length of time required giving care to a dying person would frustrate me.	1	2	3	4	5
8. I would be upset when the dying person I was caring for gave up hope of getting better.	1	2	3	4	5
9. It is difficult to form a close relationship with the dying person.	1	2	3	4	5
10. There are times when the dying person welcomes death.	1	2	3	4	5
11. When a patient asks "Am I dying?" I think it is best to change the subject to something cheerful.	1	2	3	4	5

	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
12. The family should be involved in the physical care of the dying person.	1	2	3	4	5
13. I would hope the person I'm caring for dies when I am not present.	1	2	3	4	5
14. I am afraid to become friends with the dying person.	1	2	3	4	5
15. I would feel like running away when the person actually died.	1	2	3	4	5
16. Families need emotional support to accept the behavior changes of the dying person.	1	2	3	4	5
17. As a patient nears death, the nonfamily caregiver should withdraw from his/her involvement with the patient.	1	2	3	4	5
18. Families should be concerned about helping their dying member make the best of his/her remaining life.	1	2	3	4	5
19. The dying person should not be allowed to make decisions about his/her physical care.	1	2	3	4	5
20. Families should maintain as normal an environment as possible for their dying member	1	2	3	4	5
21. It is beneficial for the dying person to verbalize his/her feelings	1	2	3	4	5
22. Care should extend to the family of the dying person.	1	2	3	4	5
23. Caregivers should permit dying persons to have flexible visiting schedules.	1	2	3	4	5
24. They dying person and his/her family should be in-charge decision-makers.	1	2	3	4	5
25. Addiction to pain relieving medication should not be a concern when dealing with a dying person.	1	2	3	4	5
26. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.	1	2	3	4	5

	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
27. Dying persons should be given honest answers about their condition.	1	2	3	4	5
28. Educating families about death and dying is not a nonfamily caregiver responsibility	1	2	3	4	5
29. Family members who stay close to a dying person often interfere with the professional's job with the patient.	1	2	3	4	5
30. It is possible for nonfamily caregivers to help patients prepare for death.	1	2	3	4	5

31. Please indicate your previous education on death and dying:

____ I have previously taken training in death and dying or palliative care.

____ I have never taken specific training death and dying or palliative care, but material on the subject was included in other courses/workshops I attended.

____ I have never taken any training in death and dying or palliative care.

32. Discipline – please check (Y) one:
(completion of this question is optional)

_____ Administration

_____ Dietary

_____ Nursing (RN, RPN)

_____ OT/PT

_____ Medicine

_____ Personal Support Worker

_____ Support Services (social work, spiritual care, life enrichment)

_____ Volunteer (palliative care volunteer, recreational volunteer)

_____ Other: _____

You are all finished. Thank you very much!

Appendix F

S-E in EOLC Survey
(RN, RPN)

Instructions

The following statements relate to common communication, patient management, and interdisciplinary issues that may be encountered by providers caring for patients at the end of life and their families.

Please answer the following questions by circling the number that best reflects your confidence in your own ability to engage in these activities.

Communication

1. Discussing the likely course of a life-limiting illness with the patient.

   Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

2. Discussing the likely course of a life-limiting illness with the patient's family.

   Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

3. Discussing general issues related to dying and death.

   Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

4. Having a discussion with the patient about his/her specific concerns about dying and death.

   Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

5. Having a discussion with the family about their specific concerns about the patient's dying and death.

   Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

6. Providing emotional support to the family upon bereavement.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

7. Responding to the patient's question: "How long have I got to live?"

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

8. Responding to the patient's question: "Will there be much suffering or pain?"

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

Patient Management

9. Assessing the patient's physical needs.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

10. Assessing the patient's emotional needs.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

11. Assessing the patient's spiritual needs.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

12. Understanding the causes of common symptoms experienced by patients at the end of life.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

13. Managing common symptoms experienced by patients at the end of life.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

14. Ensuring appropriate and adequate pain control.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

15. Understanding the therapeutic and side-effects of analgesic agents.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

16. Providing emotional support to the patient at the end of life.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

17. Providing emotional support to the family of the patient at the end of life.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

18. Providing spiritual support to the family of the patient at the end of life.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

Interdisciplinary Team-work

19. Working with other professions to provide end of life care.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

20. Referring patients at the end of life to an occupational therapist.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

21. Referring patients at the end of life to a physical therapist.

Cannot do at all 0 1 2 3 4 5 6 7 Certain can do

22. Referring patients at the end of life to a spiritual advisor/pastoral care worker.

Cannot do at all	0	1	2	3	4	5	6	7	Certain	can do

23. Referring patients at the end of life to a social worker.

Cannot do at all	0	1	2	3	4	5	6	7	Certain	can do

24. Referring patients at the end of life for complimentary therapies.

Cannot do at all	0	1	2	3	4	5	6	7	Certain	can do

25. Referring palliative care patients for psychiatric assessment.

Cannot do at all	0	1	2	3	4	5	6	7	Certain	can do

You are finished. Thank you very much!

Appendix G

Palliative Care Quiz
(RN, RPN)

Please create an anonymous identification number using *your month and day of birth*.
For example, if you were born on January 5, then your identifier code would be 0105.

____ ____ ____ ____

Please circle the correct response to the following items.
T = True
F = False
DK = Don't know

1.	Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration.	T	F	DK
2.	Morphine is the standard used to compare the analgesic effect of other opioids.	T	F	DK
3.	The extent of the disease determines the method of pain treatment.	T	F	DK
4.	Adjuvant therapies are important in managing pain.	T	F	DK
5.	It is crucial for family members to remain at the bedside until death occurs.	T	F	DK
6.	During the last days of life, drowsiness associated with electrolyte imbalance may decrease the need for sedation.	T	F	DK
7.	Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain.	T	F	DK
8.	Individuals who are taking opioids should also follow a bowel regime.	T	F	DK
9.	The provision of palliative care requires emotional detachment.	T	F	DK
10.	During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.	T	F	DK
11.	Men generally reconcile their grief more quickly than women.	T	F	DK
12.	The philosophy of palliative care is compatible with that of aggressive treatment.	T	F	DK
13.	The use of placebos is appropriate in the treatment of some types of pain.	T	F	DK
14.	In high doses, codeine causes more nausea and vomiting than morphine.	T	F	DK
15.	Suffering and physical pain are synonymous.	T	F	DK
16.	Demerol is not an effective analgesic for the control of chronic pain.	T	F	DK
17.	The accumulation of losses renders burn-out inevitable for those who work in palliative care.	T	F	DK
18.	Manifestations of chronic pain are different from those of acute pain.	T	F	DK
19.	The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate.	T	F	DK
20.	Pain threshold is lowered by fatigue or anxiety.	T	F	DK

Appendix H

PEiW Survey (PSW)

Please create an anonymous identification number using *your month and day of birth*. For example, if you were born on January 5, then your identifier would be 0105.

--------- --------- --------- ---------

Instructions:
Please indicate the extent to which you, as a health care provider, agree with the following statements. Circle the number that best reflects your answer.

1 Strongly Disagree	**2 Moderately disagree**	**3 Slightly disagree**	**4 Neither agree or disagree**	**5 Slightly agree**	**6 Moderately agree**	**7 Strongly Agree**

1. The work I do is very important to me.	1	2	3	4	5	6	7
2. My job activities are personally meaningful to me.	1	2	3	4	5	6	7
3. The work I do is meaningful to me	1	2	3	4	5	6	7
4. I am confident about my ability to do my job.	1	2	3	4	5	6	7
5. I am self-assured about my capabilities to perform my work activities.	1	2	3	4	5	6	7
6. I have mastered the skills necessary for my job.	1	2	3	4	5	6	7
7. I have significant autonomy in determining how I do my job.	1	2	3	4	5	6	7

8. I can decide on my own how to go about doing my work.	1	2	3	4	5	6	7
9. I have considerable opportunity for independence and freedom in how I do my job.	1	2	3	4	5	6	7
10. My impact on what happens in my facility is large.	1	2	3	4	5	6	7
11. I have a great deal of control over what happens in my facility.	1	2	3	4	5	6	7
12. I have significant influence over what happens in my facility.	1	2	3	4	5	6	7

You are finished. Thank you very much!!

Appendix I

Supervisory Support Survey
(PSW)

Please create an anonymous identification number using *your month and day of birth*.
For example, if you were born on January 5, then your identifier code would be 0105.

_____ _____ _____ _____

Below are 15 statements that relate to how you feel about your supervisor. The supervisor is a registered nurse (RN) or a registered practical nurse (RPN) that has the responsibility and authority to oversee your work.
Please check (Y) the box that reflects your relationship with your supervisor. Please be as honest as your can. Your answers are confidential and will not be shared with others you work with. If you work with more than one supervisor, please answer these questions in relation to the supervisor that you work with most often.

	Never	Seldom	Occa-sionally	Often	Always
1. My supervisor recognizes my ability to deliver quality care.					
2. My supervisor tries to meet my needs.					
3. My supervisor knows me well enough to know when I have concerns about resident care.					
4. My supervisor tries to understand my point of view when I speak to them.					
5. My supervisor tries to meet my needs in such ways as informing me of what is expected of me when working with my residents.					
6. I can rely on my supervisor when I ask for help, for example, if things are not going well between myself and my co-workers or between myself and residents and/or their families.					
7. My supervisor keeps me informed of any major changes in the work environment or organization.					
8. I can rely on my supervisor to be open to any remarks I may make to him/her.					

	Never	Seldom	Occa-sionally	Often	Always
9. My supervisor keeps me informed of any decisions that were made in regards to my residents.					
10. My supervisor strikes a balance between clients/families' concerns and mine.					
11. My supervisor encourages me even in difficult situation.					
12. My supervisor makes a point of expressing appreciation when I do a good job.					
13. My supervisor respects me as a person.					
14. My supervisor makes time to listen to me.					
15. My supervisor recognizes my strengths and areas for development.					

Thank you for completing this survey!

Appendix J

Qualitative Analysis Checklist

Did the participant(s) speak about the following:
(Will highlight and indicate which domain on analysis chart of interviews / focus groups)

A- Financial Resources

- Assets
  - Cash
  - Capital
  - Investments
  - Receivables
- Liabilities
  - Payables
  - Depreciation
  - Taxes
- Insurance
- Other:

B- Human Resources

- Formal Caregivers
  - Bereavement Counselors
  - Chaplains
  - Dieticians
  - Integrative Therapists
  - Nurses
  - Occupational Therapists
  - Pharmacists
  - Psychologists
  - Physicians
  - Physiotherapists
  - Psychologist
  - Social Workers
  - Speech Pathologists
  - Support Workers
  - Speech Pathologists
  - Support Workers
  - Volunteers (caregiver)
  - Consultants (eg. Ethics, clinical, legal, administrative)
- Staff
  - Administration
  - Support
- Volunteer (non-caregiver)
- Other:

C- Information Resources

- Records
  - Health
  - Financial
  - Human Resources
  - Assets
- Resources
  - Resource, reference materials (eg. Books, journals)
  - Internet, intranet
- Resource directory
- Other:

D- Physical Resources

- Environment
  - Space
  - Lighting
  - Heating, cooling
  - Utilities
  - Parking
- Equipment
  - Medical
  - Diagnostic and investigative
  - Office
  - Communication systems, (eg. Telephone, pagers, email)
  - Information technology systems (eg, computers, printers, networks, internet access)
  - Security systems
- Materials, supplies
  - Medical
  - Office
  - Other
- Other:

E- Community Resources

- Host organization
- Healthcare system
- Partner healthcare providers
- Community organizations
- Faith / religious communities
- Stakeholders
- Public
- Other:

F- Governance and Administration

- Leadership
- Board of Directors
- Management
- Structure of Organization
- Accountability
- Other:

G- Planning

- Strategic Plan
- Needs Assessment
- Mission / Values
- Values, purpose, principal activities
- Goals, objectives, strategies, tactics
- Timelines, strategic decision points
- Business Plan
- Organizational Accountability
- Resource Acquisition and Management
- Implementation
- Quality Management
- Communications
- Marketing
- Business Development
- Other:

H- Operations

- Standards of practice, policies, and procedures
- Standards for data collection / documentation
- Resource acquisition and management

- Fund development- stewardship, annual program foundation and research grants, planned giving
- Financial resources- billing, accounting, banking, dispersement
- Human Resources- recruitment / retention, credentialing, orientation, education, evaluation, staffing, support, recognition, incentives, occupational risk / stress, critical incident debriefing and support, self-actualization and spiritual growth, termination, outplacement
- Informational resources- data collection, purchasing, storage, maintenance, reporting, destruction
- Physical resources- purchasing, stock control, maintenance, disposal
- Community Resources- relationship building, contracting, relationship management, contract, relationship termination
- Other:

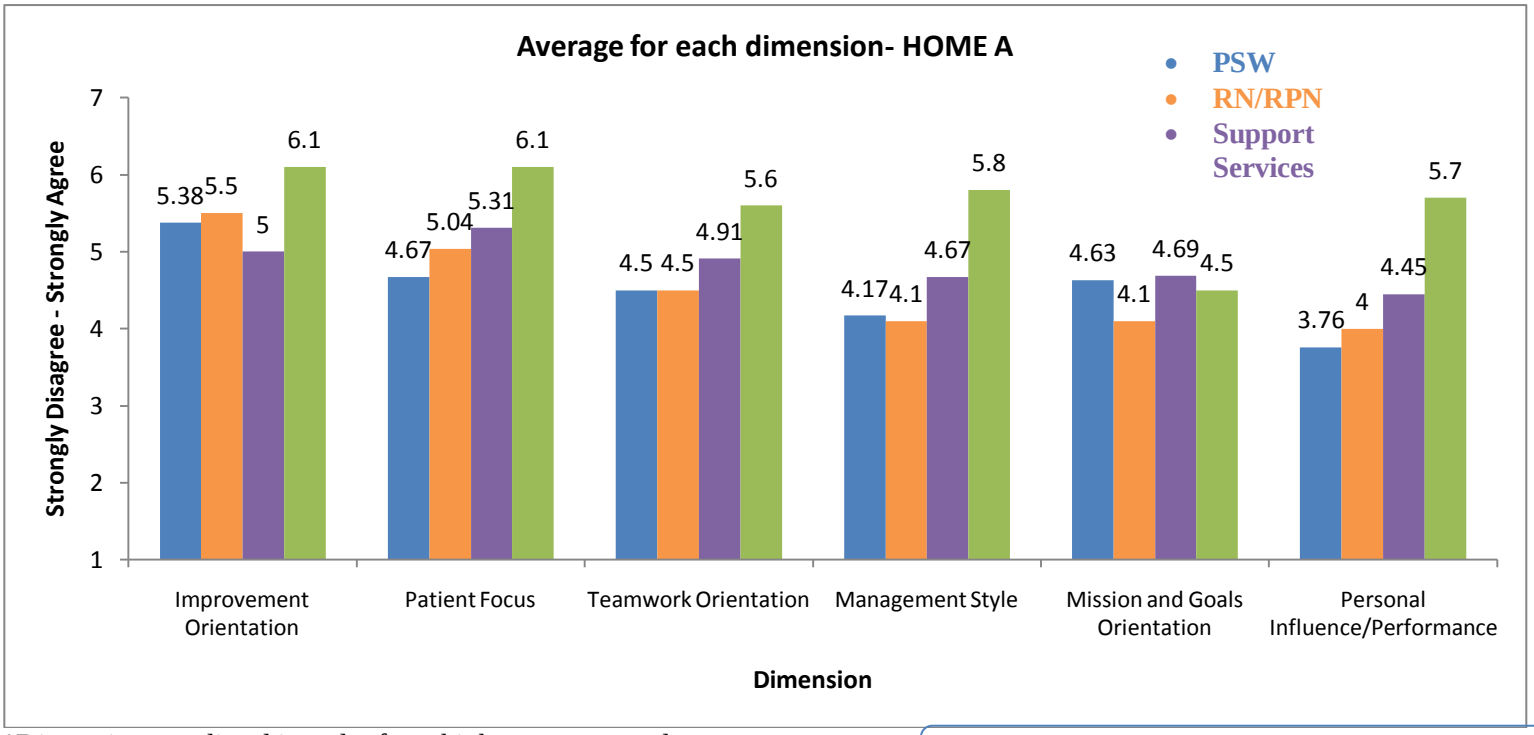
I- Quality Management (Evaluation)

- Performance improvement
- Outcomes
- Resource Utilization
- Adverse events, error, complaints
- Satisfaction
- Routine review
- Utilization review, clinical outcomes, and resources utilization
- Risk Management
- Compliance
- Caregiver and employee satisfaction
- Community needs
- Financial audit
- External accreditation
- Strategic and business plans
- Standards of practice policies and procedures, standards for data collection and documentation
- Other:

J- Communications / Marketing

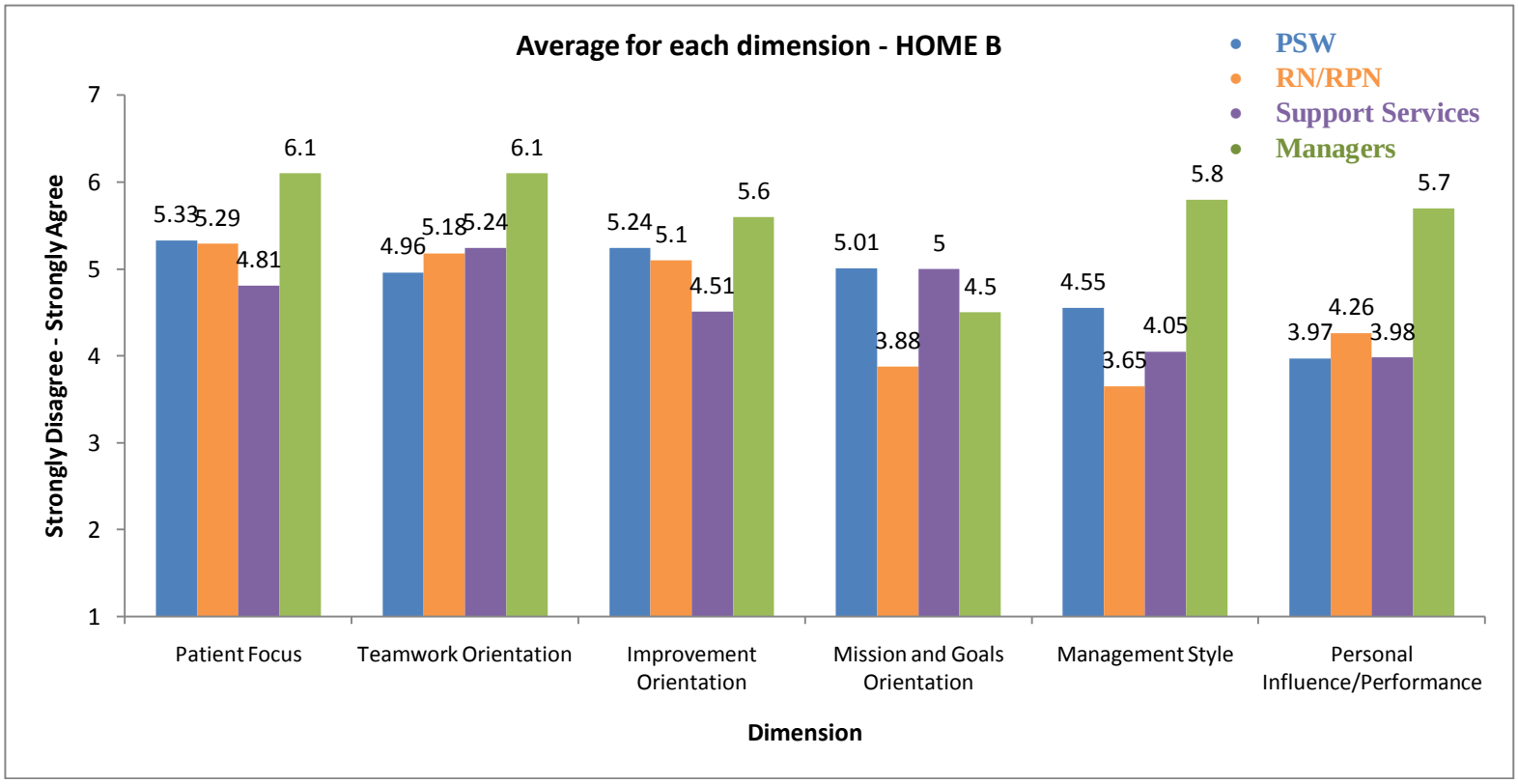
- Communication and marketing strategies
- Materials
- Support for fundraising
- Media liaison
- Adverse situations
- Other:

Appendix K- QIAS Results

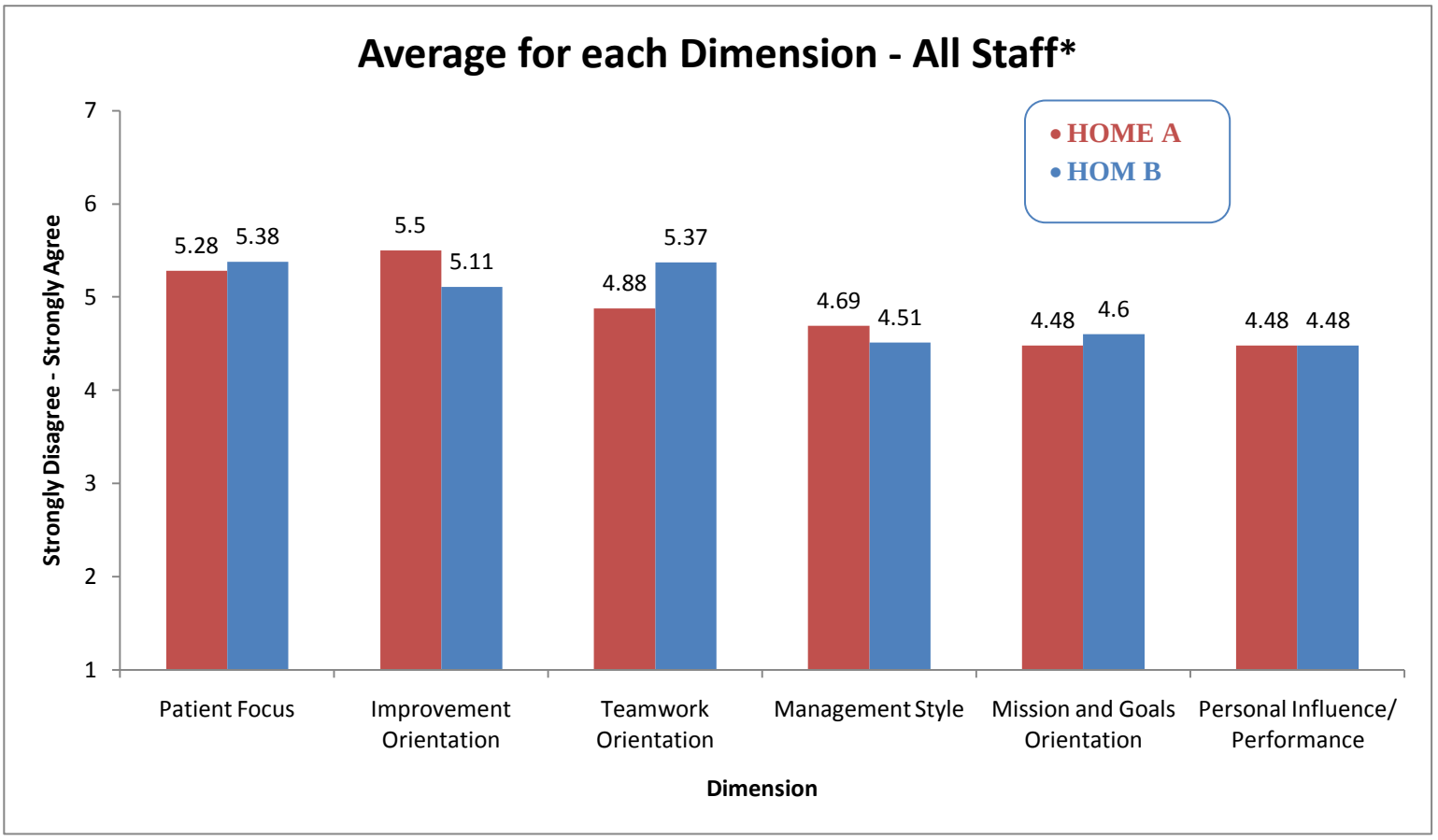


*Dimensions are listed in order from highest average to lowest

# of respondents = 61 out of a possible 135



# of respondents = 59 out of a possible 104



*All Staff = Managers, PSWs, RN/RPNs, Support Staff

Dimension	Definition	Example
Patient Focus	Perceptions of the extent to which patients are valued, treated well, and are an organizational priority.	'Most people here think it is important to ask patients what they want.'
Management Style	Perceptions of the believability of management, their commitment to quality improvement, and their involvement of others in decision-making.	'I can usually believe what I hear from management.'
Team work Orientation	The extent to which people and group cooperate, help each other out, and suggest improvements	'In this organization, people in different departments or programs try to help each other out.'
Improvement Orientation	The values and behaviour of people in the organization toward studying and improving work.	'Trying to improve the way the work gets done is part of everyone's job.'
Mission and Goals Orientation	People's perceptions of the extent that they and others understand the mission and goals of the organization and how their work relates to them.	'Most people here know how their work contributes to this organization's mission.'
Personal Influence/ Performance	The extent to which people feel that they have some control over their work, have an impact on work, and can do their best work.	'In my work situation, I have little control over how things are done.'

Appendix L- FATCOD Results

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

Results from FATCOD (All Staff - Managers, RN/RPN, PSW and Support Staff)

Individual scores for each survey question **Positive worded items** *(1) Strongly disagree (2) Disagree (3) Uncertain (4) Agree (5) Strongly agree.* ***Higher scores are consistent with Palliative Care Philosophy***	**HOME A**	**HOME B**
1. Giving care to the dying person is a worthwhile experience.(*1*)*	4.67	4.56
2. Families need emotional support to accept the behaviour changes of the dying person.(*16*)	4.49	4.53
3. Caregivers should permit dying persons to have flexible visiting schedules.(*23*)	4.62	4.49
4. Caring for the patient's family should continue throughout the period of grief and bereavement.(*4*)	4.30	4.44
5. It is beneficial for the dying person to verbalize his/her feelings.(*21*)	4.49	4.48
6. There are times when the dying person welcomes death.(*10*)	4.32	4.45
7. Dying persons should be given honest answers about their condition.(*27*)	4.24	4.24
8. Care should extend to the family of the dying person.(*22*)	4.31	4.29
9. Families should maintain as normal an environment as possible for their dying member.(*20*)	4.02	4.09
10. It is possible for nonfamily caregivers to help patients prepare for death.(*30*)	4.39	4.17
11. Families should be concerned about helping their dying member make the best of his/her remaining life.(*18*)	4.16	4.02
12. Addiction to pain relieving medication should not be a concern when dealing with a dying person.(*25*)	4.16	3.95
13. Death is not the worst thing that can happen to a person.(*2*)	3.88	3.89
14. The dying person and his/her family should be in-charge decision-makers.(*24)*	4.19	3.89
15. The family should be involved in the physical care of the dying person.(*12*)	3.65	3.61

Negatively worded items *(1) Strongly disagree (2) Disagree (3) Uncertain (4) Agree (5) Strongly agree* ***Lower scores are consistent with Palliative Care Philosophy***	**HOME A**	**HOME B**
16. The length of time required giving care to a dying person would frustrate me.*(7)*	1.62	1.58
17. I would not want to care for a dying person.*(5)*	1.61	1.55
18. I would feel like running away when the person actually died.(*15)*	1.61	1.56
19. As a patient nears death, the nonfamily caregiver should withdraw from his/her involvement with the patient.(*17)*	1.69	1.69
20. I am afraid to become friends with the dying person.(*14*)	1.60	1.73
21. It is difficult to form a close relationship with the dying person.(*9)*	1.65	1.88

22. The dying person should not be allowed to make decisions about his/her physical care.*(19)*	1.61	1.79
23. I would hope the person I'm caring for dies when I am not present.(*13*)	2.04	1.99
24. When a patient asks "Am I dying?", I think it is best to change the subject to something cheerful.*(11)*	2.03	2.10
25. The nonfamily caregivers should not be the ones to talk about death with the dying person.*(6)*	2.25	2.25
26. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.*(26)*	1.99	2.16
27. I would be uncomfortable talking about impending death with the dying person.*(3)*	2.55	2.33
28. Educating families about death and dying is not a nonfamily caregiver responsibility.*(28)*	2.21	2.23
29. I would be upset when the dying person I was caring for gave up hope of getting better.*(8)*	2.13	2.38
30. Family members who stay close to a dying person often interfere with the professional's job with the patient.*(29)*	2.24	2.60

*Bracketed numbers at the end of each statement correspond to the number of original survey questions

Who has had previous education on death and dying?

HOME A	HOME B
RN/RPN =7 respondents reported that they have had previous training on death and dying and 5 reported that they had some education on death and dying.	**RN/RPN** = 1 respondent reported that they have taken training on death and dying, 6 reported that they have had some education and 1 reported that they have never taken any training.
PSW = 11 respondents reported that they have had previous education on death, 10 reported having some training and 1 responded reported that they never have had any training.	**PSW** = 14 respondents reported that they have taken training on death and dying, 9 reported that they have had some education on death and dying and 1 reported never have taken any training.
Support Services Staff = 4 respondents reported that they have had some previous education on death and dying and 6 reported that they have never taken any training.	**Support Services Staff** = 4 respondents reported that have taken training on death and dying and 9 reported that they have never taken any training.
Managers = 7 respondents reported that they have taken previous training on death and dying, 2 reported having had some education on death and dying and 1 reported that they have never taken any training.	**Managers =** 7 respondents reported that they have taken previous training on death and dying, 2 reported having had some education on death and dying and 1 reported that they have never taken any training.

HOME A	HOME B
RNs' and RPNs' overall average score = 4.07 out of 5 Managers' overall average score = 4.13 out of 5 PSWs' overall average score = 4.08 out of 5 Support services' overall average score = 3.93 out of 5 **All staff overall average = 4.05**	RNs' and RPNs' overall average score = 4.18 out of 5 Managers' overall average score = 4.13 out of 5 PSWs' overall average score = 4.05 out of 5 Support services' overall average score = 3.88 out of 5 **All stall overall average = 4.06**

HOME A

RN/RPN # of respondents = 12 out of a possible 16
PSW # of respondents = 22 out of a possible 53
SSS # of respondents = 11 out of a possible 53
Managers # of respondents = 10 out of a possible 13

HOME B

RN/RPN # of respondents = 8 out of a possible 18
PSW # of respondents = 25 out of a possible 44
SSS # of respondents = 13 out of a possible 29
Managers # of respondents = 10 out of a possible 13

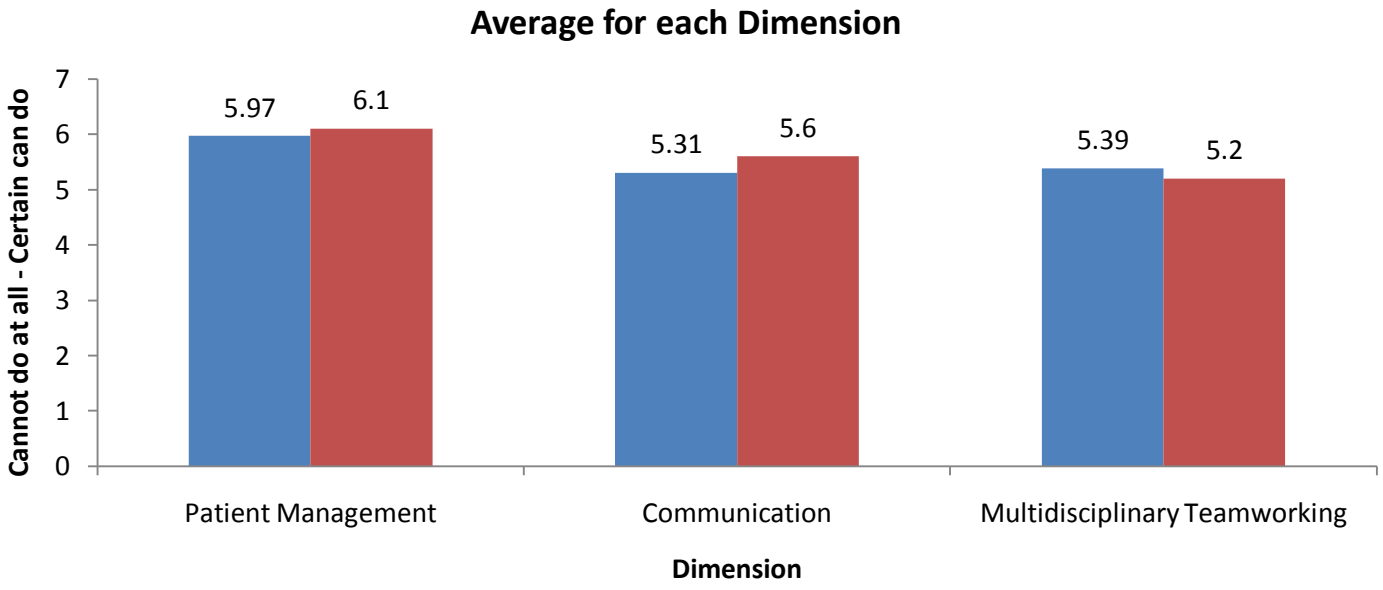
Appendix M

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

Results from Self-Efficacy in End-of-Life Care Survey (RN/RPN)
Home A and Home B (08/10)

What is self-efficacy?

Self-efficacy refers to the belief in one's ability to perform a specific behaviour or skill.



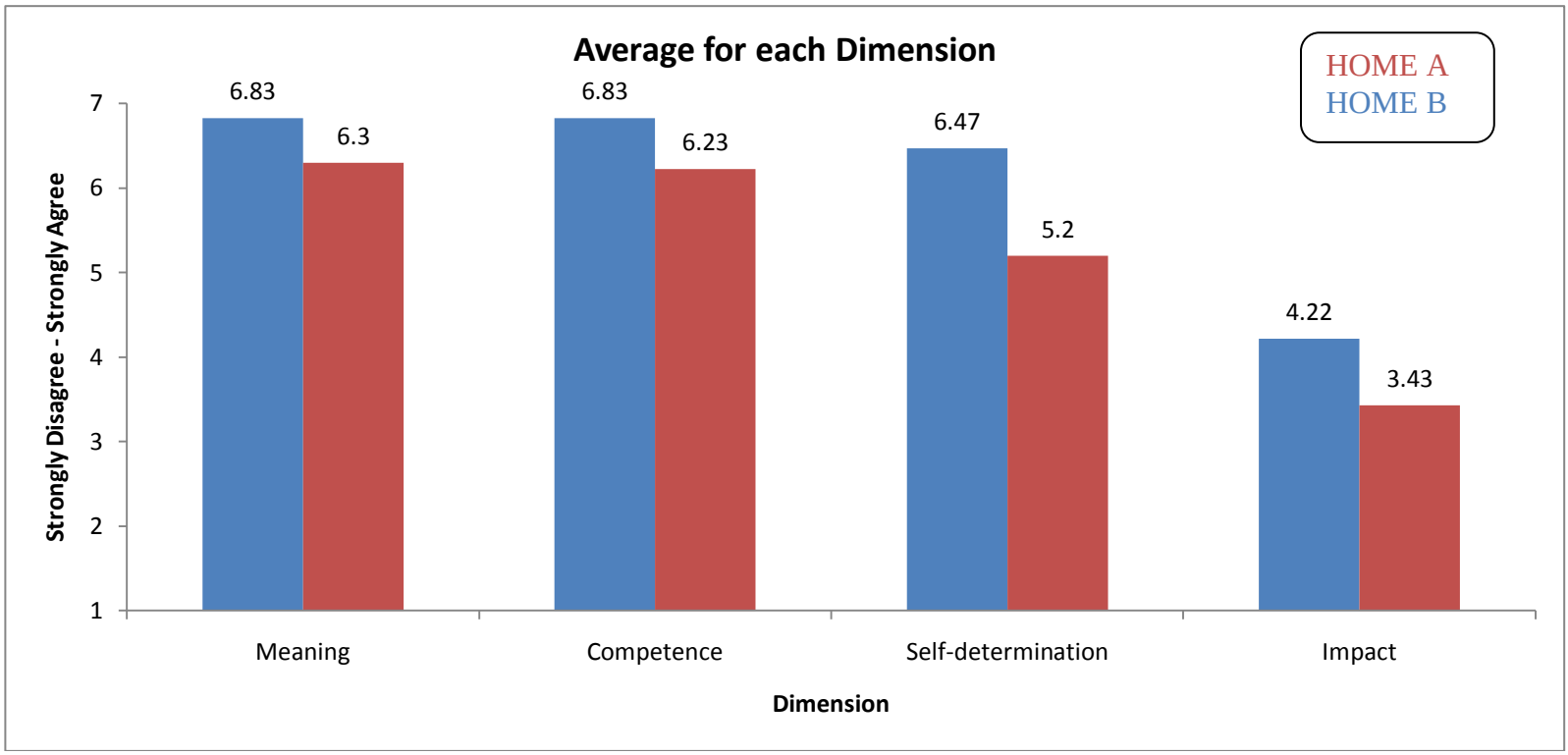
HOME A = 11 out of a possible 16
HOME B = 8 out of a possible 18

HOME A and HOME B scored similarly on all dimensions of self-efficacy. Both homes rated each dimension positively.

Appendix N

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

Results from PEiW Survey (PSW)
HOME A and HOME B (08/10)



Dimension	*Definition*	*Example*
Meaning	Fit between work requirements and beliefs, values and behaviours.	'The work I do is meaningful to me.'
Competence	Person's belief about his/her capabilities to produce effects.	'I am self-assured about my capabilities to perform my activities.'
Self-determination	Autonomy in the initiation and continuation of work behaviours and progress.	'I have considerable opportunity for independence and freedom in how I do my job.'
Impact	The degree to which an individual can influence strategic, administrative or operating outcomes at work.	'My impact on what happens in my department is large.'

HOME A # of respondents = 24 out of a possible 44
HOME B# of respondents = 47 out of a possible 53

PSWs from HOME B scored slightly higher on each dimension.

Appendix O

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

Results from Palliative Care Quiz (RN/RPN)
HOME A and HOME B (08/10)

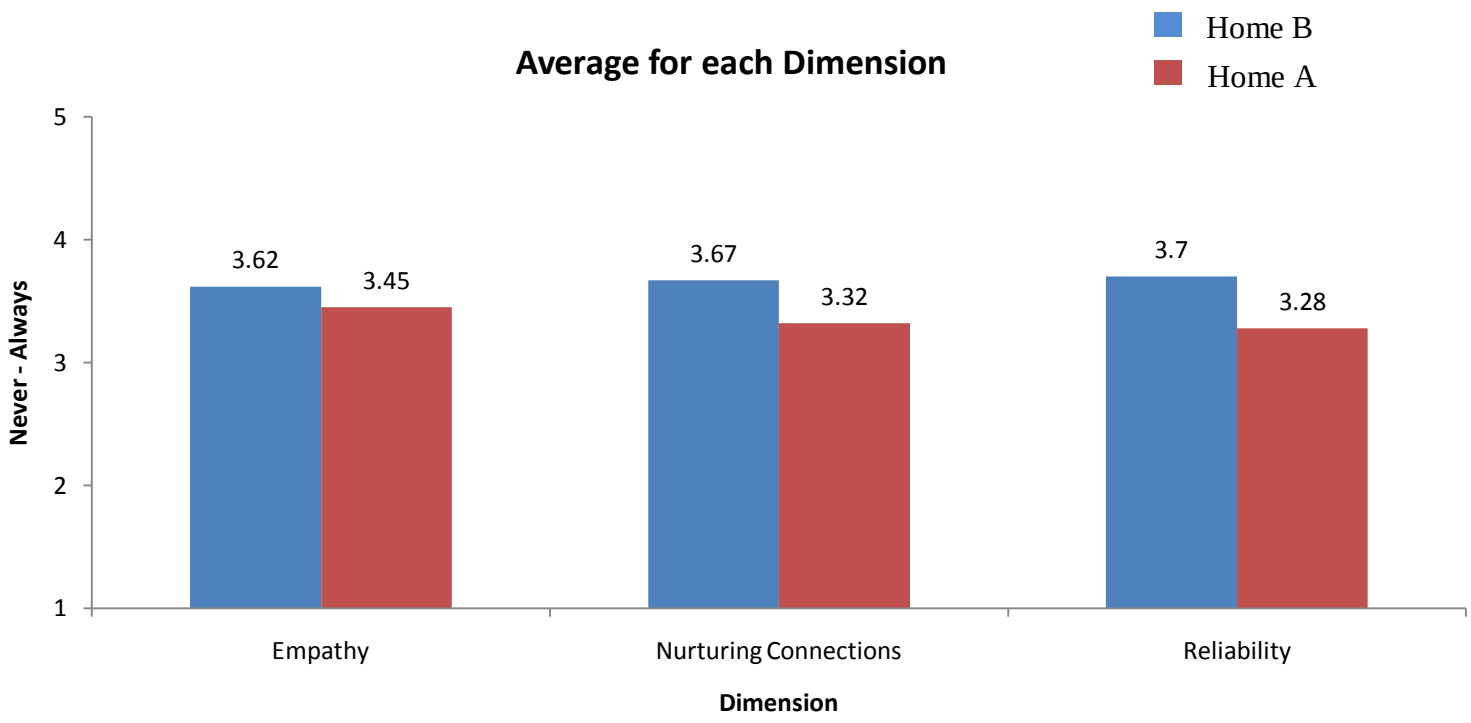
Palliative Care Quiz Questions			% of correct responses HOME A	% of correct responses HOME B
1. Palliative care is only appropriate in situations where there is evidence of a downhill trajectory or deterioration.	T	(F)	66.7%	50.0%
2. Morphine is the standard used to compare the analgesic effect of other opioids.	(T)	F	58.3%	50.0%
3. The extent of the disease determines the method of pain treatment.	T	(F)	50.0%	62.5%
4. Adjuvant therapies are important in managing pain.	(T)	F	91.7%	37.5%
5. It is crucial for family members to remain at the bedside until death occurs.	T	(F)	75.0%	75.0%
6. During the last days of life, drowsiness associated with electrolyte imbalance may decrease the need for sedation.	(T)	F	50.0%	25.0%
7. Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain.	T	(F)	50.0%	37.5%
8. Individuals who are taking opioids should also follow a bowel regime.	(T)	F	100.0%	87.5%
9. The provision of palliative care requires emotional detachment.	T	(F)	91.7%	87.5%
10. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment of severe dyspnea.	(T)	F	33.3%	87.5%
11. Men generally reconcile their grief more quickly than women.	T	(F)	66.7%	50.0%
12. The philosophy of palliative care is compatible with that of aggressive treatment.	(T)	F	8.3%	0.0%
13. The use of placebos is appropriate in the treatment of some types of pain.	T	(F)	66.7%	75.0%
14. In high doses, codeine causes more nausea and vomiting than morphine.	(T)	F	41.7%	50.0%
15. Suffering and physical pain are synonymous.	T	(F)	41.7%	37.5%
16. Demerol is not an effective analgesic for the control of chronic pain.	(T)	F	58.3%	50.0%
17. The accumulation of losses renders burn-out inevitable for those who work in palliative care.	T	(F)	66.7%	12.5%
18. Manifestations of chronic pain are different from those of acute pain.	(T)	F	66.7%	87.5%
19. The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate.	T	(F)	83.3%	50.0%
20. Pain threshold is lowered by fatigue or anxiety.	(T)	F	66.67%	37.5%

HOME A # of respondents = 12 out of a possible 16
HOME B # of respondents = 8 out of a possible 18

Appendix P

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

Results from Supervisory Support Survey (PSW)
HOME A and HOME B (08/10)



Home A # = 24 out of a possible 44
Home B # = 31 out of a possible 53

Home A and B scored similarly on all dimensions related to supervisory support, HRM scored slightly higher on all dimensions.

Dimension	*Definition*	*Example*
Empathy	To recognize the staffs' standards of care, to recognize and accommodate the staffs' expressed needs, and to understand staffs' point of view.	'My supervisor tries to meet my needs.'
Reliability	To be available for staff if things are not going well with residents or families, to protect the nursing staff from the unpredictable by keeping them informed.	'I can rely on my supervisor when things are not going well.'
Nurturing connections	To build and nurture the personal side of the relationship, e.g. knowing the person, demonstrating personal respect, listening, and showing concern and encouragement.	'My supervisor respects me as a person.'