EXAMINING PALLIATIVE CARE NETWORKS

EXAMINING PALLIATIVE CARE NETWORKS IN ENHANCING COMMUNITY PALLIATIVE CARE

by

DARYL BAINBRIDGE, B.A. (Hons.)
McMaster University, Hamilton, Ontario
Student Number: 0226856

A Thesis
Submitted to the School of Graduated Studies in Partial Fulfillment of the
Requirements for the Degree Doctor of Philosophy

Ph.D. Supervisor:
Dr. Kevin Brazil

Ph.D. Supervisory Committee:
Dr. Kevin Brazil
Dr. Paul Krueger
Dr. Jenny Ploeg
Dr. Alan Taniguchi

McMaster University
July 2011

McMaster University DOCTOR OF PHILOSOPHY (2011) Hamilton, Ontario
(Health Research Methodology)

TITLE: Examining Palliative Care Networks in Enhancing Community Palliative
Care AUTHOR: Daryl Bainbridge, B.A. (Hons.) (University of Guelph)
SUPERVISOR: Professor K. Brazil NUMBER OF PAGES: xii, 229

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ABSTRACT

Introduction

Despite increasing global interest in regional palliative care networks (PCN) to integrate care, little explicit direction exists to guide evaluation of these initiatives. The first step of this research was to develop a comprehensive conceptual framework using a systems approach for evaluating integrated palliative care. This framework was then used to guide a rigorous examination of a selected PCN.

Methods

The conceptual framework was derived from the empirical literature, incorporating principal features of network integration including inter-professional collaboration, community readiness, client-centred care, and other indicators of quality palliative care. A case study methodology was used to assess structure (administration) and process (provider) levels in the framework. In-depth data collection involved document review and an interview with the Network Director. Mail surveys were conducted with organizational administrators and health professionals who provide palliative care in the community catchment of the Network.

Results

Key features to efficient palliative care delivery, such as standards of practice, are currently lacking across this PCN area. Still, the 20 responding administrators (90% response rate) largely viewed Network accomplishments positively and the resulting partnerships as beneficial and collaborative.

Additional efforts were seen as required in ensuring the identification of patients requiring palliative care, reducing silos between community organizations, and greater by-in from regional authorities. Relative to processes, the 86 health care providers who responded (85% response rate) reported valuing collaboration and that many of the related indicators measured were present. However, insufficiencies were perceived in support for case conferencing and evaluative activities, as well as, informational access.

Conclusion

This study enabled us to test both the utility of the evaluative framework and the capacity of the selected PCN for providing quality palliative care. Process gaps found in the network may be reflective of workload constraints or an absence of key structural features. This study represents an important initial attempt at comprehensively examining network-integrated palliative care.

Medical Subject Heading Keywords: Palliative Care; Systems Integration; Community Networks; Evaluation, Health Service Networks, Integrated Care, Health Services Research

ACKNOWLEDGEMENTS

It is a pleasure to acknowledge my supervisor, Dr. Kevin Brazil, and my thesis committee members, Dr. Paul Krueger, Dr. Jenny Ploeg, and Dr. Alan Taniguchi. All provided gracious support and invaluable guidance along this journey.

Dr. Kevin Brazil deserves special thanks for his mentorship, enthusiasm, and insight, and for initially taking me on as a Master's student. My undergraduate supervisor, Dr. E. Kevin Kelloway, warrants note as well. It was the confidence he bestowed in me during completion of my undergrad thesis that initially lead me to embark on a research career.

I am grateful to Dr. Larry Librach and Dr. Denise Marshall for serving as my external examiners and for their thoughtful comments. I extend my gratitude to the Care to Know Centre who provided financial assistance to cover the costs of completing this research. Cancer Care Ontario provided a student travel grant which allowed me to present my work on palliative care at an international conference, for which I am most appreciative.

I also wish to thank the Hamilton Niagara Haldimand Brant (HNHB) Hospice Palliative Care Network, the HNHB Community Care Access Centre, and the administrators, agencies, and health care providers involved in end-of-life care in the HNHB LHIN area.

Pursuit of my doctorate would not have been possible with the backing of my employer, the Supportive Cancer Care Research Unit at the Juravinski Cancer Centre and its Director, Dr. Jonathan Sussman and lead investigator, Dr. Hsien Seow. Both whom have provided continuing support and mentorship in my part-time pursuit of a Ph.D.

Last and not least, I must thank my family. My wife, Clara, provided continuous encouragement and inspiration and daughter, Alexia a perpetual source of joy and laughter and a welcomed distraction to my studies from her birth. Finally, deserving mention is my son Dylan, whose impending arrival gave me the push I needed to see this writing through to fruition.

Again, my heartfelt thanks go out to all the individuals who assisted me in achieving this goal.

CONTRIBUTION

Under the direction of the supervisory committee, Daryl Bainbridge designed the studies, recruited respondents, completed the data collection and analyses, and wrote the papers for this thesis.

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CHAPTER 1

Introduction

The World Health Organization defines adult palliative care as:

> “...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual” (p. 14)[1].

Simply stated by the Canadian Hospice Palliative Care Association, “Palliative care services help people in later life who are ill to live out their remaining time in comfort and dignity.”[2]

The definition of palliative care has evolved over time with better understanding of the complex needs of those living with advanced illness and with growing acknowledgement of the importance of this health issue [1,2]. While at least 80% of care for those nearing the end of their life is provided by informal caregivers, including family, friends, and volunteers [3], the need for effective prevention and relief of symptoms is common, often requiring professional intervention [4,5].

Formal palliative care services can be provided in the home, hospitals, long-term care facilities, and hospices; ideally, within the context of ongoing assessment and management of the multiple facets of need identified in the WHO definition [6]. Changes in health care systems, which have resulted in a shift of care from inpatient settings to ambulatory and home settings [7] along with the finding that at least half of all persons who are palliative would prefer to die at home [8,9], further highlight the importance of the availability of these services in the community for those nearing the end of their lives. However, a considerable body of evidence shows the prevalent under-identification of those in the palliative stage of illness who have significant distress (including pain and psychosocial conditions). It has been estimated that 60 to 80% of this population remains untreated for these concerns [4,10].

Providing the necessary complement of professional services to palliative care patients and their families in the community is a challenge in the current health care environment. The aging population and the changing epidemiology of serious chronic disease, coupled with the mounting costs of institutionalization [8s], are straining health care systems [11,12]. Community-based health services, such as those for palliative care in the home, are often highly fragmented due to a combination of diverse professional groups, organizations, and approaches to care [13-15]. Specifically in Canada, sub-optimal care for those nearing the end of their life has been reported in federal publications [11,16,17] and an international study which ranked Canada ninth among OECD nations in quality of death [18].

Realizing dying peoples' needs for complex regimens of treatment and social support in a seamless, fiscally responsible manner, the difficulty of organizing these services in the community, and preventing unnecessary costly acute care utilization [19,20] are major drivers of the impetus for multi-level strategies to better coordinate palliative care. This has fuelled global interest in integrated service delivery, involving the implementation of collaborative, responsive, cost-effective systems of care at the local level [21-23].

Health Service Networks and Integration

While a universal definition of integration has yet to emerge, The Canadian Council on Health Services Accreditation (CCHSA) defines this term as “services, providers, and organizations from across the continuum working together so that services are complementary, coordinated, in a seamless unified system, with continuity for the client” [24]. This interpretation encompasses the essence of many definitions of integration found in the literature.

According to authoritative sources on integrated delivery systems of care, namely Provan [15] and Shortell [25], these systems are defined by networks of health care organizations and professionals who work together to coordinate services to meet their patients' needs. Conceptually, these networks are a way of linking fragmented services by increasing inter-organization interactions and ultimately maximizing system efficiency and seamlessness of patient transition [26,27]. The integration of activities between network agencies can include shared staff, joint policy development, joint training programs or workshops, and shared information.

Internationally, there has been a proliferation of health service networks over the last decade to create integrated systems of care among provider organizations [28-30], to advance the principles suggested by the CCHSA definition. The "network" form of integration is typically cooperative, suited to community health services that are less apt to be driven by hierarchical structures or market force [31]. The desired short-term outcome of heath service network formation is to stimulate inter-professional provider collaboration [21,29,31,32].

Palliative Care Networks

This dissertation focuses on regional PCNs as an exemplar of health program integration in the community. In many counties with universal health care such as Canada, Netherlands, Australia, and the UK, integrated systems of care have been mandated by formal policy initiatives in the form of regional palliative care networks [21,22,33,34]. PCNs aim to maximize system potential and enhance appropriate service delivery through the provision of a collaborative forum to facilitate inter-organizational communication, shared decision making, knowledge transfer, standardization of practice, and monitoring of need [35].

Ontario Context

In Ontario, a few PCNs evolved through informal arrangements between health care providers dedicated to serving the needs of those with advanced illness in the community. In 2005, following the division of the province into 14 health care planning regions or Local Health Integration Networks (LHINs) [36], the Ontario Ministry of Health and Long-Term Care formally established a PCN in each of the LHINs with the responsibility of broad system planning of community services for persons nearing the end of their life [33]. The determination of both the executive structure and capacity/relationship building activities remains at the discretion of each individual network, relying on the involvement of local stakeholders, i.e., those who coordinate or deliver palliative care services in the area.

As part of the government's End-of-Life Care Strategy, the aims of these networks are to: shift care from acute settings to appropriate alternate settings of care; enhance client-centered and interdisciplinary service capacity; and improve access, coordination, and consistency of service provision. These outcomes are anticipated through service integration at the system level, namely, encouraging the development of collaborative partnerships across providers and settings involved in palliative care delivery [35].

Need for research

Considering the promise that health service networks hold, the global rise in community-based health interventions [37-40], and the importance ascribed to interdisciplinary teamwork, there remains a relative lack of research literature on the empirical examination of integration in the context of these systems [24,41-46]. A preliminary search of the literature revealed that although network and collaborative palliative care team objectives have been delineated, there is little direction on how to operationalize these objectives or how such initiatives should be evaluated.

There is an abundance of literature on what palliative care staff should do in terms of guidelines, protocols, and standards, but little information on the actual processes of care and the relationships within teams or networks [4,47]. The majority of published work on this topic relies on conceptual approaches rather than on empirical data [4,44]. Furthermore, the research literature is lacking in examinations of interventions to improve collaboration between health care professionals, the influence of determinants on collaboration, or key factors to sustainability [41,42,44]. This lack of information complicates the task of identifying a specific model that lends itself to high quality, efficient, and appropriate palliative care [48].

OVERVIEW OF STUDY

The purpose of the dissertation was to describe and explain the nature of a community palliative care network using a theory-based approach. Particular attention was given to assessing inter-professional collaboration within this “system” of care provision as a means of determining the extent of integration. The network was considered in the context of the prevailing health care environment, using an evaluative framework developed specifically for examining palliative care networks. This framework took a systems approach with system structure, process of care, and patient outcomes levels of consideration. Conclusions and recommendations were qualified through an embedded case study approach [49].

Research Objectives

The **primary** objective of this research was to:

i) Describe the nature and extent of inter-professional collaboration and other features of sustainability within a selected palliative care network (PCN).

The **secondary** objectives of this research were to:

i) Describe the structural features of the palliative care network in the region of interest;

ii) Increase understanding of the barriers and facilitators to inter-professional community palliative care at the provider and system levels;

iii) Use study findings to further refine a conceptual framework for examining PCNs.

Assumptions proposed in this study are that: i) collaborative practice facilitates the provision of efficient and quality patient palliative care, and ii) collaboration between professionals should be promoted by the palliative care network.

Design

Study methods for the structure and process level inquiries are summarized in Table 1. The study design followed an embedded case study research approach, integrating quantitative and qualitative methods into a single research study [49,50]. The embedded case study design is an empirical form of inquiry appropriate for descriptive studies, where the goal is to describe the features, context, and process of a phenomenon; in this study, namely the delivery of palliative care within a region. This type of approach is particularly relevant to examination of a health care environment, such as in this study, where the boundaries between the phenomenon of interest (i.e.,

Table 1. ***Summary of the Methods of the Case Study***

System level	**Structure**			**Process**
Data source	Network Documents	Network Director	Advisory Committee Members	Health Care Providers
Format	Document review	Semi-structured interview	Self-completed mailed survey (77 questions)	Self-completed mailed survey (64 questions)
Sample Site	HNHB area (LHIN 4)	HNHB area (LHIN 4)	HNHB area (LHIN 4)	Selected urban area (Region of Hamilton Wentworth) and rural area (Region of Haldimand-Norfolk)
Sample	All	All	All	All "Palliative Care" Physicians 25% of other HCPs* (minimum of 4 of each HCP type from each agency)
Number	28	1	22	243
Questions	Theory-based (on conceptual framework)	Theory-based (on conceptual framework)	Partnership Self- Assessment Tool (PSAT) Select questions (9)	Index of Interdisciplinary Collaboration (IIC) Select questions (11) Demographics
Time required	NA	2 hours	20 minutes	30 minutes
Consent		Consent form completed	Implied (through completion)	Implied (through completion)
Documents required	NA	-Information sheet -Consent form -Interview schedule	-Letter of invitation -Information sheet -Postcard reminder (non-responders) -Follow-up letter (non-responders) -Advisory Committee Member Survey	-Letter of invitation -Information sheet -Postcard reminder (non-responders) -Follow-up letter (non-responders) -Health Care Provider Survey

*Sample derived from CCAC contracted agencies included nurses, therapists, and other allied health providers working in palliative care.

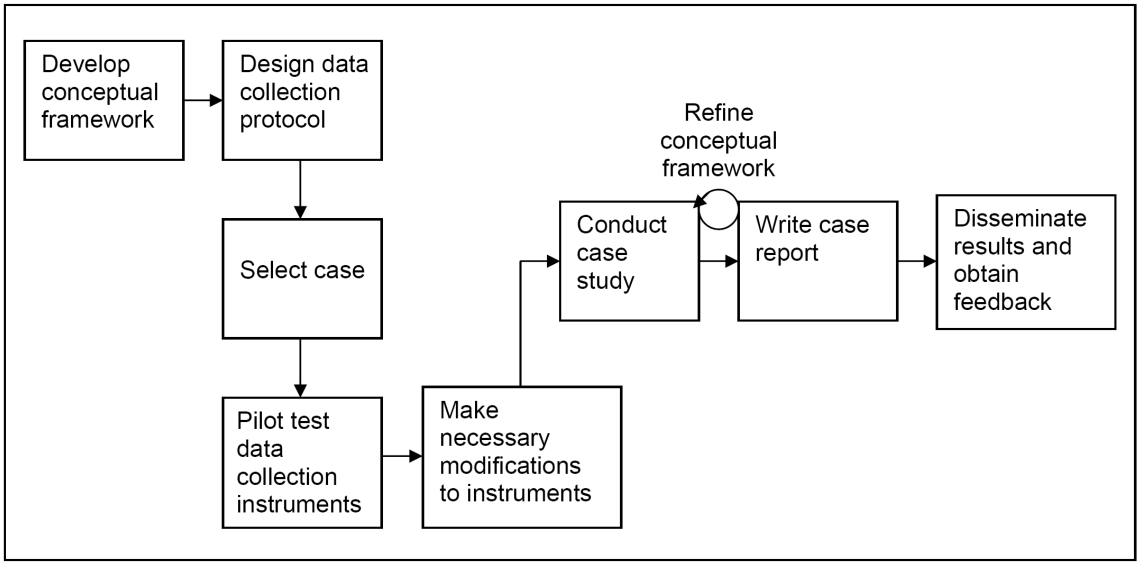
inter-professional collaboration) and context (i.e., health care delivery environment) are not clearly evident.

A case study research methodology relies on multiple sources of evidence to add breadth and depth to data collection, to assist in bringing a richness of data together in an apex of understanding through triangulation, contributing to the validity of the research findings [49]. The unique strength of this approach is this ability to combine a variety of information sources including documentation, interviews, and artifacts (e.g., technology or tools). Moreover, given that contextual conditions are taken into account, the practice issues identified through this design may also be applicable to other regional settings.

An *embedded* case study contains more than one sub-unit of analysis [49]. The identification of sub-units allows for a detailed level of inquiry. This thesis study was comprised of two sub-units, involving data collection components to examine *System Structure* and *Process of Care*. Figure 1 provides a schematic of the case study process. The unit of analysis or *case* in this study was the palliative care network.

Yin suggests the development of theoretical propositions to guide case study data collection and analysis [49]. These propositions direct attention to the features of interest, in this study being, determinants and indicators of inter-professional collaboration, client centered care, community readiness, and other features of system competency, as proposed in the conceptual framework.

Figure 1. ***Adaptation of Yin's Model for Case Study Research [49]***



Study Setting

Study site selection was purposive in choosing a region of *special interest*, [51]. The study community bounding the case and unit of analysis was the catchment area of the Hamilton, Niagara, Haldimand, Brant (HNHB) Hospice Palliative Care Network which covers the HNHB Local Health Integration Network (LHIN).

Study Population

In relation to each study component sub-unit, data were collected from:

System Structure

i) PCN Director (interview)

ii) PCN Document Review

iii) PCN Advisory Committee Members (survey)

Process of Care

i) Key informants representing a cross-section of health care providers (e.g., nurses, physicians, and allied health professionals) whose organizations of employment are members of the Network (survey)

As previously explained, the factors from the conceptual framework served as the propositions to measure the extent of collaboration and other domains of interest present in the network. A matrix based on the conceptual framework was created to map individual factors relative to one another, allowing theme formation and relationships to be drawn between the sub-units in the case. Barriers and enablers to collaboration were explained both through respondent perceptions and determinant features of the system.

LAYOUT OF DISSERTATION

This Ph.D. thesis is organized as a sandwich thesis consisting of an introductory chapter, four chapters written as manuscripts, and a concluding chapter. Together these chapters describe the process of the dissertation study from the conceptualization of the evaluative framework to its operationalization into a case study examination of a PCN. The introductory chapter provides an overview of key terms, the importance of organizing and evaluating palliative care, the study objectives, and the research design used. The final chapter summarizes all of the study findings, discusses the limitations and implications of this research, and provides suggestions for further study. I am the first author of the four manuscript (center) chapters. The submission or publication status of the manuscripts is provided below and at the start of each chapter.

Chapter 2

The first step was to develop a multi-level evaluative framework for examining PCNs using a systems approach, which is described and presented in Chapter 2. This framework outlines a conceptual map of the system structure, process of care, and patient outcome domains for organizing systems of community-based palliative care. Key constructs considered are inter-professional collaboration, client-centred care, community readiness, and contextual factors to capture the unique features of the system environment, incorporating many of the principles of health service integration. This comprehensive framework was developed based on previous models of health system evaluation, explicit theory, and the research literature on indicators of the constructs of interest. This chapter was published in BMC Palliative Care.

Chapter 3

This chapter presents the methods and findings which focus specifically on the structure level of the PCN case study. The purpose of this component of the overall examination was to describe the structural features of the PCN and determine the extent of inter-organizational collaboration from the perspectives of service coordinators and administrators, as well as to increase understanding of the barriers and facilitators to integrated community palliative care and to network sustainability in general. This chapter was published in the Journal of Palliative Care.

Chapter 4

This chapter presents the methods and findings which focus specifically on the process level of the PCN case study. The objective of this component of the overall examination was to determine the extent of inter-professional collaboration from the perspectives of health service providers, as well as to increase understanding of the process-related barriers and facilitators to integrated community palliative care at this level. This chapter was submitted to Health & Social Care in the Community.

Chapter 5

This chapter presents a combined synthesis of the three levels (sub-units) of the PCN case study: structure, process of care, and patient outcomes. A variable oriented analysis was undertaken based on the individual framework elements. The patient outcomes level study was not part of the thesis but was undertaken in a larger study that also incorporated the other two levels in the PCN case study. The findings of all three levels are brought together into a visual array that clearly displays the specific strengths and limitations of the evaluated network. This chapter was submitted to the Journal of Aging Research.

Chapter 6: Conclusions

This final chapter presents a reiteration of the accomplishments of this dissertation study. The findings for the descriptive, inferential, and variable-oriented analyses for the structure and process level inquiries are summarized. The strengths, limitations, and implications of this research are outlined. Finally, suggestions are provided as to the next steps to build upon this initial attempt at empirically and comprehensively examining network-integrated palliative care and integrated health systems in general.

CHAPTER 2

A proposed systems approach to the evaluation of integrated palliative care

Published in BMC Palliative Care, 2010:

Bainbridge, D., Brazil, K., Krueger, P., Ploeg, J., & Taniguchi, A. (2010). A proposed systems approach to the evaluation of integrated palliative care. *BMC Palliative Care, 9*(8).

ABSTRACT

Background: There is increasing global interest in regional palliative care networks (PCN) to integrate care, creating systems that are more cost-effective and responsive in multi-agency settings. Networks are particularly relevant where different professional skill sets are required to serve the broad spectrum of end-of-life needs. We propose a comprehensive framework for evaluating PCNs, focusing on the nature and extent of inter-professional collaboration, community readiness, and client-centred care.

Methods: In the absence of an overarching structure for examining PCNs, a framework was developed based on previous models of health system evaluation, explicit theory, and the research literature relevant to PCN functioning. This research evidence was used to substantiate the choice of model factors.

Results: The proposed framework takes a systems approach with system structure, process of care, and patient outcomes levels of consideration. Each factor represented makes an independent contribution to the description and assessment of the network.

Conclusions: Realizing palliative patients' needs for complex packages of treatment and social support, in a seamless, cost-effective manner, are major drivers of the impetus for network-integrated care. The framework proposed is a first step to guide evaluation to inform the development of appropriate strategies to further promote collaboration within the PCN and, ultimately, optimal palliative care that meets patients' needs and expectations.

INTRODUCTION

Palliative care, support to help those at end-of-life spend their remaining time in comfort and dignity, has evolved over time with better understanding of the complex needs of those living with advanced illness and with growing acknowledgement of the importance of this health issue [1,2]. Palliative care services can be provided in the home, hospitals, long-term care facilities, and hospices; ideally, within the context of ongoing assessment and management of the multiple physical, psychosocial, and spiritual facets of need [3]. While not all dying people require or desire the same types of professional palliative care services [4,5], requests for interventions to alleviate both symptom distress and family caregiver burden are common in the last year of life [6,7].

Providing the necessary complement of professional services to palliative care patients and their families in the community is a challenge in the current health care environment. The aging population and the changing epidemiology of serious chronic disease, coupled with the mounting costs of institutionalization [8] are straining health care systems [9,10]. Community-based health services, such as those for palliative care in the home, are often highly fragmented due to a combination of diverse professional groups, organizations, and approaches to care [11,12]. A considerable body of evidence shows the prevalent under-identification of those in the palliative stage of illness who have significant distress (including pain and psychosocial conditions). It has been estimated that 60 to 80% of this population remains untreated for these concerns [6,13].

Realizing dying peoples' needs for complex regimens of treatment and social support in a seamless, fiscally responsible manner, and the difficulty of organizing these services in the community are major drivers of the impetus for multi-level strategies to better coordinate palliative care. This has fuelled global interest in integrated service delivery, involving the implementation of collaborative, responsive, cost-effective systems of care at the local level [14-16]. In many counties such as Canada, Netherlands, Australia, and the UK, these integrated systems of care have been mandated by formal policy initiatives in the form of regional palliative care networks [5,14,15,17].

According to authoritative sources on integrated delivery systems of care, namely Provan [12] and Shortell [18], these systems are defined by networks of health care organizations and professionals who work together to coordinate services to meet their patients' needs. Conceptually, these networks are a way of linking fragmented services by increasing inter-organization interactions and ultimately maximizing system efficiency and seamlessness of patient transition [19,11]. The integration of activities between network agencies can include shared staff, joint policy development, joint training programs or workshops, and shared information.

Relative to palliative care, service networks often germinate from informal arrangements between health care providers dedicated to serving the end-of-life needs of those living in their communities. For the purposes of this paper, we define a *formalized* network as a more evolved, organized system of care, as should be evident in the advent of government mandated structuring. At a minimum, this would represent a membership-based group with multi-disciplinary representation from a variety of care settings. This network would be overseen by an executive board or steering committee, enacted to provide leadership and direction in the local provision of palliative care services. Optimally, these palliative care systems include members with decision making and resource allocating authority, and representation from the community, academia, and healthcare institutions, operating with policies and information systems that are shared among providers within the network.

Although community-based network and collaborative palliative care team objectives have been delineated in the literature, there remains little explicit direction on how to operationalize these goals or how such initiatives should be evaluated [6,20,21]. Formalized health care networks, even with key structures such as resources and policy in place, sometimes fail to achieve the goal of integration and ultimately, improvements in patient care. This is largely due to system barriers and poor interdependent functioning among members, left unexamined [22,23]. Superficial evaluations that rely on anecdotal or service use information may be adequate for informing network development in the early formative stages. However, once these networks become more formalized with top-down involvement, this growing complexity necessitates a more comprehensive evaluative approach to competently identify system gaps.

With the increasing prominence of integrated service models in palliative care, and the precarious nature of these arrangements, there is a need for a comprehensive conceptual framework to better understand the structure, process, and outcome functioning of these systems of care. While models of community disease management, such as Wagner's Chronic Care Model [24] have been proposed, these are offered more broadly as compendiums of principle components of a system of service, rather than as an evaluation framework. Furthermore, many of these disease care models have self-management and wellness orientations, not suited to a palliative care application. In the absence of an appropriate model to guide inquiry, the purpose of this paper is to offer, as a starting point, a multi-level evaluative framework for examining palliative care networks (PCNs) using a systems approach.

This paper begins with a presentation of our proposed framework and a general outline of the framework development process. This is followed by an introduction to the three-tier systems approach taken in this framework and an overview of the principal theoretical constructs included. Finally, the individual factors in the framework are described within each system level considered.

FRAMEWORK DEVELOPMENT

A conceptual framework explains the main things to be studied – the key factors, constructs, or variables – and the presumed relationships among them [25]. The framework we propose for examining palliative care system network functioning is presented in Figure 1. This framework focuses on describing the nature and extent of inter-professional collaboration, which is the central constituent of PCNs, but also takes into account features of the prevailing health care environment. This framework is based on existing models and principles of health system evaluation, explicit theory, consideration of the empirical literature on determinants and indicators of inter-professional collaboration, and previous evaluations of palliative care systems. Constructs related to network success and sustainability, such as community readiness and client-centred care, have also been integrated into the proposed framework.

This framework represents an amalgamation of empirically-supported criteria, with each element making an independent contribution to the description and assessment of the network. Examining each element in the framework is of diagnostic value in that it can specifically direct where intervention is required to improve the overall system. Key features of health system evaluation reflected in the conceptual framework include the use of theory-driven variables and a multi-tiered, systems approach. A theory-driven approach was employed to select potential predictor variables that were associated with the constructs of interest because atheoretical studies are prone to excluding potentially important factors [25,26]. In addition, the use of a theoretical framework to drive the research plan provides for a more systematic, valid, and empirically-sound method of study design, instrument development or selection, and analysis.

Figure 1*. Conceptual Framework for the Evaluation of Integrated Palliative Care Networks*

System Structure

Environment Factors
- Population Density
- Population Demographics
- Community Awareness/ Perceived Importance of Health Issue
- Profession/Specialty Base

Network Characteristics
- History/Evolution
- Network Structure
- Size of Membership
- Extent of Participation in Network among Members
- Policies and Procedures
- Power Equality
- Promotion of Network Ideals
- Vision/Culture

Economic Factors
- Network Resources
- Extent of Volunteerism
- Financial Incentives
- Capacity for 24/7 Care

Process of Care

Provider Characteristics
- Beliefs/Attitudes
- Interpersonal Style
- Job Satisfaction
- Specialty Training and Experience

Extent of Collaboration Among Providers
- Group Commitment
- Common Goals/Shared Values
- Perceived Interdependence
- Reciprocity
- Respect
- Shared Decision-Making and Problem Solving
- Shared Risk/Responsibility
- Trust

Information Transfer
- Communication
- Information Systems and Materials
- Standardized Assessment and Monitoring of Patient Need

Organization Factors
- Careteam Composition
- Educational Opportunities
- Incentives to Encourage Collaboration/Client-centred Care
- Leadership
- Role Recognition
- Standards of Practice
- Process Evaluation and Feedback

Patient Outcomes

Satisfaction with Domains of Care and Access
- Availability of Care
- Free Flow and Accessibility of Information
- Physical Care
- Pain and Symptom Management
- Psychosocial Care
- Management of Expected Death

Perceptions of Client-Centredness of Care
- Appropriate Involvement of Family and Friends
- Collaboration/Team Management
- Education and Shared Knowledge
- Rapport
- Respect for Patient Needs and Preferences
- Sensitivity to Nonmedical and Spiritual Dimensions of Care

Perceptions of Continuity of Care
- Relational
- Informational
- Managerial

A Systems Approach

The proposed framework is divided into *System Structure*, *Processes of Care*, and *Patient Outcome* (SPO) levels of consideration originally represented in Donabedian's S-P-O model [27]. This systems approach is frequently cited as a requirement of research on healthcare quality [28,29], and is particularly relevant to the examination of community partnerships [30]. In a health care context, 'Structure' is the availability of material and human resources, as well as, organizational characteristics and the physical, social, and economic environment present. 'Process' refers to activities and transactions that constitute health care, usually carried out by professional personnel (but also by non-professionals). Finally, 'Outcome' is the change in individuals attributable to the care they receive. These three tiers are inextricably linked in that system structure contributes to processes, which in turn influence patient outcomes.

Evaluative research in palliative care provision typically focuses on either patient outcomes or provider perceptions of the process. To understand the underlying mechanisms to PCN functioning and in order to be able to make informed recommendations, requires a systems approach where the antecedents to processes and, in turn, patient outcomes are delineated. While the process level attributes may best capture network operations, structure features also need to be considered to understand the environmental characteristics that serve to enable or impede PCN processes.

Framework Basis

The general influence of physical, social, and economic features of the health care delivery system on patient outcomes has been described in Aday's [31] health system evaluation framework and Tarlov and colleagues [32] structural characteristics of care. These generic models delineating factors underlying the three tiers of healthcare (i.e., structure, processes, and outcomes) form the basis of our conceptual framework. To orientate this framework in terms of palliative care, this outline was supplemented by the inclusion of system features from the Ferris and colleagues' [33] Square of Care and Organization model of quality palliative care provision. Developed through a consensus-building process across Canada, this model also takes a S-P-O approach, specifying attributes that should fall under each care level, from Resources and Functions (i.e., structure), to Process, to Common Patient Issues (i.e., outcomes) within the palliative care system. Upon this palliative care system base architecture, the principal constructs of relevance to network functioning are overlaid to create the proposed evaluative conceptual framework. These constructs are: member collaboration, community readiness, and client-centred care.

Principal Constructs in Framework

There are three key constructs interwoven throughout the framework that are integral to PCN functioning, namely collaborative care, community readiness, and client-centred care. Each of these constructs is described in detail below.

Collaborative Care

Inter-professional collaboration where physicians and other health care providers work in partnership to deliver comprehensive and profession appropriate care has gained the attention of policy makers nationally and internationally and has become a priority in most health care reforms [21,34-38]. The desired immediate outcome of PCN formation is the growth of inter-professional provider collaboration [14]. There can be no integration of health care without collaboration; accordingly, consideration of the features of this construct need to be at the core of an examination of these organized networks.

The advantages of a collaborative approach apply extensively to palliative care, where different professional skill sets are required to serve a broad spectrum of patients' needs [11,39]. Meta-analyses have confirmed the benefits of collaborative care, with palliative patients and their families reporting greater satisfaction with health services and better pain and symptom management, as well as improvement in the timeliness of services through expedition of the referral process [2,40-42]. Cost reduction has also been cited as an outcome of collaboration by reducing the amount of time patients spend in acute hospital settings.

Some ambiguity exists in the literature surrounding the term inter-professional health care [21,43]. The prefix ‘inter’ refers to a partnership where members from different professions work collaboratively towards a common purpose. These partners come together to share ideas, skills, and knowledge to structure a collective action towards the patient’s care needs [21,44]. In a multi-disciplinary team, the professional identity and ranking of individual team members usually supersedes team affiliation, whereas in the inter-disciplinary (i.e., inter-professional) team the identity of the team is primary.

Rather than a traditional hierarchy where a physician directs care, in a collaborative approach different team members may assume leadership depending on the patient’s needs [6]. Physicians, nurses, and other health care providers have complementary clinical and therapeutic skills, and different perspectives on problems the palliative patient might encounter. With these combined competencies, the inter-professional team is more responsive to the configuration of care delivery required, reducing the complexity of accessing health and social care for patients in need [3]. Synergy is often a defining feature of high functioning collaborative teams, with favourable outcomes possible from collective competences being greater that the sum of the team parts [45,46].

A theoretical model of collaboration should exhibit an understanding of the many elements of the construct and the components influencing the process, at multiple structural levels. Although the health care literature is replete with theoretical frameworks of collaboration, with 29 different models alone reported in a 1995 review [47], no single model lends itself to a comprehensive, practical application and none were designed specifically for palliative care. The majority of published work on the inter-professional collaboration construct relies on conceptual approaches rather than on empirical data [6,48]. This litany of untested frameworks cloud perceptions of exactly which interventions improve collaboration between health care professionals, the influence of determinants on collaboration, and key factors to sustainability [20,49,50]. Identification of the key components of collaboration requires comparison and contrast of the systematic review literature examining this construct, available largely from primary care and chronic care contexts.

Community Readiness

The Community Readiness Model is a theory-based approach to ascertaining the favourability of the social and political climate in a given setting to program implementation [51]. This model has been used in international contexts, often to indicate community receptivity to prevention or substance use initiatives [52]. However, community readiness can also be appropriately applied to the planning of community-based health interventions, to predict program sustainability and as a tool for program evaluation.

This model is related to the more commonly cited *organizational readiness* concept [53,54], however, community readiness goes beyond the scope of a single institution in considering multiple organizations, decision makers, and consumers. The manner in which health issues are defined and dealt with is often intertwined with community and cultural norms [51]. Attempting to alter established conventions of health care practice and structure can present a formidable barrier, just as the inertia of traditional care provider roles can impede efforts to increase system integration [55]. In considering community readiness for PCN initiatives, it is important to establish if adequate capacity and support in the general community and between providers and their organizations exists for promoting the network's ideals. System organization, provider education, and policy must all be appropriately aligned to maintain a supportive environment for health professionals practicing inter-disciplinary care.

In many respects, process level factors which imply the state of readiness and shared resolve towards collective action, such as the commitment, attitudes, and goals of both providers and their leaders towards PCN objectives, transcend into the other two principal constructs in the framework: collaborative care and client-centred care. Assessing elements of community readiness, both in system structure and care processes, are an important tenet of predicting the viability of a community palliative care initiative [56]. If a low stage of readiness is indicated, changes proposed by this program are likely to encounter resistance, illuminating the need to first attend to any model elements identified as underdeveloped.

Client-centred Care

Client-centred care refers to the provision of care that is respectful of and responsive to individual patient values, needs, and preferences [57]. This includes viewing patients holistically and allowing their unique perspectives to guide care decisions, enabling them to act as a central resource in their own health [58]. Even though the care provider may be the expert clinically, to deliver care that is client-centred requires building a relationship with the patient that facilitates the self-identification of personal goals, to ensure the giving of information and direct care that is appropriate, timely, and pertinent to the client's wishes [59].

Client-centred care has become a key principle of nursing practice in most developed countries and has also been adopted by other health professions [59-62]. This approach has been found to positively impact the satisfaction of both the patient and the provider in primary health care [63]. Likewise, care that is patient focused is vital to the success of patient education and support strategies intended to encourage successful emotional and practical adaptation to advanced chronic illness [58]. Client-centred care has definite applicability to palliative care in the community where support is provided based on the unique circumstances of patients to best sustain their quality of life.

CONCEPTUAL FRAMEWORK DOMAINS

The components of the framework as presented in Figure 1 are described in the sections that follow. Rationale and empirical support are given for the inclusion of each framework element. This description is organized by system level (S-P-O), with explanation provided for each domain (and sub-domain) within each level.

System Structure Domains

Environment Factors

Environment factors are the characteristics of the geographic area or region in which the network system of interest is located. These factors include *population demographics* such as age distribution, income levels, ethnic composition, and cancer mortality rates for the area (see Figure 1). Population density in terms of urban and rural distribution can also have implications for service delivery [56]. Creating a profile of the system environment provides context for comparison to other networks, as well as enabling generalizability of the results to other similar environments.

The capacity for change within the environment largely rests upon the readiness of those living in the planning region’s community, including policy makers and consumers. The level of *community awareness* of both the health care issue, e.g., palliative care needs, and the efforts being made to address this problem, as well as the attitude in the community towards the issue, are principal considerations in predicting the success of directed programs [56]. A lack of support in the population for a new initiative can undermine the confidence of providers involved in implementation. A network structure introduced despite community indifference or reservation, which can include opposition by influential organizations, is likely to fail [46,64]. Another prerequisite for a successful PCN is the presence of an adequate pool of nurses, physicians, and allied health care workers with some specialization in palliative care.

Network Characteristics

Characteristics of the PCN itself also provide context and indicate system level barriers and facilitators to the achievement of the network's goals and, effectively, optimal outcomes for palliative care patients. Factors to be considered are the PCN's *history*, *evolution*, *structure*, *formal/informal policies and procedures*, and *vision/culture* and whether these aspects promote continued growth of the network and a collaborative environment [33,43,45,48,53,56,65]. The number of health care providers, administrators, and other relevant disciplines in the region holding membership in the PCN (*size of membership*), the *extent of participation* of these members in network functions, and the *promotion of network ideals* internally and throughout the community, all speak to the influence, stability, and perceived value of the PCN. Cooperation between the relevant organizations in the system and their positive regard for the PCN ratifies the commitment of these organizations' employees at a process level.

Organizations that have traditionally had substantial control over healthcare resources and service planning may be unwilling to relinquish this power to accept co-dependence, limiting network cohesion [14].

Policies and procedures need to reflect clearly delineated obtainable objectives and goals [53,65]. These apply to network development, but also instilling essential features of holistic palliative care. Specifically, this includes policies for consistently offering patient-focused care, home death as a viable option, and expected death planning [66]. A final structural quality is the degree of *power equality* among network members. As previously mentioned, the authority given to each particular professional discipline within the network needs to be equitable to encourage member contribution and support collaborative patient care [48].

Economic Factors

Sufficient *resources* and infrastructure are required to make any health program sustainable and adaptive [43,53,56,67]. These assets include cash, financial investments, skilled professionals, equipment, office space, and technology [33]. The availability of designated facility-based programs, namely hospice spaces and palliative care unit beds in tertiary centres, is vital to meeting higher levels of need and providing respite for family caregivers. Liabilities that the PCN carries, such as loans or insurance payments, also need to be considered. The *extent of volunteerism* contributing to either care provider or administrative functions further increases the PCN's capital. *Financial incentives* are the provision of resources tied to the uptake of a specified approach and/or the meeting of set requirements. Incentives aligned with network development provide motivation and legitimacy to this endeavour and therefore need to be noted.

An essential component to palliative care access not found within the constructs considered, that has emerged from review of multiple models of palliative care provision reported in national research documents [68], and as a constituent of integrated care [69], is the system's capacity to offer care 24 hours per day,7 days per week (*24/7 care*) in each of the relevant professional disciplines. The availability of around-the-clock care is essential to adequately address community palliative care issues such as caregiver fatigue and end-of-life pain and symptom management [66]. Without the availability of 24/7 professional care, crises may arise which result in patient transfer from home to emergency/acute care facilities.

Process of Care Domains

Provider Characteristics

Although inter-professional collaboration and other contributing factors to quality palliative care may be encouraged under the auspices of network structures, these orientations are largely voluntary by nature. Uptake is influenced by the personal characteristics of service providers and administrators in the group [21]. Many of the elements of this domain are contained in Tarlov and colleagues [31] systems of health care model (see Figure 1 for framework). *Provider characteristics* and other process level factors also speak to readiness among the “community” of network members for integrated palliative care [56].

Beliefs and attitudes of PCN participants are ideally congruent with those of collaborative client-centred practice in members viewing this endeavour as worthwhile and being motivated towards this end [21,53,65,67,70,71]. *Interpersonal style* refers to professionalism among network members, which ultimately determines the degree to which professionals are able to work together [21,45,65,72,73]. Pertinent interpersonal factors include collegiality, the ability to articulate beliefs and communicate effectively, personal maturity, self-reflection, assertiveness in presenting one’s own professions’ perspectives with confidence, and willingness to cooperate rather than compete. *Job satisfaction*, bolstered by a favourable work environment, is a strong predictor of provider commitment to their role [45,48,70,71]. Another fundamental characteristic is s*pecialty training*, representing the professional education and skills of members. The amount of time spent as a palliative care provider and as a network participant are also important considerations [21,45].

Extent of Collaboration among Providers

Prior examination of inter-professional teams have shown that collaboration is a complex and dynamic process [21]. While there is a lack of a single definitive model of palliative care inter-professional collaboration to guide a comprehensive evaluation [74], there is some agreement in recent systematic reviews about the key factors within this construct that influence and/or indicate the state of collaborative practice [21,43,45,48,65,67,70,72,75].

Process level factors consistently mentioned in the literature as suggesting the extent of collaboration among providers, are *group commitment, common goals/shared values, perceived interdependence, reciprocity, respect, shared decision-making and problem solving, shared risk/responsibility,* and *trust*. These qualities are also consistent with the prerequisites for supporting client-centred care processes. In fact, some studies interrelate this latter construct with that of collaborative care, such that collaboration leads to desirable client-centred care outcomes [45,73].

Overall *group commitment* to collaboration and to quality care more broadly is one of the most important contributing factors to team functioning and network stability [21,45,48,56,70,71,75]. The *common goals and shared values* sub-domain necessitates members establishing a common language, similar realities and norms, and clear objectives, as well as a team task orientation. The latter implies a collective commitment to excellence in task performance in collaborative client-centred care with minimal conflict [21,45,47,65,67,71,72,75].

Perceived interdependence is apparent in team orientation and working relationships among community providers [45,47,56,65,71,72,75]. Having an interdisciplinary team base where team members can work in close physical proximity to one another contributes to interdependence potential. *Reciprocity* refers to the perceived benefits of network involvement for each member weighed against the negative consequences and that there are noticeable returns with increasing collaborative efforts [72,76]. *Mutual respect* implies an appreciation for different professional perspectives and that the contributions of each are valued [21,45,47,48,65,72,75,77]. *Shared decision-making and problem solving* is evidenced in solutions derived through an integration of the expertise of each professional [45,47,71,72]. Furthermore, decisions should be based on general consensus, so that all disciplines feel empowered.

Shared risk and responsibility pertains to the accountably for joint initiatives being fairly distributed, with members sharing in the liability for innovations involving risk [21,45,47,65,70,72,77]. Finally, a high level of *mutual trust* within the PCN is quintessential to members working effectively together [21,45,47,48,65,70,72,75,77]. This element infers confidence in others and trusting one's own abilities.

Information Transfer

Communication pervades all aspects of provider collaboration and patient-centered interactions. Activities that stimulate communication between professionals such as regular formal and informal interdisciplinary forums are crucial to collaboration between individuals and between their organizations, which in turn enhances the quality of palliative care [14]. The sharing of information that is relevant, accurate, transparent, concise, and timely is an essential element for reaching a common understanding across professional boundaries and for constructive negotiations within the network [21,45,47,48,65,71-73,75,77]. The ability and willingness of providers to engage clients in a dialogue unique to their needs and care options captures patient-centred communication from a process level.

Information systems and materials are mechanisms to facilitate the exchange of information. Systems include technologies such as pagers, smartphones, electronic health records systems, and multidisciplinary case videoconferencing [43,45,77]. Materials refer to written and visual aids to assist learning, decision making, and uptake of guidelines, network values, and activities. Standardized tools for documenting and transferring information such as an in-home patient chart, also foster effective communication.

Related to informational mechanisms are those for *standardized assessment and monitoring of patient need*. These mechanisms refer to useful clinical tools and assessment instruments and the adoption of these into broader organized approaches within the PCN. Such practices are essential in ensuring that palliative care needs in the community are uniformly identified and that available resources are accessed efficiently [33,68,78].

Organization Factors

Organizational factors identified as process determinants of collaborative client-centered care are *care team composition, educational opportunities, incentives to encourage collaboration/client-centred care, leadership, role recognition, standards of practice,* and *process evaluation and feedback*. *Care team composition* refers to the appropriateness of skill mix present in the PCN and having the right people involved both in terms of the expertise they bring to the group but also the influence they have in the community [21,56,65,71,75]. *Educational opportunities* consist of training and workshops, the provision of technical assistance, and venues providing professionals the opportunity to learn from one another [21,71,45,48,79]. *Incentives* to encourage collaborative client-centred care and quality care in general include recognition for innovation and excellence, team building exercises, and time protected for network specific responsibilities. The formalization of these inducements confirms the commitment of executive members to network development [21,71,75]. Research indicates that incentives to encourage collaborative practice are more effective when administered to the team as a whole rather than separately to individuals within the team [71].

Leadership is often cited as the single most important factor contributing to collaborative client-centered care. Leaders need to inspire and oversee the other positive process constituents of network functioning and help resolve conflicts that arise [21,46,48,65,71,75,76,79]. Weakness in this role can erode PCN cohesion. *Role recognition* speaks to role clarity in that the contribution of each member is understood, as well as their roles being valued [21,45,48,65,67,71]. *Standards of practice* are benchmarks by which team members can compare current and target values for indices of inter-professional working, client-centred care or other performance qualities [21,45,48,80]. Finally, *process evaluation and feedback* has also been indicated as an essential factor to sustaining network relationships [21,70,75,79,80]. Quality management systems for ongoing evaluation and modification of performance through the review of network activities, functions, and outputs are critical for improving efficiency and enhancing the patient experience.

Patient Outcome Domains

Satisfaction with Domains of Care and Access

The consideration of patient outcomes in the proposed framework does not delve into case complexity, such as functional dependence, which can vary greatly independently of intervention [81]. Rather, this level focuses on the reaction of the palliative care system to needs from patients' points of view. The impact of inter-professional collaboration would be assessed by patients' perceived quality of care and satisfaction with the care they received. A cluster analysis of aspects of palliative care satisfaction in the literature resulted in four dominant sub-domains emerging: *availability of care*, *information giving, physical care* (including *pain and symptom management)*, and *psychosocial care* [82].

These factors, along with *management of expected death*, have been identified as the core elements in describing palliative care processes from the care recipient's perspective [21,33,42,70] (see Figure 1).

Availability of care simply denotes the perception that services were accessible to those who needed them, when they needed them. The *free flow and accessibility of information* to the patient has also been identified as a central feature of client-centered care [79]. *Physical care* involves medical and practical aspects of care, but also *pain and symptom management* which in this framework has been designated as a separate sub-domain given its importance in palliative care [33]. *Psychosocial care* involves meeting the emotional, psychological, and existential needs of palliative care patients and their families, in helping to alleviate grief, fear, and other psychological and social problems. Finally, *management of expected death* refers to the initiative that providers take to assist family caregivers so that life closure preparations, death pronouncement, certification, and other necessary arrangements occur with little difficulty upon the passing of the palliative individual [33].

Perceptions of Client-Centredness of Care

A systematic review by Shaller [79] of nine frameworks for defining client-centered care resulted in the identification of the following core elements of this construct: *appropriate involvement of family and friends* in decision making and information giving; the sense of inter-provider *collaboration and team* *management*; *education and shared knowledge* in terms of timely and complete information on patient prognosis*,* progress, and disease process; *respect for patient needs and preferences* in care; and *sensitivity to nonmedical and spiritual dimensions of care*. The end-of-life patient and his/her family perceiving the presence of these factors in interactions with health care providers would imply that care is client centered. Furthermore, this would be particularly evident in patients feeling that care professionals had attempted to build a *rapport* with them, which in turn fostered qualities of interdependence, including trust [58,83].

Perceptions of Continuity of Care

An overview by Haggerty, Reid, and McKendry [84] identified the following three types of continuity of care: *relational continuity* (patient seeing usual practitioner); *informational continuity* (communication and knowledge where patient information flows easily between involved care providers); and *management continuity* (coordination of care so that transition between care providers is clear and seamless for the patient). Each of these facets of continuity is another positive outcome facilitated by collaborative relationships between providers, the end result of which should be apparent to patients and their family caregivers [43,45,70]. Accordingly, continuity of care is a phenomenon best measured from the perspective of the patient. Patients' perceiving that efforts had been made by providers to make the care process flow smoothly (*management continuity*) is also an attribute of care that is client-centred [85].

DISCUSSION

Evaluation and feedback plays a key role in developing organized systems of care [30,75,80]. Evaluation can determine the extent to which program objectives are met, inform policy and planning decisions, and increase community awareness and support for an initiative. Although critical, evaluation can be costly in terms of staff time and funding, and therefore is often deferred in favour of using these resources for providing care [30]. This may explain why the literature is lacking in care delivery research in palliative care [86]. With growing interest in better integrated services for those at end-of-life, there is a global need for whole system research in palliative care that captures the complexity of these initiatives. However, no evaluative framework exists for explicitly examining a network organized system of care in this context.

In this manuscript we have proposed an overarching structure for examining palliative care networks (PCNs) that can be applied to a system evaluation. Findings emerging from such an exercise would be of use to planners, administrators, and advocates of integrated palliative care systems, for the purposes previously mentioned. This paper represents an important initial effort to outline a conceptual map of the system structure, process of care, and patient outcome (S-P-O) domains for organizing systems of care for those in the palliative phase of life who are residing in the community. Research evidence was used to substantiate the choice of model factors. Our focus has been on inter-professional collaborative palliative practice, client-centred care, and community readiness constructs; taking into account contextual factors to capture the unique features of the system environment. Many of the elements derived from these constructs overlap, indicating their interdependence.

This model does not incorporate specific palliative care practices, as have been proposed by intervention guidelines such as the Liverpool Care Pathway [87]. Nor have we considered individual patient and family characteristics, which often play a decisive role in patient and caregiver outcomes [88], but yet likely reflect intrinsic attributes and dispositions that are less modifiable through formal support interventions [89]. Instead our framework is built around features of importance to PCN functioning, with provider and patient contexts. Many of the factors contained herein could also be suitably applied to the examination of integrated community systems for the management of other diseases.

In terms of application, the proposed framework assumes the employment of a mixed-methods research plan. This implies using multiple sources of data to consider the different perspectives and S-P-O levels within the PCN system. Mixed-method research is commonly advocated to provide for a broader range of questions, leading to a more complete understanding of the phenomena of study – in line with a systems approach [90,91]. Compared to single method studies, stronger evidence is possible through using mixed-methods in the convergence and corroboration of findings, with the results having greater generalizability. A case study methodology is one type of mixed-methods design that complements the proposed framework [92,93].

At the structure level, data would be obtained from PCN administrators and document review (e.g., meeting minutes, presentations, etc.). Data collection at the process level would need to include members of the PCN providing care, these being specialist nurses, primary care and palliative care physicians, pharmacists, therapists, and social workers [6,94-96]. As for patient outcomes, obtaining responses from palliative individuals can be challenging [81,97,98]. As such, it may be prudent to collect data from the primary family caregiver rather than the patient directly to gain insight into care outcomes in the community [99]. A factor matrix based on the questionnaire items developed from the conceptual framework should be created to ensure complete coverage of desired elements and to assist in analysis for mapping individual factors relative to one another. Visually depicting the data in an organized array is a useful step in progressing theme formation and in discerning relationships between the structure, provider, and patient levels of the system.

While comprehensiveness is a strength of this proposed conceptual framework, it can also be a limitation in the breadth being possibly too extensive for the practical evaluative needs of a PCN. In translating the framework into an evaluation research plan, attempting to consider all the dimensions and numerous factors at once can make operationalization a challenge, particularly if time and resources are limited. Evaluators, especially health care providers taking on this role in addition to their clinical responsibilities, should avoid making data collection too burdensome [80]. Whether it is a one-time snapshot of the network or the implementation of an ongoing surveillance mechanism, it may be advisable to start small to avoid the process becoming unmanageable and subsequently being abandoned entirely. Depending on the objectives of the inquiry, the size of the program, and the resident experience present, researchers may prioritize select elements to be included as sentinel indicators, to focus measurement efforts.

One approach to a more pragmatic examination is to limit the inquiry to issues at the patient level and then trace problems that emerge back to the processes of care to isolate and attend to contributing factors. Alternatively, a selection of factors at the process level could be assessed by using an existing validated tool that captures some of the domain(s) of interest. For example, the general state of inter-professional collaboration could be determined using an established instrument such as the Partnership Self-Assessment Tool (PSAT) [46], which is regarded as one of the better instruments to measure this construct [72] and includes a reporting module for interpreting and disseminating the results. Further testing of the proposed model may reveal a set of core indicators in network functioning and outcomes that lend themselves to the creation of a condensed version of the model, for guiding a basic evaluation of a PCN.

A network approach to service provision does not necessarily assure the best care for patients, particularly if health care funding streams continue to be competitive and encourage provider organizations to be territorial. A system driven by a single authority could potentially be more efficient and produce better outcomes than a cooperative arrangement, by dissolving organizational boundaries. Still, given the diversity of providers and organizations providing care to end-of-life patients and their families in many communities and the variable needs of this patient population, attempting to integrate existing programs seems a more feasible solution. The provision of palliative care that is client focused needs to be the grounding objective in service integration to help refocus some of the territoriality that arises as individual organizations try to protect their own interests [14].

Conclusions

It is important to remember that system integration, however advantageous, takes a long time to achieve [46,100], requiring resources and the participation of the full range of palliative care providers, from hospitals to independent practitioners. The conceptual framework proposed contains a multiplicity of key factors to palliative care system functioning. This is a first step to guide evaluation to inform the development of appropriate strategies to further promote collaboration within the PCN and, ultimately, optimal palliative care that meets patients' needs and expectations.

CHAPTER 3

Evaluating program integration and the rise in collaboration: A case study of a palliative care network

Accepted for publication in the Journal of Palliative Care, 2011:

Bainbridge, D., Brazil, K., D., Krueger, P., Ploeg, J., Taniguchi, A., Darnay, J. (2011). Evaluating program integration and the rise in collaboration: A case study of a palliative care network. *Journal of Palliative Care, 27*(4).

ABSTRACT

Background: There is increasing global interest in regional palliative care networks (PCN) to integrate care, creating systems that are more cost-effective and responsive. We examined a PCN that used a community development approach to build capacity for palliative care in each distinct community in the region, with the goal of achieving a competent integrated system.

Methods: Using a case study methodology we examined a PCN at the structure level through document review, surveys of 20 organizational administrators, and an interview with the Network Director.

Results: The PCN identified 14 distinct communities at different stages of development within the region. Despite some key features to efficient palliative care delivery lacking across these communities, administrators largely viewed the network partnership as beneficial and collaborative.

Conclusion: The study PCN has attempted to recognize specific needs in each local area. Change is gradual but participatory. Structural issues remain that may negatively affect PCN functioning.

INTRODUCTION

Providing the necessary complement of professional services to chronically or terminally ill patients and their families presents a formidable challenge to health care systems [1-6], particularly with the growing concern of cost containment. These community-based health services are often fragmented due to a combination of diverse professional groups, organizations, and approaches to care [4,7-12]. The increasing demand for these services and limited health care professional capacity further exacerbates gaps in care [6,13]. These system disparities increase the propensity for sub-optimal care, resulting in unnecessary suffering, delayed transfers to appropriate settings of care, and avoidable acute care expenditures [14-17].

The desire to optimize community health programs has fuelled global interest in integrated service delivery, involving the implementation of collaborative, responsive, cost-effective systems of care at the local level [4,18-21]. Accordingly, there has been movement towards health provision networks for the organized care of older persons [22,23]. Our study focuses on regional palliative care networks (PCNs) as an exemplar of health program integration in the community. In many counties such as Canada, Netherlands, Australia, and the UK, PCN development has been mandated by formal policy initiatives to create integrated systems of care [13,19,20,24].

In Ontario, Canada following the division of the province into 14 health care planning regions or Local Health Integration Networks (LHINs) in 2005 [25], the Ministry of Health and Long-Term Care formally established a PCN in each of the LHINs with the responsibility of broad system planning [13]. These PCNs are intended to encourage the development of collaborative partnerships across providers and settings involved in palliative care (PC) delivery, thus increasing service integration [26]. The setting of both the executive structure and capacity/relationship building activities remains at the discretion of each individual network, relying on the involvement of those who coordinate or deliver PC services in the area.

Although the importance of care integration, such as that purported by PCN structures, has been lauded both in Canada and internationally, the research literature is lacking in empirical examination of the impact of these systems [27-30]. Bainbridge and colleagues recently proposed a multi-level evaluative framework for examining PCNs using a systems approach [31], which incorporates many of the principles of health service integration [32].

We applied the structure, process, and patient domains of this model to the evaluation of one regional (LHIN-wide) PCN. This paper presents the methods and findings which focus specifically on the structure level of this examination. The purpose of this study was to describe the structural features of the PCN and determine the extent of inter-organizational collaboration from the perspectives of service coordinators and administrators, as well as to increase understanding of the barriers and facilitators to integrated community PC and to network sustainability in general.

METHODS

Design

A case study approach was used to integrate quantitative and qualitative methods into a single research plan. Data reported in this paper were collected from: a) review of materials related to the PCN selected, b) the PCN Director, and b) members of the PCN Advisory Committee. This study received approval by the Hamilton Health Sciences/McMaster University research ethics review board, Hamilton, ON, Canada, prior to enrolling participants.

Setting

The study *community* bounding the case was the Hamilton, Niagara, Haldimand, Brant (HNHB) Local Health Integration Network (LHIN). Located in Southern Ontario this LHIN covers an area of 7,000 km^2 and contains a population of 1,353,000 people, 15% which are 65 years of age or older [33]. This area has 20 hospitals (including 3 hospital systems), 5 residential hospices, and 88 long-term care facilities.

The HNHB Hospice Palliative Care Network for this LHIN area was the unit of analysis. This network was selected because it is one of the more developed PCNs in the province, having been partially established prior to the provincial LHINs, and it represents a wide diversity of urban and rural communities.

Procedure and Participants

Document Review: Materials that mentioned the structure of PC in the study LHIN area were reviewed and summarized (DB). These materials were identified through Network staff/members, hand searches of the bibliographies of key documents, internet searches, and members of the research team. A template of questions derived from the conceptual framework was used to guide the data extraction process. The purpose of this review was to provide information about the structure, policies, and functions of the PCN, and to corroborate the data obtained from the Network Director and Advisory Committee.

PCN Director: An in-depth semi-structured interview (DB) was conducted with the Network Director. This two-hour interview was digitally audiotaped and transcribed verbatim by a professional transcriptionist**.**

Network Advisory Committee: All 26 HNHB Network Advisory Committee members were mailed a survey, with the exception of 4 members who were either part of the research team [2], new to the group [1], or surveyed for a different part of the larger study [1]. The Committee is represented by organization administrators, nursing/physician leaders, and researchers from institutional and community settings. The Dillman Tailored Design Method [34] which included five potential contacts with eligible respondents, was used to maximize survey response rates.

Study Instruments

Validated survey instruments were selected that captured most of the elements in the conceptual framework from each of PCN executive and administrator (Advisory Committee) perspectives (see Figure 1). A factor matrix based on the questionnaire items corresponding to the framework was created to ensure complete coverage of desired elements and to assist in analysis for mapping individual factors relative to one another.

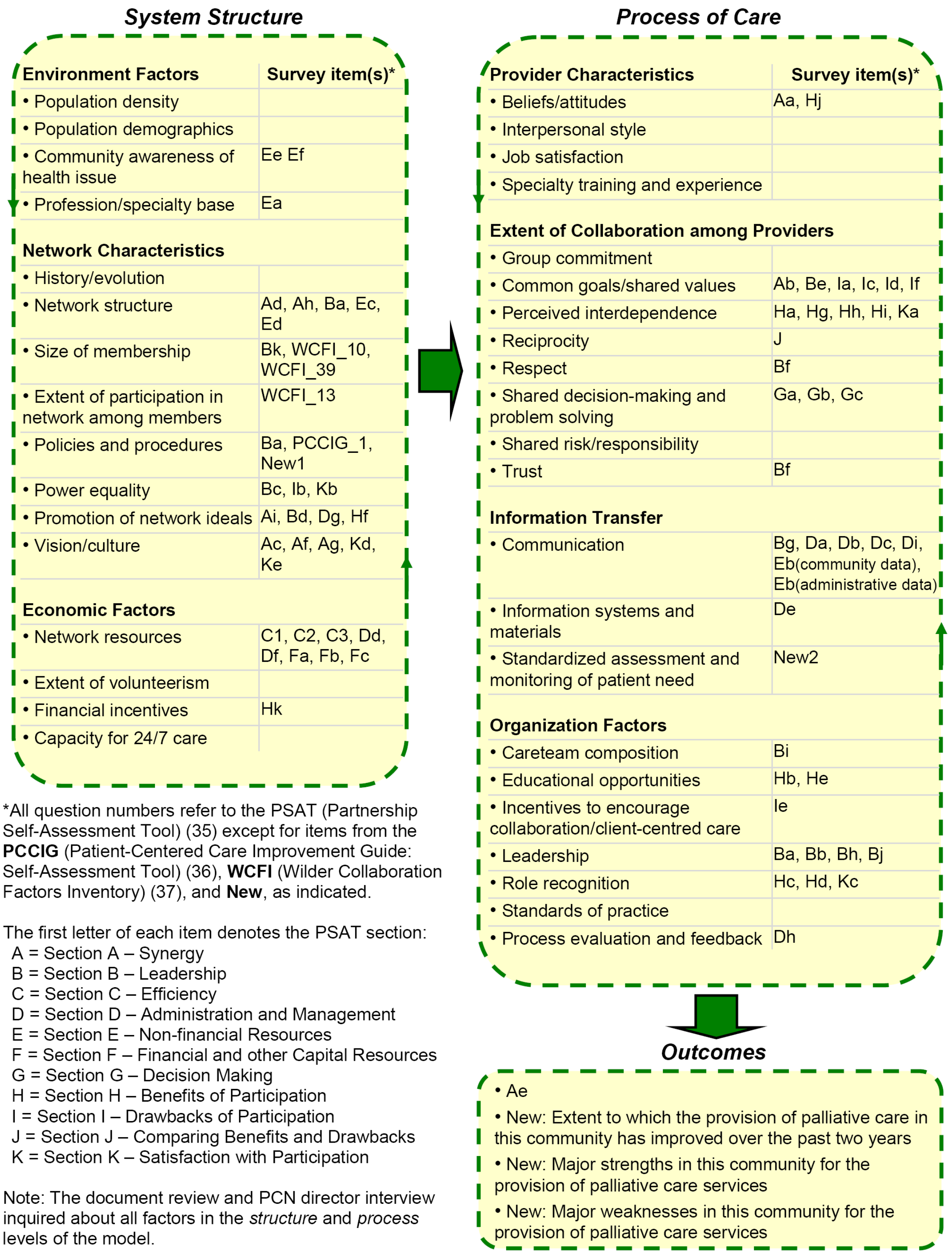
Network Director Interview Schedule

This schedule was based on the domains within the Structure (and to some extent process) level of the conceptual framework. The flow of the questions was intended to go from network specific to more general system/community questions (and from factual to more perceptual items for each).

Network Advisory Committee Survey

The Partnership Self-Assessment Tool (PSAT) [35], which is regarded as one of the more psychometrically sound instruments to measure interprofessional health partnerships [36], was included in the Advisory Committee survey. The PSAT instrument contains 67 items, 17 using a dichotomous (yes/no) scale and 50 employing a 5-point Likert scale (see Table 1 for PSAT sub-domains and

Figure 1. *Mapping of Network Advisory Committee Survey Items onto the Conceptual Framework for the Evaluation of Integrated Palliative Care*



System Structure

Environment Factors	**Survey item(s)***
• Population density	
• Population demographics	
• Community awareness of health issue	Ee Ef
• Profession/specialty base	Ea
Network Characteristics	
• History/evolution	
• Network structure	Ad, Ah, Ba, Ec, Ed
• Size of membership	Bk, WCFI_10, WCFI_39
• Extent of participation in network among members	WCFI_13
• Policies and procedures	Ba, PCCIG_1, New1
• Power equality	Bc, Ib, Kb
• Promotion of network ideals	Ai, Bd, Dg, Hf
• Vision/culture	Ac, Af, Ag, Kd, Ke
Economic Factors	
• Network resources	C1, C2, C3, Dd, Df, Fa, Fb, Fc
• Extent of volunteerism	
• Financial incentives	Hk
• Capacity for 24/7 care	

Process of Care

Provider Characteristics	**Survey item(s)***
• Beliefs/attitudes	Aa, Hj
• Interpersonal style	
• Job satisfaction	
• Specialty training and experience	
Extent of Collaboration among Providers	
• Group commitment	
• Common goals/shared values	Ab, Be, Ia, Ic, Id, If
• Perceived interdependence	Ha, Hg, Hh, Hi, Ka
• Reciprocity	J
• Respect	Bf
• Shared decision-making and problem solving	Ga, Gb, Gc
• Shared risk/responsibility	
• Trust	Bf
Information Transfer	
• Communication	Bg, Da, Db, Dc, Di, Eb(community data), Eb(administrative data)
• Information systems and materials	De
• Standardized assessment and monitoring of patient need	New2
Organization Factors	
• Careteam composition	Bi
• Educational opportunities	Hb, He
• Incentives to encourage collaboration/client-centred care	Ie
• Leadership	Ba, Bb, Bh, Bj
• Role recognition	Hc, Hd, Kc
• Standards of practice	
• Process evaluation and feedback	Dh

Outcomes

- Ae
- New: Extent to which the provision of palliative care in this community has improved over the past two years
- New: Major strengths in this community for the provision of palliative care services
- New: Major weaknesses in this community for the provision of palliative care services

*All question numbers refer to the PSAT (Partnership Self-Assessment Tool) (35) except for items from the **PCCIG** (Patient-Centered Care Improvement Guide: Self-Assessment Tool) (36), **WCFI** (Wilder Collaboration Factors Inventory) (37), and **New**, as indicated.

The first letter of each item denotes the PSAT section:
A = Section A – Synergy
B = Section B – Leadership
C = Section C – Efficiency
D = Section D – Administration and Management
E = Section E – Non-financial Resources
F = Section F – Financial and other Capital Resources
G = Section G – Decision Making
H = Section H – Benefits of Participation
I = Section I – Drawbacks of Participation
J = Section J – Comparing Benefits and Drawbacks
K = Section K – Satisfaction with Participation

Note: The document review and PCN director interview inquired about all factors in the *structure* and *process* levels of the model.

Figure 2. ***New Questions and Questions from Other Instruments Used in the Network Advisory Committee Survey***

New Questions*

New1 item: Network members and organizations are able to meet palliative care patients' wishes for place of death

New2 item: Network members and organizations are able to indentify most patients in the community requiring palliative care and assessing their needs

Questions from Other Instruments (36-37)

WCFI_10 (Wilder Collaboration Factors Inventory): All the organizations/agencies key to palliative care in this area are represented in the Network's membership

WCFI_13: Members of the Network invest the right amount of time in collaborative efforts

WCFI_39: The Network has adequate "people power" to enable it to meet its objectives

PCCIG_1 (Patient-Centered Care Improvement Guide: Self -Assessment Tool): The Network is effective in formally and consistently communicating a commitment to patient-centered care with patients, families, staff, leadership, and medical staff (e.g. mission, core values)

*The other three New Questions used are provided in the "Outcomes" box in Figure 1

response options). The PSAT was rigorously tested for face and content validity during development and has exhibited criterion validity and reliability in subsequent studies (α = 0.82 to 0.97) [37]. The PSAT is composed of 10 sub-domains: Synergy; Leadership; Efficiency; Decision making inclusivity; Management effectiveness; Nonfinancial resources; Financial resources; Satisfaction; Benefits; and Drawbacks.

Select items from other collaboration scales were also included in the survey that reflected key Structure level factors in the conceptual framework not addressed in the PSAT (see Figures 1 and 2 for items). The questions were minimally modified to make the "Network" the reference point. The survey contained three open-ended questions asking respondents to describe the strengths and weaknesses of the PCN, as well as indicate key organizations with insufficient representation in the Network.

Data Analysis

Response data from the survey forms were entered into and analyzed using SPSS (version 18.0, SPSS Inc., Chicago, 2009). Data collected from the PSAT were analyzed according to the instrument guidelines [35,38,39]. Scores were calculated for specified sub-domains within the instrument. The additional questions were analyzed individually. Reporting and comparison of quantitative item scores were descriptive (i.e., means, standard deviations, frequencies). Qualitative data were reviewed for emergent themes and coded using the constant comparative method [40]. Themes from the analysis of the Director interview were reviewed and validated by this informant for accuracy [41]. Barriers and enablers to Network functioning, collaborative efforts, and the provision of quality PC within the LHIN area were explained both through respondent perceptions and determinant features of the system.

FINDINGS

Network Documentation

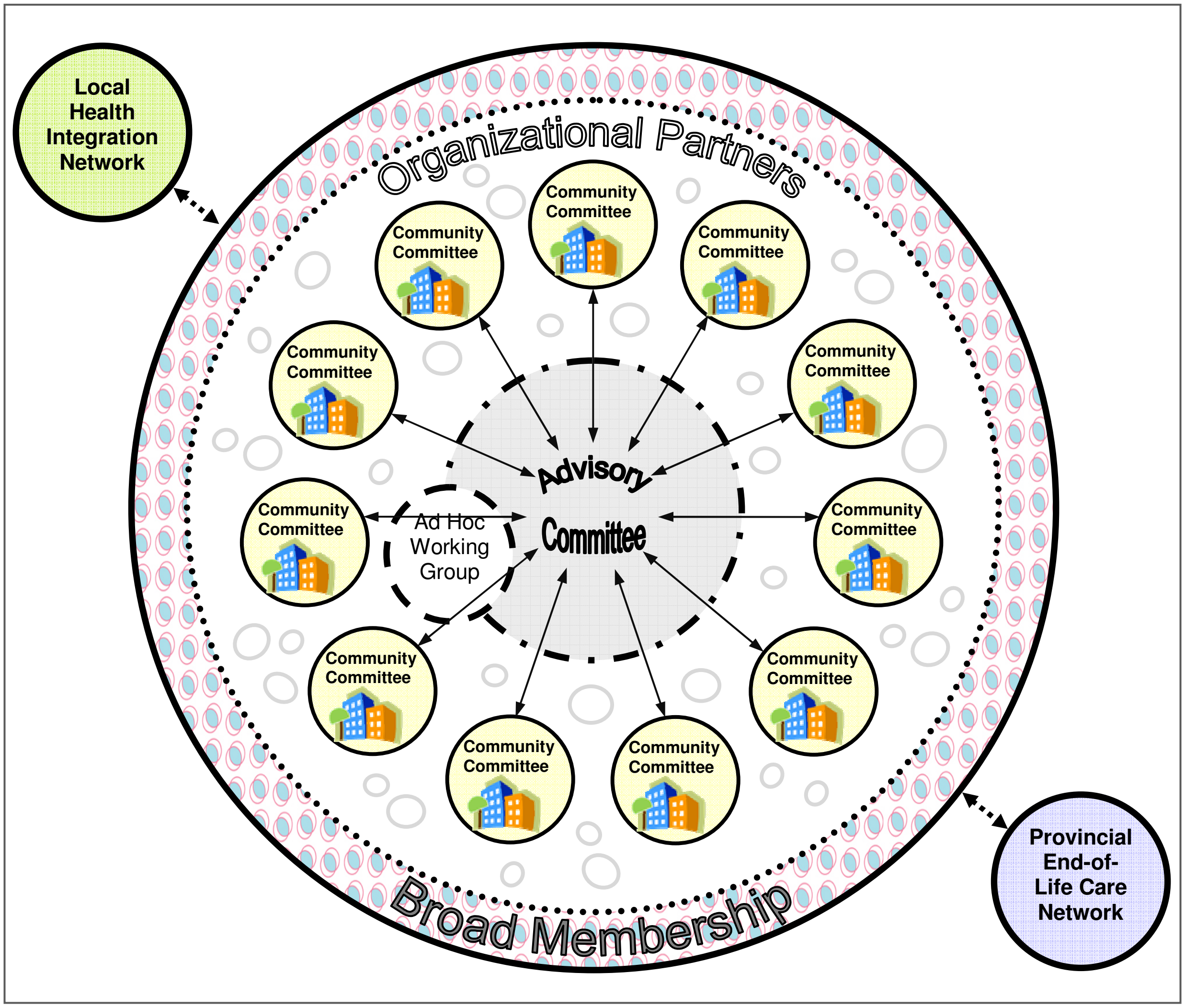
A total of 28 pieces of information dating from 2002 to July 2010 were reviewed including website content [5 pages], copies of presentations (e.g., PowerPoint slides) [7], newsletters [5], and reports [11].

Description and Organizational Structure of the HNHB PCN

Reports from the former District Health Council stated that the HNHB area, particularly Hamilton, has a history of commitment to the provision of institutional and community-based PC [42,43]. This included a regional PC program in Hamilton that existed for a period starting in 1984. The Hamilton Hospice Palliative Care Network (HHPCN) was launched in June 2003. In 2005, planning networks followed in each of the regions of Haldimand, Norfolk, Brant, and Niagara. In May 2007, the LHIN-wide HNHB PCN was established, amalgamating the previous regional networks. Since this time, PCNs across the province have been provided with $70,000 annual base funding for "leadership and development", typically to support one paid staff project coordinator/director per network. Additional funding has also been available from the province-wide PC implementation strategy envelopes (i.e., support for interdisciplinary education, hospice volunteer visiting, and pain and symptom management) originally instated in 1993 [13,44]. In-kind contributions are also provided by member organizations (hospice, nursing agencies, etc.).

A diagram of the organizational structure of the HNHB PCN is shown in Figure 3. The Network represents approximately 100 organizations that provide some aspect of palliative/end-of-life care in the LHIN area [45,46]. The PCN is governed by an Advisory Committee with several working local community committees. Broad consultation with the Network Organizational Partners occurs on a regular basis for all system planning activities.

Figure 3. ***Organizational Structure of the HNHB Hospice Palliative Care Network***



Advisory Committee (≈ 26 members): oversees the activities of the PCN by coordinating and developing system-wide strategies to respond to key issues and priorities. Comprised of elected representation from all system sectors, including both sector champions and knowledge experts.

Organizational Partners (currently 33 members and growing): a top level representative from each palliative care relevant organization (e.g., hospitals, residential hospices, LTC, CCAC, home care agencies, physicians, academic) that has signed a voluntary partnership agreement with the network. Each partner organization has an allocation of one vote on all major PCN system-wide decisions. Involved in system-wide consultation and system-wide decision making.

Figure 3 cont.

Community Committees (currently 11 groups with 6 to 20 members each): based in each of the main LHIN communities, provides input and feedback regarding the PCN and local issues, as well as managing local implementation of PCN policies, planning frameworks, and recommendations. Open membership.

Broad Membership (over 1000 individual members): represents palliative care interests across the LHIN, participating in all aspects and levels of the PCN activities as appropriate. Consists of a balance of decision makers, providers, and administrators from relevant organizations/disciplines.

Ad Hoc Working Groups: assigned on occasion by the Advisory Committee to work on projects and fulfill the mandate of the PCN.

Note: A council model was originally considered consisting of a high level executive representative from each sector (e.g., acute care, long-term care, cancer care). However, this plan was found to be flawed in the inability to identify select individuals who could represent the interests of all community partners in the LHIN area. Instead, the closed council model was modified to allow open **Organizational Partners** with the network from across the continuum of care within the LHIN area.

The HNHB PCN has undertaken two phases of PC system development. *Phase I* occurred from 2006 to 2008, with the priority on implementation of an integrated service model, to be achieved through the creation of shared-care interdisciplinary teams [47,48]. *Phase II* system development occurred from 2008 to 2010, with the intent of conducting a needs assessment across the LHIN area to identify current capacity to provide PC, identify unmet needs, and propose LHIN-wide recommendations/potential solutions based on the findings [49].

Director Interview

The themes that emerged from the Director interview related to the community approach taken by the PCN to build upon the unique capacities of the distinct areas throughout the LHIN area, the development of shared-care teams, and the inherent features of the system that serve to assist or impede service integration and the provision of quality PC.

Building Community Capacity

The communities within the LHIN area were initially represented in the PCN as three local planning committees. It was recognized that divergence in perspectives and priorities concerning the development of PC services existed across the large areas covered by each of these committees. In fact, a capacity mapping exercise to identify natural community boundaries revealed 14 distinct communities at different stages of PC development in the area. The PCN used a Community Readiness model [50] approach to assess the local structure of PC delivery in each community to compare and contrast local care organization.

The Community Readiness model proposes that there are four transitional phases to achieving optimal PC, beginning with the presence of antecedent conditions, followed by a local catalyst (e.g., local champion), then creating the interdisciplinary team of providers, and finally, growing the program [50]. A gap analysis between existing “palliative care” capacity in each community and the PCN vision for the LHIN area established each community’s position within the "readiness" continuum. As opposed to taking a global approach, each community is encouraged to develop an action plan based on their own unique needs, to gradually bring their local services up to the LHIN area standard, largely guided by the principles outlined in the *Model to Guide Hospice Palliative Care* report [51]. Engaging communities, some at an early stage, to change in ways that meet their own identified objectives was seen as a more sustaining method of building local PC capacity than imposing top-down structures. At present, 11 of 14 communities in the LHIN area have developed local PCN committees, some at a highly organized phase.

> "I think they see palliative care as an important issue. However, many communities are not in a state of readiness to change since they are not aware of newer ways of doing things… …Often times they're so overwhelmed by just trying to get done what they need to get done today, it's too overwhelming for them to even consider." [Director]

To date, a number of positive implementations have resulted from this community development approach. It was reported that these successes have in turn provided learned lessons to other communities in the PCN, as well as to those in other LHIN areas, helping them with their own efforts to mobilize.

"For instance, in [named] area they really had an issue with the availability of pharmaceutical drugs 24/7. So they ensured that a pharmacist was part of the community planning committee. And then he went out and engaged all pharmacists within that geography to say okay who would be willing to be on board for 24/7 on-call. Many pharmacists came forward and voluntarily agreed. A group of clinicians then provided those pharmacies with a list of pharmaceuticals that they needed to keep in stock. And within a month they had that issue resolved. So it's a lot of community capacity building. It's engaging the continuum of care from physicians and community nurses to the volunteers. Many used to say that if they weren't paid to come to these meetings they wouldn't come. Now they see the value and potential benefits to both them and the community and they are so excited to be there." [Director]

Shared-care teams

A common goal for all the community committees is to implement a local shared-care team. Due to limited resources, however, this has been formally achieved by only five communities in the LHIN area. The typical configuration of a shared-care team includes a palliative care physician expert, an advanced practice nurse, a psycho-spiritual counsellor, a bereavement counsellor, and administrative support, all working in conjunction with case manager home care coordinators and primary care physicians in the community. Within the other LHIN areas, community planning committees have attempted to engage existing physicians, nurses, and service providers to create virtual shared-care teams by working collaboratively. However, the long-term sustainability of these “teams” remains in question due to the lack of additional resource infrastructure.

Structural Assets

A number of system structures and features indicated in the interview contribute to the provision of accessible, responsive, and efficient PC. These include the extent of organizational commitment, educational opportunities, the use of volunteers, and PCN promotion /communication. The PCN has made efforts to ensure power equity in that all sectors (e.g., academia, tertiary care) and geographic areas are represented within the Network. Organizations that have partnered with the Network sign a voluntary partnership agreement outlining the responsibilities of the organization and the PCN in the development of the PC system plans, to help ensure both commitment and alignment with the PCN’s vision. Each partner organization has an allocation of one vote on all major PCN system-wide decisions. To date, a vast majority of hospitals, residential hospices, and home service provider agencies in the LHIN area have signed the agreement.

PC education for care providers of various disciplines has been formalized with a number of different courses being offered throughout the LHIN area by the Network. Minimum PC education credentials for providers are being built into the request-for-proposal (RFP) process as a requirement in the contracting of all palliative home care, building in the expectation of these staff having PC expertise. The availability of interdisciplinary educational opportunities has helped to increase the complement of providers with specialty training in PC throughout the LHIN area, particularly nurses, physicians, PSWs, and volunteers. Volunteers are an asset widely utilized throughout the PC system, particularly in supporting the residential hospices.

Public awareness activities to promote the PCN and PC in general include an annual meeting for the PCN membership held in conjunction with a Palliative Care Innovation Day, hosted in partnership with the local university. The website of the PCN is a common communication vehicle where PC education opportunities, events, conferences, and job vacancies are posted. In addition, it was reported that weekly email updates are sent from the PCN to its entire membership.

Structural Barriers

Although the communities continue to work on improving their local PC provision, significant inconsistencies in service accessibly exist across the LHIN area. Vital system competencies such as the possibility of home death or 24/7 pain and symptom management are only likely in communities with a shared-care team. One of the obstacles to creating additional teams is the limited number of physician posts available to be covered by an Alternative Funding Plan (AFP) fee arrangement, around which the rest of the team is based.

Many of the objectives of the *Phase I* and *Phase II* development plans have yet to be fully realized in all areas across the PCN catchment. Key features to effective PC delivery such as common assessment tools, standards of practice, central inventories of resources, shared information systems, acute PC designated beds, and common access points to care exist in some communities in the LHIN area but not others.

Additionally, the manner in which individuals are identified as requiring PC varies by community. Accessing appropriate support services can be a challenge in some areas, especially for those with non-cancer illnesses, while in others the public can self-refer. Case finding pilot projects are currently underway in the LHIN area to improve patient identification. On the other hand, there is recognition that better patient identification might increase the volume of referrals beyond the present capacity of the PC system.

Finally, the lack of dedicated and protected funding from the provincial government for existing PC services and allocation of new resources are viewed as risks to the capacity building progress made by the PCN. Historically, there has been little consistency, and to some extent equity, in the funding of these community-based programs, which relied heavily on local mobilization and funding obtained through various granting opportunities. While current resources sustain the PCN annual workplan and the growth of the PC program, this situation could change if the provincial government or LHINs shift funding priorities to other areas.

Network Advisory Committee Survey

Data were collected from 20 Network Advisory Committee members for a response rate of 90.1%. In general, these respondents rated the PSAT factors and individual item components examined favourably (see Tables 1 and 2).

Table 1. ***Summary of PCN Advisory Committee Member PSAT Factor Scores***

Factor (# items)	N	Scale	Mean (SD)
Synergy (9 items)	20	1="Not well at all" to 5="Extremely well"	3.3 (0.59)
Leadership(11 items)	20	1="Poor" to 5="Excellent"	3.6 (0.84)
Efficiency (3 items)	16	1="Poor" to 5= "Excellent"	3.8 (0.70)
Decision making (inclusivity) (3 items)	20	1="None of the time" to 5="All of the time"	4.0 (0.58)
Management effectiveness (9 items)	19	1="Poor" to 5= "Excellent"	3.9 (0.79)
Nonfinancial resources (7 items)	19	1="None" to 5="All that are needed"	3.6 (0.53)
Financial resources (3 items)	16	1="None" to 5="All that are needed"	3.2 (0.78)
Satisfaction (5 items)	19	1="Not at all” to 5= "Completely"	3.3 (0.83)

There are PSAT guidelines for interpreting sub-domain scores. The meanings assigned to mean average scores are: 1.0–2.9=Danger Zone (a lot of improvement needed), 3.0–3.9=Work Zone (more effort is needed), 4.0–4.5=Headway Zone (partnership doing well), 4.6–5.0=Target Zone (partnership currently excelling). Responses for the PSAT domains *Decision Making (Inclusivity)* and *Management Effectiveness* were in or near the Headway Zone, whereas the scores for *Synergy*, *Financial Resources*, and *Satisfaction* were at the lower end of the Work Zone.

Table 2. ***Summary of PCN Advisory Committee Member Scores for Supplementary Questions***

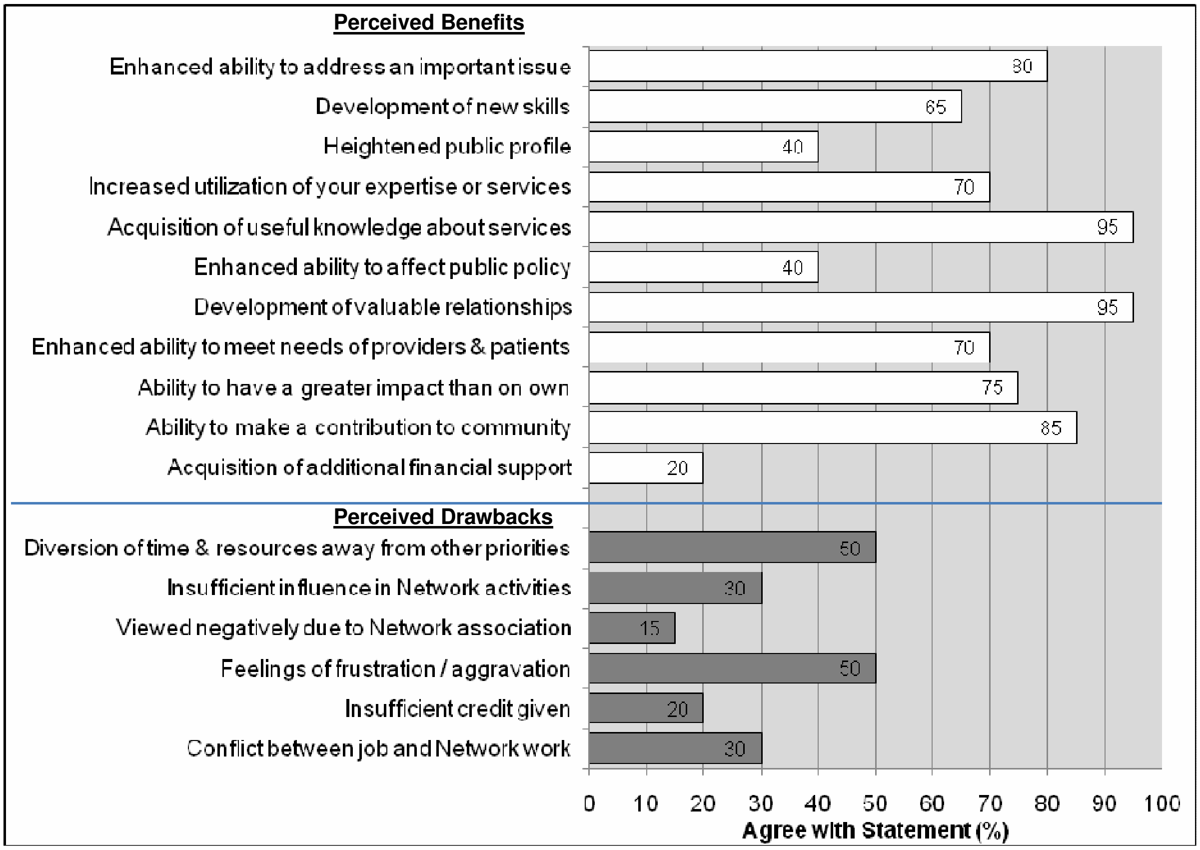
Individual items: PCN able to…	**N**	**Scale**	**Mean (SD)**
Identify most patients in the community requiring palliative care	14	1="Not well at all" to 5="Extremely well"	3.0 (0.68)
Meet palliative care patients' wishes for place of death	13	1="Not well at all" to 5="Extremely well"	3.3 (1.11)
Formally and consistently communicate a commitment to patient-centered care with patients, families, and staff	19	1="Poor" to 5="Excellent"	4.0 (0.94)
Ensure adequate "people power" to enable the Network to meet its objectives	18	1="None" to 5="All that are needed"	3.4 (0.98)
Ensure members invest the right amount of time in collaborative efforts	18	1="None" to 5="All that are needed"	3.4 (0.70)

Applying these rules for interpretation to the supplementary questions, the Network's ability to *Communicate a Commitment to Patient-Centered Care with Patients, Families, and Staff* was seen as in the Headway Zone, while *Identifying Patients in the Community Requiring Palliative Care* was viewed in the lower end of the Work Zone. The remaining supplementary items fell midway in the Work Zone suggesting greater effort is required in these areas.

We examined the scores of individual items in each PSAT domain to determine if any particular aspect fared worse than others. An item in *Synergy* that was rated relatively lower was the Network's "ability to communicate its importance to the public", with 35% of respondents indicating "not so well". Within *Leadership*, items perceived to be more problematic were the PCN's ability to "foster respect, trust, inclusiveness, and openness", "resolve conflict among members", and "combine the perspectives, resources, and skills of members", each answered as only "fair" by 30% of respondents. *Nonfinancial Resources* that were apparently lacking were "community data and information (e.g., information about community perceptions, population morbidity, and relevant politics) and "connections to political decision-makers and government agencies", with 75% and 65% responding respectively that only "some" of what is required is available. Financial resources were clearly an issue, with 30% responding that the Network had "none" or "almost none" and another 25% replying that they had "some".

Questions within the *Benefits* and *Drawbacks* domains of the PSAT are meant to be examined individually (see Figure 4). Between 70% and 95% of respondents agreed that they had received most of the benefits listed, as a result of their membership in the PCN. Fewer (40%) felt that their membership contributed to a "heightened public profile" or to their "ability to affect public policy", whereas only 20% indicated that they had benefited in "acquisition of financial support". Inversely, on the *Drawbacks* factors, half of the respondents reported that their participation in the Network had caused them “feelings of frustration or aggravation” at times and the same proportion felt that their involvement sometimes resulted in their “time and resources being diverted from other priorities”. Fewer respondents complained about some of the other potential drawbacks such as having “insufficient influence”, “being viewed negatively”, receiving “insufficient credit”, or “job conflict”, in their association with the PCN. Overall, 58% stated that the benefits of participation in the PCN exceeded the drawbacks, while 26% reported the two as equal.

Figure 4. ***Advisory Committee Respondent’s Agreement with Perceived Benefits and Drawbacks of their Participation in Network (N=20)***



In response to the open-ended qualitative items on the survey, about a third of the Advisory Committee members indicated that not all key organizations were adequately represented in the Network, whereas 40% were uncertain. Major strengths reported were the leadership, commitment, and skills of PCN members. Major weaknesses were the limitation and inequality of resources, working in silos/turf wars, and a lack of higher-level LHIN support.

DISCUSSION

Integration in the form of provider organization partnerships is critical to sustaining systems of quality health care [18]. Despite generating a high degree of interest among researchers, little empirical work has been done to measure health system integration [52]. In terms of implementation, there is no single best template for organizing community health services that suits all configurations of local contextual factors or existing system structures. Specific to PC, fundamental principles have been suggested in the empirical literature [31,53] that need to be instituted in a manner tailored to the current local and regional environment. These principles also provide indicators for evaluating the progress made towards more collaborative and competent configurations of quality PC. In promoting these guidelines and interdisciplinary synergy, PCNs are intended to provide a supportive structure and collaborative forum for maximizing system potential and creating new opportunities through broadening lines of communication, knowledge transfer, pooling of resources, and collective problem solving.

The PCN that we studied has taken a community development approach to recognize specific needs and level of readiness in each unique area in its catchment. Change is gradual but participatory – engaging rather than coercing communities towards building their PC programs. Many key features to effective PC delivery such as common assessment tools, standards of practice, central inventories of resources, information systems, or common access points to care have been collectively identified in the Network system plans as they attempt to ensure that these features are available and accessible across the entire LHIN area. The presence of shared-care teams is believed to greatly increase system competency, such as access to 24/7 care and home death planning, however, only about a third of the communities in the LHIN have the benefit of one of these formalized interdisciplinary arrangements.

Regardless of these structural gaps, Advisory Committee members' perceptions were generally favourable for the factors measured, suggesting from this perspective that the PCN promotes a collaborative PC environment to some extent. Committee members largely viewed the accomplishments of the PCN positively and most felt that their membership held more benefits than drawbacks, although many indicated an inability to elicit additional financial support or affect public policy and occasional feelings of frustration, in relation to the Network. Additional efforts were seen as required in ensuring the identification of patients requiring PC, reducing silos between community organizations, and greater political support from regional (LHIN) authorities. The lack of protected funding was also viewed as a risk to progress made to improve local PC, if regional or provincial priorities were to change.

One of the few other published studies on integrated PC was of a three-year pilot project to develop a PCN in the Netherlands [23]. These researchers found that PCN organizations continued to work cooperatively after the initial project finished, with the exception of the local hospital which withdrew from the partnership. This divergence of tertiary care was explained as a resignation to traditional roles and a lack of strong network leadership, perhaps stemming from the cut in PCN funding.

Study Strengths and Limitations

The unique strength of the case study approach we used is its ability to combine a variety of information sources such as interviews, surveys, and documents. Compared to single method studies, stronger evidence is possible through using mixed-methods in the convergence and corroboration of findings. We were able to capture most of the structure (and process) dimensions in our survey and interview instruments. Given that contextual conditions are taken into account, the issues identified through this design are likely applicable to other similar practice settings.

A detailed examination of each community was beyond the scope of this study. Although the Advisory Committee members' responses likely reflect broad perspectives across the LHIN area, we still captured some of the potential diversity in the PCN, particularly through the Network Director interview. The sample sizes for the survey and interview were small, however these responses will be considered along with our findings at the provider and patient levels in the overall case study. We did not obtain the perceptions of the members of the 11 community committees as most of these groups were too recently formed to comment sufficiently on the PCN. Otherwise, being able to corroborate these perspectives with the data that were collected would have would have helped to offset biases respondents may have had due to their network affiliation.

Implications for Policy and Future Research

System level support is essential for facilitating provider level integration [54]. System issues that emerged in our study concerned financial and political uncertainty that could undermine network functioning and the capacity building activities undertaken to improve PC delivery. Maintaining and continuing progress made through community organization/provider partnerships ultimately rests with the local and provincial authorities who determine the direction and flow of resources.

Finally, this study represents part of a comprehensive evaluation of a PCN that provides a benchmark to measure future evolution of this network and of the

PC system. To our knowledge, this is also the first attempt at operationalizing the structure level domains of the conceptual framework for evaluating PC integration and functioning. Additional analyses of regional PC systems in varying stages of progress are required to further test the framework.

CHAPTER 4

Evaluating program integration and the rise in collaboration: A theory-based examination of collaborative processes within a palliative care network

Submitted to BMJ Supportive & Palliative Care, 2011:

Bainbridge, D., Brazil, K., D., Krueger, P., Ploeg, J., Taniguchi, A., Darnay, J. (s*ubmitted*). Evaluating program integration and the rise in collaboration: A theory-based examination of collaborative processes within a palliative care network. *BMJ Supportive & Palliative Care*.

ABSTRACT

Introduction: Several countries have implemented palliative care networks (PCN) to better integrate care for those living with a life limiting illness. The objective of this study was to examine process-level factors within a selected PCN from the perspective of health care providers (HCP).

Methods: As a component of a PCN case study, we conducted a mail survey with a representative sample of nurses, physicians, and allied health professionals who provide palliative care in the community catchment of the network. The Index of Interdisciplinary Collaboration (IIC) was used, in addition to other survey questions, selected based on a theoretical framework for network evaluation.

Results: The 86 HCPs who responded (85% response rate) placed high value on working collaboratively and most reported being part of an interdisciplinary team. Many of the indicators of collaboration and quality care measured were perceived as present; however there was variability between respondent agencies on some factors. Support for case conferencing and evaluative activities were viewed as insufficient. Most HCPs reported that the benefits of working collaboratively with others exceeded the drawbacks. The presence of formalized expert palliative care teams in the community was a prominently reported strength, but the fact that access to these teams is limited to certain geographic areas was seen as a system weakness.

Conclusion: Framework elements evaluated identified organizational features needing further attention towards increasing collaboration and improving the provision of palliative care. Process gaps found in the PCN may be reflective of workload constraints, differences in agency operations, or an absence of key structural features. Implications for further research are discussed.

INTRODUCTION

Health systems around the world are having to adapt to the progressive aging of the population [1,2] and a greater realization of the medical and supportive care issues facing those in their later years [1,3-6]. In the past decade there has been a dramatic growth in services for those living with an advanced illness to keep pace with the needs of this population [7-9]. Perpetual increases in health care spending to match the rising costs of these services are not sustainable, and may be unnecessary with changes to the way care is delivered.

Providing higher quality health care can decrease the overall costs of these services through reduced reliance on expensive tertiary centre interventions [6,10-12]. Care that is well organized across provider settings, particularly those which are community-based, has the potential of offering better access, assessment, and resolution of health concerns for the respective population. It is this recognized need for quality, comprehensive, and cost-effective medical and social support in which lies the impetus for increasing health care integration.

Integration, Networks, and Collaboration

While a universal definition of integration has yet to emerge, The Canadian Council on Health Services Accreditation (CCHSA) defines this term as “services, providers, and organizations from across the continuum working together so that services are complementary, coordinated, in a seamless unified system, with continuity for the client" [13]. This interpretation encompasses the essence of many definitions of integration found in the literature.

Internationally, there has been a proliferation of health service networks over the last decade to create integrated systems of care among provider organizations [14-16], to advance the principles suggested by the CCHSA definition. The "network" form of integration is typically cooperative, suited to community health services that are less apt to be driven by hierarchical structures or market force [17]. The desired short-term outcome of heath service network formation is to stimulate inter-professional provider collaboration [15,17-19].

Interdisciplinary collaboration where nurses, physicians, and other formal providers work conjointly to deliver comprehensive and profession appropriate care is fundamental to service integration at the process level [20]. Collaborative practice is required to help ensure quality care in an efficient manner in managing the treatment and supportive needs of the whole person [21], particularly for those with multiple, complex symptoms who reside in the community [22,23]. Accordingly, the defining characteristics of collaborative partnerships need to be at the core of an examination of health care integration [24].

Palliative Care Network Development

Our study focuses on regional palliative care networks (PCNs) as an exemplar of health program integration in the community. These networks have been formalized under government mandate in many of the OECD countries with universal health care [19,25-27]. PCNs aim to maximize system potential and enhance appropriate service delivery through the provision of a collaborative forum to facilitate inter-organizational communication, shared decision making, knowledge transfer, standardization of practice, and monitoring of need [28].

In Ontario, Canada, PCNs were formally established across the province in 2005, with one designated for each of the 14 newly created health care planning regions (Local Health Integration Networks [LHINs]) [25,29]. These PCNs were granted the responsibility of broad system planning of community services for persons nearing the end of their life [25].

Considering the promise that health service networks hold, the global rise in community-based health interventions [30-33], and the importance ascribed to interdisciplinary teamwork, there remains a relative lack of research literature on the examination of integration in the context of these systems [13,34-39]. An empirically based conceptual framework for evaluating integrated systems of quality community-based palliative care was proposed by Bainbridge and colleagues (2010) using a systems approach. We applied the structure, process of care, and patient domains of this model to a case study of one regional PCN. This paper presents the methods and findings which focus specifically on the process level of this research. The objective of this study was to determine the extent of inter-professional collaboration from the perspectives of health service providers, as well as to increase understanding of the process-related barriers and facilitators to integrated community palliative care.

METHODS

Design

A case study methodology [40-42] was used for the multi-level examination of the PCN, of which the data from the cross-sectional surveys presented in this article formed the process-level component. This study received approval by the Hamilton Health Sciences/McMaster University research ethics review board, Hamilton, ON, Canada, prior to enrolling participants.

Setting

The Hamilton, Niagara, Haldimand, Brant (HNHB) Hospice Palliative Care Network which covers the HNHB Local Health Integration Network (LHIN) area was the unit of analysis. Located in Southern Ontario, this LHIN spans an area of 7,000 km^2 and contains a population of 1,353,000 people, with one of the higher proportions of elderly persons in the province [43]. Part of the originating form of this network dates back to 2003. The organizational structure and evolution of the HNHB PCN is discussed in our structural analysis of this network [24].

Procedure and Participants

For this process-level examination, data were collected from health care providers (HCP) representing family physicians, nurses, pharmacists, therapists (physio, occupational, and speech), social workers, registered dieticians, and personal support workers, who provide palliative care in the community. Because of the expanse of the HNHB LHIN area, HCPs were sampled from two selected regions within the LHIN boundary, one region representing an urban population (Hamilton-Wentworth Region) and the other representing a rural population (Haldimand-Norfolk Region). Over half of the population in the LHIN area resides within these two regions [43].

Family physicians with palliative care expertise were identified through: a) training lists held by the Division of Palliative Care at McMaster University in Hamilton, b) the Ontario Medical Association as having been granted Palliative Care Facilitated Access (PCFA) to pharmaceuticals, and c) the research team. Eight health care agencies were identified that are contracted to provide all publically funded in-home services to palliative care patients in the study communities. The total number of “palliative care” nurses and allied health care professionals was determined through consultation with the directors and managers of these agencies. A total of 282 HCPs including 16 physicians were identified as providing care to end-of-life clients in the two study regions.

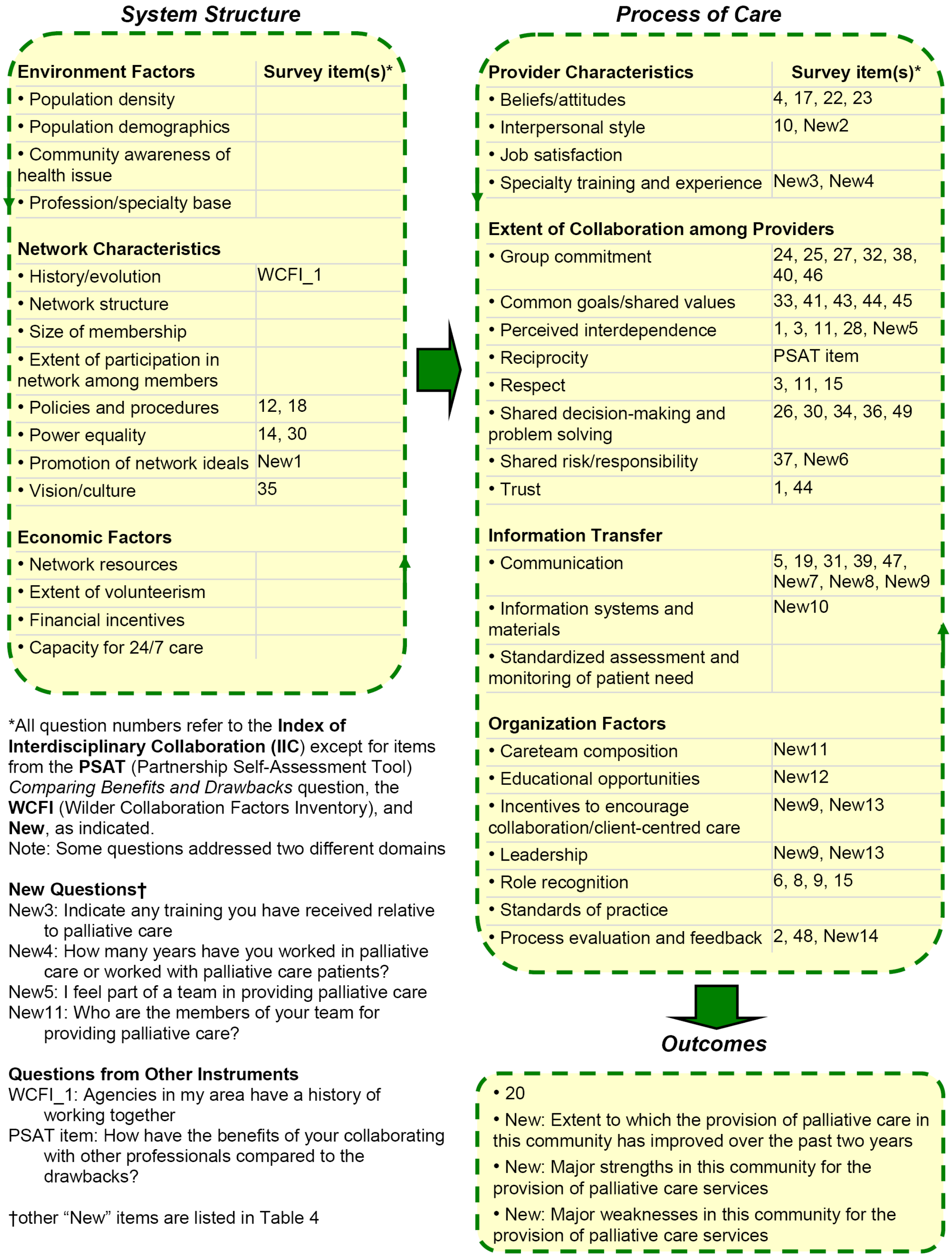
All “palliative care” physicians identified were included in the study sample, due to their small number. A proportional sample of each of the other health professions represented was selected based on the established sampling frame. This was done to ensure some minimal representation from each agency, profession (e.g., nurse, therapist, social worker), and study region (urban/rural). The guideline for selection for each professional type was a minimum of 4 participants or 25% of that agency’s professional complement working in palliative care in the given region, whatever was greater. If the number of relevant HCPs indentified from a given agency was greater than the number required for the study, a purposive sample [44] was taken to select those for whom the largest focus of their work was palliative care.

A mail survey was sent to each of the sampled providers. The survey package included an introductory letter, a study information sheet, and an incentive ($5 gift card). A modified Dillman approach which included a total of 4 potential contacts, was used to maximize survey response rates [45]. For non-physician HCPs, most of the agency directors coordinated this follow-up with their employees who had not returned a completed survey.

Study Instruments

The HCP survey included the complete questions from the Index of Interdisciplinary Collaboration – 49 (IIC) [46,47]. These and additional items included from other validated survey instruments were selected to capture most of the elements in the conceptual framework relevant to a HCP perspective (see Figure 1). A factor matrix based on the questionnaire items corresponding to the framework was created to ensure coverage of desired elements [48].

Figure 1. ***Mapping of Health Care Provider Survey Items onto the Conceptual Framework for the Evaluation of Palliative Care Integration***



System Structure

Environment Factors	Survey item(s)*
• Population density	
• Population demographics	
• Community awareness of health issue	
• Profession/specialty base	
Network Characteristics	
• History/evolution	WCFI_1
• Network structure	
• Size of membership	
• Extent of participation in network among members	
• Policies and procedures	12, 18
• Power equality	14, 30
• Promotion of network ideals	New1
• Vision/culture	35
Economic Factors	
• Network resources	
• Extent of volunteerism	
• Financial incentives	
• Capacity for 24/7 care	

Process of Care

Provider Characteristics	Survey item(s)*
• Beliefs/attitudes	4, 17, 22, 23
• Interpersonal style	10, New2
• Job satisfaction	
• Specialty training and experience	New3, New4
Extent of Collaboration among Providers	
• Group commitment	24, 25, 27, 32, 38, 40, 46
• Common goals/shared values	33, 41, 43, 44, 45
• Perceived interdependence	1, 3, 11, 28, New5
• Reciprocity	PSAT item
• Respect	3, 11, 15
• Shared decision-making and problem solving	26, 30, 34, 36, 49
• Shared risk/responsibility	37, New6
• Trust	1, 44
Information Transfer	
• Communication	5, 19, 31, 39, 47, New7, New8, New9
• Information systems and materials	New10
• Standardized assessment and monitoring of patient need	
Organization Factors	
• Careteam composition	New11
• Educational opportunities	New12
• Incentives to encourage collaboration/client-centred care	New9, New13
• Leadership	New9, New13
• Role recognition	6, 8, 9, 15
• Standards of practice	
• Process evaluation and feedback	2, 48, New14

Outcomes

- 20
- New: Extent to which the provision of palliative care in this community has improved over the past two years
- New: Major strengths in this community for the provision of palliative care services
- New: Major weaknesses in this community for the provision of palliative care services

*All question numbers refer to the **Index of Interdisciplinary Collaboration (IIC)** except for items from the **PSAT** (Partnership Self-Assessment Tool) *Comparing Benefits and Drawbacks* question, the **WCFI** (Wilder Collaboration Factors Inventory), and **New**, as indicated.
Note: Some questions addressed two different domains

New Questions†

New3: Indicate any training you have received relative to palliative care
New4: How many years have you worked in palliative care or worked with palliative care patients?
New5: I feel part of a team in providing palliative care
New11: Who are the members of your team for providing palliative care?

Questions from Other Instruments

WCFI_1: Agencies in my area have a history of working together
PSAT item: How have the benefits of your collaborating with other professionals compared to the drawbacks?

†other “New” items are listed in Table 4

The IIC questions do not presume knowledge of a network structure for collaboration, but rather focus directly on the providers' perceptions of this construct in practice [46,47]. The IIC was developed from a thorough review of interdisciplinary theoretical, practice, and research-based literature. This instrument is made up of 49 questions, all employing a 5-point Likert scale ("strongly agree"=1, "agree"=2, "neither agree nor disagree"=3, "disagree"=4, "strongly disagree"=5). The "neither agree nor disagree" original midpoint (=3) of the scale was changed to "undecided" to simplify the central response category on this interval scale.

The IIC is composed of 5 sub-scales (see Table 3). This instrument has high internal consistency (α = 0.92) and has been validated in association with other characteristics of interdisciplinary collaboration. We made minimal modifications to the questions, generalizing the original social worker respondent reference, for use by all health care professions (an option suggested by the IIC author) [47]. Questions 7, 13, 16, 21, 29, and 42 were not used, as these were determined to be redundant (by the IIC author) [47].

Questions were also included in the HCP survey that reflected key process-level domains in the conceptual framework not addressed in the IIC (see Figure 1). The survey contained two open-ended questions asking respondents to describe the strengths and weaknesses in the community for the provision of palliative care services. Respondent characteristics (e.g., professional designations, years in practice in region, etc.) were also collected.

Data Analysis

Response data from the survey forms were entered into and analyzed using SPSS (version 19.0, SPSS Inc., Chicago, 2010). Data collected from the IIC were analyzed according to the instrument guidelines [47]. Scores were calculated for specified sub-scales within the instrument. The additional questions were analyzed individually. Reporting and comparison of quantitative item scores were descriptive (i.e., means, standard deviations, frequencies). Inferential comparisons were made between scale responses based on HCPs' region, profession, and agency using analysis of variance (2-way ANOVA) for the continuous data (IIC sub-factor scores) and Pearson's chi-square (χ^2) for the categorical data.

The "strongly agree"/"agree" and "strongly disagree"/"disagree" poles of the five-point scales were dichotomized for reporting. The middle "undecided" point was retained. Qualitative data were reviewed for emergent themes and coded using the constant comparative method [49].

FINDINGS

In total, 86 HCPs from the two regions completed surveys, for a response rate of 85.1%. Our strategy resulted in data being obtained from about a third (31%) of all formal "palliative care" providers identified in the study area (see Table 1). All eight relevant agencies agreed to have surveys sent to their HCPs. No responses were obtained from one agency from which five registered nurse employees were mailed surveys. The required sample of responses was achieved from each of the seven other agencies. Six of the physicians identified as having palliative care patients (excluding the palliative care physician on the research team) completed surveys, for a physician-specific response rate of 38%.

Table 1. ***Health Care Professional (HCP) Respondents by Profession and Total Indentified in Study Regions***

Profession Type	Respondent HCP N (% of Respondents)	Total palliative care HCPs identified
Registered Nurse	28 (32.6)	113
Physiotherapist	18 (20.9)	64
Personal support worker	11 (12.8)	40
Occupational Therapist	8 (9.3)	29
Palliative care physician	6 (7.0)	16
Social Worker	6 (7.0)	7
Nutritionist /Dietician	5 (5.8)	6
Speech Therapist	3 (3.5)	3
Pharmacist	1 (1.2)	1
Total	86 (100)	279

No statistically significant differences were found in a comparison of IIC sub-scale scores between respondents from the rural and urban regions. We pooled the data from these two areas to increase the power of the other comparisons. Table 2 presents the characteristics of the HCP respondents. Most were female (93%) and had been working in their region in palliative care for at least five years.

Table 2. ***Characteristics of Health Care Provider Respondents (N = 86)***

Sample Characteristics	N (%)
Sex	
Female	80 (93.0%)
Male	6 (7.0%)
Age	
20 to 29 yrs	3 (3.5%)
30 to 39 yrs	16 (18.6%)
40 to 49 yrs	24 (27.9%)
50 to 59 yrs	31 (36.0%)
60 to 69 yrs	9 (10.5%)
70 yrs or older	1 (1.2%)
Missing	2 (2.3%)
Years working in palliative care	
0 to 4 yrs	13 (15.1%)
5 to 10 yrs	22 (25.6%)
11 to 20 yrs	24 (27.9%)
20+ yrs	26 (30.2%)
Missing	1 (1.2%)
Years working in palliative care in region	
0 to 4 yrs	23 (26.7%)
5 to 10 yrs	17 (19.8%)
11 to 20 yrs	27 (31.4%)
20+ yrs	19 (22.1%)

IIC sub-scale means are presented in Table 3. The means indicate that most of the HCPs somewhat agreed that the domains of collaboration measured are present in the community. HCPs expressed the most uncertainty about “Reflection on Process,” referring to the process of thinking and talking about working relationships and incorporating feedback to strengthen collaboration.

Table 3. ***Summary of Health Care Professional IIC Factor Scores (N=86)***

Factor (# items)	Mean (SD)
Interdependence (13)	2.06 (0.49)
Newly Created Professional Activities (6)	2.39 (0.57)
Flexibility (5)	2.27 (0.46)
Collective Ownership of Goals (9)	2.32 (0.54)
Reflection on Process (10)	2.77 (0.66)

In HCPs’ responses to the individual non-IIC questions on the survey, most (89%) agreed that health care professionals in the community behave professionally towards one another (see Table 4). However, many (48%) were undecided of whether the risks for innovative thinking and practice is shared among those providing palliative care, with the remaining respondents divided as to whether they agreed (31%) or disagreed (21%) with this statement. In terms of access to patient data, service data, or related information, respondents were nearly equally split on whether or not this was adequate for their professional needs. About a third (30%) reported that their workload does not permit them time to assess the information needs of their palliative care patients (and families) and ensure this information is understood.

Table 4. ***Health Care Professional Responses on Additional Survey Questions (N=86)***

New survey items*	Agree %	Undecided %	Disagree %
1. I am aware of the objectives and vision of the Network	42.9	26.2	30.9
2. Health care professionals in the community behave professionally towards one another	89.4	8.2	2.4
6. The risks for innovative thinking and practice is shared among the professional disciplines in the community	30.6	48.2	21.2
7. I have adequate access to patient data and information (e.g., information about individual cases included needs assessed and services provided, etc.)	44.2	11.6	44.2
8. I have adequate access to service data and information (e.g., information about palliative care services available, community needs, service usage, etc.)	41.2	21.2	37.6
9. My workload permits me time to assess my patients' and their families' information needs and ensure this information is understood by them	45.3	24.4	30.2
10. Useful technologies (e.g., pagers, smartphones, multidisciplinary case videoconferencing equipment, etc.) are available to providers in this community to assist in communication	32.6	36.0	31.4
12. Educational and training opportunities relating to palliative care are easily available to me	57.0	17.4	25.6
13. I receive encouragement from my colleagues and/or supervisors for my efforts to collaborate with other health care providers	62.4	18.8	18.8
14. There is ongoing assessment of palliative care activities, functions, and outputs in the community	36.9	46.4	16.7

*number corresponds to New items on Figure 1

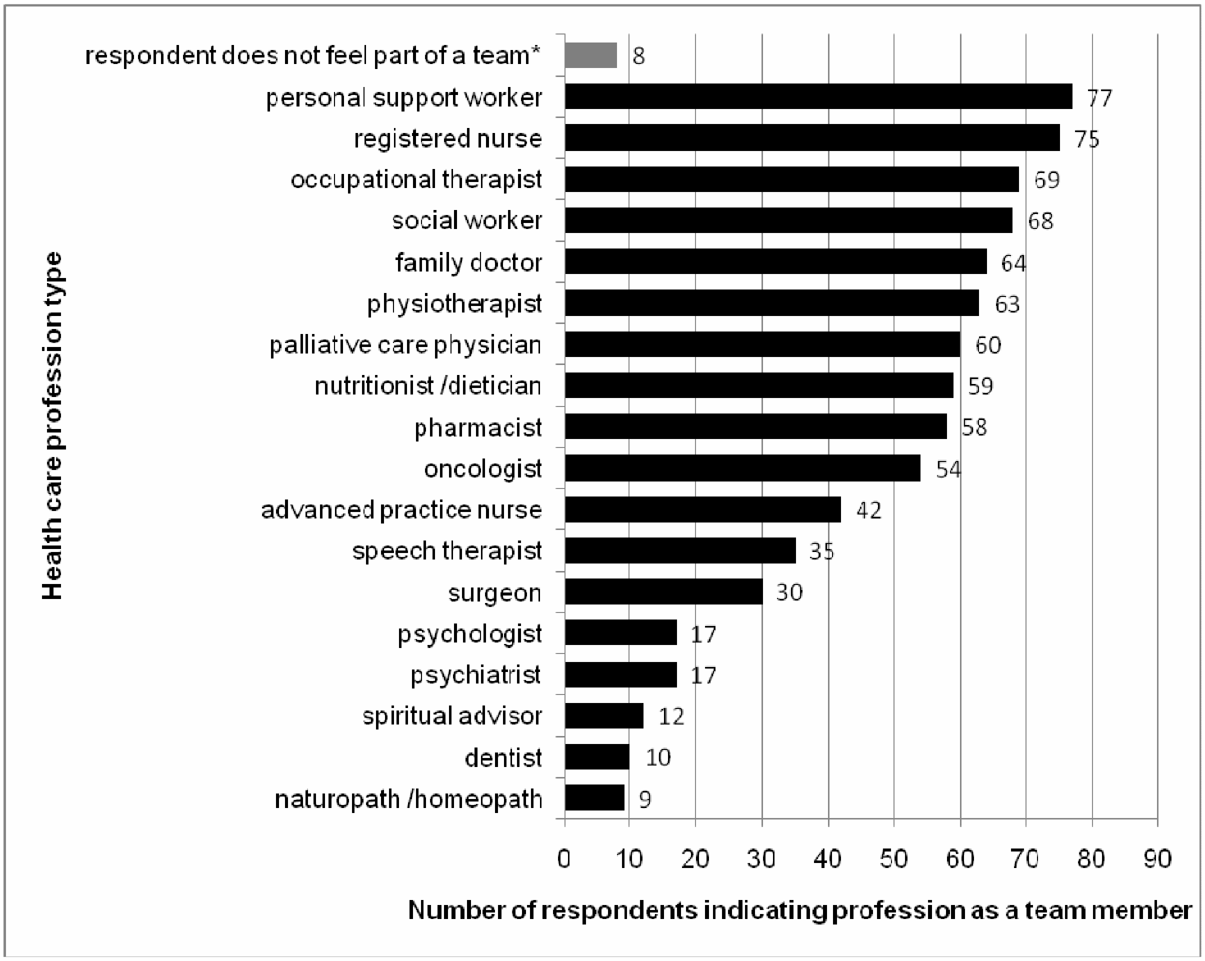
There was almost equal division among those who agreed, disagreed, or were undecided that useful technologies are available to providers in this community to assist in communication. Many either felt that they receive encouragement (62%) from colleagues and/or supervisors for efforts to collaborate with other HCPs or were undecided (19%) about this matter. Slightly over a half (57%) of the HCPs perceived that educational and training opportunities relating to palliative care are easily available to them. Finally, only 37% of respondents agreed that there is ongoing assessment of palliative care activities, functions, and outputs in the community and less than half (43%) reported being aware of the objectives and vision of the local PCN.

Significant differences were found by profession category for the IIC sub-scales “Newly Created Professional Activities” (i.e., structures that support collaboration and actuation of benefits) (p=0.029) and “Collective Ownership of Goals” (p=0.020). Physicians, registered nutritionists/dieticians, and speech therapists tended to agree more strongly with the statements composing these sub-scales than the rest of the professions. Significant differences were also found by respondent agency for IIC sub-scales “Newly Created Professional Activities” (p=0.036) and “Flexibility” (p=0.019). This effect on the first sub-scale can be explained by respondents from one nursing agency scoring closer to “strongly agree” pole of the scale (M=1.9), while respondents from another nursing agency tended to score closer to the middle “Undecided” point of the scale (M=3.1). Respondents from one of the rehabilitation agencies tended to agree more strongly (M=1.9) with the statements composing “Flexibility” than the other agencies.

There were fewer significant differences in the response patterns by profession and agency for the non-IIC questions (collapsed categorical responses analysed). Both occupational therapists and physiotherapists tended to be less aware of the objectives and vision of the local PCN than the other professions ($p=0.044$). In answer to the statement that “agencies in this region have a history of working together”, respondents from one nursing agency unanimously agreed, another was split in opinion, and a third almost all disagreed ($p=0.005$). As to having sufficient technologies to assist communication, respondents from one nursing agency largely agreed with this statement, while those from another nursing agency and a therapy agency all or mostly disagreed, ($p<0.019$).

Just over half of respondents (51%) agreed that the provision of palliative care in the community has improved over the past two years; the rest were mainly undecided (29%) or did not respond (13%) to this question. Most (86%) stated that the benefits of working collaboratively with others exceeded the drawbacks. The majority (91%) of the HCPs consider themselves to be part of a palliative care team. Respondents were asked to identify professions they consider to be part of this team. Total counts for each profession are illustrated in Figure 2. In regards to formal palliative care training received, about one third (31%) of the providers did not indicate any, of which a high proportion were physiotherapists.

Figure 2. ***Health Care Professions Indicated as Palliative Care Team Members by Respondents (N=86)***



* respondents: two each of occupational therapist, personal support worker, physiotherapist, and social worker

Major strengths and weaknesses in the region's provision of palliative care services reported in the open-ended questions are summarized in Table 5. The most frequently mentioned strengths included the presence of a formalized expert palliative care team, hospice services, the availability of community palliative care, and the dedication of HCPs to working collaboratively. Many of the weaknesses indicated reflect the fact that access to an expert palliative care team is limited to certain areas of the region. There was a perceived lack of uniformity in the organization and provision of palliative care and in HCP training across the regions. Some respondents (14%) stated that financial resources are inadequate to always provide services for the duration their palliative care patients need.

Table 5. ***Major Strengths and Weaknesses Identified by Health Care Professionals in the Region's Provision of Palliative Care Services (N=86)***

Major strengths	Number	Percent
Case management palliative care team (Community Care Access Centre)	18	20.9
Hospice services and day programs	14	16.3
Access to specialist HCPs for patients	13	15.1
Palliative care team (not specified)	12	14.0
Provider collaboration and willingness to work with other disciplines	11	12.8
Access to equipment for patients	9	10.5
Educational opportunities in palliative care for HCPs	7	8.1
Nurses with palliative care expertise	5	5.8
Palliative care physicians	5	5.8
Major weaknesses		
Lack of financial resources/budget cuts have resulted in reduced services	12	14.0
Insufficient resources provided to facilitate multidisciplinary case conferences	11	12.8
Poor communication and transfer of patient information between HCPs	11	12.8
More hospice beds and residential hospices needed	10	11.6
Lack of dedicated palliative care teams in most areas	10	11.6
Delayed referral to needed services	9	10.5
Palliative care is not always coordinated/sometimes fragmented	8	9.3
Service allotment limited	8	9.3
Variable education in palliative care among HCPs	7	8.1
24/7 home care inconsistent	7	8.1
Shortage of palliative care physicians	6	7.0

DISCUSSION

Despite there being no single model of care provision that is suitable to all system conformations, there are common elements indicative of collaboration and functionality that suggest the extent to which the care network is integrated and sustainable. This study examined these factors from the perspective of the processes of service provision within the catchment of a PCN.

Among all the professional types we surveyed we found that high value is placed on working collaboratively and that most HCPs reported being part of an interdisciplinary team. The extent of professionalism and support among these HCPs were further strengths. Very few of these providers felt that the quality of palliative care provision had declined over the past two years, suggesting stability in these services.

We were able to identify gaps in the process and structure of palliative care delivery, relating to the framework elements. Differences were evident between the nursing agencies in terms of perceptions of inter-organization cooperation, technologies available to HCPs to assist in communication, and the presence of structures to support collaboration and realize its benefits. The particular manner of operations and organizational style of each agency most likely contributes to the perceptions of their HCPs regarding some of the elements assessed.

Although our previous study [24] stated that the PCN had undertaken various activities to promote its mandate in the community, many of the HCPs were not aware of the Network's objectives, this being to "develop and ensure the implementation of strategic plans and policies for a system-wide approach to the delivery of palliative care services, including: education, research, advocacy, quality management, and communication activities related to palliative care" [50]. Providers also expressed a need for better access to both patient information and that pertaining to the service environment (services available, community needs, service usage) which likely stems from the lack of system-wide standardized information systems [24].

A considerable number of the HCPs did not indicate having received any specialized training in palliative care, even though a wide array of relevant courses are available in the area and some respondents listed educational opportunities as a system strength. Perhaps the workload of some providers precludes time available to attend paid training sessions in palliative care. In our system level examination it was suggested that palliative care education credentials for providers are being built into the request for proposal (RFP) process as a requirement in the contracting of all palliative home care [24]. This may serve to bolster the provider complement with formal palliative care training.

Further time constraints and workload issues were evident in those HCPs who reported having insufficient time to fully provide for the information needs of their end-of-life clients, inadequate support for case meetings and reflective interactions, or little ongoing assessment of palliative care activities. The RFP process through which the provider agencies are contracted likely creates a competitive environment, which necessitates the prioritization of direct service provision, above that of HCP reflective and self-enriching activities.

The importance of feedback and evaluation is often touted in health service development frameworks but in reality may lag far behind the priority of providing direct service. Although a letter of support was forwarded to each of the participating agencies from the local management organization (Community Care Access Centre) that brokers their contracts, it took a great deal of time and persistence on the part of the research team for all these agencies and their HCPs to participate in the study. Understandably, given the resource constraints facing service providers, the benefits of participating in research activities have to be clearly delineated and the time commitment required minimal. In addition to the importance of feedback and evaluation to quality improvement, opportunities to exchange opinions and develop strategies in case conferences promotes shared learning and collaborative practice [51]. In the United States, plan of care meetings among involved HCPs are mandated under the provisions of national (Medicare Hospice Benefit) palliative care services [8,52].

In previous related research, Oliver, Wittenberg-Lyles, and colleagues have published a number of studies using the IIC tool with interdisciplinary palliative care teams [36,38,53-55]. In one of their larger studies using this measure, they surveyed 95 palliative care team members including nurses, social workers, chaplains, physicians, and other providers [36,54]. Overall, they found agreement on team members’ perceived interdisciplinary collaboration (total scale M=2.20). The most positive perception of collaboration was in the sub-scale of Newly Created Professional Activities (M=2.07), followed by Interdependence and Flexibility (both M=2.19), and then Collective Ownership of Goals (M=2.22). Similar to our study, Oliver found lower agreement on Reflection on Process (M=2.31). These authors concluded that there was a positive level of interdisciplinary collaboration among the teams surveyed and that these perceptions were independent of provider education or expertise. They found no significant variance in the perceptions of collaboration measured between professional types; however, significant differences were found on the IIC measures between hospice teams.

Study Strengths and Limitations

This study has some limitations that should be considered when interpreting these results. We were able to capture most of the process dimensions from the conceptual framework in our survey instrument. Elements that we did not directly assess were job satisfaction, standardized patient assessment, and standards of practice. Job satisfaction has been found to be related to perceptions of team functioning [56,57] and so we anticipated capturing this framework element by proxy. From our system structure-level inquiry it was apparent that patient assessment and standards of practice are not being uniformly applied in palliative care across the study area, thus asking HCPs about these elements again seemed redundant [24].

We measured perceptions of collaborative processes and enablers to quality care provision without observing these activities directly. The traditionally cooperative nature of palliative care could invite a tendency to overestimate the extent of collaboration [54]. We did find diversity in responses between HCPs indicating that not all providers felt that care was always delivered in a collaborative fashion. It would be difficult to observe the interactions of all the health care profession types involved and attach meaning to counts of defining actions.

We were able to obtain data from a wide representative sample of provider agencies and HCP types. The response rate for the physicians sampled was low, even though we provided an incentive with the survey. Physician non-respondents might have different perceptions than those that were elicited. Achieving a high response rate to physician surveys, even to those involving non-physician HCPs, is often problematic [58,59].

Another limitation is that we did not include volunteer non-professionals as a respondent group. Volunteers play an important role in supporting community palliative care both in providing informal practical and emotional support. It was reasoned that they would not be able to comment sufficiently on inter-provider collaboration given the informal nature of their roles and limited involvement in multidisciplinary planning of care. As it was, the survey questions did not presume knowledge of the PCN but rather focused on the processes that should be evident from a functioning integrated structure, in expectation that even some of the HCPs might be unaware of the involvement of the PCN.

Conclusions

Each framework element we considered in this study has diagnostic value in specifying features needing attention or further investigation, towards increasing collaboration and improving the provision of palliative care. The results of this evaluation can inform stakeholders in the PCN of both process shortcomings requiring additional work and strengths, from which inspiration can be drawn. As evident in our previous structure-level study of this PCN, palliative care is at different stages of development across the region examined [24]. Recognizing the specific needs and level of readiness in each unique community, the Network has taken a community development approach in its catchment to gradually build capacity in a participatory manner. Many key structures to optimal palliative care system performance such as standards of practice, central inventories of resources, and information systems have yet to be standardized and implemented across the region, the impact of which is evident in the responses of the HCPs.

Furthermore, the providers generally perceived evaluation and feedback exercises as being undervalued. This finding highlights the need for greater engagement of provider agencies and physicians in the community in research and reflective activities. More importantly, this underlines the need for purposeful research strategies that are empirically based and yet are both unassuming and exhibit clearly defined benefits to participation. These are necessary considerations to encourage uptake by the agencies and the HCPs in evaluative exercises that can be easily used to inform improvements in palliative care delivery processes and service integration. Finally, additional research is required using the proposed framework and methodology to compare PCNs with contrasting integrated structures to determine if these dissimilarities indeed resonate at the process level, as assumed.

CHAPTER 5

Reflections on the utility of a theoretical framework for the evaluation of network-integrated palliative care: Structures, processes, and outcomes

Submitted to Journal of Aging Research, 2011:

Bainbridge, D., Brazil, K., D., Krueger, P., Ploeg, J., Taniguchi, A. (s*ubmitted*). Reflections on the utility of a theoretical framework for the evaluation of network-integrated palliative care: Structures, processes, and outcomes. *J Aging Res*.

ABSTRACT

Palliative care networks (PCNs) have been implemented in a number of countries to integrate a broad range of services in the community for those living with advanced disease. There remains a lack of direction on how to systematically evaluative these networks to inform further development. This paper presents a variable-oriented analysis from a theory-based case study of a PCN to help bridge this knowledge gap.

The evaluative framework used to guide this research proved useful in assessing qualities of integration and functioning in the PCN. The resulting visual array of elements illustrates that while this network performed relatively well at the multiple levels considered, room for improvement exists, particularly in terms of “structure”, were there was less than complete consensus that these factors are present in the PCN. This study, along with the other evaluative examples mentioned, represent important initial attempts at empirically and comprehensively examining network-integrated palliative care.

INTRODUCTION

Over the past two decades there has been a gradual shift from inpatient to community-based interventions for individuals requiring non-intensive medical, psychological, or end-of-life care [1-6]. Many governments have endorsed this transition as a means of: restraining escalating health care costs through reduction of expensive hospital-based care [7-12], improving patient outcomes through care that is more appropriate and patient centred [13-16], and accommodating patients' preferences for obtaining health services in residence rather than in institution [17-19].

Organizing these decentralized systems of care presents its own challenges. Community-based health services have a high propensity for fragmentation due to a combination of diverse professional groups, organizations, and approaches to care [20-22]. On-going assessing and monitoring of dispersed palliative or chronic care individuals has additional logistical implications. Internationally, there has been increasing development of and reliance on health service networks to initiate integrated systems of care to provide a coordinated continuum of cost-effective services at the local level [23-30]. For those with advanced disease, integrated care has been advanced through formal policy initiatives to create regional palliative care networks (PCNs) in a number of developed countries [27-29,31,32]. Organized networks of interdisciplinary providers are important to effectively serve the broad spectrum of needs that patients at this stage of illness may have [33-36].

> "Providing integrated, coordinated care to persons at end-of-life allows health and social services to mobilize a range of resources quickly to meet needs as they arise, delivering the best care possible while avoiding using resources inappropriately." p. 40 [37]

Integration has been reported to be an essential component of high functioning and sustainable healthcare organizations [38]. Outcomes anticipated through integrated service networks include the development of collaborative partnerships across provider organizations and the implementation of standardized processes. This is intended to further enhance interdisciplinary service capacity and improve access, coordination, and consistency of service provision, while shifting care from acute settings to appropriate alternate settings of care [39].

While there are has been rapid expansion of network literature in general [40,41], published examinations of these systems are scarce and even more so in terms of comprehensive studies of PCNs [42-48]. Empirical evaluation is an important component of network development to understand what attributes appear to impede or encourage progress [25,46,49-52]. There is a dire need for whole system research on health service networks and integrated care in general, with well delineated structures and processes [11,40,43,53,54]. In particular, is the dearth of studies that go beyond being merely descriptive, to being prescriptive.

A recent review by Armitage and Suter on integration of care measures concluded that no dominant model of this construct exists, nor have many tools been developed for its systematic examination [40]. The inherent multidisciplinary nature and often unique evolutionary pathway of PCNs further complicates measures of quality assurance [55-57]. Meanwhile, deficits in the availability and quality of care for those with progressive illness continue to be commonly reported in the international literature [36,58-60]. Evaluative hurdles need to be overcome to help inform strategies towards actualizing the envisioned benefits of organized systems of palliative care.

Despite a lack of consensus on how networks should be evaluated [25], comprehensive frameworks that employ multiple approaches have shown promise for evaluating integrated services or networks [49]. A mixed-methods research approach is recommended that considers different types of data from different sources to adequately capture the complexity of the system in a holistic fashion [61]. Given the intricate nature of community networks, using a framework outlining principal elements to guide the research is important, as atheoretical studies are prone to missing potentially critical factors [62,63]

Such a conceptual framework specific to PCN integration and functioning was previously developed by the authors [64]. We applied the structure, process, and patient outcome domains of this framework to the evaluation of a large PCN. A variable oriented analysis was undertaken based on the individual framework elements. The purpose of this paper is to bring together the findings of all three system domains (structure, process, and outcome) into a visual array that clearly displays the perceived strengths and limitations of the evaluated network. Reflections on the utility of this framework for this examination are also presented.

METHODS

Design

The study followed an embedded case study approach that used both quantitative and qualitative methods. Case studies are used to investigate a contemporary phenomenon within its real-life context [52] and are well-suited for palliative care evaluations [65]. The case study methodology is useful for answering a broad range of questions, leading to a more holistic understanding of the phenomena of study – congruent with a systems approach [52,66-69]. Using multiple data sources, allowing for triangulation of the information, further enhances the validity of the evaluation and lends credibility to the results [46,49,52].

The embedded case study design is an empirical form of inquiry that contains more than one sub-unit of analysis [52,68]. The identification of sub-units allows for a detailed level of inquiry. This study was comprised of three sub-units, involving data collection components to examine the system structure, process of care, and patient outcome framework components.

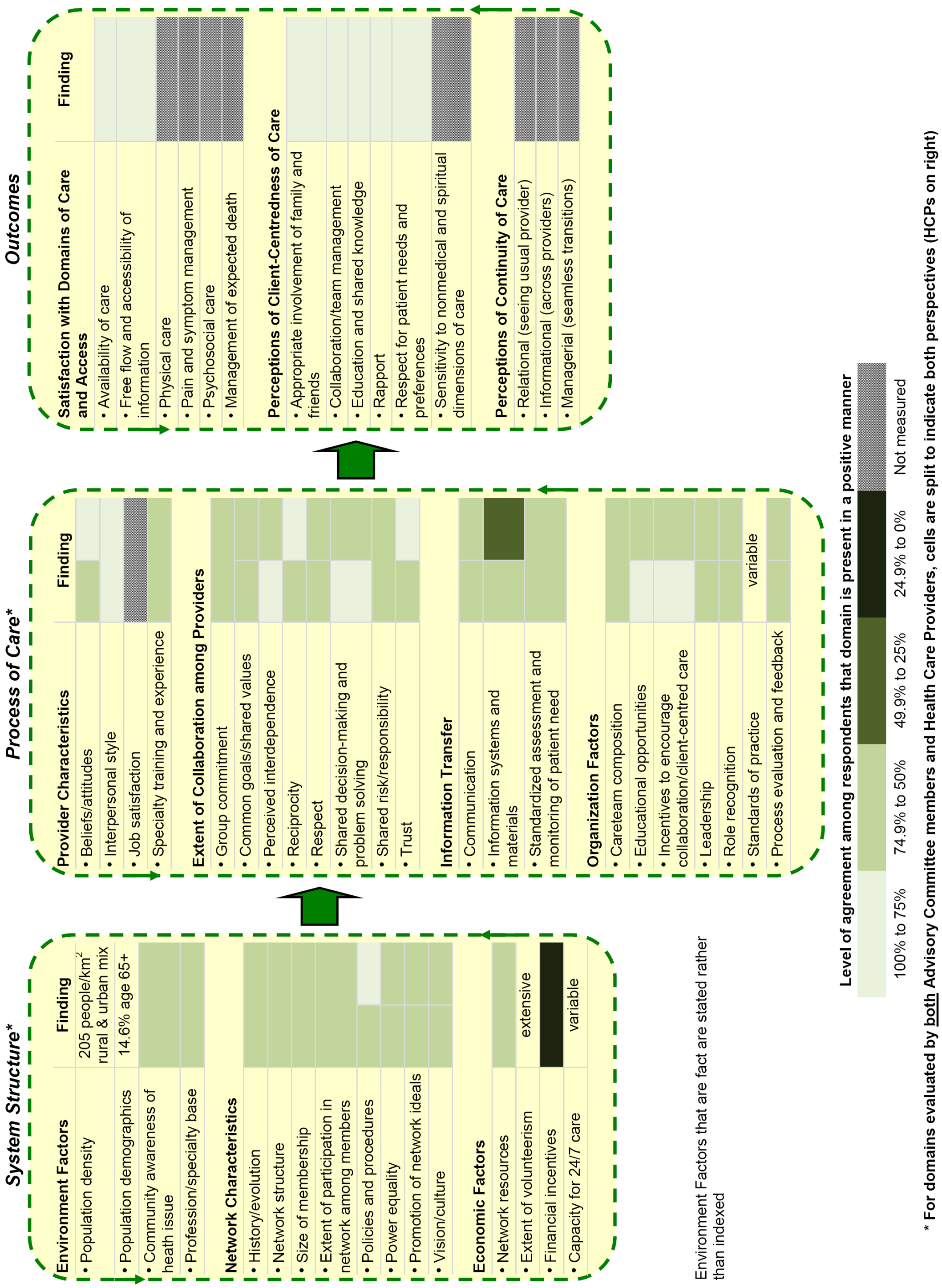
Setting

The study community bounding the case was a large health care region in Southern Ontario, Canada. The hospice palliative care network for this area was the unit of analysis. This network was selected because it is one of the more developed PCNs in the province, having been established in part since 2003, and it represents a wide diversity of urban and rural communities. Partnerships have been developed with over 100 organizations involved in some aspect of palliative care in the region, including hospitals, long-term care facilities, and nursing agencies. The structure and history of this PCN has been previously described [70].

Framework

An evaluative framework developed by the authors based on existing models of health system evaluation, explicit theory, and the relevant research literature was used to organize the examination of the PCN (see Figure 1) [64]. This framework outlines a conceptual map of the system structure, process of care, and patient outcome domains for systems of community-based palliative care. Key constructs considered are inter-professional collaboration, client-centred care, community readiness, and contextual factors to capture the unique features of the system environment, incorporating many of the principles of health service integration [71].

Figure 1. ***Mapping of Case Study Items onto the Conceptual Framework for the Evaluation of Palliative Care Integration***



System Structure*

Environment Factors	**Finding**	
• Population density	205 people/km^2 rural & urban mix	
• Population demographics	14.6% age 65+	
• Community awareness of heath issue	▒	
• Profession/specialty base	▒	
Network Characteristics		
• History/evolution	▒	
• Network structure	▒	
• Size of membership	▒	
• Extent of participation in network among members	▒	
• Policies and procedures	▒	░
• Power equality	▒	▒
• Promotion of network ideals	▒	▒
• Vision/culture	▒	▒
Economic Factors		
• Network resources	▒	
• Extent of volunteerism	extensive	
• Financial incentives	█	
• Capacity for 24/7 care	variable	

Environment Factors that are fact are stated rather than indexed

Process of Care*

Provider Characteristics	**Finding**	
• Beliefs/attitudes	▒	░
• Interpersonal style	░	
• Job satisfaction	▨	
• Specialty training and experience	▒	
Extent of Collaboration among Providers		
• Group commitment	▒	
• Common goals/shared values	▒	▒
• Perceived interdependence	░	▒
• Reciprocity	▒	░
• Respect	▒	▒
• Shared decision-making and problem solving	░	▒
• Shared risk/responsibility	▒	
• Trust	▒	░
Information Transfer		
• Communication	▒	▒
• Information systems and materials	▒	▓
• Standardized assessment and monitoring of patient need	▒	
Organization Factors		
• Careteam composition	▒	
• Educational opportunities	░	▒
• Incentives to encourage collaboration/client-centred care	░	▒
• Leadership	▒	▒
• Role recognition	▒	▒
• Standards of practice	variable	
• Process evaluation and feedback	▒	▒

Outcomes

Satisfaction with Domains of Care and Access	**Finding**
• Availability of care	░
• Free flow and accessibility of information	░
• Physical care	▨
• Pain and symptom management	▨
• Psychosocial care	▨
• Management of expected death	▨
Perceptions of Client-Centredness of Care	
• Appropriate involvement of family and friends	░
• Collaboration/team management	░
• Education and shared knowledge	░
• Rapport	░
• Respect for patient needs and preferences	░
• Sensitivity to nonmedical and spiritual dimensions of care	▨
Perceptions of Continuity of Care	
• Relational (seeing usual provider)	▨
• Informational (across providers)	▨
• Managerial (seamless transitions)	▨

Level of agreement among respondents that domain is present in a positive manner

░	▒	▓	█	▨
100% to 75%	74.9% to 50%	49.9% to 25%	24.9% to 0%	Not measured

*** For domains evaluated by <u>both</u> Advisory Committee members and Health Care Providers, cells are split to indicate both perspectives (HCPs on right)**

Procedure

The methods used for the sub-unit study at each of the three levels, including data collection, sampling, instruments, and procedures are summarized in Table 1. Different validated instruments were selected at each level to assess the respective factors. The methods used for each level of inquiry have been previously described in detail [70,72,73]. Data were collected between October 2009 and September 2010. This study received approval by the Hamilton Health Sciences/McMaster University research ethics review board, Hamilton, ON, Canada, prior to enrolling participants.

As the first key steps in considering the "case", the initial lines of enquiry were: i) development of a complete understanding of the network being examined, and ii) application of this understanding within the broader range of theory and practice as reflected by previous research (i.e., the conceptual framework) [52]. Some factors were assessed through multiple questions to consider various underlying facets. There was some overlap in the questions assessed from each respondent perspective to provide for triangulation of evidence.

Table 1. ***PCN Case Study Design***

System Level	Structure		Process	Outcomes
Data source	PCN Director / Network relevant documentation	PCN Advisory Committee Members	Health care providers (HCP) involved in palliative care in the study area	Primary informal caregivers of deceased palliative care patients of homecare services
Format (# items)	Semi-structured interview /Document review	Self-completed mailed survey (77 questions)	Self-completed mailed survey (64 questions)	Self-completed (anonymous) mailed survey (32 questions)
Survey Instrument	Interview schedule and document data abstraction tool based on domains within conceptual framework	Partnership Self-Assessment Tool (PSAT) Select questions (9)	Index of Interdisciplinary Collaboration (IIC) Select questions (11) Demographics	Client Centred Care Questionnaire (CCCQ) Service accessibility questions (3) Demographics
Sample Strategy	NA	All	All "Palliative Care" Physicians 25% of other HCPs (minimum of 4 of each HCP type from each agency)	All
Total	NA	22	277 (91 sampled)	243
Responses (%)	NA	20 (90.1%)	86 (94.5%)	111 (45.7%)

Analysis Plan

A factor matrix based on the framework items and corresponding survey/interview questions was created to ensure complete coverage of desired elements and to assist in analysis for mapping individual factors [52]. This matrix provided the propositions to guide the interpretation of data from multiple sources (e.g., surveys, interviews), allowing for theme formation.

Similar to an approach previously used by Sussman and colleagues in their system analysis [74], data were summarized graphically according to each framework factor for structure, process, and outcomes to provide a visual array of the extent to which each item was perceived by respondents as being evident in the PCN. Color gradation assigned to each factor is based on response quartiles as a percent agreeing the factor was present in a positive manner. This display enabled pattern analyses within and between system sub-units.

RESULTS

The response rates to the data collection instruments for each of the three sub-unit studies are summarized in Table 1. We were able to assess most (44 of 53) of the framework factors using the selected instruments and questions (see Figure 1). The biggest gap was within the outcomes level with eight factors missed. The instrument selected to assess palliative care patient outcomes focused heavily on caregiver satisfaction with autonomy and efficacy and less on that with specific types of care, resulting in these factors being excluded.

Sub-domain scores calculated from the data according to instrument guidelines were previously reported [70,72,73]. Figure 1 presents the percent of respondents in agreement for each framework factor assessed. In relation to outcomes, this display shows that the bereaved primary caregivers in this area reported a high level of satisfaction with community-based care for palliative care patients and good access to services.

At the structure level, it was clear that funding was inadequate or unstable to optimally support growth of the network. The capacity for 24/7 palliative care was variable across the PCN catchment. These perceptions are unquestionably reflective of the presence of interdisciplinary palliative care teams that have been implemented in some communities within the region but not in others.

It was evident that in measuring the process level factor “standards of practice”, that these were not being uniformly applied across the network area. This is also the case, according to the perceptions of health care providers (HCP), for the “information systems and materials” factor. This relates to equipment, tools, and systems to facilitate the exchange of information, critical to effective communication, decision making, uptake of standardized guidelines, and learning [64].

Overall, the responses indicate that the majority but not all participants perceived that most of the structure and process framework factors were present in this PCN. Interestingly, there were some differences in the level of agreement between the administrators and HCPs on the presence of some factors, representing the unique perspectives of these two roles.

DISCUSSION

The variable-oriented findings from our case study of a PCN suggest that this network is functioning relatively well, many features of an integrated system are evident to some extent, collaborative practice is generally valued, and family caregivers are satisfied with the accessibility and patient centeredness of services received. There is still room for improvement, particularly at the structural level, as few of these factors exhibited a high level of agreement related to their presence in the PCN. Our in-depth structural analysis of this network determined that many key features to effective palliative care delivery such as common assessment tools, standards of practice, central inventories of resources, information systems, or common access points to care are not uniformly evident in all areas of the study region [70]. These gaps have been identified in the Network plans for system development as they attempt to ensure that these features are available and accessible across the entire catchment area.

Better implementation of these structures (i.e., common assessment tools and standardized guidelines) across the health sector can further improve efficiencies in care [75]. Standards of practice are important to provide criteria against which HCPs and administrators can measure the quality or extent of the process and effectiveness [76]. Insufficient funding has been identified as one of the primary inhibitory factors to system integration efforts [77]. Finally, the presence of specialist interdisciplinary palliative care teams is believed to greatly increase system competency [35,78], along with 24/7 access to care; however, only about a third of the communities in the region have the benefit of one of these formalized arrangements [70].

Reflections on the Evaluative Framework

The evaluation framework used for this study proved useful in assessing qualities of integration and functioning in the PCN, including HCPs' and family caregivers' perceptions of the performance of the palliative care system, which are representative of the cohesiveness of the network. With the comprehensiveness of the framework and use of multiple methods, we believe that this study was able to capture the individualized nature of the PCN.

While a framework is useful in directing an investigation, it can also be limiting in side-lining information that falls outside its factors [79]. All the survey instruments we used contained an open-ended section where respondents could indicate and elaborate upon issues of personal significance. No themes emerged from these open-ended responses that appeared to have been missed by the framework. Despite this, the array in which we present the data is a generalization of the diversity in conditions existing across the PCN catchment. This highlights the importance of having a supplementary qualitative perspective to allow for deeper understanding of the unique issues and nuances across providers, organizations, and network geography.

The number of data points that are needed to be collected to fully cover all factors in the framework is unquestionably daunting. On the other hand, although the framework contains a wide spectrum of variables, it may still tend to oversimplify the complex dynamics of the network. Some of the framework factors, such as job satisfaction, are multifaceted constructs in themselves. This contributes to the dilemma between adequately measuring each element and overburdening respondents with a multitude of questions. Another potential quandary is that HCPs and administrators intimately involved in the network/system may be hesitant to commit time to this type of intensive evaluation in feeling that they already have a clear sense of the pervasive issues existing. The evaluative process nonetheless can provide an empirical record with which to confirm and share insights, rally political support, and provide a comparison for future assessment of network progress.

Previous Approaches and Evaluations

Various approaches to the evaluation of integration have been proposed using a taxonomy of “stages”, by which different professional groups indentify the level of development of their system or program. Ahgren and Axelsson’s Scale of Functional Integration tool defines five hierarchical categories to this effect: full segregation, linkage, coordination in networks, cooperation, and full integration [80]. Similarly, Boon and colleagues have developed a seven-stage continuum to identify team or organizational orientation based on types or extent of integration, from the lowest level, “parallel practice” up to “integrative” [81]. These rankings may be useful for categorizing and comparing different systems, but are unlikely to be prescriptive, offering little in the way of diagnosing specific areas to be improved. It has also been cautioned that these categorical continuums may infer a normative attitude that higher ranks of integration are always preferable to lower ones [82].

Alternatively, many network analyses quantify the “exchanges” between member organizations [83]. This is an approach to describing networks suggested by Provan [22,84] involving network mapping exercises to examine density and centrality of inter-organizational partnerships. These analyses can reveal the presence or absence of an inter-organizational linkage such as transfer of information, sharing of resources, or patient referral [83]. A limitation of this method is the focus on structured patterns of interaction without considering the individual features or actors involved [85].

We found three other examples of palliative care network or defined system evaluations in a search of the research literature; all case studies using different theoretical underpinnings. A palliative care system evaluation in Ontario by Sussman and colleagues [74] used a framework these authors developed termed the System Competency Model. This framework was comprised of structural features known to be essential indicators of quality palliative care, many which correspond to the factors within our framework for the evaluation of integrated palliative care networks [64]. The System Competency Model contains three domains: capacity (necessary resources), access, and coordination (efficient organization and continuity). Data were collected through both interviews (qualitative) and surveys (quantitative) with approximately ten key informants in each of four regions, as well as reviews of relevant program/system planning documents. The 2003 time period of inquiry predated the formal development of PCNs in Ontario, consequently little organization of palliative care existed in some of the regions examined. Unlike our framework, the model did not explicitly consider collaboration or patient outcomes.

One study examined regional PCNs in the Netherlands by surveying a total of 59 higher and middle managers and HCPs from 7 networks with respect to structure, process, and outcome level measures [27]. The survey items were developed based on content analyses of both interviews with network coordinators and network documentation. "Process" questions asked related to cooperation, care organization, leadership, and external relationships, while those for "outcomes" were the extent of shared objectives, the quality of relationships, the improvement of care services, achieved agreements, expertise, and funding. The analysis focused on the perceived rationale for network development, main achievements of the PCNs, and important success factors. The framework or survey items developed were not provided in the study publication.

Morin and colleagues conducted a qualitative case study of a PCN in Quebec using an adaptation of Patton's Model of Utilization Focused Evaluation, which is comprised of seven dimensions: origins, participation, activities, reactions, effects, expected long-term results, and the possibility of generalizing the experience [86]. Data were collected through interviews with 16 program managers and coordinators and focus groups with a total of 90 HCPs, volunteers, and family caregivers. The researchers only focused on the positive impacts of the network implementation and did not attempt any diagnostic measures. In summation, this examination along with the other two case studies [27,74], make important contributions to the sparse literature on network/system evaluation. Our study builds upon these examples by using a framework specifically for PCN evaluation from the peer-reviewed literature, providing a replicable methodology, and including patient outcomes in our measures.

Study Strengths and Limitations

We were able to capture most of the framework structure and process dimensions in our data collection. The outcome-level items were less completely assessed. A concerning observation is that no significant differences were found in family caregiver perceptions, regardless of whether the respondent resided in a community with a more or a less evolved palliative care service within the study region. This could indicate that the outcome level measure was not sensitive enough to detect discontent in the sample or failed to assess important framework variables. A review by Rosenthal and Shannon found that the response distribution of patients’ perceptions on many common measures of health care quality is often skewed towards the highest categories [87]. This may lead to difficulties in detecting discord in health delivery systems. Regardless, these authors state that the perspective of the patient is important as health care consumers and that high satisfaction with these services can still indicate process functioning and is a proxy of other positive health outcomes.

Another limitation was that the number of study respondents was insufficient to conduct multiple inferential statistics to examine co-variance and contribution among framework factors in any detail. A greater number of respondents at each level and more comprehensive instrumentation may allow a path analysis (structural equation modeling) to more definitively explore the relative strength of association between elements, ranging from structures to outcomes [88].

CONCLUSIONS

It has been postulated that in the future, health care networks will be a key organizational form [25]. Comprehensive care systems are difficult to initiate due to silos that exist between service providers and the challenge of integrating the activities of these different, often competing, organizations [89]. A global assessment of palliative care systems determined that only 15% of countries worldwide have systems that are approaching integration [90]. Canada, was one of the “fortunate” nations listed, still, in this country the organization of care for those living with a life-limiting illness varies greatly across provinces [91,92], within provinces, and even within regions [74,75]. Even with PCN formation, anticipated benefits of system integration may not be realized, depending on the predominating service and political climate and culture [25].

Health service networks are a function of the individuals involved including providers, leaders, and policy makers, making these integrative structures typically unique to their environment [46]. While there is no single model of integration suitable for all health systems [40], the framework we used contains universal principles that should be evident in a well functioning network. Each factor represented makes an independent contribution to the description and assessment of the PCN. Although some of the elements in this framework are of particular relevance to palliative care systems, this conceptualization has applicability for examining network functioning and related system integration in other healthcare contexts.

This project was a unique and challenging study to undertake as it involved primary data collection at multiple levels and commitment from all relevant health care agencies and HCPs involved in palliative care provision. The application of this framework contributes to our understanding of the selected PCN and adds to the methodological development of network evaluation. We believe that the method we have used is much more prescriptive than network mapping or categorization exercises. However, the visual array created to display the presence of the framework factors may be lacking without qualitative information to contextualize and provide additional detail to this representation.

Additional translational activities and stakeholder engagement is required to determine the practical value that our design and findings have for the network planners and HCPs.

To make health system evaluation more approachable there is a need for validated off-the-shelf measures [82] aligned to an accepted framework; specifically, the publication of complete instrumentation that, where possible, utilizes existing validated tools, enabling easy replication of the evaluation process to further test, reflect upon, and refine the framework. Complete instrumentation toolkits, such as that offered by the Australian Centre for Health Services Development [93] for the evaluation of palliative care systems are rare and the broad suite of tools provided may be overwhelming to many researchers. In this article, we presented a number of theory-based approaches to network evaluation, demonstrating some of the different forms that can be taken by this type of inquiry. Our study, along with these other examples, represents important initial attempts at empirically and comprehensively examining network-integrated palliative care.

CHAPTER 6

Conclusions of the Thesis

There is increasing interest internationally in regional palliative care networks (PCN) to integrate care, creating systems that are more cost-effective and responsive. However, little explicit direction exists to guide evaluation of these initiatives. The main objective of this dissertation study was to examine the nature and extent of inter-professional collaboration and other essential features of sustainability within a PCN. This first required the development of an evaluative framework to guide the research plan. The resulting framework embodied a systems approach with System Structure, Process of Care, and Patient Outcomes (S-P-O) domains. Research evidence was used to substantiate the choice of factors within each of these framework levels.

The theory-based evaluation of the PCN that followed incorporated the design features recommended in the initial framework paper (Chapter 2), namely:

i) Use of a mixed-methods research design with multiple sources of qualitative and quantitative data to consider the different perspectives and S-P-O levels within the PCN system,

ii) Use of validated instruments with items that matched the framework factors,

iii) Creation of a factor matrix based on the questionnaire items relating to the conceptual framework to ensure complete coverage of desired elements and to assist in analysis for mapping individual factors relative to one another,

iv) At the structure level, data were obtained from PCN administrator respondents (Network Director and Advisory Committee members) and document review (reports, presentations, etc.). Data collection at the process level included responses from a cross-section of different professional disciplines involved in the provision of palliative care in the PCN area.

A case study methodology was used to examine the framework factors of the selected PCN. Besides descriptive and inferential statistics, an alternative approach that was variable oriented was also used to analyze the data and illustrate the findings.

Findings

The PCN studied has taken a community development approach to recognize specific needs and level of readiness in each unique area in its catchment. The in-depth structural analysis of this network determined that many key features to effective palliative care delivery such as common assessment tools, standards of practice, central inventories of resources, information systems, or common access points to care are not uniformly evident in all areas of the study region. These gaps have been identified in the Network plans for system development as they attempt to ensure that these features are available and accessible.

Regardless of these structural disparities, Advisory Committee members' perceptions were generally favourable for the factors measured, suggesting from this perspective that the PCN promotes a collaborative care environment to some extent. Committee members largely viewed the accomplishments of the PCN positively and most felt that their membership held more benefits than drawbacks. Downsides of the Network expressed by many were the inability to elicit additional financial support or affect public policy and occasional feelings of frustration. Additional efforts were seen as required in ensuring the identification of patients in need of palliative care, reducing silos between community organizations, and greater political support from regional authorities. The lack of protected funding was also viewed as a risk to progress made to improve local palliative care, if regional or provincial priorities were to change.

Among all the professional disciplines surveyed most respondents held working collaboratively in high regard and reported that they were part of an interdisciplinary team. The extent of professionalism and support among these health care providers (HCPs) were further strengths. Few providers indicated that the quality of palliative care provision had declined over the past two years, suggesting that these services are at least stabile. Differences were evident between the nursing agencies in terms of perceptions of inter-organization cooperation, technologies available to HCPs to assist in communication, and the presence of structures to support collaboration and realize its benefits. The particular manner of operations and organizational style of each agency most likely contributes to the perceptions of their HCPs regarding some of the elements assessed.

Interestingly, many of the HCPs were not aware of the Network's objectives, this being to "develop and ensure the implementation of strategic plans and policies for a system-wide approach to the delivery of palliative care services, including: education, research, advocacy, quality management, and communication activities related to palliative care" [1]. Providers also expressed a need for better access to both patient information and that pertaining to the service environment (services available, community needs, service usage) which likely stems from the lack of system-wide standardized information systems.

A considerable number of the HCPs did not indicate having received any specialized training in palliative care, even though a wide array of relevant courses are available in the area and some respondents listed educational opportunities as a system strength. Perhaps the workload of some providers precludes time available to attend paid training sessions in palliative care. In the system level examination it was suggested that palliative care education credentials for providers are being built into the request for proposal (RFP) process as a requirement in the contracting of all palliative home care. This may serve to bolster the provider complement with formal palliative care training.

Further time constraints and workload issues were evident in those HCPs who reported having insufficient time to fully provide for the information needs of their end-of-life clients, inadequate support for case meetings and reflective interactions, or little ongoing assessment of palliative care activities. The RFP process through which the provider agencies are contracted likely creates a competitive environment, which necessitates the prioritization of direct service provision, above that of HCP reflective and self-enriching activities.

The variable-oriented findings from the case study provide a visual overview of the PCN's strengths and limitations. The level of detail provided by this array may be insufficient to clearly direct quality improvement efforts, however, without qualitative information to provide additional context and meaning. The results of this analysis approach cohere with the instrument-oriented findings that many features of an integrated system are evident to some extent and collaborative practice is generally valued. There is still room for PCN improvement, particularly at the structural level, as few of these factors exhibited a high level of agreement relating to their presence in the Network.

Better implementation of these structures (i.e., common assessment tools and standardized guidelines) across the health sector can further improve efficiencies in care [2]. Standards of practice are important to provide criteria against which HCPs and administrators can measure the quality or extent of the process and effectiveness [3]. Insufficient funding has been identified as one of the primary inhibitory factors to system integration efforts [4]. Finally, the presence of specialist interdisciplinary palliative care teams is believed to greatly increase system competency, however, only about a third of the communities in the PCN area have the benefit of one of these formalized arrangements [5,6].

Study Strengths and Limitations

The unique strength of the case study approach that was used for this research was its ability to combine a variety of information sources such as interviews, surveys, and documents. Compared to single method studies, stronger evidence is possible through using mixed-methods in the convergence and corroboration of findings [7]. Accordingly, this examination was able to capture most of the structure and process dimensions from the framework, some factors through multiple perspectives.

Engaging potential respondents and their health care agencies in this research process and the extensive collection of data proved challenging. The apparent strengths of using a comprehensive evaluative framework and methodology could also be limitations in the possibility of the research project becoming unmanageable and subsequently being abandoned entirely [3]. Evaluators, especially HCPs taking on this role in addition to their clinical responsibilities, should be mindful of keeping the breadth of the research proportionate to their informational needs, particularly if time and resources are limited. Depending on the objectives of the inquiry, the size of the program, and the resident experience present, researchers should prioritize select framework elements to be included as sentinel indicators, to focus measurement efforts.

This study has some additional limitations that deserve mention. Perceptions of collaborative processes and enablers to quality care provision were measured without observing these activities directly. The traditionally cooperative nature of palliative care could invite a tendency to overestimate the extent of collaboration [8]. A diversity in responses was demonstrated between respondents, indicating that not all administrators or HCPs agreed as to the collaborative disposition or the functionality of the PCN. It would be difficult to observe the interactions of all those involved within the Network and attach meaning to counts of defining actions.

The response rate for the physicians sampled was low, even though an incentive was provided with the survey. Physician non-respondents might have different perceptions than those that were elicited. Achieving a high response rate to physician surveys, even to those involving non-physician HCPs, is often problematic [9,10]. Besides palliative care physicians, data were obtained from a wide representative sample of provider agencies and HCP types.

Perceptions were not obtained from members of the 11 community-specific committees created as local intermediaries to the PCN. Most of these groups were too recently formed to have commented sufficiently on network capacity. Otherwise, being able to corroborate these perspectives with the data that were collected would have helped offset response biases the administrators may have had due to their network affiliation.

Another limitation is that volunteer non-professionals were not included as a respondent group. Volunteers play an important role in supporting community palliative care both in providing informal practical and emotional support. It was reasoned that they would not be able to comment sufficiently on inter-provider collaboration given the informal nature of their roles and limited involvement in multidisciplinary planning of care. As it was, the process survey questions did not presume knowledge of the study network but rather focused on the processes that should be evident from a functioning integrated structure, in expectation that even some of the HCPs might be unaware of the involvement of the PCN.

Finally, while a framework is useful in directing an investigation, it can also be limiting in side-lining information that falls outside its factors [11]. All the survey instruments used contained an open-ended section where respondents could indicate and elaborate upon issues of personal significance. No themes emerged from these open-ended responses that appeared to have been missed by the framework. Despite this, the findings of this study are a generalization of the diversity in conditions existing across the PCN catchment. This highlights the importance of having a supplementary qualitative perspective to allow for deeper understanding of the unique issues and nuances across providers, organizations, and network geography.

Implications of this Research and Future Directions

A network approach to service provision does not necessarily assure the best care for patients, particularly if health care funding streams continue to be competitive and encourage provider organizations to be territorial. A system driven by a single authority could potentially be more efficient and produce better outcomes than a cooperative arrangement, by eliminating organizational boundaries. However, in most palliative care service environments the integration of existing programs is a more feasible option given the diversity of HCPs and organizations providing this care and the variable needs of the patient population. The provision of palliative care that is client focused needs to be the grounding objective in service integration to help refocus some of the territoriality that arises as individual organizations try to protect their own interests [12].

Even with PCN formation, anticipated benefits of system integration may not be realized, depending on the predominating service culture and political climate [13]. Evaluation and feedback plays a key role in developing organized systems of care congruent to the existing conditions [3,14,15]. Examination of the structures and processes can illuminate the extent to which program objectives are met, inform policy and planning decisions, and increase community awareness and support for an initiative. Although critical, evaluation can be costly in terms of staff time and funding, and therefore is often deferred in favour of conserving these resources for providing care [14]. This may explain why the research literature is lacking in examinations of networks of palliative care [16-

20], despite health system integration generating a high degree of interest among researchers [21].

In this study, many of the HCPs perceived evaluation and feedback opportunities as being undervalued. This finding highlights the need for greater engagement of provider agencies and physicians in the community in research and reflective activities. More importantly, this underlines the need for purposeful research strategies that are empirically based and yet are both unassuming and exhibit clearly defined benefits to participation. These are necessary considerations to encourage uptake by the agencies and the HCPs in evaluative exercises that can be easily used to inform improvements in palliative care delivery processes and service integration.

Health system evaluation could be made more approachable with the availability of rigorous, off-the-shelf measures [22] aligned to a widely accepted framework. Specifically, this would entail the publication of complete instrumentation that, where possible, utilizes existing validated tools, enabling easy replication of the evaluation process to further test, reflect upon, and refine the framework. There is a dearth of complete instrumentation toolkits, such as that offered by the Australian Centre for Health Services Development [23] for the evaluation of palliative care systems. As it is, applying the broad suite of tools provided to a unique “system” and interpreting the results without explicit direction may be overwhelming to many researchers.

While there is no single model of integration suitable for all health systems [24], the conceptual framework used in this dissertation study contains universal principles that should be evident in a well functioning network. This framework proved useful in assessing qualities of integration and functioning in the PCN, including HCPs' perceptions of the performance of the palliative care system, which are representative of the cohesiveness of the Network. This evaluation represents one of the first attempts at comprehensively measuring the nature and extent of inter-professional collaboration and other enabling features within a network system of palliative care.

With the comprehensiveness of the framework and use of multiple methods, it is likely that this study was able to capture the individualized nature of the PCN. Each framework element considered in this study has diagnostic value in specifying features needing attention or further investigation. Although some of the elements in this framework are of particular relevance to palliative care systems, this conceptualization has applicability for examining network functioning and related system integration in other healthcare contexts.

System issues that emerged in the study concerned financial and political uncertainty that could undermine network functioning and the capacity building activities undertaken to improve palliative care delivery. Maintaining and continuing progress made through provider partnerships was seen as ultimately residing with the local and provincial authorities who determine the direction and flow of resources. Such evaluation-based findings provide important information for policy and planning for palliative care in the province of Ontario and potentially elsewhere. The results can also inform local stakeholders in the PCN of both process shortcomings requiring additional work and strengths, from which inspiration can be drawn.

This research is timely in view of the anticipated advancement of palliative care networks across the province. There are 14 PCNs in Ontario in various stages of progress. Now that Ontario is beyond five years into health integration network development, it would be auspicious to prospectively compare and contrast multiple PCNs to discern distinguishing features and administrator, provider, and user perceptions of the integration and quality of palliative care in each area. The findings of this dissertation study will provide a point of comparison by which future evolution of the network can be measured.

Further research is required using the conceptual framework and methodology to compare PCNs with contrasting integrated structures to determine if these dissimilarities indeed resonate at the process and outcome levels, as assumed. Additional translational activities and stakeholder engagement is warranted to ascertain the practical value that this evaluative design and the emerging findings have for the network planners and HCPs. In general, greater efforts are also required in educating the population as to the importance of appropriate care for those in the end-of-life stage. Both Canada and the USA lag behind many of the other OECD countries in terms of public awareness of palliative care and the understanding of what it provides [25].

Involving members of the community in research-informed capacity building strategies towards taking stock of resources and advocating for the resolution of system deficiencies is a vital constituent to achieving local service competency.

Closing Remarks

Comprehensive care systems are difficult to initiate due to silos that exist between service providers and the challenge of integrating the activities of these different, often competing, organizations [26]. System integration, however advantageous, takes a long time to achieve [27-29], requiring resources and the participation of the full range of palliative care providers, from hospitals to independent practitioners.

This paper represents an important initial effort to outline a conceptual map of the system structure, process of care, and patient outcome (S-P-O) domains for organizing systems of care for those in the palliative phase of life who are residing in the community. The application of this framework contributes to the understanding of the selected PCN and adds to the methodological development of network evaluation. This is a first step to guide evaluation to inform the development of appropriate strategies to further promote collaboration within the PCN and, ultimately, optimal palliative care that meets patients' needs and expectations.

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APPENDICES

APPENDIX A

HHS/FHS Research Ethics Board Study Approval

Hamilton
Health Sciences

RESEARCH ETHICS BOARD

McMaster
University

REB Office, 293 Wellington St. N., Suite 102., Hamilton, ON L8L 8E7
Telephone: 905-521-2100, Ext. 42013
Fax: 905-577-8378

November 2, 2009

PROJECT NUMBER: **09-401**

PROJECT TITLE: Enhancing Client Centered Care in Community Palliative Care. A Systems Perspective

PRINCIPAL INVESTIGATOR: **Dr. Kevin Brazil**

This will acknowledge receipt of your letter dated October 21, 2009 enclosing the revised CCAC Invitation Letter and revised Consent Form. These issues were raised by the Research Ethics Board at their meeting held on August 18, 2009. Based on this additional information, we wish to advise your study has been given ***final*** approval from the full REB. The submission, Protocol #05-2709 dated July 27, 2009, the Consent Form dated September 17, 2009, Letter to Informal Caregivers dated September 22, 2009, Project Information Sheet dated September 28, 2009, Information Caregiver Survey dated October 21, 2009, the Interview Registration Form dated July 28 2009, and the poster (undated) was found to be acceptable on both ethical and scientific grounds.

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of the REB meeting on August 18, 2009. Continuation beyond that date will require further review and renewal of REB approval. Any changes or amendments to the protocol must be approved by the Research Ethics Board.

The Hamilton Health Sciences/McMaster Health Sciences Research Ethics Board operates in compliance with and is constituted in accordance with the requirements of: The Tri-Council Policy Statement on Ethical Conduct of Research Involving Humans; The International Conference on Harmonization of Good Clinical Practices; Part C Division 5 of the Food and Drug Regulations of Health Canada; and the provisions of the Ontario Personal Health Information Protection Act 2004 and its applicable Regulations.

Investigators in the Project should be aware that they are responsible for ensuring that a complete consent form is inserted in the patient's health record. In the case of invasive or otherwise risky research, the investigator might consider the advisability of keeping personal copies.

Investigators in the Project should be aware that they are responsible for ensuring that a complete consent form is inserted in the patient's health record. In the case of invasive or otherwise risky research, the investigator might consider the advisability of keeping personal copies.

A condition of approval is that the physician most responsible for the care of the patient is informed that the patient has agreed to enter the study.

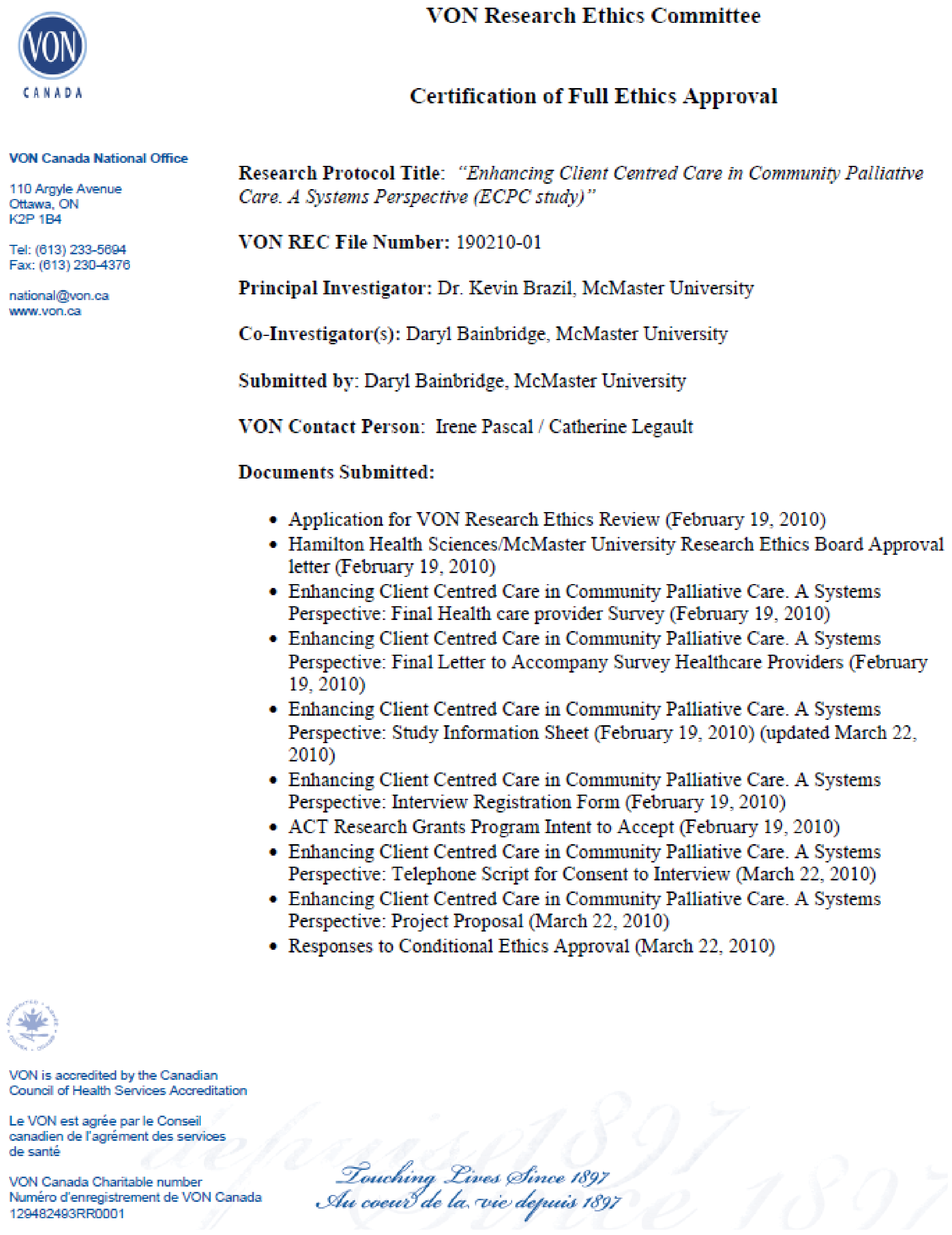
PLEASE QUOTE THE ABOVE-REFERENCE PROJECT NUMBER ON
ALL FUTURE CORRESPONDENCE

Sincerely,

Jack Holland, MD, FRCP, FRCP (C)
Chair, Research Ethics Board
/cg

APPENDIX B

VON Research Ethics Board Study Approval



VON Research Ethics Committee

Certification of Full Ethics Approval

VON Canada National Office

110 Argyle Avenue
Ottawa, ON
K2P 1B4

Tel: (613) 233-5694
Fax: (613) 230-4376

national@von.ca
www.von.ca

Research Protocol Title: *"Enhancing Client Centred Care in Community Palliative Care. A Systems Perspective (ECPC study)"*

VON REC File Number: 190210-01

Principal Investigator: Dr. Kevin Brazil, McMaster University

Co-Investigator(s): Daryl Bainbridge, McMaster University

Submitted by: Daryl Bainbridge, McMaster University

VON Contact Person: Irene Pascal / Catherine Legault

Documents Submitted:

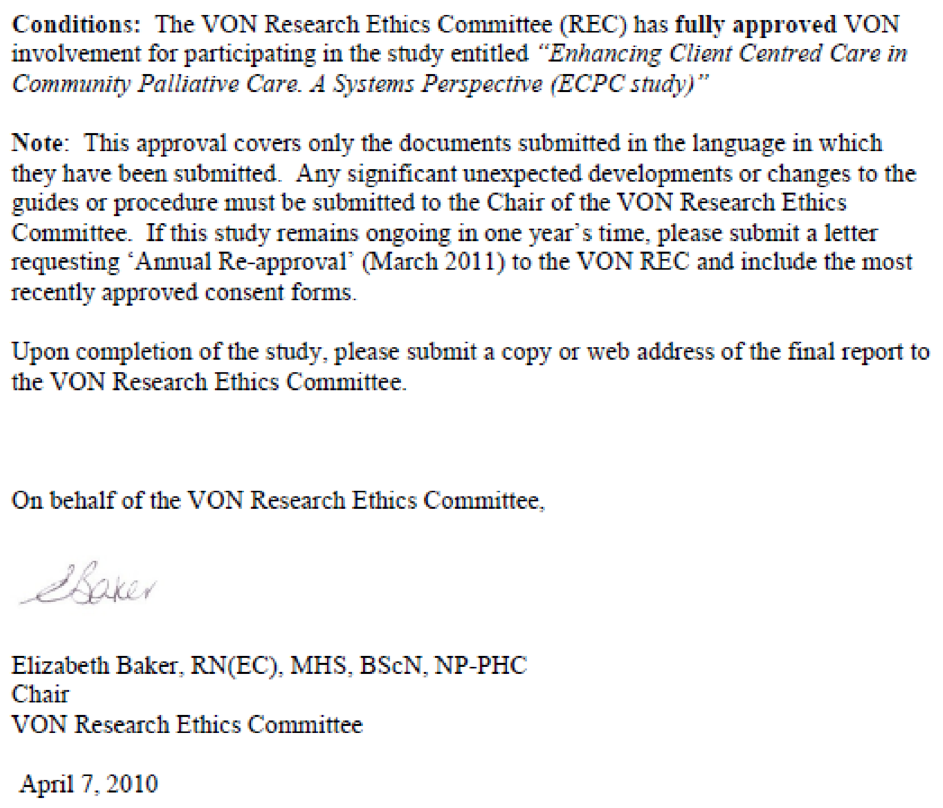
- Application for VON Research Ethics Review (February 19, 2010)
- Hamilton Health Sciences/McMaster University Research Ethics Board Approval letter (February 19, 2010)
- Enhancing Client Centred Care in Community Palliative Care. A Systems Perspective: Final Health care provider Survey (February 19, 2010)
- Enhancing Client Centred Care in Community Palliative Care. A Systems Perspective: Final Letter to Accompany Survey Healthcare Providers (February 19, 2010)
- Enhancing Client Centred Care in Community Palliative Care. A Systems Perspective: Study Information Sheet (February 19, 2010) (updated March 22, 2010)
- Enhancing Client Centred Care in Community Palliative Care. A Systems Perspective: Interview Registration Form (February 19, 2010)
- ACT Research Grants Program Intent to Accept (February 19, 2010)
- Enhancing Client Centred Care in Community Palliative Care. A Systems Perspective: Telephone Script for Consent to Interview (March 22, 2010)
- Enhancing Client Centred Care in Community Palliative Care. A Systems Perspective: Project Proposal (March 22, 2010)
- Responses to Conditional Ethics Approval (March 22, 2010)

VON is accredited by the Canadian Council of Health Services Accreditation

Le VON est agrée par le Conseil canadien de l'agrément des services de santé

VON Canada Charitable number
Numéro d'enregistrement de VON Canada
129482493RR0001

Touching Lives Since 1897
Au coeur de la vie depuis 1897



Conditions: The VON Research Ethics Committee (REC) has **fully approved** VON involvement for participating in the study entitled *"Enhancing Client Centred Care in Community Palliative Care. A Systems Perspective (ECPC study)"*

Note: This approval covers only the documents submitted in the language in which they have been submitted. Any significant unexpected developments or changes to the guides or procedure must be submitted to the Chair of the VON Research Ethics Committee. If this study remains ongoing in one year's time, please submit a letter requesting 'Annual Re-approval' (March 2011) to the VON REC and include the most recently approved consent forms.

Upon completion of the study, please submit a copy or web address of the final report to the VON Research Ethics Committee.

On behalf of the VON Research Ethics Committee,

EBaker

Elizabeth Baker, RN(EC), MHS, BScN, NP-PHC
Chair
VON Research Ethics Committee

April 7, 2010

APPENDIX C

Network Director Interview Schedule

Network Director/Executive Interview Questions

Ai. *Network Facts*

1) Describe the history /evolution of Network
2) Describe the Network structure –
    - Community representation
    - Academia representation
    - Healthcare institutions (hospitals) representation
3) Who are members of the Network (size of membership) –
    - # palliative care physicians
    - # palliative care nurses
    - # palliative care case managers
4) Describe the extent of volunteerism within the Network.
5) Network resources –
    - # palliative care beds in the LHIN
    - # hospice beds in the LHIN
    - Specific funding for palliative care
    - Specific funding for Network infrastructure
    - Office space
    - Equipment
    - Areas where resources are inadequate
6) Describe any financial incentives that align with Network objectives.
7) What are the Network policies in place relevant to:
    - Network development
    - Collaboration
    - Client-centred care
8) What is the Network vision and the prevailing culture among members –
    - Mandate
    - Apparent efforts/plan to meet objectives
    - Evidence of resistance to Network objectives
9) What has been done to raise community and professional awareness of the Network?
10) How are Network ideals promoted among network members?
11) Describe what educational opportunities relating to palliative care are available to Network members.
12) Describe any process evaluation and feedback initiatives that have occurred in the Network –
    - How is the community's capacity to provide palliative care monitored?

Aii. *Perceptions of Network*

1) What is the extent of participation in the Network among members?
2) To what extent is there power equality among members?

Bi. *System/Community Facts*

1) Describe community palliative care provision in general in the LHIN –
    - How are patients identified as needing palliative care?
    - Is home death consistently offered to palliative care patients?
    - Describe the extent of expected death planning (arrangements to pronounce etc.)
    - Describe any formal or informal venues in the LHIN (or beyond) that provide for interaction between palliative care providers/ organizers
3) How are palliative care teams organized?
4) Describe what incentives and activities to promote collaboration / client-centred care are present in the LHIN.
5) Describe what standards of practice have been enacted relating to palliative care delivery.
6) Describe the capacity for 24/7 community-based palliative care in the LHIN.
7) Describe what information systems are present to facilitate communication between providers.

Bii. *Perceptions of System/Community*

1) Describe the issues in the specialty/profession mix in the LHIN overall and how this may impact the Network –
    - Family physician / nurse shortage
    - % of relevant disciplines in Network
2) What is the perceived importance of palliative care in the community [generally and among health care professionals]?
3) What are the major strengths in the LHIN for the provision of palliative care services?
4) What are the major weaknesses in the LHIN's ability to provide palliative care services?
5) Are there any other key barriers present to patients accessing community-based palliative care services in this LHIN?

APPENDIX D

Network Advisory Council Survey

Enhancing Community Palliative Care Study (ECPC)

St. Joseph's Health System Research Network
105 Main St. East, Level P1
Hamilton, Ontario L8N 1G6

Network Committee Member Survey

The purpose of this study is to determine how the palliative care program in your Region can enhance the quality of care of patients and their families in the community.

This survey contains questions about the nature of the partnerships within the Hamilton Niagara Haldimand Brant Hospice Palliative Care Network (HNHB HPCN) and what these relationships have accomplished.

By answering the questions, you will help the Network learn about its strengths and weaknesses and about steps that can be taken to improve the collaboration process.

Please answer all the questions in this booklet and return it in the stamped envelope provided <u>As Soon As Possible</u>.

Part A

Please think about the people and organizations that are participants in the Network. By working together, **how well are Network members able to accomplish the following**:

		Not well at all	Not so well	Somewhat well	Very well	Extremely well	Don't know
1.	Identify new and creative ways to solve problems	1	2	3	4	5	DK
2.	Include the views and priorities of the health care providers affected by the Network's work	1	2	3	4	5	DK
3.	Develop goals that are widely understood and supported among other Network members	1	2	3	4	5	DK
4.	Identify how different services and programs in the community relate to the problems that the Network is attempting to address	1	2	3	4	5	DK
5.	Respond to the needs and problems of the community	1	2	3	4	5	DK
6.	Implement strategies that are most likely to work in the community	1	2	3	4	5	DK
7.	Obtain support from individuals and organizations in the community that can either block the network's plans or help move them forward	1	2	3	4	5	DK
8.	Carry out comprehensive activities that connect multiple services, programs, or systems	1	2	3	4	5	DK
9.	Clearly communicate to people in the community how the network's actions will address problems that are important to them	1	2	3	4	5	DK
10.	Indentifying most patients in the community requiring palliative care and assessing their needs	1	2	3	4	5	DK
11.	Meeting palliative care patients' wishes for place of death	1	2	3	4	5	DK

Part B

Please think about those who provide either formal or informal leadership in this Network. **Rate the <u>effectiveness</u> of the Network's leadership in the following areas:**

	Poor	Fair	Good	Very good	Excellent	Don't know
1. Taking responsibility for promoting collaboration in the Network	1	2	3	4	5	DK
2. Inspiring or motivating people involved in the Network	1	2	3	4	5	DK
3. Empowering people involved in the Network	1	2	3	4	5	DK
4. Communicating the vision of the Network	1	2	3	4	5	DK
5. Working to develop a common language within the Network	1	2	3	4	5	DK
6. Fostering respect, trust, inclusiveness, and openness in the Network	1	2	3	4	5	DK
7. Creating an environment where differences of opinion can be voiced	1	2	3	4	5	DK
8. Resolving conflict among Network members	1	2	3	4	5	DK
9. Combining the perspectives, resources, and skills of Network members	1	2	3	4	5	DK
10. Helping the Network be creative and look at things differently	1	2	3	4	5	DK
11. Recruiting diverse people and organizations into the Network	1	2	3	4	5	DK

Part C

The following questions pertain to the efficient use of resources by the Network. Choose the statement that best describes **how well the Network makes use of available**:

	Poor	Fair	Good	Very good	Excellent	Don't know
1. Financial resources	1	2	3	4	5	DK
2. In-kind resources (e.g., skills, expertise, information, data, connections, influence, space, equipment, goods)	1	2	3	4	5	DK
3. Network members' time	1	2	3	4	5	DK

Part D

Please think about how decisions are made within the Network. For the following statements indicate **how much of the time you**:

	None	Almost none	Some	Most	All	Don't know
1. Are comfortable with the way decisions are made in the Network	1	2	3	4	5	DK
2. Support the decisions made by the Network	1	2	3	4	5	DK
3. Feel that you have been included in the decision making process	1	2	3	4	5	DK

Part E

Please think about the administrative and management activities in the Network. Rate the **effectiveness** of the Network in carrying out each of the following activities:

		Poor	Fair	Good	Very good	Excellent	Don't know
1.	Coordinating communication among Network members	1	2	3	4	5	DK
2.	Coordinating communication with people and organizations outside the Network	1	2	3	4	5	DK
3.	Organizing Network activities, including meetings and projects	1	2	3	4	5	DK
4.	Applying for and managing grants and funds	1	2	3	4	5	DK
5.	Preparing materials that inform Network members and help them make timely decisions	1	2	3	4	5	DK
6.	Performing secretarial duties	1	2	3	4	5	DK
7.	Providing orientation to new Network members as they join the Network	1	2	3	4	5	DK
8.	Evaluating the progress and impact of the Network	1	2	3	4	5	DK
9.	Minimizing the barriers to participation in the Network's meetings and activities (e.g., by holding them at convenient places and times)	1	2	3	4	5	DK
10.	Formally and consistently communicate a commitment to patient-centered care with patients, families, staff, leadership, and medical staff (e.g. mission, core values)	1	2	3	4	5	DK

Part F

A Network needs financial and non-financial resources to work effectively and achieve its goals. For each of the following types of resources, **to what extent does the Network have what it needs to work effectively**:

	None	Almost none	Some	Most	All	Don't know
1. Skills and expertise (e.g., leadership, administration, clinical specialization)	1	2	3	4	5	DK
2. Community data and information (e.g., information about community perceptions, population morbidity, and relevant politics)	1	2	3	4	5	DK
3. Administrative data and information (e.g., information about palliative care services provided and finances)	1	2	3	4	5	DK
4. Connections to the palliative care patient population	1	2	3	4	5	DK
5. Connections to political decision-makers and government agencies	1	2	3	4	5	DK
6. Legitimacy and credibility	1	2	3	4	5	DK
7. Influence and ability to bring people together for meetings and activities	1	2	3	4	5	DK
8. Money	1	2	3	4	5	DK
9. Office space	1	2	3	4	5	DK
10. Equipment and goods	1	2	3	4	5	DK
11. Adequate "people power" to enable the network to meet it's objectives	1	2	3	4	5	DK
12. Members investing the right amount of time in collaborative efforts	1	2	3	4	5	DK

Part G

For each of the following benefits, please indicate whether you have or have not **received the benefit as a result of participating in the Network**.

1. Enhanced ability to address an important issue	Yes	No	Don’t know
2. Development of new skills	Yes	No	Don’t know
3. Heightened public profile	Yes	No	Don’t know
4. Increased utilization of your expertise or services	Yes	No	Don’t know
5. Acquisition of useful knowledge about services, programs, or people in the community	Yes	No	Don’t know
6. Enhanced ability to affect public policy	Yes	No	Don’t know
7. Development of valuable relationships	Yes	No	Don’t know
8. Enhanced ability to meet the needs of palliative care providers and/or patients	Yes	No	Don’t know
9. Ability to have a greater impact than I could have on your own	Yes	No	Don’t know
10. Ability to make a contribution to the community	Yes	No	Don’t know
11. Acquisition of additional financial support	Yes	No	Don’t know

Part H

For each of the following drawbacks, please indicate whether you have or have not **experienced the drawback as a result of participating in the Network**.

1. Diversion of time and resources away from other priorities or obligations	Yes	No	Don't know
2. Insufficient influence in Network activities	Yes	No	Don't know
3. Your being viewed negatively due to association with other Network members or the Network	Yes	No	Don't know
4. Frustration or aggravation	Yes	No	Don't know
5. Insufficient credit given to me for contributing to the accomplishments of the Network	Yes	No	Don't know
6. Conflict between your job and the Network's work	Yes	No	Don't know

Part I

So far, how have the benefits of participating in this Network compared to the drawbacks? (please check one box only)

☐ Benefits greatly exceed the drawbacks
☐ Benefits exceed the drawbacks
☐ Benefits and drawbacks are about equal
☐ Drawbacks exceed the benefits
☐ Drawbacks greatly exceed the benefits

Part J

Please think about your satisfaction with participation in the Network. How satisfied are you with:

	Not at all	A little	Somewhat	Mostly	Completely	Don't know
1. The way the people and organizations in the Network work together	1	2	3	4	5	DK
2. Your influence in the Network	1	2	3	4	5	DK
3. Your role in the Network	1	2	3	4	5	DK
4. The Network's plans for achieving its goals	1	2	3	4	5	DK
5. The way the Network is implementing its plans	1	2	3	4	5	DK

Part K

1. To what extent would you agree or disagree that the provision of palliative care in this community has improved over the past two years? (Please circle one response)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree	Don't know

2. Are all the organizations/agencies key to palliative care in this LHIN represented in the Network's membership?

☐ Yes ☐ No ☐ Uncertain

If NO, who is missing? ____________________

____

3. What are the major strengths in the region for the provision of palliative care services?

____

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4. What are the major weaknesses in the region’s ability to provide palliative care services?

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____

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____

____

Thank you!

Your participation in this study and the time you spent completing this questionnaire is greatly appreciated.

Should you have any questions or concerns please contact:

Dr. Kevin Brazil
Principal Investigator
(905) 522-1155 Ext. 35155

Or

Daryl Bainbridge
Co-principal Investigator
(905) 387-9711 Ext: 64515

Please return completed questionnaire in the stamped, addressed envelope provided As Soon As Possible.

APPENDIX E

Health Care Provider Survey

Enhancing Community Palliative Care Study (ECPC)

St. Joseph's Health System Research Network
105 Main St. East, Level P1
Hamilton, Ontario L8N 1G6

Health Care Provider Survey

The purpose of this study is to determine how the palliative care program in your Region can enhance the quality of care of patients and their families in the community.

By answering the questions, you will help the Niagara Haldimand Brant Hospice Palliative Care Network learn about the strengths and weaknesses in palliative care delivery in this area and about steps that can be taken to improve the collaboration process.

Please answer all the questions in this booklet and return it in the stamped envelope provided <u>As Soon As Possible</u>.

Part A

With regard to your current primary work setting/organization, please indicate the extent to which you agree or disagree with each of the following statements by circling the appropriate number beside each statement. Please answer all questions to the best of your ability.
“**Other Professionals**” refers to disciplines other than your own.

1	2	3	4	5
Strongly agree	Agree	Undecided	Disagree	Strongly disagree

1.	I utilize other professionals for their particular expertise	1	2	3	4	5
2.	I consistently give feedback to other professionals	1	2	3	4	5
3.	Other professionals utilize me and others in my discipline for a range of tasks	1	2	3	4	5
4.	Team work with professionals from other disciplines is not important in my ability to help palliative care patients and their families	1	2	3	4	5
5.	My colleagues from other professional disciplines and I rarely communicate	1	2	3	4	5
6.	My colleagues from other disciplines have a good understanding of the distinction between my role and their role(s)	1	2	3	4	5
7.	My colleagues from other disciplines make inappropriate referrals to me	1	2	3	4	5
8.	I can define those areas that are distinct in my professional role from that of professionals from other disciplines with whom I work	1	2	3	4	5
9.	I view part of my professional role as supporting the role of others with whom I work	1	2	3	4	5
10.	My colleagues from other disciplines refer to me often	1	2	3	4	5
11.	Cooperative work with colleagues from other disciplines is not a part of my job description	1	2	3	4	5
12.	My colleagues from other professional disciplines do not treat me as an equal	1	2	3	4	5
13.	My colleagues from other disciplines believe that they could not do their jobs as well without the assistance of me and others in my discipline	1	2	3	4	5
14.	Distinct new programs emerge from the collective work of colleagues from different disciplines	1	2	3	4	5
15.	Organizational protocols exist to promote cooperation between professionals from different disciplines	1	2	3	4	5
16.	Formal procedures/mechanisms exist for facilitating dialogue between professionals from different disciplines (e.g., rounds, etc.)	1	2	3	4	5
17.	I am not aware of situations in this community which a palliative care coalition, task force, or committee has developed out of interdisciplinary efforts	1	2	3	4	5
18.	Working with colleagues from other disciplines leads to outcomes that we could not achieve alone	1	2	3	4	5
19.	Creative outcomes emerge from my work with colleagues from other professions/agencies that I could not have predicted	1	2	3	4	5
20.	I am willing to take on tasks outside of my job description when they seem important	1	2	3	4	5

1	2	3	4	5
Strongly agree	Agree	Undecided	Disagree	Strongly disagree

21.	I am <u>not</u> willing to sacrifice a degree of autonomy to support cooperative problem solving	1	2	3	4	5
22.	I utilize formal and informal procedures for problem-solving with my colleagues from other disciplines	1	2	3	4	5
23.	The professional colleagues from other disciplines with whom I work stick rigidly to their job descriptions	1	2	3	4	5
24.	Professional colleagues from other disciplines and I work together in many different ways	1	2	3	4	5
25.	Decisions about patient palliative care plans are made unilaterally by professionals from other disciplines	1	2	3	4	5
26.	Professionals from other disciplines with whom I work encourage patient's and family members' participation in the care process	1	2	3	4	5
27.	My colleagues from other disciplines are <u>not</u> committed to working together	1	2	3	4	5
28.	My colleagues from other disciplines work through conflicts with me in efforts to resolve them	1	2	3	4	5
29.	Colleagues from different disciplines make decisions together	1	2	3	4	5
30.	My interactions with colleagues from other disciplines occurs in a climate where there is freedom to be different and to disagree	1	2	3	4	5
31.	Palliative care patients and their families participate in interdisciplinary planning that concerns them	1	2	3	4	5
32.	Colleagues from all relevant professional disciplines take responsibility for developing patient palliative care plans	1	2	3	4	5
33.	Colleagues from all relevant professional disciplines <u>do not</u> participate in implementing patient palliative care plans	1	2	3	4	5
34.	Professionals from different disciplines are straightforward when sharing information with palliative care patients and their families	1	2	3	4	5
35.	My colleagues from other disciplines and I often discuss different strategies to improve our working relationships	1	2	3	4	5
36.	My colleagues from other professions and I talk about ways to involve other professionals in our work together	1	2	3	4	5
37.	My colleagues from other professions <u>do not</u> attempt to create a positive climate in our organization	1	2	3	4	5
38.	I am optimistic about the ability of my colleagues from other disciplines to work with me to resolve problems	1	2	3	4	5
39.	I help my colleagues from other professions to address conflicts with other professionals directly	1	2	3	4	5
40.	My colleagues from other professions are as likely as I am to address obstacles to our successful collaboration	1	2	3	4	5
41.	My colleagues from other disciplines and I talk together about our professional similarities and differences including role, competencies and stereotypes	1	2	3	4	5
42.	My colleagues from other professions and I <u>do not</u> evaluate our work together	1	2	3	4	5
43.	I discuss with professionals from other disciplines the degree to which each of us should be involved in a particular case	1	2	3	4	5

Part B

With regard to your perceptions of the environment for delivering palliative care, please indicate the extent to which you agree or disagree with each of the following statements by circling the appropriate number beside each statement. Please answer all questions to the best of your ability.

1	2	3	4	5
Strongly agree	Agree	Undecided	Disagree	Strongly disagree

1.	Agencies in my region have a history of working together	1	2	3	4	5
2.	Health care professionals in the community behave professionally towards one another	1	2	3	4	5
3.	The risks for innovative thinking and practice are shared among the professional disciplines in the community	1	2	3	4	5
4.	There is ongoing assessment of palliative care activities, functions, and outputs in the community	1	2	3	4	5
5.	I am aware of the objectives and vision of the Hamilton Niagara Haldimand Brant Hospice Palliative Care Network	1	2	3	4	5

Part C

With regard to possible facilitators to your patient care, please indicate the extent to which you agree or disagree with each of the following statements by circling the appropriate number beside each statement.

1	2	3	4	5
Strongly agree	Agree	Undecided	Disagree	Strongly disagree

1.	I have adequate access to patient data and information (e.g., information about individual cases including needs assessed and services provided, etc.)	1	2	3	4	5
2.	I have adequate access to service data and information (e.g., information about palliative care services available, community needs, service usage, etc.)	1	2	3	4	5
3.	My workload permits me time to assess my patients' and their families' information needs and ensure this information is understood by them	1	2	3	4	5
4.	Useful technologies (e.g., pagers, smartphones, multidisciplinary case videoconferencing equipment, etc.) are available to providers in this community to assist in communication	1	2	3	4	5
5.	Educational and training opportunities relating to palliative care are easily available to me	1	2	3	4	5
6.	I receive encouragement from my colleagues and/or supervisors for my efforts to collaborate with other health care providers	1	2	3	4	5

Part D

1. How have the benefits of your collaborating with other professionals compared to the drawbacks? (Please check only one box)

☐ Benefits greatly exceed the drawbacks
☐ Benefits exceed the drawbacks
☐ Benefits and drawbacks are about equal
☐ Drawbacks exceed the benefits
☐ Drawbacks greatly exceed the benefits

2. Please indicate all the health care providers you consider as part of your team for providing palliative care in the community (Check as many boxes as apply):

☐ **I don't feel part of a Team**
☐ Advanced Practice Nurse
☐ Chiropractor
☐ Dentist
☐ Family Doctor
☐ Naturopath /Homeopath
☐ Nutritionist /Dietician
☐ Occupational Therapist
☐ Oncologist
☐ Optometrist
☐ Palliative care physician
☐ Personal support worker
☐ Pharmacist
☐ Physiotherapist
☐ Psychiatrist
☐ Psychologist
☐ Registered Nurse
☐ Social Worker
☐ Speech Therapist
☐ Surgeon
☐ Other care providers (*specify*) ______________
☐ Other care providers (*specify*) ______________
☐ Other care providers (*specify*) ______________

Part E

1. To what extent would you agree or disagree that the provision of palliative care in this community has improved over the past two years? (Please circle only one response)

Strongly disagree	Disagree	Undecided	Agree	Strongly agree	Don’t know

2. What are the major strengths in the Region for the provision of palliative care services?

3. What are the major weaknesses in the Region’s ability to provide palliative care services?

Part F GENERAL INFORMATION

Please select one response for each of the following questions.

1. I am … ☐ Male ☐ Female

2. Into which of the following categories does your age fall?

☐ 20 to 29 years	☐ 50 to 59 years
☐ 30 to 39 years	☐ 60 to 69 years
☐ 40 to 49 years	☐ ≥70 years

3. Are you a member of one of the palliative care **Expert Consult Teams** being piloted in the HNHB LHIN?

   ☐ Yes ☐ No

4. **How long** have you worked in palliative care or worked with palliative care patients?
   - ☐ 0 to 4 years
   - ☐ 5 to 10 years
   - ☐ 11 to 20 years
   - ☐ 20+ years

5. **How long** have you been involved in palliative care in this Region?
   - ☐ 0 to 4 years
   - ☐ 5 to 10 years
   - ☐ 11 to 20 years
   - ☐ 20+ years

6. Please specify any training specific to palliative care that you have received.

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Thank you!

Your participation in this study and the time you spent completing this questionnaire is greatly appreciated

Should you have any questions or concerns please contact:

Dr. Kevin Brazil
Principal Investigator
(905) 522-1155 Ext. 35155

Or

Daryl Bainbridge
Co-principal Investigator
(905) 387-9711 Ext: 64515

Please return completed questionnaire in the stamped, addressed envelope provided <u>As Soon As Possible</u>.