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SUSTAINING PALLIATIVE CARE TEAMS

SUSTAINING PALLIATIVE CARE TEAMS THAT PROVIDE HOME-BASED CARE IN A SHARED CARE MODEL

BY

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A Thesis

Submitted to the School of Graduate Studies

in Partial Fulfillment of the Requirements

for the Degree

Doctor of Philosophy

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(School of Geography & Earth Sciences, Health Geography) Hamilton, Ontario

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SUPERVISOR: Professor Allison M. Williams

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Abstract

This research examined the barriers and facilitators involved in the development and sustainability of palliative care teams using a shared care model. Shared care is established when interdisciplinary specialist palliative care teams (usually comprised of a palliative care physician, an advanced practice nurse, a psychosocial spiritual advisor, a bereavement counselor, a case manager and an administrator) form partnerships with primary care providers (usually frontline family physicians and home care nurses) to support the complex needs of terminally-ill patients and their family members in the home setting. Palliative care teams overcome gaps in the current health care system, such as: lack of palliative care specialists; poor coordination and integration of care, and; a health care workforce with insufficient training in palliative care. This type of service delivery model is common in medical specialties such as mental health and obstetrics, and various forms of palliative shared care have been implemented in other countries such as the US, Australia, UK, Italy and Spain, where it has been shown to be cost-effective. There are few palliative care teams working in a shared care model in Canada; this provided the impetus to investigate the process of how this integrated approach is developed and sustained within the context of specific populations and geographies. A longitudinal case study in a Local Health Integration Network (LHIN) area in Southern Ontario, comprised of urban and rural communities, was conducted in order to evaluate barriers and facilitators in using a shared care model from the perspective of team members, key-informants and stakeholders. The evaluation of barriers and facilitators informed recommendations to guide the sustainability of palliative care teams working in a shared care model.

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Preface

In October 2010, I returned home to Sault Ste. Marie to celebrate Thanksgiving with my family. While having breakfast, I decided to read the local newspaper, The Sault Star. This headline caught my eye:

"Palliative care, maple syrup funded"

I quickly read the accompanying article to learn that two community ventures had received funding through a federally supported not-for-profit organization. A small town in our region, Elliot Lake, had received $3000 to put towards a business plan for a residential hospice, and the region's maple syrup producers' association had also received the same amount to fund travel to Quebec to learn about the latest techniques in maple syrup production. While I was happy that both community initiatives had received support, I couldn't help but wonder why the palliative care initiative hadn't received more? Then I recalled the well-known quote taken from the testimony of Dr. Harvey Chochinov that appears front and centre in the 'Quality End-of-Life Care: The Right of Every Canadian' Subcommittee to update the "Of Life and Death" final report (Carstairs & Beaudoin, 2000):

> *"Unfortunately, in end-of-life care, we do not have a vocal constituency: The dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak"* (Harvey Chochinov, testimony before the Subcommittee, February 28, 2000).

When I returned to Hamilton after Thanksgiving, I started formal data collection for this thesis. I also started to learn more about the palliative care policy context or lack thereof, which helped me to better understand the context behind community-based

efforts such as Elliot Lake's proposal for funding. After spending a year meeting with, and interviewing individuals involved in palliative care service delivery, as well as disseminating findings at discipline-specific conferences thereafter, I think I can say without a doubt that there exists, albeit small, a vocal constituency in end-of-life care. This vocal constituency is complemented by the work of researchers, some of whom I've had the privilege to work with and learn from during my graduate studies. In the past couple of years, I've had the opportunity to witness some of the efforts of this vocal constituency which currently operates within a complicated political and health care landscape, given that health care spending is under continuous scrutiny. My personal goal is that this thesis contributes to the efforts of the vocal constituency and the discourse in palliative care in some way.

This dissertation is formatted as a sandwich thesis and is presented as a collection of research papers. The following three papers listed below are respectively, published, accepted for publication, and submitted for publication.

Chapter 2

DeMiglio, L., & Williams, A., 2012. Shared care: the barriers encountered by community-based palliative care teams in Ontario, Canada. Health & Social Care in the Community 20 (4), 420-429.

Chapter 3

DeMiglio, L., & Williams, A., In press. Enabling factors to shared care with primary health care providers in community settings: the experiences of interdisciplinary palliative care teams. Journal of Palliative Care.

Chapter 4

DeMiglio, L., & Williams, A. 2012. "It's on the will of the people and the organizations": using a scalar approach to explore the sustainability of palliative care teams that provide home-based care. Manuscript submitted for publication to Health & Place.

Please note that Lily DeMiglio, author of this PhD dissertation, undertook collection, transcription and analysis of data as well as writing of the research papers under the supervision of Dr. Allison Williams. Lily DeMiglio designed the studies with primary guidance from Dr. Allison Williams and input from supervisory committee members, Drs. Kevin Brazil, Richard Harris and Mary-Lou Kelley. The supervisory committee members provided comments and editorial feedback. The papers are presented in the preferred format specified by each journal.

References

Carstairs, S., Beaudoin, G.A., 2000. Subcommittee to update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology. Quality End-of-Life Care: The Right of Every Canadian. Final report. Ottawa ON, Senate of Canada.

Palliative care, maple syrup funded. 2010, October 9. The Sault Star, Local news

CHAPTER 1

Introduction

1.1 Scope of the research

In an effort to enhance quality of life, palliative care provides physical, psychological and spiritual support to the dying and their family members (World Health Organization, 2009). However, only a small proportion of the population has access to palliative care services (Romanow, 2002; Carstairs & Beaudoin, 2000), with the latest figure showing that 70% of Canadians are without access (Carstairs, 2010). Although palliative care is provided to people of all ages, the demand for services is exacerbated as a result of population aging because life-threatening diseases, such as cancer, coronary heart disease, dementia and diabetes, are more common in old age (McMichael, 2001). In 2005, over 230,000 people died in Canada, and of these individuals, the majority (78%) were seniors (those aged 65 and above) (Statistics Canada, 2008). In 2007, there were 4.4 million seniors in Canada, accounting for 13% of the total population; projections show that this proportion will increase to 27% by 2056 (Statistics Canada, 2009). In Ontario, 1.7 million seniors made up 13.2% of the population in 2007 and by 2031, 3.6 million will account for 21.9% of the population (MOHLTC, 2008). This growth is attributed to the aging baby boom cohort as depicted in Ontario's population age pyramid (see Figure 1).

In Canada there has been a shift in the location of death into the community with more people dying at home and in nursing facilities (Wilson, Truman, Thomas, Fainsinger, Kovacs-Burns et al., 2009). Using death certificate data, Wilson and

colleagues (2009) found a significant decline in the proportion of deaths in hospital between 1994 (77.7%) and 2004 (60.6%). During this same time frame, they found an increase in the proportion of deaths in nursing homes (3.0% to 9.9%) and private dwellings (19.3% to 29.5%). Health care restructuring has also led to a shift of care out of hospitals and into community settings, such as private dwellings. Some contend that the relegation of healthcare services into the home translates into cost savings for the government (e.g., Burke & Silver, 2005). Studies have also shown that individuals actually prefer to die in their own homes (Brazil, Howell, Bedard, Krueger & Heidebrecht, 2005; Higginson & Sen-Gupta, 2000).

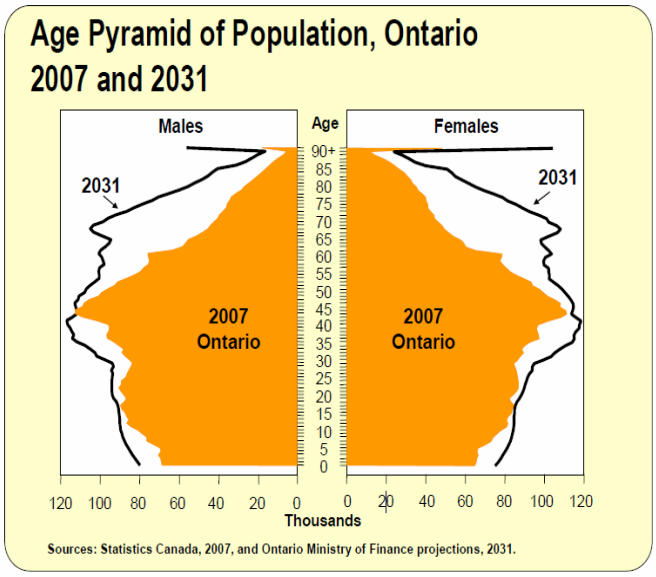

Figure 1: Population Age Pyramid of Ontario, 2007 and projection for 2031 (Source: Ontario Ministry of Finance, 2008)

In 2005, the Ontario Ministry of Health and Long-Term Care (MOHLTC) identified end-of-life[1] (EoL) care as a priority in its Health Care Transformation Agenda (Dudgeon, Vaitonis, Seow, King, Angus et al., 2007) and pledged $115.5 million towards the *EoL Care Strategy*; this provided funding to a number of palliative services, including home care and hospice programs, over a three-year period. The *EoL Care Strategy* funding was also used to implement Palliative Care Networks (now commonly referred to as Hospice Palliative Care Networks) in each of the province's 14 Local Health Integration Networks (LHINs). The Hospice Palliative Care Networks collectively seek to assist achieving comprehensive, consistent and high quality health care services for the terminally-ill across the province. In order to meet this goal, the Hospice Palliative Care Network involved in this study formulated several objectives which include: (1) to shift care of the terminally-ill out of hospital; (2) to build patient-centered and interdisciplinary service delivery capacity and; (3) to improve access, coordination and consistency of service and supports. Later, in 2007, the MOHLTC unveiled its *Aging at Home Strategy* – a four-year $1.1 billion initiative to assist LHINs in providing a variety of community-based services to senior citizens (MOHLTC, 2007). In a press release for the *Aging at Home Strategy*, former MOHLTC Minister George Smitherman stated that due to population aging, "we need to look for innovative solutions that are more responsive to [seniors'] needs and allow seniors to continue to live in comfort and with respect in their own homes, ideally for the rest of their days" (MOHLTC, 2007, n.p.). Along the same lines, in a press release for the *EoL Strategy*, Smitherman stated that "we are enhancing

[1] Please note that end-of-life care, hospice palliative care, and palliative care are used interchangeably.

end-of-life care at home and funding nursing and personal support services in residential hospices, so that people can live out their lives with as much dignity and comfort as possible" (MOHLTC, 2005, n.p.). Despite financial investment, the government provides little to no direction as to how services are to become comprehensive, consistent or high quality; this is the task of the LHINs, Community Care Access Centres[2] (CCACs) and the Hospice Palliative Care Networks.

While there are few palliative care teams working in a shared care model in Canada, this integrated form of health care service delivery has already been implemented on an international scale (Aggarwal, Glare, Clarek & Chapuis, 2006; Costantini, Higginson, Boni, Orengo, Garrone et al., 2003; Crawford & Price, 2003; Nielsen, Palshof, Mainz, Jensen & Olesen, 2003; Bruera & Sweeney, 2002). Shared care models are quite common in other areas of health care, including chronic disease management (e.g., Vrijhoef, Diederiks, Spreeuwenberg, Woffenbuttel & van Wilderen, 2002), mental health (e.g., Samy, Hall, Rounsevell & Carr, 2007; Paquette-Warren, Vingilis, Greenslade & Newman, 2006) and obstetrical care (e.g., Lombardo & Golding, 2003). For example, in the chronic disease management (e.g. diabetes) shared care model, family health team nurses and family physicians work alongside diabetic specialists and dieticians. In the mental health shared care model, family physicians, nurses and social workers work with psychiatrists, psychiatric nurses and mental health counseling specialists. In the obstetrical shared care model, family physicians work together with midwives and obstetricians/gynecologists.

[2] CCACs are funded by LHINs through the MOHLTC to coordinate health care services in the community.

The Canadian Hospice Palliative Care Association (CHPCA) states that palliative care is "most effectively delivered by an interdisciplinary team of health providers" (Ferris, Balfour, Bowen, Farley, Hardwick et al., 2002, p. 18). An interdisciplinary team ensures that all facets of palliative care – be it physical, psychological or spiritual, receive attention. In August 2008, the Hospice Palliative Care Network involved in this study unveiled its system design plan, which outlined several initiatives that would support their vision of an integrated palliative care service delivery model in the LHIN area. These initiatives are in accordance with the guidelines and norms of practice set forth by the CHPCA. One of the initiatives involved adopting a model of shared care. A shared care model promotes partnerships and collaboration between various practitioners, providing different levels of care in order to deliver seamless palliative care to patients and their family members in the home setting.

Palliative care teams working in shared care (also referred to as shared care teams, enhanced or integrated teams, see Marshall, Howell, Brazil, Howard & Taniguchi, 2008) are interdisciplinary, usually comprised of a palliative care physician, an advanced practice nurse, a psycho-spiritual care advisor, a bereavement counselor, a case manager and an administrator. A shared care model is established when the team works in conjunction with family physicians and home care nurses to support and enhance the palliative care provided to patients and their families in the community. For example, teams assist family physicians and home care nurses by providing a variety of services, including joint or alternating home visits, telephone consultation, advice about medications/treatment of symptoms and assistance with pain, cognitive and symptom

assessments. They also offer personal, emotional and spiritual supports to patients and their family members, as well as bereavement support after the patient's death.

The shared care model was endorsed by the Hospice Palliative Care Network for several reasons. First, a shared care model coordinates services being provided by various sources and practitioners so that care is less fragmented for patients. Second, the shared care teams provide primary caregivers (i.e. family physicians and home care nurses) and informal caregivers (e.g. usually family members) with additional specialist supports in order to address the often complex needs of terminally-ill patients. In this regard, teams can be considered to be a form of primary care service innovation since the model employs an integrated team-based approach to overcome existing health care challenges such as the lack of trained family physicians and home care nurses in the areas of palliative care, pain and symptom management, psychosocial spiritual and bereavement capacity. Third, not only does the shared care model work to enable patients' preferences to die at home but it also helps to keep patients out of hospital, thus decreasing costs (e.g., Lawson, Burge, McIntyre, Field & Maxwell, 2009; Brumley, Enguidanos, Jamison, Seitz, Morgenstern et al., 2007; Serra-Prat, Gallo & Picaza, 2001).

While it is important for policy makers and program managers to allocate resources and devise delivery strategies in a cost-effective manner, it is also important to ensure the provision of high quality palliative care. According to Health Canada (2009), the goal of palliative care is to maximize the quality of life for patients and their families. According to the WHO (2009), the purpose of palliative care is to enhance the quality of life of patients and their family members, most often through an interdisciplinary team approach

that can address physical, psychological, social and spiritual needs of people who are dying and their families. Palliative care teams are popular in other countries; they coordinate services between terminally ill patients, their families and healthcare professionals, as well as improve quality of life through pain and symptom management and the provision of psychosocial support (Higginson, Finlay, Goodwin, Hood, Edwards et al., 2003). Research has shown the benefits of palliative care teams from the perspective of family physicians (e.g. Marshall et al., 2008) and recipients of care (Brumley et al., 2007), but there is a dearth of qualitative research examining the perspectives of team members.

Aherne and Pereira (2005) argue for more inquiry by social scientists in the area of palliative care:

> The field of health services would benefit greatly from contributions of in-depth case studies and other forms of health services research, especially that which helps identify the range of levers and options for navigating constructive change amid complexity… Failure to effectively engage scholarship from the broader humanities and social sciences disciplines sets the stage for restricting discourse on these important issues to narrower perspectives of economic rationalism and the pragmatic orientation of service rationing (p.17).

A qualitative, social science approach may offer insight on health service delivery processes and practices that could be overlooked by using a different approach. Thus, this research makes a unique contribution to understanding the development and

sustainability of palliative care teams and the implementation of a shared care model with a population who require palliative care.

The Hospice Palliative Care Network involved in this study endorsed a shared care model for its' LHIN area, in part, based on the sustainability of a pre-existing team since 1997. This team has proven to be sustainable by existing for almost 15 years and has been well-received by family physicians while being able to achieve a continuum of care across settings (e.g. home, hospice, hospital and long-term care). Four additional teams provide services in four communities in the LHIN area (delineated by the Hospice Palliative Care Network), and six additional teams are planned for development, for a total of 11 teams to service the LHIN area. The five shared care teams currently operating in the LHIN area are heterogeneous; they vary in terms of composition, are at various stages of development, and serve different communities (see Ferris et al., 2002, pg. 68 for an example of the different types of service delivery models). Each team's service population is defined in terms of pre-determined geographical parameters, which is why some patients in the LHIN receive usual practice with no shared care option.

1.2 Research Objectives

The purpose of this research is to examine the barriers and facilitators to implementing palliative care teams working in a shared care model in a LHIN area in Southern Ontario. The primary objective of this research is twofold: (1) to examine the development (Chapters 2 & 3) and; (2) sustainability of a shared care model for delivering palliative care in a specific geography (i.e., the communities within the LHIN's geographically delineated boundaries), which consists of both urban and rural

communities (Chapter 4). Here the concept of development is understood as the process of forming the palliative care teams. ***Development*** is investigated by retrospectively and prospectively examining factors related to:

1. Team membership
2. Time to form the team
3. The ways in which team members function (i.e. their roles and responsibilities, the type of service delivery model followed according to Ferris et al., 2002, p. 68)
4. The ways in which team members communicate with one another (e.g., meetings, telephone, electronically etc.), and;
5. The ways in which team members learn from each other to improve their practice as palliative care providers.

These factors are addressed primary in Chapters 2 and 3 through an examination of the barriers and facilitators involved in shared care, respectively. The concept of ***sustainability*** is addressed in Chapter 4 and it is understood as the team's capacity to:

1. Work together over time and;
2. Work interprofessionally in a shared care model.

It is important to investigate how this team-based approach is structured and delivered within the context of the population and geographies it serves, as well as the broader health care system. A qualitative case study was conducted to examine the process of developing and sustaining palliative care services using a shared care model over time, and to evaluate what facilitates (enabling factors), or constrains (barriers), this process from the perspective of providers and stakeholders.

1.3. Methodology

Research design

This project followed a longitudinal case study design whereby data were collected over the course of one year (September 2010-September 2011). According to Yin (2009) a case study is commonly used when the aim is to examine a "contemporary phenomenon within a real-life context" (p.2). Here, the phenomenon of interest was the use of a shared care model in the context of the LHIN communities, and, more broadly, in the context of the health care system across the urban and rural continuum. More specifically, the research was an embedded single-case design whereby there was one case with several embedded units of analysis (Yin, 2009). The case was defined as the LHIN area (i.e. the geographical space which defines the case). Each palliative care team (n=5) was a unit of analysis that was studied individually to gain an in-depth understanding of how each team operates. In addition, contextual data was collected from key informants knowledgeable in the area of shared care and stakeholders. Interviews with stakeholders and key informants enhanced understanding of the overall process in the development of palliative care teams and the implementation of shared care models.

Data Sources

Multiple sources of data were used as is common in case study research (Yin, 2009). Qualitative research is the best approach for learning more about the views or insights of individuals (Pope & Mays, 1995). Health services researchers are calling for more qualitative palliative care evaluations primarily due to the "problems and pitfalls" associated with quantitative evaluations (see McWhinney, Bass & Donner, 1994). Focus

group and one-on-one interviews were conducted in order to collect qualitative data. The interviews were semi-structured using an interview schedule asking a series of questions about shared care models and the delivery of palliative services.

Data collection took place between the fall of 2010 and 2011, specifically in three phases.

Phase 1:

As a first step in the data collection process, key informants with expert knowledge on shared care were interviewed to gain a better understanding of this type of service delivery model.

Phase 2:

The primary source of data were the palliative care teams. Semi-structured focus group interviews were conducted every three-four months with members of five shared care teams. In total, each shared care team participated in three focus groups.

Phase 3:

The contextual source of data was gathered from stakeholders involved in the process of implementing shared care and/or palliative care services in the LHIN area.

Ongoing palliative care developments in the LHIN area were observed by attending and taking field notes at Hospice Palliative Care Network service delivery meetings (I was an ex-officio member of the service delivery committee). Additional data sources included public records, newspaper articles, Hospice Palliative Care Network documents, archives, newsletters, and a reflexive journal (Merriam, 1998). The data included as public records included documents such as environmental scans that used

Census of Canada data specific to the LHIN. In addition, observations were used to gather data through note taking at the Hospice Palliative Care Network service delivery committee meetings and public forums. Furthermore, since the assumption and experiences of the researcher play a role in the research process (Laverty, 2003), a reflexive journal was used as a means to record and acknowledge biases throughout the course of the study. Since the researcher is considered to act as a research instrument, there exists the potential of error and bias (Merriam, 1998). The reflexive journal was used to record interview observations (e.g., participant demeanor) as well as any decisions made throughout the course of the study for audit trail purposes. In a qualitative study, confirmability is achieved through an audit trail (Baxter & Eyles, 1997).

Thematic Content Analysis

Thematic content analysis guided the method of qualitative data analysis using the framework suggested by Burnard (1991). "The aim is to produce a detailed and systematic recording of the themes and issues addressed in the interviews and to link themes and interviews together under a reasonable exhaustive category system" (Burnard, 1991, p. 462). The coding process involved connecting similar views and ideas into wider groups (Creswell, 2003). More specifically, prior to commencing data analysis, the notes that were made during interviews (e.g., notes on participant demeanor, behaviour, body language etc.) were reviewed as a means of assisting in situating participant comments. This form of reflexive journaling is considered to be "disciplined subjectivity" which adds to the credibility of the research (Baxter & Eyles, 1997). Data analysis involved multiple readings of the transcript to become immersed in the data. Interview

transcripts were imported in NVivo to manage the dataset and emergent themes. Excerpts from participants were categorized according to theme. The generated themes were then examined and oftentimes, related themes were merged together, minimizing the overall number of themes into specific categories. As a checkpoint, it was verified whether excerpts were from different participants/standpoints to ensure representation and convergence from across participants. By combining data from both focus group interviews and one-on-one interviews, the methodological triangulation of the study was bolstered (Baxter & Eyles, 1997). Also, multiple sources of data, including notes made during Hospice Palliative Care Network meetings as well as information gleaned from applicable documents, and the use of excerpts from multiple participants, assisted in triangulation. For a detailed overview of the study's rigour see Appendix C.

1.4 Geography Lens

This body of research is situated in the sub-discipline of health geography, as it investigates a form of palliative care service delivery in a broader primary health care context and across a number of community care settings, including: hospice, long-term care facility and hospital, but with an emphasis on home-based care (e.g., Kearns, 1993). The shift to health geography from medical geography "has been portrayed as indicative of a distancing from concerns with disease and the interests of the medical world in favour of an increased interest in well-being and broader social models of health and health care" (Kearns & Moon, 2002, p. 606). This shift has also resulted in less of a focus on the utilization of health care services and a movement away from viewing the place of

care as a "container" but rather for its broad implications in health (Gesler & Kearns, 2002).

Since the mid to late 1990s, the scope of health geography has evolved and expanded. According to Andrews and Crooks (2009), "although the vast majority of the new 'place-sensitive' health geography is focused on patients and consumption… part of a renewed engagement with health care has seen some attention to political economy, workers, work, and workplaces" (p. 31). A growing body of work has also focused on the geographies of: primary care (e.g., Crooks & Andrews, 2009); rural health care (e.g., Williams & Kulig) and; care/caregiving (e.g., Milligan & Wiles, 2010; Milligan, 2009; Parr 2003). Within these areas, there has also been a broad and deep interest in palliative care. The transformation of the home space to a site of care (i.e., a therapeutic landscape) has been explored by many and, primarily with a focus on informal/family caregivers (e.g., Donovan & Williams, 2007; Williams, 2004; Williams, 2002). The effects of politics on the delivery of rural palliative care (Crooks et al., 2011) has been examined using a geographical lens in addition to the economic and political (re)-organization of home and community care services (Skinner et al., 2008; Williams, 2006; Milligan, 2000; Williams, 1996).

Taken together, the literatures related to health geography have enhanced the understanding of health service processes and utilization. However, a number of areas have yet to be addressed. More recent research suggests the need to consider matters of health care production, a subject which is often overshadowed by a focus on consumption (Andrews & Evans, 2008). An examination of the perspectives of palliative care team

members is of particular importance as it addresses this gap. As discussed above, palliative care research in health geography has focused on informal and/or family caregiving; there has also been an abundance of work in this area with a focus on rural geographies. This study extends this body of research to include inquiry on both rural and urban geographies, with a focus on those involved in the formal provision of palliative care services.

1.5 Analytical and Conceptual Frameworks

Three different analytical and conceptual frameworks were employed in this study. In Chapter 2, the examination of barriers involved the application of a political science framework that is often used in health policy analysis (e.g., Hutchison et al., 2001) and commonly referred to as the *3-I Framework* (see Figure 2 for depiction). The recurring barriers identified by team members and key-informants were categorized as either *institution-, interest-,* or *idea*-related.

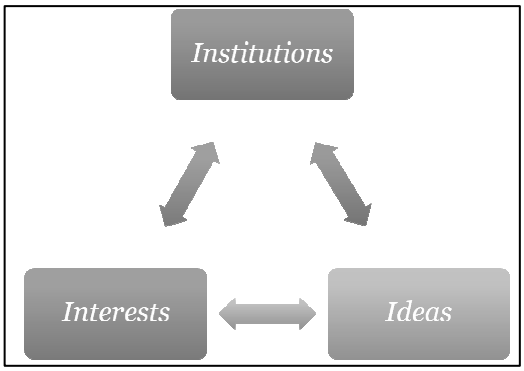

Figure 2: The *3-I* Framework

The investigation of the factors that enabled palliative care teams to work in shared care with primary care providers, as outlined in Chapter 3, involved the application of the

conceptual framework of palliative care evolution put forth by Williams et al. (2010) (see Figure 3).

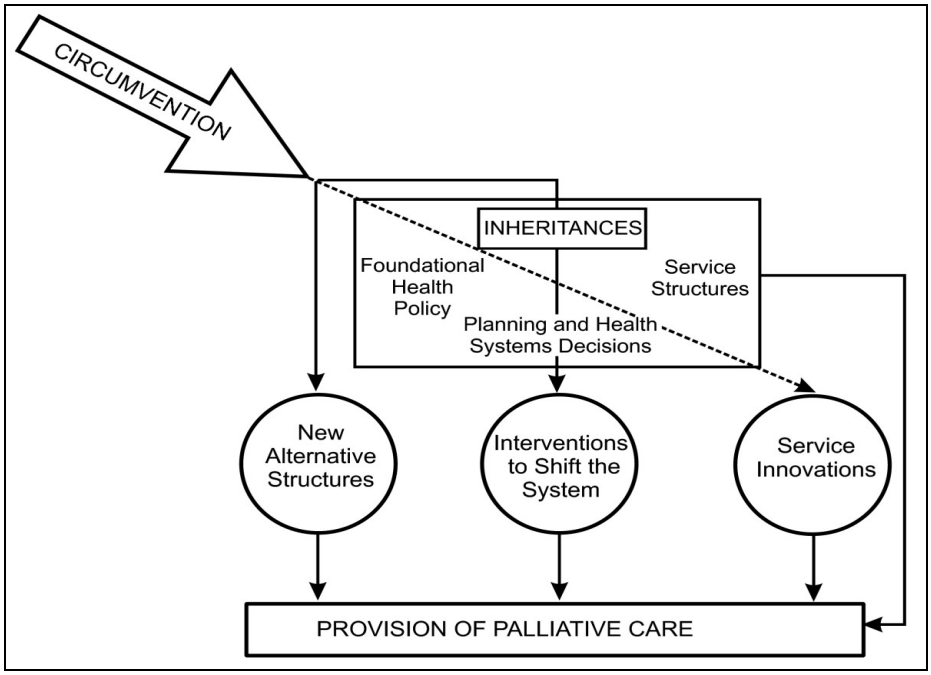

Figure 3: The conceptual model of the evolution of palliative care in Canada (Source: Williams et al., 2010)

Finally, in Chapter Four, a scalar approach, which is common in health geography (e.g., Giesbrecht et al., 2010), was used to classify factors affecting the sustainability of teams across three different scales: community, LHIN and province (see Figure 4).

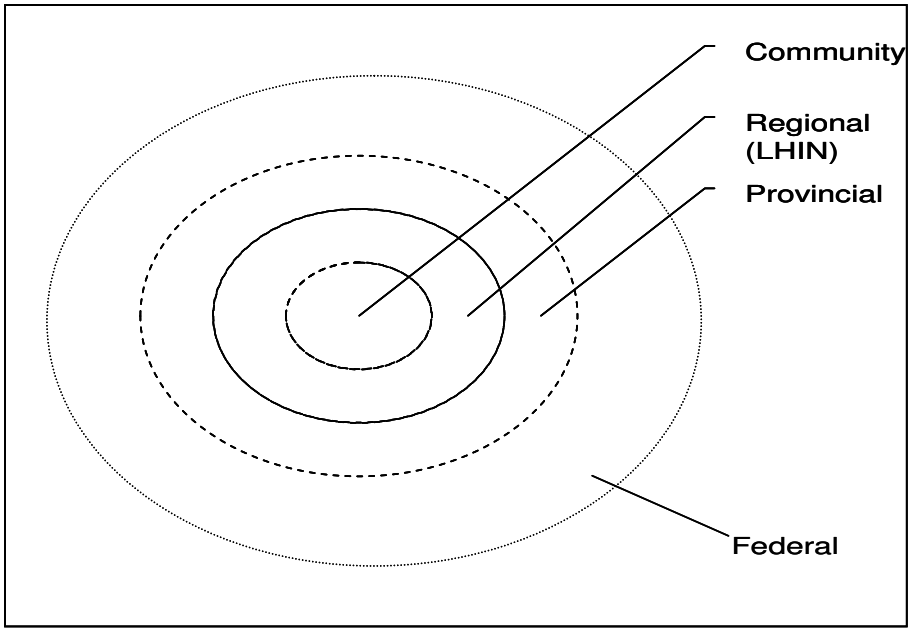

Figure 4: Scalar classification by province, LHIN and community

1.6 Reader's Guide to the Thesis

In an effort to protect the confidentiality of participants, the geographic location of this study is withheld and participants are referred to using broad terms such as key-informant, stakeholder or team member. This thesis consists of five chapters, including this introductory chapter, three research papers, and a conclusion. As noted in the preface, each paper is presented as an individual chapter. The paper in Chapter 2 was published in the journal, *Health and Social Care in the Community*, and established the socio-political barriers that palliative care teams experience in providing home-based care in a shared care model. This work provided the underlying basis for Chapter 3 which examines the enabling factors enacted by palliative care teams to work in shared care with primary care providers. This research paper was accepted for publication in the *Journal of Palliative Care*. Both Chapters 2 and Chapter 3 set the stage for the third paper presented in Chapter

4 which investigates the sustainability of palliative care teams. This paper was submitted to *Health & Place*. The final chapter, Chapter 5, provides a summary of the major findings and conclusions from each paper. A section on contributions, including policy implications and areas for further study, is also included.

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CHAPTER 2

Shared care: the barriers encountered by community-based palliative care teams in Ontario, Canada

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Abstract

In order to meet the complex needs of patients requiring palliative care and to deliver holistic end-of-life care to patients and their families, an interprofessional team approach is recommended. Expert palliative care teams work to improve the quality of life of patients and families through: pain and symptom management, and; psychosocial spiritual and bereavement support. By establishing shared care models in the community setting, teams support primary healthcare providers such as family physicians and community nurses who often have little exposure to palliative care in their training. As a result, palliative care teams strive to improve not only the end-of-life experience of patients and families, but also the palliative care capacity of primary healthcare providers. The aim of this qualitative study was to explore the views and experiences of community-based palliative care team members and key-informants about the barriers involved using a shared care model to provide care in the community. A thematic analysis approach was used to analyze interviews with five community-based palliative care teams and six key-informants, which took place between December 2010 and March 2011. Using the 3-*I* framework, this study explores the impacts of *Institution*-related barriers (i.e. the healthcare system); *Interes*t-related barriers (i.e. motivations of stakeholders) and; *Idea*-related barriers (i.e. values of stakeholders and information/research), on community-based palliative care teams in Ontario, Canada. Based on the perspective of team members and key-informants, it is suggested that palliative care teams experience socio-political barriers in an effort to establish shared care in the community setting. It is

important to examine the barriers encountered by palliative care teams in order to address how to better develop and sustain them in the community.

Keywords:

barriers, community-based palliative care, interprofessional care, qualitative research, shared care, teamwork

Introduction

Given the complex needs of patients at the end of life, the input and expertise of a variety of medical, nursing and allied health professionals is often required. For this reason, and in order to provide holistic palliative care, a team approach is often recommended (Saunders 2000, Billings 2002, Ferris *et al*. 2002, Crawford & Price 2003, Meier & Beresford 2008). Although the composition of teams vary, at a minimum they include healthcare providers with specialist training in palliative care, such as physicians, nurses and social workers, the latter, who usually have expertise in psychosocial spiritual and/or bereavement counselling (Crawford & Price 2003, Marshall *et al.* 2008). In addition, palliative care teams often vary in terms of the settings in which they practice (Saunders 2000); some teams solely serve hospitals and others work in community settings, such as nursing or long-term care facilities, private residences and hospices.

In order to better coordinate care and build capacity, community-based palliative care teams (CBPCTs) enter into collaborative partnerships with primary healthcare providers, such as family physicians and community nurses. Primary healthcare providers often lack adequate training in palliative care and CBPCTs assist by sharing their specialist knowledge and skills. A shared care model is established through

interprofessional collaborations of this kind whereby healthcare providers assume mutual responsibility for a patient (Moorhead 1995) while capacity building (Mazowita 2004).

International research from Australia, the United States, the United Kingdom and in several European countries such as Italy and Spain, has shown that palliative care teams working in integrated service models, including the shared care model, have been widely adopted and effective. Various models have been successful at improving the satisfaction of primary healthcare providers, patients and families while also reducing healthcare costs, such as by decreasing hospital usage at end of life (Hearn & Higginson 1998, Costantini *et al.* 2003, Higginson *et al.* 2003, Aggarwal *et al.* 2006, Brumley *et al.* 2007, Herrera *et al.* 2007, Zimmermann *et al.* 2008, Neergaard *et al*. 2010, Howell *et al.* 2011). On the other hand, this body of literature has also addressed the challenges and barriers encountered by palliative care teams, such as funding (Billings 2002) and interprofessional collaboration issues (Crawford & Price 2003, Neergaard *et al.* 2008, Neergaard *et al.* 2010, O'Connor & Fisher 2011). In the Canadian context, there is some research specific to the success of palliative care programmes and teams (Bruera *et al.* 1999, Bruera *et al.* 2000, Burge *et al.* 2005, Fainsinger *et al.* 2007, Marshall *et al.* 2008, Lawson *et al.* 2009, Howell *et al.* 2011); however, there is a dearth of research on CBPCTs working in a shared care model and the barriers that they face. Consequently, there is a need to fill this gap by examining CBPCTs working in a shared care model from a Canadian perspective. The research presented herein makes such a contribution through specifically examining the barriers these teams confront, and by so doing,

informs the development of this type of service delivery model in jurisdictions which have yet to adopt it.

This research is timely given that, similar to other developed countries, Canada is experiencing more people dying in community settings than in hospitals due to healthcare restructuring (Wilson *et al*. 2009); further, the number of deaths are projected to increase due to population aging (Statistics Canada 2010). Taken together, these factors demonstrate that community-based palliative care services are, and will be, increasingly needed. The goal of this study was to explore the perspectives of CBPCTs and key-informants about the barriers involved in providing palliative care in the community using a shared care model. We identify the barriers in establishing a shared care model of palliative care based on the experiences of five CBPCTs and the views of six key-informants located in Ontario, Canada. Before outlining the study's methods, it is important to provide an overview of the relevant healthcare context.

Healthcare delivery context in Canada

Provinces/territories in Canada have authority over the delivery of healthcare services while the federal government finances healthcare and monitors adherence to the principles of the Canada Health Act (Marchildon 2005). There is 100 percent public payment for all medically necessary hospital and physician services. Most of the provinces/territories in Canada have regionalized healthcare whereby health services are planned and delivered according to geography; the province of Ontario is divided into 14 geographically delineated Local Health Integration Networks (LHINs) (Marchildon 2005). In each LHIN, there are Community Care Access Centres (CCACs) which

coordinate community-based healthcare services (Witmer 2000, OACCAC n.d.). Ontario is unique in that service providers, such as for-profit and not-for-profit nursing agencies, compete for CCAC home care service contracts through a competitive bidding process (Abelson *et al.* 2004, Woodward *et al.* 2004).

As part of Ontario's *End-of-Life Care Strategy*, hospice palliative care networks were implemented in each of the LHINs in 2005 to determine LHIN-specific priorities and to select the most appropriate service delivery models (Dudgeon *et al.* 2007, Seow *et al.* 2008). This devolution of responsibility has led to the implementation and endorsement of CBPCTs working in a shared care model in only some of the LHINs; as a result, there is no consistency in palliative care service delivery models across the province. The LHIN area of concern herein has endorsed CBPCTs working in a shared care model, in part based on the success demonstrated by a pre-existing CBPCT serving a region of the LHIN area since the mid-1990s.

The specific location and name of the LHIN has been withheld in order to protect the confidentiality of participants. While the LHIN serves a vast population, each of the five teams is geographically bound, whereby services are limited to patients living within the boundaries of certain regions within the LHIN. As the five teams currently only serve part of the LHIN area, a large number of patients in the LHIN receive usual care with no access to the expertise of a CBPCT. The hospice palliative care network for the LHIN area anticipates the implementation of an additional six CBPCTs in the areas currently receiving usual care; the timing of the introduction of these teams has not yet been determined.

Methods

This qualitative study is part of a one-year longitudinal case study comprised of three phases, all of which examine the barriers and facilitators involved in the implementation of CBPCTs pursuing a shared care model of palliative care service delivery. This study is based on findings from the first phase (i.e. interviews with key-informants) and the second phase (i.e. CBPCT focus groups) specific to the barriers encountered by CBPCTs working in a shared care model. The third and last phase, not reported on herein, will encompass stakeholder perspectives. Case study research often involves the investigation of a phenomenon or issue and its contextual influences (Yin 2009). Here, the case study is bounded by the geography of the LHIN and the phenomenon of interest is the delivery of palliative care services by CBPCTs working in a shared care model.

Participants

Ethics approval from McMaster University was in place prior to data collection, which was conducted between December 2010 and March 2011. Recruitment involved one of the researchers initially meeting with each of the five CBPCTs to present a brief overview of the objectives and design of the case study, including participation logistics. Each of the five CBPCTs were formed at different times and have a unique size and make-up (see Table 1). All of the CBPCTs were comprised of service providers such as physicians and nurses (see Table 2), however, two also included administrators (i.e. hospice directors & administrative assistants). Letters of information and consent forms were distributed at each of these initial meetings and all team members were invited to

participate in a focus group interview, which was scheduled for a later date. In total, 33 team members across the five CBPCTs were invited to participate and 28 accepted the invitation in addition to two medical/nursing residents. All team members who showed up to the focus group session were included in the study. In addition, eight key-informants with either expertise on shared care models (e.g., researchers), or indirect involvement in the delivery of palliative care services using a shared care model (e.g., coordinators), were invited to participate in one-on-one interviews (see Table 3). A purposeful sampling strategy (Patton 2002) was used to choose informants who would be able to share their knowledge to help the researchers gain a deeper understanding of shared care models while also enhancing credibility (Baxter & Eyles 1997). Letters of information were sent to key-informants via e-mail requesting that those interested in participating reply directly to the researcher. Six of the eight key-informants invited to be part of the study chose to participate.

Table 1. CBPCT and focus group participant descriptors

Team	Year formed	Number of identified members	Number of focus group participants
1	1996/1997	8	7[a]
2[b]	2001	3	3
3	2003/2004	8	7
4	2008	11	10[a]
5[b]	2009/2010	3	3

[a] Includes participation from medical/nursing resident on rotation with team at time of interview

[b] Three core members comprise Team 2 and while several allied health professionals work alongside the team, they were not identified as core team members. Team 5 is the newest team and additional team members are expected to join. The range in the number of identified members varies across teams due to differences in: (1) the size of the geographical area served (i.e. smaller areas require fewer members); (2) availability of/accessibility to additional supports from community partners (i.e. sources from hospice, hospital etc.), and; (3) individual team members' work status (i.e. part-time vs. full-time etc.).

Table 2. Focus group participant discipline representation

Discipline	Number
Administration	4
Case Management	5
Medicine	9
Nursing	8
Social work (includes psychosocial spiritual and bereavement)	4

Table 3. Key-informant areas of expertise

Key-informant	Academia & research	Clinical	Planning & policy
1	X		X
2	X	X	
3		X	X
4		X	X
5			X
6		X	X

Data collection

All interviews (*n*=5 focus groups and *n*=6 key-informant interviews, see Tables 1-3) were semi-structured in nature and digitally recorded in order to be transcribed verbatim. For consistency, one researcher conducted all of the interviews. The CBPCTs

were asked open-ended questions about their: development, team dynamics, as well as barriers and facilitators to providing palliative care via a shared care model. Each CBPCT was interviewed once at their home base headquarters. The focus group interviews ranged from 60 to 90 minutes in duration. In total, 30 people took part in the focus groups. Six key-informants were also interviewed at a location of their choosing and interviews ran approximately 60 minutes. Key-informants were asked about their: experience with, and understanding of, shared care, as well as what they perceived to be the barriers and facilitators to providing palliative care in the community using a shared care model.

Analysis

The coding of focus group and key-informant interview transcripts involved the application of a political science framework, commonly referred to as the '3-*I* framework', which explores the role of *institutions*, *interests* and *idea*s in the policy process (Hall 1993, Garrett & Weingast 1993). This framework has been employed elsewhere in healthcare research as a means of situating and explaining the lack of reform in primary healthcare in Canada (Hutchison *et al.* 2001). It has also been applied in examining health system reforms in Europe (Oliver & Mossialos, 2005), rehabilitation services for children with disabilities (Wiart *et al.* 2010), and children's mental health policy (Waddell *et al.* 2005). In a similar manner, it is used here to group the socio-political barriers that have influenced the capacity of CBPCTs to provide healthcare services in a shared care model. In doing so, it will inform the prospects for the development of additional teams in the LHIN of concern and elsewhere. *Institution*s are

collegially referred to as 'the rules of the game' and here include: financing and funding mechanisms, and healthcare system policy legacies (Hutchison *et al.* 2001) or structural inheritances (Williams *et al.* 2010). *Interest*s are understood here as the perceptions, viewpoints and motivations of stakeholders. Finally, *ideas* are categorized to include the values and beliefs of stakeholders, in addition to information and research evidence. The analysis strategy involved reading through each of the transcripts thoroughly in order to become familiar with the data. Thematic coding was performed during subsequent readings (Cope 2010); it was pre-determined that thematic coding would involve categorizing text as an *institution*-, *interest*- or *idea*-related barrier.

Findings

Common *institution*, *interest*- and *idea*-related barriers were apparent across all five CBPCTs and all six key-informants. The most frequently cited barriers related to each of the 3-*I*'s, and excerpts which best illustrate these barriers are presented. Below, excerpts from key-informant interviews are denoted 'KI'. Excerpts from CBPCT members who participated in focus group discussions are denoted 'TM'.

Institution-related barriers

The two main types of *institution*-related barriers encountered by CBPCTs involve: (1) funding mechanisms, and; (2) the organization of palliative care service delivery based on geography at provincial (macro), and LHIN-wide (micro) levels.

Funding

As previously mentioned, medically necessary hospital and physician services are covered as part of Canada's universal healthcare system. This constrains CBPCTs, as

their services are being provided outside of the hospital and not all team members are physicians. Essentially, the way the healthcare system funds providers is not designed to support interprofessional collaborations such as shared care. Thus, teams must often resort to funding their non-physician team members through a combination of sources, which are often piecemeal and not secure. The following exchange between team members captures the issue of vulnerable funding:

> Our roles not being full-time is a barrier, not having an administrative assistant is a barrier… the fact that we're paid by the hospital and if the hospital with budget cuts sometimes sees us a bit of a frill… (TM)
>
> So I guess a barrier would be a sense of security because every year the annual budget comes up, there is always a threat. (TM)
>
> We're always a bit worried. Are they going to cut our programme? (TM)

As mentioned, six additional teams are set to be implemented in the LHIN of concern.

According to a key-informant, part of the delay is lack of funding for the non-physician roles, including nurses, psychosocial spiritual and bereavement counsellors. Despite being a critical component of the team, the psychosocial spiritual and bereavement advisor positions have often fallen by the wayside due to lack of funding. Team members have deemed the number of supported hours for bereavement as insufficient. Key-informants acknowledged that failure to provide bereavement support services could, in turn, be more costly in the long term as families are left to cope with unresolved issues, possibly leading to depression and anxiety.

Geographical organization of service delivery

As mentioned, not all LHIN areas in the province have adopted CBPCTs and the shared care model specifically. As one team member explained, differences in service delivery models across LHINs is sometimes problematic, especially for patients who move from neighbouring LHINs and expect homogeneity. There is a lack of consistency across the province, but also within the LHIN itself, as the areas that do not currently have teams are receiving usual care. As a result, primary healthcare providers are only able to access the CBPCTs depending on whether the patient is located within one of the five serviced geographical areas. One team member spoke about the challenge of getting requests for consultations from a neighbouring town that is currently receiving usual care.

> [We] don't have [the] budget to have [the social worker] drive an hour and a half down [there] to see a family… Have we gone down there? Sometimes yeah, for the really tough, tough cases we have helped out; but honestly, until we get more funding just for paying mileage… it makes it hard. (TM)

While it is common for patients to cross care settings, not all of the teams are able to go into hospices, long-term care homes, retirement homes and hospitals. Some team members are contractually restricted from practicing in certain settings. Depending on their employer, some team members are prohibited from entering settings other than private residences. A key-informant was concerned that this places a limitation on shared care:

> …you have a family doctor who has a family practice and also works in long-term care and they can get that support for their home-based clinic but they can't get that support for their residents in long-term care and I think it sends a really bad message about sort of the whole philosophy of it… I think it speaks to the credibility of the programme, of the philosophy… when we say I can't help you with Mr. Jones but I can help you with Mrs. Smith… (KI)

The inability to cross settings was also perceived as a barrier to the continuity of care and in fulfilling the goal of providing care to patients, regardless of where they are located.

In sum, the *institution*-related barriers illustrate that, despite the fact that palliative care teams are community-based, they are still very much part of, and greatly influenced by, the larger healthcare system.

Interest-related barriers

The next category of barriers is focused on the *interest*s of stakeholders. More specifically, these barriers stem from family physicians and community nurses that are invited to work alongside CBPCTs and to participate in shared care. Collaboration with these primary healthcare providers is imperative to the functioning of the shared care model; however, the lack of 'buy-in' from these providers due to interests specific to autonomy and time, was a commonly cited barrier.

Autonomy and time

Key-informants speculated that primary healthcare providers are concerned with maintaining their autonomy and pointed to the lack of 'buy-in' being attributed to threats to their independence:

> [Some] feel either threatened because they feel that if somebody comes and sees what they're not doing, that's a threat to them professionally… others it's: *"I already know enough, you don't need [to show me]* and: *I just don't have enough time for you"*. (KI)

The preservation of time was also viewed as one of the *interest*s held by primary healthcare providers. According to key-informants, primary healthcare providers, many of whom already are over-worked, may be concerned that participating in shared care will involve additional time.

Participants also connected the hesitation of family physicians to work with CBPCTs, and thereby build their knowledge in palliative care, as a barrier related to their busy work schedules. Due to their hectic practices, family physicians may prefer for the team to 'takeover' care as a means of saving time on both providing care through home visits and capacity building.

> Is that physician prepared to increase their skill level? And the reality is, for many, they're quite happy to have to not go beyond their office to have those decisions made for them because they are really very, very time consuming… (TM)

The lack of 'buy-in' from family physicians disables the CBPCT to work in a shared care model, often placing the experts on the team in a difficult situation in that there is no family physician to share the care with. The main difference between family physicians and community nurses seems to be the degree of autonomy. Family physicians have more autonomy in decision-making, whereas community nurses must abide by the rules and regulations stipulated by their employer. The participants noted that community nurses are diverse in terms of the extent of their involvement with teams. However, the same *interest*-related barrier associated with lack of time that was apparent with family physicians often arises with community nurses:

> Learning takes more time and they need to be supported to do that. So our nurses get paid per patient or per visit. Again there's no incentive there to spend more time learning if you're not going to meet your quota or not get paid, so depending on how the nurses are paid can have an influence. (TM)

Team members recognized that some community nurses were eager to build their palliative care skills and believed that others had not yet seen the value in working with CBPCTs. Participants raised the issue that establishing shared care not only takes time but it also requires a willingness of primary healthcare providers to engage in skill building

and interprofessional practice, the latter which may require forfeiting one's sense of autonomy.

Thus, the *interest*s of primary healthcare providers were perceived to influence whether or not they engage in shared care with CBPCTs. As illustrated above, participants explained that due to varying reasons, the *interest*s of primary healthcare providers sometimes do not align themselves with working with CBPCTs, and as a result, autonomy and time operate as barriers to forming shared care partnerships.

Idea-related barriers

Two recurrent *idea*-related barriers were identified: (1) a misperception of the shared care philosophy, and; (2) the inability to provide supporting evidence of a CBPCT's success.

Misperceptions about shared care

Conflicting *ideas* about the meaning of shared care was perceived as a barrier by CBPCTs, and corroborated by key-informants. There was a lack of understanding of the shared care philosophy among primary healthcare providers, and specifically family physicians, based on incongruent beliefs or values towards collaborative care. Collaboration among providers is an essential component of the shared care model, as explained by a key-informant:

> …responsibilities for the care is shared between partners. *"It's not my problem or your problem, it's you know, ours"*, that we allocate the work according to respective schools, experiences, comfort and availability so it's a flexible arrangement… so that the sum of the whole is greater than the sum of the parts. (KI)

While some attributed the misunderstanding due to a lack of interprofessional training of family physicians, others explained that it might be more to do with the fact that family physicians are accustomed to working independently and therefore do not know how, and/or have the desire, to engage in a shared care partnership. Participants explained that rather than perceiving shared care as a way to augment care, primary healthcare providers might misinterpret it as a criticism or interference in the care plan of patients:

> Sometimes it's [that] people don't know what they don't know, so they think they do palliative care very well so they don't want to refer to shared care. (KI)

Some participants speculated reasons for the hesitancy of providers to enter into a shared care model. For example, the inability or unwillingness to work with a team was attributed to a lack of interdisciplinary training in medical education. Many team members were optimistic that due to ongoing enhancements in interprofessional education, recent medical graduates might be more willing to participate in shared care. On the other hand, some noted that while primary healthcare providers, such as family physicians and community nurses, agreed to enter into shared care collaboration, they often failed to uphold their responsibilities. For example, some community nurses failed to keep the CBPCTs informed about changes in patients' statuses, while some family physicians failed to prescribe medications and make home visits. One team member argued that family physician home visiting is an integral part of shared care:

> …you can't manage patients on the phone, like… you can't just say, *"[the] patient has more pain, let's go up on hydromorphone"*… (TM)

Failure of primary healthcare providers to uphold their responsibilities undermined the shared care philosophy and forced CBPCTs to assume full responsibility

of patients. This not only compromised team resources, and their ability to care for additional patients, but also forced the CBPCTs to 'takeover' care.

Regardless of primary care providers' participation, teams explained that they were often willing to work outside of the shared care model for the benefit of the patient and family.

> Some of the [family physicians] want to be involved peripherally; they don't want to do the palliative part but they still want to be the family doctor … but some don't want any involvement and you try to meet the needs of that doctor but [we're] always making sure that we're not forgetting that the patient has needs. (TM)

When teams 'takeover' care, the shared care model ceases to exist and opportunities for capacity building diminish. A key-informant cautioned that 'takeover' care is not sustainable; without capacity building, the limited resources of the CBPCT will eventually be exhausted.

Lack of information/evidence

Although team members recounted numerous incidents of how they helped to avert patients from seeking care at a hospital's emergency department, the inability to provide evidence of the team's impact was the second commonly cited *idea*-related (i.e. information/evidence) barrier. Team members and key-informants expressed frustration with the inability to evaluate performance, which they felt could validate their existence. While the majority of participants equated success with improving the quality of life of patients and families, as well as capacity and relationship building with primary healthcare providers, they acknowledged that these measures of success were incongruent with evidence valued by policymakers and funding partners.

> Good utilization of the team could decrease ER [emergency room] visits, which is a huge buzzword right now. I really think [CBPCTs] can decrease ER visits but I don't know how to measure that. (KI)

On the other hand, several of the CBPCTs expressed concern over not being able to collect statistics due to a shortage of resources, including administrative support and time. Clinical work took precedence over collecting statistics. At the same time, a key-informant highlighted the fact that in order to get more resources for teams, it is important to provide evidence to funding partners.

To summarize, the *idea*-related barriers include: conflicting beliefs about what it means to work in a shared care model and the inability to collect and make available evidence to gain support for CBPCTs.

Discussion

While it is acknowledged that those barriers related to the Canadian healthcare system will not apply to other countries, it is likely that other countries may face similar challenges in developing community-based palliative care services, and especially those efforts which involve shared care. This study used the 3-*I* framework to identify the barriers of providing palliative care in a shared care model based on the perspectives of members from five CBPCTs and key-informants. A limitation of this study is that it did not include the primary healthcare providers who work with CBPCTs in a shared care model; their experiences would be valuable to explore in order to enhance the comprehensiveness of this study. Specific barriers were classified according to whether they related to *institutions*, *interests*, or *ideas.* A closer examination of the findings highlights that the barriers encountered by CBPCTs are interconnected. More specifically,

it is evident that *institutions* establish the foundation from which other barriers are informed. In fact, it is the 'rules and regulations' engrained in the healthcare system, such as funding mechanisms and the geographical organization of healthcare service delivery which present core challenges for CBPCTs that pursue the shared care model. In an effort to overcome barriers, the CBPCTs involved in the study have employed various negotiation strategies, some of which will be briefly discussed herein.

Due to funding mechanisms that privilege medically necessary physician and hospital services, funding for non-physician CBPCT members is not secure. In an effort to mitigate this *institution*-related barrier, several communities have sought alternate funding opportunities to support these roles. Some communities in the LHIN of concern are attempting to build and maintain teams by reaching out to community philanthropic groups, hospitals, Community Health Centres and Family Health Teams. This piecemeal tactic may, in turn, place limits on the type of care settings in which team members can provide services. Connected to this issue of funding was the *idea*-related barrier concerned with the inability to produce evidence to demonstrate the benefits of CBPCTs as a means to secure funding. Although it is recognized that evaluating the outcomes of palliative care services can prove to be difficult (e.g. McWhinney *et al.* 1994), a number of the CBPCTs involved in the study were collecting information for the purpose of collating statistics. Yet, teams that lacked administrative support due to a shortage of funding felt limited in their ability to balance clinical and administrative demands.

The manner in which primary healthcare providers are funded also informs the *interest*-related barriers of autonomy and time. The majority of family physicians in

Ontario work independently, or as part of small practices, and are reimbursed on a fee-for-service basis by the ministries of health in each province/territory (Hutchison *et al.* 2001), whereas community nurses are paid an hourly wage or per visit. CBPCT members and key-informants speculated that the lack of 'buy-in' for the shared care model from primary healthcare providers was due to an infringement on professional autonomy and time. The unwillingness of some family physicians to enter into shared care partnerships with CBPCTs may include preference for independent decision making, as well as the inability or unwillingness to allot time to both working alongside a CBPCT and engaging in capacity building. In recognizing this *interest*-related barrier, some CBPCTs have approached nursing agencies and family physicians on a one-on-one basis to demonstrate via meetings and presentations the advantages of working in a shared care model. Several of the CBPCTs have been successful in inviting community nurses to participate in weekly and bi-weekly rounds to build their palliative care skills through this approach. The teams perceived these types of outreach activities as a means of helping primary healthcare providers to gain a better understanding of the shared care philosophy, which is hinged on capacity building and collaboration. At the same time this also enables CBPCTs to address the *idea*-related barrier regarding the misperception of the shared care philosophy.

While various shared care models have been successful in other specialties, including chronic disease management (Vrijhoef *et al.* 2002), mental health (Hobbs *et al*. 2004, Chinna Samy *et al*. 2007), and obstetrical care (Lombardo & Golding 2003), there is little evidence that supports success in palliative care, particularly in the Canadian

context. The lack of success may be attributed to the fact that unlike other specialties employing the shared care model, community-based palliative care involves attending to patients in care settings outside of hospital and physician offices, often in private residences. As noted by participants, the unwillingness of family physicians to commit to making home visits was considered an *interest*-related barrier to establishing a shared care model. As a way to move forward, the adoption of Family Health Teams in the province of Ontario (Hutchison 2008) may produce more primary healthcare providers that are willing to work with CBPCTs, as these providers are not solely paid on a fee-for-service basis and it would be an extension of the collaborative model in which they already work.

In spite of the constraints related to *institutions*, *interests*, and *ideas*, prospects are still promising for CBPCTs in Ontario. The decrease in hospitalized deaths, in addition to population aging, may dictate the need for CBPCTs. Given the fact that provinces/territories have authority over the delivery of healthcare services, direction for the promotion and funding of CBPCTs in Ontario will have to come from the provincial ministry of health. Until then, without the political will to move CBPCTs forward, efforts to implement changes will be incremental (Hutchison *et al*. 2001, Tuohy 2004) in nature. A team member attributed the incremental nature of moving CBPCTs forward to the fact that shared care involves building relationships with primary care providers, which takes time. In the meantime, efforts to develop and sustain CBPCTs will have to rely on the ability of existing CBPCTs to advocate for change and to negotiate the barriers they face.

Conclusion

The qualitative analysis revealed that CBPCTs are constrained by: the funding mechanisms for team members; the views of primary healthcare providers and; the inability to generate evidence of their effectiveness. These barriers are interconnected, impacting both the development and sustainability of teams. Yet, the need for CBPCTs in Ontario is apparent given both changes in demographics and trends specific to the location of death. The uptake of CBPCTs will be incremental and they will be required to continue to negotiate barriers and work amongst other types of palliative care service delivery models. Given that community-based care is becoming increasingly common around the world, other regions and countries may benefit from learning about the challenges encountered by the CBPCTs in this study as they attempt to develop community-based palliative care services through the implementation of shared care. This study is primarily concerned with the views of CBPCT members and key-informants and serves as a baseline to identify barriers encountered by teams. Further inquiry may involve learning more about the perspective of primary healthcare providers who enter into shared care partnerships in palliative care. There is also further need to learn more about how CBPCTs negotiate barriers in order to ultimately inform the development of this type of service delivery model elsewhere.

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Conflict of Interests

The authors declare that there is no conflict of interests.

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CHAPTER 3

Enabling factors to shared care with primary health care providers in community settings: the experiences of interdisciplinary palliative care teams

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Abstract

Interdisciplinary palliative care (PC) teams experience a number of barriers in their efforts to establish and maintain shared care partnerships with primary health care providers (PHCPs) in caring for patients in community settings. A qualitative study was undertaken in southern Ontario to examine how teams negotiate barriers in order to share mutual responsibility for patients with PHCPs (i.e., family physicians and community nurses). Over a one-year period, focus group interviews (*n*=15) were conducted with five teams to explore their experiences to better understand the factors that enable shared care. Using a conceptual framework put forth by Williams et al. (2010), the findings reveal that teams circumvent local level barriers through four enabling factors: team characteristics, geography, adaptation of practice and relationship building. Understanding these factors and strategies to foster them will assist other jurisdictions wanting to establish a similar shared care service delivery model.

INTRODUCTION

A 2012 review of Ontario's public services, including health care, highlighted the need for better integration across care settings and the need to enhance community-based care, including palliative care (PC), in homes and hospices (1). The Ontario Ministry of Health and Long-Term Care has been supporting the need to improve the integration of PC service delivery since their implementation of palliative care networks (PCNs) in 2005 in each of the 14 health planning regions (referred to as Local Health Integration Networks or LHINs) as part of their *End-of-Life Care Strategy* (2-5). Each PCN was

tasked to contribute to shifting the care of the terminally ill out of hospitals by improving the integration and quality of community-based PC services.

While the PCNs were created with the same mandate, they are not homogenous entities. Priorities and endorsement of service delivery models varies across networks (5). For instance, some networks endorsed shared care models, which in the broadest sense refers to the collaboration between general or primary health care providers (PHCPs), such as family physicians and community nurses, and other clinicians in *sharing* the responsibility and care of patients (6,7). Here, shared care refers to the collaboration between interdisciplinary PC teams and PHCPs, in caring for patients in the home setting. By providing expert consultation to PHCPs, teams address the deficiency in PC knowledge among practitioners (8-10) but also aim to improve the quality of palliative home care (e.g., 11). Team composition varies, but typically they include PC physicians, nurses, social workers with expertise in psychosocial and bereavement counselling, and case managers.

While there are many ways to deliver PC, a team approach is favoured as it attends to patient needs beyond physical pain and symptom management such as psychological, social, and spiritual facets (12-14). Yet, unlike the majority of provinces in Canada, Ontario lacks policies to support and promote team approaches for home-based PC (15,16). Despite lack of formal policy, innovative palliative home care approaches involving teams are forging ahead (e.g.,11,17,18). To assist in the development and sustainability of interdisciplinary PC teams working in a shared care model, the larger project in which this work was conducted, explored the challenges and barriers

encountered by teams in Ontario, Canada (19). Some barriers included the inability to secure funding for non-physician team members and the lack of 'buy-in' for shared care by PHCPs. This article reports the findings of a study that was undertaken with the same teams to investigate the enabling factors involved in the pursuit of shared care partnerships with PHCPs.

FRAMEWORK

A useful conceptualization that illustrates the experiences of interdisciplinary PC teams is the work of Williams et al. (20) and their evolution of PC in Canada framework. They propose that the evolution of PC has had to contend with several "structural inheritances" including foundational health policy, such as, for example, the Canada Health Act that privileges medically necessary treatment provided in hospital and/or by physicians. They categorized three different types of "circumventions" (see Figure 1) or actions that have allowed individuals or groups to either partially or completely bypass "structural inheritances". These "circumventions" include: (i) new alternative structures (e.g., telehomecare); (ii) interventions to shift the system (e.g., commissioned reports: 21,22) and; (iii) service innovations (e.g., PCNs). "Service innovations" is most applicable here, as it builds on inheritances (PHCPs) to support new approaches to PC and/or models (shared care). PCNs are classified as "service innovations" since they meet the criteria of being funded by the public purse to improve PC within the confines of "inheritances". Therefore, teams working in a shared care model are framed as a product of a "service innovation". A closer examination of the enabling factors that assist interdisciplinary PC teams to pursue shared care partnerships with PHCPs will further

illustrate how teams attempt to circumvent barriers that impede collaboration at the community level; as shown in Figure 1, this is accomplished through: team characteristics, geography, adaptation of practice, and relationship building.

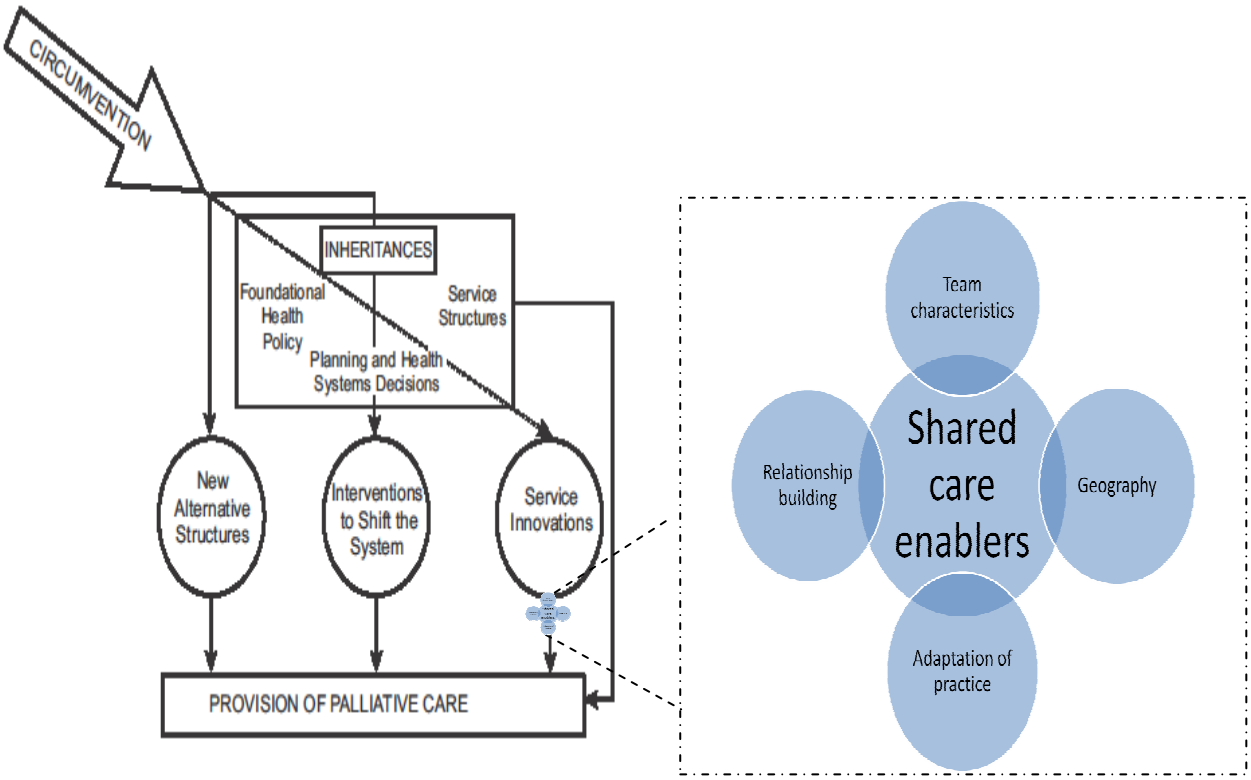

Figure 1 / Factors that enable interdisciplinary PC teams to circumvent barriers to work in a shared care model with PHCPs [Source: Adapted from Williams et al. (20)]

METHODS

Research purpose and design

The main methodology is discussed at length elsewhere (19) and will only be briefly reviewed herein. The data presented here is from qualitative focus groups, one of the data sources used as part of a one-year longitudinal case study that was conducted in

one of Ontario's LHIN areas. Currently, there are five teams that provide services to five of the 11 communities in the LHIN, which were delineated by the PCN. The teams vary in terms of the number of years in operation, membership, home base location, and whether or not they host rounds (meetings where patients on caseload are discussed) or attend wider community-based rounds with practitioners, including PHCPs, who see patients in the home setting (see Table 1).

Data collection

Data were collected from five teams who participated in three semi-structured focus group interviews between December 2010 and September 2011. Ethics approval was obtained from the McMaster University Research Ethics Board.

Participants

All team members were invited to participate in the focus group sessions. Oftentimes, focus groups were scheduled after team rounds and, as a result, student learners on rotation with the teams and community nurses present at the rounds were also invited to participate. Due to scheduling conflicts and clinical emergencies, there were instances when team members were absent. Also, over the course of the study, several teams welcomed new members. Participants worked in administration, case management, medicine, nursing, and social work.

Table 1 / Team Characteristics

Team	Year formed	Home base location	Hosting of rounds+	Number of focus group participants		
				First	Second	Third
1	1996/1997	Hospice/Hospital	Team	7*	6	8*
2	2001	Hospital	Community	3	3	3
3	2003/2004	Service coordinating agency	Community	7	5	6
4	2008	Hospice	Team	10	11**	10**
5	2009/2010	Hospice	Community	3	3*	2
			TOTAL	30	28	29

+ Denotes whether rounds were hosted by the teams or community partners.

*Denotes the additional number of participants who were medical learners and/or community nurses.

Data collection

As discussed in detail elsewhere (19), all of the interviews (*n* = 15 focus groups) were conducted by one researcher at the team's home base location and an interview guide was used. The three sets of focus group sessions were spaced approximately four months apart. Methodological rigour was ensured through longitudinal engagement with the teams which helped to capture changes in team membership and/or practices, and through maintenance of a research journal for audit trail purposes (23,24). Interviews were digitally recorded, transcribed verbatim, and imported into NVivo 8 ® for analysis.

Data analysis

Interview transcripts were analyzed following an adapted thematic content analysis approach (25). The researcher read through each of the 15 transcripts as a means of becoming immersed in the data. This process also involved cross-checking information

and notes that were made during the focus group sessions and in a reflexive journal. Additional notes were made for each transcript about emerging sub-themes through an iterative process. Next, these sub-themes were further examined and collapsed into four overarching themes. Finally, transcripts were coded in NVivo 8 ® according to theme and sub-theme.

FINDINGS

A total of 11 recurring sub-themes emerged as enabling factors in the data and were grouped into four main themes, all of which are of equal importance: team characteristics, geography, adaptation of practice, and relationship building. Quotes from team members are used to add to the interpretation and rich description of the enabling factors.

Team characteristics

The analyses revealed four types of team characteristics that enabled the teams to pursue shared care partnerships with PHCPs: (i) a common goal; (ii) a willingness to persevere; (iii) mutual reliance and; (iv) unconditional respect.

A common goal

As previous research has shown (19), establishing shared care partnerships is often an onerous endeavour. The reluctance of PHCPs to work alongside the teams was both concerning and taxing for team members. Yet it was evident that all of the teams were connected by a common goal – to improve the quality of life of their patients. It was this common goal that seemed to give the teams a sense of purpose:

"… I think we've divested ourselves of it being about us and knowing full well when we make it about the group and the patients then what we get back in spades, is what … is fulfilling."

The common goal of improving the quality of life of their patients connected team members but was oftentimes used to rationalize why the team was forced to 'takeover' care from PHCPs rather than pursue shared care:

"I think we can screen [the family doctors] and say, 'well if you're not going to assume responsibility and write medications, well we're not seeing the [patient]' but that's not reality … it doesn't service the community very well."

A willingness to persevere

The teams also recognized that pursing a shared care model involved patience and perseverance. It was common for teams to encounter PHCPs that did not want to participate in shared care for various reasons. Members from one of the longstanding teams described how their willingness to persevere helped them to make headway with health care professionals who were initially uneasy about collaborating:

"…we had roadblocks at the beginning from many areas in the community who thought 'No we're not going to do this, we can still do it ourselves' and they would look at us like we had two heads, like they just couldn't see it but we kept at it.".

Mutual reliance

Team members acknowledged the mutual reliance that existed within and between teams. For instance, when a team member was absent due to illness or vacation, the

remaining team members assumed and shouldered their responsibility. Team members had to rely on each other, and in some cases on team members from neighbouring teams due to the lack of formal back-up. Unlike their counterparts that serve hospital patients, teams that provide services in the community are left to their own devices:

> *"[When a team member is away]… I think it's a pretty organic thing… we don't have a script for that, we don't have an algorithm. We really just sort of filter our way through it."*

Another component of mutual reliance was the reciprocal nature of caring for one another in times of stress. Team members described the ebb and flow of compassion fatigue as characteristic to PC service delivery. They acknowledged that in order to work together with others, both inside and outside of the team, it was necessary to be in the right mindset. Without funded opportunities for team retreats, teams relied on informal ways of supporting each other though stress, grief and fatigue. When possible, teams devoted time for reflection during rounds:

> *"… people don't do this job for many reasons and I think if we have people who are willing to do this job and doing a good job with that, I think we really need to take care of each other and I'm glad it's a philosophy of our team."*

Unconditional respect

Team members suggested that they had to learn to work together as a team before engaging in shared care. One important aspect of teamwork was having unconditional respect for each individual's contributions and expertise. It was recognized that while

team members contributed individual skill sets, everyone's contribution was acknowledged to be equal and important:

> *"Like initially I was somewhat nervous coming in [as a social worker] thinking that there would be a barrier of [clinical] wisdom, knowledge… and there isn't anything like that…, there isn't, in my opinion, a sense of… hierarchy."*

In sum, the characteristics of a team help to facilitate shared care with PHCPs. All of the teams persevered in their efforts to improve the quality of life of their patients. They were able to address challenges by relying on each other and having respect for individual contributions and expertise.

Geography

As mentioned, each of the five teams provided services to patients within their geographical boundaries. Also, the teams varied in terms of their home base location (see Table1). Two factors related to geography that enabled the teams to work in shared care with PHCPs were: (i) defined geographical areas, and; (ii) team home base location.

Defined geographical areas

It was previously acknowledged (19) that this form of geographical delineation was often problematic when teams were unable to accept referrals for consultations for patients outside of their jurisdictions. On the other hand, teams found that providing services to patients with a confined number of PHCPs within defined perimeters allowed them to better manage both their caseloads (e.g., travelling in a defined area versus across the region), and professional relationships. This enabled them to build relationships and trust with an absolute number of providers over time:

> *"I think one of the reasons why we work so well is our population is defined. Our geography is defined, and it's manageable… you would need to have [defined geographies so] that you can actually develop relationships because it is pivotal… shared care is about relationships and if it's too unwieldy that you cannot create those relationships, it will fail…"*

Furthermore, team members found that working in defined geographies enabled them to gain a greater awareness of the services available to their patients, as well as the socio-demographic context of the area. As a result, team members were able to discuss and suggest available service options (e.g., volunteer visiting programs) with those involved in the circle of care.

Team home base location

As outlined (Table 1), teams had offices in either the hospital and/or hospice with the exception of one team whose home base was situated in a service coordinating agency located outside of the geographical area that they served. Many team members regarded the home base location as essential to enabling shared care partnerships to form. According to team members, being located in the same geographical area that they served enhanced their presence and visibility among health care providers. In addition, home base location enabled the diffusion of PC knowledge to health care professionals and helped to facilitate relationship building. For instance, a hospital-based team considered their proximity to oncologists as playing a role in receiving earlier referrals. Home base location was also considered as an important factor in the coordination and continuity of

care for patients. For example, a member of a hospice-based team explained that the team was better able to transition patients from home to hospice.

Thus, geography was deemed to play an important role in both the manageability and the proper care coordination of patients. Together these enabling factors assisted the team to better collaborate and share the care of patients with their health care colleagues.

Adaptation of practice

In an effort to both establish and maintain shared care with PHCPs, teams described how they adapted their usual ways of practice by: (i) being flexible, and; (ii) facilitating outreach activities.

Being flexible

In general, all of the teams were consistent in making adjustments to their shared care model to better support PHCPs, and each team varied in terms of their degree of flexibility. Being flexible for some teams involved taking on more of a primary care role in certain situations. In certain cases, team members explained that when there was no family physician with whom to share the care, they were willing to step in for the benefit of the patient. One of the teams that served an urban area found a lack of uptake of shared care from local family physicians. In order to provide timely care for some patients, they collectively decided to try a different approach when necessary. In many cases, team members explained that being flexible in terms of their service delivery model enabled them to negotiate barriers such as lack of buy-in from PHCPs. For instance, one of the teams recognized that community nurses found it difficult to schedule

joint visits with them due to time constraints. As a result, the team decided to forgo joint visits when they were not possible and instead communicated via telephone.

Teams were cognizant that being flexible had its limits, especially in terms of assuming more of a primary care model. In response, one team decided to inventory their shared care partnerships with PHCPs in order to determine to what extent they could be flexible.

> *"The other thing I think that we're trying to do is keep almost like a little black book of both family doctors and [community] nurses and almost coming up with a sense of being able to describe how many of them want this type of relationship with us, how many want [that] type of relationship, so we're going to try to see what percent of [community] nurses and doctors look for a different relationship with us…"*

Adaptations of practice not only illustrate how the teams circumvent barriers such as lack of PHCP buy-in but also demonstrate the extent to which teams are motivated to collaborate with PHCPs to provide PC.

Facilitating outreach activities

In order to get buy-in for shared care, teams often engaged in facilitating activities that involved them stepping outside of their clinical roles to engage PHCPs. For instance, some teams visited family doctor offices and nursing agencies as a means of relaying information about the benefits of shared care. In one case, a team decided to raise awareness about their PC services to administrators and health professionals during the early stages of development of a cancer clinic in their community.

> *"… we're getting some referrals a bit earlier because we've kind of reached out to [the cancer clinic]… I feel like communication has increased a little bit between the cancer centre now that they're in this town and us having opened up to them so I think things are good but it is going to be more workload."*

Teams also employed other forms of awareness measures including sending information materials, such as brochures, and making presentations about shared care to PHCPs in their jurisdictions.

In recognizing that not all of the PHCPs will be able or willing to participate in shared care, teams have adapted to meet the needs of the varied health professionals in their communities. Team members indicated that making accommodations was often necessary in order to ensure quality care for patients. Teams also decided to advocate for themselves through outreach activities, which led them to work beyond their clinical role to raise awareness about the benefits of shared care.

Relationship building

Several factors contributed to the teams' ability to foster shared care relationships with PHCPs. These factors included: (i) the support of people from outside the team; (ii) capacity building initiatives, and; (iii) the recognition of the importance of time.

The support of people from outside the team

Team members often attributed their ability to establish shared care as a result of certain individuals who advocated on their behalf. These individuals included: PC consultants who worked in the LHIN area; other health care professionals and; case managers. For example, teams described how PC consultants helped to introduce them to

community nurses through educational events and how case managers directed referrals to them when appropriate. In many cases, teams were able to gain the support of physicians who were willing to participate in shared care, and also to take on patients who are orphaned by their family doctors.

Capacity building initiatives

An essential component of building relationships involved capacity building with PHCPs through learning initiatives to enhance their PC skill set. Capacity building included activities such as hosting educational sessions and training student learners, while raising awareness for teams and the shared care model:

> *"We [went to family doctors' offices] when we were ramping up our team… and brought lunch and did teaching sessions. And I think that's an important thing to do, to show up in their world and demonstrate right then and there how it could work so that you're discussing their issues or their cases on the spot and that's a great teaching model in general but I think that's helpful to build relationships so they get to know who the team is and what they can do…"*

Another capacity building initiative involved the teams' hosting and/or participating in rounds. Several teams hosted rounds with a standing invitation to PHCPs to attend while other teams participated in wider community-based rounds. A community nurse present at one of the focus group sessions explained that attending rounds enabled her to not only build her own PC capacity, but also that of her colleagues since she was able to go back and share what she learned from the team with them.

Team members also noted that being present at the wider community-based rounds enabled them to maintain their presence and visibility in the community. Instead of communicating via telephone or through patient notes, they acknowledged the value of meeting in person: *"[It] probably keeps us in the [community] nurses' minds.*"

Recognition of the importance of time

Realizing the importance of time in relation to building trust with PHCPs was also acknowledged as an enabling factor to shared care. The more established teams offered advice to new teams and communities wanting to pursue a shared care model by stressing that it is a lengthy time investment:

> *"The buy-in takes a long time, the buy-in from the nurses took us a year, probably to have the nurses go – 'Thank God for your team!' or you know, 'Thank goodness that you're here!' whereas at first everyone was like, 'How is this going to work?'."*

Teams also realized that as time passed, they were able to demonstrate their competence and, as a result, gained acceptance and buy-in from PHCPs:

> *"When we think back… when we first started doing some of this, family docs really did not want to refer, it really took five years I think for family docs to say 'Okay.'… Where a community has nothing like this and just wants to start it, I always say don't get too discouraged because it's going to take a while."*

To summarize, building relationships required teams to accept the support of individuals outside their team, as well as the fact that shared care required an investment of time. A

team member accurately summed up the importance of relationship building and how working in shared care partnerships is related to improving the quality of life of patients:

> *"… we have to build working relationships where we assist in the patient and family care and we're seen as reducing the workload and actually aiding the family doctor and the other people involved in care by bringing a set of different skill sets that will make their life easier and patient care better and release some of the burden of the increased demands these kinds of patients and families have as they become more disabled, progressively with their disease."*

DISCUSSION

This study examined the factors that enable interdisciplinary PC teams to establish and maintain shared care relationships with PHCPs in order to assist dying people at home. Using the framework of Williams et al. (20), teams are considered products of the PCN (i.e., a service innovation). This study expands the framework by illustrating that teams must also circumvent barriers, similar to PCNs, to provide PC in a shared care model at the community level. The barriers encountered by teams are socio-political and engrained in wider national and provincial policy legacies (19), but the teams must negotiate the barriers at the community level. While circumventions are rooted in the teams' motivation to share care with PHCPs for the benefit of patients, their efforts also contribute to improving the integration and quality of community-based PC. In some cases, particularly with the hospital and hospice-based teams, improved continuity of care has assisted patients in better navigating the fragmented and oftentimes uncoordinated nature of PC in the community (26). Our aim was to present the enabling factors which,

in turn, allow teams to circumvent barriers. In what follows each of the main enabling factors and recommendations for fostering these factors will be discussed.

While certain characteristics (e.g., being respectful, being patient in persevering) were apparent across teams to varying degrees, it is clear that many of them are intrinsic qualities. The importance of these characteristics to the success of teams has been echoed elsewhere (13,14,27) and fit well with Meier et al.'s (13) "elements of the functioning team". It may be difficult to foster these qualities and as a result, team members must be selected carefully for compatibility (18). Team dynamics can certainly be strengthened through activities such as formulating a team philosophy or defining goals, and team retreats (13). Funding for team building activities, as well as allotted time for such activities, may address issues around interprofessional development and compassion fatigue.

One of the key features of community-based PC as described by Street and Blackford (28) is that they "increase access and equity to clients but widen the geographical space between health care providers" (p.644). Since geography plays a role in the teams' ability to manage their caseloads and foster relationships with PHCPs, situating teams in defined geographies is important. Working within the boundaries of a community presents the opportunity for teams to work closely with a finite number of PHCPs to build PC skills, and enables the teams to become better acquainted with community supports that may assist patients (e.g., non-profit and volunteer services). In addition, at a minimum, it is necessary for the teams' home base to be located within the boundaries of the geography that they serve both as a means to enhance their visibility

among PHCPs and, for more practical reasons, such as decreased travel time when making home visits.

Teams should also be cautious in terms of the degree of their adaptation of practice. It was evident that some teams were so motivated by the pursuit of shared care partnerships that they were willing to sometimes adopt a primary care model to meet the needs of patients. While being flexible highlights teams' strong motivation to improve the quality of care for patients, they should attempt to assess the feasibility of such practices. As such, teams should proceed by conducting a needs assessment of the primary care service landscape to prevent: a 'takeover' model, underservicing their community, suffering burnout, and/or infringing on the relationship between PHCPs and their patients (17). Furthermore, since facilitating outreach activities sometimes encroached on teams' clinical roles, it is recommended that such activities be pursued by administrative support when possible, and/or through the assistance of stakeholder partners such as the PCN. It is also recommended that the teams and/or representatives advocating on their behalf be proactive in approaching new PHCPs and/or partners in the community to raise early awareness and endorsement of the shared care model.

In the same regard, the importance of relationship building as a shared care enabler was essential in promoting the team to the wider community. Gathering support from PC consultants (28) and other health care professionals in the community enabled teams to raise awareness through 'word of mouth'. Capacity building initiatives promoted reciprocal relationships between teams and PHCPs; teams helped to build PC knowledge with PHCPs by participating in rounds and in turn, they were more willing to participate

in shared care. In addition, it is important for teams to train learners. For instance, a team member explained that other jurisdictions who are disenfranchised by the lack of buy-in from PHCPs could be proactive by training the next generation of learners (e.g., medical and nursing students) to appreciate the benefits of collaborative models like shared care. Finally, teams highlighted that while relationship building is imperative for shared care, it is time intensive. Recognizing the importance of time (8) in relationship building also needs to be translated to program and policy makers at both the LHIN and provincial level.

The overall findings reveal that shared care is enabled through four main mechanisms: team characteristics, geography, adaptation of practice and relationship building. While the teams described that their strategies for establishing and maintaining shared care partnerships were based on practical experiences (e.g. trial and error), the investigation into these tacit forms of practice can be transformed into recommendations on how to develop enabling factors. In doing so, other jurisdictions that want to establish a similar service delivery model will benefit from a closer examination of the ways in which enabling factors can be cultivated.

LIMITATIONS AND CONCLUSION

The experiences of the five teams in this study may be locally contingent and may not reflect the issues faced by teams elsewhere. While the teams represented communities of varying contexts, other jurisdictions may experience additional barriers and/or facilitating factors to shared care. It is also important to acknowledge that the enabling

factors presented here are not an exhaustive list and the recommendations are only guidelines.

This case study provided an examination of the factors that enable interdisciplinary PC teams to establish and maintain shared care partnerships with PHCPs. Based on the findings, it is evident that teams are motivated to improve the quality of care for dying people and, in doing so, contribute to the integration of community-based palliative. Situating the teams as products of service innovations – the PCNs – expands Williams et al.'s (20) framework by elaborating on how teams negotiate community level barriers to provide PC. The establishment and maintenance of shared care partnerships between teams and PHCPs rests on the ability to: cultivate team characteristics such as unconditional respect and perseverance; situate teams within geographically defined areas; give teams the tools and reign to respond to the needs of PHCPs, and; provide knowledge on how to build relationships. Other jurisdictions and/or teams may find it useful to examine the enabling factors that have contributed to the success of the teams in this study and apply it to their own contexts.

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CHAPTER 4

"It's on the will of the people and the organizations": using a scalar approach to explore the sustainability of palliative care teams that provide home-based care

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Abstract

Program planners have turned to innovative home care service delivery models such as palliative teams working in shared care to better support primary care providers and patients. This Canadian study of a region within the provincial jurisdiction of Ontario investigates the long-term sustainability of teams since little attention has been paid to this issue. A scalar approach is used to analyze interview data from team members, key-informants and stakeholders, and to offer recommendations. The findings suggest disparate levels of support from the province and region and a heavy reliance on community-based efforts and advocacy. Sustaining the teams requires strategic direction and support from the province due to the limited resources both in the region and community.

Keywords: Home care; Palliative care; Palliative care teams; Scalar approach; Scale; Shared care

Introduction

Sustainability is a commonly used term in health care, it is used in reference to the system as a whole or a particular program or service innovation. For instance, the sustainability of a demonstration or pilot project if often compromised when its' funding period ends and, as a result, the project is deemed unsustainable and dissolves. While the importance of sustainability is understood, the concept remains ill-defined in research studies (e.g., Hanson et al. 2009; Shediac-Rizkallah & Bone, 1998). This is clearly illustrated in a study by Hanson and colleagues (2009) through both a review of the literature and interviews with stakeholders about community-based fall prevention

programs in three sites. They found that interpretations of sustainability varied among stakeholders within and across program sites. For example, some stakeholders considered sustainability as referring to the continuance of the program in its entirety while others related the concept to the continuity of certain program components. Another study by Sibthorpe et al. (2005) proposed that sustainability consisted of six domains: (1) political; (2) institutional; (3) financial; (4) economic; (5) client and; (6) workforce (p. S78). In their investigation of five primary health care initiatives in Australia, they found that sustainability is influenced by socio-political factors such as, but not limited to: the existence of champions, financial resources, political will, and the capacity of stakeholders. These factors overlapped with the three proposed by Shediac-Rizkallah et al. (1998) in their framework for conceptualizing community-based program sustainability. Based on their review of the literature, they surmised sustainability to be affected by factors related to the following: (1) the program layout and how it was implemented; (2) the program setting and/or context, and; (3) the program's broader external environment. The aforementioned studies focus on primary care and public health; while there is an abundance of literature on the sustainability of public health programs, the literature does not adequately address the sustainability of palliative care (PC) service delivery programs (hereafter referred to as PC programs). Of the few studies that were located, the majority were not empirical, but rather descriptions of demonstration projects (Byock et al., 2006) focused on the experiences of physicians (e.g., Von Gunten & Romer, 2000; Metz Morch et al., 2003), or considered sustainability entirely from a financial perspective (Bookbinder et al., 2011).

The inherent difficulties in sustaining PC programs and the lack of guidance addressing these difficulties were recognized by a group of physicians who gathered at an international conference in San Salvatore, Switzerland (Metz Morch et al., 2003). These physicians formed the "San Salvatore group" and drew upon their collective experiences to communicate a set of recommendations for developing PC programs. They posited that other jurisdictions might benefit from learning about how they overcame the challenges involved in PC program development. As a group they devised a summary of prerequisite factors that would lay the foundation for an ideal start to a PC program (see Metz Morch et al., 2003, Table 5). However, they failed to offer concrete suggestions for established programs. Based on her 4-phase model, "Developing Rural Palliative Care", Kelley (2007) elaborates on the process of sustaining a PC program as part of her conceptualization of the process involved in developing PC programs using a community development approach. Once a team is in place (phase three), the fourth phase of the model elaborates the growth of the PC program, which includes a description on sustainability. Study respondents, the majority of whom were various health care providers and volunteers on community PC teams, considered additional resources (e.g., both human and material) and policy (e.g., guidelines to formalize the team and roles) as contributing to the sustainability of the program.

This paper focuses on existing PC teams that provide home-based care in a shared care model. Drawing on the work of Moorehead (1995) and Chomik (2005), Howell et al. (2012) describe the heterogeneous nature of shared care models: "shared care models may differ in their structure and composition but share a common goal of mobilizing the skills

and knowledge of a range of health professionals, including medical specialists, in the planned delivery and joint responsibility for a patient population" (p. 61). The teams included in this study vary in terms of their structure but, at a minimum, consist of a physician, nurse and social worker with expertise and/or advanced training in PC. Shared care is established when the team works in consultation with family physicians and community nurses. In our previous research with the teams of concern herein, identified barriers, such as lack of funding for non-physician team members and the inability to secure buy-in from primary care providers, were shown to have posed challenges in their pursuit of the shared care model (DeMiglio & Williams, 2012). Additional research has also explored the factors or facilitators employed by the teams to overcome challenges, such as securing funding from community partners for non-physician team members, and undertaking capacity building initiatives with primary care providers (DeMiglio & Williams, in press).

Using qualitative data collected in interviews, the aim of this study is twofold: (1) to explore the factors that affect the sustainability of the teams, and; (2) based on the results of this study, to propose a set of recommendations that will contribute to the sustainability of PC teams. For the purposes of this study, following Evashwick and Ory (2003), sustainability is understood and approached as the ability to continue the program over time. More specifically, participants were asked to consider sustainability as referring to a team's ability to continue working together over time. Understanding factors that influence the sustainability of teams and ways to mitigate these factors is paramount to improving the longevity and quality of service delivery models of this kind.

This study may inform program and policy specific to strategic ways to improve the provision of team-based palliative home care using a shared care model, while simultaneously providing direction for team-based program delivery and sustainability. In what follows, a brief review of the concept of scale is followed by an overview of the health delivery context and the methods section. Research findings are then presented followed by a discussion and concluding remarks.

Scale: From concept to practical application

A product of health care restructuring that has taken place across the globe is regionalization (Wiles and Rosenberg, 2009; Andrews and Evans, 2008). In Ontario, this form of restructuring involved the implementation of 14 Local Health Integration Networks (LHINs), which are geographically bound health planning regions in the mid-2000s, to improve the integration of health services and to include local citizens in health care decisions. Alongside the LHINs, End-of-Life Networks (now referred to as Hospice PC Networks), were implemented in order to improve PC in each LHIN (Dudgeon et al., 2007). The Hospice PC Networks are groups of stakeholders that identify local priorities and the appropriate service delivery models for their jurisdictions. The service delivery model endorsed in the LHIN of concern in this study was the implementation of enhanced PC teams that act as experts to support primary care providers, such as community nurses that are put in place through the service coordinating agency, the Community Care Access Centre (CCAC), and family physicians, using a shared care model. In view of the centrality of scale in this study (i.e., community-based teams endorsed at the LHIN level

by the Hospice PC Network), it is important to build an understanding of the concept of scale prior to addressing how it has been applied in health geography and beyond.

Scale has been the subject of much theorization and debate amongst geographers since the 1980s (Smith, 2000) and some have even proposed that it no longer be considered as a concept in human geography (e.g., Marston et al., 2005). Smith (2000) differentiates between three types of scale: (1) cartographic scale which refers to the information conveyed on maps; (2) methodological scale, which refers to the parameters chosen by researchers for data collection such as census tracts or neighbourhoods and; (3) geographical scale which refers to socio-environmental processes which "can be seen as a means of both containment and empowerment" (p. 726). Moreover, Howitt (1998) distinguished three elements of scale: (1) size (e.g., spatial, population); (2) level (e.g., hierarchies) and; (3) relation (e.g., culture, economy). He argued that scale should be considered from a relational perspective because focusing on size and level would lead to discrepancies since scale is "better understood dialectically than hierarchically" (p. 52). There is strong support for not viewing scale as a vertical hierarchy (e.g., Wiles & Rosenberg; Marston et al., 2005), as this can be construed as disempowering the local in comparison to the global. Marston (2000) adds that the role of capitalist production, social reproduction and consumption needs to be acknowledged to build an understanding of how scale is constructed. Moreover, Paasi (2004) states that "scales are also historically contingent; they are produced, exist and may be destroyed or transformed in social and political practices and struggles" (p. 542). Many, including Brenner (2001), have also noted the political implications of scale and the relationship between

geographic scale and politics. For instance, Brenner (2001) argues that the politics of scale be examined with a plural rather than a singular focus, whereby the interrelationships amongst a range of geographic scales are examined. Along the same lines, Smith (2000) explains the notion of "scale jumping" whereby "political claims and power established at one geographical scale are expanded to another" (p. 726).

While numerous scholars have elaborated the concept of scale theoretically (see Marston, 2000 for an in-depth review), thereby adding to its complexity, few have moved from theoretical to empirical applications of scale in health-related literature. Some have even cautioned against the use of scale as an analytical category (e.g., Moore, 2008). Ansell (2009) examined five different AIDS-focused interventions that were developed by organizations and made their way to schools in Lesotho, Africa. Through interviews with stakeholders positioned at various scales in government (e.g., UN agencies) and non-governmental agencies (e.g., local groups such as churches), it was shown that the interventions were shaped through the multiple interactions between individuals and organizations including the channeling of proposals and funding at varying scales (e.g., international, national and local). For this reason, she proposes "the existence of these flows points to the value of thinking about spatial relationships in terms of networks of interactions and flows" (p.683). According to Campbell et al. (2012), "the network metaphor opens up possibilities that e.g. particular spaces may sometimes be *both* local and global, or that the local may at sometimes be more powerful or influential than the global" (p. 449). Moreover, Wiles and Rosenberg (2009) illustrate how scale has played a role in primary health care at both the international and national scales using two case

studies. First, they focus on the international scale and more specifically the World Health Organization (WHO) and their Declaration of Alma-Ata to show how scale is implicated. They discuss how the Declaration can be analyzed from a hierarchical scalar approach by examining how the Declaration provides direction around service delivery programs and human health resources at various scales from the international arena to the local community. They also examine the Declaration from the viewpoint of scale as relational by noting its evolution as a top-down/vertical hierarchical approach to becoming more integrative and holistic. Second, they examine how primary health care in Canada is financed, organized and delivered at a national, provincial and local scales to illustrate how the contextual forces at each scale (e.g., economics and fiscal restraint) has shaped primary health care since the passing of the Canada Health Act in the early 1980s. Interestingly, they point out the lack of consistency across the provinces in the development of regional models which leads to disparities in access to health care.

In their examination of a Canada-wide social program, through interviews with frontline health care providers and program users across several provinces (successful, unsuccessful and eligible), Giesbrecht et al. (2010) found that participants repeatedly used scale (e.g., region, community and home) as a means of communicating their experiences with, and views of the program. They applied these scalar categories in their analysis of interview data and derived a set of program implications relevant to each scale. The following section provides an overview of the health delivery context to illustrate the application of scale in this study.

Health Delivery Context

Due to both the shift of care and the shift in place of death from institutions such as hospitals, to community-based settings (Wilson et al., 2009), more patients are receiving end-of-life care at home. In addition, patients often prefer to die at home (Brazil et al., 2005). While there has been a shift from hospital to community care for the dying, the provision of care in the home by family physicians has not followed suit. It is a well-known fact that little attention has been paid to PC in medical training (Oneschuk and Bruera, 1998). According to a Canadian study by Brenneis et al. (1998), family physicians are more willing to provide community-based care if they are supported through changes to fee schedules, and access to consultants, remedial education and home care services for their patients. Along the same lines, Australian-based research by Yuen and colleagues (2003) also suggests that the ability to keep patients at home requires commitment from family physicians to do home visits with the support of an enhanced specialist team.

In order to better support family physicians and other health care providers in the community, many diverse community-based models and initiatives have developed across Canada (e.g., Lawson et al., 2009; Marshall et al., 2008; Fainsinger et al., 2007; Bruera et al., 1999). As noted above, the community-based model endorsed by the Hospice PC Network in the LHIN of concern in this study involved the implementation of enhanced PC teams that act as experts to support primary care providers. At the time of the study, five teams were in place and serving five of the 11 delineated communities in the LHIN area. The overall intended goal was to introduce teams in the remaining communities as

resources became available. At the end of data collection, one additional team had formed.

As highlighted above, scale plays a significant role in health care delivery and planning. Here, scale is understood according to Howitt's (1998) interpretation of scale by size, level and relation. Fig. 1 provides a scalar representation of the health care delivery and planning context in this study; the dashed lines denote the relationships between the scales.

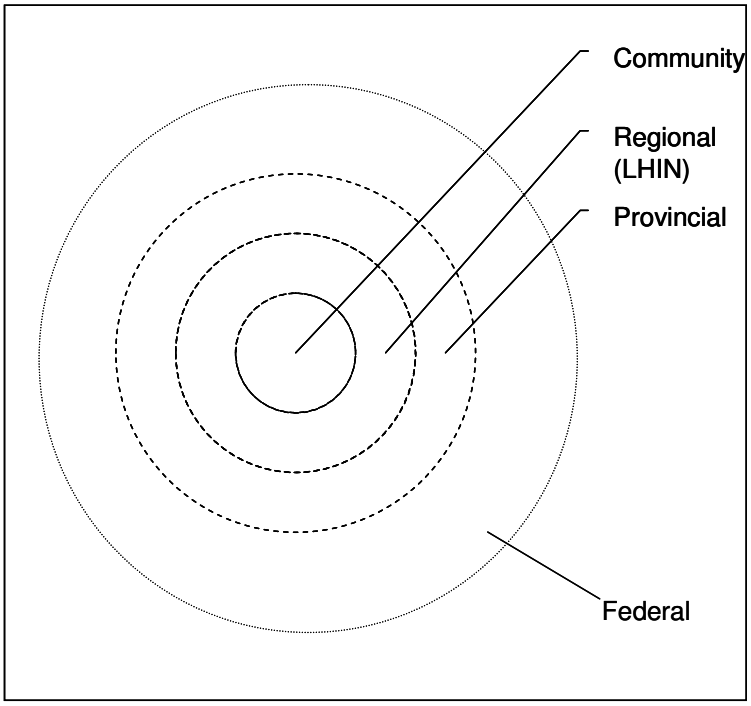

Figure 1: Scalar representation of the health care delivery and planning context

Methods

This paper is based on the results of a longitudinal case study of five PC teams

that work in consult in a shared care model to provide care to patients in the home setting in Ontario, Canada. The data were collected from September 2010 to September 2011, and, as common in case study research, data were collected from multiple sources (Yin, 2009); here, semi-structured qualitative interviews were conducted with a variety of individuals including PC team members, key-informants and stakeholders. A detailed description of the study design has been reported elsewhere (DeMiglio et al., 2012).

Ethics approval from McMaster University was obtained in advance of data collection. All participants provided written and informed consent prior to being interviewed. Due to the tight-knit nature of the PC community in the study site, specific geographic details are not provided to ensure the confidentiality of participants.

Participants

All participants were involved in either the direct (e.g., practitioners) or indirect delivery of PC services (e.g., researchers, program administrators, managers or coordinators) with the exception of one key-informant who had expertise in the shared care model within the context of another medical specialty. A purposive sampling strategy was used to recruit a rich sample of participants (Patton, 2002), and to enhance credibility (Baxter & Eyles1997). Each of the five PC teams, representing a combination of rural and urban jurisdictions, was invited to participate in a series of three focus group interviews (i.e., one interview approximately every four months). If medical and/or nursing learners were present during the time of interview, they were given the option to participate in the session. Table 1 provides a detailed overview of each team. Six key-informants who were knowledgeable in the area of shared care models through research

or practice agreed to participate in one-on-one interviews. Lastly, seven stakeholders were asked to participate in one-on-one interviews based on their vested interest in the PC teams through their role in either the management and/or delivery of PC services in various sectors within the study area. Key-informant and stakeholder details are summarized in Table 2.

Table 1: Overview of participating PC teams

Team	Year formed	Home base location	Community	Number of focus group participants		
				First	Second	Third
1	1996/1997	Hospice/Hospital	Rural	7	6	8
2	2001	Hospital	Small urban	3	3	3
3	2003/2004	Service coordinating agency	Large urban	7	5	6
4	2008	Hospice	Small urban	10	11	10
5	2009/2010	Hospice	Rural	3	3	2
			TOTAL	30	28	29

Table 2: Key-informant and stakeholder overview

Participant: Key-informant (KI) or Stakeholder (S)	Sector
KI 1	Academia
KI 2	Academia & clinical
KI 3	Clinical
KI 4	Clinical
KI 5	Clinical
KI 6	Program planning
S1	Hospice
S2	Hospital
S3	Hospital
S4	Service Agency
S5	Hospital
S6	Hospice
S6	Service Agency

Data collection

With permission from the participants, all interviews were digitally recorded. Separate interview schedules for the PC teams, key-informants and stakeholders were developed by the researchers, guided by both the literature and the objectives of the research. Teams were interviewed at their home base location (see Table 1) while key-informants and stakeholders were interviewed at a location of their choosing (e.g., coffee shop or office space). All of the interviews were conducted by one of the researchers (LD).

Data analysis

The interviews were transcribed verbatim and imported into NVivo 8 ® to support the analysis. The analysis was carried out in a three-step process. The first step involved an examination of the data from the focus group interviews with the PC teams. The interview transcripts were examined for recurring themes across teams with a particular focus on responses to questions which probed sustainability, including the following question: *What factors do you perceive as contributing to your team's sustainability?* As previously mentioned, participants were asked to consider sustainability as referring to their team's ability to continue working together over time.

A second and separate step of the analysis focused on the interview transcripts from key-informants and stakeholders. The researcher (LD) examined each of the transcripts thoroughly through multiple readings. During the readings, recurring themes were documented in an iterative process. Given the inherent scalar organization of the PC teams, with the provincial health care system being the macro scale encompassing the LHIN's Hospice PC Network which, in turn, informs service delivery at the micro scale,

a scalar approach was applied to the analysis.

Similar to Giesbrecht et al.'s (2010) study, participants repeatedly used scalar categories to articulate their responses. In particular, in discussing factors affecting the sustainability of teams, participants commonly used the terms "community", "LHIN" and "province" as points of reference. As a result, thematic coding (Cope, 2010) involved the grouping of interview data according to these three scalar categories.

The third and final step of the analysis involved merging the two participant datasets (team members and key-informants/stakeholders), which in turn bolstered the study's validity through multiple triangulation (Mitchell, 1986). Multiple triangulation is achieved when a study has more than one type of triangulation. Here, both data and methodological triangulation were present. The information from key-informants, stakeholders, and team members were combined and areas of convergence (e.g., Mays & Pope, 1995) about the factors that affect the sustainability of teams were explored.

Findings

Sustainability of the PC teams is conceptualized in Figure 2 which depicts the three scales of community, LHIN and province as the individual pillars that support the ongoing work of the team. Based on this depiction, the foundation is the impetus to provide PC to patients in the home setting (e.g., due to more patients receiving PC at home, the emphasis on providing care in the community, population aging etc.). The need for palliative care has the potential to grow and this is depicted with the arrows that point in the outward direction. The width of each pillar corresponds to: (1) the geographical area/size of the scale and; (2) the power/authority at each scale. As a result, here the

understanding of scale aligns with Howitt's (1998) conceptualization of scale as size, level and relation, with the province being the largest and most powerful followed by the LHIN and finally, the community.

The analysis of the focus group interview transcripts revealed that teams conceptualized sustainability in two different, yet interconnected, dimensions, referred to here as internal and external sustainability; this paper will focus primarily on external sustainability. In what follows, a brief overview of internal sustainability is provided followed by an in-depth examination of external sustainability from the perspective of team members (TM), key-informants (KI) and stakeholders (S).

Internal sustainability was described as the ability to work together as colleagues in an environment conducive to teamwork and collaboration. One of the members of a longstanding team described the need for teams to establish internal sustainability prior to addressing issues related to external sustainability:

> *"…I think one aspect of sustainability is just that it's deeply relational and it's probably some sort of key combination of likeability, compatibility, trust, and you need all of them for it to work and then… you stave off the other aspects of sustainability, like do we have enough money?" (TM)*

In the same regard, a member from one of the teams that struggled with issues related to poor office space set-up and lack of time for team meetings and debriefing due to workload and scheduling conflicts, likened internal sustainability to achieving a solid foundation as a team:

"...so you talk about sustainability, I'm not even sure we have a good foundation as a team to sustain to begin with. To be quite honest with you because we're all flitting in and out of here… it's frustrating…" (TM)

Facilitators, or characteristics that contributed to a team's ability to work together with primary care providers were previously explored (see DeMiglio & Williams, in press), and included: having a common goal; a willingness to persevere; mutual reliance, and; unconditional respect. In effect, a team's ability to establish internal sustainability was perceived as a community-level precursor to both considering and overcoming factors related to their external sustainability. In what follows, external sustainability is first described and then explored in relation to scale. Experts from participants are included as a means of providing context.

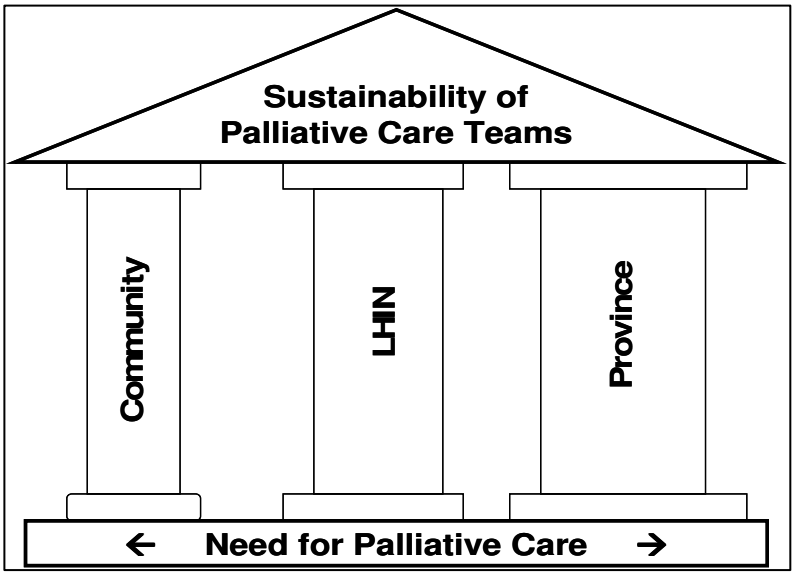

Figure 2: Scalar conceptualization of the sustainability of the PC team with support from the community, LHIN and province

External Sustainability

Through the analysis, it was apparent that although the teams operate at the community scale, their sustainability is affected by contextual issues, individual actors, partners and policies at the community, LHIN and provincial scales. Using the depiction in Figure 2, the sustainability of the teams would be compromised without adequate support from all three of the scales, depicted as pillars. Although it would be possible for one of the pillars to provide more support than another at any given time, it would be unrealistic and problematic for the team to rely on just one or two of the three pillars. A team member explained that without the macro-scale support, the teams remained vulnerable:

> *"Like what continuity can we look toward for ourselves as a little entity, you know, in the big picture…" (TM)*

Another team member elaborated on the vulnerability of teams by describing the role of decision-makers and managers in relation to their sustainability. Many team members attributed their continuity to the support of local managers and partners, who have witnessed their growth and success over time. Yet teams were aware that their futures often relied on the advocacy of certain individuals and, as a result, they recognized their vulnerability:

> *"…by the graces of people who've been around long enough, like there are enough folks who support us financially, who've been around to see the genesis of the team and the team's success that they are supportive but managers come and go and higher-up's, we could easily have a new person come by who has a*

different priority list… just because it's working well now, doesn't mean that that won't be threatened tomorrow." (TM)

The above excerpt demonstrates how external players (i.e., outside the team) have contributed to the continuity of the teams. The merging of data from team members, key-informants and stakeholders further categorizes external factors by Howitt's (1998) classification of scale as including the three facets of size, level and relation, from the smallest, most insignificant scale through to the largest, most significant: (1) community; (2) LHIN and; (3) province, as will now be explored.

1. Community

Each team provides services to patients in a geographically defined community. In effect, the five teams provide services to five communities that vary according to both physical and social environmental characteristics, such as population density and socio-demographics. The teams interact with a number of individual actors at this scale, including community nurses and family physicians, in addition to partners such as nursing agencies, acute care hospitals, long-term care facilities and residential hospices. According to participants, the sustainability of the teams is dependent on building collaborative partnerships with community actors and partners. Unlike other settings of PC, such as acute care hospitals, hospices and long-term care facilities, the community is not a contained place. As such, the data pointed to a broader and more extensive network of partners that needed to be invited to work in collaboration with the teams. To ensure an environment of collaboration, the data suggested that the team be autonomous or self-directed (e.g., via team consensual decision making) and, while team members should be

accountable to their funders, teams should not be "owned" or micromanaged by their funders:

> *"… [the team] has to be owned by everybody, it has to be high participation by everybody, you can't be dependent on any one role or any one organization." (KI 6)*
>
> *"And it depends on the manager too… we had a manager who told us that we were not allowed to meet as a team anymore…" (TM)*

However, the formation of collaborative partnerships depends on the size of the community. Key-informants and stakeholders discussed that the size of the community will dictate the number of partners involved and the power of the partners involved (e.g., a community hospital in a rural community as opposed to a hospital corporation in an urban centre). Further, the size of the community may be more conducive to collaboration and relationship building, such that in smaller communities there are less providers and settings of care which, in turn, increases a team's visibility:

> *"Potentially more rural or smaller communities are more able to know all the actors like all the family physicians know each other and the PC specialists can get together… the bigger you get, the more difficult it is to have that [sense of] community and therefore, I think in more urban settings you will see more [of a] substitution model, it will be harder to build that shared care model, the true shared care where it's really equal collaboration in a care plan." (KI 1)*

Also, in terms of community size, there are often fewer options available in smaller communities. In effect, clinicians are sometimes forced to work together because there

are no other people to refer to; in contrast, there tends to be more human health resources in urban communities.

Participants also agreed that individual actors and partners would be more willing to collaborate and work in shared care with teams if there were an after-hours on-call system in place. Only two of the five (rural and small urban) teams in the study had a 24/7 on-call system in place. It was suggested that the five teams consider partnering amongst themselves as means to provide an on-call system and in order to share resources when team members are absent due to vacation or otherwise. It was noted that additional funding would be required if such an on-call system were to be put into place. Such a system would enable teams to better support family physicians and to address the context in which many family physicians practice today:

> *"… and the medical field has gotten away from home visiting like sort of in the 80s and 90s that was sort of country bumpkin doctors, so if you're an urban doctor and you're modern and hip, everything is in your office and we got away from all that and so to get that back installed into people's ways of being it hasn't swung around, there are pockets of people who see the benefit and believe in that and do it but it's a smaller percentage of the medical practice grouping… you see these kinds of shifts and that affects this whole idea that we can provide this fullsome palliative care in the home…"(S2)*

Another important area that fosters collaboration between providers is community rounds, which provide the opportunity for team members to build relationships with people outside of the team. Rounds enable teams to meet with other primary care

providers to discuss patients who are being cared for in the home setting. These meetings allow teams to use their expertise to build the PC capacity of primary care providers. According to a key-informant, community rounds also present the opportunity for interprofessional learning which benefits the patient:

> *"Because [rounds is] really where you do the proactive planning, the triaging, that's where you avoid crisis management…" (KI 6)*

Teams also discussed the need to train medical, nursing and social work learners about PC and interprofessional practice. While the teams are working to mentor learners in the community, this could also be addressed at the provincial scale through medical education sectors and professional regulatory bodies:

> *"…There aren't enough younger nurses wanting to do end-of-life care… because we're all of a certain age… we'll probably retire somewhat all together and there's not a lot coming up behind us." (TM)*

The sustainability of teams in the community is largely based on their ability to build capacity and relationships with primary care providers, and to engage community partners in the shared care service delivery model. Teams also discussed the importance of building relationships with community stakeholders to raise awareness and gain support:

> *"I think we would want to foster a better understanding of our stakeholders and community care and their responsibility with respect to the community piece and pave the way for better communication across care settings and reciprocity across*

care settings and not feel like we exist out here without no one else accountable…" (TM)

Team members stressed that building relationships would in turn influence their workload in terms of issues related to the manageability of their caseload. They explained that earlier referrals and an on-call system would help to avoid crises:

"I think [patients] could have had a better experience also if we were involved earlier and so I think if that somehow doesn't improve, I can see, you know, more frustration, in terms of sustainability and continuing to work that way and having that real job satisfaction, it would be hard to continue." (TM)

While teams work at the community scale to enhance collaboration and partnerships, according to a key-informant, system-redesign at both the LHIN and provincial scale is required to support and sustain teams because community initiatives alone will not sustain the teams:

"…it's on the will of the people and… the organizations to play fast and loose with the rules, be flexible with the money and say okay I can protect this little piece for you, I can make that happen, we'll pay for the parking, we'll pay for the mileage, there's all these deals going on to help it to happen but I mean I've seen things fall a part on mileage, because someone was covering the mileage and now, they could no longer do it…" (S2)

The excerpt above illustrates that teams have benefited from innovative strategies and community support/advocacy but even so, the lack of secure funding from the LHIN and

provincial scales makes them vulnerable entities. In what follows, the factors affecting sustainability at the LHIN scale are discussed.

2. LHIN

While the teams provide services to communities within the LHIN area, they are affected by decisions and funding from the LHIN, which is the administrative body, which manages, funds and coordinates all health services within a bounded geography. Teams must also work together with the CCAC, which is funded by the LHIN to coordinate healthcare services for patients in the home setting (e.g., community nurses and personal support workers) for the entire LHIN area. Case managers from the CCAC are considered as team members in three of the five teams, one of which is housed in a CCAC. There is also a Hospice PC Network for the LHIN which initially endorsed the teams and the shared care model for the LHIN area. At the time of study, the Hospice PC Network was in a period of transition, due to changes in leadership/management.

Key-informants and stakeholders discussed the importance of home care service infrastructure to the teams. In order for teams to sustain the shared care model, and to support patients in the home setting, home care services were paramount.

> *"It's a very different time right now, services in the community are really sparse… if you do not have enough [home care services], and not just enough but I think enough skilled clinicians who can respond, who are able to respond, so there's skill and provision, then you cannot sustain these people no matter how much they want to be at home…" (S3)*

The state of the community care infrastructure is largely dependent on funding from the provincial government. However, it was agreed that funding for the teams, and especially non-physician team members from the LHIN, would ensure the long-term sustainability of the teams. It is necessary for the LHIN to recognize that the teams and the shared care model are a worthy investment. At the time of the study, a neighbouring LHIN had received support for a similar service model:

> *"… I think it's a great example of when the LHIN is recognizing that it's a worthwhile model, that it gives the results that they're looking for and makes a commitment to it and says to the other partners - this is important, you need to all work together - and I think that shows what can be done when there's, you know, good leadership and direction and clarity about what's important…" (KI 4)*

Therefore advocacy for and championing of the shared care teams from the LHIN is vital. Additionally, direction from the Hospice PC Network in terms of planning and execution was also discussed. Participants were impressed with the Hospice PC Network's efforts in making certain that teams were housed in the best possible environment, allowing them to have meeting places that were conducive for clinical learning and confidential conversations. The data also determined that team members cannot be expected to inventory their community to determine the composition of the team. They must be informed and equipped with the knowledge of their patient population in order to respond to the needs of their community from macro scale planning bodies such as the LHIN or Hospice PC Network.

At the time of the study, without a leader at the Hospice PC Network, there seemed to be a lack of support and advocacy for teams from individuals beyond the community scale. As one stakeholder noted:

> *"I think there needs to be push and pull from change champions who have to be senior leaders that know the system." (S4)*

Moreover, a stakeholder also cautioned that support for the teams needed to be engrained in a strategy at either the LHIN or provincial scale in order for the teams to overcome their vulnerability at the community scale. As the excerpt below demonstrates, there often was an overlap in terms of designating an issue as a LHIN or provincial responsibility.

> *"… that's where the strategy comes in so whether there's a LHIN wide strategy or there's provincial strategy, and I know there's a lot of work happening at the provincial level…, but it has to set out some guidelines as to what are the kind of minimum levels of service that are required and then back that up with resources, right, and resources that are envelope funded, they're protected because if you put everything in global budgets, things can be taken away on a difficult year, you can turn around and say 'We've got to save ten percent, where are we going to take it from? What's that little PC team over there – does that match the number we're looking for?' It could be as simple as that." (S2)*

Secure funding was one of many resource issues related to the sustainability of teams. In what follows, participants expand on the types of resources from the provincial scale that could help to sustain teams.

3. Province

There is a need to (re) consider funding models at the provincial scale to support collaboration and non-physician team members.

> *"Because it's about funding... these teams came about from specialized grant funding… or yeah, little pockets of money have either continued or died and hence the teams [that haven't] died… have been protected, otherwise the teams are in jeopardy and fall a part because we don't have a way to fund these independent providers that can move across settings, the hub of the team being the nurse. The family physicians still exists, they're going to provide PC or not, the specialists still make home visits, they're going to be in there or not but it's the collaboration of the team that's the power..." (KI 1)*

At the time of study, an interest group, the Quality Hospice PC Coalition of Ontario (2010) submitted a policy document to the provincial government highlighting the need for a provincial vision, policy, integrated system design and additional investment. The need for support of PC models such as teams working in a shared care model was also included in the document.

An integrated system would enable teams to cross settings of care seamlessly. The teams agreed that the ability for them to access patients in various settings would enable them to provide better coordinated and patient-centred care. For example, only a few of the teams were able to provide consultation in long-term care facilities:

> *"…We don't have a seamless integrated Ontario such that somebody can coordinate across care settings fully." (TM)*

Participants noted that the sustainability of the teams depended on the value that government placed on the home care sector. They pointed out that an infusion of services and funding was not the only solution; there was also a need for clear and concise direction. A provincial strategy would provide clear expectations about service delivery and standardize services so that access to teams was not based on geography alone.

> *"I think [a provincial strategy would help because]… if it kind of laid out the rules, like what are the minimum that you need to provide then you wouldn't have all this sort of at the whim of certain organizations or certain individuals deciding, because you have really [keen] LHINs where they are all cooperating and things are going really well and they get great things, and they get money and they get more things happening and you get other areas that are having some dysfunctions and they can't get anything, well it's the same tax payers, so why is that happening, so why is [City X] and [advocate] getting higher levels of funding than anybody else and why is the [City Y] area getting more money and more attention, like why is that happening? And it's either because these are either high profile individuals who use their influence or there's been a real demonstration of cooperation and so people have been creative and they've made it happen and then over here because we're struggling and we've got sectors that aren't cooperating, with each other, our citizens get a lower standard of care?" (S2)*

While key-informants and stakeholders were able to articulate a system perspective as shown above, teams related the provincial role in their sustainability to the provision of 'on-the-ground' resources. For team members, resources from the province

encompassed human, material and knowledge resources. With additional funding, positions such as administrative support and psychosocial and bereavement roles, together with an increase in the number of hours for these positions would be possible:

> *"…our role is to be out seeing the patient… but we're spending half our time as nurses doing clerical stuff…" (TM)*

Additional sources of funding would reduce the vulnerability of the teams. At the time of the study funding for non-physician team members was piecemeal, with a heavy reliance on the support of community partners and in some cases, volunteers. Additional resources would also assist the teams in establishing collaborative partnerships with primary care providers. For example, funding for technological resources, laptops and other electronic devises could help to better coordinate care between team members and primary care providers in a timelier manner.

> *"And I think there are so many efficiencies that could be built in if we had simple things like electronic access to get communication, like we wait sometimes two weeks for a discharge summary, it's insane and we're going out to see that person without having a clue about what happened in the hospital…" (TM)*

Overall, additional resources would provide the teams with the ability to provide funders and policy makers with tangible evidence to demonstrate their cost-effectiveness and their ability to keep patients out of hospital.

Discussion and Concluding Remarks

The findings of this study add to the limited empirical research on the sustainability of PC programs and/or service delivery models. The themes generated

from the interviews with team members, key-informants and stakeholders were used to conceptualize the factors that contribute to the long-term viability of teams that provide home-based care in a shared care model. Many of the factors discussed below resonate with the sustainability literature previously reviewed, such as the need for resources, policy support and champions (e.g., Kelley, 2007; Sibthorpe, 2005; Shediac-Rizkallah, 1998). A limitation of the study is that it did not include stakeholders from the LHIN and the provincial government. These individuals may have provided additional and/or varied insight.

Sustainability was conceptualized from two angles: internal and external. Team members elaborated that, first and foremost, it was necessary for the team to be a cohesive unit with a common goal. However, team members recognized that their human agency and, in some cases, the agency of their managers, would not be sufficient to sustain them in the long-term. An overview of external sustainability was provided and the merging of data from all participant groups showed that the sustainability of teams was largely dependent on actors and organizations at the local (community), regional (LHIN) and provincial scales. These three scales were depicted in Figure 2 as pillars in the support and sustainability of PC teams.

The three scales are not self-contained or singular entities but rather are connected; Brenner (2001) argues, the interrelationships among scales should not be ignored. The decisions at one scale will impact the others. For example, the provincial government recognized the need to improve PC at the community level and an influx of funding in the mid-2000s led to the development of the Hospice PC Networks in each

LHIN. The Hospice PC Network in this study sought to improve the quality of care for patients at the community scale while at the same time decreasing the use of acute care (which in turn has an effect at both the LHIN and provincial scales). While teams attempt to improve the quality of PC care in the community, which is in line with both provincial and LHIN goals, they are seemingly doing so without adequate and dedicated support from the LHIN and provincial government. Figure 3 is used to illustrate the result from an imbalance in support, and it depicts the current situation.

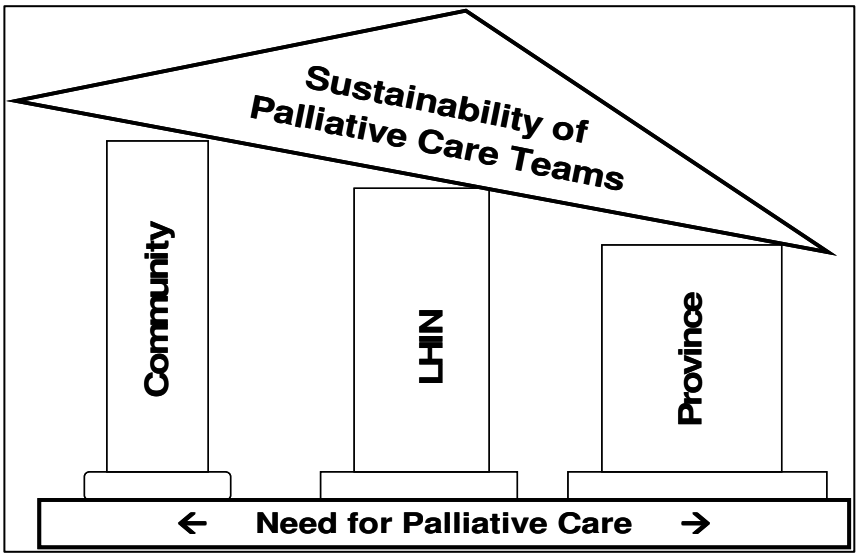

Figure 3: Scalar conceptualization of the sustainability of the PC team with unequal support from the community, LHIN and province

However, in times of fiscal restraint, the provincial government may be positioning itself as a vertical hierarchy making it difficult for community-based practices such as PC teams working in shared care, and champions of this model, to engage in 'scale jumping' (Smith, 2000) to influence the LHIN and/or province.

A synthesis of the perspectives and knowledge of the participants helped to inform recommendations for the sustainability of PC teams (see Table 3). While the recommendations may seem straightforward, difficulties may result from the fact that scales are inherently relational (Howitt, 1997). Integration and collaboration within and between scales is necessary, as community capacity will inevitably reach its threshold without support of the province, which provides funding to the LHIN. While the community continues to advocate for the teams, in the long-term, they will need additional supports from the LHIN and province. The province has the authority and capacity to engrain its support for teams through a formal strategy. The recommendations are presented based on scale and in priority order to better illustrate how actors and organizations could move forward.

While these recommendations may seem far-reaching to some, there is a strong impetus for sustaining PC teams. The combination of population aging, increases in chronic disease and preferences for home death will impact community-based care; teams are capable of easing the pressure that this will exert on primary care providers, the acute care sector and the health care system as a whole. In effect, community-based efforts will benefit the LHIN and the province. Take together, the top priority recommendations demonstrate that it is possible to restore the imbalance depicted in Figure 3 if teams continue to engage primary care providers in capacity building initiatives, the LHIN, Hospice PC Network and CCAC enhance their advocacy efforts, and the province provides financial support.

Table 3: Community, LHIN and Provincial Recommendations

Scale	Recommendations
Community	1) Teams must continue to engage primary care providers through capacity building initiatives. 2) Teams should be housed in a therapeutic environment such as a residential hospice or community hospital in order to assist with patient transitions. 3) The type of shared care model pursued by the team should be informed by community and primary care context (e.g., via needs assessment or community meeting). 4) Teams should refrain from a total 'takeover' model as it may decrease the capacity of primary care providers, and become unmanageable.
LHIN	1) The LHIN, Hospice PC Network and CCAC must align themselves and work in collaboration to champion the service delivery model and to advocate for team resources. 2) It would be advised that the CCAC work with nursing agencies to negotiate that nurses attend community rounds to enhance their capacity. 3) The LHIN must play a role in integrating, fostering and formalizing partnerships between community stakeholders and teams. 4) The LHIN in collaboration with the Hospice PC Network should assist teams in demonstrating their relevance by building on existing evidence of cost-effectiveness (e.g., Klinger et al., 2012).
Province	1) The province needs to allocate dedicated funding to non-physician health care providers on PC teams. 2) The province must acknowledge current disparities in the provision of home-based PC and the added value of PC teams. 3) A provincial PC strategy endorsing PC teams and the shared care model is a step in the right direction. 4) Incentives for family physician home visits should be considered as a means of improving the buy-in for shared care.

Another important scale that was absent from the data but may also influence the sustainability of teams, albeit indirectly, is the federal government. Changes at the national scale related to negotiations around transfer payments from the federal government to the provinces for health care, a national home care strategy, as well as

knowledge translation activities facilitated through the national interest group, the Canadian Hospice Palliative Care Association (see Williams, 2010), have the potential to impact the sustainability of teams.

The sustainability of PC teams that provide home-based care is required to ensure that patients and primary care providers are better supported. PC teams that work in shared care ultimately assist in enhancing the care that is provided to patients and their family members. Without the proper support from community partners, planners and administrators at the larger LHIN and provincial scales, the sustainability of PC teams will be compromised given the limitations of the micro community scale; as the title of this paper suggests, the people and the organizations at the frontline, at the community scale, will be at the helm of driving change.

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CHAPTER 5

Conclusion

5.1 Introduction

This thesis sought to gain a better understanding of the barriers and facilitators to implementing palliative care teams working in a shared care model, which, in turn, provided a basis for informing how to sustain teams. Although interdisciplinary teams are considered best equipped to provide holistic and quality palliative care (e.g., Meier & Beresford, 2008; Crawford & Price, 2003; Billings, 2002, Ferris et al., 2002; Saunders, 2000), much of the research on integrated palliative care programs is quantitative and concerned with issues related to cost-containment, place of death and other symptom indicators and outcomes (e.g., Howell et al., 2011; Klinger et al., 2011; Fainsinger et al., 2007; Bruera et al., 2000). This area of research often fails to take the perspective of the health care providers into account. To address this gap, this study examined the perspectives of five palliative care teams that provide services to several communities in a LHIN area in Southern Ontario. Their accounts were supplemented with information provided by key-informants and stakeholders. The analysis of participant perspectives and tacit knowledge provided a basis for understanding the challenges that teams face and the ways in which these challenges are mitigated in order to sustain teams over time.

In what follows, a summary of key findings will be presented in addition to the contributions, both scholarly and policy-related, of this research. The chapter

will conclude with an overview of study limitations and directions for future research.

5.2. Summary of Key Findings

The teams in this study responded to broader health care system challenges, such as an inadequately trained primary care workforce and the need to improve the quality of palliative care. Concomitantly, the teams endured challenges to providing home-based care in partnership with family physicians and home care nurses. As noted in Chapter 1, there has been a shift away from viewing the place of care as merely a "container" in the health geography literature. Instead, the place of care has broad implications for policy as illustrated through a synthesis of the findings from the research papers in this thesis which led to the organization of key findings related to place in the following three areas: (1) geography; (2) human agency and; (3) governance.

1. Geography-related findings

The role of geography was apparent in several different ways. To begin, palliative care can be provided in various material places, including homes, residential hospices, acute care hospitals and long-term care facilities. The mere fact that the teams served distinct communities within the LHIN area while some communities received usual care reinforced the notion that place-based disparities in access to palliative care services exist (e.g., Collier, 2011). More broadly, the lack of consistency in service delivery models both within the LHIN area and between LHINs in the province was highlighted as an issue that remains to be

addressed. The challenges that teams faced also highlighted the silos that exist across the settings of care, which was demonstrated by the inability of some teams to cross care settings; this obviously perpetuates fragmented care, and a lack of integration.

While the larger literature acknowledges patient preference for home deaths (Brazil et al., 2005), teams attempted to improve the quality of care provided in the home setting. The lack of buy-in for home visits from family physicians illustrated the possibility that a shared care model, which involves home-based care, is different from shared care models in other specialties that are primarily based in hospitals and physician offices. This suggests that shared care models may be easier to implement in clinical settings rather than in private dwellings.

Teams also noted the benefits of working in defined geographies, which enabled them to become more acquainted with the community context (e.g., services available to patients), and to build relationships with a finite number of health care providers. This illustrates the role and importance of social capital and social cohesion in the development of shared care models. The landscape of the community (i.e., urban vs. rural) was found to influence the extent of relationship building and buy-in teams needed to engage in. Teams that provided services to urban centres were forced to exist in and negotiate with a larger health care landscape which was not the case for teams in smaller urban and/or rural communities. However, other factors related to locality also played a role. In some communities, the “culture” of family physicians was described as “cradle to grave”

which meant that the physicians wanted to stay involved in the care of their patients at end-of-life, and in effect, they were more willing to participate in shared care.

Some teams considered their work to be "virtual" in the sense that they seldom visited patients together as a group; rather they met at weekly or biweekly rounds, or communicated via telephone or by electronic means. As a result, the issue of home base location was viewed as important. It was recommended that teams be located in either hospices or hospitals to allow for: team collaboration/access to colleagues; an environment conducive to confidential information exchange, and; as a means of better coordinating patient transitions.

Overall, it was noted that while teams provide services in the community and in private homes, they have to contend with regional (LHIN), provincial, and national scale socio-political issues. An examination of teams at the community scale showed that they do not exist in a vacuum; support from other scales through infrastructure, advocacy, resources and policy are essential to their sustainability.

2. Human Agency-related findings

Despite the fact that teams are vulnerable due to the lack of secure funding for team members, together with no secure structure reflected in no long-term plan with respect to policy or program support, the human agency (Giddens, 1984) of teams was demonstrated through the various ways in which they worked to overcome challenges. Teams sought buy-in from family physicians and community nurses through outreach activities such as hosting 'lunch and learns' and community rounds. They engaged in capacity building initiatives as a means of

gaining buy-in but also to improve the quality of care provided in the community by their primary care colleagues (e.g., some team members noted that their goal was to capacity build to the extent that they would work themselves out of jobs).

Their attempts to negotiate barriers demonstrated their motivation and human agency (e.g., reaching out to community partners for funding for non-physician members, which was often piecemeal and not secure). For some teams this also involved reaching out to the voluntary sector to fill positions (e.g., social work). On the other hand, by finding short-term solutions to overarching issues, teams reinforced the root of the issue, which was lack of support from the LHIN and/or province. Although the majority of team members worked beyond their clinical roles to champion the shared care model, it is not feasible for teams to continue to work beyond these roles to advocate for their service delivery model and to appease funding partners by producing data on their effectiveness.

The human agency of team members is illustrated by the fact that they often worked beyond their clinical roles and, when necessary, assumed primary responsibility for patients rather than share the care. This is noteworthy as it confirms that teams have often acted as champions for the shared care service delivery model and for patients; this reaffirms that much of the progress in palliative care has been through the work of champions (see Williams et al., 2010).

3. Governance-related findings

Although teams provide home-based care in a shared care model, which is considered a micro-geography at the community scale, they are constrained by

macro-geography policies and decision-making bodies at the provincial and national scale. For example, based on the Canada Health Act, there is a privileging of physician and hospital-based services across the country; this does not support nurses, social workers and other non-physician team members in community settings. Policies and practices that relate to the ways that primary care providers are funded (e.g., fee-for-service family physicians and hourly-waged home care nurses) also pose challenges in terms of 'buy-in' for shared care, as family physicians are often not willing to make home visits and both family physicians and home care nurses may view the capacity building involved in shared care as time consuming. These funding/remuneration issues are largely related to the lack of a policy structure or strategy for interdisciplinary collaborative practice which could be mitigated through proper supports and infrastructure from the government (Hutchison, 2008).

Capacity building was considered to be a key component of shared care; the teams considered building the palliative care skill sets of their primary care colleagues as essential to the shared care model. The teams' commitment to capacity building underlined the need for more remedial palliative care education for family physicians and home care nurses. Additionally, the lack of buy-in for shared care from primary care providers points to the need for more education about interprofessional practice in undergraduate medical and nursing training.

Without additional policy support and/or resources from the provincial ministry of health, teams will remain vulnerable. The teams may continue

community-based capacity efforts but without formalized policy and resources from either the LHIN and/or province (in the form of a strategy or guidelines), their sustainability will be short-lived.

5.3. Health Service Contributions

This was the first empirical qualitative study, to our knowledge, that examined palliative care teams that provide home-based care in Ontario, Canada, specifically around issues related to their sustainability. The proposed recommendations regarding the sustainability of teams may be useful for those in positions of palliative care leadership and/or the policy sector. Based on the fact that teams are central to the provision of palliative care, this investigation is useful for other jurisdictions wanting to implement teams.

The study also explores the human agency of team members by demonstrating how they work proactively within the confines of the health care system to provide services to patients at the community scale. Other supports also need to continue to be nurtured, such as initiatives that address and mitigate compassion fatigue, for example through team building exercises and/or retreats. In addition, some of the teams were unable to cross care settings in order to follow patients who had been transferred from their homes to other settings for care. The teams have the ability to improve the integration and coordination of care for patients but are often constrained by policies and guidelines put in place by the LHIN and/or province; interestingly, the province created the LHINs to better integrate care.

The concept of shared care is not new. For example, the mental health community in Canada put forth a position paper on shared mental health in the mid-1990s, which offered strategic direction for better collaboration (Kates et al., 1997). The mental health community maintained that the viability of shared care depended on a number of key players and partners at various scales, which they refer to as levels:

"[Shared care] needs to be reinforced by collaboration at many different levels, including that of planners and administrators of regional and provincial health delivery systems" (Joffe et al., 1997, p. 809).

They also noted the importance of collaborative partnerships between academia and, in particular, departments of psychiatry and family medicine in research, education and practice. Despite the fact that the shared care model in mental health does not typically include home-based care (i.e., it is community-based with mental health care providers working with primary care providers mainly in family medicine clinics), there is much to be learnt from their experiences. While their progress has been incremental (their 2nd position paper was published in 2011, see Kates et al. 2011), the shared care model in mental health has received a number of accolades in the health services research arena. The implementation of the shared care model in mental health can be used as a template in palliative care. For example, mandatory community-based placements for medical and nursing students in palliative care might help to provide relevant training but also encourage learners to consider the field as a prospect for future practice.

5.3.1 Scholarly Contributions

Above all, this study adds to the health geography literature as the relationship between health service delivery (i.e., palliative team-based shared care) and place (e.g., in the home setting in various communities) is explored (Kearns, 1993). This study also goes a step further to address gaps in the health geography literature. There is lack of inquiry on health care production and a need for more engagement with "geographies in health care work" (Andrews & Evans, 2008, p. 760) given the increasing trend of home-based care (Kearns & Collins, 2009). This is one of the few studies that contributes to the understanding of how teams work in interprofessional collaboration to provide palliative care in the home setting, in spite of the socio-political constraints. Furthermore, this study addresses how the various features of communities (e.g., urban and rural) impact practice and relationship building.

This study also contributes to the health geography literature by exploring a home-based model of health service delivery while also adding to the geographies of care and caregiving literature. This is a growing area of interest for health geographers given the implications of the political economy of health services restructuring and caregiving. Previous research in the area of home-based health care services in health geography has been limited to a rural perspective (e.g., Skinner & Rosenberg, 2006). This study adds a varied perspective as it includes both urban and rural geographies in a non-Northern setting and builds on the literature on care of the aging in community/home settings which is often focused

on informal caregivers (e.g., Donovan et al., 2011; Milligan, 2009; Yantzi & Skinner, 2009; Wiles, 2003; Williams, 2002; Milligan, 2000).

It is acknowledged that shared care might not work the same everywhere and that *place* is important (Kearns & Moon, 2002); collaboration depends on geography both at the micro and macro scale (i.e., collaboration among settings/providers of care in the community). In terms of implications for practice, the information generated will provide useful guidance to the teams in this study as they move forward. According to Williams et al. (2010), "good health service planning requires us to examine past events in order to determine what has worked and has failed before moving on to the future" (p. 14). The results may also prove useful to future planning at the LHIN (e.g., Hospice Palliative Care Network) and provincial scale, as well as to other communities across the province, country and on an international scale, interested in emulating the model.

5.3.2 Methodological Contributions

This study offers several methodological contributions. It adds a rigorous qualitative perspective (see Appendix C) to an area of health services research that has a strong quantitative foundation (as noted above in the Introduction). The use of qualitative methods helped to build an understanding through the "real world" experiences of teams and through a rich description of the context. The findings of this study provide an additional lens that can be used to complement the quantitative evidence in this subject area, which is often free of a contextual framing.

Moreover, the practical application of three different frameworks represents a further contribution. The application of the *3-I* framework in Chapter 2 is primarily used in policy analysis to understand policy development and government decision-making. The illustration of the employment of this framework may be useful for others examining new and innovative forms of health service delivery models. In Chapter 3, Williams et al.'s (2010) conceptualization of the evolution of palliative care in Canada was elaborated by focusing on the teams as a the product of a service innovation and the ways in which community-based barriers were circumvented in the provision of palliative shared care. Scholars examining community-based barriers in program delivery (i.e., health or non-health) may also find this modified framework to be relevant. According to Atkinson (1995) "relatively little research attention has been given to [the] role of human agency in shaping organizational change at different geographical scales in a health system and in linking this relationship to how healthcare is delivered" (p. 494). In Chapter 4, the use of the scalar approach contributes to the few practical applications of this form of analysis that exist in the health geography literature

5.3.2 Policy Implications

The findings demonstrated the strong willingness of teams to provide home-based care in spite of the lack of support. The sustainability of teams working in shared care will require policy leadership and health care transformation in the form of a provincial strategy. The teams are currently working in a curative health care system that lacks integration. For instance, it was often difficult for participants to

assign responsibility for teams to either the LHIN or province. The province exerts control over the LHIN through funding. While the LHIN should have the ability to assert the need for teams, it does not seem to have enough authority. LHINs' lack of authority has been recognized as a province-wide issue that needs to be addressed (Drummond et al., 2012). As recommended in Chapter 4, the province needs to acknowledge the disparities in access to quality palliative care across the province and to make palliative care a priority on their decision agenda.

Teams demonstrate their value as they address broad health care challenges, including issues related to quality through the provision of holistic and patient-centred care, in addition to capacity building with primary care providers. There is a need to support team approaches for home-based care in Ontario and this will require the provincial government to realize that palliative home-based care is a unique form of home care (e.g., it cannot be confined to regular work day hours and does require physicians to leave their clinics/offices). It is also imperative for governments to realize how place characteristics influence palliative care teams and their pursuit of shared care models. For example, the home base location of the team will have an effect on the team's ability to integrate care in the community due to their proximity to colleagues and/or visibility. Teams located in non-clinical institutions such as service provider agencies will be at a disadvantage due to their relative separation from colleagues. Place characteristics such as the rurality of the community also influences teams. It is evident that teams in rural communities better facilitate relationship building and therefore, shared care partnerships, due to

the small and tight-knit community-oriented nature of rural areas. Relationship building which is vital to establishing shared are partnerships may also be better facilitated in rural and/or mid-urban communities in comparison to larger urban areas due to the common lack of human health resources which often leads health care professionals to work together, in partnership, out of necessity. Teams located in urban communities will be required to interact with a larger pool of stakeholders, and as shown in the research, these stakeholders may be larger hospital corporations as opposed to the small community hospitals encountered by teams that provide services in small rural and mid-urban areas. Therefore, policy makers must acknowledge that place characteristics inform how palliative care teams pursue shared care models, and that place acts as both a barrier and facilitator in the sustainability of teams working in shared care.

An area that deserves policy attention is sustaining the non-physician members of the team through dedicated funding. This research showed that there is a need to recognize the importance and contributions of human health resources beyond physicians in palliative care. One of the palliative care physicians made this point clear:

> *…From my perspective, it is a very practical decision [to work in a team], I don't have all of the expertise to answer and address all the concerns a patient and family might have, I need input from nursing and insights that I as a medical person haven't got to the same degree and so from a practical perspective I think you can be much more helpful to patients and families*

when you have all the pieces working together at the same time because it is very hard to give psychosocial support and emotional support to someone who's in extreme pain but if the two of you work together you can address both issues at the same time and improve things more quickly.

Buy-in for shared care could also be addressed by providing physicians with incentives for home visits. If family physicians are considered responsible for palliative care, they should be properly supported to provide palliative care, with support from a team. A key informant noted recent changes to funding schedules that created a billing code for specialist and family physician phone consultations; this is a step in the right direction. Without incentives, family physicians may prefer palliative care teams to 'take-over' care since "most Ontario family doctors, as in other provinces, are paid on a fee-for-service basis. Provincial medicare plans typically pay for palliative care services at one-third the rate that the doctor could bill for seeing a series of patients with colds" (Rachlis, 2005, p. 77). In addition, there is also the need to ensure the attendance of nurses at community and/or team rounds for capacity building purposes. It is recommended that the CCAC build this component into their contracts with nursing agencies. It is important for regional (LHIN) and provincial stakeholders to mobilize around palliative care teams.

5.4 Future Research

This study provided an in-depth understanding of the barriers that palliative care teams encounter in the provision of home-based care, the ways in which they negotiate these barriers and what contributes to their sustainability. The study added to the limited research on health care production in the health geography literature

and offered a qualitative perspective to the health services literature.

This study was primarily concerned with the perspectives of team members that worked in a shared care model. A future research direction that would add to the comprehensiveness of this area would be to include additional stakeholders. This study presents one-side of the shared care relationship and suggests that further research with those involved on the other side is necessary. For example, it would be important to invite family physicians (i.e., those who work with teams and those who do not) to get their perspectives on shared care. This would build on research examining family physicians' motivation to practice palliative care (e.g., Brown et al., 1998) and Danish research examining the perspectives of family physicians and nurses that work with a palliative home care team (Goldschmidt et al., 2005). Although a few home care nurses participated in several focus group sessions, a larger group may offer additional insights (e.g., the type of shared care relationship that is desired). Additional research could also involve personal support workers and the volunteer sector as both of these groups are key players in the provision of home-based care.

Further research in this area might also include an evaluative component to compare communities with access to a team to those currently receiving usual care. The LHIN area of concern in this study would provide the setting for such a case study given the fact that teams have yet to be implemented in several of the communities. It would be possible to assess and compare whether teams have an effect on, for example, care transitions and/or the quality of care through various

measures.

Ultimately, this study has shown that palliative care teams strive to work in a shared care model in spite of the barriers that they face. The teams involved in this study have demonstrated that they are willing to work without adequate supports for the benefit of their patients. However, without proper supports from the region and province, the sustainability of the teams remains uncertain.

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APPENDICES

Appendix A: Interview Guides

A1: Key-Informant Interview Schedule

Macro Shared Care:

1. What is your experience with shared care?
2. What areas/specialties are you most familiar with in terms of the shared care model?
3. What is your understanding of shared care model(s)?
4. How would you define shared care?
5. How would you describe shared care?

Micro Shared Care in hospice palliative care:

1. How is shared care in hospice palliative care different from other types of services using shared care models?
2. The Canadian Hospice Palliative Care Association describes different types of palliative care service delivery models based on how primary healthcare providers can access interdisciplinary teams. Do you think shared care can be classified according to one of the following categories?

Primary healthcare providers can access the team for:

a) a one-time consultation with no ongoing follow-up
b) consultation with follow-up where the primary healthcare providers maintain overall responsibility for the patient's/family's care and the experts maintain a supporting role
c) consultation with follow-up where the experts assume overall responsibility and the original primary healthcare providers maintain a supporting role
d) consultation followed by assumption of the primary responsibility for the patient's/family's care (as the original primary providers stop being involved).

3. In your opinion, what are the advantages to providing hospice palliative care using a shared care model?
4. In your opinion, what are the disadvantages to providing hospice palliative care using a shared care model?
5. In your opinion, what are the barriers to providing hospice palliative care using a shared care model (e.g., system/institution, policies, clinician attitudes etc.)?
6. In you opinion what are the facilitators to providing hospice palliative care using a shared care model?
7. What type of leadership is usually in place in shared care teams? Is this the most appropriate type of leadership for shared care in hospice palliative care?
8. What ideally needs to happen with respect to professional development?
9. What ideally needs to happen with respect to team communication?
10. What ideally needs to happen with respect to individual team members learning from each other?

11. How is success measured with respect to: i) team development; ii) team sustainability?
12. What is the impact of longevity?
13. How long does it usually take to form/develop a shared care team?
14. What are the necessary minimum conditions?
15. What is the ideal representation of professionals/make-up on a shared care team?
16. In your opinion, how important is geography to shared care teams? (e.g., being located in the same workspace, having a home-base, the geography served by the team etc.)?
17. What is your impression of the shared care teams in the X LHIN?
18. In your opinion, what's working (facilitators)?
19. In your opinion, what's not working (barriers)?
20. Anything else you want to add? Would you be open to participating in a follow-up interview?

Appendix A2: Focus Group Demographic-Related Questionnaire

Please complete the following questionnaire by providing a response in the space provided or by indicating your response by checking the appropriate box(es). Please skip those questions that you are not comfortable answering.

1. What is your role on the team?

2. How many years of experience do you have in hospice palliative care?

3. How long have you been a member of the team?

4. How did you hear about/become interested in the team?

5. Do you live in the community where your team provides services?

6. What is your employment status?

□ Full-time □ Part-time □ Casual □ Other (please specify):

7. Who supports your role on the team? Please check all that apply:

□ Community Care Access Centre (CCAC)
□ Home Care Agency
□ Hospice
□ Hospital
□ Local Health Integration Network (LHIN)
□ Ministry of Health and Long Term Care (MOHLTC)
□ Other (please specify):

Appendix A3: Focus Group Interview Schedules

FOCUS GROUP #1 QUESTIONS

1. Are all team members present? If not, who is missing?
2. Are there any other roles that you want to have filled on the team? Which ones? By when (i.e., is there a plan in place to fill this role)?
3. What attracted you to apply/work on this team?
4. When did the team form (e.g., year/month)?
5. Has the team membership changed since the team formed? If so, please outline, starting with the first change. [Use chart paper to illustrate]
6. How long (i.e., #months, #weeks, etc.) did it take for the team to start working in the community once it formed? (Probe: if it was a lengthy or short process – why? OR is this process still ongoing?)
7. How did it move from formation to implementation)
8. What has impacted the speed of actually working in the community?
9. How would you describe your team practices/service delivery model given the following categories from the Canadian Hospice Palliative Care Association (Ferris et al., 2002, p. 68) [See below for handout; ask participants to take a moment to indicate on spectrum with an "X"]

Primary healthcare providers can then access the team for:

a) a one-time consultation with no ongoing follow-up
b) consultation with follow-up where the primary healthcare providers maintain overall responsibility for the patient's/family's care and the experts maintain a supporting role
c) consultation with follow-up where the experts assume overall responsibility and the original primary healthcare providers maintain a supporting role
d) consultation followed by assumption of the primary responsibility for the patient's/family's care (as the original primary providers stop being involved).

Follow-up: Is this where you envision your team being placed or is it somewhere else on this continuum?

10. When you first heard of the team, what was your vision of what it was?
11. What was your vision of what the team was meant to accomplish?
12. Do you feel that your team is meeting those expectations?
13. How does your team communicate/keep in touch? What is the most common medium (e.g., weekly rounds, via telephone, e-mail)? What is the next most common medium?
14. What is the preferred medium?
15. In which settings does your team work (e.g., hospital, long-term care, home, hospice)?
16. In what order would you place them from most to least?
17. Is the amount of time devoted to individual patient care variable across settings? Please explain/provide details.

18. Does your team meet outside of work (i.e., on a social basis)? If so, when? Where? How often?
19. Does your team participate in professional development activities together? If so, who organizes these activities? Who sponsors these activities?
20. Do you as individuals participate in professional development activities? If so, who organizes these activities? Who sponsors these activities?
21. As a team, what have you learned so far? (e.g., Is constant communication important? Is having regular meetings important ?)
22. Do you learn from each other? How so?
23. What do you feel has facilitated the functioning of the team to date?
24. What barriers have presented themselves in the successful functioning of the team?
25. Does your team meet face-to-face? If so, how often?
26. On average, how many cases do you have during any given week? Month?
27. Does your team have a "home-base"? If so, where is it? (follow-up questions: Do you have workstations? If so, are they located beside each other?)

FOCUS GROUP #2 QUESTIONS
Follow-up questions:
At the beginning of the focus group, I will confirm whether team member roles and responsibilities have stayed the same or changed since the first focus group session. I will also inquire whether communication strategies have stayed the same or changed. More broadly, I will ask if any changes to how the team functions have occurred since the first focus group session. Some questions will be repeated from Focus Group #1.

Question #9 from the Focus Group #1 will be repeated:
How would you describe your team practices/service delivery models given the following categories from the Canadian Hospice Palliative Care Association (Ferris et al., 2002, p. 68)? *Please note: these categories will be displayed on a handout.*

Primary healthcare providers can then access the team for:

a) one-time consultation with no ongoing follow-up
b) consultation with follow-up where the primary healthcare providers maintain overall responsibility for the patient's/family's care and the experts maintain a supporting role
c) consultation with follow-up where the experts assume overall responsibility and the original primary healthcare providers maintain a supporting role
d) consultation followed by assumption of the primary responsibility for the patient's/family's care (as the original primary providers stop being involved).

1. On average, how many cases do you have during any given week? Month? OR Last time I was here you mentioned that your caseload was [X]. Has that changed? If so, how? Why?

2. Do you generally get positive feedback from families, clients or clinicians? Examples?
3. Do you feel that the community is aware of your team's services? What types of advocacy (if any) does your team engage in?
4. What are some of the barriers/facilitators that your team experiences in providing care?
5. If barriers are identified: What is your team doing to overcome these barriers?
6. What is your vision for your team's future?
7. Are you familiar with the geography you serve? How familiar are you with the communities in your jurisdiction?
8. Does geography impact your team? (e.g. in terms of collaboration, urban centre vs. rural centre)?
9. Your team provides services to a particular geographical area. How do you ensure equitable services are provided by your team across space?
10. How do you learn from each other?
11. As a team, what have you learned? (e.g. Is constant communication important? Is having regular meetings important?)
12. Since the last time I was here, has your team participated in professional development activities together? How about individual professional development activities? If so, who organized these activities? Who sponsored these activities?
13. Are there any other changes to your team that I've not asked about?
14. Last time I was here, you mentioned a few barriers that your team experiences in providing care such as [give examples]. If you were to pinpoint the main barrier that your team experiences in providing care, what would it be?
15. What is your team doing to over come these barriers?
16. Last time I was here, you mentioned a few facilitators that your team experiences in providing care such as [give examples]. If you were to pinpoint the main facilitator that your team experiences in providing care, what would it be?
17. Your team and the rest of the teams in the region are defined by geographical boundaries. Do you think this was a good idea? Why or why not?
18. Do you think your team could function in downtown Toronto?
19. Do you think you team could function in a rural community north of Thunder Bay?
20. Do you think it would be possible to provide expert/specialist palliative care consultation in a shared care model through telehealth/telemedicine? (i.e., nurse or general practitioner located at a distance and experts communicating via telehealth). [Follow-up: For shared care to work in palliative care, is it important to be physically present?]
21. If you could give one piece of advice to a team that is just starting out, what would it be?
22. In terms of your team's sustainability, and when I use the term sustainability I mean your team's capacity to work together over time interprofessionally and to continue doing what you're doing, what factors contribute to your team's sustainability? (e.g., funding, collaboration, cooperation of stakeholders etc.)

23. What factors hinder your team's sustainability? (e.g., stress, burnout, funding, politics etc.)
24. In terms of how your team was implemented, if you could turn back the clock, would you change anything? If so, what? Why?
25. Do you think it would it would be helpful to meet with other teams in the region to learn about how their teams function? If so, why? If not, why?
26. Do you think changes in demographics such as population aging and increases in chronic disease rates will affect your team? If so, how?
27. What do you foresee as the most probable challenge your team will have to face in the next five years? Ten years?

FOCUS GROUP #3 QUESTIONS
Follow-up questions:
At the beginning of the focus group, I will confirm whether team member roles and responsibilities have stayed the same or changed since the previous focus group sessions. I will also inquire whether communication strategies and caseloads have stayed the same or changed. More broadly, I will ask if any changes to how the team functions have occurred since the first focus group session. Some questions will be repeated from the previous focus group sessions.

Question #9 from the Focus Group #1 will be repeated:
How would you describe your team practices/service delivery models given the following categories from the Canadian Hospice Palliative Care Association (Ferris et al., 2002, p. 68)? *Please note: these categories will be displayed on a handout.*

Primary healthcare providers can then access the team for:

a) a one-time consultation with no ongoing follow-up
b) consultation with follow-up where the primary healthcare providers maintain overall responsibility for the patient's/family's care and the experts maintain a supporting role
c) consultation with follow-up where the experts assume overall responsibility and the original primary healthcare providers maintain a supporting role
d) consultation followed by assumption of the primary responsibility for the patient's/family's care (as the original primary providers stop being involved).

1. How do you learn from each other?
2. As a team, what have you learned? (e.g., Is constant communication important? Is having regular meetings important?)
3. Since the last time I was here, has your team participated in professional development activities together? How about individual professional development activities? If so, who organized these activities? Who sponsored these activities?
4. In previous discussions, a number of barriers to providing care in the community have been discussed (for example, family physician participation). Has your team

experienced any *new* barriers to providing care in the community since the previous focus group session?

5. In previous discussions, a number of facilitators to providing care have been discussed (for example, having community rounds). Has your team experienced any *new* facilitators to providing care in the community since the previous focus group session?
6. Based on previous focus groups, there didn't appear to be a lot of formal team building activities or exercises taking place mainly due to financial and time constraints. Is this correct? Is this still the case? What are your thoughts on potential new interventions and/or programs that could support team building initiatives? Do you think such initiatives would be worthwhile?
7. From a policy perspective, at a local level, are there any potential new polices or modifications to existing policies that would better support teams? Prompt: For example, policies specific to arrangements with nursing agencies?
8. From a policy perspective, at a provincial level, are there any potential new policies or modifications to existing policies that would better support teams? Prompt: For example, policies to enhance collaboration or changes to funding schemes?
9. Community-based palliative care teams working in a shared care model do not exist across the province of Ontario. Do you think a shared care service model should be consistent across the province? Why or why not?

Appendix A4: Stakeholder Demographic-Related Questions

1. What is your role/position in your organization?
2. How many years have you been in this position?
3. How many years have you worked in hospice palliative care?
4. How much of your time is devoted to hospice palliative care?

Appendix A5: Stakeholder Interview Schedule

1. What is your understanding of shared care?
2. Are you familiar with the shared care model that is used in the X LHIN area?
3. Do you think that shared care is working in this LHIN? Why? OR Why not?
4. What are your thoughts on using a shared care model to provide hospice palliative care in the community? In hospice? In long-term care? In hospital?
5. What are some of the barriers/facilitators to providing shared care? (e.g. systemic, policies, clinician attitudes etc.).
6. What are some of the advantages/disadvantages associated with shared care teams?
7. Do you think shared care is an innovative form of hospice palliative care delivery? If yes, why? OR If no, why not?
8. Please describe your experience(s) of working with a community-based palliative care team in a shared care model.
9. What are your positive experiences of working with a community-based palliative care team in a shared care model? What are your negative experiences of working with a community-based palliative care team in a shared care model?
10. Did the opportunity to work with a community-based palliative care team in a shared care model enhance your capacity in palliative care?
11. Can you discuss any changes that would help to *improve* community-based palliative care teams working in a shared care model? (E.g., changes to team composition, policies, communication with partners, geographic boundaries of services areas, resources, communication with other partners such as hospital etc.)
12. Can you discuss any changes that would help to *support* community-based palliative care teams working in a shared care model? (E.g., changes to team composition, policies, communication with partners, geographic boundaries of services areas, resources, communication with other partners such as hospital etc.)
13. Do you think that community-based palliative care teams working in a shared care model improve coordination for individuals who wish to die at home and their family members?
14. Do you think that community-based palliative care teams working in a shared care model are sustainable? Do you think these teams will be around in the next 2-5 years?
15. What advice would you offer for implementing new community-based palliative care teams?

Appendix B: Letters of Information and Consent

Appendix B1: Letter of Information and Consent Form for Key Informants

Letter of Information

Title of the Study:	Implementing hospice palliative care services using a shared care model
Investigators:	
Student Investigator:	Lily DeMiglio School of Geography & Earth Sciences McMaster University 905-525-9140 ext. 28617
Supervisor:	Dr. Allison Williams School of Geography & Earth Sciences McMaster University Hamilton, Ontario, Canada 905-525-9140 ext. 24334
Research Sponsor:	Canadian Institutes of Health Research (CIHR)

Please read this information form carefully. If you have any questions, ask the investigator before signing the form. You have been asked to be a key informant.

Purpose of the Study:
The purpose of this study is to learn more about the process of developing and sustaining community hospice palliative care services using a shared care model. This will be accomplished by examining how shared care teams work in the context of the populations and geographies they serve. The ultimate goal of this study is to evaluate barriers and facilitators in using a shared care model to inform a framework to guide best practices.

Procedure:
If you volunteer to be part of the study, you will participate in a key informant interview during which you will be asked to share your knowledge about shared care models and teams. You will be asked questions such as: *How would you describe/define shared care? What is your understanding of shared care models? What areas/specialties are you most familiar with in terms of the shared care model? What is your experience with shared care?* With your permission, the interview will be audio-taped and will take about 60 to 90 minutes.

Potential Risks:
The risks associated with participating in this study are minimal. Nonetheless, we want to remind you that you do not need to answer questions that make you feel uncomfortable or

that you do not want to answer. There is a slight risk that you may feel a loss of privacy and/or reputation. For this reason, we ask that you make only those comments that you would be comfortable making in a public setting, and to refrain from comments that you would not say publicly.

Potential Benefits:
Your expertise as a key informant will help the student researcher to gain a better understanding of the shared care model and shared care teams. Your involvement in this study might benefit society as research findings could be applied to providing best practices to enhance shared care teams in hospice palliative care as well as in other specialties.

Remuneration for Participation:
You will not be remunerated for your participation however you may request a copy of the research summary by indicating so on the consent form.

Confidentiality:
If you prefer that your identity remain confidential, your privacy will be respected. Please indicate your preference on the consent form. Any information that you provide during the study will be stored in a locked filing cabinet and on a password protected computer in the office of the student investigator and only she will have access to it.

Participation and Withdrawal:
Your participation in this study is voluntary. If you decide to participate, you are free to stop at any time, even after signing the consent form or part-way through the study. If you decide to stop participating, there will be no penalty to yourself. If you do not want to answer some of the questions you do not have to but you can still be in the study. You may exercise the option of removing your data from the study at any time.

Study Debriefing:
You may obtain information about the results of the study by indicating so on the consent form. The research findings will be sent via e-mail or post to the address you provide.

Rights of Research Participants:
You may withdraw your consent at any time during the study without consequence. If you have any questions or concerns about the research study, please feel free to contact Lily DeMiglio at 905-525-9140 ext. 28617.
This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions regarding your rights as a research participant or about the way the study is conducted, you may contact:
McMaster Research Ethics Board Secretariat
Telephone: 905-525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

Consent Form

Signature of Participant:

I understand the information provided for the study "Implementing hospice palliative care services using a shared care model" being conducted by Lily DeMiglio under the supervision of Dr. Allison Williams at McMaster University. My questions have been answered to my satisfaction. I understand that I may withdraw from the study at any time, if I choose to do so, and I agree to participate in this study. I have been given a copy of this form.

_____

Name of Participant

_____ _____

Signature of Participant Date

I agree that the interview can be audio-recorded. _____ Yes _____ No

I would prefer that my identity remain confidential. ____ Yes ____ No

You would like a copy of the research summary? _____ Yes _____ No (If yes, please provide your contact information below)

E-mail address: _____

OR

Apt/House # and Street: _____

City: _____

Postal Code: _____

Appendix B2: Letter of Information and Consent Form for Focus Group Participants

Letter of Information

Title of the Study: Implementing hospice palliative care services using a shared care model

Investigators:

Student Investigator: Lily DeMiglio
School of Geography & Earth Sciences
McMaster University
905-525-9140 ext. 28617
demigllf@mcmaster.ca

Student Faculty Supervisor*:* Dr. Allison Williams
School of Geography & Earth Sciences
McMaster University
Hamilton, Ontario, Canada
905-525-9140 ext. 24334
awill@mcmaster.ca

Research Sponsor: Canadian Institutes of Health Research (CIHR)

Please read this information form carefully. If you have any questions, ask the investigator before signing the form. You have been asked to participate in a focus group.

Purpose of the Study:
The purpose of this study is to learn more about the process of developing and sustaining community hospice palliative care services using a shared care model. This will be accomplished by examining how shared care teams work in the context of the populations and geographies they serve. The ultimate goal of this study is to evaluate barriers and facilitators in using a shared care model to inform a framework to guide best practices.

Procedure:
If you volunteer to participate, you will be a member of a focus group that will be asked to discuss your shared care team. Focus group sessions will take place three times over the course of one year, spaced approximately four months apart. At the first and last focus group session, you will be asked to complete the "Interdisciplinary Team Process and Performance Scale (ITPPS)" which assesses interdisciplinary team performance. During the focus group sessions, you will be asked questions about how your team formed and how it continues to evolve over time. You will be asked to answer a few demographic questions at the end of the first focus group session such as: *What is your*

role on the team? How many years have you been working in hospice palliative care? You will also be asked to answer questions about your shared care team such as: *How does your team communicate? On average, what is your weekly or monthly caseload?* With your permission, focus group discussions will be audio-taped. The duration of the focus group will be about 60 to 90 minutes. Please note that if you are unable to attend the focus group session, you are invited to contact the student investigator to arrange a one-on-one interview.

Potential Risks:
The risks associated with participating in this study are minimal. Nonetheless, we want to remind you that you do not need to answer questions that make you feel uncomfortable or that you do not want to answer. There is a slight risk that you may feel a loss of privacy and/or reputation. For this reason, we ask that you make only those comments that you would be comfortable making in a public setting, and to refrain from comments that you would not say publicly.

Potential Benefits:
You might gain a better understanding of how your shared care team contributes to hospice palliative care in the local community as well as the barriers and facilitators experienced by your team. You may also benefit from knowing that your contribution to the study might benefit the scientific community gain a better understanding of shared care. Your involvement in this study might benefit society as research findings could be applied to providing best practices to enhance shared care teams in hospice palliative care as well as in other specialties.

Remuneration for Participation:
You will not be remunerated for your participation however you may request a copy of the research summary by indicating so on the consent form.

Confidentiality:
Anything that we find out about you that could identify you will not be published or told to anyone. You will not be referred to by your name but rather your role on the team. Your privacy will be respected. Any information that you provide during the study will be stored in a locked filing cabinet and on a password protected computer in the office of the student investigator and only she will have access to it.

Participation and Withdrawal:
Your participation in this study is voluntary. If you decide to participate, you are free to stop at any time, even after signing the consent form or part-way through the study. If you decide to stop participating, there will be no penalty to yourself. If you do not want to answer some of the questions you do not have to but you can still be in the study. You may exercise the option of removing your data from the study at any time.

Study Debriefing:
You may obtain information about the results of the study by indicating so on the consent form. The research findings will be sent via e-mail or post to the address you provide.

Rights of Research Participants:
You may withdraw your consent at any time during the study without consequence. If you have any questions or concerns about the research study, please feel free to contact Lily DeMiglio at 905-525-9140 ext. 28617.

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions regarding your rights as a research participant or about the way the study is conducted, you may contact:
McMaster Research Ethics Board Secretariat
Telephone: 905-525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

Consent Form

Signature of Participant:
I understand the information provided for the study "Implementing hospice palliative care services using a shared care model" being conducted by Lily DeMiglio under the supervision of Dr. Allison Williams at McMaster University. My questions have been answered to my satisfaction. I understand that I may withdraw from the study at any time, if I choose to do so, and I agree to participate in this study. I have been given a copy of this form.

_____
Name of Participant

_____ _____
Signature of Participant Date

I agree that the interview can be audio-recorded. _____ Yes _____ No
You would like a copy of the research summary? _____ Yes _____ No (If yes, please provide your contact information below)
E-mail address: _____
OR
Apt/House # and Street: _____
City: _____
Postal Code: _____

Appendix B3: Letter of Information and Consent Form for Stakeholders

Letter of Information

Title of the Study: Implementing hospice palliative care services using a shared care model

Investigators:

Student Investigator: Lily DeMiglio
School of Geography & Earth Sciences
McMaster University
905-525-9140 ext. 28617

Student Faculty Supervisor: Dr. Allison Williams
School of Geography & Earth Sciences
McMaster University
Hamilton, Ontario, Canada
905-525-9140 ext. 24334

Research Sponsor: Canadian Institutes of Health Research (CIHR)

Please read this information form carefully. If you have any questions, ask the investigator before signing the form. You have been asked to participate in an interview as a stakeholder.

Purpose of the Study:
The purpose of this study is to learn more about the process of developing and sustaining community hospice palliative care services using a shared care model. This will be accomplished by examining how shared care teams work in the context of the populations and geographies they serve. The ultimate goal of this study is to evaluate barriers and facilitators in using a shared care model to inform a framework to guide best practices.

Procedure:
If you volunteer to be part of the study, you will participate in a one-on-one interview during which you will be asked for your opinions on the advantages/disadvantages and facilitators/barriers to the shared care model and shared care teams in hospice palliative care. You will be asked questions such as: *What is your understanding of shared care? What are your thoughts on using a shared care model to provide hospice palliative care in the community? In hospice? In long-term care? In hospital? What are some of the barriers/facilitators to providing shared care?* You will also be asked to answer a few demographic-related questions such as: *What is your role in your organization? How many years of experience do you have working in your current position?* With your permission, the interview will be audio-taped and will take about 60 to 90 minutes

Potential Risks:
The risks associated with participating in this study are minimal. Nonetheless, we want to remind you that you do not need to answer questions that make you feel uncomfortable or that you do not want to answer. There is a slight risk that you may feel a loss of privacy and/or reputation. For this reason, we ask that you make only those comments that you would be comfortable making in a public setting, and to refrain from comments that you would not say publicly.

Potential Benefits:
Your participation will help the student researcher to gain a better understanding of the shared care model and shared care teams. Your involvement in this study might benefit society as research findings could be applied to providing best practices to enhance shared care teams in hospice palliative care as well as in other specialties.

Remuneration for Participation:
You will not be remunerated for your participation, however, you may request a copy of the research summary by indicating so on the consent form.

Confidentiality:
Anything that we find out about you that could identify you will not be published or told to anyone. You will not be referred to by your name but rather as a "Stakeholder". Your privacy will be respected. Any information that you provide during the study will be stored in a locked filing cabinet and on a password protected computer in the office of the student investigator and only she will have access to it.

Participation and Withdrawal:
Your participation in this study is voluntary. If you decide to participate, you are free to stop at any time, even after signing the consent form or part-way through the study. If you decide to stop participating, there will be no penalty to yourself. If you do not want to answer some of the questions you do not have to but you can still be in the study. You may exercise the option of removing your data from the study at any time.

Study Debriefing:
You may obtain information about the results of the study by indicating so on the consent form. The research findings will be sent via email or post to the address you provide.

Rights of Research Participants:
You may withdraw your consent at any time during the study without consequence. If you have any questions or concerns about the research study, please feel free to contact Lily DeMiglio at 905-525-9140 ext. 28617.

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have concerns or questions regarding your rights as a research participant or about the way the study is conducted, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: 905-525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

Consent Form

Signature of Participant:
I understand the information provided for the study "Implementing hospice palliative care services using a shared care model" being conducted by Lily DeMiglio under the supervision of Dr. Allison Williams at McMaster University. My questions have been answered to my satisfaction. I understand that I may withdraw from the study at any time, if I choose to do so, and I agree to participate in this study. I have been given a copy of this form.

_____
Name of Participant

_____ _____
Signature of Participant Date

I agree that the interview can be audio-recorded. _____ Yes _____ No

You would like a copy of the research summary? _____ Yes _____ No (If yes, please provide your contact information below)

E-mail address: _____
OR
Apt/House # and Street: _____
City: _____
Postal Code: _____

Appendix C: Methodological Rigour Breakdown

Table 1: Assessment of validity, reliability and objectivity

Criteria	Strategy	Practice(s) to satisfy criteria
Credibility	Purposeful sampling	- Purposive sampling strategy employed for participant recruitment (i.e., criterion sampling used for teams and key-informants; maximum variation sampling for stakeholders)
	Prolonged engagement	- Longitudinal case study (1-year); multiple visits/focus group interviews; field work involved attending service delivery meetings and community presentations/meetings (since April 2009)
	Disciplined subjectivity	- Reflexive journaling
	Triangulation	-One-on-one interviews and focus groups (multiple methods); multiple sources (e.g., documents, excerpts from several participants)
	Member checking	- Confirmation of information at follow-up focus groups; presentation of findings at conferences with palliative care community
	Peer debriefing	- Discussions related to data analysis/interpretation with supervisor
Transferability	Purposeful sampling	- Purposive sampling strategy employed for participant recruitment
	Thick description	- Study context description; detailed description and use of verbatim excerpts
Dependability	Recorded data	- Interviews digitally recorded; field notes & process notes manually recorded and reviewed to inform context and data analysis
	Multiple researchers	- Discussion of coding strategy and codes with supervisor
Confirmability	Audit trail	- Log book to track methodological changes; reflexive journaling

Note: Table 1 adapted from, Baxter, J., Eyles, J., 1997. Evaluating qualitative research in social geography: establishing 'rigour' in interview analysis. Transactions of the Institute of British Geographers 22 (4), 505-525.